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DEVELOPING AND EVALUATING A MULTIMEDIA TECHNOLOGY APPROACH TO SURVEYING INDIVIDUALS WITH COGNITIVE DISABILITIES TO PROMOTE PERSON CENTERED PRACTICE

Izel Steinmann Obermeyer

A thesis submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy.

Johannesburg

July 2025

Declaration

I, Izel Steinmann Obermeyer, hereby declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



29th Day of July, 2025

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Dedication

I dedicate this work to my three children:

Danielle Obermeyer

September 3, 1996 – September 3, 1996

Brigitte Obermeyer

December 15, 1997

Alexander Steinmann Obermeyer

September 10, 1999

And all the individuals with cognitive disabilities that I had the privilege of working with over the past 37 years

All of the work in this thesis comes from what I have learned from these people, how they shaped me as a human being and as an occupational therapist…

“A pessimist sees the difficulty in every opportunity; an optimist sees the opportunity in every difficulty.” Winston S. Churchill

“There is only one way to see things, until someone shows us how to look at them with different eyes.” Pablo Picasso

“We do not “do” inclusion “for” people with disabilities. Rather, it is incumbent upon us to figure out how all the things we do can be inclusive. “ Lisa Friedman, *Removing the Stumbling Block*

Publications and presentations arising from this study

Presentations

Obermeyer, I., 2019, Developing and evaluating a multimedia technology approach to surveying individuals with cognitive impairment to promote person centered practice – an introduction, November 19, 2019, AUCD 2019 Conference, Washington D.C.

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Steinmann Obermeyer, I., Patrick, P. A., Pena, K., 2023, Use of Online, Cognitively Accessible Software to Empower Individuals with Intellectual and/or Developmental Disabilities, November 6, 2023, AUCD 2023 Conference, Washington D.C.

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Abstract

Introduction

The lack of accessible surveys available to obtain feedback and information about health directly from individuals with cognitive disabilities, or intellectual and/or developmental disabilities (IDD) themselves, and not by proxy from family members or guardians, is a major concern. Although literature describes guidelines and examples of accessible surveys, most commercial survey platforms do not provide an interface that is accessible to individuals with cognitive disabilities. There is little detailed research on the provision of a co-developed platform on which accessible surveys can be created in conjunction with stakeholders, including individuals with cognitive disabilities, with limited evidence of what accessibility has been achieved.

Overall Methodology

The design of the Westchester Institute for Human Development Easy Survey (WES) platform was based on the design cycle for the development of technology by Verschuren and Hartog (2005). The multimethodology study was completed in three phases.

Phase 1 - Development of technology for a cognitively accessible survey software platform

Methods

Phase 1 of the study initialized the co-development process through consultation with experts who work with individuals with cognitive disabilities as well as individuals with cognitive disabilities themselves to identify features that would be needed to design a cognitively accessible survey platform. A case study was used to determine the perceptions of expert researchers/survey developers and end-users with IDD with emphasis on what was needed to develop a platform to make surveys accessible to individuals with IDD for self-report in a health services setting (Phase 1a and 1b). Phase 1c compiled and analyzed the information gathered from stakeholder interviews in Phases 1a and 1b into a comprehensive statement of requirements for the development of the accessible survey platform. Thereafter, Phase 1d considered the structural specifications for planning delivery of this platform and how it could be accessed/interacted with by individuals with cognitive

disabilities. In this stage of the study, the first version of WIHD EasySurvey was created. Lastly the evaluation of this built prototype was completed by expert researchers/survey developers and end-users, and pilot tested with individuals with IDD using an already-established patient satisfaction survey (Phase 1e).

Results

Two themes emerged in Phase 1 from expert researchers/survey developers – ensuring that the technical specifications of the survey platform software allow for accessible features, and adhering to accessibility requirements when developing a survey for individuals with cognitive disabilities. In Phase 1b, end-users with IDD identified their needs to be able to self-report through surveys to ensure accessibility of a survey platform; discussions with these individuals were analyzed to extract themes related to software, device, and population specific considerations.

A statement of requirements document was developed in Phase1c from the themes found in Phases 1a and 1b, which was used to inform the first design concept in consultation with the software developer, after reviewing currently available survey platforms and evidence in literature for accessibility of online surveys. A software developer and graphic designer then created a draft user-interface design also during Phase 1c. Results in Phase 1d confirmed the need for survey delivery on various devices, and a prototype survey, which was shared with the participants from Phase 1a and 1b for review, was modified and reported to be accessible during a pilot test with individuals with IDD in Phase 1e.

Discussion and conclusion

The thematic analysis highlighted the need for the development of an online software platform with flexible and comprehensive front-end and back-end capabilities that a survey developer can utilize to create an accessible survey that individuals with cognitive disabilities can access and complete to ensure self-report. Both experts and end-users with IDD stressed understanding the varied abilities of end-user and device compatibility. The feedback from experts and end-users with IDD in conjunction with an analysis of industry standard survey platform features and available literature confirmed survey platform requirements for subsequent study phases. Insights from this phase informed the principal investigator (PI) in developing the new technology platform.

Phase 2 - Implementation and testing of the multimedia technology in a survey format

Methods

Phase 2 addressed the implementation step in the designing cycle by recreating an existing Self-Advocacy Survey on the WIHD EasySurvey prototype platform. The prototype survey was transferred to a real-life context in a 10-question abbreviated WIHD self-advocacy survey (SAS), created on WIHD EasySurvey (WES), used for self-report by individuals with cognitive disabilities (Phase 2a). A group consensus research design was used with occupational therapy students who had a unique background in activity analysis and disability knowledge to select multimedia images for each question (Phase 2b). These images were evaluated by expert researchers/survey developers and end-users for content validity (Phase 2c).

Results

The 10 questions chosen for the WES abbreviated WIHD SAS were set at a readability level of 3rd - 5th Grade in valid assessments adapted for adults. Sound and video multimedia were activated in the survey and at least two images, with 80% consensus agreed upon by co-investigating occupational therapy students, were selected for each question to improve accessibility. The content validity ratio (CVR) and item content validity index (CVI) score based on input from developers/researchers and end-users were both above 0.85 indicating content validity for the multimedia images in the survey. Summative content analysis indicated the most common reason for approval of the multimedia added to the survey was the clear link between the image/question which helped to clarify the question.

Discussion and conclusion

Implementation of readable questions with sound and video links were supported by validated multimedia images in creating a survey for those with mild and moderate IDD to provide self-report options.

Phase 3 - Evaluation of the multimedia survey platform for people with cognitive disabilities

Methods

A quasi-experimental within-group research design was used to evaluate the completion of the WES abbreviated WIHD SAS with multimedia adaptations and compared to the completion of the same survey presented on SurveyMonkey (SurveyMonkey abbreviated WIHD SAS). Both completion time and assistance required were recorded for all 27 end-users with IDD on both surveys as well as their preferences for the survey format and interface.

Results

Participants required significantly more assistance in reading, selection, and understanding to complete the SurveyMonkey abbreviated WIHD SAS. There was no significant time difference in completing the SurveyMonkey abbreviated WIHD SAS compared to the WES abbreviated WIHD SAS. Participants with IDD preferred the WES abbreviated WIHD SAS due to audio feedback, the presence of images, video explanation, large text, and simplified layout.

Discussion and conclusion

The WES abbreviated WIHD SAS was found to be significantly more accessible in terms of performance related to assistance required and was reported as useable for comprehension, operation, and navigation of the platform.

The highly adaptable nature of the digital environment, as supported by the inclusion of multimedia and additional features in the survey platform, was highlighted by this study to have high potential for improving accessibility for individuals with cognitive disabilities to self-report. As an environmental modification, this should underlie further research, teaching, and practice in occupational therapy and other fields.

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Operational Definitions

Accessible Surveys	a survey that ensures that anyone can participate regardless of physical, cognitive, sensory, or technological limitations. The survey must be understood by survey respondents, which requires the use of clear and simple language (Nikivincze and Ancis, 2018). It is important that question types be accessible to all users. Consider the relevance of questions to people with disabilities.
Usable survey	this considers the ease of use of the survey including navigational or multimedia access and operability, as well as comprehensibility or understandability (Nikivincze and Ancis, 2018) • Navigational – use of clear icons, color contrast and brightness, links, labels and multimedia • Operability - User interface components must be operable. This involves making all functionality available from a keyboard and giving users enough time to read and use content. • Understandable - Information and the operation of the user interface must be understandable. This means that text content should be readable and understandable, and web pages should appear and operate in predictable ways
Ability based design	a design approach that focuses on leveraging users' abilities rather than their disabilities. This method emphasizes creating interactive systems that adapt to what users can do, rather than what they cannot do (Wobbrock *et al.*, 2018)
Universal design	a design philosophy aimed at making products, environments, and systems usable by all people, to the greatest extent possible, without the need for adaptation

	or specialized design. This approach seeks to create inclusive and accessible solutions that accommodate a wide range of abilities, ages, and other factors. (Universaldesign.org, 2024)
Cognitive disabilities	refer to a broad range of conditions that affect an individual's ability to perform one or more mental tasks compared to the average person. These disabilities can impact various cognitive functions, including memory, problem-solving, attention, and comprehension. (Funk, 2024)
Multimedia	refers to the integration of various forms of media, such as text, graphics, audio, video, and interactive elements, to create a cohesive and engaging user experience (Miesenberger *et al.*, 2019)
Person centered practice	an approach to healthcare and social services that emphasizes treating individuals as unique persons, involving them in their own care, and respecting their preferences, values, and needs (Berntsen *et al.*, 2021)
Person with cognitive disabilities/IDD	Person with a cognitive disability/intellectual and/or development disability (IDD); a person with significant limitations in intellectual functioning and adaptive behavior. These limitations are evident in areas like learning, problem-solving, and everyday life skills (American Psychiatric Association, 2025).
Survey platform	a software or online tool that facilitates the creation, distribution, and analysis of surveys or questionnaires (Wilson, 2013)

Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
ABD	Ability-Based Design
ACDM	Allen Cognitive Disability Model
ACL	Allen Cognitive Level Screen
ADLs	activities of daily living
ASD	Autism Spectrum Disorder
COGA	Cognitive and Learning Disabilities Accessibility Task Force
CVI	Content Validity Index
CVR	Content Validity Ratio
DIX	Disability Interaction
HCI	Human-Computer Interaction
HREC	Human Research Ethics Committee
IADLs	instrumental activities of daily living
ICF	International Classification of Functioning, Disability and Health
ICT	information and communication technology
ID	intellectual disability
IDD	intellectual and/or developmental disability
IRB	Institutional Review Board
MVP	minimally viable product
NCI-IDD	National Core Indicators® - Intellectual and Developmental Disabilities
NYMC	New York Medical College
OTPF-4	The Occupational Therapy Practice Framework, 4th Edition
PI	Principal Investigator

SAS	self-advocacy survey
SO	Steinmann Obermeyer
TBI	traumatic brain injury
UBACC	University of California San Diego Brief Assessment of Capacity to Consent
UCEDD	University Centers for Excellence in Developmental Disabilities
USA	United States of America
WAI	Web Accessibility Initiative
WCAG	Web Content Accessibility Guidelines
WES	Westchester Institute for Human Development Easy Survey
WIHD	Westchester Institute for Human Development

CHAPTER 1: INTRODUCTION

1.1 Introduction to the problem

In the United States of America (USA) patient surveys are used extensively to evaluate clinical and nonclinical health care services. Patients' perspectives are used to provide improved comprehensive, efficient care by making changes to suit patients' needs. When providing feedback after a consultation or intervention, or on other health care services, individuals with neurotypical cognitive functioning can communicate with their health care providers to explain what their concerns are and have these be addressed. Individuals without disabilities are able to have an active say in their health care solutions without any difficulty, because survey tools provided to share their feedback are accessible and have been standardized for this population (Patwardhan and Spencer, 2012).

However, for individuals with cognitive disabilities or limitations there are very limited survey tools available that enable access to share their opinions (Kärpänen, 2021). Some researchers have gone so far as to call them "invisible populations". Information about their needs or health is often obtained from proxy reports from family or caregivers (Rosencrans *et al.*, 2021). Individuals with cognitive disabilities, especially those with intellectual and/or developmental disabilities (IDD), are therefore often not included in research or given the opportunity to share their input into services they receive (Walton *et al.*, 2022).

The many individuals with cognitive disabilities in the world present with limitations that are varied both in scope and in severity based on the diagnoses of the individuals as well as their ability to perform in an adapted environment. Some of the most commonly identified difficulties experienced by these individuals deal with memory, learning new things, concentration or making decisions (Wehmeyer *et al.*, 2020; Henni *et al.*, 2022). Providing accessible survey tools that take these limitations into account for individuals with cognitive disabilities can potentially assist in improving the healthcare disparities that these individuals experience (Wehmeyer *et al.*, 2020).

Nicolaidis et al. (2020) indicated that in the field of survey accessibility cognitive accessibility is the area most often overlooked or not given the same attention in the development of surveys as other factors (Nicolaidis *et al.*, 2020). That is why some of the most important aspects to consider are the provision of adaptations to the environment and form of surveys that allow for accessibility, so that these individuals can express their choices and have their input valued when collaborating with their providers to improve their healthcare and ultimately their lives (Wehmeyer et al., 2020). When considering developing or using survey tools for individuals with cognitive limitations, cognitive accessibility should be the essential underlying concept and the foundation on which everything is built (Kärpänen, 2021).

1.2 Background and setting of the problem

The Westchester Institute for Human Development (WIHD) is one of 68 University Centers for Excellence in Developmental Disabilities (UCEDD) in the United States. The institute is dedicated to fostering fulfilling and meaningful futures for individuals with cognitive disabilities or IDD and their families and caregivers through professional education, comprehensive support services, community training and technical assistance, and innovative research and information dissemination. As such, the organization also works to advance policies and practices that ensure the health and self-determination of individuals with IDD of all ages and the safety and well-being of vulnerable children. The vision of the institute is a world in which individuals with IDD live healthy and productive lives as full members of society.

Feedback on services is currently obtained from clients to support their health care decisions and service improvement initiatives using surveys. Two such surveys used at the WIHD are the WIHD self-advocacy survey (SAS) and the WIHD patient satisfaction survey. There is a lack of platforms on which to create assessable online surveys and self-report surveys/health measures which can be used to obtain feedback and information from persons with cognitive disabilities or IDD themselves and not by proxy (Gottliebson, Layton and Wilson, 2010). Research is available on the adaptation of surveys to make them accessible, but studies published describe the modification or development of a single assessment or survey measure and there is

little detailed research on the provision of an accessible computer-based platform on which many accessible surveys can be developed. It was proposed that this gap in the research and practice be addressed by the development of an accessible survey platform and in this study the development and evaluation of the WIHD Easy Survey (WES) based on a multimedia technology initiative is described. This new survey platform was created during this study to provide survey designers with the opportunity to develop new surveys or adapt existing surveys to make them accessible to those with cognitive disabilities. A survey, the Westchester Institute for Human Development self-advocacy survey (SAS), was utilized in an abbreviated form on the WES platform for evaluation in the study. Input from both expert researchers/survey designers and end-users with IDD was elicited and considered in conjunction with the Web Content Accessibility Guidelines 2.1 (WCAG) published by Web Accessibility Initiative (WAI) (W3C, 2024c) and evidenced in review by Kooijmans and co-workers for adaptations of multimedia components, such as sound and images, required in surveys for individuals with cognitive disabilities (Kooijmans *et al.*, 2022). These sources emphasize the importance of including individuals with cognitive disabilities in the creation of content, response formats, and layout of surveys. These guidelines and evidence should be supported by a design based on the two recognized meta-functional dimensions of **ease of use** (usability), including **navigational** or multimedia access and operability, as well as **comprehensibility** or understandability (Blanck, 2014).

Working as an occupational therapist, the principal investigator (PI) has learned over her more than 37 years of experience that individuals with cognitive disabilities can have a broad range of functional abilities and limitations that need to be accommodated to provide surveys that are accessible for this population. The PI worked with many different areas of cognitive disabilities, covering all four pillars of the Steinmann-Obermeyer cognitive disability framework. (See Figure 1.1) Therefore, a focus on the development of a suite of multimedia technology including the WES platform for individuals with diverse cognitive disabilities was envisioned, which became the focus of this thesis.

1.3 Problem statement

Individuals with cognitive disabilities are not typically included in making their own choices and are often overlooked in giving their own opinions, especially when those opinions are solicited by survey. The National Core Indicators project, a performance measurement system in the USA that tracks progress toward person centered outcomes in the field of IDD, makes extensive use of surveys which in this thesis are considered for individuals with mild and moderate IDD (Stancliffe *et al.*, 2014, 2023; Butler *et al.*, 2016; Stancliffe, Kramme and Nye-Lengerman, 2018). Even in cases where surveys are administered verbally by an interviewer these surveys often include a component for getting responses from a caregiver/family member (National Core Indicators, 2025a). However, the rights of individuals with cognitive disabilities are often compromised by having a proxy respond on their behalf, which decreases their ability to self-advocate.

Both traditional 'paper and pencil' surveys and computer-based surveys are not designed to give appropriate access for individuals with cognitive disabilities in terms of their comprehension of the material and participation in taking the survey (Wehmeyer and Shogren, 2013; Davies *et al.*, 2017; Wehmeyer *et al.*, 2020). Traditional paper surveys have a strong language foundation that make it difficult for individuals with cognitive impairments to understand and make their own choices. When it comes to internet accessibility including computer-based surveys, digital exclusion can present as an issue. As described by Pouncey (2010), "Web accessibility for individuals with cognitive disabilities and learning difficulties is one of the most overlooked subtopics of general web accessibility, despite it affecting the largest numbers" (Pouncey, 2010, p.1).

Survey platforms in health and other settings, such as "SurveyMonkey™" and "Qualtrics™" are commonly used for the development and distribution of surveys online (Qualtrics XM, 2025; SurveyMonkey.com, 2025). These platforms provide a cost-effective way to create surveys but have little evidence of customizations which may support their feasibility and effectiveness in gaining responses from individuals with cognitive disabilities. Therefore, when responses are required from individuals with cognitive disabilities, caregivers or family usually complete the online survey instead (Kramer et al., 2015; Pratt et al., 2008). There is some sophisticated software

currently available that allows for the developer to build appropriate measures (Davies *et al.*, 2017), but very little available that can be customized in situ to do surveys as simple as basic patient satisfaction in a clinic for individuals with cognitive disabilities.

1.4 Research questions

a. How does the technology of a software platform need to be adapted to allow for cognitive accessibility and usability?

b. How can technology improve access to surveys for individuals with cognitive disabilities to facilitate self-report?

1.5 Research aims and objectives

1.5.1 Overall aim

To develop and evaluate an online platform using a multimedia technology approach to surveying individuals with cognitive disabilities to promote person centered practice.

This study was completed in three phases with specific aims and objectives outlined for each phase. The focus of the surveys in the thesis was on health services but the platform design included surveys in any context.

1.5.2 Phase 1 – Development of a survey platform for individuals with cognitive disabilities

Aim

To develop a customizable multimedia technology survey platform that will allow survey developers to produce surveys with rich media to enhance the comprehensibility of the survey, specifically for individuals with cognitive disabilities.

Objectives

1. to identify the perceptions of two groups of participants: expert survey developers who have worked with individuals with IDD and as well as end-users with IDD, regarding their needs for making online surveys accessible to those with cognitive disabilities

2. to develop a first design concept of the survey platform
3. to evaluate this design concept document
4. to finalize the survey platform for delivery of the surveys
5. to evaluate the prototype of the survey platform

1.5.3 Phase 2 - Transfer Survey to Multimedia Format and Test Multimedia Selections (Content Validity Testing)

Aim

To evaluate the multimedia selections for a survey on the WES platform.

Objectives

1. to select questions from an existing WIHD self-advocacy survey and enhance the sample of questions with relevant multimedia to improve cognitive accessibility
2. to evaluate content validity of the multimedia images in this sample survey

1.5.4 Phase 3 – Evaluation of the multimedia survey platform for individuals with cognitive disabilities

Aim

To evaluate the effectiveness of this multimedia survey technology in soliciting responses from individuals with developmental disabilities.

Objectives

1. to compare the accessibility of the WES abbreviated Westchester Institute for Human Development self-advocacy survey (WIHD SAS) and the abbreviated WIHD SAS on the SurveyMonkey platform in terms of completion time and assistance required
2. to evaluate the accessibility and usability of the WES abbreviated WIHD SAS and SurveyMonkey™ WIHD SAS

Null Hypothesis:

There will be no difference in the survey completion time, the support needed and the usability when self-reporting on the abbreviated WIHD SAS, on the WIHD WES platform, and the Survey Monkey™ platform for individuals with IDD.

1.6 Significance of the Study

This research project focused on the development and evaluation of the WIHD Easy Survey (WES) online survey platform. The WES was based on information and communication technology (ICT) for persons with cognitive disabilities. Through the use of multimedia technology, accessibility in terms of usability and comprehension, and, thus, survey administration, can be enhanced by using adapted technology interfaces and the four components of multimedia: text, pictures, videos and sound. This allows users to respond to surveys more independently by using aspects such as touch screen technology and other user interfaces. By using a multimedia platform, users with cognitive disabilities have access to content within the range of their abilities (Blanck, 2014). Providing the means by which individuals with cognitive disabilities can self-advocate through technology will increase patient compliance and satisfaction, which ultimately leads to improved health outcomes (Fujiura, 2012). The benefits of self-advocacy can include a focus on person centered care and quality of life as well as reducing the burden of care. Client self-advocacy has also been linked to satisfaction with services. Clients may also feel more competent in influencing their care which may reduce inequities and disparities within the health care system (Tyabashe-Phume and Kleintjes, 2025). The development of the platform provides a foundation for surveys with transferability to other contexts where individuals with cognitive disabilities are attempting to access services.

1.7 Organization of the thesis

The general outline of the thesis is summarized as follows:

Chapter 1: Introduction

The background of the study, problem statements, aim. Objectives and the significance of the study are presented. This chapter also includes the underlying philosophy, theoretical models, and design approaches focusing on end-user inclusion used to support the study, as well as ethical considerations and the research setting.

Chapter 2: Literature Review

Cognitive disabilities with focus on IDD as a core subgroup and the approach to these individuals are reviewed in general, as well as self-advocacy and person centered practice. Self-report related to individuals with cognitive disabilities and the methods available to enable reporting are also reviewed. Cognitive accessibility with an emphasis on the virtual environment and co-development including collaboration and participation of individuals with IDD is considered. Multimedia technology and cognitive accessibility are also examined.

Chapter 3: Underlying Philosophies, Frameworks, Approaches and Overall Methodology

The underlying philosophy including the frameworks and models that pertain to the study and all ethical considerations are shared in this chapter. Additionally, there is an introduction of the overall methodology used in the study. The chapter concludes with an explanation of the research setting.

Chapter 4: Phase 1 - Development of technology for a cognitively accessible survey software platform

The overall designing cycle for the development of technology by Verschuren and Hartog (2005) is described. The methodology, results, and discussion for Phase 1 are included.

Chapter 5: Phase 2 - Implementation and testing of the multimedia technology in a survey format

The methodology, results, and discussion for Phase 2 are included.

Chapter 6: Phase 3 - Evaluation of the multimedia survey platform for people with cognitive disabilities

The methodology, results, and discussion for Phase 3 are included.

Chapter 7: Conclusion

Summary of main findings, strengths and limitations of the study, conclusion, and recommendations.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter describes cognitive disabilities as a broad term but also focusses on intellectual and developmental disabilities as a core subgroup. The approach to individuals with cognitive disability through an occupational therapy lens is reviewed in general, as well as pertaining to self-advocacy and person centered practice. Self-report and proxy-report and how this relates to individuals with cognitive disabilities, and the methods available to enable reporting are also reviewed. Cognitive accessibility and how it relates to environmental adaptations with an emphasis on the virtual environment forms the next part of the literature review. It is also described how to design virtual environments for individuals with disabilities and how co-development including collaboration and participation, is being viewed in the literature. The last aspect covered in the literature review is multimedia technology and how this could potentially improve cognitive accessibility.

The databases that were accessed for the literature review included, but are not limited to, Google Scholar, Mendeley, PubMed and Scopus. Most of the literature included in the review ranged between the years 2000 and 2024. A few seminal articles published in the 1990's were included to set the stage for the history of cognitive accessibility and how it has changed over past decades.

2.2 Cognitive Disability

According to the Centers for Disease Control and Prevention (CDC) (2011), "cognitive disability or impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life" (p1). Cognitive disabilities range from mild to severe and lead to deficits within a person's executive functions (O'Hara et al., 2016).

There is a large percentage of the population that has cognitive disabilities and variations thereof; this group is considered larger than physical and sensory disabilities combined (Kärpänen, 2021). The ability for those with cognitive disabilities to advocate and influence the services they receive is therefore essential as they form the population using these services. It is important since those with cognitive disabilities are routinely denied the opportunity to provide input into their care (Tyabashe-Phume and Kleintjes, 2025). As will be indicated in the Cognitive Disability Framework in Chapter 3, cognitive disabilities can be acquired through progressive decline or developmentally. Acquired cognitive disabilities are seen in stroke or traumatic brain injury (TBI) or occur in older individuals and can be caused by Alzheimer's and other dementias.

Intellectual and/or developmental disabilities (IDD) are defined as intellectual functioning significantly below average which may be present from early childhood (Centers for Disease Control and Prevention, 2011). Individuals with IDD are identified as a specific separate group of individuals that present with cognitive disability. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), IDD is characterized by "significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18 years" (Schalock *et al.*, 2009, p. 317). AAIDD has since amended this characterization to age 22, rather than age 18 (American Association on Intellectual and Developmental Disabilities, 2025).

Broadly, IDD also includes other developmental disabilities and includes a category of individuals with lifelong disability that can be intellectual, physical, or both (American Association on Intellectual and Developmental Disabilities, 2025). Thus, the term IDD is used to describe a person with an intellectual disability as well as other disabilities that may impact multiple body parts and systems. Given the range of body systems that may be involved, individuals with IDD can also have: vision, hearing, speech or language difficulties; behavioral disorders; sensory disorders; seizure disorders; and/or physical/mobility limitations. It is often better to consider the physiology or body systems that are affected, for e.g. the nervous system, the sensory system, metabolism and degenerative disorders, rather than individuals' disorders or limitations. Examples of IDDs include cerebral palsy, Down syndrome, Fragile X syndrome, and autism spectrum disorders (ASDs). In this thesis and literature review

individuals with IDD and cognitive disabilities are considered but much of the research and literature available reports only on IDD (Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2021)

Globally it is estimated that 1-3% of the population experience IDD, affecting potentially 200 million individuals (Nair *et al.*, 2022). In America, where this study was conducted, using a conservative 1%–2% prevalence, there are currently between three and six million individuals living with IDD who are challenged by disability-related conditions in their daily living activities (Bryant, Seok, Ok & Bryant, 2012). National data on individual outcomes for adults with IDD shows that the largest group (58%) live with a parent or relative (Larson, Salmi, Smith, Anderson & Hewitt, 2013). Only 14% regularly participate in integrated community activities, 15% have paid jobs, and 23% do not have friends beyond their family or caregivers. In New York, only 17% of individuals with IDD have paid jobs in their community (National Core Indicators, 2025b).

The prevalence of IDD among children, aged less than 18 years, has risen with estimates at approximately 8.56% in children in the United States in 2021 affected (Zablotsky *et al.*, 2023). The number of children with disabilities such as autism, attention deficit hyperactivity disorder, and other developmental delays specifically, has increased, requiring more health and education services (Boyle *et al.*, 2011; Zablotsky *et al.*, 2023).

2.3 Approach to Individuals with Cognitive Disabilities through an Occupational Therapy Lens

The PI approached the software development through her 37+ years of experience in working with individuals with cognitive disabilities in various settings and countries. This formed the foundation of bringing together the person, the environment, the tasks, and the technology as a modification to the SETT model by Joy Zabala, that focuses on the Student, Environment, Task and Tools context/structure through which adaptations can be made (Sweet, Jones and Drummond, 2024).

Regardless of the cause of cognitive disability, when working with individuals with these conditions, it is crucial to provide appropriate services to enhance an individual's

functioning and personal well-being. Services offered should align with principles enshrined in the philosophy of the occupational therapy profession which make the support provided person centered, facilitate participation, offer choice and autonomy, and align personal goals and values (Schalock, Luckasson and Tassé, 2021).

It is the role of the occupational therapy practitioner to use tools and clinical judgement to evaluate the abilities and limitations of those with cognitive disabilities and to ensure that an individual can achieve wellbeing and the highest quality of life they desire. In the latest edition of the Occupational Therapy Practice Framework (OTPF 4), the following overarching statement is shared to describe the domain and process of occupational therapy: “Achieving health, well-being, and participation in life through engagement in occupation” (American Occupational Therapy Association, 2020, p.5). Participation is achieved when an occupational therapy practitioner finds the tools needed to assess how an individual with a cognitive disability can engage in the activities they value, including their healthcare. This supports “involvement in a life situation” as defined by the World Health Organization (2002) in their International Classification of Functioning, Disability and Health (ICF) which highlights the interplay between body function, engagement in activities, participation and their impact on health when considering personal and environmental factors (World Health Organization, 2002, p. 8). This links well with the frameworks to be discussed in Chapter 3.

Using these frameworks, with an occupational therapy lens, for the purposes of this study the focus was on determining how an individual with cognitive disabilities or IDD can better participate in their healthcare and ultimately autonomously contribute to their own health. The use of the occupational profile allows for an occupational therapy practitioner to determine the challenges and strengths of an individual and then environmental adaptation can be applied to help shape resources to assist in improving their participation (American Occupational Therapy Association, 2017). Understanding the personal needs and context of each individual with cognitive disability and providing services to allow for knowledge of self and knowledge of rights to develop, and using the proper environmental stimuli and support, is essential to achieve outcomes supporting wellbeing and quality of life. Each section below is described from an occupational therapy perspective, to ensure clarification of the concepts within OT.

2.3.1 Self-advocacy and Person Centered Practice

In providing healthcare and educational services, promoting the skill of self-advocacy, or the ability to advocate on one's own behalf, has been shown as essential to improve life outcomes among youth and adults with cognitive impairments (Aune, 1991; Wehmeyer, 1992; Wehmeyer and Schwartz, 1996; Test and Neale, 2004). Self-advocacy requires the fundamental skill of knowledge of self, which includes understanding one's own needs, strengths, interests, preferences, and goals within the boundaries of intellectual disability (Feldman *et al.*, 2012). The skill of self-advocacy is a critical component of the broader concept of self-determination, or the ability to control aspects of one's own life. Being able to participate in personalized care or taking part in surveys about one's life to inform services should form a cornerstone for individuals with cognitive disabilities to ensure they can share their own opinions and choices. Self-determination and self-advocacy are integral parts of being involved in one's health care decision making and health service evaluation, often through participating in surveys.

Self-determination cannot be promoted if services and supports do not follow a true person centered philosophy (Sanderson, Smull and Harvey, 2008). Within occupational therapy, the concept of person centered practice encompasses not only ensuring autonomy and choice enablement, contextual congruence, accessibility, flexibility, and respect for diversity when providing services but also being collaborative, consultative, and respectful of the individual (Brown, 2013). Person centered practice has been described by Holburn (2002) as "a way to better understand the experiences of individuals with disabilities and, with the help of allies, to expand those experiences … through reducing social isolation and segregation, facilitating the establishment of friendships, increasing opportunities to engage in preferred activities, developing competence and promoting respect" (Holburn, 2002, p. 250). Person Centered Practice is no longer an approach only on the edges of service systems; it has been integrated into the delivery of services and forms the foundation to promoting self-determination in individuals with cognitive disabilities (Smull and Lakin, 2002; Butterworth, 2003; Sanderson, Smull and Harvey, 2008; Smull, Bourne and Sanderson, 2010; İsvan, Bonardi and Hiersteiner, 2023).

Understanding what it means for services and providers to be truly person centered, the person with a cognitive disability should be able to provide feedback as to their

experience of the services and practices implemented. A person centered approach may ask an individual with IDD, for example: Were they allowed to share their own thoughts and goals when asked questions? Were they even included in the decision-making process? (Sanderson, Smull and Harvey, 2008; Orentlicher and Dougan, 2011). The ability to communicate individual characteristics, to articulate and disseminate the knowledge of self, and understand the right to do so in a persuasive and appropriately assertive manner, either directly or through activities such as making informed decisions and taking responsibility for those decisions, is the key to reach the goal of self-advocacy (Adams, 2015; Van Reusen *et al.*, 2015).

2.3.2 Self-report vs Proxy Report

Individuals with cognitive disabilities are often excluded from self-advocacy and making their own decisions because the means which are used to elicit their opinions are not accessible or accommodating to their communication needs, which makes it difficult to get them to share their own ideas and preferences. When responses are required from individuals with cognitive disabilities, caregivers or parents are usually surveyed instead and more often provide feedback for the individual, rather than the individuals themselves (Kramer *et al.*, 2015). The rights of individuals with cognitive disabilities are therefore often compromised by having a proxy respond on their behalf, which decreases their ability to self-advocate (Kramer *et al.*, 2015).

Even though it has been clearly identified over the past 17 years that individuals with cognitive impairments should be allowed to self- report, limited availability to do so still prevails (Pouncey, 2010). In instances where assessments are administered by an interviewer, these traditionally include a component for getting responses or require collateral information from a caregiver/family member. A comparison between proxy report and self-report of 90 individuals with IDD, as completed by Scott and Havercamp in 2018, indicated that health data obtained from individuals with IDD that had capacity to communicate using interviews did not correlate with the written proxy report completed independently by caregivers. They found that agreement between proxy and self-report responses varied from poor to moderate. The parody between self-report and proxy report was especially significant where reporting was about internal thoughts and feelings. The study further stated that it is important to realize these differences when interpreting data gathered from individuals with cognitive disabilities and care givers, and confirmed the importance of individuals with cognitive

impairment being allowed to self-report (Fujiura, 2012; Scott and Havercamp, 2018). The work by Walton et al., published in 2022, supported the value of allowing for self-report for individuals with intellectual and other cognitive disabilities in lieu of proxy report, but indicated the challenges faced in trying to obtain accurate self-reports from individuals with IDD. The findings indicated the reports could be completed independently and elicit a range of responses but only with modest internal consistency and test-retest reliability. More research is needed to confirm the reliability and validity of the adapted measures for individuals with IDD to support not only their autonomy but for improvement of services and providing supports that is aligned with the needs of these individuals (Walton *et al.*, 2022).

2.4 Methods of Self-Report for Individuals with Cognitive Disabilities

One means of increasing the well-being, health, and capacity of individuals with disabilities is through the use of large-scale surveys which provide an opportunity for citizens to report on their life experiences and opinions. In the United States collecting information regarding health and quality of life is used to determine health outcomes, health risk, and lifestyle (Gallagher *et al.*, 2016). The use of surveys to gather information about individuals with cognitive impairment has been utilized since the 1960's. The National Core Indicators® - Intellectual and Developmental Disabilities (NCI-IDD) program is an example of such a project, where surveys specifically targeting individuals with intellectual disability are used, but has been limited in its success (Stancliffe *et al.*, 2015). More often survey feedback has been gathered from caregivers or family members and not the individual themselves. When looking at literature beyond the US, both self and proxy report are often utilized when surveying individuals with IDD, even when utilizing computer-assisted personal interviewing (CAPI) methods, though proxy appears to be the method of choice when abstract topics are covered (King *et al.*, 2022).

In 2010, Pouncey confirmed that individuals with cognitive disabilities are not typically included in making their own choices and giving their own opinions, especially when those opinions are often solicited by interview or paper-based surveys (Pouncey,

2010). Traditional paper surveys have a strong language foundation and, therefore, cannot allow individuals with cognitive impairments to make their own choices. Both traditional paper and pencil surveys, as well as computer-based ones, are not designed to give access for individuals with cognitive disability to improve their comprehension of the material and participation in taking the survey.

Scott & Havercamp (2018), in an attempt to improve self-advocacy and accessibility to those with cognitive disabilities, used interviews to complete paper and pencil standardized assessments specially designed for individuals with IDD on stress, social support and physical activity. They reported issues with incomplete answers on these assessments as well as poor interrater reliability, thus bringing the reliability of these assessments into question (Scott and Havercamp, 2018). Similar limitations were discussed by Walton et al. in 2022 when using interviews for existing self-report measures for individuals with IDD. These authors also identified this mode of administration as an area of concern, especially regarding the sharing of sensitive information (Walton *et al.*, 2022).

Some success has been had with using technology to assist individuals with cognitive impairment in facilitating the person centered process (Glang, McLaughlin and Schroeder, 2007; McLaughlin *et al.*, 2013). According to Pouncey (2010), “Web accessibility for individuals with cognitive disabilities and learning difficulties is one of the most overlooked subtopics of general web accessibility, despite it affecting the largest numbers” (Pouncey, 2010, p. 1). Walton et al. (2022) have made a significant shift in adapting computer based self-report health measures for use with individuals with IDD but remain concerned about the lack of cognitively accessible measures for these individuals (Walton *et al.*, 2022). One of their recommendations was to continue with the use of computerized surveys, which allow for more privacy, when “paper-and-pencil” measures might typically be used. This leverages technology to maximize access, but existing survey technology of mainstream platforms such as “SurveyMonkey ™” and “Qualtrics™” have little evidence to support their feasibility and effectiveness in gaining responses from individuals with cognitive disabilities (Qualtrics XM, 2025; SurveyMonkey.com, 2025).

In investigating survey technology for cognitive accessibility, it became clear from the literature that a specific design approach that includes a user centered design prioritizing the preferences and limitations of end-users with varying levels of digital

literacy was needed (Wobbrock *et al.*, 2011). Walton et al. (2022) described in detail the process for adapting measures based on an informed procedure, specifically using surveys based on advanced technology (Walton *et al.*, 2022). From an occupational therapy perspective, it is imperative to consider the profile and capabilities of potential users for appropriate environmental adaptation when developing technology solutions for cognitive accessibility (Sarsenbayeva *et al.*, 2022).

2.5 Environmental Adaptation

The next aspect to consider is the environment in and through which individuals interact with technology.

2.5.1 Virtual Environment

The use of technology to support self-advocacy and person centered practice is supported in the OTPF 4, where different contexts are described as being critical for an occupational therapy practitioner to consider the domain of a person's participation. One of the contexts described, the virtual environment, focuses specifically on environmental factors including technology, as being either barriers or facilitators of participation (American Occupational Therapy Association, 2020). Engagement in an activity can be supported by modifying said contexts or using a compensatory approach which can be accomplished by adapting the context through enhancing some features. For the current thesis, any modification or enhancement to the virtual environment is designed for maximum participation by individuals with cognitive disabilities in computer-based surveys.

2.5.2 Cognitive Accessibility in the Virtual Environment

In this digital age, it is known that access to technology is a critical component for anyone to live an autonomous, self-determined life (Wehmeyer *et al.*, 2020). Nicolaidis et al (2020) reported on six different studies and found existing surveys were inaccessible to individuals with cognitive disability (Nicolaidis *et al.*, 2020). They reported that these individuals became confused, frustrated, anxious or even angry when trying to complete the surveys. Some answers were unreliable and individual questions and/or entire surveys remained unanswered, affecting the validity of the data collected. Therefore, adapting the virtual environment to allow cognitive

accessibility is becoming an area of growing interest for those providing services for individuals with cognitive limitations (Nicolaidis *et al.*, 2020).

In order to adapt the virtual environment to improve accessibility for individuals with cognitive disabilities, adaptations must engage with principles/theories of software/technology development, focusing on the field Human Computer Interaction (HCI). Human Computer Interaction offers a valuable framework for addressing cognitive accessibility challenges by focusing on user centered design, adaptability, and context awareness. Improving accessibility in the virtual environment must consider three phases of HCI: the stimulus identification stage, which involves cognitive, and motor processes based on recognition and understanding of the displayed information; the response selection stage to react to a particular stimulus; and the response execution stage, which usually requires a motor or verbal response (Nolte *et al.*, 2022).

Technological issues which were of concern in cognitive accessibility included logging in to surveys to protect privacy and lack of familiarity with survey websites (Kärpänen, 2021). Content and language were reported as issues with most websites, with individuals with cognitive disabilities needing assistance to understand the content, particularly if the surveys included culturally and linguistically diverse users (Kärpänen, 2021).The use of non-simple language, including vocabulary and complex sentence structure as well as double negatives, was identified as complicated phrasing which poses a barrier to access. Attempts to change this need to be carefully monitored so that long, convoluted sentences are not used. It was found that individuals with cognitive disabilities also struggled when vague definitions were used with Likert-scale options such as always/usually/sometimes (Kärpänen, 2021).

It is also reported that anxiety about responding to the survey may affect participation with those with cognitive disabilities. The reason for lack of answers and the reliability of answers may be due to concerns that they have not remembered some events or cannot answer correctly on fact-based questions. It was suggested that questions that concern participation in occupations, which may differ depending on context and times during the day, should be avoided or carefully constructed to avoid confusion. The use of written responses is limited by language ability, and verbal responses may be preferred but can be affected by difficulties with speech, such as stuttering or slow speech (Bayor et al., 2021). The ability to consent to complete the survey also needs

to be carefully adapted beforehand (Cobigo *et al.*, 2020). In addition, acquiescence bias should also be considered and addressed. In development of a cognitively accessible survey platform, the internal features and virtual environment of technology and/or traditional survey methods must be considered in conjunction with the wide range of limitations and abilities of individuals cognitive impairment.

2.5.3 The virtual environment and individuals with cognitive disability

Literature indicates that it has been assumed that the emphasis on the virtual environment could increase the independence of individuals with cognitive disabilities and increase their participation in their occupations and provide them with a platform to view their opinions. However, due to the variety of cognitive abilities it was found that individuals with cognitive disabilities require adaptation of the virtual environment and HCI in stimulus identification, response selection, and response execution (Wehmeyer *et al.*, 2020).

Adapting the virtual environment therefore should use principles of HCI to maximize human participation by matching the abilities of the individual with cognitive disability to the computer tasks by providing demands that meet their cognitive and sensori-motor functions. There is a lack of research on the specific task components in the virtual environment that limit the ability of a user with IDD to interface with computers and the mismatch of the task and the abilities of individuals with cognitive disability. Wong et al. (2009) analyzed computer tasks while assessing the capabilities of individuals with a variety of cognitive disabilities using an internet search engine. They found all the tasks required visual acuity, vigilance, and orientation abilities. Motor tasks were more easily completed as were those that consisted of, at the most, three to four steps. Achieving stimulus identification was related somewhat to the participants' level of working memory, reading ability, visual acuity, and decision-making. The response selection requires the ability to shift attention, vigilance, and orientation for progression; and for remaining on the task, motor ability was needed for response execution for successful performance if a mouse is used (Wong *et al.*, 2009). Kärpänen (2021), in a literature review, highlights the premise that cognitive accessibility benefits these users, and that research which focuses on this should be shared. The author describes cognitive accessibility as a part of the cognitive accessibility framework that explains digital services that are simple, consistent, clear, multi-modal, error-tolerant and attention-focusing to use. It is also important to note

that there are two layers of barriers, namely survey/survey platform design, and accessibility online.

2.6 Design of virtual environments for individuals with disabilities

There are several design approaches that can be considered when looking at human computer interaction (HCI). This is discussed in more detail in Chapter 3, as a framework. In using this approach to enable individuals with cognitive limitations to self-report on any survey, the technology needs to be adapted to their abilities (Tanis *et al.*, 2012). Therefore, ability-based design means the capability of the end-users is the central focus of the design. In this approach, the system is expected to adapt to the user's ability and does not expect the user to change to technological demands (Sarsenbayeva *et al.*, 2022).

Ability-based design includes seven principles, the first four of which are: ability or being aware of the users' capabilities; accountability of designers in changing the technology; adaptation that is interface and user-adaptable; and transparency so that end-users are aware of the adaptations. The fifth principle is performance in that the system allows the end-user to perform as expected. The final two principles are context allowing the technology to anticipate the effect of the context on the end-users' abilities, and commodity which indicates technology should be low-cost and readily available. Bayor et al. (2021) indicate that although this approach has the potential to support all kinds of disabilities, most effective applications are in accommodating abilities with physical and sensory attributes that may more easily identified. Research using the ability-based design approach for those with cognitive disabilities and capabilities that vary is limited. The abilities of individuals with cognitive disability are divergent and may be impacted by other impairments, making it difficult to provide adaption in ability-based design across their functional abilities which affect the individuals' competencies and their participation (Bayor *et al.*, 2021).

Ability-based design requires an understanding of both the capabilities of individuals with cognitive impairment and the virtual platforms which can make surveys accessible to these users. These aspects need to be considered from the point of feasibility and

cost. Although the context is important in this approach, rather than producing individually tailored products, benefits from adapting mainstream platforms should be considered. Support within the context of accessing the virtual environment, not just for actual completion of surveys, also needs to be considered (Bayor *et al.*, 2021).

Completing a survey can be a complex cognitive task as a question must be recognized (perception), understood (comprehension), and reasoning for the answer be made (decision). The ability of individuals with cognitive disabilities will be impacted by the presentation and features of the survey. A numeric rating scale may rely on a concept of consecutive numbers. Texts should be as short and simple as possible, since reading is another complex task. Research has shown that linking emotions to cognitive tasks in diagrams, such as happy/sad face icons, may improve performance, and attention. The number of questions used also needs to be considered in view of attention span and actions taken to keep the individuals with cognitive disabilities focused (Wehmeyer *et al.*, 2020). Adaptation of the virtual environment and a modified HCI therefore suggest adoption of a color to reduce the cognitive load to free up working memory for other cognitive aspects to lower the demand on attention, working memory, and visual search. When adapting technology for individuals with cognitive impairment, Watfern et al. (2019) suggest that using images and text need more explanation, and that quick and easy access to content within the same site should be considered (Watfern *et al.*, 2019). Breaking information into manageable sections can assist with attention. Usability may also be improved by subtitles, recognizable icons, and simple typefaces (Crabb *et al.*, 2019). Suggested solutions are ‘‘hotlinks’’ that direct users to an example, or the use of diagrams for Likert scales.

