User Experience with Brain-Computer Interface (BCI) Devices for Leisure: A Qualitative Study

by

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Abstract:

In this study, I explore the experiences of individuals with disabilities with brain-computer interface (BCI) technology to access leisure activities. The goal of the study was to understand the user experience, to inform BCI development and implementation by meeting the unique needs of users who have disabilities.

Leisure is a vital element in life, significantly contributing to the quality of life and overall well-being (Lapa, 2013, Badia et al., 2013). Studies emphasize the relationship between leisure participation and mental and physical health, noting leisure provides benefits such as enhanced self-concept, increased self-esteem, and improved social connections, particularly for individuals with disabilities (Spetch et al., 2002, Paggi et al., 2016). Previous studies of BCI use by individuals with disabilities highlighted BCI as a potential game-changer for enabling individuals with physical impairments to participate in leisure activities.

I used a qualitative research approach to evaluate users' experience using BCI for accessing leisure. Four participants, two adults, one youth, and the youth's caregiver, reflected on their experience after they or their child (n=1) participated in two to five sessions of video game control using BCI. Participants used the Emotiv EPOC X electroencephalography (EEG)-based BCI, with the motor imagery (MI) paradigm. Their imagined movement command was translated to a "space bar" press to control the video games. I used semi-structured interviews, and each interview was tailored to the communication needs of each participant. One adult typed responses into an augmentative communication device as their communication method. The responded to questions with yes and no gestures. The other adult participant and the caregiver

used verbal communication. Interviews were transcribed, coded, and analyzed using thematic analysis.

Five key themes emerged. 1. "I never experienced or have been able to play games on my own": BCI as a Potential for Access to Leisure, 2. "Getting his sass back": BCI facilitates individuals to build confidence, 3. "His body is stuck in mud": BCI compensates for the body's physical impairment, 4. The importance of BCI as a potential for effective communication, 5. Improving BCI acceptance for end-users. These findings spotlight the transformative potential of BCI, showcasing its ability to build confidence, the participants' desire to use BCI beyond leisure and the need for enhancements to ensure the BCI is functional for the target audience. Furthermore, this study contributes insights into the experience of individuals with disabilities when they use BCI technology, highlighting its transformative potential in the accessing of leisure.

There will be challenges in the widespread adoption of BCI because of cost, operation difficulty, and calibration. Future research will be needed to explore applications of BCI beyond clinical settings, develop cost-effective devices, and place a heightened focus on user acceptability.

Preface

(Mandatory due to research ethics approval)

This thesis is an original work by Matin Dokht Taghirad. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Access to Play through a non-invasive Brain Computer Interface", Pro00096816, 2/8/2021

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Chapter 1: Introduction

Leisure is a vital element in life, significantly contributing to quality of life and overall well-being (Lapa, 2013, Badia et al., 2013). It is a "non-obligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep" *(American Occupational Therapy Association [AOTA], 2014).* Research has emphasized the relationship between leisure participation and mental and physical health, noting leisure provides benefits such as enhanced self-concept, increased self-esteem, and improved social connections, particularly for individuals with disabilities (Spetch et al., 2002, Paggi et al., 2016). Leisure can also play a pivotal role in reducing stress and inducing transformative changes associated with growth (Chun et al., 2012).

Leisure has a significant role in child development, offering children opportunities for independence, decision-making, emotional regulation, and mastery (Caldwell and Witt, 2011). For children with disabilities and their families, leisure is crucial, serving as a vital link to social and community life (Piskur et al., 2015). Studies, such as that by Woodgate et al. (2012), have highlighted families' perceptions of importance and have emphasized the urgent need for safe and inclusive environments that support enjoyable free time (Woodgate et al., 2012).

While leisure is often given less attention compared to self-care and productivity in occupational areas, it is also crucial for adults with disabilities to actively engage in leisure activities. Knowing the vast impact of leisure, it is advocated to be an end goal of occupational therapy and not just a means for achieving other goals (Chen et al., 2018).

When an individual with disabilities has physical impairments, they may use assistive technology (AT) to facilitate access to different leisure activities (Copley et al., 2004). Using AT for leisure helps individuals with physical disabilities feel included in group activities and also

gives them a chance to spend time on their own in solitary play (Pederson et al., 2021). There are different ATs, such as eye gaze-based and speech-based interfaces, that individuals with physical impairments can use to access devices such as computers (Cook & Polgar, 2014). However, traditional assistive technologies typically require at least minimal limb, body, or eye movement (Lancioni et al., 2019). Individuals with significant motor disabilities may require options that are not reliant on motor control (Cinocotti et al., 2008). Therefore, ATs that use brain signals as input, such as brain-computer interfaces (BCI), are an important option to explore for individuals with significant motor impairments.

BCI technology has assisted individuals with disabilities to interact with their environment and manipulate objects (Lazarou et al., 2018). Brain signals are produced in response to external stimuli (exogenous) or when an individual thinks about an action (endogenous stimuli). Electrodes detect the cortical electrical activity of the brain. There are two types of BCI electrodes: invasive and non-invasive. In invasive BCI, the electrodes are surgically implanted and positioned at the informative brain regions (Ramsey, 2014). Non-invasive electrodes are placed over the motor cortex on the scalp to capture motor imagery brain signals. (Mikołajewska and Mikołajewski, 2014). The focus of this thesis will be on non-invasive BCI.

Electroencephalogram (EEG) is a commonly used brain signal in non-invasive BCIs. EEG signals are detected, classified and used as input to control devices (Zhang et al., 2019). There are several BCI paradigms, which are ways signals are generated and detected (Lee et al., 2019). In the motor imagery (MI) paradigm, brain signals are produced in the primary sensorimotor areas while imagining a movement. For example, imagined movements can be thinking about moving the left hand or any part of the body (Pfurtscheller et al., 2001). The event-related potential (ERP) paradigm detects brain signals produced after receiving visual,

auditory, or tactile stimuli (Höhne et al., 2012). The steady-state visual evoked potential (SSVEP) paradigm detects brain signals in response to visual stimulation in specific frequencies (Müller-Putz et al., 2005). Patterns linked to the different paradigms are identified and classified. An individual must repeat paradigm calibration tasks several times so the BCI system can classify between the signal(s) generated by the paradigm and the resting state (Sridhar & Rao, 2012). Finally, the classified brain signals are to control a switch attached or embedded within a desired device, such as a computer or robot (Lazarou et al., 2018).

It is important to consider users' perspectives during the development of BCI activities and devices to create a technology usable for the targeted group (Taherian et al., 2016). A recommended approach in BCI research and design is to use the user-centred design (UCD) approach, which is "early and continuous involvement of potential users, understanding of user requirements and the whole user experience, and iterative processes between developers and users" (Kübler et al., 2014, p.2). To pursue user-centred design in BCI development, Kübler (2014) recommends measuring the usability of the technology. Usability examines how well a specific technology accomplishes its purpose and meets the needs and requirements of the targeted users. Usability is defined as:

> "The extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" (International Standards Office (ISO) 9241-11).

Effectiveness measures how wholly and accurately a task has been completed by the user. Efficiency relates to the costs, in terms of effort and time, invested by the user to reach the level of effectiveness. Satisfaction refers to the user's comfort and acceptability of the product (Kübler et al., 2014).

Most BCI studies have focused on measuring effectiveness in terms of BCI system classification accuracy and efficiency in terms of information transfer rate (i.e., the amount of information transmitted per time unit). The attention to user satisfaction and user-centered design has been minimal, with few studies even including people with disabilities as participants, and limited studies evaluating individual experience with BCI technology (Kübler et al., 2020). A better examination of satisfaction and user experience, and a shift from focusing only on how the device functions to considering the values important to users is needed (Nijbore, 2015).

Qualitative methodology can be an effective way to learn about user experience with BCI and the values that inform the meaning of experiences of BCI users. Engaging individuals with disabilities in interviews enables understanding of their subjective experiences with BCI, including how BCI meets their needs, and how they think the BCI can enhance daily functioning. It is also essential to gain insight into parents' perspectives on how well the BCI can support their children since they will know their child's successes, improvements, failures, and discomforts throughout the time using BCI. Interviewing parents can also be an additional pathway to learning about stakeholders' perspectives of BCI and how it can be improved. Furthermore, parents can engage in open discussion and reflection on behalf of themselves and their children.

Research Purpose

This study aimed to explore the perspectives of individuals with disabilities regarding their experience with BCI for leisure. This exploration can help us evaluate users' opinions regarding the device, and their needs and wants in order to improve the BCI experience and device.

Research Questions

The research questions for this study were:

- What are the perspectives of individuals with motor disabilities regarding their experience using BCI for leisure?

- What are the perspectives of caregivers of children with motor disabilities regarding their child's experience using BCI for leisure?

Chapter 2: Literature review

In this literature review, background information on how BCI has been applied with individuals with disabilities and how they might have been involved in determining user satisfaction will be provided. First, review papers regarding children using BCI are presented. Next, studies from the reviews will be summarised and evaluated. In addition, studies regarding BCI for leisure for adults will be presented. Last, a summary of studies where adult users were involved in BCI evaluation is provided.

Overview of the reviews

Three reviews on the topic of BCI research for children were found [Mikołajewska and Mikołajewski (2014), Beraldo et al. (2020), and Orlandi et al. (2021)]. Overall, they highlight that, although there has been very limited work with BCI for children, the results are promising and warrant further investigation.

The review conducted by Mikołajewska and Mikołajewski (2014) summarizes that the procedure of applying BCI for children has many differences compared to experiences with adults. This difference is noticeable in each process step, such as BCI system selection, assessment, and training. It is crucial to have a BCI system that can adapt to the child's continuous nervous system development by changing the sensor location, filters, and algorithms accordingly. This adaptability can help to keep the device functional as the children develop cognitively. Moreover, the system must adapt to the child's changing needs and interests. Mikołajewska and Mikołajewski (2014) also mention that recording EEG in children has special requirements: using a child-friendly

environment, avoiding stressful and fearful situations, and positioning the child and BCI headset comfortably.

In their review, Beraldo et al. (2020) included 13 papers about using BCI for communication or to control other devices. They emphasized how BCI research has mainly been focused on adults, with only a few studies focused on the pediatric population. They summarized examples of challenges for implementing BCI for children, such as finding the appropriate setup and environment for performing the sessions, obtaining parents' consent, keeping the attention of the children, and the potential to experience unknown side effects. Like Mikołajewska and Mikołajewski, these authors also point out the special challenge of updating the BCI system due to continuous nervous system development. The authors stress that more research is needed to prepare the setup better and understand the challenges of implementing BCI for children (Beraldo et al., 2020).

Orlandi et al.'s (2021) review supported the idea that knowledge about BCI for pediatrics is still in an early stage. They included seven papers focussed on communication, control, and motor-related activities and five focussed on mobility. The authors mentioned that the customization of BCIs for children needs to be investigated in future research. Areas to address in the future included (how to??) selecting appropriate devices, creating engaging games to use with BCI for children, preparing the environmental setups appropriately, and improving BCI system accuracy (Orlandi et al., 2021).