2.6.1 Collaboration for co-development of cognitively accessible surveys

Over the past three decades, co-development of technology with individuals with disabilities has changed from merely having individuals with disabilities test the designed technology to fully including individuals with disabilities in the design process from the start (Braddock *et al.*, 2013; Wehmeyer and Shogren, 2013; Davies *et al.*, 2015; Bayor *et al.*, 2021; Schwartz *et al.*, 2022; Walton *et al.*, 2022; Moreno *et al.*, 2024).

Bayor et al. published an article in 2021 discussing two specific approaches to the co-designing of technologies, namely participatory and collaborative. Both approaches

support the basic tenets that the individuals for whom the design is intended have the best knowledge of their own lives, and therefore should have a say in the design. The participatory approach actively involves all the stakeholders, irrespective of their expertise, in the design process aimed at cognitive accessibility. The two concepts included in this approach are pragmatic, “those for whom the design is intended have the best knowledge of their own lives;” and moral , “they ought to have a say in the design that is intended for them” (Bayor *et al.*, 2021, p. 9). While this approach does allow for collaboration and empowerment, challenges using the approach with those with cognitive disabilities have been presented. The co-design approach is end-user centered and differs from the participatory approach since it is more pragmatic in involving the users and stakeholders collaboratively in the process of the design for cognitive accessibility. The co-design approach meets the needs of the end-users, since they co-create the virtual environment so that it can be used by them, ensuring the inclusion of individuals with cognitive disability.

2.7 Multimedia

Multimedia uses a virtual device to present text, graphics, audio, and video in combination with navigation links and tools to guide users to interact, create, and communicate on the platform. Four components are essential to multimedia. First, there must be a virtual device to coordinate what is seen and heard, secondly links that connect the information must be present, thirdly a navigational tool must exist, and finally gathering, processing, and communicating information must be allowed.

Multimedia technologies are interactive applications that make it possible for individuals to share their ideas and information (Hussain, Ali and Amin, 2019). This type of computer application can reach a large population using surveys, who do not have the means to be reached in a different manner (Glang, McLaughlin and Schroeder, 2007; McLaughlin *et al.*, 2013). Within online survey tools, multimedia is considered one of the best and most effective ways to gather information from individuals, but simply providing a survey to respondents does not make it effective. As indicated above, it is important to tailor the questions and other data collection methods to the specific target audience such as those with cognitive disabilities (W3C

working group, 2021). Web-based interventions and adaptations using multimedia to communicate online has been developed since the mid 2000's. Although some modifications do consider the use of multimedia by individuals with cognitive disabilities, this is restricted due to the lack of universal design features and cognitive accessibility. The use of multimedia has increased in this population over the last decade as virtual environment has expanded, but barriers to using multimedia remain access to and cost of devices and adapted software as well as the ability to use the applications (Davies *et al.*, 2017). Tanis, in 2012, found the most used devices were for environmental control or daily living, such as leisure and guiding activities, as well as communication. Research on the effective use of multimedia in surveys for individuals with cognitive disabilities is limited and requires further research (Tanis *et al.*, 2012).

2.8 Summary

Even though there has been a significant shift towards allowing individuals with cognitive disabilities to self-report, there still remains a significant gap in making this an easily accessible means for developing surveys. Over the past 17 years, much more has been done than in the three decades before to start developing measures that are cognitively accessible and also to use technology on which to specifically develop these measures. It is imperative to address the research questions posed: How does technology need to be adapted to allow for cognitive accessibility and usability?, and How can technology improve access to surveys for individuals with cognitive disabilities to facilitate self-report? An obvious gap in the research was identified that the researcher will aim to address in this study.

CHAPTER 3: Underlying Philosophies, Frameworks, Approaches and Overall Methodology

3.1 Introduction

This chapter will focus on the underlying philosophy including the frameworks and models that pertain to the study, as well as all ethical considerations. Additionally, there will also be an introduction to the overall methodology used in the study. The chapter concludes with an explanation of the research setting.

3.2 Underlying Philosophy of the Study

3.2.1 Introduction

The disability rights slogan: “Nothing about us, without us!” sets the stage well for this research study, as the inclusion of individuals with disabilities forms the foundation of the rest of the work. It is imperative to discuss the theoretical and conceptual frameworks underpinning a study to ensure a credible foundation and clear path was established for the research (Adom, Hussain and Joe, 2018).

In addition to the frameworks and theories, the research design and methodology will also be discussed. The overall research design will be Design and Development Research using multiple methods. Both qualitative and quantitative methods will be utilized to inform the problems underpinning the needs of individuals with cognitive disabilities and how these can be addressed in the development of an accessible platform in this study. The worldview or paradigm that best fits with this project is that of pragmatism. This study focused on an identified real-world problem.

3.2.2 Philosophic View: Pragmatic Paradigm

The overall research design employing a multiple methods approach aligns with the pragmatic paradigm, which is well-suited for addressing real-world problems through a combination of qualitative and quantitative methods (Creswell and Plano Clark, 2018). Pragmatism offers a flexible philosophical framework that focuses on practical outcomes and "what works" to answer research questions, rather than adhering strictly to a single epistemological stance (Morgan, 2014).

The ontology for this study is that individuals with cognitive disabilities are often not included when decisions are being made about their lives and their services based on proxy reporting. The ontology uses both objective and subjective knowledge to address the research problem by allowing participants to share their knowledge and factual data to ensure that the software being developed meets the needs of individuals with cognitive disabilities. This aligns with the pragmatist view that reality is both singular and multiple, experienced and interpreted through many individuals and groups (Teddlie and Tashakkori, 2009). This ontological position recognizes the complex reality of individuals with cognitive impairments and their often-marginalized voices.

The epistemological approach in pragmatism allows for both objective and subjective knowledge, embracing multiple ways of knowing how to address the research problem (Creswell and Creswell, 2018). By developing an innovative method for self-reporting, this study aims to empower individuals with cognitive disabilities, enhancing person centered practice and promoting self-advocacy and self-determination. This goal reflects the axiological stance of pragmatism, which values both biased and unbiased perspectives and emphasizes the importance of conducting research that benefits individuals and society (Mertens, 2014).

The use of multiple methods in the survey platform development research design in this pragmatic approach allows for a more comprehensive understanding of the complex issues surrounding cognitive impairment and decision-making. Qualitative methods can provide rich, contextual data on participants' experiences, while quantitative methods can offer measurable outcomes and potential for generalization (Johnson and Onwuegbuzie, 2004). This methodological pluralism is characteristic of pragmatism, which advocates for selecting methods based on their appropriateness

to the research questions rather than adhering to a single methodological doctrine (Tashakkori and Teddlie, 2015). (Table 3.1)

Table 3.1 Philosophical Base of the Study

Aspect	Description
Research Design	Design and Development Research (DDR) using a multi methodology structured design to develop technology (Verschuren and Hartog, 2005) utilizing both qualitative and quantitative methods to ensure breadth and depth and achieving a more complete picture of the potential for understanding the experiences of both technology developers, as well as individuals with cognitive disability, when using technology to ensure development and evaluation of online surveys.
Paradigm/ Worldview	Pragmatism In this paradigm, knowledge and reality are based on the belief that reality can never be determined (Pansiri, 2005), but rather a normative concept that reality is what works when developing and implementing surveys for individuals with cognitive disability, and that context-dependent meaning is inseparable from their human experience and needs (Dillon, O'Brien and Heilman, 2000). In this study the paradigm is used to support the aim of the research, not search for absolute definitions and truth (Goles and Hirschheim, 2000). Knowledge generation is practical and involves the development and evaluation of actual surveys for individuals with cognitive disability based on previous experience and theoretical premises. Shared beliefs across the community of technology developers and technology users are necessary to support development aligned to the abilities of the individuals with cognitive disability as required in this paradigm (Tashakkori and Teddlie, 2015).
Ontology	Reality is both singular and multiple, experienced and interpreted through many individuals and groups. Ontology refers to the shared understanding, amongst all those involved, of issues related to

Aspect	Description
	individuals with cognitive disabilities accessing technology to solve related problems (Uschold and Gruninger, 1996). The single reality in this study refers to the fact that individuals with cognitive impairment are often excluded from decisions about their lives and services. Ontology recognizes that by adapting the environments for individuals, their participation can be transformed to allow for more inclusivity. Exploring alternative strategies by developing cognitively accessible survey technology for individuals with cognitive impairments follows the principles of ontological assumptions. This is supported by the integration of models and approaches described in this chapter.
Epistemology	Allows for both objective and subjective knowledge, embracing multiple ways of knowing how to address the research problem. In this study, the focus will be on allowing participants to share their subjective knowledge to ensure that the software being developed will meet the needs of individuals with cognitive disabilities. During the research of the literature, more objective knowledge was obtained to underpin what was being learned from the participants. By combining multiple ways of gathering knowledge, a software program can be developed that can improve participation for individuals with cognitive disabilities and allow for effective person-center practice and ultimately enhancing self- advocacy and self-determination.
Axiology	Values both biased and unbiased perspectives; emphasizes research that benefits individuals and society. By utilizing the values and essential principles of ethics during this research project, the principal investigator will ensure that results are presenting a true reflection of the data, and that the participants' contribution will justify the outcomes of the study. This will confirm that the actions taken when developing the software and then evaluating its efficacy with individuals with cognitive disabilities will contribute to all

Aspect	Description
	participants, and future users of the software will be treated fairly and will have an opportunity to have their voices heard without bias.
Methodology	Methodological pluralism or multiple methodology: selection of methods based on appropriateness to research questions rather than adherence to a single methodological doctrine. The survey development design, with systematic steps for survey development which included quantitative and qualitative methods, allowed for both exploratory and confirmatory questions to be answered. This study used methods to obtain the information needed to develop survey software that is cognitively accessible to allow individuals with cognitive disabilities to self-report on matters that are important to them, for e.g. their healthcare or their satisfaction with their plans of care. The survey development design included the development of items and content; testing of the platform and evaluation of the new software by applying the tool in further research using both qualitative and quantitative approaches provides a more complete picture and allows for reflection and possible new theoretical insights (Lund, 2012).
Purpose	To develop a new and innovative way for individuals with cognitive impairment to self-report on their health and lives, improving person centered practice, self-advocacy, and self-determination.

3.3 Theory and Theoretical Models Influencing the Study

This research project was based on a number of theoretical models that were utilized to establish links between concepts, which in turn described the specific phenomena that were addressed by the study. These models also aided in understanding how the development of cognitively accessible survey technology can assist in addressing the participation of individuals with cognitive disabilities. Each model will be discussed in more detail below.

3.3.*1* *Occupational Therapy Practice Framework (4th edition) – OTPF-4*

The Occupational Therapy Practice Framework, 4th Edition (OTPF-4) provides a comprehensive structure for understanding and implementing occupational therapy practice (Ghasemi Fard *et al.*, 2023; Muranaka and Sasada, 2023). The framework identifies several categories of occupation, including activities of daily living (ADLs), instrumental activities of daily living (IADLs), health management, education, work, leisure, and social participation. In today's digital age, many of these occupations involve interaction with virtual environments, making cognitive accessibility in these spaces a critical concern for occupational therapists (American Occupational Therapy Association, 2020).

Occupational therapists are encouraged to consider both person factors and environmental factors when developing intervention plans. Person factors include the client's cognitive abilities, sensory processing, and previous experiences with technology. The OTPF-4 also recognizes the importance of context in occupational therapy practice, therefore environmental factors are defined as the physical, social, and attitudinal surroundings in which individuals live and conduct their lives. This broad definition encompasses both natural and human-made environments, including digital environments (American Occupational Therapy Association, 2020). Environmental factors in digital contexts might include the design of user interfaces, the complexity of information presentation, and the availability of assistive technologies (American Occupational Therapy Association, 2020).

Occupational therapists use environmental adaptation to enable patients to participate more fully in their daily activities and occupations (American Occupational Therapy Association, 2020). The OTPF-4 emphasizes the importance of understanding the transactional relationship between the client, their engagement in valuable occupations, and the context in which these occupations occur. This holistic approach is essential when designing interventions for cognitive accessibility in digital environments (American Occupational Therapy Association, 2020). It also relates back the adapted SETT model that was mentioned before, where the person, environment, task, and technology all need to be taken into consideration in the development of solutions (Sweet, Jones and Drummond, 2024). This supports the environmental adaptation approach within the framework which is particularly relevant

when addressing cognitive accessibility in digital environments and is considered a crucial intervention strategy.

It is important to note that the OTPF-4 views occupation as the core therapeutic medium. Therefore, assessments and interventions should focus on participation in meaningful occupations rather than solely on improving cognitive functions in isolation and should be in the context of digital environmental adaptations (American Occupational Therapy Association, 2020). Occupational therapists can use the OTPF-4 to guide their assessment and intervention planning. When considering digital environmental adaptations for cognitive accessibility, occupational therapists must consider various aspects of the client's needs and the environmental demands. The framework suggests considering the following aspects:

- Client factors: Assessing the client's cognitive abilities, including attention, memory, executive function, and information processing speed.
- Performance skills: Evaluating the client's ability to navigate digital interfaces, process digital information, and complete digital tasks.
- Performance patterns: Understanding the client's habits, routines, and roles in relation to digital technology use.
- Context and environment: Analyzing the digital environments the client interacts with, including websites, apps, and digital devices.
- Activity demands: Identifying the cognitive requirements of specific digital tasks and activities.

Based on these assessments, occupational therapists can develop intervention plans that may include:

- Modifying digital interfaces: Simplifying layouts, reducing visual clutter, or implementing consistent navigation structures.
- Implementing assistive technologies: Introducing screen readers, text-to-speech software, or cognitive support apps.
- Training in compensatory strategies: Teaching clients techniques for managing information overload, improving focus, or enhancing memory in digital environments.
- Gradual exposure and skill-building: Developing a progressive plan to build the client's confidence and competence in navigating digital environments.

- Collaborating with developers: Working with software and web developers to implement accessibility features that support cognitive accessibility.

The OTPF-4 also emphasizes the importance of measuring outcomes and continuously evaluating the effectiveness of interventions. For digital environmental adaptations, this might involve assessing improvements in the client's ability to complete digital tasks, their level of independence in using digital technologies, or their overall participation in digitally mediated occupations.

The framework also recognizes the rapid pace of technological change and its impact on occupational therapy practice. As such, it encourages practitioners to stay informed about emerging technologies and their potential applications in improving cognitive accessibility. Moreover, the OTPF-4 acknowledges the importance of considering diverse populations and cultural contexts when designing interventions. This is particularly relevant in digital environments, where global accessibility standards may need to be adapted to local cultural norms and preferences (American Occupational Therapy Association, 2021).

In conclusion, the OTPF-4 provides a comprehensive guide for occupational therapists addressing cognitive accessibility in digital environments. By emphasizing the interplay between person factors, environmental factors, and occupation, the framework supports the development of holistic, client-centered interventions. As digital technologies continue to evolve and integrate into daily life, the principles outlined in the OTPF-4 will remain crucial in guiding occupational therapy practice in this domain.

3.3.2 Models and Frameworks for Understanding Cognitive Disability

The models and frameworks used in this thesis support the underlying person centered approach rather than broader social or human rights models.

3.3.2.1 Allen Cognitive Disability Model

The Allen Cognitive Disability Model (ACDM), developed by Claudia Allen, provides a structured approach for conceptualizing, assessing, and supporting individuals with cognitive impairments. The ACDM is a conceptual framework outlining cognitive ability linked to actions and activities that a person with a cognitive disability can do (Kang and Tadi, 2020). For the purpose of this study, the ACDM will be used to guide

understanding of cognitive ability. The framework presents a hierarchical understanding of cognitive functioning and focuses on an individual's remaining cognitive abilities rather than deficits--this promotes understanding of cognitive functioning and the level of activities that individuals with cognitive impairment are able and willing to perform. Regardless of the level of cognitive ability, cognitive processes are maximized and behavioral responses become more effectively organized when environmental stimuli are presented to the impaired person in a manner that matches their level of cognitive functioning (Levy, 1989).

The framework defines six cognitive levels, ranging from severe impairment (Level 1) to normal cognition (Level 6), with each level characterized by specific cognitive and functional capabilities. A key component of the framework is the Allen Cognitive Level Screen (ACL), a standardized assessment tool used to determine an individual's cognitive level. The ACL involves simple tasks that evaluate information processing, new learning abilities, and problem-solving skills. This assessment helps clinicians identify an individual's current cognitive level and guides intervention planning (Kang and Tadi, 2020).

The framework emphasizes matching environmental demands and activity requirements to an individual's cognitive level. This approach aims to promote successful engagement in meaningful activities while minimizing frustration and maximizing functional independence. For example, an individual assessed at Allen Cognitive Level 4 may benefit from step-by-step instructions and visual cues when performing daily tasks. This model was primarily founded within the field of mental and psychiatric illness, with some studies focusing on dementia (Warchol, 2006; Allen *et al.*, 2009; Kang and Tadi, 2020; Stewart *et al.*, 2022). The ACL can be used to guide the selection of appropriate activities and required adaptations to an individual's specific cognitive abilities and needs. For the purpose of this thesis the model will be used for:

1. Comprehensive assessment: Understanding the levels of cognitive disability of clients required to complete surveys.
2. Activity analysis: Breaking down tasks into cognitive components and adapting them to match an individual's cognitive level.
3. Environmental modifications: Adjusting the physical and social environment to support cognitive functioning and minimize confusion or overstimulation.

4. Caregiver education: Providing training and support to caregivers on effective communication strategies and activity adaptations to facilitate independence in individuals with cognitive disabilities in completing surveys.
5. Ongoing monitoring: Of the adaptations made to the activity to ensure participation of individuals with cognitive disability.

When planning activities such as completion of surveys using technology, the needs of the individual with cognitive impairment are considered and changes to tasks are implemented. Tasks should be modified and adapted to the appropriate level of required cognitive functional ability. By applying the framework thoughtfully and ethically, outcomes can be achieved and enhancement of the lives of individuals with cognitive disabilities across various settings and stages of life can be ensured.

3.3.2.2 Steinmann Obermeyer (SO) Cognitive Disability Framework

No framework which comprehensively includes all types of cognitive impairment as needed for technology development was found in the literature (Dhakal and Bobrin, 2023; Kiely, 2023). The principal investigator (PI) therefore created a cognitive disability framework for the purposes of this thesis to clarify what is included in the concept of cognitive disability as it influences the development of technology solutions for those with any form of cognitive impairment.

Designing cognitively accessible survey technology requires a comprehensive understanding of the challenges faced by individuals with cognitive impairments and the implementation of specific design principles to mitigate these challenges. Therefore, cognitive disabilities were conceptualized as impairments which encompass a range of conditions that affect an individual's ability to process information, remember, solve problems, and communicate effectively. These impairments can significantly impact the usability of technology, including survey tools, which are increasingly used for data collection in various fields.

The cognitive disability framework is summarized in Figure 3.1 and text below:

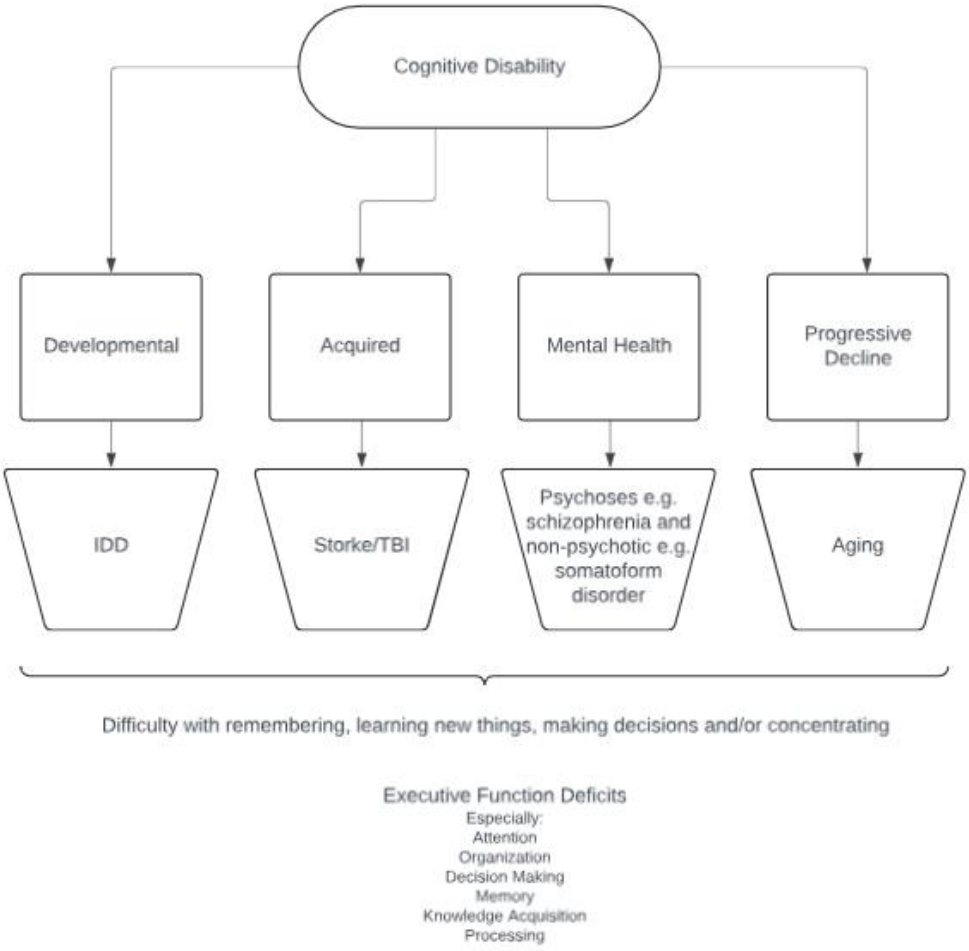


Figure 3.1 Steinmann Obermeyer Cognitive Disability Framework

The framework provides an overview of four major categories of cognitive disabilities: developmental, acquired, mental health-related, and progressive decline. Each category has distinct characteristics, etiologies, and implications for treatment and support.

1. Developmental Cognitive Disabilities

Developmental cognitive disabilities are those that originate during the developmental period, typically before the age of 18. These disabilities are characterized by significant limitations in both intellectual functioning and adaptive behavior (Schalock, Luckasson and Tassé, 2021). Key features include: being present from birth or early childhood, affecting multiple areas of development and often having genetic or environmental causes.

Examples of developmental cognitive disabilities include:

a) Intellectual Disability (ID), formerly known as mental retardation, is characterized by significant limitations in intellectual functioning and adaptive behavior. The severity can range from mild to profound (Tassé, Luckasson and Schalock, 2016).

b) Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by difficulties in social communication and interaction, as well as restricted and repetitive patterns of behavior or interests (Lord *et al.*, 2020).

c) Down Syndrome is a genetic disorder caused by the presence of an extra copy of chromosome 21, though other genetic disorders are also pertinent which may consist of other chromosomal abnormalities, often resulting in intellectual disability and characteristic physical features (Antonarakis *et al.*, 2021).

2. Acquired Cognitive Disabilities

Acquired cognitive disabilities result from injuries or conditions that occur after the developmental period. These disabilities can affect individuals who previously had typical cognitive functioning (Rabinowitz and Levin, 2014). Key features include occurrence after normal development, often resulting from specific events or injuries and may have sudden or gradual onset.

Examples of acquired cognitive disabilities include:

a) Traumatic Brain Injury (TBI) describes cognitive impairments resulting from external force to the head, leading to various cognitive deficits depending on the location and severity of the injury (Dikmen *et al.*, 2009).

b) Strokes can result in cognitive impairments resulting from interruption of blood supply to the brain, which can affect various cognitive domains depending on the location of the stroke (Sun, Tan and Yu, 2014).

c) Anoxic Brain Injury, wherein cognitive deficits result from a lack of oxygen to the brain, which can occur in the normally developing or developed brain in older children and adults. Various causes include cardiac arrest, choking, near-drowning, drug overdose, and exposure to toxic substances (Hopkins, Tate and Bigler, 2005).

3. Mental Health-Related Cognitive Disabilities

Mental health disorders can significantly impact cognitive functioning, leading to impairments in attention, memory, and other executive functions. While these cognitive deficits are often secondary to the primary mental health condition, they can

significantly affect an individual's daily functioning (Millan *et al.*, 2012). Key features include that the condition often co-occurs with mental health disorders, may fluctuate in severity over time, and can improve with treatment of the underlying mental health condition.

Examples of mental health-related cognitive disabilities include:
a) Major Depressive Disorder has in many cases been associated with impairments in attention, memory, and executive function (Rock *et al.*, 2014).

b) Schizophrenia is often associated with significant cognitive deficits across multiple domains, including attention, memory, and executive function (Green, 2006).

c) Bipolar Disorder can result in cognitive impairments, particularly during mood episodes, affecting attention, memory, and executive function (Martínez-Arán *et al.*, 2004).

4. Progressive Decline Cognitive Disabilities

Progressive decline cognitive disabilities are characterized by a gradual deterioration of cognitive functions over time. These conditions are typically associated with aging but can also occur in younger individuals (Scheltens *et al.*, 2016). Key features include a gradual onset and progression that may lead to significant loss of independence over time.

Examples of progressive decline cognitive disabilities include:
a) Alzheimer's Disease is the most common form of dementia characterized by progressive memory loss and decline in other cognitive functions (Scheltens *et al.*, 2016).

b) Parkinson's Disease is primarily a movement disorder, though it often includes cognitive decline, particularly in executive function and processing speed (Aarsland *et al.*, 2017).

c) Huntington's Disease is a genetic disorder characterized by progressive motor cognitive, and psychiatric symptoms (Bates *et al.*, 2015).

Understanding the different categories of cognitive disabilities is crucial for developing appropriate interventions, support strategies, and policies. Each category presents unique challenges and requires tailored approaches to assessment, treatment, and support. Cognitive disabilities encompass a wide range of conditions that affect an

individual's ability to process information, remember, solve problems, and communicate effectively. These impairments can significantly impact the usability of technology, including survey tools which are increasingly used for data collection in various fields. Designing cognitively accessible survey technology requires a comprehensive understanding of the challenges faced by individuals with cognitive disabilities and the implementation of specific design principles to mitigate these challenges, which leads this section to a discussion on the frameworks related to Human Computer Interaction (HCI).

3.3.3 Human-Computer Interaction (HCI) Theory

3.3.3.1 Cognitive Accessibility

Human-Computer Interaction (HCI) theory has emerged as a crucial field in designing accessible technologies for individuals with cognitive disabilities. Cognitive accessibility aims to make digital content and interfaces more accessible to individuals with cognitive disabilities. Nolte et al. (2022) emphasize that cognitive accessibility goes beyond traditional accessibility concerns, focusing on the mental processes involved in perception, memory, and reasoning (Nolte *et al.*, 2022). Another aspect that has been addressed in the literature is Disability Interaction (DIX) and how this interfaces with Human-Computer Interaction. Cognitive disabilities have become more of a focus in technology design because of these theories and their interaction.

The application of HCI principles and methodologies was explored in relation to enhancing cognitive accessibility, focusing on the unique challenges faced by users with cognitive impairments. The key concepts, design approaches, and frameworks within HCI that contribute to improved cognitive accessibility are included.

Human-Computer Interaction to promote Cognitive Accessibility

Several HCI key concepts have been identified as particularly relevant for cognitive accessibility:

1. **User Centered Design**: Wobbrock et al. (2011) proposed the concept of ability-based design, which shifts the focus from disabilities to abilities. This approach encourages designers to create systems that leverage users' existing capabilities, rather than trying to compensate for perceived deficits (Wobbrock *et al.*, 2011; Chammas, Quaresma and Mont'Alvão, 2015).

2. **Adaptability**: Gajos et al. (2007) demonstrated the importance of adaptive interfaces that can adjust to users' cognitive abilities in real-time. Their SUPPLE system generates user interfaces based on users' abilities as measured through simple tasks (Gajos, Wobbrock and Weld, 2007).
3. **Simplification**: Moreno et al. (2024) highlighted the importance of content simplification for users with cognitive impairments. They proposed design patterns for cognitive accessibility, including clear and concise language, consistent layout, and step-by-step instructions (Moreno *et al.*, 2024).
4. **Multimodal Interaction**: Kosmyna et al. (2019) discussed the potential of attention-aware interfaces that adapt to users' attention levels, which can be particularly beneficial for individuals with attention deficit disorders (Kosmyna *et al.*, 2019).

3.3.3.2 Design Approaches in Human-Computer Interaction used to promote Cognitive Accessibility

Several design approaches within HCI have shown promise in addressing cognitive accessibility:

1. **Participatory Design**: Involving users with cognitive disabilities in the design process is crucial, as this design approach ensures that digital technologies are accessible, usable, and contextually appropriate. This methodology is particularly impactful when designing for individuals with cognitive disabilities, as it centers their lived experiences and cognitive needs in the development of digital tools. Research has shown that involving people with cognitive impairments in co-design processes leads to more inclusive and effective digital health solutions, as it helps identify specific usability barriers and fosters the creation of systems that support autonomy and comprehension (Henni *et al.*, 2022). Bayor et al. (2021) proposed a competency-based approach to co-designing technologies with individuals with intellectual disabilities, extending the concept of ability-based design (Bayor *et al.*, 2021).
2. **Universal and Universal Usability Design**: While ability-based design focuses on individual adaptations, universal design principles can be applied to create interfaces that are inherently more accessible to a wide range of users,

including those with cognitive disabilities (Ford, 2009; Steinfeld and Maisel, 2012).

3. **Context-Aware Design**: Nolte et al. (2022) emphasized the importance of considering the context in which cognitive abilities are used. This approach involves designing systems that can adapt to different environments and situations (Nolte *et al.*, 2022).

3.3.4 Human-Computer Interaction Frameworks for Implementing Cognitive Accessibility

Several frameworks have been proposed to guide the implementation of cognitive accessibility in HCI:

1. **Web Content Accessibility Guidelines**: The Web Content Accessibility Guidelines (WCAG) are a globally recognized framework developed by the World Wide Web Consortium (W3C) to ensure that digital content is accessible to all users, including those with disabilities. For individuals with cognitive disabilities—who may experience challenges with memory, attention, problem-solving, or language—WCAG plays a critical role in shaping software that is not only usable but also inclusive. These guidelines emphasize clarity, simplicity, and consistency in design, which are essential for reducing cognitive load and enhancing comprehension (Borina, Kalister and Orehovački, 2022). For example, recommendations such as using plain language, consistent navigation, and multimodal content (e.g., combining text with icons or audio) directly address common barriers faced by users with cognitive impairments. The Web Content Accessibility Guidelines (WCAG) 2.1 include specific guidelines for cognitive accessibility, such as providing sufficient time for users to read and use content and making text content readable and understandable (W3C, 2023).
2. **Cognitive and Learning Disabilities Accessibility Task Force (COGA)**: This W3C initiative provides detailed guidance on making content accessible to individuals with cognitive and learning disabilities (Moreno *et al.*, 2024).
3. **Ability-Based User Modeling**: Nolte et al. (2022) proposed a systematic approach to conceptual user modeling that addresses abilities and their interdependencies with tasks and contexts. This framework provides a

structured method for implementing ability-based design principles (Nolte *et al.*, 2022).

It is important to understand that Human Computer Interaction (HCI) is a multidisciplinary field that focuses on the design and use of computer technology, emphasizing the interfaces between individuals (end-users) and computers. In addition to the key concepts, design approaches, and frameworks discussed above, the discussion will now focus on the design approaches within HCI that can be considered when developing technology for individuals with cognitive disabilities which were incorporated into the development of the survey platform. HCI integrates various design approaches to create systems that are accessible and usable by a diverse range of end-users. Three key approaches in this context are Ability-Based Design, Universal Design, and Disability Interaction (DIX). These approaches, while distinct, complement each other in creating inclusive and adaptive technologies and guide this study throughout.

3.3.4.1 Ability-Based Design (ABD)

Ability-based design (ABD) has emerged as a promising approach in HCI that focuses on end-users' abilities rather than their disabilities. This approach aims to create systems that adapt to the user's capabilities, thereby maximizing their performance and interaction with the technology. This section explores how ABD can be applied within the framework of cognitive accessibility, addressing the needs of users with diverse cognitive abilities.

Principles of Ability-Based Design

Wobbrock et al. (2011) introduced ABD as a refinement to accessible computing, emphasizing the importance of focusing on ability throughout the design process. The core principles of ABD include:

- Ability-focused: Design for what users can do, not what they cannot do.
- Adaptability: Systems should adapt to users, not the other way around.
- Transparency: Interfaces should be transparent and easily understood.
- Performance: Systems should make the best use of users' abilities to maximize performance.
- Context: Design should consider the context in which abilities are used.

These principles shift the focus from disability to ability, encouraging designers to create systems that leverage the full range of human potential.

Ability-based design offers a promising approach to addressing cognitive accessibility in HCI (Wobbrock *et al.*, 2018; Moreno *et al.*, 2024). By focusing on end-users' abilities rather than disabilities, ABD encourages the creation of adaptive, personalized interfaces that can support end-users with diverse cognitive abilities. While challenges remain in implementing ABD for cognitive accessibility, the potential benefits in terms of inclusivity, performance, and end-user satisfaction are significant.

3.3.4.2 Universal Design

Universal Design aims to create products and environments that are usable by all individuals to the greatest extent possible, without the need for adaptation or specialized design. This approach is broader and seeks to accommodate the widest possible range of abilities and situations. Key principles of Universal Design include:

- Equitable Use: The design is useful and marketable to individuals with diverse abilities.
- Flexibility in Use: The design accommodates a wide range of individual preferences and abilities.
- Simple and Intuitive Use: The design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.

3.3.4.3 Disability Interaction (DIX)

The Disability Interaction (DIX) approach is a contemporary framework within HCI that emphasizes the importance of designing technology that is inclusive and accessible to individuals with disabilities (Coleman-Fountain and McLaughlin, 2013). This approach builds on established concepts such as ability-based design and universal design, while also incorporating insights from social movements and critical disability studies. The DIX approach seeks to understand and address the complex interactions between individuals with disabilities and their environments, aiming to create more equitable and empowering technological solutions. DIX focuses specifically on the needs and experiences of individuals with disabilities. This approach often involves direct engagement with users who have disabilities to understand their unique

challenges and requirements. For example, Motti and Evmenova (2020) emphasize that traditional user centered design methods often fail to accommodate neurodiverse users, advocating instead for adaptive, inclusive design practices that align with ability-based design principles (Motti and Evmenova, 2020). Similarly, Butcher and Lane (2024) critique the dominance of the medical model in higher education and call for neurodiversity-affirming practices that recognize systemic barriers rather than individual deficits (Butcher and Lane, 2024). These perspectives are grounded in the social model of disability, which is central to both the disability rights movement and critical disability studies, and they support the idea that technologies should adapt to users' abilities rather than requiring users to conform to normative standards (Holloway and Barbareschi, 2022).

The DIX approach is grounded in several theoretical perspectives, including symbolic interactionism, embodiment, and intersectionality. Symbolic interactionism, as discussed by Coleman-Fountain and McLaughlin (2013), focuses on how individuals make sense of themselves and their bodies through social interactions. This perspective highlights the importance of everyday interactions, and the narratives that emerge from them, in shaping individuals' identities and experiences of disability (Coleman-Fountain and McLaughlin, 2013). This may impact whether individuals with cognitive disabilities are willing to even consider using technology to communicate.

Embodiment theory, which emphasizes the materiality of the body and its role in social interactions, is also central to the DIX approach. This theory argues that differences in bodily capacities and appearances, often labeled as impairments, become significant in social contexts and contribute to the marginalization and exclusion of individuals with disabilities. By incorporating embodiment into the DIX approach, designers can better understand how physical and cognitive differences impact users' interactions with technology, for example utilizing design that does not require vision or fine motor skills.

Intersectionality, as discussed by scholars such as Shakespeare (2009), provides a framework for understanding how multiple social categories, such as disability, race, gender, and class, intersect to shape individuals' experiences and opportunities (Shakespeare, 2009). This perspective is crucial for the DIX approach, as it recognizes that individuals with disabilities are not a homogenous group and that their experiences are influenced by a range of intersecting factors. Digital accessibility thus

needs to consider the different skills and abilities of each individual with cognitive limitations.

The DIX approach is guided by several key principles that inform the design and evaluation of technology for individuals with disabilities:

- User Centered Design: The DIX approach emphasizes the importance of involving individuals with disabilities in the design process. This includes conducting user research, usability testing, and co-design sessions to ensure that the technology meets the needs and preferences of its intended users.
- Adaptability and Flexibility: Technology designed using the DIX approach should be adaptable to the diverse abilities and preferences of users. This includes providing multiple modes of interaction, such as voice, touch, and gesture, and allowing users to customize the interface to suit their needs.
- Empowerment and Agency: The DIX approach seeks to empower individuals with disabilities by providing them with tools and technologies that enhance their independence and agency. This includes designing technology that supports users in achieving their goals and participating fully in society.
- Social and Cultural Context: The DIX approach recognizes that technology does not exist in a vacuum and that its use is shaped by social and cultural contexts. Designers should consider the broader social and cultural factors that influence how technology is used and experienced by individuals with disabilities.

While the DIX approach offers a promising framework for designing inclusive technology, several challenges remain (Holloway and Barbareschi, 2022). One significant challenge is the need for more comprehensive and inclusive End-user research that captures the diverse experiences and needs of individuals with disabilities. This requires engaging with a wide range of end-users and considering the intersectional factors that influence their experiences.

Another challenge is the need for greater collaboration between designers, researchers, disability advocates, and those with disabilities. The DIX approach emphasizes the importance of involving individuals with disabilities in the design process, but this requires building strong partnerships and fostering a culture of collaboration and mutual respect.

Even though the DIX approach represents significant advancement in the field of HCI by offering a comprehensive framework for designing technology that is inclusive and accessible to individuals with cognitive disabilities, a combination of approaches is needed to comprehensively address cognitive accessibility.

3.3.5 Integration of these Approaches

The approaches described above are not mutually exclusive and can be integrated to enhance the inclusivity and adaptability of technology:

- Ability-Based Design and Universal Design: While Universal Design aims for broad usability, ABD can refine this by adapting interfaces to individual users' abilities, providing a more personalized experience.
- Ability-Based Design and Disability Interaction: By focusing on abilities, ABD can inform DIX by highlighting the strengths of users with disabilities and designing systems that leverage these strengths.
- Universal Design and Disability Interaction: Universal Design principles can be applied within the context of DIX to create environments and products that are inherently accessible to users with disabilities, reducing the need for specialized adaptations.

In summary, the integration of Ability-Based Design, Universal Design, and Disability Interaction within HCI creates a comprehensive framework that addresses the diverse needs of all users, ensuring that technology is accessible, usable, and empowering for everyone.

3.3.6 Additional Design Approaches Focusing on End-user Inclusion

Apart from the approaches included in the HCI framework, other design approaches which include end-users in the development of accessible products are also important. These consider the design process in general, and include: Inclusive Design, which is creating products and environments to be accessible; User Sensitive Inclusive Design, which considers diverse needs of users; and Co-Design, which involves all stakeholders cooperating in the design process.

3.3.6.1 Inclusive Design

Inclusive design, as articulated by Bayor et al. (2021), emphasizes the importance of creating products and environments that are accessible to the widest possible range of people, regardless of their abilities or disabilities. This approach is rooted in the principles of equity and diversity, aiming to eliminate barriers that might prevent individuals from fully participating in various aspects of life. Bayor et al. (2021) argue that inclusive design is not just about compliance with accessibility standards but involves a proactive effort to understand and address the diverse needs of users from the outset. This involves engaging with a broad spectrum of stakeholders, including those with disabilities, to ensure that their perspectives are integrated into the design process. By doing so, designers can create solutions that are not only functional but also enhance the user experience for everyone (Bayor *et al.*, 2021).

Furthermore, Bayor et al. (2021) highlight the role of technology in advancing inclusive design. They point out that digital tools and platforms can be leveraged to create more inclusive environments, particularly in education and workplace settings. For instance, the use of assistive technologies can help bridge the gap for individuals with disabilities, enabling them to access information and participate in activities that might otherwise be challenging. The authors also stress the importance of continuous feedback and iteration in the design process, ensuring that solutions remain relevant and effective as user needs evolve. This iterative approach, combined with a commitment to inclusivity, can lead to more innovative and effective design outcomes that benefit a broader audience (Persson *et al.*, 2014; Bayor *et al.*, 2021; Benson-Goldberg, Geist and Erickson, 2025).

3.3.6.2 User Sensitive Inclusive Design

User-sensitive inclusive design, as discussed by Bayor et al. (2021), focuses on creating products and environments that cater to the diverse needs of users, particularly those from marginalized groups. This approach goes beyond traditional inclusive design by emphasizing empathy and a deep understanding of the users' experiences and challenges. Bayor et al. (2021) argue that designers should engage directly with users, employing methods such as ethnography and participatory design to gather insights and ensure that the final product is genuinely accessible and usable.

This user centered approach helps in identifying specific needs and preferences, leading to more effective solutions (Bayor *et al.*, 2021).

Supporting this design strategy, Newell et al. (2011) highlight the importance of developing empathy with user groups, particularly older adults and individuals with disabilities. They suggest that designers should immerse themselves in the users' environments and experiences to better understand their needs and challenges. This can be achieved through techniques such as ethnographic studies and the use of professional theater methods to simulate user experiences (Newell *et al.*, 2011). Additionally, Cezarotto (2023) emphasizes the role of inclusive design in educational media, advocating for the integration of diverse user needs into the design process to create more engaging and effective learning tools. By adopting a user-sensitive approach, designers can create products that not only meet accessibility standards but also enhance the overall user experience (Cezarotto, 2023).

3.3.6.3 Participatory Design

Participatory design is a collaborative approach that involves all stakeholders, including end-users, in the design process to ensure the final product meets their needs and is usable. This method is particularly beneficial for individuals with cognitive disabilities, as it empowers them to contribute their unique perspectives and experiences. According to Bayor et al. (2021), participatory design can significantly enhance the usability and accessibility of technology for individuals with cognitive disabilities by involving them directly in the design process. This approach not only helps in creating more effective and user-friendly solutions but also fosters a sense of ownership and empowerment among participants (Bayor *et al.*, 2021).

Bayor et al. (2021) highlight several key principles of participatory design that are crucial when working with individuals with cognitive disabilities. These include ensuring inclusivity, fostering collaboration, and providing continuous support throughout the design process. By adapting the design activities to meet the specific needs of participants, designers can create an environment where individuals with cognitive disabilities feel valued and capable of meaningful contribution. This inclusive approach not only improves the design outcomes but also promotes social inclusion and enhances the overall well-being of participants (Bayor *et al.*, 2021).

3.3.6.4 Co-Design

Co-design, as explained by Bayor et al. (2021), is a collaborative approach that involves stakeholders, including individuals with cognitive disabilities, in the design process to create more effective and accessible technologies. This method emphasizes the importance of leveraging the competencies of individuals with cognitive disabilities, which are the practical skills they develop through participation in everyday activities and mainstream technologies, like social media. By focusing on these competencies, co-design ensures that the resulting software is not only accessible but also engaging and usable for the target users. Bayor et al. (2021) demonstrated this approach through the development of SkillsTube, a web application co-designed with young adults with intellectual disabilities to help them learn life skills through videos. The familiar social media-inspired design features of the app fostered confidence, participation, and usability among the participants (Bayor *et al.*, 2021).

Additional research supports the effectiveness of co-design in developing cognitively accessible software. For instance, Herriott (2015) discusses the use of proxies in social co-design to address communication barriers faced by individuals with severe cognitive disabilities. This approach ensures that the needs and preferences of these individuals are accurately represented in the design process, leading to more inclusive and user-friendly outcomes (Herriott, 2015). Similarly, Benz et al. (2024) highlight the benefits of community-based participatory research through co-design, which includes balancing idealism and realism, ensuring accessibility, and fostering collaboration among all stakeholders (Benz *et al.*, 2024).

These design approaches focusing on end-user inclusion underscore the importance of involving individuals with cognitive disabilities in the design process to create software that truly meets their needs and enhances their quality of life.

3.4 Conclusion

Human computer interaction offers a valuable framework for addressing cognitive accessibility challenges by focusing on user centered design, adaptability, and context awareness. HCI approaches can significantly improve the accessibility of digital

technologies for individuals with cognitive disabilities. The integration of ability-based design, participatory design methods, and adaptive interfaces shows particular promise in creating more inclusive and empowering technological experiences. As research in this field progresses, we can expect to see more sophisticated and effective solutions that cater to the diverse needs of users with cognitive impairments. However, it is crucial to remember that cognitive accessibility is not a one-size-fits-all solution. The diversity of cognitive abilities and the complex interplay between individual, task, and context factors necessitate ongoing research and development in this field. The role of the occupational therapist in understanding the abilities of individuals with cognitive disabilities, environmental adaptation and modification of tasks and activities to ensure optimal participation is essential in guiding the process of cognitively accessible design. By continuing to refine and expand HCI approaches to cognitive accessibility, all can work together towards a future where digital technologies are truly inclusive and accessible to all users, regardless of their cognitive abilities.

Designing cognitively accessible survey technology is a complex but essential task to ensure that individuals with cognitive disabilities can participate fully in data collection processes. By adopting a user centered design approach, simplifying information architecture, preventing and recovering from errors, using multi-modal communication, and ensuring consistent navigation designers can create survey tools that are accessible and user-friendly. Continued research and collaboration is necessary to address the challenges and improve the accessibility of technology for all users.

3.5 Methodology

3.5.1 Introduction

This study was carried out in three sequential phases: to develop technology suitable for a survey platform for individuals with cognitive disabilities, to transfer the technology developed to a survey for testing, and then for individuals with cognitive disabilities to evaluate the multimedia selections for a survey on the WES platform. Overall, a structured design for steps to develop technology was used in the study

(Verschuren and Hartog, 2005). The study used a multi methodology approach with different methodologies within and between the three phases.

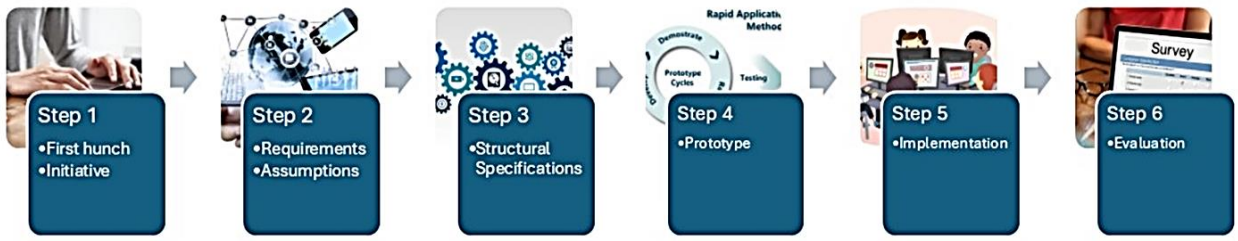


Figure 3.2 The Design Cycle in Design-Oriented Research

3.6 Ethical considerations

Ethical Approval was obtained from the Human Research Ethics Committee (HREC) (M190706) at the University of the Witwatersrand (Appendix B) as well as the New York Medical College (NYMC) Institutional Review Board (IRB) (IRB ID 12689) (Appendix C), which serves as the academic affiliate and governing IRB of WIHD.

3.6.1 Respect for persons (Dignity and Autonomy)

The IDD population for this study is considered vulnerable in terms of ethical considerations and requires special protections to ensure their privacy and confidentiality are maintained.

- **Capacity to Consent:** The participants' capacity to provide consent in Phase 3 was confirmed by the occupational therapist and/or quality programs manager who enrolled the client into the study. Participants during this phase came to the health clinic and were invited to participate based on their ability to give informed consent. The principles of the University of California San Diego Brief Assessment of Capacity to Consent (UBACC) (Appendix D), described in Phase 3, were employed to confirm the ability of individuals with IDD to provide informed consent. This instrument was found to have good internal consistency, interrater reliability, concurrent validity, high sensitivity, and acceptable specificity (Jeste *et al.*, 2007; Duron *et al.*, 2013). This was crucial as participants were not identified based on their guardianship status, unlike in

Phase 1 and Phase 2 where participants with IDD do not have a legal guardian and are legally considered capable of making their own decisions and providing informed consent.

- **Adaptation of Instrument Directions:** The instrument directions were adapted as needed to ensure that participants understood the questions, enabling them to make an informed decision about responses to questions.

3.6.2 Upholding Confidentiality and Anonymity

Confidentiality was achieved by using participant codes in place of identifiable information. In addition, all identifying data was removed prior to the commencement of any data analyses. Lastly, all project materials and data, including video recordings, will be kept locked in the PI's office with access limited to those involved in the research project.

- **Data Protection**: Robust measures were implemented to protect the confidentiality and privacy of participants' data by ensuring all data were stored on password protected devices and available to the PI and supervisors only.

- **Anonymity**: Data were anonymized where possible to protect participant identities - deidentification was completed with the use of participant codes.

3.6.3 Beneficence and non-maleficence

This principle highlights the obligation of minimizing possible harm and maximizing benefits in the research process.

- **Risk Minimization**: Potential risks to participants were identified and minimized. This includes physical, psychological, and social risks.

- **Maximizing Benefits**: The study aimed to provide benefits to participants or the broader community to ensure the research had a positive impact. The development of cognitively accessible survey technology will allow for individuals with IDD to be included in surveys about their lives and their services and give their own opinions about their care, especially healthcare.

3.6.4 Distributive Justice (Equality)

This principle ensures a balance of risks and benefits in the research process, ensuring that the population on which the study is based, namely individuals with cognitive limitations, benefits equally from the research.

Fair Selection of Participants: A fair and inclusive selection process was implemented to avoid exploitation or exclusion of certain groups. Participants were selected according to criteria set for this thesis and not vulnerability, privilege, or other unrelated factors.

Equitable Distribution: The benefits and burdens of research were distributed fairly among all participants who were vulnerable in the context of research, and no one was inappropriately included in research.

3.6.5 Informed consent

In compliance with the declaration of Helsinki, participants with IDD were adequately informed in an information sheet (Appendix E) about the following:

- the aim and methods,
- possible risk factors,
- potential benefits of the study and participation in the study,
- the freedom to decline participation in the study with no consequence on the services they receive from WIHD, and
- the right to withdraw from the study at any time with no consequence on the services they receive from WIHD.

For potential participants who could not give informed consent an assent form was developed (Appendix F) as well as a signed consent for guardians/caregivers (Appendix G) for Phase 2.

- **Caregiver Contact**: Guardians/Caregivers could contact the principal investigator for additional information if interested in having the patient participate.

- **Verbal Assent**: Once consent was obtained from the caregiver, the client was enrolled in the study if they gave verbal assent or indicated assent by nodding.

3.7 Research Setting

The research was conducted at the Westchester Institute for Human Development (WIHD). This Institute envisions a world in which IDD individuals live healthy and productive lives as full members of society. As such, the organization also works to advance policies and practices that ensure the health and self-determination of IDD individuals of all ages and the safety and well-being of vulnerable children.

WIHD is an independent not-for-profit organization that operates a diagnostic and treatment center in Valhalla, New York, certified pursuant to Article 28 of the New York State Public Health Law. The WIHD Adult Health Program provides primary health services as well as specialty care as follows: cardiology, dermatology, endocrinology, metabolic services, neurology, nutrition services, ophthalmology, physical medicine and rehabilitation, podiatry, psychiatry, psychological services, urology and women's health.

Clients' complex medical, dental, behavioral, clinical and social service needs across Westchester County and the Lower Hudson Valley are served by the WIHD. Professional education, advocacy, and research ensures better programs and policies for individuals with disabilities and vulnerable children nationwide. As part of WIHD's mission, they provide services to the IDD population and share their expertise with other institutions and professionals to promote systemic improvements to IDD healthcare.

In addition to providing healthcare services to individuals with IDD, WIHD contracts with third parties to provide social services to individuals with disabilities and at-risk children and adults in Westchester County, New York and surrounding communities. WIHD maintains an academic affiliation with New York Medical College and is nationally recognized by the Association of University Centers on Disabilities (AUCD) for its work promoting family and self-advocate partnerships in all its activities.

Clinical services at WIHD are geared specifically to individuals with IDD. As their website states:

> "Each year our clinical staff serves more than 5,500 individuals with disabilities, who make 33,000 visits for primary and specialty care. That experience makes our staff uniquely qualified to understand and anticipate the needs of individuals

with intellectual and developmental disabilities. In addition, our providers are recognized experts in their specialties, with many serving on the faculty of New York Medical College. We provide the broadest array of health services and medical specialties in Westchester and beyond to serve the needs of individuals with developmental disabilities. In addition to primary care, we offer many behavioral health resources including psychiatry, neurology, and behavioral psychology. WIHD offers appointments with medical specialties from cardiology to podiatry, as well as comprehensive dental care. We evaluate and meet our patients' needs for shoes, braces, and wheelchairs. We don't just treat diseases — we promote health and wellness in our patients" (Westchester Institute for Human Development, 2025a).

WIHD also supports the development of self-advocacy skills and the Community Support Network (CSN), which is committed to an innovative program offering for self-advocates in New York State aimed at empowering, educating, and developing social connections for self-advocates (Westchester Institute for Human Development, 2025b). There are three major components to the self-advocacy network:

- ***Hear Our Voices***
  An educational program that explores relevant topics for self-advocates and meets via zoom monthly the third Wednesday of each month from 6pm to 7pm.
- ***GetWIHDit***
  A social engagement platform with events both in person and online across Westchester County. Their social engagement activities are both designed and led by WIHD Self-Advocacy Coordinator, Brendan Klein.
- The ***Speakers Network***
  Offers individualized presentation skills coaching to self-advocates interested in sharing their experiences to impact policy development and disability awareness in New York State.

CHAPTER 4: PHASE 1

Overall, the methodology covers the process of a designing cycle suggested for design-oriented research in social sciences which covers a systematic research and evaluation methodology. The study used a multi methodology approach with multiple data sources, research methodologies and perspectives within and between the three phases (Watkins, 2004).

4.1 PHASE 1: METHODOLOGY - DEVELOPMENT OF TECHNOLOGY FOR A COGNITIVELY ACCESSIBLE SURVEY SOFTWARE PLATFORM

Phase 1 of this study was completed in five parts and used the four steps in the designing cycle for the development of technology (Verschuren and Hartog, 2005). Step 1 (Phase 1a and 1b) addressed identifying the problem to initiate the development of technology by understanding the needs of stakeholders; Step 2 (Phase 1c) developed requirements for software; in Step 3 (Phase 1d) structural specifications for planning delivery were made; and lastly in Step 4 (Phase 1e) a prototype was built and evaluation in a pilot study took place.

See Figure 4.1 below for a summary of phase 1 and its components for the development of technology for a cognitively accessible survey software platform.

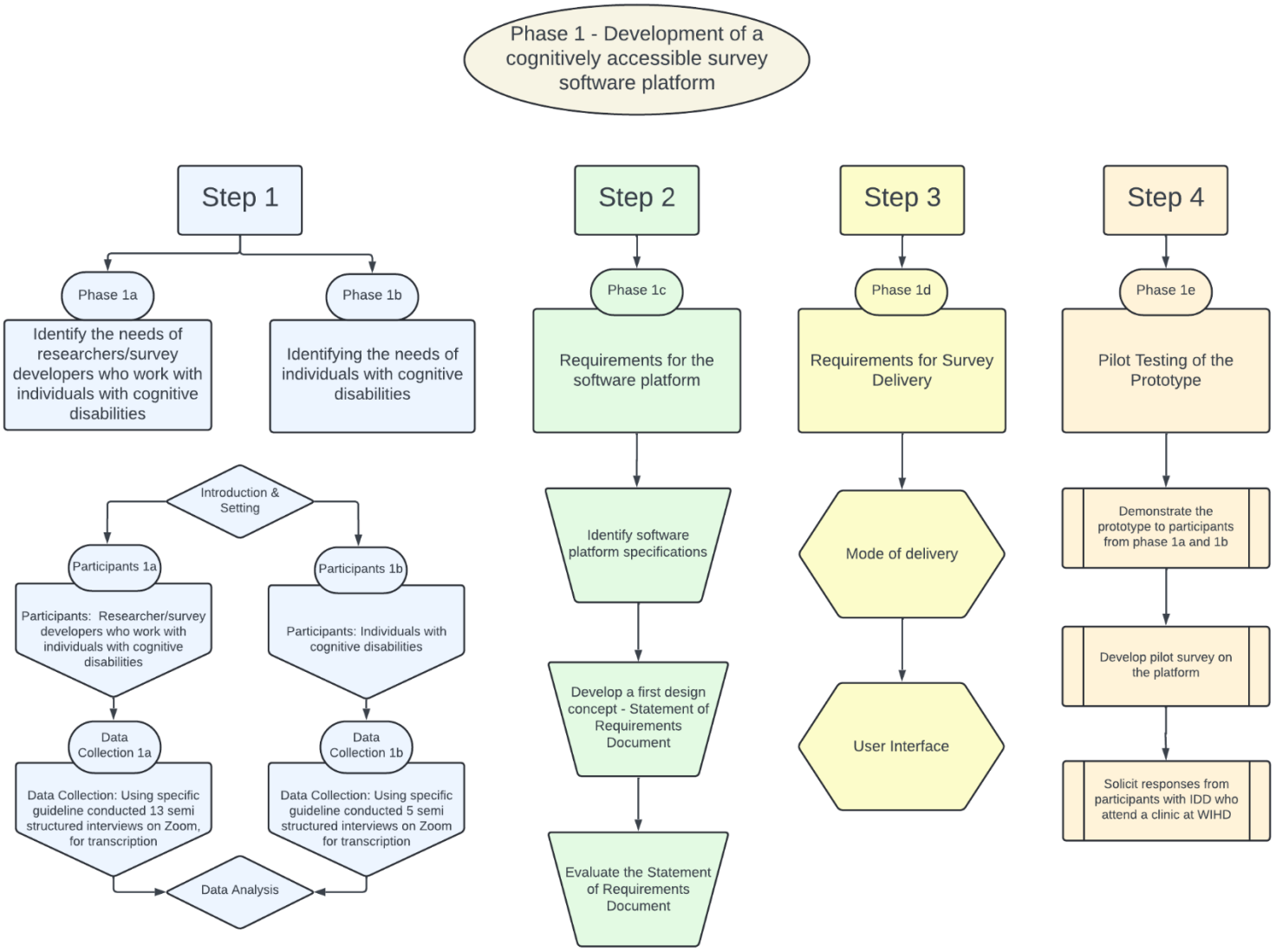


Figure 4.1 Phase 1 Overview of the 5 methodological sections

4.1.1 PHASE 1a and 1b: Identifying the needs of stakeholders

4.1.1.1 Research Design

This part of phase 1 addressed Step 1 in the design process, which was establishing the needs of the stakeholders, researchers/survey developers as well as individuals with cognitive disabilities, by exploring their expectations of the proposed technology (Verschuren and Hartog, 2005). These phases used a descriptive, qualitative, multi-case study research design to determine the needs of survey developers/researchers and individuals with cognitive disabilities regarding a survey platform. This research design was suited to this phase of the study since the multi case study includes determining the concepts from different perspectives ensuring cases are selected accordingly (Miles and Huberman, 1994; Stake, 2006). Miles and Huberman (1994) indicate the sample, or cases, should be representative of the stakeholders, recognizing the concept that binds the cases together even if the cases have a differing relationship to the concept. This multi case study was bound to the needs of developers/researchers and individuals with cognitive disabilities in creating technology to provide an accessible survey platform for persons with cognitive disabilities. Thus, the phase of the descriptive multi case study focused on a real-life context was used (Yin, 2014).

Phase 1a and 1b were very similar in their research design. See Figure 4.2 for an explanation of the methodology used.

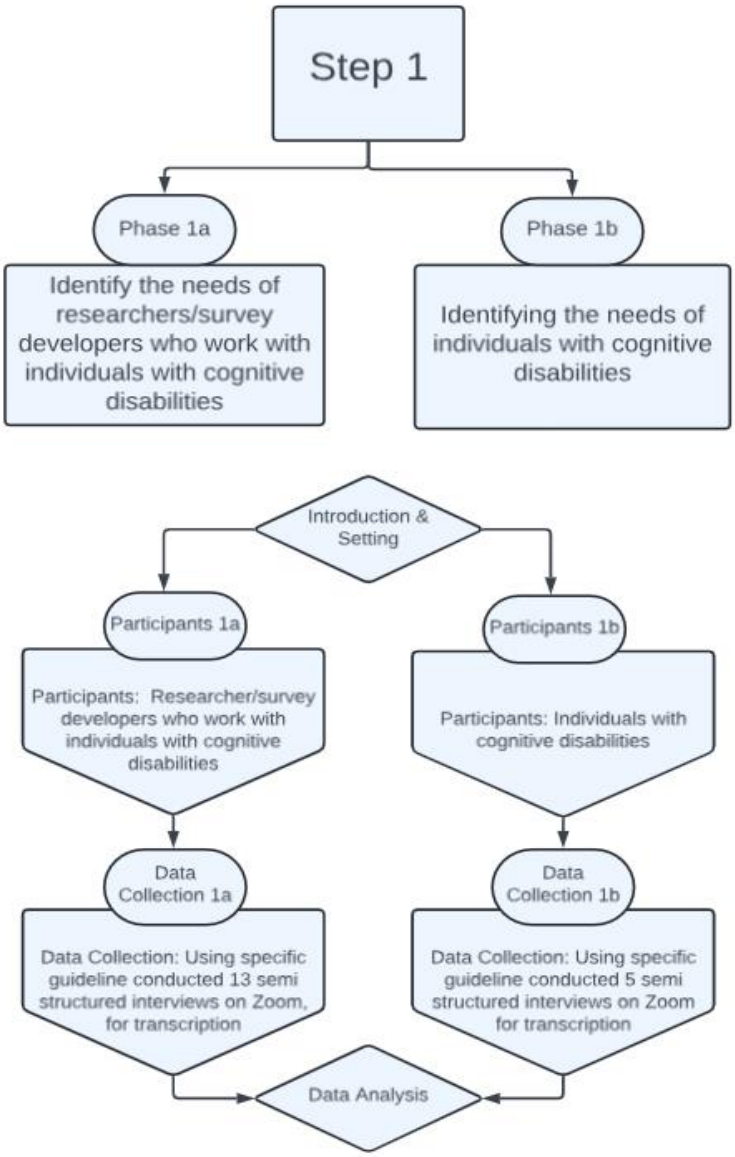


Figure 4.2 Phase 1a and 1b overview

4.1.1.2 PHASE 1a

Population and sampling

The population of participants included survey developers/researchers who work in the Northeastern part of the United States and individuals with cognitive disabilities living in the Westchester County area of New York State and have an affiliation with the WIHD. The Principal Investigator (PI) utilized purposeful sampling to identify survey developers/researchers for participation in this part of the study. These

participants would be most likely to be information-rich on the topic (Walsh *et al.*, 2019). A purposive sample was utilized as all who met the criteria and agreed to be interviewed were included. Although the number of researchers/developers who met these criteria was unknown, the Principal Investigator (PI) utilized purposeful sampling based on criteria for qualitative research.

i. Inclusion criteria

The inclusion criteria for participants demanded that they must be survey developers/researchers, who are professionals working with individuals with IDD, using surveys to conduct research or do program evaluations for persons with cognitive disabilities, with at least three years of experience.

ii. Exclusion criteria

Any researcher/survey developer who do not have experience working with individuals with cognitive disabilities.

iii. Sample size

Typically, 4-10 participants are included in a multi-case study (Stake, 2006), but the number of participants considered sufficient for data saturation in qualitative research is no longer a fixed number, as was stated by Guest in 2006 (Guest, 2006). The deciding factor of the emergence of new codes/themes, and the point where no new themes or codes are found, is the saturation point + 1 (n+1). Thus, for this study, at n interviews no new codes emerged and so the sample included in the study was n+1. This point was reached at 12, so 13 participants were included (Braun and Clarke, 2021b).

Research Instrument

The PI developed an interview schedule based on the literature to explore their perceived needs for developing technology for use by individuals with IDD. The schedule consisted of a section with demographic questions as well as a guideline for individual interviews, that was developed to impose a directive structure on the interview process, which probed five areas of inquiry: The following questions were posed:

- What difficulties exist in doing surveys with individuals with cognitive limitations?

- What supports could help get better information from persons with cognitive limitations?
- What kind of data output would be most effective?
- What would an ideal platform in surveying individuals with cognitive limitations entail?
- What other thoughts would you like to share?

The questions were not piloted before the interviews. Each question was posed to each participant, but additional prompts (see data collection section below) were used at the discretion of the PI and dependent on the participants' responses.

Research Procedure

Recruitment

The PI identified 13 potential participants based on her knowledge of colleagues who met the inclusion criteria, and sent an individualized email invitation to each, based on her relationship with them. All 13 consented to being interviewed.

Data Collection

Using the guideline described above, individual semi structured interviews were conducted with 13 survey developers/researchers who met the inclusion criteria. The participants were interviewed using the guideline questions with added prompting regarding differences between paper and pencil surveys and online platforms, adding multimedia to surveys, platforms that participants are familiar with, and what data collection capabilities they may need. The interviews were conducted via Zoom™ teleconference, using this platform during COVID-19 restrictions, and, with consent, were video recorded (see Appendix P) so the PI could view and assess body language, and the transcriptions could be used for analysis online. The PI conducted each interview, and the interviews lasted approximately an hour each. Demographic data was collected as part of the interview.

4.1.1.3 PHASE 1b

Population and sampling

The PI utilized purposive sampling to identify individuals with IDD attending WIHD for participation in this study. The participants for the study were drawn from clients at

WIHD which only provides services for individuals with developmental disabilities. The objective was to triangulate and confirm findings from phase 1a. A purposive sample was utilized as all who agreed to be interviewed were included, but a specific group was targeted. (See inclusion criteria)

i. Inclusion criteria

The inclusion criteria for participants were that they:

- must be an individual who identified as having IDD with verbal communication skills and are legally able to make their own decisions and do not have a legal guardian,
- understand verbal communication and provide feedback,
- must be over the age of 20 years,
- must have had previous exposure to technology.

ii. Exclusion criteria

- Additional medical frailty, non-verbal or unintelligible status.
- Having a guardian or being under guardianship.

iii. Sample size

The sample of individuals with IDD was limited due to the number of possible participants who met the inclusion criteria that were willing to participate in the study. Using this second sample of participants in Phase 1b, for data triangulation, strengthened the credibility and validity of the findings, enriched the data and provided a more comprehensive picture of the phenomenon while mitigating bias. A smaller sample can provide adequate data for this purpose (Carter *et al.*, 2014). Data saturation was achieved over the two samples, and it is important to note that participats with IDD are not always included in research, and therefore all their contributions were valuable, regardless of the number of participants.

Research Instrument

The PI developed an interview schedule based on the literature to explore the needs for developing technology for use by individuals with IDD from their perspective. The schedule, consisting of a section with demographic questions as well as a guideline

for individual interviews, was developed to impose a directive structure on the interview process which probed five areas of inquiry. The language of proposed questions was simplified; as exampled below, the unchanged questions are followed by their simplified counterparts:

- What difficulties exist in doing surveys for individuals with cognitive disabilities?
    - What is difficult for you when you answer surveys?
- What supports could help get better information from persons with cognitive disabilities?
    - What would make it easier to answer surveys?
- What would an ideal platform in surveying individuals with cognitive disabilities entail?
    - What should look like so you can answer the questions?
- What other thoughts would you like to share?
    - What else can you tell me about making it easier for you to answer surveys?

Research procedure

Recruitment

Participants from WIHD's Hear Our Voices self-advocacy group were identified, since these individuals would be most likely to be information-rich on the topic (Walsh *et al.*, 2019). The chairperson was contacted to disseminate information about the study (Appendix E). Once the information was shared with the group, those who voiced an interest in participating in the study were contacted by the PI to enroll them into the study. The PI does not treat these clients and it was clearly explained that they could withdraw from the study at any time. There were no conflicts of interest in the recruitment of the participants.

Data Collection

Data from Phase 1a were analyzed before Phase 1b to ensure the interview guide and prompts for Phase 1b covered all relevant aspects for using an accessible survey platform according to the Phase 1a results. Using this guideline, individual semi-structured interviews were conducted with five individuals with IDD who met the inclusion criteria. The participants were interviewed using the guideline questions with added prompting regarding differences between paper and pencil surveys and online

platforms, adding multimedia to surveys, and surveys that participants are familiar with. The interviews were conducted via teleconference, using a Zoom™ platform during COVID-19 restrictions, and, after consent was obtained (See Appendix F and P), were video recorded so transcriptions could be used for analysis. All recorded data were available to the PI only and kept on a password protected computer to protect this vulnerable sample. The PI conducted each interview and collected demographic information as part of the interview. Each interview lasted approximately 30 minutes.

4.1.1.4 Data Analysis for phases 1a and b

Demographic data of the participants were analyzed descriptively. Interviews were transcribed verbatim. Once transcribed, the PI reviewed the transcripts for accuracy and revised errors when necessary to ensure the transcripts were an accurate reflection of the interviews. The transcripts were also reviewed by an additional investigator to ensure accuracy. Using MaxQDA software (MAXQDA.com, 2018), the PI conducted an inductive thematic analysis by reviewing the transcripts. An inductive thematic analysis is a systematic, yet flexible, approach to analyzing qualitative data. The research process involves identifying, analyzing, and reporting patterns (themes) within the data, with the aim of capturing something important about the data in relation to the research question (Hecker and Kalpokas, 2025). The following six steps were followed during the thematic analysis:

- Familiarizing yourself with your data
  Read through all transcripts twice and identified common ideas
- Generating initial codes
  Common ideas were noted and became codes
- Searching for themes
  Overall themes were created by combining similar codes
- Reviewing themes
  All coding and themes were reviewed by a second researcher with experience working with individuals with IDD and surveys
- Defining and naming themes
  Consensus was reached between the two researchers as to the names of the themes
- Producing the report (Braun and Clarke, 2021a)

Tables were created with themes, categories, subcategories and codes

Coding was verified by an additional investigator to confirm themes identified.

After the interviews with the five participants were transcribed, the transcriptions were checked and verified for accuracy by the PI. A detailed thematic analysis was then conducted on the data in the transcriptions, and one theme was identified and related to the independence of self-report surveys. The coded theme identified was verified by an additional investigator for accuracy. Within the theme three categories identified were accessibility specific, device specific, and population specific supports.

4.1.2 PHASE 1c: Determining Software Requirements

4.1.2.1 Research Design

This part of Phase 1 addressed Step 2 in the design process which used a descriptive analytic quantitative study to determine the requirements for the software based on the inclusion of all aspects identified in the codes from the results of Phase 1a and 1b (Verschuren and Hartog, 2005). The analysis focused on what was required for technology to be accessible to individuals with cognitive disabilities by identifying existing software platform specifications, developing a statement of requirements, and evaluating the statement of requirements that were comprehensive, consistent, and unambiguous. (Figure 4.3)

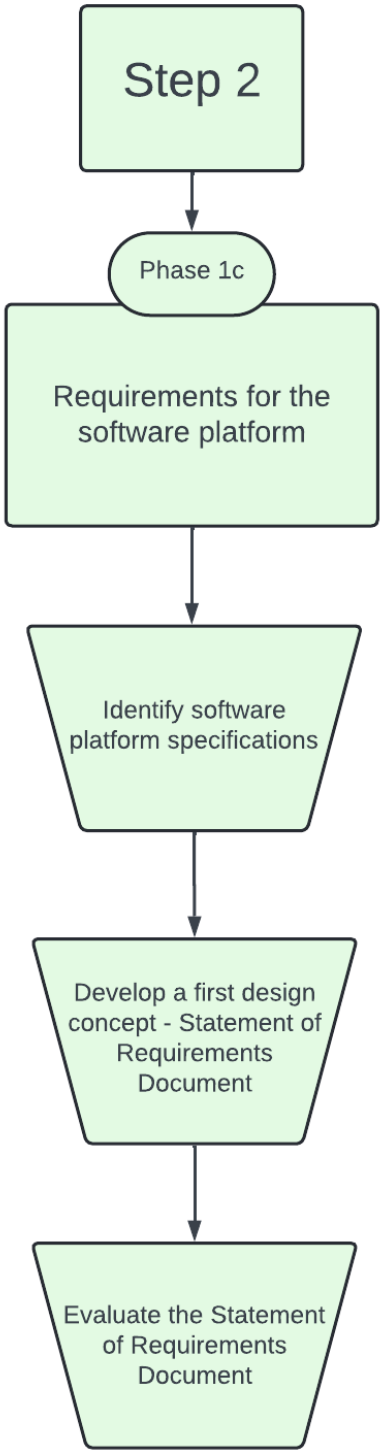


Figure 4.3 Phase 1c – Software Requirements

4.1.2.2 Participants

Since this phase involved analysis of software and requirements for software platforms, a software developer and three of the survey developers/researchers who participated in Phase 1a were included. These three survey developers/researchers were selected using convenience sampling, because of their proximity to the PI (all worked at WIHD) and their overall familiarity with the study.

4.1.2.3 Research procedure

Identify platform specification requirements

Existing survey platforms commonly used, for e.g. SurveyMonkey™, and the evidence for various adaptations suggested in Phase 1a and 1b, were analyzed by the PI to determine specifications specific to survey platform development. The PI also reviewed literature from Chapter 2, and theories related to accessibility of online surveys in Chapter 3, which reported on aspects of research evidence to support accessibility for individuals with cognitive disabilities in the virtual environment. This was based on scoping reviews by Kooijmans et al., (2022) and Friedman et al. (2007). After a desktop review of the survey platforms mentioned by researchers/developers as those they use for survey development, the information gathered was used to develop the research instrument that was utilized to compare it with the evidence for the criteria obtained from the interviews with the participants in Phase 1a and 1b. The research instrument used to collect this information was a data extraction form which was the required initial step for the Statement of Requirements document. This led to the development of a comprehensive technical specifications document in consultation with a software developer.

Develop a first design concept

The results of the analysis from Phase 1a and 1b and the existing survey platforms were shared with a software developer to review regarding the identified software requirements. Consultation with the software developer, who is a familiar consultant for WIHD (who covered the costs of the development of the prototype) and has developed software for the institute before, then focused on technical expertise and clarification of the concepts of multimedia technology and accessibility requirements for individuals with cognitive disabilities. The Statement of Requirements Document

was then developed in collaboration with the software developer. The research instrument was developed once the results were analyzed. The data extraction form used in this phase summarized the data gathered in the previous phases and was used to create the Statement of Requirements Document for use during the rest of the study.

Evaluate the Statement of Requirements Document

Once the Statement of Requirements Document was developed, it was reviewed with three of the researcher/survey developers from Phase 1a. Three participants were selected because it is indicated by Polit and Beck that at least three reviewers are required when developing a survey and these participants had already been made familiar with the project (Polit and Beck, 2006). These three participants were selected because of their proximity to the PI (All working at WIHD) and their overall knowledge and familiarity with the project. An in-person meeting was scheduled between the PI and these participants to discuss the specifications and whether this meets their needs since it is essential that a team achieve consensus on the requirements. A consensus discussion group was used to facilitate group decision-making by seeking agreement from all participants for changes and solutions that everyone could use (Tran, Felfernig and Le, 2023). Each specification was discussed and adapted if needed, to everyone's satisfaction. The Statement of Requirements Document was shared during the meeting on a large wall mounted TV screen and changes were made in the document as the group discussed each concept. At this stage, the different specifications in this document were classified as "must have", "would be good to have, but not essential right now" and "maybe somewhere down the road". This was done to create a minimally viable product (MVP), which is an essential step in software development (Lortie *et al.*, 2024).

After this development period, any changes that needed to be made were identified. Based on this discussion, the Statement of Requirements document outlined in Figures 4.7 – 4.12 (P95-100) in the results section, was finalized and shared with the software developer for final consultation.

4.1.3 PHASE 1d: Requirements for Survey Delivery

4.1.3.1 Research Design

Phase 1's fourth part considered Step 3 in the design process (Verschuren and Hartog, 2005) in terms of the structural specifications with planning the delivery of the platform and how this could be accessed by individuals with cognitive disabilities. The requirements identified in Phase 1c were considered in terms of the software platforms available and the functional units required in surveys using a quantitative descriptive analytical deign to systematically collect and analyze numerical data to describe the use of technology by individuals with IDD without manipulating any variables.

4.1.3.2 Participants

The five participants with IDD who completed interviews in Phase 1b were interviewed for a second time about their online devices and which devices they were able to access.

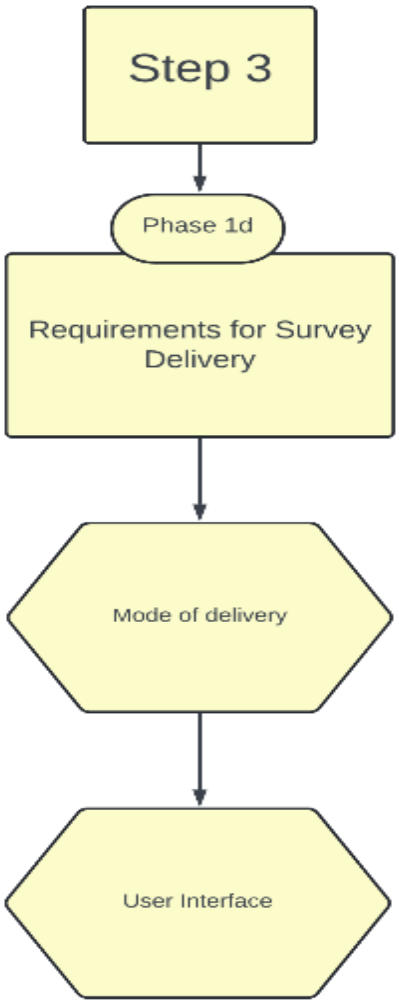


Figure 4.4 Requirements for Survey Delivery

4.1.3.3 Research instrument

A short data collection sheet (Appendix H) was developed by the PI to record the possible options for analysis and identification of a mode of delivery of the technology to be developed. This included all possible presentation on online devices, applications, logistics of including these on the platform, costs, and accessibility options to guide the decisions of what would be required on the platform. The mode of delivery and the interface with the user guided this process.

The literature regarding mode (web based, online/offline, app or desktop) for development of the platform was reviewed by the PI. Another data collection sheet (Appendix I) was developed to determine what access individuals with IDD had to online surveys and the devices (accessibility) for delivery to end-users of surveys.

4.1.3.4 Research Procedure

Participants with IDD were interviewed about their personal online devices and which devices they were able to access. This second interview with the individuals with IDD was used to superficially ask about technology use. This was separate from the first interview so as not to confuse the participants about the focus of the interview. A meeting was scheduled with each of the participants, and they were asked what kinds of device they used on a daily basis. They were also asked which technology platforms they have used to access surveys, if any. The answers were recorded on a fact sheet (Appendix J) which was developed by the PI. Since data were based on close ended questions about technology use and accessibility, the fact sheet was not validated. Discussion with the participants with IDD was included in the interview to determine if there was agreement with the results of an adjacent study which determined technology use by individuals with IDD (Patrick *et al.*, 2020).

In addition, the software developer and the PI consulted with a user interface design expert and a graphic designer on the layout of the user interface based on the results obtained from the participants in this phase of the study and the statement of requirements in Phase 1c. The user interface design expert and the graphic designer were employed by the software developer for their expertise in this step of the software development.

4.1.4 PHASE 1e: Pilot testing of the prototype

Based on the outcomes of the steps in phase 1c and 1d, the development of the technology according to the specification for the user interface was developed in consultation with the software developer. The software developer built the Minimum Viable Product (MVP) prototype as suggested in Step 4 of the design process to introduce the technology according to the Statement of Requirements Document. Adaptions to the MVP would then be included based on evaluation in further steps in the study (Verschuren and Hartog, 2005).

4.1.4.1 Research Design

A descriptive evaluation research design was used to combine descriptive and evaluative approaches to systematically describe and assess the survey prototype. This design uses various methods, including interviews, to gather both qualitative and

quantitative data. This was used for the last part of Phase 1, which included Step 4 to evaluate the prototype. A pilot study was used to test the interface on the prototype platform developed in Phase 1c on devices identified in Phase 1d from the perspective of the stakeholders. Phase 1e considered the outcome and whether this could address the needs identified and have the result expected in relation to accessibility of surveys for individuals with cognitive disabilities. This research design used qualitative and quantitative research methods. First the protocol platform (WIHD Easy Survey = WES) developed in Phase 1c was evaluated from the perspective of the developers/researchers and individuals with IDD who took part in Phase 1a and 1b using discussion groups (Figure 4.5). A routine survey used at WIHD was then created on the prototype platform and the accessibility of the survey was evaluated by having individuals with IDD attending a clinic at WIHD complete it online to determine if the platform could be used to make surveys accessible.

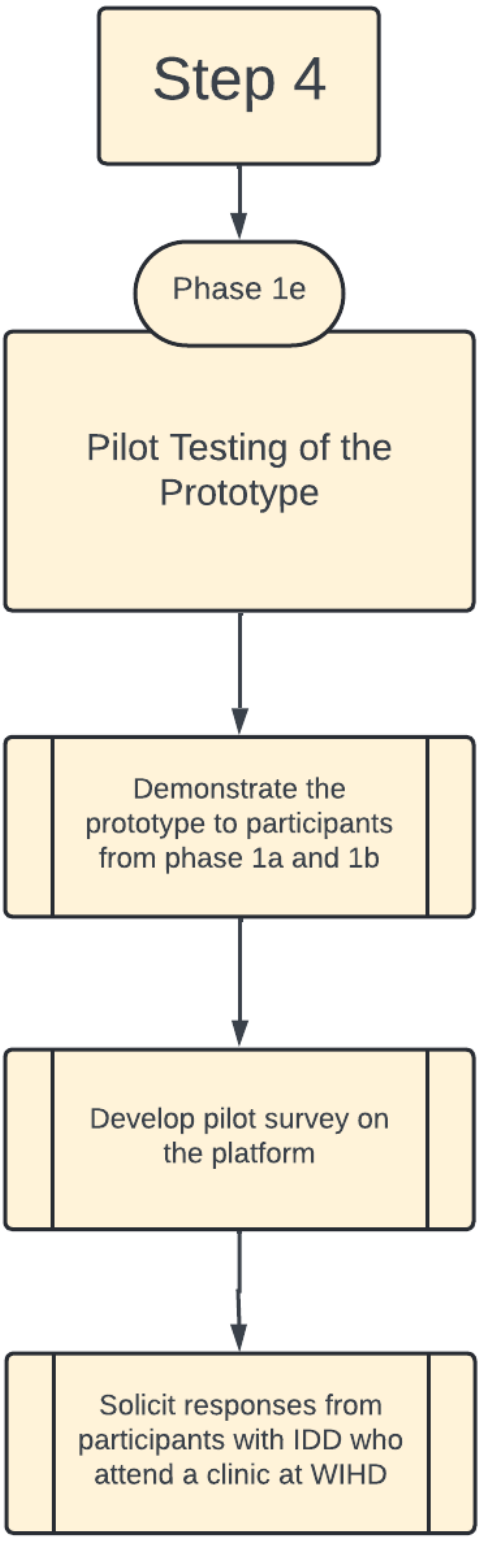


Figure 4.5 Pilot testing of the prototype

As can be seen in Figure 4.5 above, this phase had three parts. The first part was to demonstrate the prototype to the participants from phase 1a and 1b, the second part was to transfer an existing survey onto the platform to evaluate the technology, and the third part was to solicit responses from individuals who attended the WIHD adult health clinic for this pilot testing of the technology options in survey questions.

4.1.4.2 Participants

Phase 1e Part 1 – Review of prototype by experts and end-users with IDD

The participants who took part in Phase 1a and 1b were included in the first part of Phase 1e. The PI used a discussion group consensus format (Tran, Felfernig and Le, 2023).

Phase 1e Part 3 – Pilot study to evaluate the accessibility of the technology by end-users

The third part of phase 1e was completed by 24 individuals not previously involved in the study, who attended the adult health clinic at WIHD. There was an invitation to participate notice displayed within the clinic. Participants were asked if they would give feedback about their services, as was routine to ask after a visit to the clinic. It was explained that this standard survey would be done on an iPad, instead of doing this with pencil and paper, and once the individuals with IDD attending the clinic or their guardian provided consent, they were enrolled. This pilot study aimed to determine if the content of the terminology provided accessibility in the pilot survey before moving to Phase 2 of the research project. A convenience sample from the population of individuals with IDD who attend the health clinic was utilized as all who agreed to participate in this pilot were included. Determining an appropriate sample size for a pilot study can be challenging, scholarly references suggest that sample sizes for pilot studies typically range from 10 to 40 participants per group (Hertzog, 2008).

iv. Inclusion criteria

The inclusion criteria for participants were that they:

- must be an individual with IDD with previous exposure to technology experience and online surveys,

- must not need a legal guardian and be able to give consent or have a guardian who can give consent,
- must be over the age of 18 years,
- must be accompanied by a family member/caregiver,
- must be able to provide verbal feedback.

v. Exclusion criteria
- Additional medical frailty, non-verbal or unintelligible status.

4.1.4.3 Research instrument

Part 1 - Review of prototype by experts and end-users with intellectual development disabilities

The PI used a discussion group format to obtain feedback from the researchers/survey developers and separately from individuals with IDD on the interface in the prototype developed. The themes from Phase 1a as well as 1b were used to guide the group discussion so that the interface developed could be evaluated according to the initial needs identified by the survey developer/researcher participants as well as the participants with IDD. The PI met with the researchers as well as the end-users who were identified for this part of the study separately and demonstrated the prototype that was developed. The themes identified during phases 1a and 1b respectively, were shared with each group for consideration during the demonstration. After the demonstration was completed, the group discussed how they felt each subcategory and category was addressed and consensus was reached on changes required. Observations and comments from the discussion in the groups were qualitatively analyzed. Any comments made were shared with the survey developer.

Part 3 - Pilot study to evaluate the accessibility of the technology by end-users

For evaluation of the features of the technology, a pilot survey on the WES prototype was made available to 24 individuals with IDD. A recording sheet (Appendix K) was developed to record observations of the participants while they completed the survey to determine how much assistance they required. The form was also used to record answers to a question that was added to the survey as to how hard or easy it was to use the platform. Feedback from the participants and an accompanying family

member/caregiver was also recorded on the checklist. The survey utilized for this pilot study was the patient satisfaction survey that is being conducted in the clinic on a regular basis. This survey had been used in paper and pencil format until now. The patient satisfaction survey was transferred onto the newly developed WES prototype survey platform and multimedia options were added. Patients were asked to complete the survey in the same way they have been asked to complete the paper and pencil version. For this pilot study, one of the two research assistants was present to explain how to use the iPad to conduct the survey, to get their consent, and to record the observations regarding assistance needed as well as any feedback the patient or their caregiver was willing to share.

4.1.4.4 Research Procedure

Part 1 – Review of the prototype by experts and end-users with IDD

The prototype was demonstrated to four participants in total from Phase 1a and 1b for evaluation and feedback.

With the survey developers/researchers, a face-to-face discussion was had regarding the design components of the interface that this group identified during the initial interviews and how this was addressed by the prototype. The PI created a document to record the information shared, which included a content validity index (Yusoff, 2019). Researchers/survey developer expert participants were asked to review appearance in terms of accessibility and usability which included simplicity, clarity, navigation options, and steps required to complete tasks. As each feature was demonstrated, participants were encouraged to share their thoughts and opinions in an open discussion forum. This open discussion allowed for all comments to be considered and recorded by the PI as needed.

The items that were identified during the thematic analysis of Phase 1b were shared with end-users with IDD, and the prototype was demonstrated to show how it addressed the identified supports, in a face-to-face discussion. Participants with IDD were guided through the evaluation of the prototype in a step-by-step manner and they were asked to consider the same criteria as the expert participants with each option being pointed out to them. They indicated and explained their preferences to the PI who recorded their comments.

This enabled any changes to be made to the prototype before end-user testing. No consensus was required, but all suggestions were discussed by the group and the ones that the group identified as necessary for improved cognitive accessibility were recorded and included into the scope of requirements for additional consideration.

Part 2 - Development of the pilot survey on the platform

The changes and suggestions from the discussion group were noted and included in the development of a survey on the prototype platform, for trial with individuals with IDD. Since an existing Patient Satisfaction Survey from the WIHD health services clinic, which was usually completed in a paper format after each visit, was available, no new content or questions were developed for this part of the study. The PI and the director of research at WIHD developed this survey for use in the clinic and were familiar with the questions which were then transferred onto the new survey platform prototype. Questions were adapted using the new technology requirements and presented using the new interface.

Part 3 - Pilot study to evaluate the accessibility of the technology by end-users

Evaluation of the technology content in the online Patient Satisfaction Survey was solicited from participants with IDD. The individuals with IDD who agreed to complete this online version of the survey rather than the paper version after their visit were included in the pilot study. The answering of this survey is routine after every visit to WIHD so the individuals with IDD were familiar with the questions and the pilot study only involved a change to the online version of the survey. One question was added to the end of the survey asking how easy they found it to complete the online version of the survey.

Once they provided informed consent, they were observed by the survey administrator, who usually oversees the administration of the pen and paper surveys, while they completed the survey. The survey was provided on an iPad in a kiosk style base, which allowed them to login anonymously. The survey administrator explained to each participant how the survey was to be completed on the iPad. These participants were accompanied by a family member/caregiver while they completed the prototype survey, as is consistent with when they would complete the pen and paper version. The family member/caregiver could provide assistance with the questions if the participants could not understand what was required at any stage.

A volunteer student intern was trained by the PI as a research assistant to observe the participants while they completed the survey. The study was completed in the clinic and the research assistant completed a recording sheet developed by the PI, while observing each participant (See Appendix K). The research assistant documented whether they were able to complete the survey independently or needed support from their family member/caregiver. The answers to the question on how easy or hard it was for them to use the survey technology was also recorded, and participants' perceived ease of use was confirmed after the survey was completed with the them as well as their family members/caregivers.

4.1.4.5 Data analysis

Part 1 - Review of prototype by experts and end-users with intellectual and/or development disabilities

Data was analyzed by the PI and another researcher at WIHD who has been involved with this study since the beginning. Observations and comments were qualitatively analyzed by the two researchers, comparing the comments recorded with the specifications document and deciding by consensus which recommended changes to incorporate. Then, each was rated as to whether it is essential to incorporate in the MVP phase, or whether it could be done at a later iteration of the platform.

Part 3 - Pilot study to evaluate the content of the technology by end-users

Data was deidentified and descriptive statistics were used to identify questions with which participants needed assistance to determine which questions were difficult for them to understand and access. Similar results were included for the answers to the question about the ease of use, and any comments that differed from these answers were considered.

4.2 PHASE 1 RESULTS - DEVELOPMENT OF TECHNOLOGY FOR A COGNITIVELY ACCESSIBLE SURVEY SOFTWARE PLATFORM

The results for Phase 1, as for the methodology, are presented in five sections. Phases 1a through 1e will be described separately.

4.2.1 PHASE 1a and 1b: Identifying the needs of stakeholders

4.2.1.1 PHASE 1a - Experts

Demographics

Thirteen survey developers/researchers were included in this study and their demographic information is presented in Table 4.1. All participants were individuals with tertiary degrees, and nine had health science degrees, with two being epidemiologists and two educators.

Table 4.1 Demographic information of participants

ID	Profession	Gender	Experience (yrs)	Education (highest degree)
1	Social worker	Male	55	PhD
2	Epidemiologist	Female	23	DrPH
3	Psychologist	Female	7	PhD
4	Psychologist	Female	20	PhD
5	Occupational Therapist	Female	27	PhD
6	Occupational Therapist	Female	30+	PhD
7	Occupational Therapist	Female	25	PhD
8	Epidemiologist	Male	5	MPH
9	Teacher	Female	12	MA
10	Special Ed	Female	45	PhD
11	Occupational Therapist	Female	28	OTD

12	Occupational Therapist	Female	28	PhD
13	Psychologist	Female	21	PsyD

For referencing quotes in the text of this thesis, the participants ID numbers were coded as prefixed by 1.1 if they were from the expert group and 1.2 if they were from the individuals with IDD group.