#	Authors	Title	Year	Diagnosis	Sample Age (years)	Sample Size	Activity	BCI method	Objective	Participant role
1	Cincotti et al.	Non-Invasive Brain-Computer Interface System: Towards its application as Assistive Technology	2008	14 with motor disabilities 14 non-disabled	12-35	28	controlled a target to the opposite side of the screen by thinking about its movement	EEG non-invasive (MI)	validate the BCI system	participant in experiment
2	Norton et al.	The Performance of 9-11-year-old Children Using an SSVEP-Based BCI for Target Selection	2018	non-disabled	9 - 11	15 children 11 adults	visual target selection	EEG non-invasive (SSVEP)	evaluate if children can perform target selection	participant in experiment
3	Beveridge et al.	Can teenagers control a 3D racing game using motion-onset visual evoked potentials?	2017	non-disabled	13-16	15	Control the direction of a car by focusing on one of five motion-related stimuli	EEG non-invasive (mVEP)	evaluate if teenagers can control a 3D racing game	participant in experiment
4	Beveridge et al.	Neurogaming With Motion-Onset Visual Evoked Potentials (mVEPs): Adults Versus Teenagers	2019	non-disabled	13-16 18-40	15 teenagers (2017 study) 19 new adults	Control a car by choosing the right flashing lane	EEG non-invasive (mVEP)	compare BCI naïve adults' performance compared to BCI naïve teenagers	participant in experiment
5	Zhang et al.	Evaluating if Children Can Use Simple Brain-Computer Interfaces	2019	non-disabled	6-18	26	-Move the cursor in a rightward direction to a circular target -Move a remote-controlled car	EEG non-invasive (MI)	evaluate if non-disabled school-aged children can perform simple tasks using BCI	participant in experiment

6	Beraldo et al.	Towards a Brain-Robot interface for children	2019	non-disabled	10.4 +- 2.19 26.33+- 1.53,	5 children 3 adults	controlling a robot	EEG non-invasive P300	evaluate if children can mentally drive robots	participant in experiment
7	Taherian et al.	Are we there yet? Evaluating commercial-grade brain-computer interface for control of computer applications by individuals with CP	2016	CP	7-43	6	imagined limb movement to move a virtual cube left or right	EEG non-invasive (MI)	evaluate BCI feasibility for computer access	participants reflected on the comfort of the device
8	Kelly et al.	A Child's Right to Play: Results from the Brain-Computer Interface Game Jam 2019	2019	CP	6-13	4	Give opinions about what they liked/disliked about the games created in a BCI game Jam	EEG non-invasive (MI/ P300)	obtain feedback on the games submitted to the BCI Game Jam	participant in experiment
9	Diep et al.	Perceptions of Brain-Machine Interface Technology among Mothers of Disabled Children	2015	Mothers of disabled children (non-verbal, limited speech)	moms over 18 Children 7-16	9	individual, semi-structured, face-to-face interviews	qualitative interview	understand the perceptions that parents of disabled children have about BCI technology	participant in experiment

Note: list of acronyms used in table: EEG = electroencephalograph, MI=motor imagery, SSVEP: Steady-state visual evoked potential, *mVEP: motion-onset visual evoked potentials, CP: cerebral palsy*

Relevant studies from the reviews

The following section summarises the studies from the reviews above that included studies about the use of BCI for the control of communication and other devices. A summary of the papers is presented in Table 1. Studies using invasive EEG, papers targeted at patients with epilepsy and attention deficit hyperactivity disorder (ADHD), and articles only examining the BCI system features are not addressed here.

Examination of the articles revealed that early studies evaluated if BCI use was applicable for children, while subsequent research focussed on engaging children in leisure using BCI, such as videogames. Recent research began to involve the end-users in the design of BCI systems. In a few studies children and their caregivers were asked about their opinions about the BCI system. Although the intended end-user target was individuals with disabilities, most studies were with non-disabled participants.

Early studies on examination of BCI applicability for children

The earliest work that applied non-invasive BCI for children was by Cincotti et al. (2008). They conducted a study to help people who have disabilities control devices in the environment in a house-like setup. In this study, 14 participants with disabilities aged 16-55 participated in system training and the experiment. This study was conducted in two phases. First, the participants used a rehabilitation system prototype created by the team to control their environment or a robotic platform (a Sony AIBO) (Cincotti et al., 2008). If a participant could not master this level, they were recommended to start BCI training in the second phase. Out of the 14 participants who had disabilities, four went on to the BCI training.

For the BCI training, participants completed BCI system calibration sessions. Next, participants used motor imagery (imagining the movement of a leg, hand, etc.) to control their desired device. For example, participants could move a robot to a certain location by controlling a cursor on a map on the screen (Cincotti et al., 2008). Cincotti et al. reported that after 8-12 sessions, subjects achieved brain control with an average accuracy higher than 75% (Cincotti et al., 2008). This study demonstrated that people with significant disabilities can maintain control of their brain signals and use them to control output devices (Cincotti et al., 2008). This study was a clinical implementation of BCI devices, and the challenges mentioned emphasized the work a functional BCI system requires. Although the participants completed a questionnaire after the experiment, second stage survey data were not reported.

Norton et al. (2018) examined whether children could use an SSVEP-based BCI. Fifteen neurotypical 9–11-year-olds and 11 adults volunteered to participate in the study. There was a short calibration and a longer experimental phase. Three circles flashed black and white in the calibration phase with different frequencies. Participants were asked to focus their visual attention on the circle specified by an arrow and outlined in yellow. During the experimental phase, the procedure was the same, with the exception that the target was not specified with an arrow; it was, however, outlined in yellow. When the system classifier guessed a target, visual feedback of a checkmark was presented beside the target, as well as a target selection tone. Eleven out of 14 children achieved an accuracy of 85% or above in the calibration phase and an average accuracy of 79% in the experimental phase. These results were similar to data collected from adults; thus, the authors summarized that children are able to use SSVEP-based BCI similarly to how adults use it (Norton et al., 2018).

BCI for leisure

Studies moved towards using BCI in game-like activities, which has the benefit of keeping children's attention (and engagement). Beveridge et al. (2017) investigated whether teenagers could control a 3D racing game using motion-onset visual evoked potentials (mVEPs). For this study, 15 typically developing teenagers (13-16 years old) participated. Participants were asked to direct the cars to the chosen lane by focusing on the motion-related stimuli. A custom-made 3D car-racing game was developed to provide an engaging game environment and online feedback for the experiment (Beveridge et al., 2017). The BCI system was calibrated at the beginning of each session. A red arrow was placed above the stimuli to indicate the one that the participant should focus on. Each participant had one calibration lap. Next, participants controlled the car for three laps. Five mVEP stimuli were placed at the top of the screen to indicate the lanes. Participants could choose any, but one turned green to indicate the optimal lane (Beveridge et al., 2017). Beveridge et al. reported that teenagers could select the correct stimuli with an accuracy of 95% to 100% (Beveridge et al., 2017).

In 2019, Beveridge et al. continued their research by comparing teenagers' results in the previous study with adults (Beveridge et al., 2019) using a similar protocol developed for teenagers (Beveridge et al., 2017) to investigate if BCI naïve adults would perform better than the BCI naïve teenagers. Thirty-three adults, 19 of whom were BCI naïve, participated in this study. The adults participated in three calibration laps: slow, medium, and fast speeds. Higher average accuracy was achieved by the adults, both BCI naïve and BCI experienced, compared to teenagers in the calibration. The offline performance differences between BCI naïve adults and teenagers were not statistically significant in the first two laps, but in the third lap, adults gained

higher accuracies than the teenagers. From this study, Beveridge et al. suggested that although adults had higher scores, teenagers had promising results demonstrating they can use mVEP-based neurogaming (Beveridge et al., 2019).

A study in 2019 by Zhang et al. involved 26 typically developing children to evaluate children's ability to use BCI. Participants aged 6-18 were asked to perform driving a remote-controlled car or moving a computer cursor using brain signals. To complete the task of moving a car or a cursor, children used motor imagery (MI) and goal-oriented strategies. In the MI strategy, the participant has to think about moving a body part, like opening or closing both hands. However, MI may be non-intuitive for children and cause a lack of motivation, engagement, and attention, so the authors tried a goal-oriented approach to try to make it more practical and engaging for children (Zhang et al., 2019). In the goal-oriented approach, the participant just thought about reaching the target by car or cursor. Two sessions were conducted in this research. In the first session, every child completed eight trials of calibration of MI and goal-oriented thought tasks. In the next session, ten testing trials were applied for system performance evaluation (Zhang et al., 2019). They reported that children were capable of quickly achieving the ability to control EEG-based BCI, and they reached 70% classification accuracy during their training.

Beraldo et al. (2019) presented a BCI for children to drive a robot (Beraldo et al., 2019). To check the feasibility of the protocol, three adults participated in the experiment prior to the children. Next, five BCI naive children aged 8-12.5 years old participated in this study. A P300 BCI system was used to control a Pepper robot (Aldebaran Robotics, Paris, France). The participants sat in front of a screen with a BCI headset placed on their heads. Four boxes corresponding to moving forward, stopping/going backward, turning right, and turning left were shown on the screen. Four coloured arrows flashed in random sequence in the boxes on the screen.

The user could drive the robot by concentrating their vision on the desired command. The experiment was over two days. The first day was explaining the experiment, protocol, and BCI calibration. A cue appeared on the screen to indicate which box the participant should focus on (Beraldo et al., 2019). The second day was dedicated to controlling the robot. The participant only needed one calibration run before controlling the robot. The participants controlled the robot by concentrating on the desired box on the screen to dictate the direction of the robot's movement. The participant was provided with visual feedback on the position of the robot via a map of the environment (Beraldo et al., 2019). The authors concluded from the results of this study that children can successfully drive a robot using BCI. Children mentioned that the training was boring despite their capability to control the robot (Beraldo et al., 2019).

Involvement of child end-users in informing BCI design

In 2016, Taherian et al. attempted to gather participants' feedback after trying BCI for a puzzle game. In addition, they evaluated the feasibility of implementing an EEG-based BCI for individuals with cerebral palsy (CP). In their study, a commercial EEG-based BCI system, EMOTIV EPOC, was used. After successful calibration using motor imagery tasks, participants could use BCI to play a puzzle game (Taherian et al., 2016). This research started with eight participants who had CP, five of whom were children aged 7-17 years. After the first session, two of the participants were not able to continue the study. All participants reported that the headset was uncomfortable since the head support of their wheelchairs could not be worn during the sessions. In addition, they mentioned that it was tiresome to have the EMOTIV on for more than 15 minutes. Researchers mentioned factors such as limitations of the EPOC device design for the use of individuals with disabilities, uninteresting software user interface design, participant concentration difficulties and physical illness that led to ineffective BCI utilization.

Although a questionnaire regarding participants' feedback on their experience with BCI was developed, after the first few sessions, the research group concluded that the questionnaire was too difficult to pursue with the participants due to communication challenges (Taherian et al., 2016).

To create child-friendly BCI-compatible games suitable for children with significant neurological disabilities, Kelly et al. (year) organized the first North America BCI Game Jam in November 2019. Teams of primarily university students had 48 hours to design a game that used motor imagery or visual P300 paradigms. Thirty teams across North America submitted nine games. Four children with bilateral Cerebral palsy (CP) were invited to be judges of the Game Jam. These children first told the teams about their interests, likes and dislikes. A pre-judging ranking survey was filled in by the children before evaluating the games. This survey asked them to rank the game's criteria in order of least to most important on the theme, art/graphic, music/sound, challenge, enjoyment, and replayability (being able to play again if wanted) . After trying each game, children were asked yes or no questions to rank the games. Three of the child judges rated art/graphics highly. This suggests that the child's enjoyment of a game may be positively correlated with their interest in the game's graphics (Kelly et al., 2019). However, other results varied, indicating each child's individual preferences. Overall, this experience implies that Game Jams may be an effective way to generate BCI-compatible games for children with significant motor impairments that suit their individual preferences (Kelly et al., 2019).

In 2015, Diep et al. interviewed nine mothers of children with disabilities to investigate their perception and attitude toward BCI. Although this study did not include children or sessions using BCI, it is included here because it had rich information regarding the caregivers of end-users' expectations and opinions. None of the parents had prior experience with BCI and did not

have any knowledge regarding the device (Diep et al., 2015). The analysis of the open-ended interview questions led to the creation of five themes: 1) "The potential benefit to aid mothers in interpreting their children's needs." Mothers who participated were motivated to use the BCI device to help their child's social participation. 2) "The preference for the non-invasive BCI approach." Most mothers showed disagreement with the application of invasive electrodes for their children. 3) "The potential benefit of expanding a child's social network." Mothers saw the BCI technology as an opportunity to help their children with disabilities to self-express and engage in society. They thought of this device as an opportunity for the child to communicate and deepen relationships. 4) "BCI use by people without disabilities." Overall, mothers believed that these devices should only be used by their children with disabilities since the other children had other means to access games, etc. 5) "Cost and qualification barriers" (Diep et al., 2015). Mothers mentioned being worried about who would be qualified to have government coverage for a BCI system and how the finances would be granted (Diep et al., 2015).

Additional studies regarding involvement of child end-users in informing BCI design

In 2021, Javadji et al. conducted research focused on knowing the perspective of families of children with disabilities who have tried BCI. Children with disabilities had participated in a program in which they used commercially available BCIs to control game activities such as driving a toy car, guiding a Sphero SPRK+ robot through a maze, painting with the Sphero SPRK+, or playing single-command computer games. Seven caregivers participated in a semi-structured interview with open-ended questions. Four of the children who had been involved in the program for more than three months and could verbally communicate or could indicate "yes" and/or "no" responded to brief yes or no questions. This research highlighted that there was limited prior knowledge about BCI among families. It also noted that parents were happy that

their children experienced independent play and were pleased thinking about how their children could use BCI to have a future career. Families were excited to be part of the BCI program and felt like their opinions were being heard, and they mentioned the personalization of the sessions (e.g., tailoring activities to the child) was the key to their maintenance of participation. Children indicated that they liked being able to control things on their own. They were interested in environmental control, art, music, surfing the internet, and using social media, but BCI for gaming was one of their top two choices (Jadavji et al., 2021).