Experience with surveys

All participants could be considered experts in terms of their experience of 5 years or more. (Table 4.2)

Table 4.2 Participants' experience with surveys

Code	Reason for survey	Type of surveys	Survey platforms used	Surveys with clients with IDD or caregivers
1	Government mandated; adapted for cognitive accessibility; research	Paper and pencil; computer based	SurveyMonkey; Qualtrics	Yes
2	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Google Forms	Yes
3	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics	No
4	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics	Yes
5	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics	Yes
6	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics; Redcap	Yes
7	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics	Yes
8	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Google Forms	Yes

9	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Google Forms	Yes
10	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey	Yes
11	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics; Redcap	Yes
12	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics	Yes
13	Research; satisfaction	Paper and pencil; computer based	SurveyMonkey; Qualtrics	Yes

All participants had used surveys for a variety of reasons, including, but not limited to, for research purposes, getting patient satisfaction about services rendered, health care data related to initiatives launched by a clinic, government mandated surveys, and adaptation of existing government surveys for cognitive accessibility. They had all used paper and pencil as well as computer-based surveys. The participants utilized various online platforms, i.e. SurveyMonkey™, Qualtrics™, Google Forms™ and Redcap™ (Google Workspace, 2025; Qualtrics XM, 2025; REDCap, 2025; SurveyMonkey.com, 2025). The most frequently used online platforms were SurveyMonkey™ and Qualtrics™. When asked why these were the platforms of choice, the aggregate response cited ease of access, favoring pre-acquired software or less cost-prohibitive options. All participants worked with individuals with cognitive limitations including individuals with IDD. Twelve of the participants have used surveys with individuals with IDD and their caregivers.

Thematic Analysis

The thematic analysis of the interviews revealed two themes: Theme 1 - Adherence to technical specifications of the survey platform, which focused on the features the software platform should adhere to; and Theme 2 - Requirements when developing a survey for cognitive accessibility.

Theme 1 - Adherence to technical specifications of the survey platform

The subthemes of functionality and interface emerged from the coding of the interview data and are presented with the categories, subcategories, and codes identified during the analyses as well as the frequency of the codes, in Table 4.3.

Table 4.3 Theme 1 - Adherence to technical specifications of the survey platform

Subtheme	Categories	Subcategories	Frequency of persons reporting	Codes
Functionality	Customizability	backend	13	basic statistical calculations
				exportable to other software programs
		visual supports	13	add to both question and answer options
		auditory supports	11	text-to-speech capability
		question options	10	select - predetermined list
				automatic formatting
				different versions of a survey
		cost – create and edit survey	7	use existing customizable platform
	Simplicity/ease of use	question options	13	one question and answer option per page
		answer options	8	fewer answer options
		prompting/ clarification/ directions	7	coach and prompt options
				inclusion of video directions
	Inclusion consumers (co-development)	feedback	7	Verbal on completion of a survey
Interface	Physical access supports	interactivity	10	touch screen
				digital device with supports built in
				flexible support structure
		layout options	8	appearance of questions and answers
				scroll and orientation preferences

Functionality:

Functionality related to categories of customizability, simplicity of use, and inclusion of consumers (co-development); and interface, as related to physical access supports. The categories that emerged from the analysis focused on the principles that the

platform should incorporate and were ordered according to opinions commonly expressed amongst participants as an indication of the perceived importance of each subcategory (Sandelowski, 2000).

Under customizability, there were five sub-categories that were emphasized: backend, visual supports, auditory supports, question options, and cost. All participants felt a backend, which allowed for basic calculations of data and export of data to other programs, was essential.

"an online survey, as opposed to where paper survey once they're complete,…should create an excel spreadsheet or database… give you some quick stats or quick summary data, and it can produce some simple charts" (1.1.2)

"*should have some basic statistical application - not just give me a percentage, it should be able to run a simple T test… when you're doing a survey you're typically running cross tabs you're also typically running a correlation"* (1.1.7)

They also all suggested being able to customize the survey using visual supports such as pictures in questions and answers -- this included color, contrast and font size as well as the use of pictures and symbols. Auditory supports requiring voice to text capabilities to enhance question answering was mentioned by 10 participants.

"*how we ask a question, and how the person processes … what are some options in presenting questions orally, do we do it in written format, do we do it in picture format … I tend to ask open ended questions. Those often are not understood, … part of my challenge is reframing and cutting my narrative to get to the actual question I'm asking and then being able to, as best I can, understand whether they understood what was asked."* (1.1.13)

Ten participants also focused on the ability to customize the style of the questions to be included as options on the survey platform, and they suggested question options using selection from a predetermined list with automatic formatting, allowing different versions of a survey to be made available.

"It should have the ability to customize in a way that you know whether you want to do a multiple-choice question, or you want to fill in question are hugely important." (1.1.10)

"I don't think there's anything wrong with SurveyMonkey, I guess, the only thing that it lacks is customization. I don't think you could apply in voices or anything like that." (1.1.8)

The cost of development of such customized surveys was a concern for seven participants who suggested that existing platforms be investigated for suitability.

The category of simplicity included question and answer options and considered the simplicity/ease of accessing surveys considering the general difficulty experienced by persons with cognitive limitations in understanding the questions and answer choices. Subcategories of question options, answer options, and prompting/ clarification/ directions were identified. All participants indicated the need for fewer answer options.

"visual and visual processing difficulties so being able to use very different size fonts, color font…. Pictures as needed. I had young adults who would only read, communicate using the symbol system" (1.1.5)

"the purpose of the survey and understanding exactly what the questions are asking, - we become increasingly aware of readability in terms of text - larger, more white." (1.1.2)

Online coaching to give directions, clarify, or prompt an individual to ensure they understood the questions and answer options was identified as another aspect to improve self-report by individuals with cognitive limitations.

"So maybe having those prompts on every page, so that they are clear on the definition". (1.1.8)

This included having written or auditory directions available, which the individual could return to as needed, in order to ensure successful completion of a survey. Having this feature built into the platform, where a survey developer/researcher could provide additional support by creating video to explain what certain questions mean or what a group of questions are about, was discussed.

"*the individual who's being surveyed had an opportunity to ask questions or things be clarified that that's sort of where you're going with the comment right"* (1.1.7)

Seven participants indicated that if they were able to first be introduced to a topic and then asked some questions (coach and prompt), it would put the questions into perspective and increase comprehensibility.

For the category of inclusion of consumers with cognitive limitations, when participants were asked if they had thoughts to share on co-development, seven supported this concept.

"*we have to bring consumers into the design, as a required element*." (1.1.5)
"*we always need to get feedback from consumers on how well the survey works for them."* (1.1.8)

Thus, in order to accommodate participatory design co-development, it was suggested that either verbal or practical feedback by completion of the survey should be used.

Interface:

The interface/physical access of the surveys was identified with two sub-categories: interactivity and layout options.

An online platform also ensures for the inherent accessibility features built into the device, which can be utilized in conjunction with what the survey platform offers. Thus, the survey should be flexible in allowing the use of supports available on different devices. An example of this is that an individual may be able to dictate their free text answer into the device, by utilizing a voice-to-text feature already available on the device's operating system.

"for the survey to be easily accessible... an ideal device for conducting this survey should be an online platform, it should have the elements that would help the individual understand clearly without having to struggle with the abstract." (1.1.8)

"because some people, especially if they had cognitive deficits that impacted their visual perception so maybe the ability to read the questions aloud to them could help." (1.1.8)

The responses from 10, and eight participants respectively, were in favor of touch screen access with a simple user interface so that individuals can directly select their choices.

"touch, of course, is much better and because the mouse access or a pad is much more cumbersome if there are any motor problems that involves more motor planning and really more cognition, and so the touch is just more of a direct method and it's much easier for people with cognitive disabilities." (1.1.13)

Layout (user interface) was explained as how the questions and answers appear on the device and also that it should be adjustable for different sized devices. It was shared that persons with cognitive limitations were easily distracted if there was too much information presented at the same time.

"One question at a time simple and short, that's better than having it long because I feel like they lose interest after a certain period of time." (1.1.8)

One question and answer per page/screen was recommended and the ability to touch a button or scroll to proceed to the next question was suggested by almost all participants. It was also shared that having the option to choose whether a Likert scale

answer was vertical or horizontal may be beneficial, as some individuals understand the concept better if it is presented in a vertical format.

"*to facilitate a greater readability and a greater comprehension. Making sure that questions are formatted in a way that are optimal for the greatest user comprehension."* (1.1.2)

"some people with cognitive disabilities don't understand a horizontal rating scale. A vertical rating scale that goes literally from low and is positioned low to high makes more sense." (1.1.6)

Theme 2 - Requirements when developing survey technology for cognitive accessibility

Table 4.4 summarizes the second theme identified during the thematic analysis with two sub themes focused on taking into consideration the disability profile of the population the survey is targeting, and basic implementation principles to consider in cognitively accessible surveys. (Table 4.4)

Consider Disability Profile

The participants emphasized the importance of knowing the target audience when considering the requirements for the survey technology for individuals with cognitive limitations.

"there's really a need to have a platform that could be tailored to the person's cognitive abilities." (1.1.6)

The disability profile of end-users included considering both literacy levels in terms of reading ability and in terms of a grade level, having questions read to them in the survey, and comprehension of language.

"I think 3-5 grade level is the max for this population anything beyond that could be a little bit hard to understand." (1.1.8)

"because some people, especially if they had cognitive deficits that impacted their visual perception so maybe the ability to read the questions to them." (1.1.7)

Table 4.4 Theme 2 – Requirements when developing a survey for cognitive accessibility

Subtheme	Categories	Subcategories	Frequency of persons reporting	Codes
Consider Disability Profile (Know the target audience)	Literacy level	Reading level (Best at around 3rd grade level)	8	read out loud support
		Language (Simple vs Complex)	11	complexity of language less jargon simple vocabulary
	Cognitive processing	Comprehension	13	understanding questions understand symbols
		Metacognitive level	12	ability to monitor understanding and performance
		Working memory and recall	7	knowledge, processing speed, attention being able to remember
	Communication skills	Verbal Non-verbal	6	accommodations used
Basic Implementation Principles	Technology options	Comfort level with technology	8	touch screen access general accessibility device specific
	Survey options	Complexity of options	11	2 - 3 response options are optimal
	Survey length	Survey length	9	shorter is better
	Flexibility	Flexibility	13	customizability self-report data extraction

Eleven participants felt that the language used should be simple with no jargon, and the vocabulary used should be in line with the reading level to facilitate understanding of the questions.

“ In terms of the language level. Do you think that there's grade level that one would consider or is it just simplifying the vocabulary.” (1.1.8)
“about how do you ask a question… how do you make a question really clear. How do you get it, so people don't just shut your survey down.” (1.1.7)

The requirements for reading and vocabulary aligned with opinions about taking cognitive processing into account to accommodate comprehension of those with cognitive limitations in terms of understanding the questions and answer options; this was of concern to all 13 participants. They felt it was important to understand different levels of ability and questioned if this should be measured so as to be accommodated in surveys.

“what is their IQ is helpful, but not so much, I wonder about if there's a measure for their verbal comprehension on if that's ever been measured or an achievement measure for them.” (1.1.13)

The understanding of commonly used symbols was also a concern and how those completing the survey could be guided in understanding what the symbols mean.

“they didn't know even simple symbols like you know the angle pointing to the right is to start the video.” (1.1.13)

The comprehensibility and layout of the questions needed to consider that the metacognition of individuals with cognitive limitations performance is limited, the survey needs to be structured so their performance is checked, and that prompts make completion of questions and progression through the survey, for example, clear to them.

“I think another issue is that it's self-report, so you have a metacognitive issue, especially if it's about your own performance because. with people who have cognitive issues… don't really have a full or an accurate understanding of their own limitation.” (1.1.7)

Seven participants noted taking the working memory used in the execution of cognitive tasks and processing speed of individuals with cognitive limitations into account. Attention and memory, being able to remember the question as well as events from the past, such as how many times they have seen their service provider, also need to be understood in terms of the abilities of those who will report on the survey.

“ we took into consideration: memory issues and cognitive issue, working memory, so how many options you can give them so they remember, otherwise they always say, the last thing

they remember… how much time do you give them because you need to let them process, but if you give too much time for processing, then you lost them they forgot the question." (1.1.5)

"we're asking for are recall and they may have difficulty recalling like we know in the last month, you know how frequently did this happen and they'd be like… They can think about today, you know yesterday, maybe." (1.1.11)

Taking this into account is important when developing technology for individuals with cognitive limitations. These factors all affect the type and number of questions that can be used in a survey. Knowledge of the method of communication used by individuals with cognitive impairments, whether this was verbal or nonverbal, was considered important by six participants in making a survey accessible. The technology should accommodate those with hearing loss as well as those who are non-verbal.

"I'd be interested in knowing their communication style? Are they verbal, do they have any hearing impairments, do they themselves use electronics; to convey or do they use something in writing." (1.1.11)

Basic Implementation Principles

This subtheme included both technology and survey options. Regarding technology, it is important to understand the comfort individuals with cognitive limitations have in using different devices so the survey could be developed on an appropriate platform. One participant indicated that not all individuals with cognitive limitations have had adequate access to technology, and they may need assistance or to be cued on basic use of the device. As with the first theme, touch screens were considered as the most appropriate, but there were concerns about the ability to use all the functions of the touch screen affecting general accessibility.

"take a step back to say okay let's go through some basic use… kind of like understanding, of, a light touch versus a kind of like press type of thing or how to use their finger to move on the touchpad." (1.1.13)

Eight participants were aware that many of their clients with IDD were familiar with the use of technology and different devices, but one suggested that the survey be suited to a cell phone size.

“adults with IDD that had their own cell phone or maybe an iPad….were more familiar with it and they used it commonly and I think they were just as easy to use a touchscreen as anything else.” (1.1.11)

“A platform should be well presented on mobile devices in particularly on cell phones… that's probably the greatest frequency in terms of ownership among individuals with disabilities.” (1.1.2)

The survey should limit the use of complex applications, and the options used should be considered. Guidelines included in the requirements for implementation of survey development need to accommodate the cognitive limitations of the end-users of the survey. The quantity of choices available for each question should be limited to avoid confusion, and additional supports should be considered for integration into the technology, such as the correct level of readability, both auditory and visual supports to improve comprehension, and other methods.

“you need answers to be restricted to just say three choices, or answers to be a multiple choice based… a choice of different formats is necessary but have the user dictate what the survey looks like in terms of page setup, type, font, audio cues, video cues.” (1.1.2)

“so you can do a card sorting format on a screen, where you are, you are showing a picture and then you just have to indicate two choices, for example, I think it would be good to choose the rating scale and the number of items so, is it just two choices.” (1.1.11)

The lack of complexity should also be balanced by a survey that is not too long and is manageable within the attention span and endurance of individuals with cognitive limitations.

“we try to stay brief but when you're trying to get as much information as possible for people I think there's that whole idea of survey fatigue… as you get to the end of the survey you're just getting a lower and lower end right because people drop off at some point.” (1.1.7)

All of the participants emphasized the need for the platform on which the survey was generated to be flexible and customizable. Other than being able to choose items, the ability to change pictures, scales, fonts, and question formats are essential. The format of the survey should facilitate self-report based on the end-users’ abilities.

“customizable and to be able to input your own items and to be able to use pictures, words… to be able to limit or choose the format… color code certain parts of the screen or have high contrast, large print… I would want to be able to choose, but that would be a lot that would allow a lot of flexibility.” (1.1.6)

'self-report - getting answers that have (not) been filtered through a family member or caregiver … really know what the person meant or how the person wanted to respond... with the ultimate goal of improving services." (1.1.2)

Flexibility in the data extraction was also seen as important, including the importance of allowing for self-report from individuals with cognitive disabilities.

"you want so it's a maximum flexibility, sometimes you only want to look at subscale rather than total score sometimes you want to want to look at certain item… for a survey system to immediately flag missing items or missing data." (1.1.6)

4.2.2 PHASE 1b: End-users

Demographics

Five individuals with IDD who were able to be interviewed verbally and provide consent to participate were included in Phase 1b of the study. Their demographic information is summarized in Table 4.5.

Table 4.5 Demographic information

ID	Gender	Age	Degree of IDD
1	Male	26	Moderate
2	Female	28	Mild
3	Female	23	Mild
4	Male	33	Moderate
5	Male	28	Moderate

Experience with surveys

The experience of each participant in completing surveys is summarized in Table 3.6. All five participants shared that they had experience with both paper and pencil surveys, as well as computer-based ones. (Table 4.6)

Table 4.6 Experience with surveys

ID	Reason for survey	Type of surveys
1	OPWDD; Fun online social media	Paper and pencil; computer based
2	OPWDD; work, research, social media	Paper and pencil; computer based
3	Work; satisfaction; social media	Paper and pencil; computer based
4	Research; Buzzfeed	Paper and pencil; computer based
5	Satisfaction; social media	Paper and pencil; computer based

Two of the participants shared that they have completed surveys sent out by the New York State (NYS) Office of People with Developmental Disabilities (OPWDD) regarding services for individuals with IDD. Two of the participants regularly do surveys for their jobs, and two of the participants have had experience with surveys for research purposes. All the participants often do surveys and questionnaires on social media.

Thematic Analysis

The first category had the most information shared and was related to supports to improve accessibility of a survey. Eight subcategories were identified by the frequency that they appeared in the data. The two top subcategories were providing auditory and visual supports to make it easier to "read" and understand the information.

"*pictures would be also helpful for people who need visual... I'm big on visuals um I think a visual videos or pictures and media will be helpful to show an example, is another way as well."* (1.2.1)

Layout supports were mentioned, and ensuring simplicity in both the supports and development of a specific survey were emphasized.

Simplifying the survey and considering the length with one question/topic per page can help to reduce distraction, as was also mentioned by participants.

"something that doesn't have like five zillion questions like sometimes like too long it's just kinda like. By the end of it, you just lose focus and you're just checking things off as check it off… this is just too much so, keeping it more like manageable." (1.2.2)

Table 4.7 Theme - Independence in completing self-report surveys

Theme	Categories	Subcategories	Frequency of persons reporting	Codes
Independence in completing self-report surveys	Accessibility specific	Auditory supports	5	easier to understand the information
		Visual supports	5	easier to "read" easier to understand the information
		Layout supports	5	length of survey simplicity one question per page
		Explanations/ examples/ understanding	4	video text
		Support person	4	assistance if required
		Language	3	variety in languages
		Survey design ideas	2	indicate percentage completed
	Device and population specific	Built in supports because of doing survey on digital device	5	preferred online use of own device various devices reading text and typing
		Know your population's disabilities	3	person specific co development

Another subcategory that emerged, was that having explanations and/or examples can make it easier to understand what a survey was asking.

I think this idea again short of sentences, easy question with examples, but below it and then, and then you can pick." (1.2.1)

"*just explaining things in a way that makes sense to people."* (1.2.2)

“at the beginning, they like have such like a long like description before you start that I just kind of like skim through it or not really read it, but like if there was like a video like it just played and you watched it.” (1.2.2)

In addition, it was mentioned that it is helpful to have a support person with you when you are asked to do a survey, and that this person can often help to explain the questions.

“I usually, when I took a survey some time with me and sometimes a someone.” (1.2.1)

Another aspect that was identified as helping one understand questions better was the language used, and that simpler language, and native language or translation into native language, will help individuals with IDD understand better. The use of video and subtitles to explain the survey and questions was also considered as making the survey more accessible

“ whoever would do survey, they can they have in a different language and for those who need have a speaker in different language is also will be helpful for a lot of people.” (1.2.1)

“I can understand them more because sometimes when they do those alternative text things for like a video.” (1.2.3)

The second subcategory was design and population specifics, which tied into the device specific supports and knowledge of the end-users. It was mentioned that a simple user interface with limited concurrent information can improve independence for individuals with cognitive disabilities.

“ one question at a time, ” (1.2.2).

The use of specific features built into electronic devices that help to make information more accessible for individuals with disabilities emerged as a category. Some of the features mentioned were a touch screen, the ability to make things larger, and being able to listen to text, as well as using speech-to-text features to type.

“there's a lot of surveys are like do you have to read it on that I would have to read the survey and instead of having the what do you call it, a computer read it to you.” (1.2.1)

“typing is easy to and there that when people can, if they want to use Siri that they can type it with Siri, or that Siri types it for them.” (1.2.1)

Each of the five participants was highly comfortable using their own device independently and said that this was something that really became essential during

the COVID-19 pandemic. They indicated they felt pressured when doing pen and paper surveys with someone watching them and expecting them to finish while being in one place.

"Using a phone using a I think it's a very painful if a survey is real long." (1.2.1)

"and it's just like when you have it like on the computer it was kind of in your face it's like easier to deal with it." (1.2.2)

"I think it would be easy on phone or on the computer I think both are easier." (1.2.1)

They shared that most of their friends became a lot more used to technology during the pandemic, even if they were not so comfortable with a device before.

The last category specifically focused on how important it is to know the population you are targeting and the specific disabilities they may have. Participants shared that each person finds the supports they need on their specific device based on their disability. They emphasized that it is important to have a conversation with the person with the disability and to learn what specifically each needed.

The study's focus on online survey technology was upheld by conversation that advocated for this format rather than paper-and-pencil.

"I would say that the easiest for a lot of people with disabilities and I think because, and also for the body part is hard to write." (1.2.1)

The information obtained in phases 1a and 1b was used to draft the first version of the statement of requirements document that formed the basis of Phase 1c.

Summary from thematic analysis

The insights, opinions and suggestions identified in the thematic analysis included requirements for the development of online technology to make it accessible to individuals with cognitive limitations and suitable for use with surveys where data needed to be analyzed in relation to services offered.

For the developers, the extraction of data from the surveys, as well as the ability to customize the survey using technology that was flexible, was considered essential. The choice of layouts for questions and answers, the ability to embed videos to guide the end-users, as well as access to various fonts and visual and auditory prompts, were all seen as important when presenting the survey.

Both the experts and end-user individuals with IDD emphasized the importance of knowing the limitations of the survey end-users as well as identifying the devices on which the surveys would be completed. The perceptions, opinions and suggestions of the expert and IDD participants were summarized and compared to evidence in the literature to confirm the survey platform requirements for Phase 1c of the study.

4.2.3 PHASE 1c: Determining Software Requirements

4.2.3.1 Identify platform specification requirements

The results from Phase 1a and 1b were consolidated, with an analysis of existing survey platforms and literature, into requirements for the technology platform.

A review and analysis of existing online survey platforms was completed by the PI to identify options common to these applications. The results from Phase 1a and 1b were then consolidated, with features described in existing survey platforms and literature, into requirements for the technology platform. Aspects such as entry, type of questions, addition of visual and auditory supports, customization, entry and ability to export data, as well as security were considered. Most platforms had numerous features for answers including single and multiple select, text and checkbox entry, and the use of rating scales and rank lists in various question options. Survey platforms analyzed were those identified in the results of Phase 1a and included SurveyMonkeyTM, QualtricsTM, Google FormsTM and RedcapTM (Google Workspace, 2025; Qualtrics XM, 2025; REDCap, 2025; SurveyMonkey.com, 2025). The categories mentioned in Table 4.8 emerged as important in a survey platform in the results of Phase 1a and 1b (Table 4.8).

Table 4.8 Review of online survey platforms

	Question types	Visual/ auditory	Select	Entry	Customize	Export data	Security	Ease of use (as described by online reviews)
	Survey Applications							
Google forms™ (Google Workspace, 2025)	multiple-choice, checkboxes, drop-down, short answers, paragraphs, grid questions	add images and videos to questions	single, multiple	key in text check box	basic logic basic fonts, color and header images	summary export to google sheets basic analysis	Secure Sockets Layer (SSL) certificate	Good
SurveyMonkey™, (SurveyMonkey.com, 2025)	multiple choice checkboxes comment box single textbox text star rating dropdown slider multiple textboxes matrix/rating scale ranking	add images to questions	single, multiple	key in text check box slide	branching logic, templates and question banks	online tracking export of data advanced analysis	SSL certificate data encryption single sign-on	Good
Qualtrics™, (Qualtrics XM, 2025)	multiple choice text entry: text matrix table: slider: form field: rank order: side by side	graphic: text- add pictures	single, multiple	key in text check box slide		online tracking export of data advanced analysis	SSL certificate data encryption single sign-on	
REDCap™ (REDCap, 2025)	matrix of fields text notes: checkbox: slider: yes no: true false:	optional image addition	single, multiple	key in text check box slide radio buttons		online tracking export of data advanced analysis	SSL certificate data encryption single sign-on	Poor

A critical review of the relevant literature, which reported on aspects to support or refute the perceptions and suggestions from Phase 1a and 1b required to improve accessibility for individuals with cognitive disabilities in the virtual environment, was reviewed and summarized to further inform requirements for the new survey platform. (Table 4.9) This was done after the analysis of the software platforms, as some references were mentioned by the platforms.

Relevant literature, which reported on aspects of research evidence to support the perceptions and suggestions from Phase 1a and 1b required to improve accessibility for individuals with cognitive disabilities in the virtual environment, was summarized to further inform requirements for the new survey platform. Two seminal articles by Kooijmans et al (2022) and Friedman et al. (2007) indicated different levels of evidence and reporting of various methods to improve accessibility in social media, education providing health information, as well as other patient report assessments. Their work did not, however, include evidence of the use of customization in any self-report self-advocacy surveys as reported in the literature summarized (Friedman and Bryen, 2007; Kooijmans *et al.*, 2022). Little empirical evidence for methods used to support accessibility was reported. Kooijmans et al (2022), in their systematic review, only reported evidence based on The GRADE Confidence in the Evidence from Reviews of Qualitative Research. This was used for assessing confidence in the findings of qualitative research to support guideline and software requirement development. These findings most strongly supported the specific accommodation of memory, some question types and visual supports, and avoiding negative questions. Friedman (2007), in their review of web accessibility design recommendations for individuals with cognitive disabilities, indicated how often various methods used to improve accessibility were mentioned in other studies, thus indicating which may be easier to implement, without evaluation of the change in usability of the various customizations reported.

This information was then used to create the first set of options to be built into the new survey platform. This allowed a variety of options for question-and-answer types. It also incorporated using fonts, color, and addition of prompts/pictures to each question and/or answer. It also allowed for the presentation of options to be either vertical or horizontal (Kooijmans *et al.*, 2022). Options for questions and answers that could be

changed visually, and that allowed auditory or speech options, were also included. The addition of multimedia to any aspect of answers and questions should be possible.

Table 4.9 Review of aspects for accessibility to the virtual environment for individuals with cognitive disabilities

Accessibility	Accommodation	GRADE Qualitative evidence (Kooijmans et al 2022)	Percentage of studies reporting (Friedman et al. (2007)
Usability			
Layout	clear- reduce clutter consistent navigation and design adjustment of text size and font short introduction display one question per page. color contrasts to assist clarity	moderate moderate low	30% 60% 30% 15%
Readability	evaluate readability with standard measures	moderate	15%
Pace of response	no time limits		5%
Memory of events	support time frame with specific references to an event don't ask long term recall ask current opinion	high moderate moderate	5%
Provide feedback while completing survey	prompts on completion, alert to errors		15%
Assistance	allow someone to clarify questions if End-user requires	low	Not reported
Visual supports	visual representations to support the meaning of questions use video to supplement text	high	70% 5%

Auditory supports	audio/voice-overs to read aloud voice captions for text	moderate	15% 15%
Content			
Question types	dichotomous questions Include "don't know" option follow- yes/no with open questions use 3-point Likert scales VAS scales multiple choice- simple	high high moderate high moderate moderate	Not reported
Vocabulary	avoid negative words keep simple concrete concepts avoid metaphors and proverbs	high moderate low	70%
Sentences	short avoid more than one clause, direct comparisons active voice	moderate	Not reported

4.2.3.2 Develop a first design concept

Results of the analysis from Phase 1a and 1b and the review of current online survey platforms that were used at WIHD were shared with the software developer to identify positive and negative components to be considered for inclusion in the first design concept of new technology. The focus was especially on the inclusion of multimedia and accessibility requirements for individuals with cognitive disabilities. The backend was also analyzed further, needs were identified around the requirements for user profiles and roles, as well as survey export options. Common features for answers were single and multiple select, text and checkbox entry, and the use of rating scales and rank lists in various question options.

4.2.3.3 Statement of requirements for the Westchester Institute for Human Development EasySurvey (WES)

Using the suggestions from Phase 1a and 1b and the information gathered from the analysis by the software developer and the PI, the functional requirements of the technology platform was organized into a statement of requirements documents for the WIHD EasySurvey (WES).

Statement of Requirements Document

Principal Objective

The principal objective of the statement of requirements was to develop the WIHD EasySurvey: a Web application that includes additional accessibility features that allow for improved cognitive accessibility for developing custom surveys for individuals with cognitive disabilities. The various components for the functional requirements for the application are described below. These features are standard survey software development features shared by the software developer as required for the survey platform. These features were not necessarily known to the participants in Phase 1a and 1b interviewed for the cognitive accessibility features.

Roles and Authentication

Roles

The application should support the following roles:

- Registered users - have accounts with logins
- Super Administrator - a user with complete access to a system's objects, folders, groups, and role templates and access surveys created by all users
- Administrator - a user who creates and manages a survey
- Survey Viewer – End-user who views and provides input to survey questions
- Named Voters – voters can belong to voter groups – nominated individuals who can vote on issues in a survey
- Anonymous Voters - individuals who can vote on an issue in the survey anonymously (there is the ability to create a universal link to a survey, where anyone with the link can complete the survey)

Authentication

- Registered users should be able to login with their username (email address) and password.
- Users should be able to recover their passwords via “Forget Your Password” functionality using their email address.
- After logging in, super administrators, administrators and survey viewers should see a dashboard where they can manage registered users, organizations, voters, surveys and media.

Figure 4.6 Roles and Authentication for the WIHD Easy Survey

The roles of all users and administrators of the WIHD Easy Survey were defined as logon, administrators’ management of end-users, and users. (Figure 4.6)

Survey Management and Survey Creation and Editing

The management of the survey in terms of creation and deletion, storage, and viewing results in real time were described in the statement of requirements. The customization in the creation and editing of surveys allowed the creator to set the survey parameters and determine survey sections and questions. (Figure 4.7)

Survey Management

The application should allow administrators to manage their surveys, including editing and deleting them. The user should also be able to view the results of the surveys in real-time. The Survey Management page should have a listing of all surveys, the ability to create new surveys, and be able to select a survey to manage.
When selecting a survey, the user should see an Overview that displays a summary of:

- Description of the Survey
- Status
- Survey contents
- Survey mode
- Engagement graph that shows the number of survey questions asked by date

From the Survey Management page users should be able to:

- View the invitation details
- See an activity report
- View and be able to delete entries
- Preview the survey
- Edit the survey
- Clone the survey
- Export the survey

Survey Creation and Editing

The application should allow administrators to create and customize surveys. The user should be able to create questions, specify answer options, and set the survey parameters. When creating or editing a survey, the user can enter the following fields:

- Survey name
- Survey media: image, audio or video
- Status: Active / Inactive / Archive /Date range. For “Date range” a start and end date should be required
- Display mode:
    - Invite only: Each voter is provided a unique URL to access the survey
    - Kiosk/Open to all: Survey has a fixed URL that anyone can access anonymously
- Enable skip logic
- Show/Hide Section Titles
- Survey Description
- Survey sections and questions management
- Save survey
- Delete survey

Figure 4.7 Survey Management and Survey Creation and Editing for the WIHD Easy Survey

Questions Management

The management of sections, introductions, and questions were defined to allow for customization. At this stage the guidelines and standards of the WCAG 2.1 (W3C, 2023) and evidence from literature were considered, as this is standard practice in the

US. All web-based applications are compared to the WCAG guidelines to determine the level of accessibility considered. The results of Phase 1a and 1b were incorporated in customizing the survey platform and confirmed by the guidelines and standards of the WCAG 2.1 described in Chapter 3 (W3C, 2023). The features identified in other survey platforms and the research evidence from literature were considered. (Table 4.7 and 4.8) (Figure 4.8)

Questions Management

Users should have the ability to add/edit/delete sections and questions of a survey. Questions must support predefined formats to give survey creators flexibility. .In survey edit mode, user should be able to: sections: create, delete and organize questions into sections

- Questions: Ability to add, edit, delete, organize and clone questions
- Information Pages: Ability to add, edit, delete, organize and clone info pages

Sections

Users must be able to:

- Create new Sections and enter names for the sections
- Delete a section
- Reorder sections via drag-n-drop
- Organize Questions and Info Pages via drag-n-drop into sections

Questions

From survey edit page, users must be able to:

- Click on the Add button to take user to a screen to fill out new question's properties
- Delete a question
- Clone a question within the survey
- Organize questions via drag-n-drop into sections

Information Pages

From survey edit page, users must be able to:

- Click on the Add button to take user to a screen to fill out new info page's properties
- Delete an info page
- Clone an info page within the survey
- Organize info pages via drag-n-drop into sections

Add/Edit Question

On the Add/Edit Question page a user can enter the question text, add media and select a question format. When selecting a question format, the user must be presented with fields relevant to the format

- Question text
- Question format: single select, multiple select, rating scale (horizontal), rating scale vertical, ranked list and text entry
- Is Required check box
- Question page media: Separate large intuitive buttons for user to upload either an image, audio or video.

Add/Edit Information Page

On the Add/Edit Information page a user can enter the title text, add media and enter the body text.

- Title text
- Admin title text to allow admins to provide more specific titles for admin organization purposes
- Body text
- Is Required check box
- Info page media: Separate large intuitive buttons for user to upload either an image, audio or video.

Figure 4.8 Questions Management for the WIHD Easy Survey

Question Formats and Media

The statement of requirements was specifically designed for question formats and media to incorporate predictable component guidelines from the WCAG, based on evidence from the literature and specific needs identified in Phase 1a and 1b. This included consistent navigation and identification on icons, visible controls, labels, and help functions with each of the question formats provided. (Figure 4.9)

Question Formats

Create a question editor mode with 6 predetermined question formats:

- Single select
  - Can add response options to format answer choices
- Multiple select
  - The user can enter the number of response choices
  - The user can determine what the maximum number of choices is
  - The user can determine whether this is a required entry or not
- Rating scale
  - The user can enter as many response options as they want
  - The user can determine whether this is a required entry or not
  - The layout of the rating scale is from left to write horizontally across the screen
- Rating scale vertical
  - The same as the rating scale, but the layout is from top to bottom vertically on the screen
- Ranked list
  - The user can enter as many response options as they want
  - The user can determine whether this is a required entry or not
  - The user interface should support dragging and dropping the response options to change the rank in the list
- Text entry
  - The user can add response options with free text
  - The user can determine whether this is a required entry or not

Media

The application will have to ability to add media to both the question and response options.

- For the question section, there should be the ability to upload an image, an audio file or a video
- Next to each response option, there should be the option to upload media

Figure 4.9 Question Formats and Media for the WIHD Easy Survey

Media options were designed to be customizable and addressed the perceivable guidelines from WCAG 2.1 (W3C, 2023), this included the ability to add audio, images and video, alongside other media alternatives, and the ability to adjust orientation, use of color, contrast, and resize text.

Survey Distribution, Response Collection, User Management and Security Survey Entry

The administration requirements for the distribution of the survey, collecting responses, and ensuring security when using the survey and storing responses, as well as how the survey could be viewed by end-users, were all defined. (Figure 4.10)

Survey Distribution

The application should allow users to distribute their surveys to named and anonymous voters. The user should be able to send survey invitations via email, sharing the survey URL, or QR code.

Response Collection

The application should allow users to collect survey responses from end-users and voters. The application should store and record the responses in a secure and organized manner.

User Management

The application should allow super administrators and administrators to manage users, including adding, editing, and deleting users, as well as assigning roles and permissions.

Security

The application should be secure and protect user data. The application should use encryption and secure connections to protect against unauthorized access and ensure data privacy. The application has to be hosted in a Health Insurance Portability and Accountability Act (HIPAA) compliant environment.

Survey Entry

When viewing a survey, end-users and voters should land on a survey home screen from where they can start the survey.

Figure 4.10 Survey Distribution, Response Collection, User Management and Secure Survey Entry for the WIHD Easy Survey

Accessibility

The application should be accessible to all end-users and voters, including those with disabilities, and should comply with WCAG 2.1 (W3C, 2023) web accessibility guidelines described in Chapter 3. All text on survey pages should have text-to-speech icons that would provide the text via audio. Text-to-speech should be a built-in feature across the entire platform.

Browser Compatibility

The web browsers that the platform was compatible with, as well as the devices that the survey could be completed on, were defined in the statement of requirements. (Figure 4.11)

Browser Compatibility

The application should be compatible with different devices and browsers. The application should work on desktops, laptops, tablets, and mobile devices, and should be compatible with various web browsers, such as Chrome, Firefox, and Safari. The first phase will be optimized for the Chrome browser and the user interface will be optimized for tablet size but will work on any device.

Supported Browsers*:*

- Google Chrome: Latest 2 versions
- Mozilla Firefox: Latest 2 versions
- Safari: Latest 2 versions on macOS and iOS
- Microsoft Edge: Latest 2 versions
- Mobile Browsers:
  - iOS Safari: Latest 2 versions
  - Android Chrome: Latest 2 versions

Supported Devices:

- Desktop:
  - Windows (latest versions)
  - macOS (latest versions)
- Tablets:
  - iPad (latest iOS versions)
  - Android Tablets (latest Android versions)
- Mobile:
  - iPhone (latest 2 iOS versions)
  - Android Phones (latest 2 Android versions)

Figure 4.11 Browser Compatibility for the WIHD Easy Survey

4.2.3.4 Evaluate the Statement of Requirements Document

The statement of requirements document, which listed all technical requirements for the survey platform, was reviewed with three of the researcher/survey developers from Phase 1a during a face-to-face meeting and discussion. As suggested by Montgomery et al. (2022), these participants were asked to assess the requirements according to criteria for content validity, including ambiguity and completeness, adaptions suggested, redundancy, and relevance (Yusoff, 2019; Montgomery *et al.*, 2022). Each participant had the opportunity to review the Statement of Requirements document line by line during the group discussion, having been informed of these criteria from the literature at the beginning of the meeting. No additional changes were recommended by this group.

4.2.4 PHASE 1d: Requirements for Survey Delivery

In this phase the results of the survey to determine access to and use of technology, conducted by the PI with five individuals with IDD, is presented.

4.2.4.1 Mode of delivery

The PI asked each participant about the kind of technology they have access to, to confirm the survey delivery requirements set in Phase 1c (Table 4.10). A variety of devices were used by the participants: tablets, laptops and desktops were provided by work and/or private purchases; phones were private purchases.

Table 4.10 Access of participants with intellectual development disability to technology

Mode	Steps	Logistics	Cost	Accessibility
Tablet: iPad	Web-based; App	Own purchase; sometimes work provides; some schools provided	Less than $500	Touch screen; Voice typing; text-to-speech
Phone	Web-based; App	Own purchase; apple/android	More than $500	Touch screen; Voice typing; text-to-speech
Desktop	Web-based; installed program	Own purchase; work provides	Less than $1000	Mouse access
Laptop	Web-based; installed program	Own purchase; work provides	Around $1000	Touchpad or mouse access

4.2.4.2 User interface

All participants had access to a variety of devices. Web browsers and accessibility used for technology were commonly available and included in the technology requirements in Phase 1c (Table 4.11). Four of the five participants were very comfortable using their devices and accessing web browsers, and one participant was somewhat comfortable.

Table 4.11 Use of and comfort with technology

Participant	Device	Platform	Comfort level
#1	Phone; laptop; desktop; tablet	Chrome; Safari	3 = Very comfortable
#2	Phone; laptop	Chrome	2= Somewhat comfortable
#3	Phone; laptop; tablet	Chrome; Safari	3 = Very comfortable
#4	Phone; tablet	Chrome; Safari	3 = Very comfortable
#5	Phone; laptop; tablet	Chrome; Safari	3 = Very comfortable

Based on these results, which were supported by an adjacent study at WIHD, it was decided that a web-based platform may be the most suitable (Patrick *et al.*, 2020).

Once the decision about the supported browsers and devices was confirmed by the results above and the PI had been assured by the individuals with IDD that the individuals were comfortable with using technology, a graphic designer was consulted to assist with developing the interface for the WES survey platform. The PI scheduled a Zoom™ meeting with the graphic designer and the software developer. The results of the study thus far were shared with them both. The design concepts were discussed, and the graphic designer and software developer were able to ask clarifying questions. After the graphic designer designed the first graphics, another meeting between the PI, graphic designer, and developer was scheduled to evaluate these designs. During this meeting additional points were clarified, and the designs were finalized to be shared with the participants for the next phases of the study.

4.2.5 PHASE 1e: Pilot testing of the prototype

4.2.5.1 Part 1: Review of prototype by experts and end-users with IDD

Interface design options shared with two participants from Phase 1a and two participants from Phase 1b elicited feedback indicating that everybody preferred the second option with a white background.

The discussion with these four individuals also indicated they preferred a darker font on a white background to increase visual contrast and make the questions more accessible. Another aspect the group shared was that it would be preferable to have

the image on the left side of the page and that the layout on the device should be in landscape mode and not portrait.

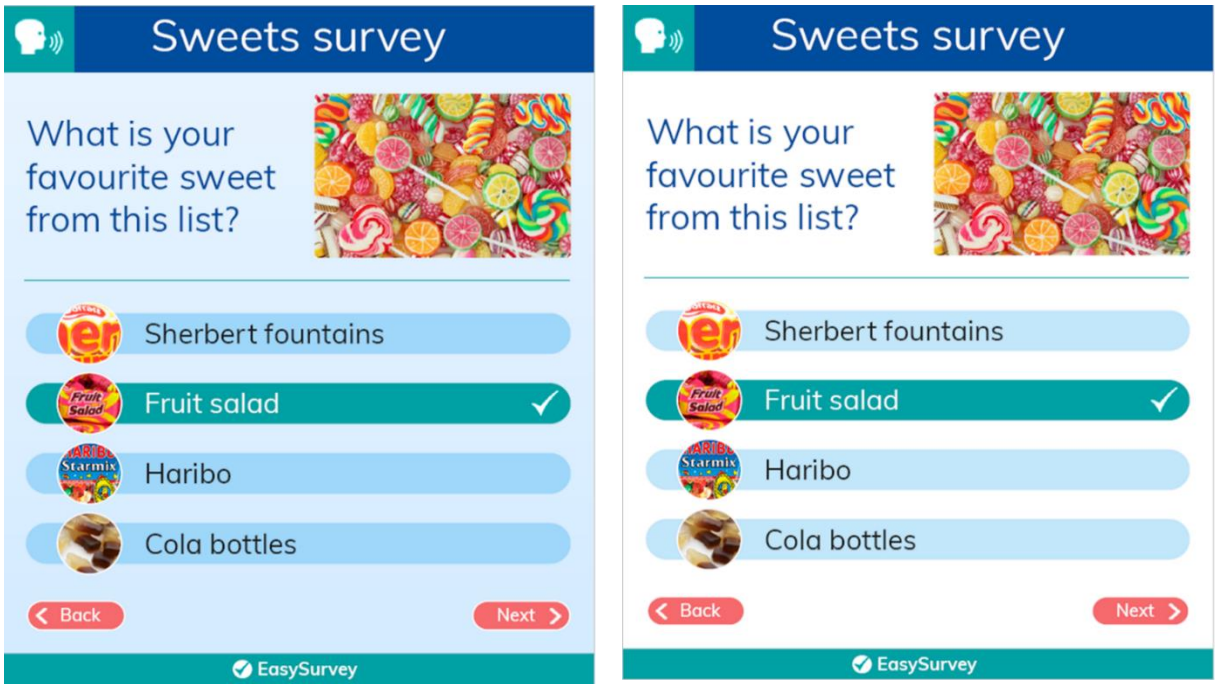
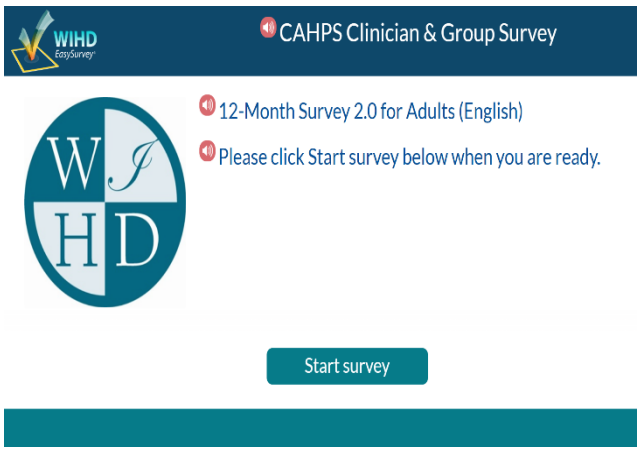


Figure 4.12 Interface design option 1 and option 2

4.2.5.2 Part 2: Development of the pilot survey on the platform

Feedback on all the options was shared with the graphic designer who adapted the design and created the pilot patient satisfaction survey with eight questions. Examples of the integrated design for the title page, question options, and text entry are presented in Figure 4.13 to 4.16.