BCI for leisure by adults

Akhtar et al. presented a study using SSVEP BCI to play a checkers game (Akhtar et al., 2014). Each square on a physical checkers board contained a single LED to produce the visual stimuli. When the participant focused on the LED, analysis of the SSVEP signals determined which square the participant was looking at. First, the participants looked at the square where they wanted the piece moved. Next, the robot reached out and held the game piece from that square. For the robot to take the next step and place the piece in the game, the participant had to focus on their desired target square. Akhtar et al. (year) evaluated the different parameters affecting the algorithm classification accuracy. Two non-disabled individuals participated in this research. Participants completed four games. In total, 98 selections and 17 errors were made. The first participant had an accuracy of 72.9%, and the second participant had an accuracy of 92.2%. These findings indicate participants could successfully play through full games. Akhtar et al. concluded SSVEP to be a practical BCI to be used to enable access to physical games.

Involvement of adult end-users in BCI informing design

A search for BCI use with adults revealed that studies were mainly focused on communication rather than leisure. However, Zickler et al. evaluated the usability of the BCI

Brain Painting application for end-users with motor disabilities (Zickler et al., 2013). The BCI Brain Painting application was designed based on P300 BCI. Four participants took part in this study. They all had physical impairments and were dependent on caregivers (Zickler et al., 2013). The Brain Painting application was evaluated in terms of effectiveness, efficiency, and user satisfaction. To evaluate the system, each participant tried copy spelling, copy painting and free painting. All participants had two copy tasks and five free painting sessions. All participants reached at least 80% accuracy in all three tasks (Zickler et al., 2013). One participant reached 100% correct selection in the copy painting task (Zickler et al., 2013). Participants responded that the BCI tasks were at a low to moderate workload for them. Participants reflected satisfaction with the BCI brain painting. One participant living in a care home reflected concerns regarding lack of support in case of future use in daily life. Participants asked for improvements in the colour, shape, and grid size. Fewer electrodes and no cap were suggested by the participants to make the device more suitable for everyday life (Zickler et al., 2013).

Huggins et al. conducted a telephone survey with 61 people with Amyotrophic lateral sclerosis from the University of Michigan's Motor Neuron Disease clinic (Huggins et al., 2011). The objective of this research was to study the opinions and priorities of people with Amyotrophic lateral sclerosis about BCI design. The survey asked participants about the physical interface of BCI, setup and training time, desired BCI performance, and user priorities for BCI tasks and design. Sixty-one participants answered BCI questions. Thirty participants used caregiver assistance to relay their responses. "Accuracy of command" was the highest priority of the participants. Participants chose an accuracy of at least 90% for a potential system. In addition, speed of operation of 15 to 19 letters per minute and not having accidental exits more than once every 2-4 hours were their top picks (Huggins et al., 2011). When participants were

asked about their preferred method of electrode placement, 84% of the participants were willing to use electrode caps (non-invasive), 72% of participants were willing to undergo outpatient electrode implant surgery, and 41% were willing to undergo a short hospital stay if that indicated access to BCI.

In 2015, Huggins et al. conducted another telephone survey to understand the perspective of individuals with spinal cord injury (SCI) regarding BCI application acceptance (Huggins et al., 2015). The authors evaluated the characteristics of potential BCI users with SCI, their interest in BCIs, and their BCI design priorities. Forty participants participated in a telephone interview. Ten participants who were part of the BCI program answered questions prior to the start of their first BCI scheduled session. All respondents answered questions verbally. All participants were BCI naïve (Huggins et al., 2015). Twenty-four of the participants were classified as low function. The participants ranked "Functions the BCI provides, "Simplicity of BCI setup," "Accuracy of BCI operation," "Electrode type," "Setup time," and "Speed" as the most important design features. The features rated as least important were "Appearance" and "Training time." "Emergency communication" was selected as the most important task (Huggins et al., 2015). 96% of the participants who had low function showed interest in using BCI (Huggins et al., 2015).

In 2020, Kögel et al. conducted research to evaluate BCI users' experience, self-reflection and attitudes toward their rights and vision for the social and ethical implications of BCI (Kögel et al., 2020). Nine BCI users participated in this study. Participants were between 24 -77 years old. Six of the participants were from Germany, two from the US and one from France. Two participants used invasive- BCI with electrodes implanted in their motor cortex. An EEG cap was used by all other participants. Semi-structured interviews were used to collect data.

Interviews were then analyzed using grounded theory. After analysis, Kögel et al. reported the themes as: "BCI can maintain or recover a sense of agency," "can provide opportunities for participation," and "can have positive effects on a user's self-image." BCI users mentioned participating in BCI research gave them the feeling of being part of a team. Using BCI outside of research also helped with participants' self-image and self-definition (Kögel et al., 2020).

Kevin M. Pitt and Jonathan S. Brumberg conducted a study in 2021 to examine the perspective of those with physical impairments while learning to use BCI-controlled communication devices. Though it investigated BCI access to communication rather than leisure, it is included here because the study included a good examination of user experience and satisfaction with the system. In this study, four participants with Amyotrophic lateral sclerosis took part in 12 sessions of letter selection training using a motor-imagery-based BCI (Pitt et al., 2021). Row-column scanning was used to sequentially highlight potential target letters on an onscreen keyboard. During automatic item scanning, participants could choose their desired highlighted selection by BCI by imagining or attempting a limb movement. Participants were aged 38-64 years, and all had a diagnosis of ALS. All participants were able to engage verbally in the feedback questionnaire, and their primary communication method was speech. The authors asked participants to rate their experience on a 9-point scale regarding fatigue, satisfaction with the device, frustration, physical and mental effort, and overall level of effort (Pitt et al., 2021). There was a wide range of ratings among participants indicating unique experiences with the same BCI device, but all participants rated the device as high in mental effort. The authors reported that the lower the system performance was, the higher the mental effort reported by the participants. Surprisingly, the average pre- to post-training session fatigue reveals less fatigue

after participants' experience with BCI. This might be due to engaging in an interesting activity. The paper suggests further study should take place to optimize the BCI application procedure.

Summary

This literature review shows how limited the studies are in gathering opinions of children and adults about leisure using BCI. There are only a few qualitative research studies looking at end-users' perspectives. Only one study (Jadavji et al., 2021) asked children to participate in a questionnaire regarding their experience with BCI, but it was brief. A few telephone survey studies are mentioned above, but participants were BCI naïve, and open-ended questions were not used (Huggins et al., 2011; Huggins et al., 2015). The study of Kögel et al. (2020), included rich, in-depth interviews with individuals who had used BCI, but BCI was used for more than just leisure, and only adults were included. Seeking in-depth insight into child, youth and adult users' experience with non-invasive BCI used for leisure is needed in order to develop a practical and useful technology for all potential end-users.

Chapter 3: Methods

I used a qualitative research method with a generic qualitative approach for this study. A generic qualitative study approach is used when the research does not follow the philosophy of a single established qualitative methodology (Kahlke, 2014). Like all qualitative research, generic studies are about understanding "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences" (Merriam, 2002, p. 23). Generic qualitative research is sub-categorized into interpretive and descriptive qualitative research (Caelli et al., 2003). Interpretive is what I focused on in this research, as it is a methodology that bridges theory and practice (Thorne, 2008). In Interpretive Description, the research questions are created based on their potential to inform practice. In this methodology, interviews with individuals are usually the primary source of data collection (Hunt, 2009). In this study, I aimed to capture end-users' individual experiences with BCI to inform BCI technology development and also help tailor BCI sessions and activities in a way that best fits users' desired preferences and needs.

Participants

This study had two adult participants and one youth participant and caregiver (total n=4). The adult participants were familiar with our research lab and were interested in trying BCI. I ran the sessions where the adults used a BCI system. The youth and his caregiver were recruited through the Glenrose Hospital BCI Program (GRH BCI). The GRH BCI program patients were invited by the program research coordinator and the occupational therapists (OT) to participate in this study. The program OT and the engineer ran the BCI sessions, and I was an observer in those sessions. The inclusion criteria considered while recruiting participants were:

• Markedly restricted functional upper limb use

• Reliable method to indicate yes/no (to guide researchers in preferences, comfort, etc.)

• Functionally intact vision and/or hearing (to hear instructions, see feedback on a computer)

• Ability to understand two-step instructions

A short description of each participant follows:

- Adult 1 will be referred to as "P1" in this thesis. P1 is a 28-year-old female with cerebral palsy (CP). She uses a powered wheelchair and can drive the wheelchair herself. She is verbal and has a Gross Motor Function Classification System (GMFCS) level of III. P1 had never tried BCI prior to this study. However, she had heard about BCI while being a research assistant at the University of Alberta, Assistive Technology lab.

- Adult 2 will be referred to as "P2" in this thesis. P2 is a 34-year-old female with CP. She is non-verbal and uses an Accent 1400 communication device. She types out what she wants to communicate, and the device speaks the text out loud. She uses a powered wheelchair, and she drives herself. Her GMFCS level is IV. P2 had never tried BCI prior to this study.

- The youth participant will be referred to as "P3" in this thesis. P3 is 16 years old. He has CP with a GMFCS level of V. He uses a manual wheelchair, propelled by someone else, with neck support. He is highly dependent on other's assistance for mobility and daily activities. He also uses hearing aids. He is non-verbal. He uses facial gestures to indicate "yes" and "no" (i.e., smiling for "yes" and sticking his tongue out for "no"). P3 had experience with BCI prior to this study, as he had participated in five clinical BCI sessions.

- P3's caregiver will be referred to as "P3's mother" in this thesis. P3's mother interpreted her son's choices for the Glenrose team during BCI sessions and my interview. P3's mother also participated in an interview to reflect on her thoughts and experience with BCI.

Ethical approval was sought from the University of Alberta Human Research Ethics Board (approval letter in Appendix 1). Appendices 2, 3, and 4 include the adult consent form, parent consent form, and youth assent form.

BCI Setup

Motor Imagery (MI) based BCI was used by all the participants for the BCI sessions. A commercially available headset, EMOTIV EPOC (EMOTIV, San Francisco, USA), was used to collect MI EEG brain signals. This device has 14 electrodes and two additional reference electrodes over the right and left mastoids. The electrode pads were moistened with a saline solution to have a reliable connection between the electrodes and the participant's scalp. The software included in the EMOTIV package was used to calibrate the system. At the beginning of each session, the BCI headset was placed on the participant's head, and the Emotiv calibration routine was done. First, the participant was asked to relax their mind. Relaxing meant keeping their mind empty or thinking of something relaxing to calibrate the system for the "rest" mode. Next, the participants were asked to choose a MI command. They had to think of the same command repeatedly to calibrate the system to recognize the brain signal pattern of that specific command. It took repeating the MI command five to ten times to obtain a reliable separation between "rest" and the MI command by the BCI system. This repetition also helped participants better build their skills in thinking of the MI command they had chosen. The Emotiv software uses the movement of a box to provide visual feedback to the user about their mental command

(seen in Figure 1). For example, if the system detects that the participant is making the MI command to lift the arms, the box moves up on the screen. To connect the Emotiv classification of rest or MI command to a video game, software created by the GRH BCI program engineer was used. This software translated the Emotiv commands to a space button press to enable the participants to control video games.
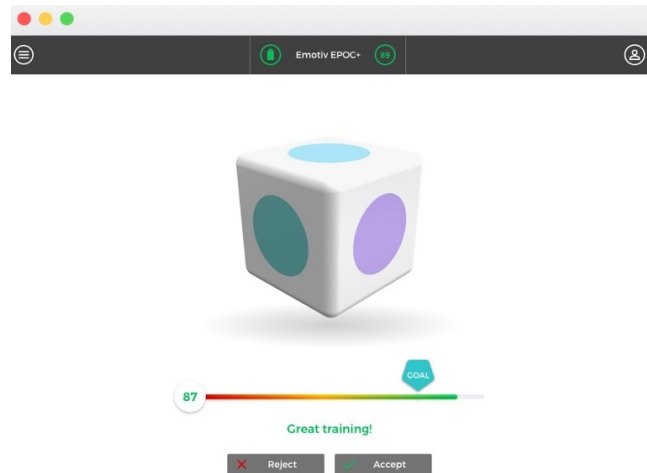
Figure 1: the screen during training. The participant would move the existing cube using motor imagery(https://www.emotiv.com/emotiv-bci/)

BCI Sessions procedure for adults

     P1 had two sessions at the University of Alberta. After headset placement, and the BCI calibration routine, P1 used BCI to play video games. The same procedure was repeated for each of the sessions. She participated in three games where she used the "push" command to jump a pig onto some logs to cross a river, hit a baseball at some targets, and throw basketballs into a hoop. Screenshots of the video games are shown in Figures 2, 3 and 4.