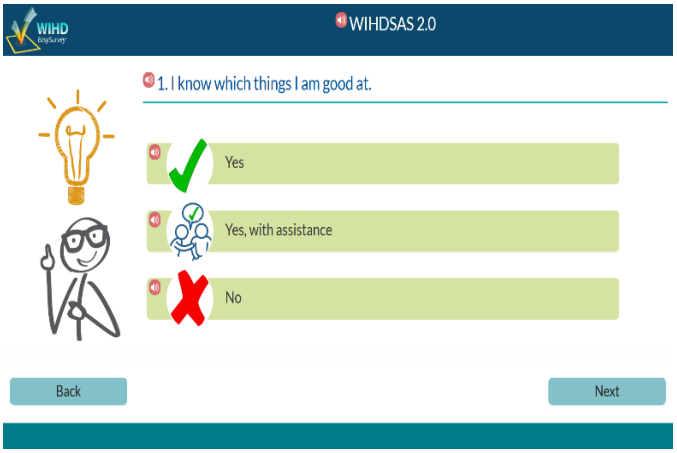
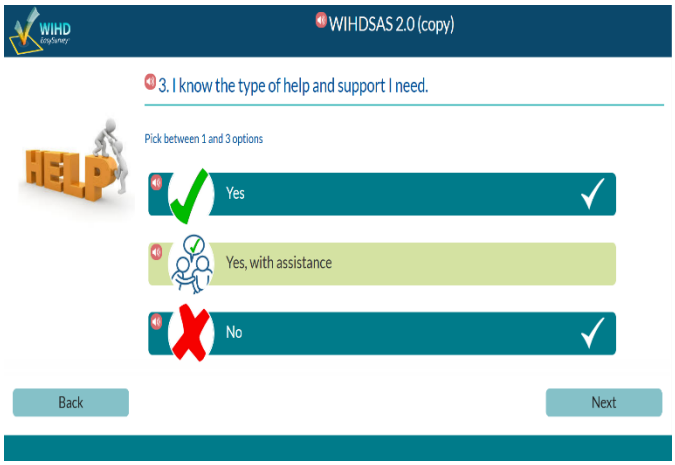


Figure 4.13 Title Page and Single Select question page



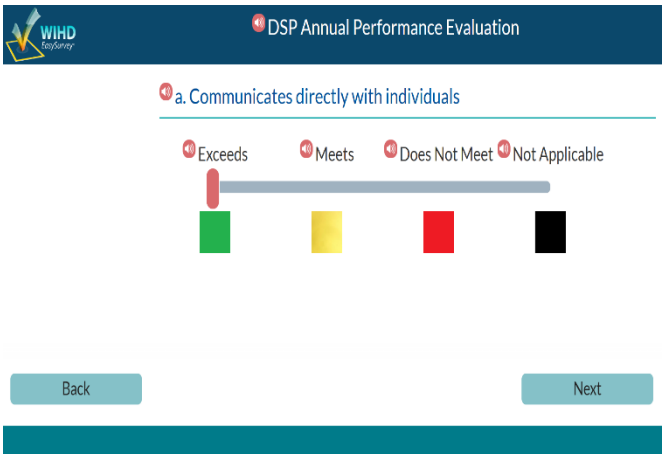
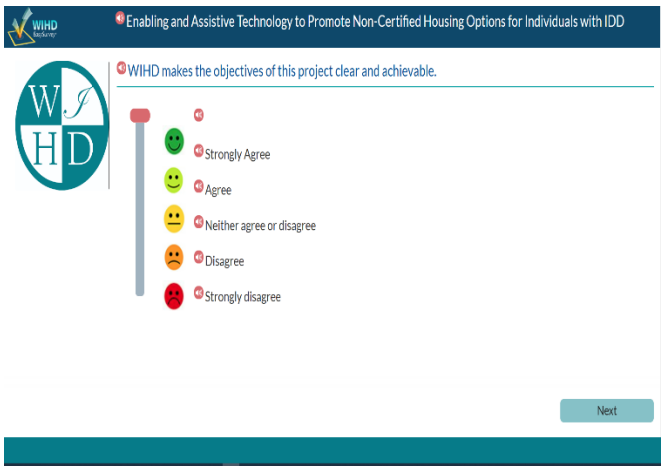


Figure 4.14 Multiple Select question and Rating Scale



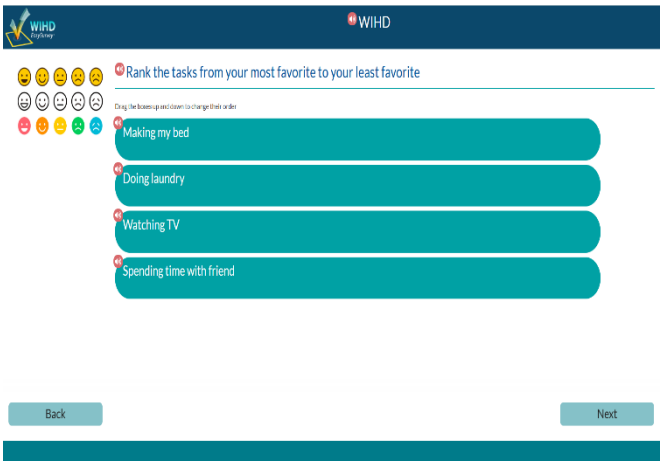


Figure 4.15 Vertical rating scale and Ranking List

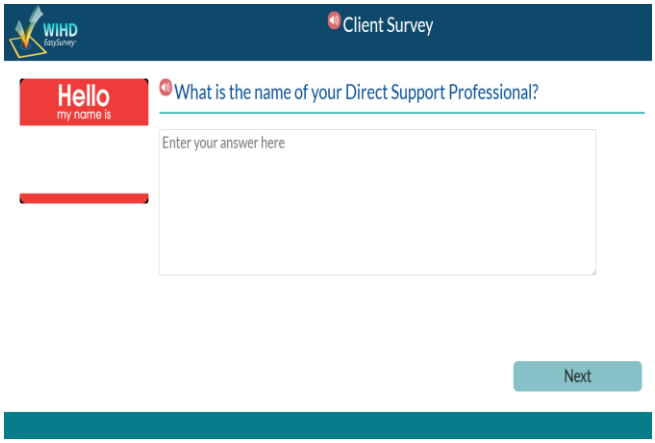


Figure 4.16 Text Entry

The content and wording of the questions on the patient satisfaction survey were not changed since the objective was to see if patients with IDD could complete the online survey themselves, rather than the paper and pencil version usually completed by proxy. The survey was uploaded on the WIHD EasySurvey platform. All the questions on the survey were single select responses except for Question 8 which required text entry.

4.2.5.3 Part 3: Pilot study to evaluate the accessibility of the technology by end-users

During phase 1e, pilot testing of the survey, by 24 individuals with IDD attending the adult health services clinic at WIHD, was completed on the pilot patient satisfaction survey online. Table 4.12 summarizes the results obtained from the 24 participants. Demographics of the individuals were not collected as the survey is typically done anonymously. The data was collected during the following timeline: June 21st, 2023 – September 1st, 2023.

Table 4.12 Answers on the Patient Satisfaction Data from WES pilot testing

No	Question	%	n	Question option
#1	What service were you here for today? (Single select)	80.3%	20	To see a doctor
		4.2%	1	To get lab work done
		12.5%	3	To see a doctor and get lab work done
#2	Were you seen within 15 minutes of your appointment time? (Single select)	69.6%	16	Yes
		13%	3	No
		17..4%	4	I do not know
#3	At today's appointment, did the staff explain things in a way that you could understand? (Single select)	95.7%	22	Yes
		4.3%	1	No
		0%	0	I do not know
#4	At today's appointment, did the staff spend enough time with you to listen to you and answer your questions? (Single select)	100%	23	Yes
		0%	0	No
		0%	0	I do not know
#5	How happy are you with your visit today? (Single select)	95.7%	22	Happy
		4.3%	1	A little happy
		0%	0	Not happy
#6	Overall, would you consider recommending WIHD to a friend for services? (Single select)	87.5%	21	Yes
		4.2%	1	No
		8.3%	2	I do not know
#7	Is there anything else that you (the patient) want us to know? (Please enter 'N/A' if patient is unable to provide feedback) (Text entry)	n/a		
		To better address medical problems.		
		Wait time improvement		
		(3 respondents answered this question)		
#8	How easy was it for you to answer this survey on your own? (Single select)	100%	22	Extremely easy
		0%	0	Easy
		0%	0	Hard

The research assistant who monitored the participants while they completed the questionnaire observed that none of them requested assistance from a family member/caregiver to complete the questionnaire. This was supported by most participants indicating they found the completion of the questionnaire with adapted layout and input options very easy to complete, which was confirmed by their caregivers. However not all the questions were answered by all the participants, which may indicate some difficulty with the accessibility of the survey. In addition to this qualitative data, the following quantitative data was also collected:

Between 22 and 24 participants answered all the questions. Questions 1 and 6 were completed by all 24 participants, while questions 2,3,4 and 5 were completed by 23 participants. Question 8 was completed by 22 participants and three participants completed questions 7.

The single select questions had a high percentage of positive answers although 17.5% of participants were not sure if their waiting time was exceeded. In terms of the presentation of the questions, navigation on the platform, and ability to indicate answers in the single select questions, no questions were missed. However, in the text entry only three (12.5%) participants provided answers.

4.3 PHASE 1 DISCUSSION - DEVELOPMENT OF TECHNOLOGY FOR A COGNITIVELY ACCESSIBLE SURVEY SOFTWARE PLATFORM

4.3.1 PHASE 1a and 1b: Identifying the needs of stakeholders

The objective for this phase of the study was to identify the perceptions of two groups of participants, expert survey developers who have worked with individuals with IDD and end-users with IDD, about their needs for making online surveys accessible to those with cognitive disabilities.

4.3.1.1 PHASE 1a - Experts

Demographics

The thirteen participants' demographic information and experience were recorded in Tables 4.1 and 4.2 in the results section. They met the inclusion criteria that deems them as very experienced or experts with more than 7 to 55 years' experience, and represented a group with different perspectives in terms of their professions (Schell and Schell, 2008). These were the two main criteria that were considered in the purposive sampling used when recruiting the participants, so that they could provide rich data regarding a survey platform that could improve cognitive accessibility for individuals with IDD (Taherdoost, 2021). The experts were included not only for their expertise in working with individuals with cognitive disabilities, which was essential to their understanding of the needs of these individuals, but also their experience and research with surveys and survey technology (Pichiliani and Pizzolato, 2021).

Thematic Analysis

The two themes which emerged from the data of the expert interviews considered adherence to technical specifications and requirements when developing a survey for cognitive accessibility. In the first subtheme "Functionality", most participants shared their perceptions about what was needed in a survey platform to increase the customizability of a survey. The one concern of the participants was that the survey protects end-users' data while also functioning to provide survey administrators with adequate access to the data from the survey. The access to survey data supports the

reason for using surveys to improve the services of the end-users of the survey. Thus, participants were concerned that any new platform developed conforms to security protocols around end-users' data but allows adequate access to and analysis of the data in the backend, once the surveys had been completed (Biffignandi & Bethlehem, 2021). All 13 participants responded that they would like to be able to easily export the data in order to upload it to any analysis software. Common responses were that some basic statistical calculations may be helpful (but not essential), but any sophisticated analyses would be done on specific data analysis software. Therefore, the data needs to be exportable in a format that can be easily imported into other software programs for analyses; Microsoft Excel would be the most widely accepted format for this.

Needs related to the process of customizing the survey to match the abilities of individuals with cognitive disabilities as well as the need of those administering the surveys were considered by these experts. While many of the suggestions about requirements made are supported by the literature, those previously described do not reflect requirements for self-advocacy surveys, but rather accessibility to education , providing health information, and social inclusion (Wehmeyer *et al.*, 2004; Terras, Jarrett and McGregor, 2021; Alshammari, 2022).

The participants shared that in their experience working with individuals with cognitive disabilities, that, despite an emphasis on incorporating universal design features (Wobbrock *et al.*, 2018), present surveys did not support self-advocacy in those with cognitive disabilities since they often need assistance to complete them. Participants indicated that the survey platforms available to them did not allow the customization they required, and they supported the development of a new platform. An Australian study reported on the lack of accessibility in 11 online commercially available survey tools and agreed that many individuals living with disabilities are unable to access surveys on these platforms which do not meet current accessibility guidelines (Gottliebson, Layton and Wilson, 2010). There is often a lack of tools and strategies that are available to survey developers/researchers that allow them the ability to design and/or modify their standardized surveys so that they can be more cognitively accessible for individuals with cognitive disabilities (Shogren et al., 2021).

The participants supported the development of a new customizable platform, particularly since, in the view of one participant, it is cost-prohibitive to have each survey custom developed by a software developer. According to this particular

participant, their organization had this done twice at great cost and there was an additional cost incurred for any changes that needed to be made. This is supported in the literature especially if the survey is directed at a limited audience (Groves, 2005).

It would be beneficial for survey developers/researchers to use a customizable platform where they can create their own surveys, so that they can adjust it as needed without additional expense. Most participants felt the ability for the survey designer to easily customize the survey for the intended participatory population was essential. By creating a customizable platform, survey developers can promote cognitive accessibility for all surveys, thus allowing persons with cognitive disabilities the opportunity to self- report on most surveys they complete. This, in turn, improves access and inclusion for individuals with cognitive disabilities (Davison et al., 2022).

When discussing the actual survey platform, participants shared that they would like to be able to select the style of question from a predetermined list and that the basic layout then be formatted on the platform. By having the platform allow for the choice of how many answer options are offered, it is ensured that different versions of a survey can be trialed with the target population to see which number of answer choices would be optimal. They prefer a system where text is manually entered and the question formatting is done automatically. These suggestions support recommendations for universal design and the customization of the HCI to make online applications accessible to individuals with different abilities and strengths, including those with cognitive disability (Wobbrock *et al.*, 2018). It is suggested for individuals with cognitive disabilities that the customization of the platform consider not only the end-users' ability, but that designer is held accountable for the adaptability of the platform, rather than a user being responsible for changes that need to be made when engaging with the application. Developing a survey platform which enables varying levels of adjustments was suggested (Bayor *et al.*, 2021).

Bayor et al. (2021) concur, as indicated by the expert participants in the current study, that, based on the principles of ability-based design, adaptations should be competency based in an effort to achieve universal design in technology. The participants indicated that the addition of visual or auditory supports to both the question and the answer options is essential to improve comprehensibility for persons with cognitive disabilities. Both visual and auditory supports increase comprehensibility, which is also one of the two key components of cognitive

accessibility in the literature (Blanck, 2014). Adding multimedia (visual and auditory) has also been emphasized (Davies et al. 2017). The W3C Web Accessibility Initiative (WAI), the WGAC, and the COGA also recommend the use of images and audio prompts to increase cognitive accessibility (W3C, 2024).

Visual supports may include pictures, drawings, illustrations, or videos supporting text questions within the survey platform. These concepts are supported in other applications such as accessing health information by the use of images (Sutherland and Isherwood, 2016). However, complexity must be considered since images presented with written words may increase the demand on working short-term memory to process both simultaneously (Hurtado, Jones and Burniston, 2014). Although the general consensus is that written content supported by pictures is helpful (O'Keeffe *et al.*, 2019), presenting pictures alone (Mander, 2016), or using symbols as suggested in the description of SymbolCha and other software applications for those with cognitive disabilities (Keskinen *et al.*, 2012), is not feasible in self-advocacy surveys. Auditory supports were suggested by 11 participants since limited literacy skills were also identified as a challenge for individuals with IDD. Auditory supports were identified as the ability to upload an auditory file, and/or having auditory prompts and text-to-speech capability built in, as suggested in promoting accessibility by Hasnain, et al. (2014) (Hasnain *et al.*, 2014). The participants explained that, in the past, they often had someone read their surveys to individuals with cognitive disabilities and they felt that having this feature could improve self-report from the individual and reduce the assistance needed (Alshammari, 2022). Although the inclusion of customizable visual and audio supports is recommended to improve accessibility for individuals with cognitive disabilities, research confirming the effectiveness of these has been provided for health information systems rather than for web based online surveys (Wobbrock *et al.*, 2011; Alshammari, 2022).

The second category in the analysis of the expert participant data to improve accessibility considered the usability of the survey or the simplicity/ease of use. All participants mentioned simplifying surveys for cognitive accessibility as important. Some focused their comments on the ability to change the reading level as suggested by Wilson et al. (2013) by using simple words and clear questions (Wilson *et al.*, 2013). Other participants mentioned reducing the number of response options (Kooijmans *et al.*, 2022). While both these adaptations are mentioned in the literature, sufficient

guidance on what this means is rarely offered (Bell *et al.*, 2018), but simplification should include only positively phrased questions to prevent misunderstanding and accommodate the level of cognitive impairment (Kooijmans *et al.*, 2022).

Clarification, or directions, and possibly prompting and coaching, when starting, and while navigating, the survey was perceived as important in improving the usability for individuals with cognitive disability. Most surveys do not include a coach and/or prompt ability, so individuals with IDD often have difficulty understanding the context of a set of questions and following the flow of the survey (Nicolaidis et al., 2020). Davies et al. (2017) found system-generated audio prompts for navigation provided self-direction and independence for those with cognitive disabilities. To ensure usability expert participants emphasized including feedback from individuals with cognitive disabilities. Collaboration on the survey with the individuals for whom the platform will be designed is also the best way to determine what features to include. This suggestion correlated with the literature, where co-development is becoming an acceptable practice in development of surveys for individuals with disabilities; some authors even suggest this as the first step in development (Vereenooghe and Westermann, 2019). Collaboration supports the concept of inclusive design and the importance of the input and feedback from user groups with specific needs (Bayor *et al.*, 2021).

The second subtheme identified in the analysis addressed the interface on which the survey will be presented and perceived needs for physical access supports. Although this was further detailed in Phase 1d, since the topic emerged during the interviews with these participants, the initial discussion is included here. To support interactivity, there was consensus that an online platform would be most ideal because it allows for a number of devices to access the survey. The flexibility of the survey platform to be used with different devices, including, for example, phones, tablets, and computers that are accessed by individuals with cognitive disabilities, was considered important by the participants. Thus, individuals with cognitive disabilities will be able to use the supports that allow them use to their specific device to access the survey platform (Bayor *et al.*, 2021).

Many participants shared that the ability to answer the survey on a touch screen device was most suited to online surveys. For many users with cognitive disabilities, the direct method of touching an answer on a screen reduces the barrier of having to move and click a mouse. This input method was supported by Schwartz et al. (2015) as

accessible and popular with individuals with IDD for successful operation of the survey (Schwartz *et al.*, 2022). The flexible support structure that a digital platform offers enables better interaction which can be motivating for persons with cognitive disabilities (Keskinen *et al.*, 2012).

The last category that emerged from this group focused on the navigation and layout options for the screen and the user interface. Most perceived certain criteria, in terms of the layout and type of questions, which should be used, and suggested having one question with its answer options per page, as supported by Wehmeyer et al, (2004) who suggest presenting information one concept at a time for those with cognitive disabilities (Wehmeyer *et al.*, 2004). Participants felt the question layout also needed to be simplified. Simplifying the layout of questions in surveys for individuals with cognitive disabilities was also described by Ruddick and Oliver (2005), who found reliable responses can be elicited with the use of closed questions and questions requiring a yes/no answer (Ruddick and Oliver, 2005). One of the participants shared that it may be helpful to have the option of a vertical layout option for Likert scale questions. It was explained that having the visual layout assists with understanding of the concept better. This way the lowest answer option is on the lower end of the vertical scale and the higher answer option is on the top of the vertical scale. On the one hand, this can assist with understanding a concept, but it may also influence the answers given, so both options may need to be presented on the survey platform.

It was further clarified during the interviews by participants that the scroll and orientation preferences of end-users of the survey should be accommodated. The participants suggested that moving from one question to the next should be done by prompting or touching a “next” button. It was also discussed that if there is not a scroll feature, it would be necessary to then also have a “back” button on each page if someone wanted to go back and change an answer on a previous question. This aligns with suggestions from Wehmeyer et al, (2004), who suggest using standardized layouts and controls, and having needed information available until the user chooses to move on or confirms they have completed a step (Wehmeyer *et al.*, 2004).

The second theme identified during the thematic analysis of this phase related to the actual requirements a survey developer must adhere to so that individuals with cognitive disabilities can complete the survey with more independence. The first subtheme identified in the analysis was considering the disability profile of the target

audience; for this study, this related specifically to readability, language use, and accommodating cognitive skills. This incorporates the concept of user centered design and ability-based design (Wobbrock *et al.*, 2018).

Participants indicated that the requirements for reading and language should be in line with the abilities of different end-users, and it is the survey developers understanding of the end-user population which should ensure these are correctly reflected in the eventual design. It is important to assess the reading level of instructions and questions on the survey. Kollia et al. (2019), using a number of different readability scales including the Flash-Kincaid grade level, found health literacy websites present online material at a grade 12 level which is inaccessible to most individuals with ASD, for example. Language should be familiar to the end-users and should be kept simple in terms of sentence length, word length, the number of syllables per word, and difficult vocabulary (Kollia *et al.*, 2019). Although there are limited studies providing empirical evidence that these adaptations improve accessibility to surveys, end-users of health information have been found to benefit from substituting difficult vocabulary words or figures of speech with more straightforward terms (Nicolaidis *et al.*, 2020) and consistent use of terms (Sutherland and Isherwood, 2016).

Both readability and language used affect the comprehension of the instructions and questions on the survey. Participants were concerned that this aspect is difficult to measure in online surveys. They felt the addition of symbols should be kept to a minimum, and it should be established that end-users are familiar with common navigation symbols used in online applications. The addition of clipart or photos was found to help individuals with cognitive disabilities to understand answer choices in keeping them more engaged when testing comprehension of text (Huenerfauth, Feng and Elhadad, 2009). One of the difficulties in setting requirements is that content must be interpreted reliably by end-users with a variety of abilities, and, thus, adaptations for those with a lower level of ability must include facilitating comprehension (Hasnain *et al.*, 2014).

Twelve participants also perceived that the requirements for the survey should accommodate metacognitive and other cognitive abilities of individuals with cognitive disabilities. Metacognition includes monitoring, or evaluating, one's understanding of information and regulation, in achieving consistency if knowledge elements of a text appear to be inconsistent. This may impact comprehension and accuracy of answers

due to misinterpretation. Understanding that these individuals may have limited metacognitive knowledge, or awareness of their own cognitive strategy implementation, is important in providing prompts that provide end-users with information about their progress or the option to return to previous questions (Moreno and Saldaña, 2005).

Possible deficits in working memory and recall in end-users of the survey also need to be accommodated to make the survey accessible. Half the participants felt that issues of attention and memory, in relation to the question asked as well as events from the past, should be accommodated. They suggested providing limited options in terms of information on the screen, and prompts which allow a question to be repeated. It was suggested by participants that questions be simplified; this is supported by literature which indicates that the cognitive load in surveys should be reduced to accommodate the working memory in individuals with cognitive deficits. Participants suggested using short and simple text as well as tick boxes rather than text input be used in accessible surveys. These concepts support accessibility as described by Haimerl and Riener (2021) and Kooijmans et al. (2022) who advocate for limited, consistent prompts. There is, however, only moderate evidence that these adaptations may improve accessibility (Kooijmans et al. 2022). Six participants were also concerned that the survey be able to accommodate those with cognitive difficulties who were nonverbal. Since online surveys are essentially nonverbal, no literature to support these requirements was found; however, instructions and questions should not rely on the ability of end-users to hear or speak. This was accommodated in the prototype platform.

The second subtheme in the analysis under Theme 2 considered basic implementation principles considering technology and survey options which should be included in the requirements for an accessible survey. Participants were of the opinion that the survey should be presented on technology with which the end-users were comfortable; this was included as a requirement. This supported their previous comments about the survey being device specific so it can be answered on different types of devices. Research on technology use by individuals with IDD indicated computers/laptops were used by half of respondents with IDD, while a third use tablets, and 20% use smartphones (Patrick *et al.*, 2020), confirming the need to

provide a survey suited to all these devices, particularly considering the size of text and presentation on cell phones.

The option for using a touch screen in providing accessibility to the survey was confirmed, and the need to consider the sensitivity of the touch as well as the direction of allowed scrolling was suggested. Kversøy et al. (2020) confirm the possibility that touch screens provide more independence for online applications for individuals with IDD since input is not dependent on understanding letters and numbers, and most touch inputs are easier to use than a keyboard or mouse (Kversøy *et al.*, 2020).

To accommodate the accessibility of the survey, it was the opinion of the participants that many options discussed above need to be included in the requirements for the new survey platform. The participants made specific comments about guidelines to provide standards for the number of responses that should be presented for each question. Some of these standards are suggested in the WCAG guidelines for adapting online content for individuals with cognitive disabilities. While techniques and examples are provided on this website, specific requirements for presenting content in different ways for self-report online surveys are not available (W3C, 2024a). Formatting questions so that no more than two or three responses was perceived to be the best principle for the development of the survey. Two option questions with yes /no or true/false have been suggested as suitable. Kooijmans et al. (2022) confirmed a large proportion of individuals with cognitive disabilities do understand yes/no answers, but that “I don’t know” options should be added to reduce acquiescent responses since two options may lead end-users’ to simply agree with all questions. Additionally, since survey respondents with IDD may be more prone to acquiescence due to an inability to engage, mental effort question types should be simple so as not to increase cognitive load affecting their motivation to answer truthfully. Three options as indicated above were preferred by Kooijmans et al. (2022). They also report evidence that Likert scales should be limited to three ratings when presented to individuals with mild to moderate ID (Kooijmans *et al.*, 2022).

Participants felt it was essential to limit the number of questions on the survey to accommodate the end-users’ ability to process information and attend to questions. Bell (2018) reported that due to the difficulties individuals with IDD have in sustaining attention, a greater number of questions increases encoding and memory demands, leading to fatigue (Bell *et al.*, 2018). Therefore, requirements should consider a save

option at each stage allowing further sessions for completion, at an individual's own pace (Hasnain *et al.*, 2014).

The final category in the implementation principles subtheme addressed the flexibility of the new survey platform. As indicated above, all participants required the platform to be customizable, and principles allowing this therefore needed to be incorporated including programmatic questions and survey flow, as well as custom interaction modes and exportation of data (Kaufman, 2020). The platform should allow reconfiguration of questions to meet end-user needs based on formal steps or process control to achieve desired outputs (Pan *et al.*, 2022). Participants suggested these include page setup, type, font, and audio and video cues. They felt the information gained in a survey specifically designed for self-report by this population may provide more accurate information and be reflective of the needs of the end-users (Kooijmans *et al.*, 2022).

The perceptions, opinions and suggestions of the researcher/developer experts were summarized and compared to evidence in the literature to confirm the survey platform requirements from their perspective. In the next section the perceptions of the individuals with IDD are discussed from Phase 1b.

4.3.1.2 PHASE 1b – End-users

This phase of the study supported emerging participatory design since individuals with IDD were provided the opportunity to give input into what needs they had in terms of a survey platform (Sitbon & Farhin, 2017).

Demographics

The five individuals with cognitive disabilities who were interviewed during this phase of the study, with either mild or moderate IDD, were recruited to discuss their needs in terms of completion of self-report surveys to improve their health and self-advocacy. This was done intentionally so that feedback could be obtained from individuals themselves and not from family members or caregivers. According to Sanders and Stappers (2008), these participants can be considered as "experts" in terms of their lived experiences as individuals with IDD and their previous experience in answering surveys (Sanders and Stappers, 2008). Each one of the individuals in this part of the study shared that they have used surveys in both pencil and paper and online formats.

They confirmed they often do surveys and questionnaires on social media, for example on TikTok, Facebook, or Instagram, and they are familiar with technology and very comfortable using their own phone, laptop, or tablet for many different tasks.

The limited number of participants willing to participate in this phase of the research reflects the issues reported by Convoy et al. (2021) with recruiting participants with cognitive disabilities into studies. They report that direct representation from these individuals is often limited due to practical and social challenges. Their participation in research may require accommodation of data collection, as individuals with cognitive disabilities and their family members/caregivers have been found to be wary of researchers (Conroy *et al.*, 2021), since findings are not disseminated in a way they can understand (John *et al.*, 2018). The PI who conducted the interviews has experience of completing such data gathering techniques with individuals with IDD. Adjustments were made by simplifying the language used to ask the questions, providing time for participants to answer, prompting using concrete examples, and reminding them of the focus of the interview when they wandered off topic (Sigstad and Garrels, 2018). End-user interviews were shorter and data gathered were not as extensive, as compared to the descriptions obtained from the researcher/developer expert participants, but provided personal insights into the challenges faced by participants with IDD in completing online surveys.

Thematic analysis

When analyzing the data, one theme emerged - the independence in completing self-report surveys. The participants' focus was around their accessibility needs to ensure that individuals with cognitive disabilities complete online surveys by themselves. They reported during the interviews that they often were given surveys that did not allow them to complete the survey without assistance. This correlates with the literature where many surveys are set up to be completed by proxy-report for this population, who are frequently not given the opportunity to self-report. Typically, the format of surveys makes it difficult for them to participate (Nicolaidis *et al.*, 2020; Walton *et al.*, 2022).

The category of accessibility included auditory and visual supports, and the actual layout of the survey which was mentioned by all participants. These results aligned with those expressed by the expert participants in Phase 1a, indicating their

importance in supporting independent completion of surveys for individuals with cognitive disabilities. Participants with IDD indicated auditory supports were helpful for individuals with disabilities who cannot read effectively to complete a survey. Having software that will read the questions to them, instead of having to ask a family member or caregiver to read it aloud, allows for independence in answering (LoPresti, Bodine and Lewis, 2008). The participants also shared that it improves independence if they can listen to the information as often as they need to help them understand it better. They found it difficult and embarrassing to ask a family member or assistant to read the question multiple times, resulting in the participant often not answering the question or picking a random answer so that they don't have to ask someone to repeat questions. Having a device read text aloud to a respondent was mentioned as an auditory support. One of the participants mentioned that a device that can give the information in a different language would be helpful for some. Similar comments were made about visual supports which help in understanding concepts by using images and pictures. These accommodations improve the context of the information/question on the screen and reduce the need for reliance on reading and memory (LoPresti, Bodine and Lewis, 2008).

In support of the perceptions of the experts, the participants with IDD felt the use of simpler language would help more individuals to be able to understand questions better, and that keeping the survey short and presenting each question on a new page to help focus was important (Bell *et al.*, 2018). The perceptions supported those of the expert participants, and although the research evidence for this type of accommodation is low, it does allow concentration on one concept at a time (Wehmeyer *et al.*, 2004; Ikeda *et al.*, 2016).

Four participants felt that having explanations of questions or examples of answers could also make the survey easier to complete. Although they suggested that a video at the start of the survey explain the purpose or how to complete it was useful, they emphasized this should be short and to the point. It was also pointed out that if a video was used for a prompt during the survey that this also be short so that they could maintain attention. While video prompting and instruction has been effective in improving various skills and occupations with individuals with cognitive disabilities, there is limited mention for its use in online surveys (LoPresti, Bodine and Lewis, 2008).

In addition, it was mentioned by four participants that they would like to have a person to support them when they are completing the survey in case they need assistance with understanding questions. This concept is supported by Wilson et al. (2013), who indicate that independence in completing self-report surveys by those with IDD can also include assistance or support without compromising autonomy (Wilson *et al.*, 2013). Research also indicates that an experience sampling method using mobile devices may also provide assistance and support to individuals with cognitive disabilities when self-reporting on surveys. Messages on the device and interaction with survey designers were found to be effective (Wilson *et al.*, 2020).

The participants with IDD confirmed suggestions by the expert participants that language be simplified in the questions, and added they would like incremental prompts that indicate to them how much of the survey they have completed. Two participants felt the latter would allow them to know whether to save and take a break to refocus on answering questions if there was still a large percentage of the survey they had not completed (Bell *et al.*, 2018). Participants reported they preferred online assessments that could be completed at their own pace.

In the second category related to design and population specifics, participants indicated that device supports which provide simple interfaces improve their independence in answering surveys. Participants confirmed that touch screens and being able to listen to text should be incorporated to make surveys accessible. Participants noted that they were comfortable with a number of devices used to complete surveys, as they had been used more extensively during COVID 19 lockdown (Terras, Jarrett and McGregor, 2021), even though literature indicates digital exclusion of those with IDD was greater than usual at this time (Chadwick *et al.*, 2022). One participant mentioned that using a smartphone, the device least used by individuals with IDD (Patrick *et al.*, 2020), was difficult since enlarging text on this device was not always possible (Dedo *et al.*, 2024).

The participants with IDD also emphasized the importance of the ability-based approach and knowledge of the population of end-users who would complete the survey. Participants shared that each person's adaptations should accommodate what they need on their specific device for their disability. The collaboration with individuals with cognitive disabilities tied in with literature, which also stressed that co-development with individuals with disabilities will enhance the outcome of the

technology or supports being designed (Alshammari, 2022). This is another reason why individuals with IDD were included in the study and their feedback correlated with the literature.

The information obtained in phases 1a and 1b was analyzed and used to draft the first version of the statement of requirements document that formed the basis of Phase 1c.

4.3.1.3 PHASE 1c: Determining Software Requirements

The objective of phase 1c in this study was to develop a statement of requirements document for the new survey platform, a crucial step in software development to ensure all requisite features are comprehensive, consistent, and unambiguous (Akbar and Siregar, 2024). This phase was a major component of the development process which filled the gap identified in existing research by summating data collected by end-users and expert survey developers/researchers into a guiding list of requisite features to ensure cognitive accessibility.

Overwhelming input from both experts in Phase 1a and 1b about accessibility of surveys made it clear that commercially available surveys did not meet their needs. The lack of accessibility of online survey tools has been reported by Hasnaian et al. (2014) Gottliebson et al. (2010) and Neves (2020) (Gottliebson, Layton and Wilson, 2010; Hasnain *et al.*, 2014; Neves, Augusto and Terra, 2020). Many of these platforms did not allow customization of each question on a new page, or the option to format the page color and layout. The addition of video introduction and explanation, as well as input via a touch screen, and the addition of images to explain questions of text to speech, was not available. SurveyMonkey was found to be the most accessible online survey tool since they had improved usability by providing a wider range of options for question types, structure, and layout. However, these criteria do not support universal design principles, and greater access to individuals with disabilities is still required since SurveyMonkey's customization was found to have the lowest reliability score for nine online surveys in a study by Rea et al. (2022) (Rea, Marshall and Farrell, 2022).

The literature also provided very little specific criteria for requirements for the modification of accessible online platforms although many studies support the concept of accessibility for individuals with cognitive disabilities in the virtual environment. Studies which provided examples about question content, response options, reading level, and incorporating more visual layout, did so for a single assessment or survey,

in the context of health information systems, education applications and other patient report assessments (Kooijmans *et al.*, 2022). Other studies simply indicated that accessibility had been considered for these adaptations (Gjertsen, 2019). The literature indicated that despite these many measures, substantial modifications are still required to improve accessibility for individuals with IDD (White *et al.*, 2022).

The development of the new WIHD WES platform was the principal objective of the study, and the statement of requirements was guided by the PI and one software developer as suggested by Kaczmirek (2016) (Kaczmirek, 2016). A review by Johnson et al. (2023) indicated that an occupational therapy practitioner, such as the PI, was well placed to apply the principles associated with occupational therapy frameworks, such as the OTPF-4, Allen Cognitive Levels as well as the Person Centered Approach, to support adults with IDD, due to their understanding of the occupational performance and functional level of these individuals in utilization of technologies (Johnson, Blaskowitz and Mahoney, 2023).

As requested by participants in Phase 1a, as survey developers and administrators, a detailed list of required criteria was added to the new survey. According to Rea et al (2022) all these criteria were necessary for survey administrators to customize the look and feel of the survey (Rea, Marshall and Farrell, 2022). All important aspects of a survey platform were considered including user roles, and criteria for user login, among others (Fielding, Lee and Blank, 2016). In addition, authentication, survey management, and access to the platform, as well as ease of access were considered (Fielding, Lee and Blank, 2016). The survey was developed within the WIHD, where funding for the project was available. Cost implications for future surveys were addressed by having an accessible survey platform available for survey designers and administrators. As requested by participants in phase 1a, having this platform available for survey designers can significantly reduce the cost associated with survey development.

The modification and customization of the survey layout, questions, and other aspects by administrators improved access to surveys on the platform using Web Content Accessibility Guidelines (WCAG) 2.0 (W3C, 2023) and COGA standards (Moreno *et al.*, 2024). Principles from occupational therapy, as well as HCI accessibility, were considered in the development of the requirements as related to the WIHD context and the individuals it serves (Nolte *et al.*, 2022). User centered design (Wobbrock *et*

al., 2018), adaptability (Gajos, Wobbrock and Weld, 2007), simplification (Moreno *et al.*, 2024), and multimodal interaction (Kosmyna *et al.*, 2019) were incorporated in developing the statement of requirements. Ability-Based User Modeling (Nolte *et al.*, 2022), activity analysis, and understanding the demands that the surveys placed on end-users in designing digital interfaces to be used (American Occupational Therapy Association, 2020) were used to accommodate as many levels of cognitive dysfunction as possible (AMCD) (Warchol, 2006; Allen *et al.*, 2009; Kang and Tadi, 2020; Stewart *et al.*, 2022).

Question management allowed flexibility in editing and/or addition of questions, sections and information pages (Best and Krueger, 2012). The ability to edit questions and response options to support the creation of layout, and the addition of visual and auditory multimedia, as well as the ability to choose the formats appropriate for individuals with cognitive disabilities were, therefore, specified as criteria in the statement of requirements. This supported multimodal interaction (Kosmyna *et al.*, 2019). It was decided to have a voice-to-text feature built into the platform that will allow the user to touch a speaker icon and have text read out loud to accommodate adaptability (Gajos, Wobbrock and Weld, 2007). Survey designers would have the ability to add a still image, a video image, or an audio file to each question. Visual images could also be added to the answer options. Best et al. (2016) emphasize the need for this type of customization in online surveys while accommodating download times and bandwidth barriers (Best and Krueger, 2012).

Other than the customization using visual and auditory prompts in terms of question formats, the PI determined that five initial question types, all of which could be aligned to touch input, would be included in the new online platform. The small screen on phones and a large number of interaction methods for touch screens, such as tap, flick, slide, or pinch, were taken into account (Williams and Shekhar, 2019). Therefore, the question formats included were: single select, multiple select, rating scale (both horizontal and vertical), ranked list, and text entry via an onscreen keyboard. Although not all of these formats were supported by the literature, they did align with the perceptions and suggestions from participants in Phase 1a and 1b and their experience in designing or answering surveys incorporating user centered design into the WES survey platform (Wobbrock *et al.*, 2018). The platform allowed for the creation and customization of questions, answer options, and layout; the WES

platform also restricted question types to those that were considered most accessible for individuals with cognitive disabilities (Kaczmirek, 2016). Criteria for layout simplified the appearance and navigation of the survey with one question per page, consistent color, and reduction of visual clutter on the page (Moreno *et al.*, 2024). Survey distribution, response collection, exportation, analysis of data, and survey entry were all specified according to suggested criteria for online survey development and the requirements suggested by the expert participants in Phase 1a (Fielding, Lee and Blank, 2016). These details, of how users would develop surveys in the backend, how the surveys would be made available to individuals with cognitive disabilities for completion, and how the results are recorded and exported, were all discussed with the developer (Fink, 2016). The criteria for these aspects were included into the requirements document, which formed the blueprint for the newly developed WES software platform (Best and Krueger, 2012).

Once the statement of requirements document was finalized by the PI and the system developer, analysis and negotiation with stakeholders, an essential step in the development of a statement of requirements, was carried out (Dermeval *et al.*, 2016). Three of the researcher/survey developers from Phase 1a reviewed the document to evaluate the requirements and confirm they were complete and consistent. This step ensured credibility and validity in the findings as suggested by Montgomery et al. (2022) (Montgomery *et al.*, 2022).

The completeness of the statement was of the greatest concern before the survey platform was developed (Montgomery *et al.*, 2022). The researcher/survey developer participants felt all components of an online survey had been included, particularly requirements for survey developers and designers in terms of suitability for individuals with cognitive disabilities, in terms of logon, display, basic security and device and browser compatibility, as well as data capture, analysis and representation. They commented on the proposed adaptations for improving accessibility which they felt would improve comprehension. No requirements included were seen as redundant.

4.3.1.4 PHASE 1d: Requirements for Survey Delivery

This phase of the study addressed the final validation of the requirements document by clarifying it represented an acceptable description of the system to be implemented in alignment with technology use by individuals with IDD (Dermeval *et al.*, 2016). The

results indicated that all participants with IDD had access to a phone, with four having access to a tablet, laptop, or both. A scoping review by Johnson et al. (2023) supported the use of technology by individuals with intellectual difficulties including the use of personal computers or smartphone technology to access applications, and the internet (Johnson, Blaskowitz and Mahoney, 2023). Patrick et al in 2020 reported that tablets were more commonly used than phones. After COVID-19, Björnsdóttir et al. (2024) found that more individuals with IDD answered surveys using a phone, confirming the findings of this study that phones may now be the most common device used by this population (Björnsdóttir, Snæfríðar- og Gunnarsdóttir and Gunnarsdóttir, 2024). Only two participants used a mouse, and voice typing and text to speech were utilized by two other participants. The use of voice assistance in accessing technology by individuals with IDD has been reported by Balasuriya et al. (2018) to increase independence (Balasuriya *et al.*, 2018). A similar finding confirmed touch input as a preferred input for technology interfaces by the participants in this phase, as reviewed by Braun et al. (2020) who also suggested this aspect needs further research since they found issues with button size, length of touch, and ability to isolate a single finger amongst their participants with cognitive disabilities (Braun *et al.*, 2020).

All participants utilized web-based programs and common web browsers, and all were comfortable with using technology. An expert survey reported by Braun et al. (2020) that the numerous skills required to access different interface types indicated an understanding of how individuals with cognitive disabilities access the internet and browsers (Braun *et al.*, 2020). These skills were considered to allow as many individuals as possible to log on and complete the WES survey, and supporting adaptations were included in the statement of requirements to best accommodate these abilities, which also indicated the importance of including phones as a response device for the new WES platform.

The results for the supported browsers, devices, and technology use were presented to the system developer and the graphic artist. How best to suit these parameters, user interface, and layout was discussed, and the foundation for the final options that were included in the platform was confirmed.

The PI provided guidance for the graphic designer based on criteria from Phase1a and 1b, as well as the literature and WCAG 2.1 (W3C, 2023) standards, to improve accessibility to the survey platform for individuals with cognitive disabilities. Bell et al.

(2018) emphasized the need for a clear and attractive layout in the survey to improve comprehension and attention of respondents (Bell *et al.*, 2018). Criteria such as the use of headings, prompts, use of larger fonts, maintaining space on each page, wide margins, clear and large navigation buttons, use of color for contrast, and use of letter case were all discussed with the graphic designer. Participants in Phase 1a and 1b suggested some of these adaptations, among others, were further confirmed by Friedman et al. (2007) in their review to make surveys accessible (Friedman and Bryen, 2007). They reported 15% to 75% of existing web design guidelines about accessibility for individuals with cognitive disabilities recommended these criteria be considered.

The feedback from the participants in phases 1a and 1b guided the development of the final version of the graphics used for each style of question and answer options, as well as the information page.

4.3.1.5 PHASE 1e: Pilot testing of the prototype

Part 1: Review of prototype by experts and end-users with intellectual development disabilities

The prototype of the WES survey, built according to the procedure in Phase 1c and 1d, was evaluated by two expert participants from Phase 1a and the end-users with IDD in Phase 1b. Participatory design (Sitbon and Farhin, 2017) and collaboration with stakeholders (Bayor *et al.*, 2021) was continued in this phase to confirm the user interface of the new WES platform complied with the suggestions made by these participants. Brown et al. (2011) emphasized the importance of including all stakeholders throughout the development process, particularly the end-users, in evaluating the prototype to fulfil the objectives of the project (Brown *et al.*, 2011). Participants were presented with two options with a similar layout but different color contrasts.

Participants were satisfied with the usability of the interface in terms of simplicity and clarity, including the size of clickable areas and controls since these were large enough to be easy to use and the interface presented consistent design (Moreno, Alarcon and Martínez, 2021; *Web Content Accessibility Guidelines (WCAG) 2.1*, 2025). When an answer was selected, the participants felt that the change in color was important, as it

allowed the respondent to be able to confirm their response, review their response, and provided an indication that they could move on to the next question.

For appearance, the white background was preferred as it was perceived to be easier to read the text, identify images, and select answers than on the blue background. One of the participants specifically mentioned that it provided “better contrast” (Participant 1.2.1). Castilla et al (2020), when designing a system prototype for use by individuals with cognitive disabilities for elder care, reported a similar finding, although the white screen was not effective in the study since the response option was presented separately from the image or comment on the screen (Castilla *et al.*, 2020). They did find that placing images to the left ,as suggested by participants in the current study, was more effective in achieving responses (Castilla *et al.*, 2020). While the navigation buttons were of an acceptable size, and well placed, participants indicated that a landscape layout would be preferable and fit better with the option of one question per page. The number of steps to complete each question on a page was acceptable, as was the input using both touch and a keyboard if preferred. These interface adaptations supported the standards presented by a WCAG 2.1 draft published in 2024, as did the use of color prompts, symbols and the consistency of the navigation tools (W3C, 2024d). All these latter criteria were seen by participants as accommodating findings in Phase 1a and 1b.

Based on feedback, the design was adapted, and the final designs were shared in Tables 3.8 – 3.11 in the results section of this chapter.

Part 2: Development of the pilot survey on the platform

The accessibility of the new WES survey platform interface, in terms of usability and comprehensibility, was considered based on the input received in all previous phases of the current study. The PI was familiar with the survey questions which were all single select answers, except one that was a text entry question. Therefore, in this short eight question survey, multiple select, rating scale, and ranked list questions were not assessed.

Based on the WCAG 2.1 standards and checklist suggested by Moreno, et al. (2021), the PI confirmed the following adaptations included in the survey interface, using the new WES platform protocol, met the criteria, all of which were functional in the online

Patient Satisfaction Survey for Part 3 of this phase (Moreno, Alarcon and Martínez, 2021).

The survey used a layout hierarchy that was familiar to the participants in the pilot study in Part 3 with a simple logon and consistent visual design. Controls at the base of the page were clearly identified for easy navigation with a back button, and each question was on a separate page with feedback as to when a question had been answered. The relationship between the images or symbols, and the content they applied to, was ensured, and the simple layout supported focus on the task on each page. The survey questions were already worded in simple clear language with no negative statements and abstract concepts. The interface supported the use of sufficient contrast to distinguish items, white space and controls and content were fixed on the page, such that only responses respond to touch. The survey was presented on an iPad, so at this stage touch input and typing on a virtual keyboard was tested. Additionally, by using an iPad, the speech-to-text feature that is built into the operating system of the device could be utilized if a participant so required.

Part 3: Pilot study to evaluate the accessibility of the technology by end-users

Part 3 of this phase was completed by piloting the new version of the existing patient satisfaction survey with 24 individuals with IDD who attended the WIHD health clinic in 2023. The pilot study did include individuals with IDD with diverse abilities, but all 24 participants were able to independently navigate the survey after the new WES survey platform was explained to them.

The findings of the pilot of the new Wes survey were in line with guidelines suggested by Esposito et al. (2024) for new accessible surveys (Esposito *et al.*, 2024). The use of a touch screen and the questions in the survey were both familiar to the participants. This reduced the stress in completing the survey using a new online interface independently and they could also request assistance if it was required (Moreno, Alarcon and Martínez, 2021). It was observed that the participants did understand the explanation about how the survey should be completed and could select a single answer of their choice, supported by recognizable symbols, on the screen (Moreno, Alarcon and Martínez, 2021).

No issues with the navigation of the site was observed, and participants recognized, and could use, the buttons at the base of the screen. Touch sensitivity was set at the

correct level even if a button was pressed for a longer period. These findings were supported by all the participants who indicated that navigation and the ability to complete the survey on the new WES platform was very easy. There were some concerns, however, in terms of answering questions. A small percentage did not answer some questions, and Question 2 about whether they were seen on time received some “don’t know” answers. The inclusion of “I don’t know” did indicate that participants did not acquiesce and simply answer yes, but it was not clear if the reason for this was to do with a lack of understanding of time periods or comprehension of the question. Another aspect that could influence this answer is that many of the participants are accompanied by a caregiver who manages their appointments, so the actual patient may not have been aware of the time of their appointment. There was also a lack of completion of the question which required text entry. It was clear that requesting text input may require more skill, but this was a question that would only be answered if there was some dissatisfaction. It may be difficult for the participants to type in an answer, although they could have asked for assistance or used the speech-to-text feature. It was also one of the questions on the previously used pen-and-paper version that was often left blank, or if it was filled out, it was done by the care giver. However, a small percentage of participants did indicate this type of question can be answered independently.

Based on the results of the pilot study, an adaptation was needed to the introduction of the survey to indicate that all questions on the survey should be answered, and a feature was built in that did not allow progression unless a question was answered. It was also decided that a survey that required single select answers would be used for the other phases of this study, although varied question type options did remain on the new WES platform.

Overall the evidence in the literature was supported by the findings from both groups of experts during this phase (Friedman and Bryen, 2007; Kooijmans *et al.*, 2022).

CHAPTER 5: PHASE 2

5.1 Introduction

Phase 2 addressed the implementation of the technology developed in Phase 1 into questions on a self-advocacy survey. This phase was conducted in three steps. Phase 2a was conducted to identify the questions that were included in the survey; in Phase 2b the questions were added to the WIHD Easy Survey (WES) platform and adapted using multimedia; and, in Phase 2c the validity of the multimedia selections was evaluated.

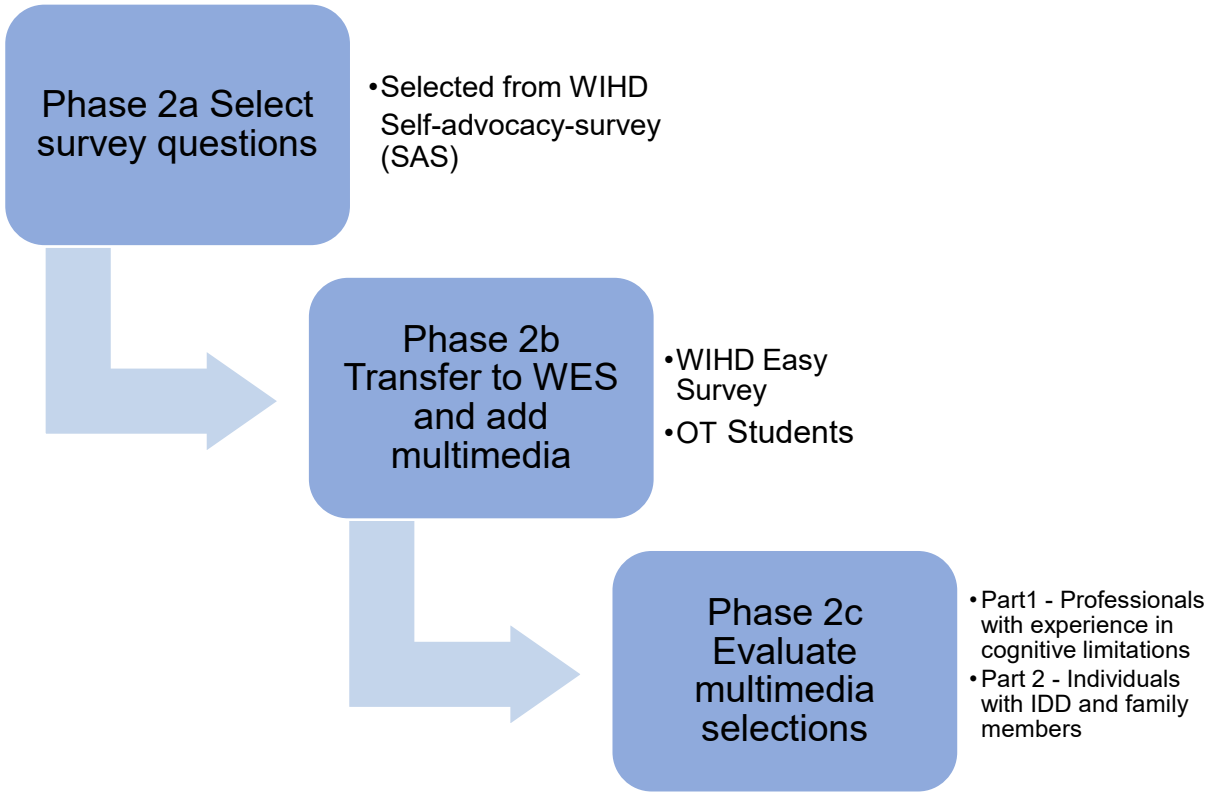


Figure 5.1 The three steps of Phase 2

5.2 PHASE 2 METHODOLOGY - IMPLEMENTATION AND TESTING OF THE MULTIMEDIA TECHNOLOGY IN A SURVEY FORMAT

5.2.1 Research Design

Phase 2 of the methodology addressed the fifth step in the designing cycle for technology described by Verschuren et al (2005), namely "Implementation" (Verschuren and Hartog, 2005). In this stage the prototype in Phase 1 was transferred to a real-life context in a survey to be used for self-report by patients with cognitive disabilities. A process evaluation was implemented as part of the research design at this stage to ensure the validity of the multimedia enabled for use with the technology developed in Phase 1, when added to a survey, would ensure accessibility and usability of the survey for people with cognitive limitations (Bess, King and LeMaster, 2004). A process evaluation is a method used to assess the platform so it can be implemented; it focuses on the implementation steps rather than the outcome to identify factors, such as multimedia, that may influence success (Moore *et al.*, 2015).

5.2.2 PHASE 2a: Identify the survey questions

The process followed for the identification of the questions consisted of three steps:

Step 1 – Choice of survey from available surveys

Step 2 – Evaluation of the questions chosen to be adapted to multimedia technology

Step 3 – Confirmation of selected questions by an expert

The PI, in consultation with one of the participants from phase 1a, decided to choose the WIHD Self-Advocacy Survey (WIHD SAS) for Phase 2. This is a survey that was developed at WIHD for use with individuals with cognitive disabilities as part of an initiative to develop self-advocacy skills training. This project started in 2019 with a group of self-advocates identified by WIHD who chose to participate in this initiative. The WIHD SAS was based on the work of Dr Michael Weymeyer and co-workers, out of the University of Kansas (Wehmeyer and Palmer, 2003; Wehmeyer *et al.*, 2017). Since the emphasis of this study was not on the development of a specific survey but

the survey platform, it was decided to use a survey that has been utilized with this population before.

Items on the WIHD Self-Advocacy-Survey (WIHD SAS) were utilized to identify individual questions for a sample multimedia survey (See Appendix L for the WIHD SAS). The WIHD SAS includes 40 statements that describe certain self-advocacy skills suited to individuals with mild IDD, and is usually completed with assistance. The survey covers the construct of self-advocacy.

The PI evaluated the questions according to their potential for adaptation to the multimedia technology developed in Phase1 in terms of response options, including language and response formats, as suggested by Kooijmans et al., (2022).

Ten questions from this established survey were selected to form a WES abbreviated WIHD SAS for this phase of the research. It was ensured that all selected questions met the language criteria and were at a reading level of between the 3rd and 5th grade, by determining the Flesh-Kincaid reading level for the questions (Readable.com, 2025). Flesh-Kincaid reading levels are easily evaluated in MS Word, as a built-in feature. Regarding response format, yes/no questions and those with no more than three response options were included.

The choice of questions was reviewed by an expert staff member at the WIHD who had experience in working with, and doing research with, individuals with IDD (Yan, Kreuter and Tourangeau, 2012). She was asked to evaluate the selected questions because she is also familiar with the WIHD SAS instrument as part of the group who developed it. The expert was one of the participants who participated in Phase 1 of the study, so she was aware of the aim of the study and the criteria on which the questions were selected (Almanasreh, Moles and Chen, 2019).

5.2.3 PHASE 2b - Addition of multimedia to WES abbreviated WIHD Self-Advocacy-Survey questions

Once the questions were selected and confirmed for inclusion, the final WES abbreviated WIHD SAS survey was transferred onto the WES platform. The PI typed each question into the platform. All four components of multimedia (text, pictures, videos, and sound) were implemented at this stage for evaluation in Phase 3. Multimedia for text to speech was activated for each question. Questions were placed

on a separate page as per the layout interface agreed on in Phase 1e and the answer option for single select was utilized.

The objective for this step in Phase 2 was to determine which visual multimedia (pictures and videos) should be added to the survey to improve accessibility. In order to determine which multimedia images were most suited to the questions on the WES abbreviated WIHD SAS, a nominal group consensus research design was used. A formal decision-making group was used, in which a group reached agreement where different options were discussed, to achieve the specific multimedia perceived as most suited to people with cognitive limitations for each question (Black *et al.*, 1999).

Population and sampling

Occupational therapy students from a local graduate program, who were completing a rotation in fieldwork with people with IDD, were recruited to participate in this phase of the study. Over the course of three semesters, three groups of occupational therapy students (one group of two students and two groups of 4 students, total n=10) worked with the PI to review and adjust the selected multimedia choices for each of the questions on the WES abbreviated WIHD SAS. Occupational therapy students were included in this part of the study to incorporate impartial views, but still have the clinical expertise and background of an occupational therapist in understanding the strengths and challenges of individuals with IDD as well as experience in activity/task analysis.

Inclusion criteria

- Students in at least their second year of their master's degree in occupational therapy.
- Students who had finished their course work on activity analysis, self-determination, and person centered practice.

Research procedure

The PI then worked with the occupational therapy students to choose and apply various relevant multimedia image options to enhance the usability, navigation, operation, and comprehensibility of the content of each question. Cognitive load, based on the PI's experience with people with IDD, was taken into account (Fraser, Ayres and Sweller, 2015). Extraneous cognitive stimuli were accommodated by the arrangement and presentation of the multimedia images to minimize cognitive

processing of irrelevant stimuli. Intrinsic cognitive load depends on the complexity of the presentation of the questions and capacity of the respondents to interpret what is presented (Triono and Retnowati, 2019). In consideration of HCI, incorporating user centered design, adaptability, simplification, and multimodal interaction, more than one version was developed (Figure 5.2) for each question based on abilities described in the Allen Cognitive Disability Model levels for concept development.

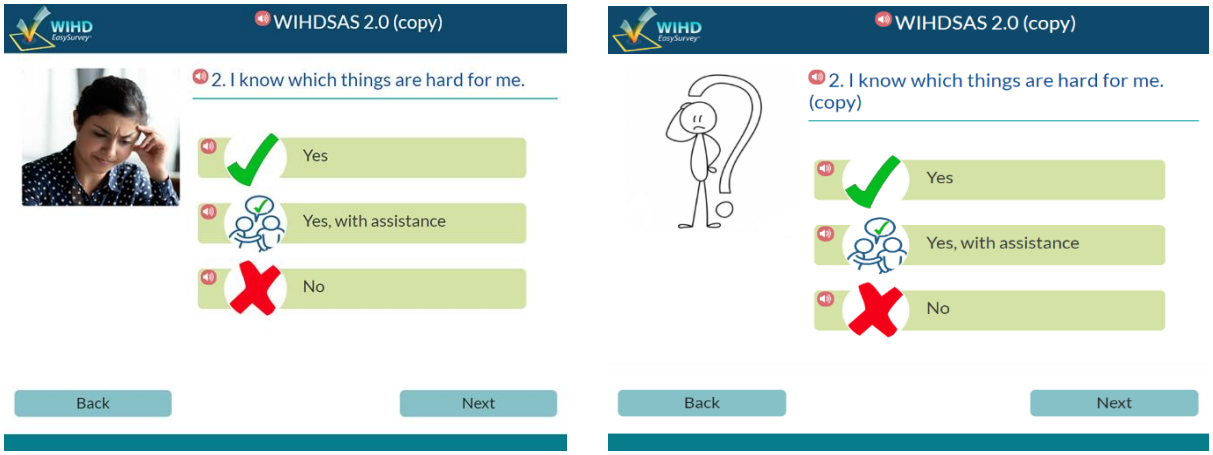


Figure 5.2 Examples of multimedia choices added to survey questions

As part of this phase of the study, the PI and one faculty member from the same local university reviewed person centered practice and HCI with the students. A formal nominal consensus procedure was then followed with each group, in that the aims of the study were explained to the group of students and they were asked to consider all options for multimedia loaded by the PI for all questions. In order to determine which multimedia images were most suited to the question, the occupational therapy students (n=10) were asked to review the multimedia choices and suggest adjustments.

The directions given to the occupational therapy students were to do an AI supported Google search of images related to key phrases taken from the questions in the survey. The results of these searches were then used as a basis for critical conversation and reflection by each group of occupational therapy students with the PI. Based on this discussion, a paid stock photo library was then utilized to find the images that were included into the survey platform. All questions had three or more options initially, and some of these were then eliminated by discussion and group

consensus. Formal feedback and discussion on the feedback was elicited from all the students by the PI. An explicit consensus of 80% was achieved in face-to-face meetings for all decisions made to apply multimedia to each question. Final decisions were noted and added into the WES abbreviated WIHD SAS. Each question had at least two choices of multimedia included.

The final part of preparing the survey for administration in Phase 3 was to create an initial explanation page with a video that explains to participants what the response options mean. This video was created by the PI in collaboration with the occupational therapist who was going to administer the surveys. (Figure 5.3)

The transcript of the information shared in the video is as follows:

> "Welcome to this survey. There is a selection of 10 statements about self-advocacy. Please choose one of the three answer options for each statement. The answer options are: Yes, Yes with assistance, and No. Choose the answer that is best for you, then tap or click the next button to go to the following question. Here is an example of one of the questions: I know which things are hard for me. Your answer options are Yes, Yes with assistance, and No. Now, normally I would ask my mother for help with these things, so in this case, I would choose 'Yes with assistance' and then click the next button. You may begin the survey."

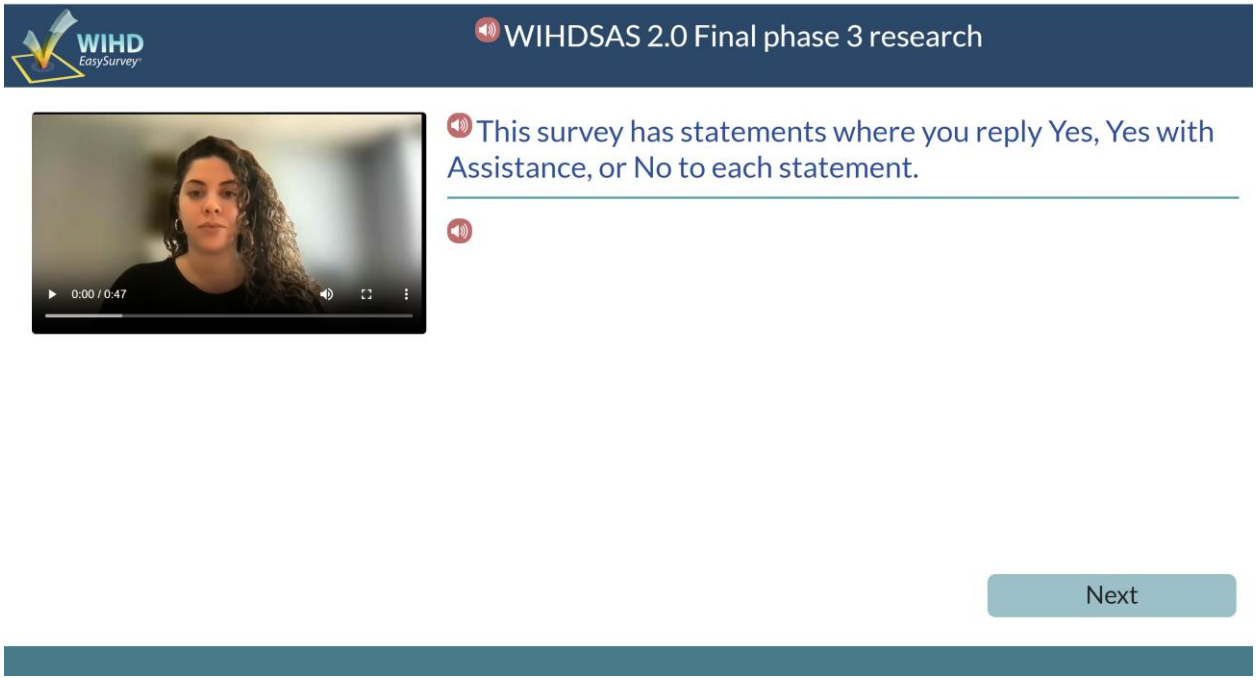


Figure 5.3 Image of the information page with the video explanation

5.2.4 PHASE 2c: Content validity of multimedia in the WES abbreviated WIHD Self-Advocacy-Survey.

The content validity of the multimedia included in the WIHD SAS questions determined in Phase 2b was assessed by both professionals administering the survey and end-users with IDD. There were still at least two choices of multimedia for each question in this part of the research.

5.2.4.1 Population and sampling

Part 1: Experts

Five experts from Phase 1a, who work with people with IDD, were asked to review the multimedia and layout of each of the questions on the WES abbreviated WIHD SAS in relation to comprehensibility and accessibility for self-report by people with IDD. Meurer et al. (2002) stated that a minimum of five experts is sufficient to control for chance agreement (Meurer *et al.*, 2002).

Inclusion criteria

- Individuals who have a professional degree or credential, or have worked closely with individuals with IDD in a professional capacity - psychologists, medical doctors, speech language pathologists, assistive technology professionals, occupational therapists, public health professionals, special educators, and behavior consultants,
- Individuals who have at least five years' experience working with individuals with IDD and use surveys regularly.

Part 2: End-users - individuals with IDD

Three new individuals with IDD were recruited to participate in this phase of the study. Two of the individuals with IDD were individuals who worked with a colleague of the PI, on a previous project that pertained to person centered practice and expressed an interest in learning more about software that is aimed at improving cognitive accessibility. Both of the participants identify as active advocates for individuals with IDD and have mild-moderate IDD. The third individual was part of the WIHD Hear Our Voices Self-advocacy group and was also interviewed as part of the initial group of individuals with IDD who participated during phase 1b of this study.

Inclusion criteria

- Individuals with mild-moderate IDD,
- Individuals with reading ability of 5th Grade,
- Individuals who could provide informed consent and did not have a legal guardian.

5.2.4.2 Research instruments

Part 1: Experts - Content Validity sheet

The overall content of the various different multimedia for each question on the WES abbreviated WHID SAS was evaluated based on the question “Does the multimedia enhance the accessibility and comprehensibility of the content?” The experts were provided with a content validity Likert scale with 4 choices: 4 = totally agree, 3 = agree, 2 = somewhat disagree, and 1 = totally disagree, on the previously mentioned statement for each question (Appendix M). The Likert scale was developed by the PI and reviewed by one of the experts from phase 1a for validity. They were asked to also consider the different multimedia suggested for each question based on the visual display, layout image, and the navigation on the screen. Space for comments was provided for each question to support the responses given on the Likert scale. The experts were consulted in Zoom™ meetings where they were afforded time to provide feedback. Consent was obtained and recorded.

Part 2: End-users Interview

An interview schedule was developed and interviews were conducted with questions that would allow participants to indicate if they thought the picture (multimedia) on the page helped with understanding each question. Their responses aligned with the content validity index criteria, which were scored by the PI for each question in collaboration with the participants.

5.2.4.3 Research procedure

Part 1: Experts

Five participants from Phase 1a were asked to participate in the evaluation of each of the questions in the survey, and they agreed to participate in a Zoom™ meeting to give their feedback (Fernández-Gómez *et al.*, 2020).

The expert reviewers were informed that the final survey was going to be administered to young adults with mild to moderate developmental disabilities. Each question, with its selected multimedia, was then shared with the experts who were asked to evaluate the content of the multimedia for enhancing the accessibility and comprehensibility of the question. They were provided with the principles of both ABD and universal design as background to make informed decisions.

Part 2: End-users with IDD

The survey was shared with individuals with IDD and their feedback was obtained on the multimedia choices in a structured interview. Of the three individuals with IDD recruited to participate in this phase of the study, two of them were interviewed together, by their choice, and the third participant was done alone, during Zoom™ sessions. The interviews were recorded, after their consent was obtained, for further review to ensure that their comments were all captured. They were given the opportunity to answer independently, and the results of their responses were interpreted in combination with the explanation they gave for making that choice.

5.2.4.4 Data Analysis

Part 1: Experts

The Likert scale responses, answers between 1-5 as selected by respondents, from the experts were analyzed descriptively. The mean scores for each question were determined and those with 3 and 4 were retained. For questions with a mean of 2, adaptations to the selected multimedia were made, and for those with a mean of 1, the multimedia was discarded. Comments provided were analyzed using summative content validity.

Part 2: End-users with IDD

The interviews with the individuals with IDD were recorded and the information shared as well as the scores they provided for each question were summarized for analysis. Summative content analysis was used to determine perceived accessibility and comprehensibility. The multimedia selected by the most participants was reviewed in association with the reasons shared by the individuals with IDD about their understanding of each question based on the multimedia used. The PI then made the final determination in collaboration with the participants as to a score for their options

according to the content validity criteria (Hsieh and Shannon, 2005). The content validity criteria focused on accessibility and comprehensibility as provided by the multimedia choices included in the survey.

A content validity ratio (CVR) score (a numeric value indicating the instrument's degree of validity determined from expert ratings of CV) and an item content validity index (CVI) score (a quantitative assessment of the degree to which the item or measure is content valid by an evaluation of a panel of experts) was calculated from the scores provided by the eight participants (Gilbert & Prion, 2016).

5.3 PHASE 2 RESULTS - IMPLEMENTATION AND TESTING OF THE MULTIMEDIA TECHNOLOGY IN A SURVEY FORMAT

5.3.1 PHASE 2a – Identification of the survey questions

The entire WIHD SAS was analyzed for its reading level and the results of that analysis were recorded in Microsoft Word, using the built-in reading level option to give a Flash-Kincaid international reading level (Readable.com, 2025). The reading level of the 40 questions on the WIHD SAS was identified as Flash-Kincaid reading level: Grade 5.2. Ten questions from the WIHD SAS were identified as suitable for this phase of the study with a Flash-Kincaid reading level: Grade 3.7. The criteria considered in this selection were the grade level of the language of the questions for the research survey as well as the applicability of a question to a more general IDD population.

Table 5.1 WIHD Self-Advocacy Survey Questions and their reading levels

Questions		Reading level
1.	I know which things I am good at.	
2.	I know which things are hard for me.	Flash-Kincaid reading level: Grade 3.7
3.	I know the type of help and support I need.	
4.	I can ask for help when I need it from people I know.	Flash-Kincaid reading level: Grade 3.7
5.	I can ask for help when I need it from people I do not know.	
6.	I can tell other people when not to help me, when I can do things for myself.	
7.	I know the ways I like to learn.	
8.	I know the type of help I need to learn.	
9.	I can share with others something I would like to get better at doing.	
10.	I know my interests.	Flash-Kincaid reading level: Grade 3.7

11.	I know that I have legal rights.	
12.	I know I can go to college if I choose to.	Flash-Kincaid reading level: Grade 3.7
13.	I know that if I am in college, I can ask for accommodations from the college.	
14.	I know my legal rights if I am employed.	
15.	I know that when I am at work, I can ask for accommodations from my employer.	
16.	I know that I can participate in choices made about my healthcare.	Flash-Kincaid reading level: Grade 3.7
17.	I enjoy making my own decisions.	
18.	I want to learn to make more of my own decisions.	Flash-Kincaid reading level: Grade 3.7
19.	I talk about the things I am good at.	Flash-Kincaid reading level: Grade 3.7
20.	I talk about the things that are hard for me.	
21.	I let others know what I do not like.	
22.	I let others know how I like to learn.	Flash-Kincaid reading level: Grade 3.7
23.	I let others know what my interests are.	
24.	I ask questions to find out more about my interests.	
25.	I know who to share my goals with so I can get help in achieving them.	
26.	I talk about my dreams.	
27.	I do free time activities based on things I like.	
28.	I work on things that will improve my job opportunities.	
29.	I help to make my life plans.	
30.	I help to make my healthcare decisions.	Flash-Kincaid reading level: Grade 3.7
31.	I have career plans for now.	
32.	I have career plans for the future.	

33.	I work or have worked/volunteered without pay.	
34.	I work or have worked and made money.	
35.	I have had the opportunity to attend job training.	
36.	I have attended job training.	
37.	I have looked into job interests by visiting work sites or talking to people in that job.	
38.	I know what kind of disability I have.	Flash-Kincaid reading level: Grade 3.7
39.	I can explain my disability to others.	
40.	I can explain accommodations I need at work because of my disability.	

5.3.2 PHASE 2b - Addition of multimedia to WES abbreviated WIHD Self-advocacy-survey questions

The identified questions, which all had a single select response option, were then typed into the WIHD EasySurvey platform (Figure 5.4). Once the questions were on the survey platform, multimedia was added to each question to enhance the understandability of the content.

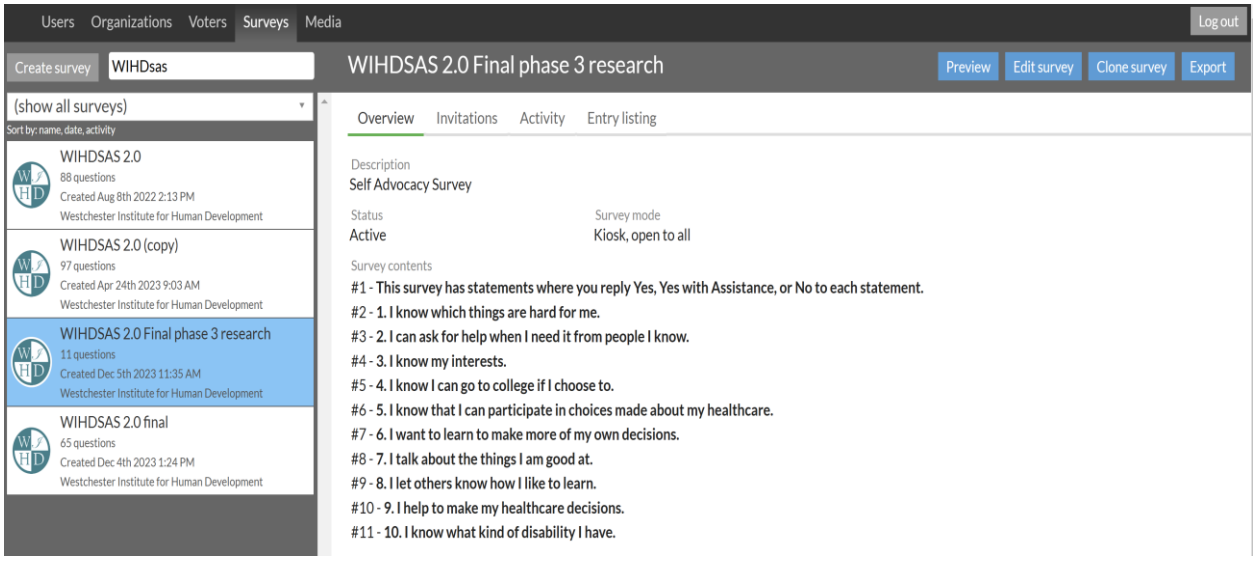


Figure 5.4 Entry of questions into the WIHD EasySurvey platform

5.3.2.1 Demographics

The demographic information of the 10 occupational therapy students who participated in this part of the study is summarized in Table 5.2 below.

Table 5.2 Demographic information of occupational therapy students

Student ID	Age	Gender	Education
OT1	20 – 30	Female	Second year entry level Masters in OT
OT2	20 – 30	Female	Second year entry level Masters in OT
OT3	20 – 30	Female	Second year entry level Masters in OT
OT4	30 – 40	Female	Second year entry level Masters in OT
OT5	20 – 30	Female	Second year entry level Masters in OT
OT6	30 – 40	Female	Second year entry level Masters in OT
OT7	20 – 30	Female	Second year entry level Masters in OT
OT8	40 – 50	Female	Second year entry level Masters in OT
OT9	50 – 60	Male	Second year entry level Masters in OT
OT10	20 – 30	Female	Second year entry level Masters in OT

All the students were in the second year of their three-year entry level master's program at a local occupational therapy program in New York City. Occupational therapy is a second career for four of the students. Sixty percent of the students were in the 20-30 year age bracket. Twenty percent were in the 30-40 year bracket, 10% were in the 40-50 year bracket and 10% were in the 50-60 year bracket. Ninety percent of the students were female and 10 % were male.

5.3.2.2 Multimedia options

Figures 5.5 - 5.14 provide the different multimedia options that were included for the next phase of the study. A broad range of criteria were applied, for example photo image vs clip art, color vs black and white, grey scale as well as multiple aspects per design.



Figure 5.5 Question 1: Multimedia options 1 and 2



Figure 5.6 Question 2: Multimedia options 1 and 2



Figure 5.7 Question 3: Multimedia options 1 and 2



Figure 5.8 Question 4: Multimedia options 1 and 2



Figure 5.9 Question 5: Multimedia options 1 and 2



Figure 5.10 Question 6: Multimedia options 1 and 2



Figure 5.11 Question 7: Multimedia options 1 and 2

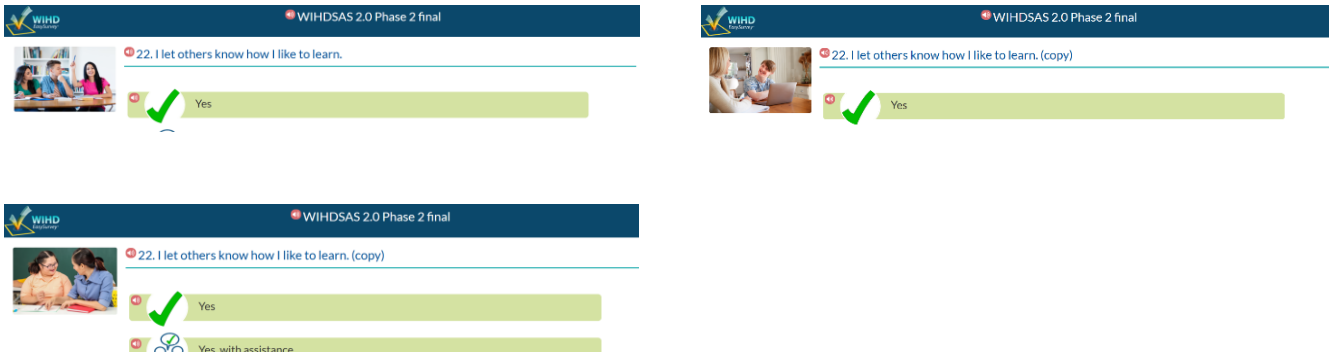


Figure 5.12 Question 8: Multimedia options 1, 2 and 3



Figure 5.13 Question 9: Multimedia options 1 and 2



Figure 5.14 Question 10: Multimedia options 1 and 2

Four to five options were curated for each question by the OT students, and these were then reduced through the discussion with the PI and the students together. Two multimedia options were agreed on for each question, except for question 8 which had three options because the group were unable to select only two. The group came to an agreement that all three would be shared in the next part of this phase for the next two groups to give their input.

5.3.3 PHASE 2c - Content validity of multimedia in the WES abbreviated WIHD Self-Advocacy Survey.

5.3.3.1 Demographics

Part 1: Experts

The demographic information of the experts in this part of the study is summarized in Table 5.3.

Table 5.3 Demographic information of the experts

ID	Profession	Gender	Experience (yrs)	Education (highest degree)
1	Epidemiologist	Female	23	DrPH
2	Psychologist	Female	7	PhD
3	Occupational Therapist	Female	25	PhD
4	Epidemiologist	Male	5	MPH
5	Teacher	Female	12	MA

Part 2- Endusers with IDD

The demographic information of the individuals with IDD end-users is summarized in Table 5.4

Table 5.4 Demographic information of the individuals with IDD

ID	Gender	Age	Degree of IDD
1	Male	26	Moderate
2	Female	28	Mild
3	Female	23	Mild

5.3.3.2 Content validity of multimedia options

Content validity index

The multimedia options were shared with the three individuals with IDD and five experts from phases 1a and 1b (n=8), and they were asked to rate the options on a

scale of 1-4 for relevance in enhancing the comprehensibility of the content. (Table 5.5)

Table 5.5 Content validity of the WES abbreviated WIHD Self-Advocacy Survey

	Option 1			Option 2			Option 3		
Questions	Mean score	CVR score	CVI score	Mean score	CVR score	CVI score	Mean score	CVR score	CVI score
1	3.8	0.94	0.95	1.5	0.38	0.38			
2	4.0	1.00	1.00	1.3	0.31	0.31			
3	1.5	0.38	0.38	3.5	0.88	0.88			
4	3.9	0.97	0.98	1.1	0.28	0.28			
5	3.6	0.91	0.90	1.5	0.38	0.38			
6	1.7	0.41	0.43	3.5	0.88	0.88			
7	3.8	0.94	0.95	1.1	0.28	0.28			
8	1.5	0.38	0.38	1.5	0.38	0.38	3.6	0.91	0.90
9	3.6	0.91	0.90	1.6	0.41	0.41			
10	3.4	0.84	0.85	2.0	0.50	0.50			

A content validity ratio (CVR) score was accepted at 0.84 and an item content validity index (CVI) score was accepted at 0.85 with input from eight participants (Gilbert & Prion, 2016).The final scale CVI score, once all the options with high CVI scores had been accepted, was 0.87. This was considered acceptable for the survey.

Content validity discussion

Part 1 - Experts

The comments for each question and the general issues related to providing assessible content in surveys were extracted from the content validity sheet for the expert participants. Data was analyzed into three themes: General application of multimedia images, reasons for accepting multimedia images, and reasons for rejecting multimedia images.

One expert considered the relevance of the literal interpretation that end-users with IDD would make in using the images to improve comprehension of the questions and noted that they may misinterpret images. However, comments on most questions did indicate a clear link of image to the question content, and images depicting interaction between people and people choosing from displayed options were seen as facilitating accessibility and comprehensibility. It was felt that in the cases where real life images and illustrations were an option, real life images were preferable and that images end-users may better identify with were also more acceptable.

Comments about rejecting images indicated little apparent value in improving comprehension of the question due to a perceived vague link of an illustration to the question. Some text in images was too small, missing, or presented in bubbles in the images which was identified as confusing. (Table 5.6)

Table 5.6 Content validity discussion by expert participants

Theme	Category	Question	Responses	Comments
General application of multimedia images	Ability of individuals with IDD		all	• "You have to remember that individuals with IDD can be very literal, so bear that in mind when you select images. For you or me a picture can look like someone is thinking about something, but for my patients, it may look like someone has a headache."
	Interaction protrayed in the images	Q3, Q6,Q8	3	• "I like that the two people look as though they are having a conversation." • "Clearly the tilt of the head and the finger tells you they are thinking about something."
	Choice within the image	Q6	2	• . And the fact that there are choices within that graphic makes it terrific." • having two options in the thinking bubble, it shows that a decision should be made."

	Clear link of image to the question content	Q4, Q8,Q9, Q10	7	• "clearly someone with an intellectual disability." • "The stethoscope makes it clear it deals with a doctor." • "doctor helps to bring across the health agenda." • "people have gotten used to symbols, so I like the first one because it has many different disabilities."
	Type of image	Q1, Q4,Q7	5	• "Both pictures obviously show the college theme, but the one with the person works better." • "Again the real person will appeal more." • "A picture of a real person may be better than an illustration – that that was a more concrete option."
	Identification with the image	Q6,Q8	1	• "The male subject may appeal more to male participants and vice versa – as they may relate more to someone with the same sex." • "food choices will appear more than the balls."
Reasons for rejection of images	Size of text with images	Q3	1	• "but the options in the talking box may be too small"
	Portrayal with illustraion vague	Q10, Q3	1	• "you can see the entire person in the illustration, but the real situation better." • "too many options and the other one too few"
	Lack of link to question	Q7	3	• "the empty bubble helps explain the question."

Part 2 End-users with IDD

In addition to the score calculated for each option, the PI also recorded the face-to-face meetings with the participants. Comments were recorded and analyzed into three themes: Need to adapt the interview technique; Reason for inclusion of multimedia images; and Reason for rejection of multimedia images. (Table 5.7)

Table 5.7 Content validity discussion by end-user participants

Theme	Catagory	Question	Responses	Quotes
Need to adapt the interview technique	Clarification during interview		all	• “can I give you a heads-up? we need you to give clear instructions and will ask if we need more information.” • "talks about images, it means little pictures that will help you understand the question better.”
	Real in time discussion between participants		all	• “and the two of us want to do this together, because we like to talk to each other about our opinions.”
Reasom for inclusion of multimedia images	Type of image	Q1	2	• “the real person is better. It kind of gets the mind thinking. The other one has a drawing that I find…I find confusing.”
	Clarity of message from the image	Q2, Q6, Q7	8	• “where they look at something together.” • “because it shows that the person is being helped.” • “she looks like she is thinking, not looking down.” • ”because it looks like a person is thinking It will help people if there is a person with a disability.” • “because there are a lot of disabilities out there.” • “the pictures in the bubble.”

	Interaction protrayed in the images	Q3	2	• "Looks like she is telling her friend."
	Clear link of image to the question content	Q4, Q9	3	• "I like the cap – looks like a college student" • "The fact that there is a doctor I think helps. I think that is a good one, do you agree."
	Identification with the image	Q8	1	• "the girl with the disability looks very friendly."
Reason for rejection of multimedia images	Difficulty in understanding some images	Q6	4	• "Oh, this is challenging., There is two people talking."

Participants commented on the need to adapt the interview technique to provide clarity in the questions and about the options they were presented with. They emphasized the need for simplicity and the need to confer amongst themselves. The reason to accept the images for most questions was the clarity of message from the image followed by a clear link of the image to the question content. Thus, participants with IDD reported that the addition of the images did improve comprehensibility of the questions and thus accessibility to the survey for end-users. In agreement with the experts the participants with IDD preferred real life images to illustrations, interaction portrayed in the images, and images they could identify with in a positive way. The reason they rejected most images was due to their difficulty in understanding what the image meant and how it related to the question.

5.3.4 Summary of results

An abbreviated WES SAS, with 10 questions, was created from questions with a low readability level from an existing self-advocacy survey. Occupational therapy students assisted in choosing and applying multimedia images for each question. Consensus at level of 80% was used to agree on two to three images for each of the 10 questions in the abbreviated WES SAS.

The identified multimedia options were presented to five experts and three end-users, which is close to the maximum number of subject matter experts recommended for establishing content validity (Lynn, 1986). A CVR score of 0.84 and a CVI score of 0.85 was achieved for the preferred images which were retained for the WES SAS. The reasons for accepting the images included clarity of message from the image and a clear link of image to the question content, which improved comprehensibility and access to the survey for those with IDD.

5.4 DISCUSSION: PHASE 2 - IMPLEMENTATION AND TESTING OF THE MULTIMEDIA TECHNOLOGY IN A SURVEY FORMAT

Phase 2 consisted of three steps in order to implement the visual component of multimedia into a survey using the WES platform.

5.4.1 PHASE 2a – Identification of the survey questions

Since the focus of the study was to evaluate the accessibility to surveys provided by the platform, rather than the content of a survey, questions were selected from an existing WIHD SAS, which has been validated for the final WES abbreviated WIHD SAS survey. The WIHD had used a self-advocacy survey for a previous project, consisting of 40 statements. In order to ensure simplicity and comprehension the reading level of the questions in the WIHD SAS were analyzed, and ten questions with a reading level between the third and fifth grades were identified for inclusion into the WES abbreviated WIHD SAS. The applicability of the questions to a more general IDD population was also taken into consideration. The PI wanted to have a selection of questions included in this final phase of the research that was appropriate specifically for individuals with IDD, as that was the target population for this phase. The PI also decided that if two questions were reasonably similar, she would select one of the two so that a broader number of topics could be included.

Establishing the simplicity of the content of the survey was in line with literature (Wilson *et al.*, 2013; Bell *et al.*, 2018; Bayor *et al.*, 2021; Kooijmans *et al.*, 2022) and the specific needs of the experts and end-users with IDD who participated in Phase 1a and 1b of the study. Using simpler language makes it easier for people with cognitive disabilities to understand what is being asked of them and be more independent when completing surveys. Thus, a reading level suited to participants with mild to moderate IDD was chosen. A suitable reading level for these individuals has been shown to be between a third and fifth grade level, although those with moderate IDD may have a lower reading level and require assistance (World Health Organization, 2025). The simplified language and lower reading level, as indicated by Haimerl and Riener (2021), accommodates the working memory by reducing cognitive load for individuals with IDD (Haimerl and Riener, 2021). Literature confirms this increases ease of

understanding and accessibility. Kooijmans et al. (2024) found that adapting the reading level and reducing the number of words in a self-report survey for individuals with mild intellectual disability and borderline intellectual functioning significantly reduced the number of questions indicated as difficult to answer (p = 0.046) (Kooijmans *et al.*, 2024).

The number of questions in the WES abbreviated WIHD SAS was also reduced to prevent fatigue and loss of attention while completing the survey. While there is moderate evidence to support this concept, which was also mentioned by participants in Phase 1a as a need, there is no guidance as to how many questions are appropriate (Bell *et al.*, 2018). Surveys typically range from 20 to 50 questions depending on the context and what the survey assesses. Gjertsen (2019) reported that their self-report survey with 76 questions for individuals with mild and moderate IDD in a living conditions study was too long, affecting the response rate (Gjertsen, 2019).

While the WES abbreviated WIHD SAS did meet the readability and language simplicity criteria for mild to moderate IDD, the number of questions was limited. However, this was accepted as during the evaluation in Phase 3 respondents had to complete the survey twice on different platforms and participants with varying degree of ability. Although some individuals may be able to complete 10 questions relatively quickly, for others this may be the limit that they can achieve in a longer time frame while still attending to the task at hand.

5.4.2 PHASE 2b - Addition of multimedia to WES abbreviated WIHD Self-Advocacy-Survey questions

Phase 2b was the addition of multimedia images to each question. Two components of multimedia, text and sound, were implemented at this stage and these options were included in the customizable platform. The addition of images and video was also possible, but these had to be chosen or created for inclusion in the survey. The criterion in the WCAG 2.1 (W3C, 2023) indicating that an image of text can be visually customized to user requirements, and is essential to the information being conveyed to improve accessibility, was implemented. Video directions in the introduction were also included, meeting the WCAG 2.1 (W3C, 2023) criterion for accessibility, using Audio Description (Prerecorded).

Evidence for using visual representations to support the meaning of questions and facilitate comprehension was found to be moderate (O'Keeffe *et al.*, 2019). However, comprehension improved when images were used to represent questions in an interview self-report survey with individuals with mild to moderate IDD where the interviewer could explain the meaning of the picture if necessary. This was confirmed by Raymaker et al. (2019) who recommended simple concrete images to accommodate multiple ways of understanding information in surveys for individuals with autism (Raymaker *et al.*, 2019).

Visual multimedia in surveys have been tested in other studies to improve accessibility, including: a visual analogue scale representing emotions (Haimerl and Riener, 2021); social media icons (Bayor *et al.*, 2021); custom images created for the surveys, in this case assessing grief (O'Keeffe *et al.*, 2019); and the inclusion of images in the measurement of subjective well-being for adolescents with IDD (Davison et al., 2022).

Although including the appropriate images was reported to assist in maintaining the attention of individuals with IDD, keeping them on-task for longer, increasing independent performance and the quality of responses (Davison *et al.*, 2022), the inclusion of stock items and images specifically selected to enhance the meaning of survey questions has not been tested. In 2018, Hollomotz suggested that images available in search engines have become a valuable tool to add clarity to surveys for individuals with IDD. If it is impossible to find an image that the survey developer feels the respondents can identify, then she suggests also using pictures taken by the survey developer, possibly in a familiar venue. She confirmed that the inclusion of images facilitated accessibility in her study on sex, risk, social life, and leisure (Hollomotz, 2018).

Thus, the inclusion of the multimedia images to the WES abbreviated WIHD SAS needed to be carefully selected to ensure these provide better accessibility and independent performance, and limit the amount of assistance required to complete the survey. Images were found online for all questions, facilitated by occupational therapy students who were knowledgeable in the process of analyzing activities, a skilled process practiced in occupational therapy to access the potential value of the components of a task in relation to the individuals' abilities and the support or adaptation they may need to participate in the activity (Dancza, Head and Mesa,

2018). The selection of images also considered the concrete thinking and levels of functioning of individuals with cognitive disabilities (Bell et al., 2018), and the intrinsic cognitive load which is affected by the complexity of the images and capacity of the respondents to interpret what is presented (Triono and Retnowati, 2019). The students were aware of person centered practice and the importance of maintaining a simplified approach in choosing images to enhance and not impede comprehension of the questions on the survey.

This phase of the study emphasized the importance of discussion about the suitability of the images for each question based on the factors described above. This step in the process was time consuming and indicates a possible barrier in the addition of multimedia images to surveys on the WES platform. It is important that criteria for suitable images be developed, and a library of images be made available to other survey developers. As early as 2001, Finlay and Lyons indicated that visual media included in surveys should facilitate understanding of questions and be tested with end-users and stakeholders, as was done in Phase 2c (Finlay and Lyons, 2001). Overall, photo symbols were not included since the end-users would be required to have prior knowledge of these symbols. Although a new accessible platform is now offered commercially by Rix software, this platform was not yet available when this study started and is currently only available within the United Kingdom.

5.4.3 Phase 2c – Content validity of multimedia in the WES abbreviated WIHD Self-Advocacy Survey

Evidence for the inclusion of multimedia images that are appropriate to improve comprehension in surveys for individuals with IDD needs to be validated. To understand if images were considered appropriate and if images preferred by the participants in Phase 2c in supporting the accessibility of the survey were valid, a content validity methodology was used. This was done with experts who had participated in Phase 1a as well as collaboration with individuals with IDD (Fernández-Gómez *et al.*, 2020; Ausderau and Smith Dawalt, 2024).

The CVR score of 0.84 and higher, as well as a CVI score of 0.85 or higher, indicated agreement amongst the participants in this phase of the study and the acceptability of the images included in the WES abbreviated WIHD SAS as valid.