P2 participated in two sessions at her home using all of the required materials, including the Emotiv headset, computer monitor, and laptops,. Each session started with headset placement. The calibration of the BCI was done for the "push" command. P2 used BCI to control the baseball and basketball games (Figures 3 and 4).
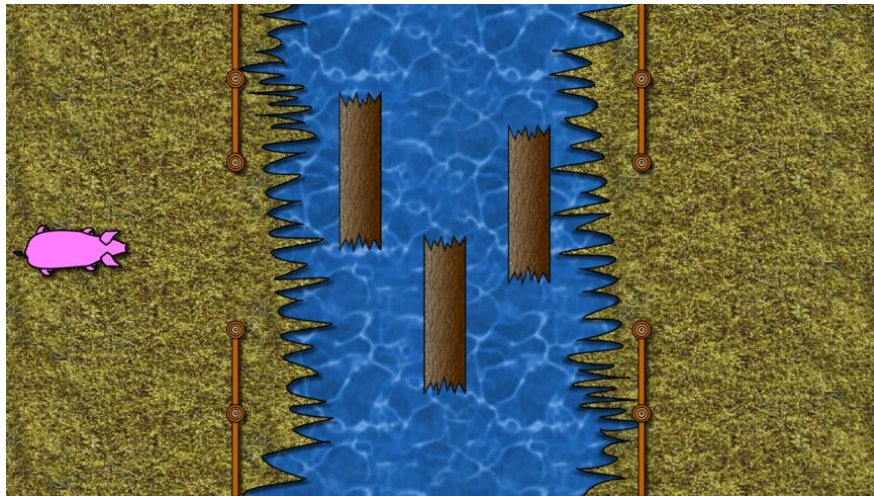
Figure 2: Screenshot of the Pig and Log game (Credit: Shiny Learning 2016-2020). This game required participants to time the jump of the pig so it did not fall into the water.

Figure 3: Screenshot of Baseball Game (Credit: David Vincent- 2012). This game required the participants to time the bat's swing to hit the ball.
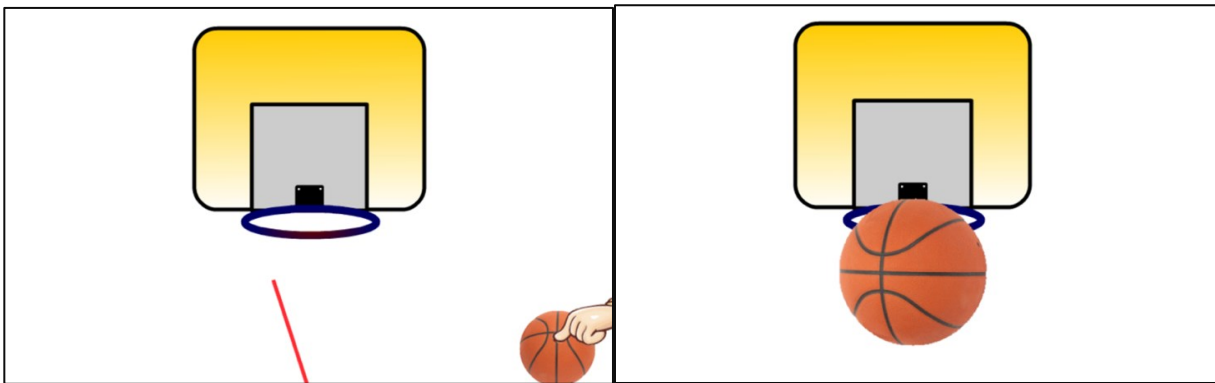
Figure 4: Screenshot of Basketball Game (David Vincent- 2012. This game required the participants to time the ball's throw when the red line was directed at the hoop.

Procedure for youth and his caregiver

P3 and P3's mother had an initial meeting with the OT of the GRH BCI program to explore their goals, interests, and strengths. The options they were presented for BCI control were: environmental control activities such as turning a light or a fan on and off, playing video games, controlling remote control toys, or painting using a Sphero robot toy. P3 chose to play video games and did five sessions. P3 used the MI command of imagining reaching out and touching the OT's finger (to reinforce what he should be doing, the OT said: "boop my finger"). After the calibration step, he started controlling his chosen activity. P3 usually started his set of games by playing Sumo Bootle. Sumo Bootle is a two-player game that P3 played against the GRH BCI program's engineer. To play this game, players must push the space button when the arrow is aimed toward their competitor's avatar. In this game, the player with the most hits and still had "lives" was the winner. After playing this game for a few rounds, P3 continued playing by either playing Fall Guys or Alex Run. Multiple actions, such as running, jumping, and throwing, were required in both games. In these multi-command games, the participant was only responsible for throwing bubbles (Alex run) or jumping (Fall Guys). The other commands needed for the game were controlled by the GRH BCI program's engineer. Screenshots of each game are shown in Figures 5, 6 and 7.
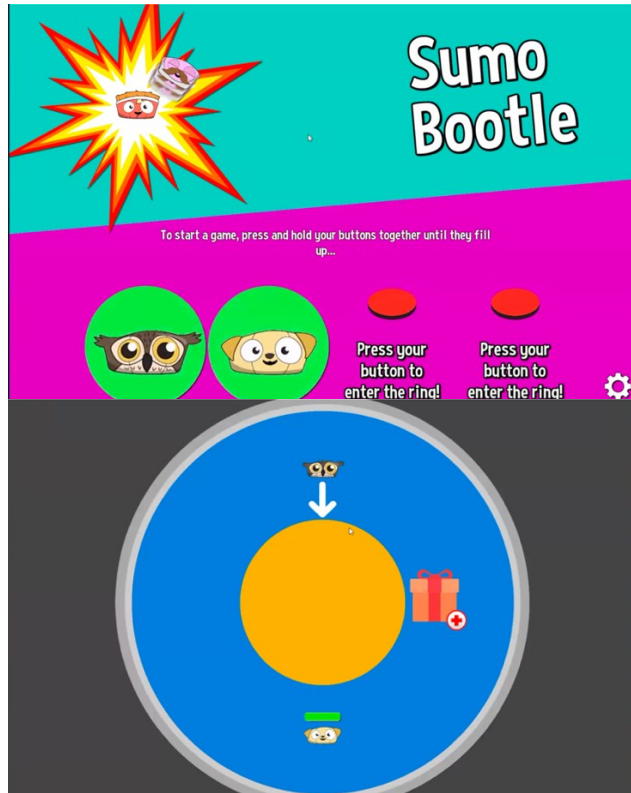
Figure 5: Screenshots of Sumo Bootle game (Credit Alexander Hodge- 2019).
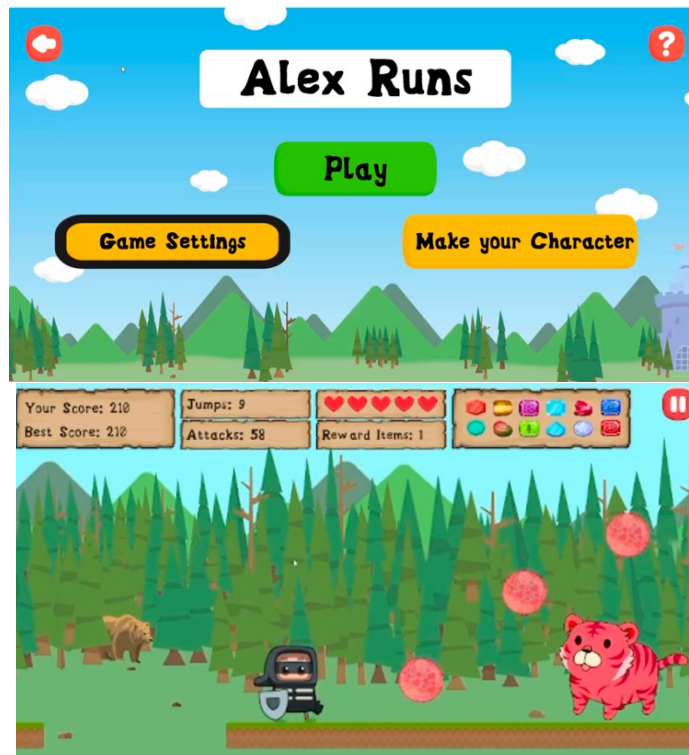
Figure 6: Screenshots of Alex Runs game. (Credit: Holland Bloorview- 2019).
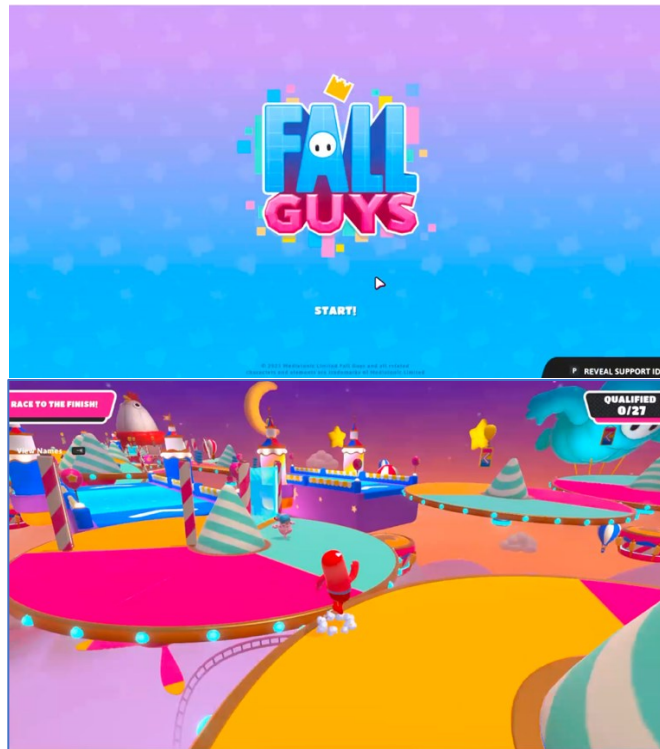
Figure 7: Screenshots of Fall Guys game (Credit: Mediatonic- 2020).

Interview data collection

Since they were BCI naïve, P1 and P2 were interviewed both before and after experiencing BCI. The pre-intervention interview focused on participants' previous experiences with assistive technology, their understanding and knowledge of BCI, their preferences for the activities they would like to perform, and their expectations about the upcoming BCI sessions. A semi-structured interview with open-ended questions was used to collect data.

All participants were interviewed after completing all BCI sessions. This interview was to learn participants' perspectives about their experience with BCI and was 45 minutes to an hour long. Each interview guide was tailored to the participant's communication needs (see Appendix 5 to 8). P1 and P3's mother answered open-ended questions. P2's interview was tailored to have

a mix of multiple-choice and open-ended questions. She could add additional information to her multiple-choice questions, if desired.

It was crucial to use special communication strategies to overcome communication limitations and enhance the interaction between the researcher and P3 as much as possible during the interview. To interview P3, I reduced the open-ended questions to potential answers (i.e., multiple choice). P3 could choose one or more options using his yes or no signals. P3's mother was present during P3's interview to assist him whenever needed as she was a known communication partner. I used several partner-enhanced communication strategies, depending on the type of question:

- Choice-making with hand selection: In this strategy, I presented two choices to P3 using my two hands. For example, I asked, "What would you like to do using BCI? If you want to play video games, look at my right hand. If you want to use it for wheelchair control, look at my left hand." The participant looked at my right hand to choose to play video games.

- Auditory partner scanning: First, I asked the question, and next, I read each answer choice to him. He indicated yes or no after each choice. For example, I asked, "From all the games you played using BCI, which one/ones do you like?" Then, I said each game's name and waited for his response. P3 smiled to show his yes indicator and stuck his tongue out to indicate no.

- Scale meter: I first described the two ends of the smiley face scale (e.g., "one end means "very bad" and the other end means "very good". "). Then, I slowly slid my finger on the smiley face scale from one end to another. The participant signaled "yes" when he wanted me to stop on the scale.

Interviewing caregiver

An interview with P3's mother was scheduled over Zoom the week following the interview with P3. I used a semi-structured interview guide to lead the discussion. The questions were open-ended to encourage the interviewee to freely share her thoughts without feeling constrained by the questions. The discussion was about exploring P3's BCI session, P3's mother's opinions and ideas on how the BCI sessions and experience were and her suggestions on how the BCI system and sessions can improve.

Analysis

The most common approach for analysis in generic qualitative research is using codes, categories, and thematic analysis (Lim, 2011). For this study, interview sessions were recorded. After each interview, I precisely transcribed the recordings for further analysis. I used a thematic analysis approach for the analysis of this research data. In thematic analysis, patterns in qualitative data are identified and reported in six recursive steps (Clarke & Braun, 2013). The first step is familiarization. Since I was present during the interviews, I had a good sense of the flow of the interview. However, it was important to read the data repeatedly and listen to the recordings to notice every detail. The second step is coding the data. This step involved labelling essential sections of the data into codes. The third step is searching for themes. Patterns in codes should be recognized by searching through codes for similarities and grouping them. The fourth step is reviewing themes. This step includes checking the relationship of the codes, themes, and transcripts in order to find a captivating story. In the fifth step, themes should be named, with names representative of the story. The last step is the write-up. In this step, the analytic narrative is weaved together to represent the data and represent it in the context of existing literature.

Rigour in qualitative research is ensuring the research is trustworthy (Thomas et al., 2011). Rigour has four elements: research: (a) truth–value (credibility); (b) applicability (transferability), (c) consistency (dependability); and (d) neutrality (confirmability) (Thomas et al., 2011). The credibility of research depends on the researcher and their ability to choose the representative data as a whole (Thomas et al., 2011). To enhance the credibility of my study, I had my peer researchers debrief and examine my analysis. Transferability is the ability to use findings or methods of one study in another study. For this matter I have written a description of participants, setup and method. I tried to describe the physical and verbal abilities of the participants as best I could so other researchers could see if their participants had similar abilities. When research participants, setup and methods are well described, the reader can judge transferability to their own setting (Thomas et al., 2011).

Dependability is when another researcher can follow your logic of decision-making step-by-step (Thomas et al., 2011). To achieve dependability, Thomas et al. suggest (a) describing the specific purpose of the study, (b) discussing how and why the participants were selected for the study; (c) describing how the data were collected and how long the data collection lasted; (d) explaining how the data were reduced or transformed for analysis; (e) discussing the interpretation and presentation of the research findings; and (f) communicating the specific techniques used to determine the credibility of the data (Thomas et al., 2011). Confirmability occurs once credibility, transferability and dependability have been established. For confirmability, researchers should be critical of themselves to recognize how they may be biased to avoid affecting the study (Thomas et al., 2011).

There were some things about my perspective that may have come into play in this study. I have a mechanical engineering background and I have an interest towards technology. I tried to

be aware of not assuming that the participants would also love technology. Also, I ran the adult participant sessions and interviewed them afterwards. This could have affected participants' comfort expressing negative opinions towards the handling of the session. I tried to let participants know they could answer honestly, and not try to satisfy me with their answers. I have tested a BCI device personally and faced many difficulties using it. I did not expect participants to be able to use the device smoothly, but I tried not to show any discouraging attitude towards the session. In addition, during the interviews, I used semi-structured interviews and asked follow-up questions to the participants' answers to be able to follow their lead, and to try to be a true presenter of their opinions instead of leading them into answers. In addition, I have only done quantitative research prior to this study. Taking field notes of my experiences and perceptions during the interviews and during analysis of things that may personally affect my interpretations helped me be aware when biases might be playing a part. I also asked my supervisors who were experienced with qualitative research to critique my analysis. Finally, I have not had prior experience interviewing or working with non-verbal individuals with disability.

Chapter 4: Results and Discussion

This chapter includes the findings of the study, which employed semi-structured interviews to explore the perspectives of individuals with disabilities regarding their use of BCI (BCI) technology for access to leisure activities. The interviews were analyzed using thematic analysis as described by Braun and Clark (2013). Five main themes were identified from interviews with three participants and a parent:

1. "I never experienced or have been able to play games on my own": BCI as a Potential for Access to Leisure, 2. "Getting his sass back": BCI facilitates individuals to build confidence, 3. "His body is stuck in mud": BCI compensates for the body's physical impairment, 4. The importance of BCI as a potential for effective communication, 5. Improving BCI acceptance for end-users. Each theme is described below. The responses of P3 in his interview can be found in Appendix 9.

1. "I never experienced or have been able to play games on my own": BCI as a Potential for Access to Leisure:

Participants noted how the pursuit of being "included" begins at a very young age and how it was important to engage in the same games and activities as other children. P1 speaks about her experience as a child:*"Early in childhood, all you worry about is being involved and being part of the group. And you care a lot about, you care a lot about, like, games and being able to participate."*

The complexity of the participants' physical impairments necessitated frequent reliance on others for assistance. P2 shared that she had not been able to play **independently** because she always **needed help** to access leisure:*"I never experienced or have been able to play games on my own. Before someone had to help me."*

Participants mentioned how their families and friends had attempted to integrate them into group activities and leisure. However, a true sense of participation was hard to feel due to the participants' lack of independence. It was seen that the lack of independence had an impact on participants' perception of personal accomplishments, rendering game achievements seemingly meaningless. P1 mentioned how she always needed help to "level up" in a game, and she perceived that as cheating, not winning. Because of her physical limitations, she was not able to accomplish the tasks needed to play the game, and she needed help: *"I would always lose [if I played on my own]. Or I would have to have someone 'CHEAT' and help me get through,"* Through the interview, it was illustrated that questioning the authenticity of their achievements can impact the self-esteem of individuals with disabilities. The uncertainty surrounding whether these accomplishments truly belong to the participants or not was reflected, which introduced a considerable emotional challenge, further influencing their sense of self-worth.

Participants revealed their exhaustive attempts to access leisure, with most conventional methods proving unsuccessful. The participants' attempts for discovering the appropriate avenues for accessing leisure seemed like a journey. P3's Mother shared how she and P3 spent a long time finding something engaging for him to do, before finding BCI: *"We were searching for something that, that he might like to do other than, you know, other than watching TV. Because that's what that's all that he was doing other than school for the last three years".*

P3 creatively described the kinds of things he would like to do in a writing assignment for his English class. It's remarkable how he thought of the idea of controlling things with his mind as something farfetched. P3's Mother: *"He wrote a story in his English class, saying how he wants to be a villain who controls things with his brain and wants to talk with dolphins."*

Facing different setbacks and failures through her pathway of accessing leisure, P1 decided to stop trying to access play to avoid negative emotions. However, her experience with BCI was different than her other experiences, leaving her with a positive feeling:

P1: "Playing was associated with a lot of negative emotions, and having this opportunity where it was actually like it, like it was very positive, it challenged my thought process in a way, and maybe like changed the way I think."

Throughout the interviews, it was evident how the introduction of the BCI brought about a new mindset for participants, offering them a newfound ability to access leisure independently. P2 thought BCI had the potential for independence and inclusivity in leisure for children who have physical disabilities: *"They (children) can play with their friends and or siblings without help from parents."*

Overall, it seems that participants reflected they believe BCI can be an effective tool to help individuals with disabilities in the journey of accessing leisure.

2. "Getting his sass back": BCI facilitates individuals to build confidence.

Successful accomplishments can influence an individual's confidence. Using BCI to control a video game can demonstrate to other individuals the great power that their brains have. P3's mother reflected on how confidence gained from using BCI made him more like his previous self*: "But I think he is getting his sass back."*

P3's Mother explains the noticeable visual transformation in her son, as he gained confidence in his abilities after using BCI: *"After a few sessions of BCI, his right hand started to go, and he started to use his voice more... like he's been really proud of himself."*

It is observable in the interviews that the appearance of an assistive technology plays a significant role in either boosting confidence or undermining the user's self-image.

When an AT goes beyond mere functionality and is "cool" it can enhance confidence. The use of visible ATs also shapes how others perceive individuals with physical disabilities, which can directly impact the user's acceptance of the device.

P1:*"It's when you have technology that is cool. It makes you like a cool kid. It's part of who you are. So, it kind of like makes the child feel a lot better about themselves, a lot more confidence and they also bring attention to them in a positive light in a positive way."*

How BCI looks can affect if a child with disabilities will try it. Children's acceptance is highly dependent on how their peers perceive them with the BCI device. P2 believes that the headset would be interesting to children with disabilities upon seeing it: *"They [children with disabilities] would say: the headset looks cool."*

3. "His body is stuck in mud": BCI compensates for the body's physical impairment:

Throughout the interviews, participants reflected on how various assistive ATs lack the ability to fully facilitate access to the environment and communication. But what could be highly understood was their frustration to find a way to channel their true self through assistive technologies. There has been a huge gap between what they could achieve using assistive technologies and the full extent of their brain's capabilities due to physical limitations. P3's Mother expressed: *"He has a whole lot of great power, and sometimes he just doesn't have the capability of getting it out of his body."*

Through the interviews, participants reflected on how their bodies worked against them in reaching their goals. To describe the frustration of being mentally capable yet, having very limited access physically, P3's Mother says: *"Because his brain is going like, a mile a minute, and his and his body is stuck in mud."*

P1 expresses how her body is constantly working against her brain, which causes her to not be able to accomplish tasks on time. *"In real life, there's always this competition between, my brain is too fast, my body is too slow."*

The participants articulated how BCI allowed them to transcend physical limitations, enabling participation in leisure activities that were once challenging or inaccessible. The interviews highlighted the transformative potential that BCI holds in enhancing the overall leisure experience for individuals with disabilities. BCI empowered participants to feel a sense of control, allowing them to navigate activities using their brains instead of competing against their bodies. P1 described her experience using BCI: *"I think of BCI as ... collaboration between the human and a device. This is the most voluntary experience I've ever had."*

4. The importance of BCI as a potential for effective communication

As the interviews unfolded, the theme of the need for communication became increasingly evident in the conversations. Communication was mentioned as crucial in life for expressing who you are, standing up for yourself, socializing, becoming independent, and reaching one's full potential. P3 has not been able to use a communication device independently due to his significant physical limitations. But P3's Mother emphasized the need for P3 to have a way to communicate: "*He has no way of talking. He has no way of answering."*

P3's Mother is worried about his future like every other parent is worried for their child. But, in addition to the concerns of every typically developing child's mother, P3's Mother is worried about how P3 can navigate his life without communicating. P3's Mother describes how P3s's communication is amplified through her: *"I'm I am his microphone."*

But she has been judged in society because of being his microphone. Since others do not understand how their communication functions, she's been accused of forcing P3 into things*:*

"People think that I'm running the agenda... but the agenda is from P3. That's why I've made a conscious effort to consult him about things for him because it's not my body. It's not my life, it's not my brain, it's his."

These types of experiences have grown more concerns for P3's Mother as to how the future will look if P3 isn't able to find a way to advocate for himself. Not everyone has the experience P3's Mother has in understanding her child and not everybody cares enough to facilitate P3's wants. Finding a way to communicate is crucial for P3. P3's Mother believes BCI can be a way to give P3 the chance to communicate: *"If he had something that could go Hi! My name is Blah Blah when he thinks."*

Participants' experience with current communication devices has not been the best regarding speed. After using BCI and experiencing its speed and accuracy, the adult participants thought of using it for their daily struggles with communication. P2 reflects on her current augmentative communication device: *"So much time typing. Sometimes I can't keep up with other people."*

P1 suggests BCI be used for written communication:

"Wouldn't that be so cool if I could write something, with that kind of accuracy with that kind of speed?"

Although the other participants pinpointed their desire to use BCI for communication, P3 strongly disagreed. He only wanted to use BCI for video games.

5. Improving BCI acceptance for end-users

The participants identified several areas for improvement in the BCI experience. Throughout the interviews, it was revealed that the accuracy and efficiency of the BCI device directly impacted

an individual's experience during a BCI session. All participants agreed that the time needed for BCI system **calibration** was long. A shorter calibration time may have lessened fatigue and subsequent effects on the engagement of an individual during a BCI session. In addition, the calibration procedure itself was difficult for the youth participant. While calibrating the system, the computer makes a sound to count down the start of an action needed from the participant. The first action to calibrate is to "rest", and the second action is to "move" (i.e., think about moving your hand). P3's Mother mentioned that for P3" to count down, 3, 2, 1 and then tell him to think of nothing" was confusing. After she mentioned that, the sound was turned off for the calibration for "rest". This had a positive impact on the quality of calibration, and the time it took to do.

Equally important was the user's experience with the comfort of the device. All participants reported having red and irritated skin after the BCI session. Although participants believe this is not something that would alter their decision regarding using BCI or not, they believed an adjustable headset would add so much to the comfort of this experience. There were several contributors to the discomfort. First, the headset was not adjustable in size, so it fits everyone's head shape differently. The headset also felt quite heavy after wearing it for a while. Finally, the Emotiv headset has saline-soaked pads for maximizing electrode connectivity to the scalp, and all participants had difficulty tolerating the wetness. Some believed the wetness would be very distracting and unbearable for children with sensitivity issues. Participants noted that individuals with CP often have sensitivity issues along with their main diagnosis. P1 emphasized that we would have to consider each individual's sensitivities and adapt each session to them as much as possible. Baltzer et al. (2023) reported similar finding with other assistive technologies where individuals with disabilities thought the ATs used for gaming were heavy, caused pain,

and were expensive. The discomfort, pain and cost could cause individuals with disabilities not

to be able to participate in leisure through video games.