Some general comments were made by an expert about the importance of assessing the multimedia images based on the ability of the end-users of the survey. This supported the ABD and principles of user centered design, and the need to listen to the participants' preferences and implement adjustments to ensure accessibility to the population the survey was intended for (Coleman-Fountain and McLaughlin, 2013).

The same expert commented on the need for simplicity and clarity with individuals with IDD, as did some of the end-user participants with IDD. The adaptation of the interviews with the end-user participants with IDD incorporated these comments and allowed for consultation between participants in evaluating the multimedia images. The PI attempted to prevent cognitive overload by clearly indicating when the evaluation of the images for one question was complete before introducing the next question, and by posing similar concrete questions about each image on the survey regarding abstract language. Encouragement and repetition were used as necessary, and participants were given time to consider their answers (McFarland *et al.*, 2024).

The reasoning for including the multimedia images in the survey for both the experts and end-users with IDD incorporated the clear link of image to the question content and/or the clarity of the message from the image. Other aspects which made images acceptable to all stakeholders were the depiction of interaction in the image, as well as choices in the image, and images with which the end-users could identify. These images were not static representations but included semantic associations of pictures designed for individuals with IDD (Nakamura and Zeng-Treitler, 2012) that both the experts and end-users with IDD could recognize. These associations which specifically support the comprehension of images that were used have been characterized as:

- comparison or contrast, as in question 2 where the person who is helping is further back in the picture indicating the person in the foreground is the one asking for help,
- exemplification or multiple examples used to represent a category, such as the disability symbols in question 10 ,
- physical decomposition where one part represents the whole, such as a graduation cap being used to represent college in Question 4,
- body language in the depiction of facial expressions and posture, such as question 3 and question 12 which depict conversation or interaction,

- contiguity or items commonly used to represent a specific concept, such as a stethoscope indicating a doctor.

Semantic narrowing, which represents a verb from a concrete image; metaphors or symbols depicting ideas; and temporal decomposition which considers events in time; were not used since they often include abstract concepts and require complex comprehension, which were avoided as much as possible. Expert participants and end-users with IDD indicated they did not prefer some images due to a vague link with the question, such as depictions of an empty thought/word bubble which did not guide the direction of the question, some pictures in thought/word bubbles being small, and too many options present when one picture would suffice. In Figure 5.15 the image was identified as being vague in relation to Question 1 (“I know which things are hard for me”) as the person may be identified as in pain.



Figure 5.15 Accepted and rejected images for Question 1

However, in consultation with end-users with IDD and later with the experts, it was not changed as it became evident that it was generally supportive of the concept of having trouble with something. The alternate to this image was the following line drawing, and this was rejected as it displays a symbol that was confusing, and real-life images were considered more acceptable. This supports the findings reported as the physical properties of the object/person in a real-life image are more recognizable and easier to understand and relate to (Carmien and Wohldman, 2008) than symbols for individuals with cognitive disabilities. Other research did not find a significant difference between using color photographs and line drawings, however, when testing the text comprehension of adolescents, the range of correct answers was greater for

those who saw the photographs (Saletta *et al.*, 2019). It would appear that the use of symbols with a line drawing that does not adequately depict the question in this case should be avoided.

Recommendations for multimedia images therefore include:

- concrete images which link clearly with the content of the question,
- real life images if they clearly link to the question,
- images that add clarity to the text if they do not link directly to words in the question,
- clear choice to be made from options in the images relating to the question ,
- images that allow respondents to identify with people depicted,
- include comparison, multiple examples, physical decomposition, body language and contiguity in images if this represent the text,
- avoiding symbolic representation if possible.

CHAPTER 6: PHASE 3

6.1 Introduction

Phase 3 addressed the evaluation of the accessibility of the WES abbreviated Westchester Institute for Human Development self-advocacy survey (WIHD SAS) survey, which incorporated technology developed in Phase 1, and which was enhanced with multimedia in Phase 2 on the WES platform.

6.2 PHASE 3 METHODOLOGY - EVALUATION OF THE MULTIMEDIA SURVEY PLATFORM FOR PEOPLE WITH COGNITIVE DISABILITIES

6.2.1 Research Design

A quasi-experimental within-group research design was used in this phase of the study. This dependent group design allows measures from the same participants on different assessments to be evaluated (Gorvin *et al.*, 2017). In the within-group design, the study participants acted as their own control and provided a baseline for survey completion. The same participants completed an abbreviated WIHD SAS as a control on the SurveyMonkey platform (which was the platform used at WIHD until the new WES prototype was developed) as well as completing the WES abbreviated WIHD SAS with multimedia adaptations for individuals with cognitive limitations on the Westchester Institute for Human Development Easy Survey (WES) platform. The goal was to measure outcomes in terms of performance on both surveys; the order of presentation of the surveys was counterbalanced to avoid bias of time and possible carryover effects due to repetition of the survey questions. This design was used as it allows for the recruitment of a relatively small sample of individuals with IDD with variations in individual differences in cognition and performance being controlled (Bhandari, 2023).

6.2.1.1 Null Hypothesis

The completion of the abbreviated WIHD SAS on the WES platform will not reduce survey completion time, reduce support needed, and facilitate self-report (instead of someone reporting on their behalf) for individuals with IDD compared to completion of the WIHD SAS on the SurveyMonkey platform.

6.2.2 Participants and Sampling

Patients 18 years of age and older presenting to the Adult Health Program at the WIHD between January 1, 2024, and November 30, 2024, with IDD as identified with the ICD-10 codes of F70, mild intellectual disabilities (I.Q. 50-70), and F71, moderate intellectual disabilities (I.Q. 35-49), were eligible to participate in this study. All participants were accompanied by a caregiver or family member who would be able to offer support while completing the surveys if necessary.

Inclusion criteria

- Clients with IDD who could provide informed consent according to the capacity to consent, as per the University of California San Diego Brief Assessment of Capacity to Consent (UBACC) (Appendix D), and approved in the ethics application for this study.

6.2.2.1 Sample Size

A sample of 30 subjects was required for this phase of the study. A sample of 30 subjects had 80% power with a significance level (alpha) of 0.05 (two-tailed) to detect a difference between mean completion times with at least a four-minute difference in completing the two surveys. This criterion was set by the PI from the results of Phase 2, and the calculation assumes a 10-minute standard deviation within the group for each version of the survey (Suresh and Chandrashekara, 2012).

6.2.3 Research instruments

6.2.3.1 University of California San Diego Brief Assessment of Capacity to Consent (UBACC)

The UBACC (Appendix D) assesses whether adults can make an informed decision to participate in a research study. The assessments can be administered in less than 5 minutes by someone with a graduate degree. Three domains of capacity to consent are measured. These include: understanding, or the ability to comprehend the information (4 items); appreciation, or the ability to apply the information to respondents' context (4 items); and reasoning, by appreciating the consequences of respondents' participation (2 items) (Jeste *et al.*, 2007). Satisfactory ability in these domains does not depend on the ability to read, as the information sheet and consent form can be explained verbally. Each of the 10 items is scored on a 3-point scale, with 0 reflecting incapable and 2 reflecting capable, with a cut off score of 14.5. Questions on the UBACC can be rephrased to improve comprehension, but rephrased questions can only yield a score of 1 or 0, and can only be rephrased a total of 3 trials (Jeste *et al.*, 2007). Low scores on the UBACC indicate difficulty in providing consent. Literature indicates that the UBACC has good psychometric properties for concurrent validity, with Mini Mental State Examination (MMSE) ($r= 0.56$, $p < .001$). Discriminant validity against the Trust in Medical Researchers (TMR) showed a low, negative correlation ($r=-0.25$, $p= .006$). The UBACC has strong internal consistency ($\alpha= 0.75$) (Seaman *et al.*, 2015), and aligns with the federal minimum standards for informed consent (Department of Health and Human Services: National Archives and Records Administration, 2009).

6.2.3.2 Control Survey - Abbreviated Westchester Institute for Human Development self-advocacy survey (WIHD SAS) on the SurveyMonkey platform

The ten questions chosen from the original WIHD SAS were compiled into an abbreviated WIHD SAS control survey for this phase of the study. These questions remained in the original format and were presented in the same order on SurveyMonkey as the survey that was previously administered on pen and paper. The answer options for each question were: yes, yes with assistance, or no. No research on the validity of this survey is available, but the current research project is about

evaluating survey use of the new WES platform, not about validating the survey content.

6.2.3.3 Experimental Survey - Abbreviated Westchester Institute for Human Development self-advocacy survey (WIHD SAS) with multimedia on the Westchester Institute for Human Development Easy Survey (WES) platform

The WES abbreviated WIHD SAS with multimedia consisted of the 10 questions chosen and adapted using multimedia in Phase 2 of the study. The content validity of the multimedia in the survey was confirmed in said Phase 2.

6.2.3.4 Observation report and videos

An observation checklist for this phase of the study was developed by the PI (Appendix N), and reviewed by another researcher from Phase 1a for validity, based on the clinical experience gained from working with individuals with IDD and technology for more than 37 years. The checklist took into consideration evaluating the participants' ability to complete the surveys based on the disability interaction approach to evaluate the accessibility of the surveys to participants with IDD (Coleman-Fountain and McLaughlin, 2013; Holloway and Barbareschi, 2022). Each participant's age and gender were recorded on the checklist used to observe their performance.

The focus was on the accessibility and usability of the two platforms of the survey and participant performance as described in ability-based design (Wobbrock *et al.*, 2011). The checklist required information on the completion time for each survey as well as the number of times support was needed and the type of support needed to facilitate self-report during completion of the surveys. More specifically, completion time was a measured number of minutes an individual needed to complete each survey, and support was measured by the number of interactions between a respondent and the caregiver or family member accompanying them.

The type of support was recorded according to the questions asked by each participant and based on adaptation of the Core Elements Method (CEM) (De Werd *et al.*, 2016; Golisz *et al.*, 2018). A core element in the CEM is defined as the task steps grouped in a logical way that can be observed as the participant carries out the activity of completing the survey. Thus, it was noted if assistance was needed, for example, with navigating the screen or reading the question.

In order to ensure accurate observations, each participant was also video recorded during the completion of the two surveys, if they gave consent or assent. Using videos is often described in the literature for confirming a set of observable behaviors (Mian *et al.*, 2015; Sadideen *et al.*, 2016). Video analysis was conducted on each video to confirm the time and kind of support provided to the participant on the observation report. The observations on the checklist were recorded while the participants completed the questionnaires and /or by viewing their performance on the video.

Pilot study

The pilot study was conducted for validity purposes. The factors to be assessed on the CEM instrument on the checklist for this study were confirmed by having two independent observers (an occupational therapist on staff at WIHD, and the Quality Programs Manager) of the survey completion review and add to the checklist as appropriate. Both observers felt the content of the checklist was appropriate and that they could observe the participants' performance and record their time according to the checklist.

6.2.3.5 Evaluation of the survey platforms

Participants were asked to evaluate their experience of the survey platforms. This was done as part of a post survey administration interview with each participant and was recorded by the interviewee.

6.2.4 Research procedure

Clear and simply worded announcements regarding the study were displayed and made available in waiting areas within the Adult Health Clinic at WIHD. (Appendix O) This allowed both individuals and caregivers to become aware of the study prior to being approached. Once the recruitment period started, eligible participants were approached by an occupational therapist and/or the quality programs manager and invited to participate in the study. The information sheet explaining the study was shared with the potential participants, while waiting for their visit. (Appendix E)

If there was interest in project participation, the individual was evaluated regarding their capacity to consent based on the UBACC by the quality programs manager and occupational therapist.

All individuals for whom capacity to consent was confirmed and from whom signed informed consent (Appendix E) was obtained, were asked to consent to be video recorded while completing the surveys.(Appendix P). Not all, however, agreed to consent to the video recording. The PI then produced a password-protected Excel list of names and visit date to provide to WIHD's quality programs manager, who then used that list to retrieve requested demographic and medical information – age, gender, and diagnosis in terms of severity of IDD for each individual who had agreed to participate. Once returned, the PI replaced patient name and visit date with a subject number and used the Excel file for inclusion of additional study variables. (Appendix Q)

6.2.4.1 Data Collection:

After their scheduled appointment with Adult Health, identified participants were asked to complete the surveys in both formats. To reduce bias introduced by content familiarity, participants were randomly assigned using a random tables list to either complete the abbreviated WIHD SAS control survey or the WES abbreviated WIHD SAS with multimedia first. Each format of the survey should take approximately 10 - 15 minutes to complete, for a total study participation of 20 - 30 minutes. Two assessors, the quality program manager and the occupational therapist, were present with each participant while they completed the surveys. One assessor observed the client if the participant consented to be videoed, while the other assessor videoed the client during the survey completion. For those participants who did not agree to be video recorded, the two data collectors (the quality programs manager and occupational therapist) recorded their observations on the checklist while the participant completed the surveys.

For participants that were video recorded, the assessor who videoed the participant completed the observation checklist when viewing the video. For both the observations completed by watching the video and made observing the client in situ, or two observations made in situ, the two assessors discussed any difference in observations and consolidated the findings for each participant on one observation form.

Data on the evaluation of the surveys was collected from the participants with IDD by the person who administered the surveys and recorded on the observation form.

6.2.5 Data Analysis:

Descriptive data (age, gender, and UBACC scores) were first summarized using appropriate frequency measures. Due to the small sample size and data which were not normally distributed, median scores were used to analyze the data.

Primary outcome measures for the observations on the completion of the two surveys included completion time, the number of times support was given and how many participants required support. The reason why support was needed was also recorded. These variables were compared for the two survey formats using the Wilcoxon signed-rank test (Rosner, Glynn and Lee, 2006). Difference in completion time and number of participants requiring support were compared for the two survey formats using a Kruskal – Wallis test (Frey, 2023).

To determine validity of the surveys, the answers provided on the two surveys were compared using a Wilcoxon sign ranked test to determine if the same answers were given each time (Rosner, Glynn and Lee, 2006). The reliability of the surveys was determined by addressing the internal consistency using Cronbach's alpha (Tavakol and Dennick, 2011). These analyses were performed using SPSS v. 22; all tests were two-tailed and results with p-values of <0.05 were considered statistically significant.

For the observations on the kind of support required, the PI coded this information for analysis using summative content analysis based on the questions asked by the participants, recorded by the assessors, and the factors assessed on the CEM. Frequencies according to the codes and factors recorded will be reported.

The comments made by the participants with IDD were coded by the PI for analysis using summative content analysis based on answers. Frequencies according to the codes and factors recorded were reported.

6.3 PHASE 3 RESULTS - EVALUATION OF THE MULTIMEDIA SURVEY PLATFORM FOR PEOPLE WITH COGNITIVE DISABILITIES

6.3.1 Introduction

The results for Phase 3 consider the demographic information of the participants, the time required to complete the SurveyMonkey abbreviated WIHD SAS and WES abbreviated WIHD SAS surveys, and the assistance required while doing so. The answers on the two surveys were compared to assess if they were similar, and comments by the participants on their experience of the surveys were analyzed.

6.3.2 Demographics

Table 6.1 Demographics of the participants (n=27)

Variable		n	%
Gender	Male	16	59,26
	Female	11	40,74
Age	20-29	2	8.00
	30-39	9	35.00
	40-49	1	4.00
	50-59	5	20.00
	60-69	5	20.00
	70-79	2	8.00
	80-89	1	4.00
	Missing	2	
Diagnosis	Mild IDD	13	44.44
	Moderate IDD	16	55.56
UBACC score	15	3	11,11
	16	4	14,81
	17	5	18,52

	18	4	14,81
	19	7	25,93
	20	4	14,81

Although 30 individuals were assessed using the UBACC, three did not achieve the cut off score; thus 27 participants were included in this phase of the study. Non-parametric statistical analyses were used throughout because of the small sample size and data that were not normally distributed.

There were more male participants (59%) than females (41%). Their ages range from 24 years to 67 years, and a slightly higher percentage of participants were diagnosed with moderate IDD compared to mild IDD.

The participants' UBACC scores were between 15 and 20 and above the cut-off of 14.5 for informed consent (Table 6.1).

6.3.3 Evaluation of surveys

6.3.3.1 Time and Assistance required to complete the surveys

Time to complete the surveys

As part of the research to determine the accessibility and usability of the WES abbreviated WIHD SAS with multimedia, it was compared to the abbreviated WIHD SAS control survey on SurveyMonkey by establishing the difference in time participants took to complete each survey (Table 6.2). While the minimum time score was three minutes for both surveys, a maximum score of 51 minutes was recorded for the SurveyMonkey abbreviated WIHD SAS and 43 minutes for the WES abbreviated WIHD SAS.

Table 6.2 Time to complete the surveys (n=27)

	Median			p value
	minutes			
SurveyMonkey abbreviated WIHD SAS	12.00	4.00	22.00	0.190
WES abbreviated WIHD SAS	8.00	5.00	20.00	
Significance set at p≤0.05				

The participants' median time score for the WES abbreviated WIHD SAS was shorter than the median time score for the SurveyMonkey abbreviated WIHD SAS, but the difference in time was not found to be statistically significant (p= 0.190).

The very strong correlation of r=0.96 between the time taken for SurveyMonkey abbreviated WIHD SAS and WES abbreviated WIHD SAS indicated participants took a similar time on both surveys regardless of the order in which they were completed.

Assistance with questions

For the 27 participants, assistance was required 21 times to complete the SurveyMonkey abbreviated WIHD SAS by 17 (62.9%) participants, and eight times for the WES abbreviated WIHD SAS by three (11.11%) participants. The difference between the times assistance was required and the number of participants requiring assistance for the two surveys was statistically significant and lower for the WES abbreviated WIHD. (Table 6.3)

Table 6.3 Number of times participants required assistance and number of participants requiring assistance (n=27)

	SurveyMonkey abbreviated WIHD SAS *only*		WES abbreviated WIHD SAS		
	n	%	n	%	p value
Assistance needed	21	77.78	8	29.62	0.0001
Number of participants requiring assistance	17	62.9%	3	11.11	0.0017
Significance set at p≤0.05					

Type of assistance

The type of assistance required, most commonly, was reading of the questions for participants when completing the SurveyMonkey abbreviated WIHD SAS (Table 6.4). Significantly more participants, when completing SurveyMonkey abbreviated WIHD SAS, required assistance with reading and selection. Some participants required assistance with more than one aspect, but assistance with understanding the question was similar for both surveys.

Table 6.4 Type of assistance needed to complete the surveys (n=27)

	SurveyMonkey abbreviated WIHD SAS		WES abbreviated WIHD SAS		
	n	**%**	**n**	**%**	**p value**
Reading	14	51.85	1	3.70	0.0001
Selection	8	29.62	2	7.40	0.0002
Understanding	3	11.11	3	11.11	P = 1.00
Significance set at p≤0.05					

Time and assistance required

The time needed to complete the WES abbreviated WIHD SAS was subtracted from the time needed to complete the SurveyMonkey abbreviated WIHD SAS. Seven participants completed the SurveyMonkey abbreviated WIHD SAS in a shorter time, while seven took the same time. The other 13 participants completed the WES abbreviated WIHD SAS more quickly.

When considering participants who took longer than the expected time of 15 minutes to complete the surveys, eight (29.6%) of the participants did not complete the WES abbreviated WIHD SAS in this time frame. The same result was found for 10 (37.0%) of the participants for the SurveyMonkey abbreviated WIHD SAS. Regarding assistance for this group: one participant required no assistance, one required assistance with the SurveyMonkey abbreviated WIHD SAS, and eight required assistance with both surveys. Of the 12 (44.44%) participants who completed the WES abbreviated WIHD SAS, and the 13 (48.14%) who completed the SurveyMonkey abbreviated WIHD SAS, in between one and seven minutes, four required no assistance, five required assistance with the SurveyMonkey abbreviated WIHD SAS,

and four required assistance with both surveys. There was no significant difference in the time taken according to the assistance requested for the WES abbreviated WIHD SAS (p=0.117) and the SurveyMonkey abbreviated WIHD SAS (p= 0.605).

One participant had a difference in time of more than 10 minutes in completing the surveys and required assistance with both surveys. Four of the seven participants who completed the SurveyMonkey abbreviated WIHD SAS in a shorter time required assistance with this survey, and one participant required assistance with both surveys in reading. For the seven participants who completed the surveys with the same time, all required assistance with the SurveyMonkey abbreviated WIHD SAS.

Table 6.5 Differences in time in completing the surveys and assistance required/provided (n=27)

Difference in time in completing surveys	Number of Participants (n=27)	Assistance needed		
		No	Yes - SurveyMonkey abbreviated WIHD SAS only	Yes- for both surveys
		n(%)		
-3	1	1(3.7)		
-2 to -1	6	3(11.1)	2(7.4)	1(3.7)
0	7		7(25.9)	
1 -2	6		6(22.22)	
4 -5	4	1(3.7)	2(7.4)	1(3.7)
6 -7	2	2(7.4)		
11	1			1(3.7)
Significance set at p≤0.05				

There was no significant difference (p=0.548) between the difference in the time taken and the assistance required with no assistance being required for participants who completed both the SurveyMonkey abbreviated WIHD SAS and eight times for the

WES abbreviated WIHD SAS in a shorter time. All participants with a similar time for completion of both surveys (0-2 minutes difference) required assistance with the SurveyMonkey abbreviated WIHD SAS.

6.3.3.2 Validity and reliability of answers on the survey

Validity

To determine the validity of the answers, the percentage difference of answers, based on the incidence of a respondent selecting a different answer for the same question between platforms, was determined by subtracting WES abbreviated WIHD SAS surveys from those administered on the SurveyMonkey abbreviated WIHD SAS. Although there were no statistically significant differences between the answers given, some did differ. (Table 6.6 and Figure 6.1) The largest difference in answers was seen for Question 7 and 8 where more participants answered yes on the SurveyMonkey abbreviated WIHD SAS.

Table 6.6 Differences in answers provided on the two surveys (n=27)

Question		Answer	Percentage Difference (WES abv. WIHD SAS/Survey Monkey abv. WIHD SAS)	P value
1	I know which things are hard for me	Yes	-7.42	0.963
		Yes, with assistance	7.41	
		No	0	
2	I can ask for help when I need it from people I know	Yes	0	0.982
		Yes, with assistance	-3.71	
		No	3.71	
3	I know my interests	Yes	3.71	0.683
		Yes, with assistance	3.71	
		No	-7.41	
4	I know I can go to college if I choose to	Yes	18.53	0.986
		Yes, with assistance	-7.41	
		No	-11.12	

5	I know that I can participate in choices made about my healthcare	Yes	-7.41	0.479
		Yes, with assistance	7.41	
		No	0	
6	I want to learn to make more of my own decisions	Yes	-3.71	0.971
		Yes, with assistance	0	
		No	3.71	
7	I talk about the things I am good at	Yes	18.51	0.983
		Yes, with assistance	-18.81	
		No	0	
8	I let others know how I like to learn	Yes	18.52	0.077
		Yes, with assistance	-22.22	
		No	3.7	
9	I help to make my healthcare decisions	Yes	0	0.647
		Yes, with assistance	7.4	
		No	-7.4	
10	I know what kind of disability I have	Yes	-7.41	0.617
		Yes, with assistance	3.7	
		No	3.71	

“For three questions: Question 4, “I know I can go to college if I choose to”; Question 7, “I talk about the things I am good at”; and Question 8 “I let others know how I like to learn”; more Yes answers were recorded for the SurveyMonkey abbreviated WIHD SAS.

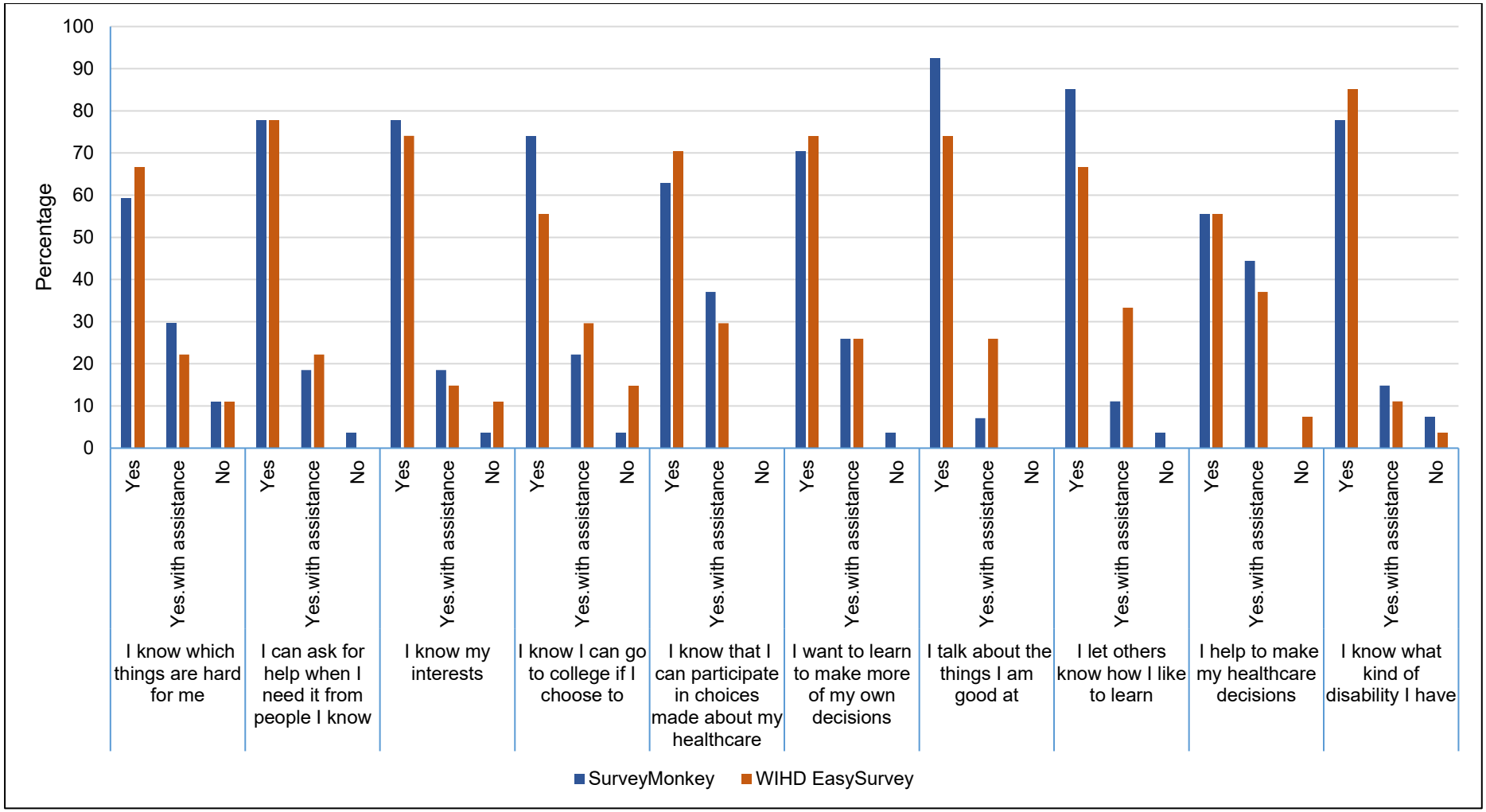


Figure 6.1 The percentage answers provided on the SurveyMonkey and Westchester Institute for Human Development Easy Survey abbreviated self-advocacy survey (WIHD SAS) (n=27)

Reliability

In determining the reliability of the surveys, Cronbach alpha for the two surveys indicated an unacceptable score of ά= 0.54, but the internal consistency was acceptable for the WES abbreviated WIHD SAS ά= 0.72 (Nunnally and Bernstein, 1994). This indicates that the consistency of results across different items achieved on the WES abbreviated WIHD SAS made it a reliable test for assessing self-advocacy. This did not hold true for the Survey Monkey version of the abbreviated WIHD SAS.

6.3.3.3 Evaluation of surveys by participants

Of the 27 participants in this phase of the study, 24 shared comments on their experience of completing the surveys and indicated a preference of one platform over the other. Twenty-one participants preferred completing the WES abbreviated WIHD SAS over the SurveyMonkey abbreviated WIHD SAS.

Table 6.7 Preference for survey platform (n=24)

Preferred survey	SurveyMonkey abbreviated WIHD SAS		WES abbreviated WIHD SAS		
	n	%	n	%	p value
Participants	3	12.5	21	87.5	0.0001
Significance set at p≤0.05					

Participants' comments about the WIHD WES Platform were analyzed and coded. No negative comments were made, and the positive comments indicated that the audio readback support was found by over 70% of participants to make the survey platform accessible to them.

All three participants who preferred the SurveyMonkey abbreviated WIHD SAS preferred all the questions on one page. Of these participants, one took three minutes on each survey with assistance on the SurveyMonkey abbreviated WIHD SAS, while the other two took between 40 - 51 minutes to complete each survey, one of whom required assistance with both surveys.

Table 6.8 Evaluation of the Westchester Institute for Human Development Easy Survey platform (n=21)

Comment	n	%
Audio read back support "I like that it can read the questions" "I think the reading is good" "I can hear the question many times"	15	71.43
Added images "The pictures helped me a lot" "The pictures made it better" "I like the pictures, makes the words less confusing"	14	66.66
Video explanation "The video tells me how to answer the question" "I like that the video explains things – makes it clearer" "I like the video, because it explains things to me before starting to answer the questions"	11	52.38
Larger font "the bigger words can help people who can't see so good" "I like the big font, because it makes it easier to read"	11	52.38
One question per page "I like that there is only one question on a page, it makes it easier"	7	33.33
Larger icons/buttons "Bigger buttons help me touch them better" "Better for my eyesight"	2	9.52

Reminder to answer "Sometimes I forget – I like that it tells me" "I can't go to the next question before I answer this one"	1	4.76
Back button "I like that I can go back" "If I want to read a question again, I can just touch the back button"	1	4.76

6.3.4 Summary of results

The completion of the surveys was assessed by considering the time and assistance required. Seventeen participants needed assistance 21 times to complete the SurveyMonkey abbreviated WIHD SAS, and three participants needed assistance eight times for the WES abbreviated WIHD SAS. For assistance required, the number of times assistance was required and the types of assistance, the null hypothesis was rejected as participants require significantly more help with the SurveyMonkey abbreviated WIHD SAS. Assistance was required for reading questions, selection of answers, and comprehension of questions.

The null hypothesis for time to complete the surveys was accepted since there was no significant time difference in completing the SurveyMonkey abbreviated WIHD SAS and the WES abbreviated WIHD SAS. In the evaluation by participants with IDD, there was a significant difference in their preference for the WES abbreviated WIHD SAS. The audio feedback, the presence of images, video explanation, and large text were preferred by the majority of participants.

6.4 PHASE 3 DISCUSSION - EVALUATION OF THE MULTIMEDIA SURVEY PLATFORM FOR PEOPLE WITH COGNITIVE DISABILITIES

6.4.1 Introduction

This section considers demographics of the sample, the comparison of the completion of the final version of the WES abbreviated WIHD SAS survey and the SurveyMonkey abbreviated WIHD SAS survey, in terms of time to complete and assistance needed. The similarity of questions answered on both surveys is discussed as well as the preference for and evaluation of the accessibility of the surveys.

6.4.2 Demographics

The sample was representative of patients receiving services at the WIHD Adult Health Clinic in terms of age and gender. The participant's ages ranged across six decades. Although Heslop et al. (2021) found individuals with IDD have a lower life expectancy by 24 years, the support offered by WIHD has resulted in older patients still attending services at the institute and these individuals were also included in this study (Heslop *et al.*, 2021). A majority of younger adults between 30 and 39 years characterize the adult patient load at the clinic.

The sample for the study was recruited after posters displayed at the clinic (Appendix O) informed those attending the clinic of the research. The sample was selected based on eligibility to provide informed consent, and although 91 patients were approached, only 30 were interested in participating and were included since participation was voluntary. This challenge of recruiting participants with IDD into research has been supported by McDonald (2024), who emphasized the inclusion of individuals with IDD as participants remains important, but not easy (McDonald *et al.*, 2024). To ensure trust, the participants were not pressured to participate, and the research was introduced by familiar staff members. Both of the staff members who were administering the surveys have experience in working with individuals with IDD at WIHD and used a person centered approach when recruiting participants into the study. Prospective participants were

informed as to the possible benefits or risks in taking part in the research. In addition, one of the issues faced at the WIHD clinic is that patients are brought for their appointment by staff from agencies where patients live, and these staff members are often adherent to a schedule and pursue a rapid turnaround in the clinic to return patients to their day program. They typically don't want to stay at the clinic longer than is needed for activities that are not directly required for the patients' medical visits.

The importance of using recognized criteria to include the individuals with IDD in research which affects their self-advocacy or health was emphasized by Bishop et al. (2024) to improve clinical outcomes and services to these individuals. Research needs to be representative of the population if findings are to be generalizable (Bishop *et al.*, 2024). Though, for this specific study the sample was too small for generalizability. Although guidelines which support enhanced decision making for individuals with IDD in terms of providing informed consent do exist, various authors have reported that they are rarely used, with only 2% of studies on the health of this population including participants with IDD (Feldman *et al.*, 2014; Shepherd *et al.*, 2019; McDonald *et al.*, 2022). It was ensured that all 27 participants included in this study were all able to give informed consent according to the criteria on the UBACC, as required by the committees which gave ethical clearance for this study. (Appendix D)

Another barrier to including participants with IDD in the research process includes finding suitable assessments and outcome measures (McDonald *et al.*, 2022). This was addressed in the purpose of this phase of the study, which was to establish if the survey developed was accessible.

6.4.3 Evaluation of surveys

6.4.3.1 Time and Assistance required to complete the surveys

The objective of this phase of the study was to evaluate the accessibility of the SurveyMonkey abbreviated WIHD SAS and the WES abbreviated WIHD SAS in terms of time to complete the surveys and assistance required, and the validity and reliability of the answers on the two surveys. Thus, the adaptation and addition of multimedia on the

WES platform was assessed to determine if completion of the WES abbreviated WIHD SAS was more efficient and independent, with less assistance required(Neuman, 2024).

Results indicate the time taken by participants to complete the SurveyMonkey abbreviated WIHD SAS was longer overall than the time taken to complete the WES abbreviated WIHD SAS. The time difference was not statistically significant -- this was due to variation in the difference in times in completing the surveys, since seven participants completed the SurveyMonkey abbreviated WIHD SAS more quickly and seven others used the same time to complete both. Thus, efficiency in terms of time was improved for 50% of the participants.

The number of times assistance was required to complete the surveys was significantly less for the WES abbreviated WIHD SAS. As suggested by Wilson et al. (2017) and discussed in Phase 1, the documented strategy providing support and assistance while completing a survey is understood to provide support without compromising autonomy (Wilson *et al.*, 2013). Most participants (88.8%) did not require assistance with the WES abbreviated WIHD SAS, while 36.1% did not require assistance with the SurveyMonkey abbreviated WIHD SAS. This indicates a significant improvement in independent performance when using the adapted multimedia WES abbreviated WIHD SAS. Research which studied accessibility and the utility of iPad use and self-care prompting applications found 30%-50% independent use for individuals with IDD (Castilla *et al.*, 2020; White *et al.*, 2022). Other studies were found that compare time taken and assistance required for the completion of an assessment and corresponding learning modules on an accessible software application (Davies *et al.*, 2017). The participants' ability to use the WES abbreviated WIHD SAS without assistance was higher than that reported in other studies on adapted accessible software for individuals with cognitive disabilities.

The participants were observed during the administration of the survey and the assistance they required was recorded. A reduction in assistance was considered as a change in their performance. This supported the principle of performance in ABD (Wobbrock *et al.*, 2011) as a subcategory of HCI, in an attempt to make the best use of the participants abilities. Although it was envisioned, initially, that the exact times the participants were

assisted should be recorded, this was not possible due to the speed with which the surveys were completed by some participants. Assistance with selecting or inputting an option took only milliseconds for some.

Most assistance was required by having someone read the questions to the participant, while fewer participants required assistance with the actual selection of icons or question and answer options on the screen; significantly more participants required this help on the SurveyMonkey abbreviated WIHD SAS. Three participants required assistance with clarifying what a question meant (understanding) on both surveys. These aspects align with Tourangeau's model of survey response (Tourangeau, 1984), which were considered within HCI and universal design of the multimedia WES survey platform. In this process the initial aspect of comprehension required the most assistance, especially on the text-based SurveyMonkey abbreviated WIHD SAS, so the participants could understand and interpret the question. Attention to questions and instructions was enhanced by verbal input which participants could access independently on the WES abbreviated WIHD SAS. It was clear, however, that one participant still required assistance with this aspect since they might have missed the speaker icon and did not access this feature of the multimedia, or they had trouble understanding the speech on the iPad. Another reason could be that they may be more severely cognitively impaired and might need some clarification regardless of the mode of survey delivery.

Cognitive processing to retrieve or reflect on the question, so judgment can be used to answer the question, was addressed in the selection aspect (Tourangeau, 1984). Fewer participants required assistance with selecting a response option, but significantly more still asked for help when completing the SurveyMonkey abbreviated WIHD SAS. This result confirms that the multimedia may increase the accessibility of the WES abbreviated WIHD SAS for individuals with mild and moderate IDD (Rubenzer and Pierce, 2023). The significant difference in the assistance required to comprehend questions and select answers supports the cognitive accessibility of the WES abbreviated WIHD SAS, since both platforms had exactly the same questions.

The variation in time and assistance required correlated with the differing abilities of the participants when completing the surveys. Results indicate no significant difference in the

time taken. Only two of the participants who required extended time of more than 20 minutes did not ask for assistance, one of whom took nearly an hour to complete the 10 questions on the SurveyMonkey abbreviated WIHD SAS. The accessible platform, WES, yielded a statistically significant improvement in assistance required, and was therefore seen to accommodate the participants' preferences but confirmed the need for assisted self-report. For the 29.6% of participants who took longer than 15 minutes to complete the WES abbreviated WIHD SAS, further investigation should be considered, especially for the duration of attention required to complete the survey. Extended time has been indicated to be a necessary accommodation associated with a lack of cognitive, reading and retrieval fluency; and processing and decision speed (Ofiesh, Mather and Russell, 2005). Since most respondents with IDD took an extended time to complete both surveys, it can be assumed that these cognitive limitations may play a role in the abilities of individuals with IDD. Features targeting cognitive and reading fluency, such as audio /visual prompts and a simplified layout, in the WES abbreviated WIHD SAS did result in a shorter completion time of between two and eleven minutes for six of the eight participants.

The results indicate, as supported by the ACDM (Kang and Tadi, 2020), that within the diagnosis of mild to moderate IDD, cognitive abilities differ with a large range of performance in answering the surveys. However, it was clear that the presentation of the modified surveys did support the cognitive functioning of the participants in the current study (Kooijmans *et al.*, 2024). It appears the WES abbreviated WIHD SAS better provided appropriate environmental demands and activity requirements for the participants, resulting in more successful performance in supporting autonomous completion of the surveys.

Overall performance is better influenced by adapting environmental demands and activity requirements, with particular emphasis on attention and cognitive load, to meet end-users' need for assistance, rather than focusing on the pace at which participants function in completing the surveys. It is of concern that the extended time may have impacted respondents' levels of attention and resulted in distraction while completing the surveys. These results also reflect the importance of considering how many questions should be

in a survey for individuals with IDD, considering the length of time it took some participants to complete the survey even with assistance.

Although the content of the surveys and establishing the validity and reliability of the surveys was not the focus on the study, some basic statistics to support these concepts were analyzed. The answer selection could, if not consistently, indicate possible issues with comprehension of the questions and acquiescence in answering yes to questions. Thus, the answers on the two surveys were compared. Although there were no significant differences in the answers provided for each question, answers did differ (Figure 5.1). These differences were between answers of “Yes” and “Yes with assistance” which may need further clarification in the introduction to the survey or rewording to clarify clearly the difference between these concepts. The answer “No” differed for zero to two participants between the two surveys indicating very little change in this concept, which confirms the participants’ ability to distinguish between yes and no. Though it is possible that an option of “I don’t know” could be added to this survey as suggested by Kooijmans et al. (2022), the PI elected to rather include “Yes with assistance” as suggested by expert participants in Phase 3 (Kooijimans et al., 2022).

Since there are no correct and incorrect answers on a self-advocacy survey, it is difficult to align these differences in answering questions with comprehension and accessibility. The reliability of the WES abbreviated WIHD SAS based on internal consistency was at an acceptable level above 0.70 (Nunnally and Bernstein, 1994), which was not the case for the SurveyMonkey abbreviated WIHD SAS. In both cases, Question 4: “I know I can go to college if I choose to”; had the greatest effect on the internal consistency. This result appears to support improved comprehension and consistency in the completion of the WES abbreviated WIHD SAS, confirming improved accessibility in this survey format.

6.4.3.2 Evaluation of surveys by participants

The final part of the evaluation of the surveys was to understand the opinion of the participants in terms of their preference for the survey format. This part of Phase 3 used a qualitative research method which was in line with other studies where researchers, participants, and carers evaluated accessible software applications. Thus, evidence for

preferences and ease of use of the software is based on GRADE-CERQual criteria (Wainwright *et al.*, 2023). It was outside the scope of the current study to establish which of the components that participants indicated improved their efficiency and performance in accessing the WES abbreviated WIHD SAS.

The comments from the participants as to which survey they preferred indicated 19 participants preferred the WES abbreviated WIHD SAS presented on the WES platform. Only three participants preferred the SurveyMonkey abbreviated WIHD SAS, and this was because for all of them, the questions all appeared on one page. They preferred the option of scrolling down a page to having each question on a separate page, even though they could go back to questions they had seen previously. This preference was expressed irrespective of whether they required assistance or not, and although two participants completed the SurveyMonkey abbreviated WIHD SAS in a shorter time by two minutes, the third participant took 11 minutes longer to complete this survey without assistance. There was therefore no clear indication of why these participants may have preferred the SurveyMonkey abbreviated WIHD SAS in terms of time or assistance required. It may be, as suggested by (Esposito *et al.*, 2024), that although vertical scrolling is challenging for individuals with IDD, it was the participants who were already proficient at scrolling that preferred this option. Thus, it may be familiarity with aspects such as scrolling that influenced the preferences for the SurveyMonkey abbreviated WIHD SAS in the current study.

For the other participants who preferred the WES abbreviated WIHD SAS the results indicate, as suggested by the ACDM (Kang and Tadi, 2020), that the analysis and selection of the multimedia adaptation supported their specific cognitive abilities and needs. The adaptations accommodated spatial abilities, memory, attention, and processing speed, as well as reading, comprehension and linguistic difficulties (Esposito *et al.*, 2024). Audio read back support in the WES abbreviated WIHD SAS was the aspect which was most preferred by over 70% of respondents and which provided accessibility in terms of comprehension to the survey. The one participant who required reading out loud assistance with the WES abbreviated WIHD SAS did indicate that the audio instructions on the questions improved accessibility. It was evident, however, that the audio may not have been adequate to provide the assistance this participant needed,

which may relate to the speed or clarity of reading on the platform. Castillo et al. (2020) suggest in their study on using accessible software for elderly participants, that the speed of the audio speech output needed to be adjusted to two words per second to provide time to process information (Castilla *et al.*, 2020).

In terms of visual input, the added images in the WES abbreviated WIHD SAS were perceived to cue participants to the content of the question, and were seen as improving accessibility and utility by over 65% of participants. The addition of this adaptation is supported by a number of authors in improving accessibility to technology interfaces and software for individuals with cognitive deficits for self-report assessments (O'Keeffe *et al.*, 2019), independent living (Castilla et al., 2020), user experience of museums (Esposito *et al.*, 2024), and clinical consultations (Gibson *et al.*, 2020) as well as in education (Davies *et al.*, 2017). These studies describe the inclusion of images for improved comprehension of the text or interview questions, with participants or caregivers reporting better access when using images in accessible software. The use of images which have been properly selected and evaluated (Gibson *et al.*, 2020), as in the current study in Phase 2, may have resulted in improved efficiency for half the participants and improved performance for over 80% of participants. However, the effects of auditory prompts and images were not considered separately and the role of each in cognitive accessibility was not determined.

More than half the participants indicated the video introduction in the WES abbreviated WIHD SAS improved their experience in accessing the survey. This guided them in understanding the survey, but no research which indicated the effect of such an adaptation on performance was found. Gibson et al (2020) did find that participants with IDD preferred video tutorials to familiarize themselves with software for health education (Gibson *et al.*, 2020). The larger font was also preferred by more than half the participants when completing the WES abbreviated WIHD SAS. This aligns with the reported reading preferences of individuals with IDD in improving comprehension and readability in online health education by Balasuriya et al (2021) (Balasuriya *et al.*, 2021).

Participants expressed a preference for the WES abbreviated WIHD SAS due to it having one question per page, as noted by 33% of participants, and large navigational icons, as

mentioned by 10%. These aspects adhered to HCI principles by using a client centered design or ability-based approach (Wobbrock *et al.*, 2011) in an attempt to make the best use of the participants performance. These adaptations accommodate aspects such as linear navigation to improve the usability of the survey (Castilla *et al.*, 2020).

The large icons appeared to be familiar to some participants and matched their previous experience with icons at the bottom of the page (Castilla *et al.*, 2020), although two participants did need assistance with selection for the WES abbreviated WIHD SAS. Issues with touch pressure and being able to easily touch the icons appear to have been accommodated for the participants who found the large icons added to the navigational usability of the survey (Moreno, Alarcon and Martínez, 2021). The reminder to answer and the back button were mentioned by one participant as helpful in completing the survey which again emphasizes the importance of facilitating empowerment and agency as described in the DIX approach (Holloway and Barbareschi, 2022) using user centered principles to accommodate all the needs of those with cognitive disabilities.

6.4.4 Value of person centered approach for making surveys assessable

This study includes stakeholders in the development of a survey platform to make surveys accessible to those with cognitive disabilities. This phase of the study indicated that individuals with IDD were better able to complete an accessible WES abbreviated WIHD SAS survey unassisted and preferred the multimedia supported version of the survey. This indicated the use of such a survey supports the person centered approach as these individuals are better able to express their needs for services autonomously. Öhrvall et al. (2024), in investigating the experiences of individuals with IDD in relation to service support received, found similar positive feedback from participants who felt listened to and supported in expressing their views through self-report (Ohrvall *et al.*, 2024). Kooijmans et al., (2024) also found that adapting surveys to make them accessible, according to participant experiences and preferences, improved comprehension, usability, and accuracy of completion. Self-reported assessment scores showed greater convergence to those provided by carers and other professionals; because individuals

with IDD could complete the self-report measure they used, more effectively (Kooijmans *et al.*, 2024).