Chapter 5: Overall Discussion and Conclusions

This qualitative study aimed to explore the perspectives of individuals with disabilities regarding their experience with EEG MI-based BCI for leisure. This exploration was expected to help us to understand end-users needs and help address them in efforts to improve BCI technology and activities. Our findings provide insight into five main themes: 1. BCI as a Potential for Access to Leisure, 2. BCI facilitates individuals to build confidence; 3. BCI allows the brain to compensate for the body's physical impairment 4. Wanting to use BCI for communication 5. Improving BCI acceptance for end-users.

In this study, participants highlighted the unique experience that BCI provided them in accessing leisure. The BCI utilized in our study allowed participants to access leisure without the necessity of physical movement, relying solely on brain activity. This distinction underscores the potential of BCI to offer a means for individuals who cannot perform reliable motor movements to engage in leisure activities.

Langone (2000) emphasized that assistive technology acts as a game-changer. It becomes an equalizer and enabler, granting disabled children the chance to participate in activities—often for the first time—with success comparable to their typically developing peers. This resonates with my study, highlighting how technology empowered individuals with disabilities by offering new ways to engage and succeed in leisure activities. Participants highlighted the transformative potential of BCI for individuals with disabilities, offering the chance to engage independently in various activities and fostering a sense of confidence. Confidence and self-esteem significantly impact individuals throughout their lives, providing the strength to embrace new challenges and grow as individuals (Valle et al., 2021). It was illustrated through the interviews in the current study how building confidence was particularly challenging due to limited activities that foster a

sense of accomplishment, coupled with the constant need for assistance, which may have diminished the authenticity of their achievements in their minds. The chance to independently participate in a leisure activity using BCI helped participants feel confident in their abilities. This was particularly clear in P3's Mother's comments about his being more vocal and making more physical movements, which she attributed to using his brain and believing in himself. Kögel's interviews with adults resulted in similar findings; they emphasized that BCI was not only a technological advancement but it was a means to enhance overall well-being and self-esteem for individuals with disabilities (Kögel et al., 2020).

Having BCI could help individuals with disabilities to overcome misconceptions held by others and self-advocate. Everyone wants recognition for their achievements (Kögel et al., 2020). In this study, BCI served as a method to empower the participants to show their power using their brains. BCI has helped individuals to believe in their potential and build their self-image (Kögel et al., 2020). For those with disabilities, especially those with limited communication abilities, the inability to advocate for themselves can disrupt their self-image, creating a sense of separation from peers (Kögel et al., 2020). Participants in our study also indicated this matter, suggesting that they would like to use BCI for communication. Participants all reflected on difficulties they face during communication, and they all had different needs. P3 was completely non-verbal, and with further training might be able to use a P300 system for communication someday. P1 and P2 needed a way to speed up their written communication, and perhaps BCI could be used to augment their current abilities.

Independence during the BCI experiences was a pivotal component, reminding participants of their true capabilities despite physical limitations. Participants seized the opportunity to challenge themselves, exert control over their surroundings, and independently

achieve success in the video games. A salient example of this was the participant's shift from thinking she was "cheating" when she had help, to feeling like she was "winning" when she used the BCI. The BCI experience gave all participants a chance to feel an authentic win with no assistance from others needed. Participants also reflected on BCI helping them to know the potential they had within themselves and how they could bypass body limitations using BCI. Kögel et al. (2020) report a similar finding where participants reflected that BCI helped them know they are more than just their body.

Although BCI technology holds great potential for individuals with disabilities, offering various benefits that can significantly improve their daily lives, the widespread daily use of BCI remains a distant reality. Currently, BCI is primarily employed in clinical settings, with professionals overseeing sessions to address clinical and engineering aspects. Most studies regarding BCI focus on system reliability, but so much more than just reliability needs to be examined (Nijboer, 2015). To do so, the future of BCI development should focus on what end-users think and experience, not just measuring effectiveness and efficiency. Kübler et al. (2020) suggest that user-centred design should be the main guiding principle for shaping the evolution of BCI technology. The key to unlocking the full potential of BCIs is active participation by end-users throughout the design process. A collaborative approach between end-users and technology developers can help bridge the translational gap, enabling the uptake of the device by end-users. Users contribute valuable insights when included in research and technology development and implementation processes (Kögel et al., 2020). For example, P3's Mother's suggestion not to count down during the calibration for "rest", and to just sit record signals when sitting calmly is something that may help other individuals with cerebral palsy, too. Doing user-centred design

could help make BCI more functional for users, and help transition them out of clinics and laboratories and into homes (Kübler et al., 2020).

To have an acceptable BCI device, factors such as cost, ease of use, applicability beyond clinical settings, and device appearance are crucial (Kübler et al., 2020). Presently, BCIs are not really used outside clinics, and even if individuals wanted to purchase them, the devices are costly (Kübler et al.,2020). Currently, the ease of use of BCI is often tested with typically developing individuals, and the special head shape of someone who has physical impairments, sensory sensitivities, etc., have not often been considered (Kübler et al., 2020). Measures of ease of use will only be valid if end-users with physical impairments give their opinions about it. In this study, we realized how the appearance of technology can impact an individual in different ways. The "cool" BCI technology may increase a user's self-esteem and impact how others view an individual, and therefore an individual might put effort into mastering it.

A technology's acceptability can qualitatively be assessed by asking users regarding how they received and experienced the technology (Moore et al., 2015). Conducting comprehensive studies such as this, where we asked end-users about the BCI experience, and sharing results with developers, researchers and clinicians, can help BCI not only eventually meet minimal functionality requirements but also be acceptable to end-users. Sekhon et al. (2017) defines acceptability as: A multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention." (page 13). In this study, we as well suggested improvements needed for BCI device to be acceptable by interviewing end-users regarding their experience with BCI.

Limitations and future research

While providing valuable insights, this study's sample size is relatively small and lacks geographical and age diversity. The findings likely do not fully capture the diverse range of experiences among individuals with disabilities using BCI for leisure. In addition, this study focuses on short-term user experiences. Participants only had between two and five sessions using BCI. This might restrict understanding of long-term implications and changes in user perspectives over extended periods.

Although the study acknowledges the importance of parental perspectives, the depth of exploration into this aspect was limited because only one mother was interviewed. A more extensive investigation into parents' experiences, challenges, and expectations related to their children's use of BCI for leisure could offer additional valuable insights.

These acknowledged limitations provide a context for interpreting the study's findings but also pave the way for future research endeavours to address these issues. A more extensive and diverse participant pool, considering a broader geographical range and mixed age groups, should be considered in future studies. This inclusionary approach would ensure a more comprehensive understanding of how individuals with disabilities across various backgrounds experience BCI technology for leisure. In addition, a longitudinal study should be implemented in future studies. This approach would involve participants over an extended period, allowing for a more in-depth exploration of the evolving nature of BCI use and users' values and needs. Understanding long-term implications and changes in user perspectives would provide a comprehensive view of the technology's impact.

Other future research directions

To bridge the gap between clinical settings and real-life applications, future research should specifically focus on evaluating the use of BCI technology in home settings. This approach would allow individuals with disabilities to set up and utilize the BCI system on their own, without the clinical professionals doing everything for them. Assessing satisfaction and usability in everyday life scenarios could provide valuable insights into the practical implications of BCI use and its impact on users' daily routines.

Future studies should consider involving individuals with disabilities as active team members. They should be involved from the study's inception to help inform the research design. Collaborating with end-users in the early stages of study creation could lead to more relevant and meaningful research questions, methodologies, and outcomes. This would foster a collaborative environment where the perspectives of those who use BCI technology are entwined into the research process.

Given the rapid evolution of BCI technologies, future studies could expand the focus beyond BCI for video games and explore a broader spectrum of leisure activities such as painting, robot control, etc. Comparing user experiences across different BCI technologies would provide valuable insights into the unique advantages and challenges presented by each, contributing to a more comprehensive understanding of BCI's applications.

Conclusion:

In conclusion, our exploration into the experiences of individuals with disabilities using BCI for leisure has illuminated five themes. 1. BCI as a Potential for Access to Leisure, 2. BCI facilitates individuals to build confidence, 3. BCI allows the brain to compensate for the body's physical impairment, 4. Wanting to use BCI for communication 5. Future considerations for improving

BCI acceptance for end-users. The identified themes provide valuable insights for refining BCI technology, emphasizing the pivotal role of user perspectives in shaping its evolution and ensuring its broader acceptance among individuals with disabilities in their leisure pursuits. BCI emerged not only as a technological tool but as a catalyst to help individuals achieve overall well-being. This study lays the groundwork for future research and development.

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Appendix

Appendix 1 Ethics Approvals

NACTRC
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EDMONTON ZONE
ADMINISTRATIVE APPROVAL FOR CLINICAL RESEARCH

All clinical research being conducted within the Edmonton Zone requires operational approval to access
AHS areas and ethics approval by a recognized Alberta Research Ethics Board.
Other related documents may be required depending on the scope of the study.
Research in the Edmonton Zone cannot begin until Administrative Approval has been issued.

PROJECT: PRJ37021

Protocol Title: Access to play for children with complex physical needs through a non-invasive brain computer interface

Principal Investigator:
Kim Adams
Rehabilitation Medicine

Funding Agency: Glenrose Rehabilitation Hospital Clinical Research Fund
Funding Type: Investigator-Initiated/Grant
Overhead Rate: 0%

Related Documents:	ID#	Status	Effective
Research Ethics:	Pro00096816	Approved	Feb 21, 2020
AHS Data Disclosure Agreement:	RA94035	Not Required	

AHS Operational Approval: The following AHS areas have agreed to support your research. To gain access, you must have Edmonton Zone Administrative Approval.

51675:   Glenrose Rehabilitation Hospital - I CAN Centre for Assistive Technology

Edmonton Zone Administrative Approval

Approved: Mar 19, 2020
Approved By: Simon Wong
                     Director of Operations, NACTRC

Approval Form

Date:	February 21, 2020
Study ID:	Pro00096816
Principal Investigator:	Kimberley Adams
Study Title:	Access to play for children with complex physical needs through a non-invasive brain computer interface
Approval Expiry Date:	Friday, February 19, 2021

Approved Consent Form:	Approval Date	Approved Document
	2/21/2020	Parent consent form
	2/21/2020	Adult consent forms

Sponsor/Funding Agency:	Glenrose Rehabilitation Hospital	GRH

		Project ID	Project Title	Speed Code	Other Information
RSO-Managed Funding:	View	RES0047932	Access to play for children with complex physical needs through a brain computer interface		

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application, including the following, has been reviewed and approved on behalf of the committee;

- Recruitment Letter (2/21/2020)
- Recruitment Poster (2/21/2020)
- Assent Form (2/21/2020)
- Canadian Occupational Performance Measure (COPM) (2/10/2020)
- Grant Application (1/24/2020)

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries

Appendix 2 Adult consent form

Alberta Health Services

FACULTY OF REHABILITATION MEDICINE
UNIVERSITY OF ALBERTA

Title of Project: Access to play for children with complex physical needs through a non-invasive brain-computer interface

Principal Investigator:
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Matin Dohkt Taghirad, Research Assistant, Masters Student, Faculty of Rehabilitation Medicine
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Co-Investigators:
Corinne Tuck, I CAN Centre for Assistive Technology, **780-735-6070**
Dr. John Andersen, Facility Chief, Child Health, Glenrose Rehabilitation Hospital, **780-735-7918**

What is the purpose of this research study?

We are studying how children who have physical disabilities can use brain signals to control computers and toys. We think the brain-computer interfaces (BCI) available for purchase nowadays could be used for some fun play activities. A BCI is sensors placed on the scalp that detect the electrical activity of the brain. We can convert that activity to commands to control computers and remote controlled toys. We want children who have physical disabilities that limit their access to computers and toys to try the BCI systems.

Before children try the systems we would like you to try them and tell us what you think. This will inform us what activities can be done easily, and look for ways to improve the systems.

The purpose of this information sheet is to provide you with the information needed to decide if you wish to participate in this study. Before you make a decision, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

Children who cannot play with toys may miss developing some skills. Example skills are cognitive skills, self-efficacy and resilience. There is little work in the area of BCI for children. Most research is with adults with disabilities. BCI systems are already available for playing games and families have been asking us about them. They wonder how to implement them for their children who have disabilities. So far, there are no assessment procedures or training programs to guide our practice or family choice.

What will you be asked to do?

You will participate in four to sixteen sessions. We will discuss with you the number of sessions that works best for you. Each session will be about one hour long, with many breaks. The session will be at

the Glenrose Rehabilitation Hospital or the University of Alberta. We could also try another location that might be more convenient (for example, home).

Videos of the sessions will be made only with your consent. You will be asked to do one or more of the following tasks:

- A first meeting to try on the BCI interface (a headset or cap to see how it fits) and try the BCI system and an activity.
- Following sessions to try to improve the system as much as possible.
- After each session we will ask you about the system and how you think it worked.
- If you approve, we will give your email address to children's families in case they have questions for you about your experiences.

You will be reimbursed for any cost to park while at the sessions.

What are the benefits to you?

There may be no benefit to you. You may find that BCI works well for you and you may want to to use it in the future. This project may lead to better BCI for adults and children in the future.

What are the risks and discomforts?

You may feel discomfort from the BCI cap or headset because of the electrodes on your scalp. Some electrodes are made of hard plastic and need to be tight against the head. It might be very uncomfortable if you have a wheelchair headrest. You may have some redness on the skin of the scalp. The redness should go away 10-15 minutes after the cap/headset is removed. You may not be successful with this technology right away. You may get frustrated or tired during the session. Breaks will be given frequently, and whenever you ask for one. The BCI is isolated from a power supply, so there is no danger of electrical shock. The items from the activities will be out of reach, thus, there is no risk of a toy hurting you.

There are risks going to the Glenrose or the University during the COVID-19 pandemic. You would be spending time in public places where you will be near other people.

We have taken measures to reduce the risk including the following.

- Everyone who comes into each facility is screened for COVID-19. The Glenrose has staff at the building entrance who ask questions. The University staff and students do an online self-assessment before entering the building (Building Access Log).
- Everyone wears masks in the hallways (except children who are intolerant of masks).
- The maximum number of people allowed in the labs at one time is 6 people in the Glenrose lab, and 4 in the University of Alberta lab.
- We stay 2 meters apart when possible. When we have to be closer to you we wear masks. If you do not have a mask, we will provide one.
- We have hand sanitizer and a sink in the labs to clean our hands often. Researchers and participants will be asked to sanitize their hands when entering and exiting the room.
- We do careful cleaning of the equipment used in the sessions. We follow the Alberta Health Services routine practice of cleaning equipment for infection prevention and control.
- We clean common surfaces such as doorknobs and table surfaces often.

If you chose that the sessions should happen in your home, there are risks associated with a researcher coming to your home. We would take measures to reduce the risk including the following.

- We will do the online self-assessment to make sure we do not have COVID-19 symptoms.
- We will wear masks and stay 2 meters away from you when possible. If you do not have a mask, we will provide one.
- We will use hand sanitizer when enter and exiting the home.
  We will do careful cleaning of the equipment used in the sessions according to the Alberta Health Services routine practice of cleaning equipment for infection prevention and control.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to study participants.

Will my information be kept private?

The information you provide will be kept confidential. We will use the video recordings to do data analysis. If you consent, we may use video clips for research presentations. We will not identify anyone by name. The information will be kept for at least five years after the study has ended. It will be kept in a locked file cabinet and in an encrypted computer file. The information will be only available to the researchers.

Do I have to take part in the study?

You are free to refuse to participate, and you are free to withdraw from this study at any time. You do not have to give a reason. This will not affect your program or treatment in any way.

If you decide to end participation in the study, you can tell the researchers at any time. If the data collection has been completed, we will still use your information anonymously. If you withdraw before the data collection is completed, we will ask you if you would like us to withdraw all of your data.

What if I have questions?

If you have any questions about the study please contact us.
  Kim Adams (Phone: 780- 392-0309, e-mail: kdadams@ualberta.ca) Faculty of
  Rehabilitation Medicine, University of Alberta.

If you have any questions or concerns about the ethical aspects of this study, please contact
  University of Alberta Research Ethics Office at reoffice@ualberta.ca.

The Institution and Principal Investigator have been awarded a Glenrose Clinical Research Grant to cover the costs of doing this study. You are entitled to request any details concerning this compensation from the Principal Investigator.

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Consent Form

Title of Project: Access to play for children with complex physical needs through a non-invasive brain-computer interface

Principal Investigator:
Kim Adams, Associate Professor, Faculty of Rehabilitation Medicine
Contact info: **Phone: (780) 492-0309, Email: kdadams@ualberta.ca**
Research/Study Coordinator:
Matin Dohkt Taghirad, Research Assistant, Masters Student, Faculty of Rehabilitation Medicine
Contact info: **Phone: (780) 492-5422, Email: dohkttag@ualberta.ca**
Co-Investigators:
Corinne Tuck, I CAN Centre for Assistive Technology, **780-735-6070**
Dr. John Andersen, Facility Chief, Child Health, Glenrose Rehabilitation Hospital, **780-735-7918**

To be completed by the research participant or guardian:

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or to withdraw from the study at any time without giving a reason and without negative consequences?	Yes	No
Do you understand that we need information such as age and diagnosis?	Yes	No
Has the issue of confidentiality been explained to you?	Yes	No
Do you understand who will have access to your data including personally identifiable information?	Yes	No
Do you consent to be videotaped for research purposes?	Yes	No
Do you consent to have short videotaped clips used in research presentations?	Yes	No
Do you consent to the researchers sharing your email address with parents of children who may try the brain computer-interface system?	Yes	No

By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about you as described above.

This study was explained to me by: _____

I agree to to take part in this study.

_____   _____
Signature   Date

_____
Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____   _____
Signature of Investigator or Designee   Date

Appendix 3 Parent consent form

Title of Project: Access to play for children with complex physical needs through a non-invasive brain-computer interface

Principal Investigator:

Kim Adams, Associate Professor, Faculty of Rehabilitation Medicine
Contact info: **Phone: (780) 492-0309, Email: kdadams@ualberta.ca**

Research/Study Coordinator:

Matin Dohkt Taghirad, Research Assistant, Masters Student, Faculty of Rehabilitation Medicine
Contact info: **Phone: (780) 492-5422, Email: dohkttag@ualberta.ca**

Co-Investigators:

Corinne Tuck, I CAN Centre for Assistive Technology, **780-735-6070**
Dr. John Andersen, Facility Chief, Child Health, Glenrose Rehabilitation Hospital, **780-735-7918**

What is the purpose of this research study?

We are studying how children who have physical disabilities can use brain signals to control computers and toys. We think the brain-computer interfaces (BCI) available for purchase nowadays could be used for some fun play activities. A BCI is sensors placed on the scalp that detect the electrical activity of the brain. We can convert that activity to commands to control computers and remote controlled toys. We want children who have physical disabilities that limit their access to computers and toys to try the BCI systems. This will inform us what activities can be done easily, and look for ways to improve the systems.

What is the reason for doing the study?

Children who cannot play with toys may miss developing some skills. Example skills are, cognitive skills, self-efficacy and resilience. There is little work in the area of BCI for children. Most research is with adults with disabilities. BCI systems are already available for playing games and families have been asking us about them. They wonder how to implement them for their children who have disabilities. So far, there are no assessment procedures or training programs to guide our practice or family choice. Some children may not be successful with this technology right away. It is difficult for us to predict who will be successful and why. This study will help inform who might have success with BCI or not.

What will your child be asked to do?

Your child will participate in four to sixteen sessions. We will discuss with you the number of sessions that works best for you. Each session will be about one hour long, with many breaks. You will be present during the session. The session will be at the Glenrose Rehabilitation Hospital, or we could try another location that might be more convenient (home, University of Alberta).

Videos of the sessions will be made only with your consent. Your child will be asked to do one or more of the following tasks:

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- A first meeting with the occupational therapist and researchers to pick a goal to work on. Goals might include clicking the mouse in computer game, or moving a remote controlled car.
- A second meeting to try on the BCI interface (a headset or cap to see how it fits) and try the BCI system and activity.
- Following meetings to try the activity, and try to improve the system as much as possible.
- After each session we will ask your child and you about the system and how you think it worked.
- At the end of the study, we will ask your child and you some questions about your experiences and opinions about the system.

You will be reimbursed for any cost to park while at the sessions.

What are the benefits to your child?

Children often see peers and siblings playing video games or other games with their hands. BCI may give your child an opportunity to play with the same sorts of technology. This may help your child build confidence. Plus, it may increase their interest in trying technology tools and toys. This project may lead to better BCI for other children in the future.

What are the risks and discomforts?

Your child may get tired during the session. Breaks will be given frequently, and whenever you or or child ask for one. The BCI is isolated from a power supply, so there is no danger of electrical shock. The toys will be out of reach of the children, thus, there is no risk of a toy contacting the child. Your child may feel discomfort from the BCI cap or headset because of the electrodes on their scalp. Some electrodes are made of hard plastic and need to be tight against the head. Your child may have some redness on the skin of the scalp. The redness should go away 10-15 minutes after the cap/headset is removed. Some children may not be successful with this technology right away.

There are risks going to the Glenrose or the University during the COVID-19 pandemic. You would be spending time in public places where you will be near other people.

We have taken measures to reduce the risk including the following.
- Everyone who comes into each facility is screened for COVID-19. The Glenrose has staff at the building entrance who ask questions. The University staff and students do an online self-assessment before entering the building (Building Access Log).
- Everyone wears masks in the hallways (except children who are intolerant of masks).
- The maximum number of people allowed in the labs at one time is 6 people in the Glenrose lab, and 4 in the University of Alberta lab.
- We stay 2 meters apart from each other when possible. When we have to be closer to you we wear masks. If you do not have a mask, we will provide one.
- We have hand sanitizer and a sink in the labs to clean our hands often. Researchers and participants will be asked to sanitize their hands when entering and exiting the room.

- We do careful cleaning of the equipment used in the sessions. We follow the Alberta Health Services routine practice of cleaning equipment for infection prevention and control.
- We clean common surfaces such as doorknobs and table surfaces often.

The pandemic may get worse, and you may not be allowed to come to the Glenrose or university. If that happens, you could take a laptop and brain computer interface home. It will depend if the equipment is available, and if you want to do this. We would give you instructions to set up the system for your child. We will be available on the phone or videoconferencing to assist you. Brain signal recordings and computer actions will be collected on the laptop. No identifying information will be saved. We will ask you to email us the data once in a while on our secure Alberta Health Services or University email addresses.

Will my child's information be kept private?

The information you provide will be kept confidential. We will use the video recordings to do data analysis. If you consent, we may use video clips for research presentations. We will not identify anyone by name. The information will be kept for at least five years after the study has ended. It will be kept in a locked file cabinet and in an encrypted computer file. The information will be only available to the researchers.

Do I have to take part in the study?

You and your child are free to refuse to participate, and you are free to withdraw from this study at any time. You do not have to give a reason. This will not affect your child's program or treatment in any way.

What if I have questions?

If you have any questions about the study please contact us.
Kim Adams (Phone: 780- 392-0309, e-mail: kdadams@ualberta.ca) Faculty of Rehabilitation Medicine, University of Alberta.

If you have any questions or concerns about the ethical aspects of this study, please contact University of Alberta Research Ethics Office at reoffice@ ualberta.ca.

The Institution and Principal Investigator are getting money from the Glenrose Clinical Research Grant to cover the costs of doing this study. You are entitled to request any details concerning this compensation from the Principal Investigator.

Consent Form

Title of Project: *Access to play for children with complex physical needs through a non-invasive brain-computer interface*

Principal Investigator:
Kim Adams, Assistant Professor, Faculty of Rehabilitation Medicine, Glenrose Rehabilitation Hospital
Contact info: **Phone: (780) 492-5422, Email: kdadams@ualberta.ca**

Research/Study Coordinator:
Matin Dohkt Taghirad, Research Assistant, Masters Student, Faculty of Rehabilitation Medicine
Contact info: **Phone: (780) 492-5422, Email: dohkttag@ualberta.ca**

Co-Investigators:
Corinne Tuck, I CAN Centre for Assistive Technology, **780-735-6070**
Dr. John Andersen, Facility Chief, Child Health, Glenrose Rehabilitation Hospital, **780-735-7918**

To be completed by the research participant or guardian:

Do you understand that you and your child have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in your child taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you and your child are free to refuse to participate or to withdraw from the study at any time without giving a reason and without negative consequences?	Yes	No
Do you understand that we need information such as your child's age and diagnosis?	Yes	No
Has the issue of confidentiality been explained to you?	Yes	No
Do you understand who will have access to your child's data including personally identifiable information?	Yes	No
Do you consent to have your child videotaped for research purposes?	Yes	No
Do you consent to have short videotaped clips of your child used in presentations?	Yes	No

By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about your child as described above.

This study was explained to me by: _____

I agree to allow my child to take part in this study, and attend the sessions and answer questions.

_____   _____
Signature of Parent or Guardian   Date

_____
Printed Name

_____
Name of Child

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____   _____
Signature of Investigator or Designee   Date

Appendix 4: Youth assent form

PARTICIPANT ASSENT FORM

Title of Study: Access to Play Through a Non-Invasive Brain Computer Interface

Principal Investigator:
Kim Adams, Associate Professor, Faculty of Rehabilitation Medicine
Contact Info: Phone: (780) 492-0309, Email: kdadams@ualberta.ca

Research/Study Coordinator:
Matin Dohkt Taghirad, Research Assistant, Masters Student, Faculty of Rehabilitation Medicine
Contact Info: Phone: (780) 492-5422, Email: dohkttag@ualberta.ca

Co-Investigators:
Corinne Tuck, I CAN Centre for Assistive Technology, 780-735-6333
Dr. John Andersen, Facility Chief, Child Health, Glenrose Rehabilitation Hospital, 780-735-7918

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out if using brain signals is a good way to play games and make robots and toys move. You are being asked to join this study because you have a physical disability that may make it hard for you to use other assistive technologies.

What will you have to do? We might start by asking you and your parents some questions about other assistive technology you have used. This can happen in person or over Zoom. Then, you will come to our office several times. The sessions will be about one hour long. You can have lots of breaks, and your mom, dad, or someone you know will be there with you.

We will place a head set like this on your head to record your brain signals. You will try to control games or toys by thinking about making them move, or by looking at commands on a computer screen.

After 4-16 sessions, we will ask you and your parents some questions about what you liked and didn't like about the session.

Will it help? You may enjoy playing with the games and toys. What we learn from you might help us make the system better for other kids in the future.

Will it hurt? We will try to make the headset as comfortable as possible. But it might press on your head and feel bad for a while. You may get frustrated when the system doesn't do what you want it to.

Can you quit? You don't have to take part in the study at all. You can quit any time. No one will be mad at you if you decide you don't want to do this, or if you decide to stop part way through. You can tell your parents or a researcher if you don't want to continue.

Who will know? No one except your parents and the researchers will know you are taking part in the study unless you want to tell them. Your name and your information won't be seen by anyone except the researchers during the study.

Your signature: We would like you to sign this form to show that you agree to take part. You can sign however you like. For example:
- You can write your name if you are able.
- You can nod or say "Yes" with your voice or with your talker if you have one.
- You can make the sign that you make for "yes".
Your mom or dad will be asked to sign another form agreeing for you to take part in the study.

Do you have more questions? You can ask your mom or dad about anything you don't understand. You can also talk to Matin. Her phone number is 780-492-5422.

☐ Yes, I will be in this research study. ☐ No, I don't want to do this.

Child's Name	Child's Signature	Date

Witness Name	Witness Signature	Date

I have discussed this research study with, _____, using language which is
<div align="center">Child's Name</div>

understandable and appropriate for the participant. I believe that I have fully informed him/her of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assent to participate in this study.

Investigator/Designee Name	Investigator/Designee Signature	Date

Appendix 5 Parent Interview Guide

Interview Date: _____   BCI Program Enrollment Date: _____

PT ID#: _____

Interviewee (Circle One):   Mother   Father   Other_____

Introduction

- Thank you for agreeing to participate in this interview today.

- We are interested in understanding your thoughts on the BCI. We would like to learn more about any impact the BCI may have had on your child, family and the directions you would like to see where BCI goes.

Procedure

- I will be asking a series of questions; you are welcome to add information as you see fit. You are also able to decline to answer any questions or end the interview at any point.

- There are no right or wrong answers, we are really just trying to learn from you and gain insight into your ideas and opinions.

- I will be recording our discussion but all of your and your child's identifying information will be kept private. You and your child's name and other personal information will not be included when we report our results. There is no way for other people to know that it was you that answered these questions.

- Did you have any questions before we start?

BEGIN AUDIO RECORDING

First, how familiar were you with BCI when you were invited to join the program?

1) Let's talk about how you felt at the beginning of trying the BCI

   a) How did you expect the BCI experience to be for your child (for ___name___)? How different or similar were the actual experience and your expectations?

   b) Were there any specific hopes that you had?

   c) Were there any specific worries that you had before trying BCI?

2) Thinking about your child, do you think that experiencing BCI has **impacted** them at all? How so?

   a) How does it feel to see your child using BCI?

b) How engaged do you think your child is in using BCI?

c) How do you think it has impacted them emotionally?

    i) What do you think could help improve their interest and engagement?

3) Does your child use other assistive technologies?

a) How has your experience been with other ATs?

4) How do you feel using BCI compared to other activities that your child may be involved in?

a) In terms of enjoyment

b) In terms of interest and engagement

5) Has your child experienced any difficulties or setbacks with the current BCI technologies they have tried?

a) Do you think there are any facilitators or things that would make your child's BCI experience easier?

b) Are there any other difficulties that make using BCI challenging for you? (e.g., head set, set up, training time)

6) How do you think BCI might be useful for your child throughout their life?

7) What would you like to see the BCI being used for in the near future?

8) Is there anything else you would have wanted me to ask that I did not touch on? Do you have any additional comments?

Appendix 6 Youth Interview Guide: Non-verbal Communication

Interview Date: _____   BCI Program Enrollment Date: _____   PT ID#: _____

Mode of Yes/No communication: _____

1.   How does using BCI to play video games make you feel?

Very bad   bad   so so   good   very good

2.   I'm going to say some things that I wonder if you like about using the BCI. Say yes to the things that you like:

[ ]   Controlling things on my own

[ ]   Playing video games

[ ]   Trying new things

[ ]   Playing against someone

        Other:

3.   I'm going to say some things that you may not like about the BCI. Tell me the things you don't like:

[ ]   The way the headset feels

[ ]   How long it takes to set up

[ ]   There are not enough activities to choose from

[ ]   How hard it is to make the BCI work

[ ]   How tired my brain feels from concentrating

[ ]   How my body feels afterwards (ex. tired, sore)

[ ]   It can be boring

       Other:

4.   Which of these things would be good to do?

[ ]   Should we invite other people to join the program

[ ]   Should we have group camps where you meet other people and practice BCI together?

[ ]   Should we find ways for you to practice using the BCI at home

5.   From all of the games that you have tried, what is your favourite to do with the BCI?

[ ]   Sumo bootle

[ ]   Fall guy

[ ]   3 Bubble shooting game

[ ]   none

[ ]   all of them

6.   What has been your least favourite game that you have tried with the BCI?

[ ]   Sumo bootle

[ ]   Fall guy

[ ]   3 Bubble shooting game

[ ]   none

[ ]   all of them

7.   Is there something else that you would like to try using BCI?

[ ]   Drive the remote-controlled car

[ ]   Paint with a robot ball (Sphero)

[ ]   Drive the robot ball (Sphero) through a maze

[ ]   Using a spelling board

[ ]   Play an Xbox game

Appendix 7 Adult Interview Guide – For verbal adult (P1) -

7.1 Pre session interview guide

1) Childhood assistive technologies
    a) Did you use AT as a child?
    b) How was your experience with AT in your childhood?
    c) If you could change one thing about ATs back then, what would it be?
2) BCI knowledge
    a) What do you know about BCI?
    b) Have you ever seen/tried BCI?
    c) What would you like to use BCI for?
    d) Thinking back to when you were a child, what would you have thought about BCI as a child?

7.2 Post session interview guide

   A. Experience:

       a.   How would you describe your overall experience?

         i. If you could change anything about this experience, what would it be?

       b.   Was your experience the same as your expectations?

         i. What was the same/different?

       c.   What do you think you would have thought about BCI if you had tried it as a child?

         i. What would you have used it for? (games, environmental control)

   B. Device

       a)   What did you think of the headset? (and if there were problems, then what improvements would it need)

       b)   Do you think the device would be comfortable for children with physical impairments?

c)   What did you think of the software? (and if there were problems, then what improvements would it need)

d)   What did you think of the Activities? (and if there were problems, then what improvements would it need)

e)   Are overall any changes needed to anything so children can better use the BCI?

      i) How?

f)   Is there anything else you would like to add?

Appendix 8 Adult Interview Guide – For nonverbal adult (P2) -

8.1 Pre session interview guide

1) Assistive technologies

    a) Do you use AT?

        i) What ATs do you use?

    b) How would you describe your experience with AT?

    c) If you could change one thing about your ATs, what would it be?

2) BCI knowledge

    a) Do you know what Brain-computer interface is?

    b) Have you ever seen or tried BCI?

    c) What might you like to use BCI for?

    d) How do you feel about trying BCI?

8.2 Post session interview guide

        A. Experience.

      1. How would you describe your overall experience?

      2. How would you rate your experience?

            1. Excellent

            2. Good

            3. Moderate

            4. Hard

            5. Bad

            6. Very bad

            7. Other… if other, please explain.

          i. If you could change anything about your experience with BCI, what would it be?

      3. Was your experience with BCI the same or different from your expectations?

            1. Same

            2. Different (it was better)

            3. Different (it was worse)

        i. Please explain

4. If it worked well, what might you like to use BCI for?

    1. Games

    2. Environmental control

    3. Communication

    4. Other…

5. Explain why you chose to use BCI for [above]

6. How do you see BCI's future?

B. Device

    1. What did you think of the headset?

    2. How would you rate the headset?

        1. It was excellent

        2. It was good

        3. It was comfortable

        4. It was uncomfortable

        5. It was bad

        6. It was very bad

      ii. What improvement do you think the headset might need?

        1. Be more comfortable

        2. Be lighter

        3. Be less itchy

        4. Look different

        5. other…

    5. What do you think about the comfort of the device?

    6. What did you think of the software?

    7. How would you rate the software?

        1. It was excellent

        2. It was good

        3. It was easy

4. It was hard

5. It was confusing

6. It was bad

7. It was very bad

 i. What improvements do you think the software might need?

  1. Be more user-friendly

  2. Be easier

  3. Look better

  4. Other … explain

8. What did you think of the Activities (game/environment control)?

9. How would you rate the Activities?

  8. It was excellent

  9. It was good

  10. It was easy

  11. It was hard

  12. It was confusing

  13. It was bad

  14. It was very bad

 i. What improvements do you think the activities might need?

  1. Have more variety

  2. Be more interesting

  3. Be easier

  4. Other…explain

10. What is your opinion about children using BCI?

11. How do you think they would feel about BCI ?

12. What do you think children would like to use BCI for?

13. What sort of advice would you give us for working with children?

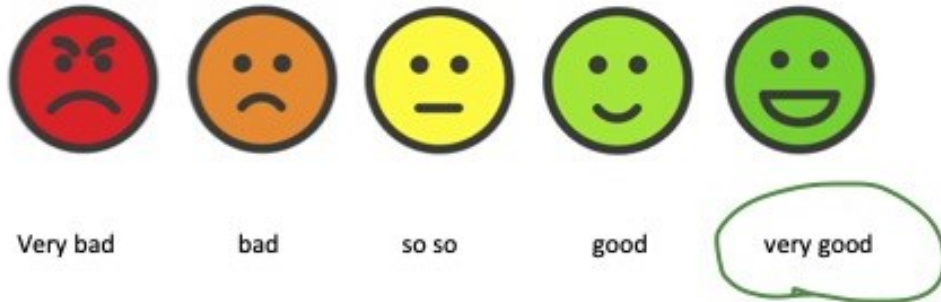Is there anything else you would like to add?

Appendix 9 P3's filled questionnaire

Child Interview Guide: Non-Verbal Communication

Interview Date: Jul,20,2023   BCI Program Enrollment Date: _____   PT ID#: P3_____

Mode of Yes/No communication: Smile for yes. Sticking tongue out for no.

1. How does using BCI to play video games make you feel?

Very bad   bad   so so   good   very good

2. I'm going to say some things that I wonder if you like about using the BCI. Say yes to the things that you like:

[✓] Controlling things on my own
[✓] Playing video games
[ ] Trying new things
[ ] Playing against someone

Other:

3. I'm going to say some things that you may not like about the BCI. Tell me the things you don't like:

[ ] The way the headset feels
[✓] How long it takes to set up
[ ] There are not enough activities to choose from

[ ]   How hard it is to make the BCI work
[ ]   How tired my brain feels from concentrating
[ ]   How my body feels afterwards (ex. tired, sore)
[ ]   It can be boring

Other:

4. Which of these things would be good to do?

[✓]   Should we invite other people to join the program
[ ]   Should we have group camps where you meet other people and practice BCI
together?
[ ]   Should we find ways for you to practice using the BCI at home

5. From all of the games that you have tried, what is your favourite to do with the BCI?

[✓]   Sumo bootle
[✓]   Fall guy
[✓]   Alex run
[ ]   none
[ ]   all of them

6. What has been your least favourite game that you have tried with the BCI?
[ ]   Sumo bootle
[ ]   Fall guy
[ ]   3 Bubble shooting game
[✓]   none
[ ]   all of them

7. Is there something else that you would like to try using BCI?

[ ]   Drive the remote-controlled car
[ ]   Paint with a robot ball (Sphero)
[ ]   Drive the robot ball (Sphero) through a maze
[ ]   Using a spelling board
[ ]   Play an Xbox game

[✓]   Video games