CHAPTER 7: CONCLUSION

7.1 Introduction

This chapter will cover the main findings and outcomes of the research study, the strengths and limitations of the study, the implications, and finally the recommendations for future research and continuation of the use of the survey technology.

7.2 Main Findings and Outcomes

This research project allowed for the development and evaluation of a new customizable web-based survey platform that can be utilized to create surveys with improved cognitive accessibility for individuals with cognitive limitations, to improve the ability to self-report rather than a continued reliance on proxy report, as is standard practice.

As shown in the phases of this project, individuals with cognitive disabilities were able to utilize the software in answering survey questions and provided detailed responses about the different survey platforms.

Phase 1 - Development of a survey platform for people with cognitive disabilities

During phase 1, the development of the software platform was researched with experts who work with individuals with cognitive disabilities. In addition, during this phase individuals with cognitive disabilities were consulted in a co-design capacity to inform the development of the software platform.

Phase 2 - Transfer Survey to Multimedia Format and Test Multimedia Selections

Phase 2 focused on the development of a statement of requirements based on the thematic analysis of the feedback from experts and individuals with cognitive disabilities

in Phase 1, and collaboration with a software developer and graphic designer to create the actual software platform adherent to said requirements to ensure improved cognitive accessibility.

Phase 3 - Evaluation of the multimedia survey platform for people with cognitive disabilities

Phase 3 was the evaluation phase, where an already established self-advocacy survey was recreated on the new software platform (WES abbreviated WIHD SAS) and multimedia supports were added for improved cognitive accessibility. The research design used for evaluating the effectiveness of multimedia adaptations in the WES abbreviated WIHD SAS allowed for rigor in comparing the completion of the WES abbreviated WIHD SAS to the same questions on the SurveyMonkey abbreviated WIHD SAS. The ability of the individuals with cognitive disabilities to self-report was significantly improved, as a statistically significant decrease in assistance was required. The time needed to complete the WES abbreviated WIHD SAS presented with mixed results as compared to the time required to complete the SurveyMonkey version. The feedback obtained from all participants as to the ease of use and understandability of the accessible software was positive.

The results of the study, particularly the performance of participants in terms of the assistance required, indicate the effectiveness of the multimedia adaptations which enhance the accessibility and usability of the WES abbreviated WIHD SAS for end-users with cognitive disabilities. The evaluation of the surveys indicates the importance of providing user centered adaptations in promoting autonomy among individuals with IDD. Participants' preference for the WES abbreviated WIHD SAS supported the use of multimedia adaptations in improving cognitive access to and usability of the survey. The concept that accessible survey tools can play a role in empowering individuals with cognitive disability was supported.

7.3 Strengths and Limitations

7.3.1 Strengths

Phase 1 - Development of a survey platform for people with cognitive disabilities

Phase 1a included an adequate sample size of experts who work with individuals with cognitive disabilities as well as individuals with IDD. In addition, the experts who participated in Phase 1 of the study were from a broad area in the northeast of the United States with many years and a wide array of experience with different populations of people with cognitive disabilities.

Phase 2 - Transfer Survey to Multimedia Format and Test Multimedia Selections

Phase 2 focused significantly on the addition of multimedia and the inclusion of individuals with cognitive disabilities in the development of the survey on the new platform for Phase 3. The key principles of participatory design, namely inclusivity, fostering collaboration, and providing continuous support, were all emphasized during this phase.

Phase 3 - Evaluation of the multimedia survey platform for people with cognitive disabilities

The importance of informed consent and ethical considerations in recruiting individuals from a vulnerable population was accommodated by using recognized standards and procedures. This also ensured inclusivity, allowing for a diverse range of participants to contribute to the research findings. The research instruments utilized in this study were all selected since they accommodated the needs of individuals with IDD.

The evaluation of the effect of the surveys was supported by the study design since participants acted as their own control variables which eliminated variability in cognitive abilities and performance, which would have been difficult to achieve with separate groups of individuals with IDD. By altering the order in which the surveys were administered, the bias-related carryover from repeated exposure to similar questions was mitigated.

General

The whole research study supported the Disability Interaction (DIX) framework within the field of Human Computer Interaction that emphasizes a user centered design. Throughout the study, individuals with cognitive disabilities were involved in the design process. Researchers/developers, as well as individuals with IDD, were involved in as many steps of the design process as possible, so the users' voices were heard and the project was person centered. There was a consistent focus on adaptability and flexibility by incorporating multiple modes of interaction and allowing users to share their custom needs. Through empowerment and agency, the individuals with cognitive disabilities show improved independence in self-report by using the technology in this study. The software was developed within comprehensive social and cultural contexts that captured the diverse experiences and needs of individuals with cognitive disabilities.

7.3.2 Limitations

The Phase 1b sample size for individuals with IDD was small and data saturation may not have been achieved. Phase 3 had a small sample size as well, which limits generalization. Another limitation of the study was that the research sample for Phase 3 of the project was confined to one site. All participants in Phase 3 of the study were individuals with cognitive disabilities who utilize the services at the Westchester Institute for Human Development (WIHD).

Seeing as this study was, however, primarily about the development of software, with input from professional experts in the field of cognitive disabilities as well as individuals with cognitive disabilities themselves, and emphasized the evaluation of the software, the evaluation of the content of the survey was limited and should be further investigated.
It was also a limitation that the Statement of Requirements document was not reviewed by a larger group of people.

Another aspect that was difficult to accommodate during the study, was the broad range of abilities that are seen in the different levels of cognitive disabilities. In Phase 3, the study population consisted of primarily individuals with IDD, as this population most

frequently utilizes the services at WIHD. Only small samples of individuals with IDD were recruited throughout the study to participate in the various phases. It is not uncommon to have difficulty in recruiting participants from this population as they find the research process intimidating and needed to be supported (Dudley *et al.*, 2025).The small sample of individuals with IDD does limit the generalizability of the findings as well.

During the interviews conducted with the individuals with IDD who participated in Phase 1b, it was also evident that it can be challenging to interview people with limited cognitive abilities as the limitations of understanding and language can make it difficult to facilitate conversation to focus on some of the more abstract concepts of usability and understandability.

All surveys were completed by participants with IDD on iPad tablets provided at the WIHD. The survey format has not yet been tested on phones or laptops and other computers.

7.4 Implications

The development of this software platform allows for organizations and individuals who want to survey individuals with cognitive disabilities to develop surveys on WIHD Easy Survey. The platform allows developers to add multimedia and distribute surveys on touch screen devices to give individuals with cognitive limitations maximum support for self-report. The surveys developed on this platform can be adjusted easily as needed.

It is recommended that the role of occupational therapists in environmental adaptations and activity analysis be emphasized in relation to the development of online access for individuals with cognitive disabilities. This should be further researched and considered both in training and practice.

It is important to remember that although the platform allows for better cognitive accessibility, the surveys still need to be developed for the specific target population by selecting the appropriate reading level for the language used and ensuring that the multimedia added is meaningful to the intended audience.

This study provides an example for the inclusion of individuals with IDD into the research process. Providing adequate selection criteria, as well as support and accommodation by being flexible in the interviewing process and discussion groups, allows for valuable data to be collected and creates an empowerment opportunity for these individuals.

7.5 Recommendations

It would be beneficial to develop surveys on this platform and distribute it to a broader audience beyond WIHD. The survey platform should be used in different settings and with individuals with other cognitive disabilities as well. Another aspect would be to allow other researchers and/or survey developers who are not as intimately familiar with the software platform to use it and give feedback as to the ease of use of the platform on various topics and utilizing different content.

Since individuals with IDD and researchers do not always feel completely comfortable engaging in the research process together, it is important to develop training for researchers to increase their understanding of how to include individuals with IDD in the research process and know how to better interact with this population. Addressing structural barriers that discourage researchers from pursuing engaged IDD research should also be considered.

It is important to continue to ask end-users to evaluate the surveys on the platform, so that it can be adjusted and updated as necessary. Encouraging the continuation of the research on the platform can improve the body of knowledge about how to ensure individuals with cognitive limitations can give accurate and valuable information about their lives and services.

As with any technology, it needs to be supported by a software developer to ensure any glitches are addressed and updates are made at regular intervals. It is also important to keep the development aspect active to ensure that the software stays current within the world of software development and the disability realm.

7.6 Conclusion

The entire research project focused on the inclusion of individuals with cognitive disabilities and their access to surveys concerning their health. The gap identified in the literature was addressed throughout the study to develop a cognitively accessible software platform that will allow for the custom creation of surveys through which individuals with cognitive disabilities can self-report. Findings indicated the need for including additional supports, as well as the simplification of the presentation, to improve accessibility. By following an inclusive design approach, individuals with cognitive disabilities provided input from their unique lived experiences in identifying needs and piloting the new WIHD Easy Survey platform. A survey on this platform was found to be more accessible in terms of comprehension, with less assistance required to complete the questions, thus reducing proxy report significantly. Therefore, a platform developed specifically for the addition of multimedia can be used to improve self-advocacy for individuals with cognitive disabilities.

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Appendices

Appendix A: Senate Plagiarism Policy

University of the Witwatersrand, Johannesburg

S2003/351B Replacing S2002/2038 and S2002/2039

Plagiarism Policy

Section One: Context of policy and procedures

1 PREAMBLE

Senate has approved the following policy on plagiarism. A set of procedures for the implementation of the policy is appended along with examples, and a suggested format for use by schools for a statement that student work has been unaided except where explicitly stated otherwise.

Effectively the documents attempt to answer the following broad questions and concerns:

- What is plagiarism and is it different from copying/cheating?
- What position should be taken on plagiarism – should it be handled as an offence or a developmental issue or a combination of these?
- What approach should be used for managing plagiarism at Wits University?

2 OVERVIEW

Plagiarism is an issue of general concern that requires a standard University response that is sensitive to differences between academic disciplines and that provides sufficient developmental focus to ensure that students are given adequate opportunity for induction into the conventions of the academic community.

This policy proposes that:

- All academic staff should ensure that students are inducted into the values and practises of their discipline with respect to the conventions associated with acknowledging the work of others.
- All schools are responsible for ensuring that adequate information, and opportunities to assimilate the information, are provided to new students.
- Plagiarism in all its forms should be dealt with developmentally first, at school and individual academic level but that it is important that repeated or serious plagiarism be handled as a disciplinary offence.

- A structured approach to plagiarism offers the best protection for the student and the best protection for the rights and thoughts of others.
- All students should be required to sign a declaration that the work they have submitted is their own unaided work and acknowledging that plagiarism is unacceptable in academe.[1]

3 PLAGIARISM

The use of the ideas of others without appropriate acknowledgement is an ongoing concern within the academic enterprise. The extent of the debate about plagiarism is as varied as the practices involved. Some incidents clearly involve deliberate dishonesty (such as the purchase or inappropriate use of material off the internet) and require a particular disciplinary management process. Other incidents reflect the lack of understanding of the need to attribute source (as a result of poor schooling or poor induction to tertiary study) and require attention to the teaching and learning practises of the University. Others are less clear and are politically harder to manage (such as copying from classmates with their consent or off the internet) – there are serious disputes about what constitutes plagiarism and what are simply the inappropriate attempts of an academic elite to claim ownership of knowledge over which they have no right. This is particularly pertinent when plagiarism involves the use of secondary sources – especially those that deal with areas of academic knowledge that have become increasingly part of what is commonly known and understood (for instance it is acceptable practise in psychology to refer to the id without referencing Freud or in physics to make use of Newtonian concepts without referencing Newton). The line between plagiarism and rote learning and reproduction of concepts, ideas or thoughts of others is not always a clear one.

This policy proposal focuses on plagiarism as the "failure to acknowledge the ideas of another" or "presentation of the ideas of another as one's own" and should be read to cover intentional and unintentional failure to acknowledge the ideas of others. The School of Economic and Business Sciences uses the following definition:

> Plagiarism refers to the copying of passages in the written work of other people (e.g. authors of books or articles, other students) without acknowledgement. An essay or other assignment that is substantially copied from one or more sources, with little or no original contribution from the student submitting it, is plagiarised and represents a dishonest effort.

[1] Schools or faculties can best decide when to get such a signed acknowledgement from their students.

Plagiarism does thus not incorporate poor or incomplete referencing – these are issues of convention (each referencing style requires very different amount of information from the user) and they are discipline related. Academic schools will need to manage inadequate referencing by the rules of fair administrative procedure – the expectations need to be made clear to students in written form in a document to which all students have access (such as a course outline or rule book) and the penalties for not conforming should also be stipulated (and enforced). With respect to the management of referencing individual schools and faculties will need to satisfy themselves that students have enough information (and training) to take on the conventions set out. If this is done then the schools will be in a stronger position to impose penalties (usually related to deduction of marks or refusal to mark work until it is properly referenced). Penalties are often on a continuum depending on the extent to which the referencing does not conform to requirements.

Clearly the year of study of a student is particularly pertinent in this regard and postgraduate students who do not reference adequately should be handled with less leniency. Again, this should be based on the certainty that all students (especially those who are new to Wits) are given enough information to enable them to comply.

The secondary school experience of the majority of students would not have adequately equipped them with an understanding of what plagiarism is and why it is considered problematic. Even those students who have been exposed to referencing conventions are rarely exposed to the more subtle use of unattributed ideas.

Clearly the process of inducting a student into academic conventions (such as giving credit for the use of the ideas of others) is the responsibility of the academic staff members who are required to make known to the student the conventions of referencing. In addition, academic staff are expected to make clear to students why the use of unattributed material is unacceptable from a collegial academic perspective – academic teachers have to model and instil both correct practise and an understanding of the issues of ownership of ideas and the ethics associated with acknowledging the work of others. The under preparedness of students (both in the conventions and also in issues of language) for academe conducted in English further complicates the ability of students to make sense of what is plagiarism and it is thus absolutely vital that each academic in each discipline takes full responsibility for engaging students in the discourse of their discipline. Without this engagement the conventions may or may not be adopted but their relevance and value will definitely not be appreciated and thus they are unlikely to be transferred to other elements of academic writing.

There is concurrence that Wits has an educative developmental responsibility to induct students into these conventions and their underlying principles. There is however less consensus on how much effort and time should be involved in this induction and at which point it is reasonable to expect a student to have taken on board the necessary practices. Deciding on the point at which the student is accountable is important and this decision underpins the possibility of any disciplinary response to plagiarism.

Intent is central to the debate. It is argued by some that once the students have been inducted (about half of their first year) any plagiarism in unacceptable and is an offence. Intent is no longer an issue as long as the student has been given time, information and practise opportunities with feedback. Others argue that some students – because of their educational backgrounds will take much longer to incorporate the values that mitigate against plagiarism and thus that intent to "steal" the work of others has to be proved for any incident of plagiarism to be considered an offence.

This point of view would in a sense be the *status quo* because current management of plagiarism, using the definition of misconduct from the Rules for Student Discipline, would suggest intent as a defining point. The "gap" between these positions appears to be whether claimed ignorance of the rules of academic writing (and therefore possible lack of intent) constitutes the dividing line between an offence and a bad habit.

Irrespective of the personal or discipline position on the continuum, the management of plagiarism within the University is a common faculty concern and this is an attempt to develop a policy which could be used for the management of the perceived increasing incidence of plagiarism.

This policy and procedure proposes that:

> A school based committee (which could be a committee of one) considers allegations of plagiarism brought to its attention by academics within the school. The committee is tasked with ensuring that appropriate developmental opportunities are offered to students and that penalties have a developmental element. Their greatest sanction would be awarding a student 0% for a piece of work. For any plagiarism incident in which the school committee felt that there may have been intent to use the work of another without giving appropriate recognition the matter would be referred to the student disciplinary committee through the normal channels. School committees would keep records that would enable the school and faculty to track the kind of incidents reported and this would assist in ensuring the appropriate kind of developmental teaching within the school.

4 CURRENT WITS POLICY (PRIOR TO THIS POLICY)

Plagiarism (intentional failure to acknowledge the ideas of another) is currently handled under the misconduct rule in the Rules for Student Discipline. The definition of misconduct appears in Rule 18 of the Rules for Student Discipline and states as follows:

"Misconduct comprises behaviour within or without the precincts of the University, without just excuse, which

1) constitutes a breach of any statute, regulation or rule of the University; or
2) constitutes a failure or refusal to comply with any punishment or order imposed under these rules; or
3) constitutes a failure or refusal to obey a lawful order; or
4) constitutes conduct that tends to bring the University or any part of it or a member of its staff or a student or any part of its student body into contempt or disrepute; or
5) interferes with the governance and proper administration of the University; or
6) interferes with the conditions necessary for teaching learning and research."

Items 1), 4), 5) and 6) cover failure to acknowledge the work of another.

5 WHAT OTHERS ARE DOING

Many South African Universities have policies in place, most have taken a more structured approach to plagiarism recently and many now require students to submit a declaration with all written work that it is their own work (a practice we have at Wits). The range of approaches is significant and it is thus difficult to take guidance from them[2].

Some universities use the ordinary student disciplinary committees to handle plagiarism while others have set up committees that deal only with plagiarism. The problems associated with having a special committee include the management of an additional structure plus the risk of different standards of fairness/ administrative justice being applied to students. Clearly, keeping within the existing system once the matter is handled as a disciplinary one makes sense but it does not address the real difficulties currently being experienced as a result of the time scale for completion of enquiries through the current system. In the case of plagiarism, matters need to be handled quickly so that the next academic work of the student can

[2] The proposed system for Wits has emerged from a range of discussions. The idea of a committee focused on handling incidents of plagiarism occurs in the Rhodes University policy but this is a central University committee.

reasonably be expected to be free of plagiarised content or so that fair decisions can be made about examinations and re-registration without undue delays.

SECTION TWO: SENATE POLICY ON PLAGIARISM

1. Plagiarism

Plagiarism is the "failure to acknowledge the ideas or writing of another" or "presentation of the ideas or writing of another as one's own" and should be read to cover intentional and unintentional failure to acknowledge the ideas of others. In this context "others" means any other person including a student, academic, professional, published author or other resource such as the internet. The University of the Witwatersrand, Johannesburg believes that failing to acknowledge the use of ideas of others constitutes an important breach of the values and conventions of the academic enterprise.

2. Academic staff and school responsibility

Academic staff, especially those that work with first year students, are responsible for a process of induction into their disciplines. This includes an induction into what constitutes acceptable use of the ideas of other people.

Schools should engage in a developmental process with their students that at least includes making explicit information available to students in first lectures and tutorials, publishing requirements with respect to referencing conventions, providing opportunities for students to practise the conventions, providing limited opportunities for students to resubmit work if the conventions are not followed. It is the responsibility of the school to ensure that there is as little ambiguity as possible within the above process and that members of the school staff adhere to the same level of expectations with respect to all of the above.

The aims of this process are to ensure that:

- Students understand the concept of plagiarism – by explaining what it is and by outlining what kinds of practises constitute plagiarism in the discipline concerned.

- Students know what conventions to use when using material from other people, books, journals or the internet.

- Students are provided with training (with structured feedback) on the use of these conventions within the context of real assignments for the discipline.

- Students sign an appropriate declaration (see appendix) to be submitted with all written work or to be submitted annually after registration for each discipline.

3. Management of suspected cases of plagiarism in the first instance

In all instances of dealing with plagiarism it is the responsibility of the individual academic to initially assess the seriousness of the infringement – this could be done in consultation with others. Action is dependent on the seriousness – first, minor infringements should be managed developmentally while serious or repeat offences should be handled with more gravity. In all instances, a record of the infringement and of the action taken should be kept within the school and forwarded to the student registry. This will ensure that students who have been given appropriate developmental opportunities are held accountable for future infringements. Wits recognises that plagiarism is a serious threat to academic quality but that many students initially commit plagiarism as they do not have the information or skills they need to negotiate the academic context.

4. Levels of infringements

Level One: Minor, first time

A Level One infringement is an infringement of pre-published academic conventions that involves the unacknowledged or inaccurately acknowledged use of the ideas and/or writing of others.

These infringements are minor and are first offences and are considered to have been unintentional. The staff member concerned, who may impose a penalty of up to 100% of the mark for the work in question and may require the student to resubmit the work concerned, handles these infringements. Should the student wish to appeal the penalty a written account of the penalty should be given to the appropriate committee but if the student is willing to accept the penalty no records are required.

Level Two: repeated minor or first time major offences that may not have been intentional

This level refers to repeated offences of a minor nature, or to first time, major offences. These are handled in the first instance by a School Plagiarism Committee (SPC), provided that they deem the offence not to be such that it might suggest a penalty more severe than the loss of a DP, and requires that records be kept of the decision and offence. These decisions are subject to appeal to the Dean who may refer the matter back to the SPC or to the University central disciplinary process.

Level Three: repeated offences and/or major offences that are possibly intentional or are serious enough to suggest collusion or deliberate dishonesty

These are serious offences, which the SPC has deemed as requiring consideration by a University disciplinary committee. These are major offences and/or repeat offences that indicate that the penalties imposed by the SPC have not had the intended effect of curbing the behaviour. All plagiarism at postgraduate level (except for the initial assignments, usually in the first quarter, of any taught postgraduate programmemes) is considered to occur at Level Three.

5. School Plagiarism Committee

5.1. Rationale for committee

A school based plagiarism committee will provide the disciplinary (subject) experts to assess offences and to allow students fair and consistent administrative process. It is also argued that while this "escalates" the seriousness with which these matters are handled it avoids flooding the central disciplinary structures with relatively minor cases and protects individual academics from making subjective decisions. As the limit of the penalty that this committee will be able to impose is refusing a student permission to write the examination for a subject and as the decision will be subject to usual appeals a school based committee could act in the best interests of the students and academe. The school committee may refer the matter to a central disciplinary committee if in its judgement there appears to be or have been the *intent* to commit plagiarism. Thus a full disciplinary process (with the possibility of a formal outcome being recorded against a student's disciplinary history) would only be conducted by the normal university disciplinary structures.

5.2. Membership of committee

Normally, this is a committee of at least three academics and one student chaired by a senior academic (senior lecturer or above). This committee considers reported infringements (reactive role) and scrutinises the publication of conventions within the school to ensure clarity (proactive role). Periods of service on the committee should not exceed three years and should be staggered to ensure continuity. The membership of these committees should be reported on an annual basis to the faculty board. Where it is considered more appropriate, a school may have a "committee of one" where one senior academic is delegated by the school executive structure to monitor the implementation of the plagiarism policy.

5.3. Brief of committee

The brief of the committee is to:

- Note the nature of minor infringements and penalties imposed by academic staff members and refer patterns to the Head of School and individual academic staff members for attention. This information could be of value to education development staff.
- Monitor that accurate records are kept as needed.
- Consider appeals against the decisions of individual staff members.
- Consider whether or not to hear a particular infringement themselves or refer the matter on immediately to the University process
- In reaching this determination the committee may request to see the student file to ascertain if there are other similar decisions recorded with respect to the student.

6. Procedure for School Plagiarism Committees and academic staff

6.1. A staff member who is of the opinion that a plagiarism offence at Level One has been committed, should manage the situation themselves by ensuring that a developmental approach is taken which can include requiring resubmission of the work and/or penalties of up to 100% of the mark. If the student accepts the penalty the matter ends there. (Guidelines as to the extent of the loss of marks must be published by Schools and be made available to the students).

6.2. If a student wishes to appeal the penalty imposed by an individual staff member he or she may do so by referring the matter to the *SPC*.

6.3. If the staff member is of the opinion that the offence is a repetition of a minor infringement, or that the infringement is major he or she should refer the matter to the SPC.

6.4. If it can be established that the infringement, although major, was unintentional (Level Two), the SPC can impose a penalty of loss of marks up to a maximum of 100%, plus refuse the student permission to write the examination or equivalent (loss of DP) and record the offence and penalty on the student record. Similarly, evidence of repeated minor offences could be handled with the same penalty. The record of any student appearing before an SPC should be consulted as a prior record of unintentional major and/or repeated plagiarism will enable the determination that the infringement in the instance before the SPC is not unintentional. It would be essential that the record of earlier infringements was accurate and detailed.

6.5. If it is suspected that the offence is a Level Three offence (serious, or repeated or clearly intentional), the case shall immediately be referred to the appropriate University processes.

6.6. In all cases falling into Level Two (and appeals against Level One decisions) the student concerned must be asked if he/she wishes to appear before the School Committee, and shall be provided with written reasons for any sanctions imposed on them. If the committee considers the offence to be a Level Three offence they may refer the matter to the University committee, do not have to ask the student if he/she wishes to appear before them but must provide the reason for referring the matter to the University committee to the student in writing.

6.7. If after hearing an appeal by a student against the penalty imposed by a staff member, the School Committee is satisfied that an offence has in fact not been committed, the Committee shall withdraw the penalty and advise the staff member who laid the complaint accordingly. The decision of the committee with respect to these Level One offences is final.

6.8. In the handling of Level Two offences a student may request that a University committee handle the matter in the first instance and not by the school. Students must be informed of this right and must waive it in writing if they choose to do so. A school committee is only empowered to penalise students up to 100% of their marks, require resubmission of the work, remove the DP for that course and record the penalty and offence at central level OR refer the matter to a University Committee.

6.9. Appeals against the decisions of the SPC are made to the University committee. Decisions of the University committee on these appeals are final.

6.10. Suspected Level Three offences must be referred to the University committee.

7. Managing serious plagiarism incidents centrally

Serious incidents are referred to the existing disciplinary structures that function in terms of the procedures laid down in The Rules for Student Discipline with particular reference to sections 7 and 8. The penalties that can be imposed will be in line with section 6.5 of The Rules.

A student shall have the right to appeal to the Appeals Committee of the University (Section 8 of The Rules).

8. Publication of information

The Student Handbook and the General Rules Book should in future include general information about the nature of plagiarism and about the University's policy with respect to plagiarism and should indicate that plagiarism is considered a serious offence. Individual schools are responsible for ensuring that students

fully understand the nature of legitimate academic practice in the disciplines concerned as these vary. The schools and individual academics must manage plagiarism consistently – it is the responsibility of academic leaders to ensure that information is available, that academic staff understand the consequences of an inconsistent management of the issue and that appropriate developmental strategies are in place for first year students.

Appendix B: WITS HREC Clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Postgraduate Affairs

TO: Ms I Obermeyer
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: iobermeyer@wihd.org

CC: Supervisor: Drs J van der Linde & T Rauch-van der Merwe
<Janine.vanderLinde@wits.ac.za>
and <HREC-Medical Research Office@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2020/12/11

REF: R14/49

PROTOCOL NO: **M190706** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: Developing evaluating a multimedia technology approach to surveying individuals with cognitive impairment to promote person-centered practice

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

Appendix C: NYMC IRB Clearance

From: IRB Office
To: Obermeyer, Izel
Subject: Full Board Approved - IRB ID: 12689
Date: Thursday, January 24, 2019 10:47:14 AM

Downloadable Attachments:
NYMC Consent edited December 2018 Focus group (1).pdf
NYMC Consent edited December 2018.pdf
NYMC Guardian Consent Form edited December 2018.pdf

NYMC IRB *Approval Notification*

To: Izel Obermeyer
From: Cassandra Cartagena, Administrative Assistant
Subject: Protocol #12689
Date: 01/24/2019

The protocol *Developing and Evaluating a Multimedia Technology Approach to Surveying Individuals with Cognitive Impairment to Promote Person Centered Practice*, Westchester Institute for Human Development, 12689 has been approved by the Institutional Review Board GMB on **12/10/2018**. The following items associated with this protocol have been approved:

HIPAA Authorization Form	06/25/2018 Research Authorization Form (HIPAA) IRP2018.doc
Approved Application	01/24/2019 Protocol clean version November 2018 NYMC IRB.docx
Approved Consent Form	01/24/2019 NYMC Guardian Consent Form edited December 2018.pdf 01/24/2019 NYMC Consent edited December 2018.pdf 01/24/2019 NYMC Consent edited December 2018 Focus group (1).pdf

This email constitutes New York Medical College approval to initiate the referenced study.

The approval of your study is valid through 12/09/2019, by which time you must submit an annual report either closing the protocol or requesting permission to continue the protocol for another year. Please submit your report by **10/14/2019** so that the IRB has time to review and approve your report if you wish to continue it for another year.

If you have any questions, feel free to contact me.

Cassandra Cartagena
Administrative Assistant
New York Medical College
40 Sunshine Cottage Rd.
Valhalla, NY 10595
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www.nymc.edu

Appendix D: The University of California San Diego Brief Assessment of Capacity to Consent (UBACC)

Adapted for Use with the WES Project

Instructions

After reviewing study details and the informed consent document, explain that you are going to ask a few brief questions about the study. Participants should be allowed to refer to the Informed Consent Form when answering these questions but should be encouraged to respond in their own words. Rate the participant's responses on a scale of 0 – 2, with "0" being the lowest (little to no understanding of this aspect of the study) and "2" being the highest (clear understanding of this aspect of the study). Also note:

-- If a participant has trouble understanding one of the questions on the UBACC, rephrase the question.
-- A deviation from any acceptable answer will be scored as 1 or 0.
-- If an answer to a question is ambiguous or uncertain, the subject should be asked follow-up questions to clarify.
-- If a subject does not get a score of 2, the information on the items missed may be repeated and the specific question(s) asked again. This may be done for a total of 3 trials. During the second and third trials, it is important to ensure that the subject does not merely parrot back information but shows clear understanding of the issue.

	Score
1. What is the purpose of the study that was just described to you? Response: (2 = To see how people with disabilities use surveys)	0 1 2

2. What makes you want to consider participating in this study? Response: (2 = Find a way to help people with disabilities be able to use surveys better/find out what kind of way people with disabilities need to be surveyed)	0 1 2
3. Do you believe this is primarily research or primarily treatment? Response: (2 = Research)	0 1 2
4. Do you have to be in this study if you do not want to participate? Response: (2 = No)	0 1 2
5. If you withdraw from this study, will you still be able to receive regular treatment? Response: (2 = Yes)	0 1 2
6. If you participate in this study, what are some of the things you will be asked to do? Response: (2 = I will be asked to take a survey in two ways)	0 1 2
7. Please describe some of the risks or discomforts that people may experience if they participate in this study. Response: (2 = None)	0 1 2
8. Please describe some of the possible benefits of this study.	0 1

Response: (2 = None for me, but maybe help make surveys better for people with disabilities)	2
9. Is it possible that this study will not have any benefit to you? Response: (2 = Yes)	0 1 2
10. Who will pay for medical care if you are injured as a direct result of participating in this study? Response: (2 = No risk of injury is expected)	0 1 2
TOTAL SCORE	

A score of 15 or higher is needed for inclusion in the study. If a patient scores lower than 15, the person obtaining consent can review the study details and have the patient return on another day in order to re-do the UBACC and obtain consent.

Appendix E: Participant Information Sheet





STUDY INFORMATION DOCUMENT

Study title:

Developing and Evaluating a Multimedia Technology Approach to Surveying Individuals with Cognitive Impairment to Promote Person Centered Practice

Greeting:

Hello. My name is Izel Steinmann Obermeyer and I work here at the Westchester Institute for Human Development (WIHD) in the assistive technology program.

Introduction:

I am doing research on technology for people with disabilities. Research is a process used in seeking new knowledge. In this study we want to learn how to develop survey technology to ensure that people with disabilities can use it effectively to communicate their wants and needs.

Invitation to Participate:

We are inviting you to take part in a research study.

What is involved in the study:

The study has three phases. The first phase will gather information from two groups of people to guide the development of the technology platform. The second phase will collect information from a different group of professionals about the ability of the survey technology to make information more understandable and the third phase will evaluate

two versions of the same survey, by asking people with disabilities to complete both version of the survey. There will be an interview style survey and then one on the newly developed survey technology platform.

The study will begin around November 2018 and continue through December 2024.

Here is some additional information specifically for each phase of the study:

Phase 1

Two groups of people will be asked to participate in this phase of the study.

Group 1 consists of professionals who use surveys regularly in their work, to gather information from people with disabilities. They will be asked to share what kind of requirements they have for a survey platform.

Group 2 consists of individuals with cognitive disabilities who receive services through the Office of People with Developmental Disabilities (OPWDD) in New York State, who are 18 years of age and older. They will be asked to participate in a focus group to discuss features in survey technology that will make it easier for them to access the survey, as well as make the content more understandable.

Phase 2

I will put a sample survey onto the new survey platform and add multimedia to it and then we will ask a group of professionals who work with clients with cognitive impairment to rate the materials on the survey platform in terms of whether they improve the understandability of the information. This will allow us to either change the materials added to each questions or exclude the question altogether. The questions in the survey will focus on how you experience your services and other information related to person centered practice.

Phase 3

During phase 3, individuals who attend the adult health clinic at WIHD will be invited to participate in the study. Study participants will be asked to complete the survey from phase 2, in two formats. One format will be conducted by an interviewer and the other

format will be on a tablet using the newly developed survey platform. Completing both surveys will take between 30 and 40 minutes. The participants will be video recorded when they complete both surveys. The videos will be stored in a locked cabinet in the principal investigator's (PI's) office. The data collected from the interviewer survey will also be stored in a locked cabinet, and the online survey data will be password protected on a computer in the PI's office and online on the survey platform, which is also protected in compliance with HIPAA regulations. The survey used in this phase deals with person centered practice and is part of a national survey by the Human Services Research Institute (HSRI).

Risks of being involved in the study:
The research team does not anticipate any risks to you in participating in this study beyond those encountered in daily life.

Benefits of being in the study:
While the research team do not expect you to have any direct benefit from agreeing to be in this study, we believe it will help us understand whether the use of WIHD Easy Survey could be helpful in gaining information from patients with disabilities in the future. Patients can then directly participate in such topics as their healthcare decisions and the quality of the healthcare services they receive here at WIHD.

Any alternative procedures or treatments if you do not participate in the study:
There are no alternatives; you can choose whether to participate or not. Not participating will not affect any of your treatment here at WIHD.

Reimbursements for "out of pocket" expenses:
No out-of-pocket expenses are anticipated for participating in this study.

You will be given pertinent information on the study while involved in the project and after the results are available.

Participation is voluntary, and if you choose not to participate, there will be no negative impact on any of the services you receive here at WIHD. You can also decide that you no longer wish to participate at any time during the process, and any data we collected up till then will in default be destroyed, unless you specifically give permission for us to keep it.

Confidentiality: Normally personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) and his/her Supervisor, in the case wherein the PI is a postgraduate student. The only exceptions - and all of them are rare - would normally be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit
3. the South African Health Products Regulatory Authority (SAHPRA), which is the successor body to the South African Medicines Control Council (SAMCC), might conceivably require access to personal data, if conducting an investigation into a drug trial

Where a study involves focus group discussions, Participants may very well recognize each other and while the PI may request confidentiality, he/she is not in a position to enforce it. For the same reason, anonymity cannot be guaranteed in focus group discussions.

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

Anonymity can usually only be guaranteed in questionnaires, whether in hard copy or online

Contact details of researcher/s:

You may call the Principal Investigator, Izel Obermeyer, OTR/L, ATP, FAOTA, at 914-493-1317, if you have any questions about your participation in the study or a research-related injury. You may call the Office of Research Administration at 914-594-2600 if you have questions about your rights as a research subject.

Outputs:

The goal of this study is to develop a multimedia technology survey platform that will improve our ability to get input and feedback from clients with cognitive impairments.

Contact details of HREC administrator and chair:

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

Date: July 2019

Appendix F: Assent Form for Participant

Assent Form for Participation in Research New York Medical College

Name of the Subject: _____

Title of the Research Project:

Developing and Evaluating a Multimedia Technology Approach to Surveying Individuals with Cognitive Impairment to Promote Person Centered Practice

What is this study about and how does it affect me?

The Westchester Institute for Human Development (WIHD) is doing research on technology for people with disabilities. Research is a process used in seeking new knowledge. In this study we want to learn how to develop survey technology to ensure that people with disabilities can use it effectively to communicate their wants and needs. We are asking you to participate in this study so that we can develop a way to do surveys that will allow people with all different abilities the best possible way to share their own opinions about the services and supports they receive.

What will happen to me?

If you choose to participate in this study, you will be asked to complete a survey in two different ways. One will be someone asking you questions and writing down your answers and the other one where you will use a tablet to answer the questions.

Will I get anything for being in this study?

No

Can being in this study hurt me?

No – you will only be completing the surveys. Your privacy is also protected by only allowing the research team access to the information.

Do I have to be in this study?

No – you can choose to be in the study or not.

Will I learn new things from this study?

I hope you will learn how to share your own opinions and ideas about your services so that you can have a say in how these services are done.

Will you tell anyone what I did in this study?

Not by using your name, but we will publish the results of the study so that we can share with other people how to use technology so that people with disabilities can give their own opinions.

By signing your name below, you agree to be in this study.

Name of Subject (please print): _____

Subject to sign or print the name: _____ Date:_____

Investigator Obtaining assent (printed name): _____

Signature: _____ Date: _____

Appendix G: Consent Form for Caregiver/Guardian

Consent Form for Participation in Research
New York Medical College

Affiliate: Westchester Institute for Human Development (WIHD)

Name of Patient/Subject:

Address:

Chart Number:

Title of Research Project: Developing and Evaluating a Multimedia Technology Approach to Surveying Individuals with Cognitive Impairment to Promote Person-Centered Practice

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Note:

☐ **This project involves the experimental use of a new drug/device/procedure called:**

☒ **This project does not involve the experimental use of a new drug/device/procedure.**

The individual in your care is being asked to participate in a research study. Before you agree, both of you must be told about the following in your language.

Explanation of Research Project:

(1) **Purpose of Study:** The purpose of this study is to compare how individuals use the WIHD EasySurvey—a web-based software that allows for the creation of surveys with added pictures and audio to explain the questions—with a standard, interviewer-administered survey that contains the same questions but without any pictures to explain the questions. We are asking the individual in your care to take part in this research project because he/she uses the health care services here at WIHD and is at least 18 years of age;

(2) **Study Summary:** The study has three phases. The first phase will gather information from two groups of people to guide the development of a new survey technology. The second phase will collect information from a different group of professionals about the ability of the survey technology to make information more understandable. During phase 3, individuals who attend the adult health clinic at WIHD will be invited to participate in the study. Study participants will be asked to complete the survey from phase 2, in two formats. One format will be conducted by an interviewer and the other format will be on a tablet using the newly developed survey platform. Completing both surveys will take between 30 and 40 minutes. The participants will be video recorded when they complete both surveys. The videos will be stored in a locked cabinet in the principal investigator's (PI's) office. The data collected from the interviewer survey will also be stored in a locked cabinet, and the online survey data will be password protected on a computer in the PI's office and online on the survey

platform, which is also protected in compliance with HIPAA regulations. The survey used in this phase, deals with person centered practice and is part of a national survey by the Human Services Research Institute (HSRI).

The study will begin around January 2019 and continue through July 2019.

(3) **Risks and discomforts:** Investigators do not anticipate any risks to the participants in this study beyond those encountered in daily life. While there is a risk to participant privacy, this risk will be minimized by restricting access to study data to only those on the research team.

(4) **Benefits:** While investigators do not expect participants to have any direct benefit from agreeing to be in this study, we believe it will help us understand whether the use of WIHD Easy Survey could be helpful in gaining information from patients with disabilities in the future. Patients can then directly participate in such topics as their healthcare decisions and the quality of the healthcare services they receive here at WIHD;

(5) **Alternatives to participation:** The participant can choose to participate or not.

(6) **Outcomes:** There are no commercial outcomes to this study that the participant will benefit from.

(7) **Consenting to Additional Research:** There are no plans to conduct future research using information that is collected during this study.

Research-related Injury: New York Medical College and its affiliated institutions, Metropolitan Hospital Center (New York City Health and Hospitals Corporation), Westchester Medical Center, Westchester Institute for Human Development, and Terence Cardinal Cooke Health Care Center) do not provide financial compensation for injury or illness resulting from participation in research. Unless the study sponsor provides otherwise, payment for treatment of any injury or illness resulting from participation in their research study will be your responsibility or paid for by your medical insurance. You must contact the investigator in the event of a research-related injury.

Confidentiality: This consent form and your medical records are subject to review by representatives of New York Medical College, the study sponsor, associated review agencies, and state and federal regulatory agencies, including, but not limited to the Food and Drug Administration. Additionally, if they are involved, Metropolitan Hospital Center, Westchester Medical Center, Westchester Institute for Human Development, and Terence Cardinal Cooke Health Care Center may review this consent form and your medical records. If results of the study are published, you will not be identified by any personal data. You will be given a copy of the signed consent form. Other copies will be kept in confidential files in the investigator's office and (if appropriate) with your medical chart. Additionally, the HIPAA authorization form associated with this study, that you will be required to sign, discusses how the privacy of your personal health information will be protected.

Voluntary Participation: Your signature indicates that you understand this consent form and freely consent to participate in this study. You are free to refuse or to discontinue participation in the study at any time without penalty or loss of benefits to which you are otherwise entitled.

Offer to answer questions: You may call the investigator if you have any questions about your participation in the study. You may call the Office of Research Administration at (914) 594-2600 if you have questions about your rights as a research subject.

_____	_____
Subject's Signature	Date

_____	_____	_____
Signature of person authorized to consent for subject or witness if consentor is illiterate or unable to sign	Position	Date

_____	_____
Signature of person obtaining consent	Date

Name of Principal Investigator:
Patricia A. Patrick, DrPH

Telephone Number:
914-493-8203

Name of Sponsor:

The Committee for Protection of Human Subjects is the Institutional Review Board for New York Medical College, Metropolitan Hospital Center, Westchester Medical Center, Westchester Institute for Human Development, Terence Cardinal Cooke Health Care Center

Appendix H: Data Collection Sheet for Survey Delivery Requirements

Mode	Steps	Logistics	Cost	Accessibility

Appendix I: Data Collection Sheet for Survey Delivery Requirements (End-users)

ID	Reason for survey	Type of surveys
1		
2		
3		
4		
5		

Appendix J: Fact Sheet for End-user Technology Platforms

Participant	Device	Platform	Comfort level
#1			
#2			
#3			
#4			
#5			

Appendix K: Recording sheet for Phase 1e

Patient ID code:

Patient agreed to complete survey:

Yes

No

Assistance needed from care giver:

Yes

No

How easy was it to complete the survey on this platform:

Extremely easy

Easy

Hard

Comments:

Appendix L: WIHD Self-Advocacy Survey (SAS)

WIHD Self-Advocacy-Survey (Adult)	
1.	I know which things I am good at.
2.	I know which things are hard for me.
3.	I know the type of help and support I need.
4.	I can ask for help when I need it from people I know.
5.	I can ask for help when I need it from people I do not know.
6.	I can tell other people when not to help me, when I can do things for myself.
7.	I know the ways I like to learn.
8.	I know the type of help I need to learn.
9.	I can share with others something I would like to get better at doing.
10.	I know my interests.
11.	I know that I have legal rights.
12.	I know I can go to college if I choose to.
13.	I know that if I am in college, I can ask for accommodations from the college.
14.	I know my legal rights if I am employed.
15.	I know that when I am at work, I can ask for accommodations from my employer.
16.	I know that I can participate in choices made about my healthcare.
17.	I enjoy making my own decisions.
18.	I want to learn to make more of my own decisions.
19.	I talk about the things I am good at.
20.	I talk about the things that are hard for me.
21.	I let others know what I do not like.
22.	I let others know how I like to learn.
23.	I let others know what my interests are.
24.	I ask questions to find out more about my interests.

25.	I know who to share my goals with so I can get help in achieving them.
26.	I talk about my dreams.
27.	I do free time activities based on things I like.
28.	I work on things that will improve my job opportunities.
29.	I help to make my life plans.
30.	I help to make my healthcare decisions.
31.	I have career plans for now.
32.	I have career plans for the future.
33.	I work or have worked/volunteered without pay.
34.	I work or have worked and made money.
35.	I have had the opportunity to attend job training.
36.	I have attended job training.
37.	I have looked into job interests by visiting work sites or talking to people in that job.
38.	I know what kind of disability I have.
39.	I can explain my disability to others.
40.	I can explain accommodations I need at work because of my disability.

Appendix M: Likert scale

Question	Totally Agree	Agree	Somewhat Disagree	Totally Disagree	Comment
1a	4	3	2	1	
1b	4	3	2	1	
2a	4	3	2	1	
2b	4	3	2	1	
3a	4	3	2	1	
3b	4	3	2	1	
4a	4	3	2	1	
4b	4	3	2	1	
5a	4	3	2	1	
5b	4	3	2	1	
6a	4	3	2	1	
6b	4	3	2	1	
7a	4	3	2	1	
7b	4	3	2	1	
8a	4	3	2	1	
8b	4	3	2	1	
8c	4	3	2	1	
9a	4	3	2	1	
9b	4	3	2	1	

10a	4	3	2	1	
10b	4	3	2	1	

Appendix N: Observation Checklist for phase 3

A	B	C	D	E	F	G	H	I	J	K
Checklist										
ID Code	**Last Name**	**First Name**	**DOB**	**Age**	**Gender**	**DX**	**Assistance needed Y/N**	**Kind of assistance:** **1. Read question** **2. Access buttons** **3. Watch video** **4. Read answers** **5. Next vs Back buttons** **6. Understanding questions**	**Time: WES**	**Time: SM**

Appendix O: Study Announcement

ANNOUNCEMENT

Study Title: "**Developing and Evaluating a Multimedia Technology Approach to Surveying Individuals with Cognitive Impairment to Promote Person Centered Practice**"

We would like to find out more about surveys and how they are used with people with disabilities.

A staff member may invite you to be part of a research study about surveys.



If you choose to be part of this study, you will be asked to complete a simple survey about your healthcare services in 2 ways on a tablet device.

Each survey will take about 15 minutes to complete.

You do not have to be a part of this study.
The study is voluntary and not participating will not affect your usual services or treatment.
Thank you!

Appendix P: Consent/Assent Form for Video Recording

Consent/Assent Form for Video Recording New York Medical College

Name of the Subject: _____

Title of the Research Project:

Developing and Evaluating a Multimedia Technology Approach to Surveying Individuals with Cognitive Impairment to Promote Person Centered Practice

What is this study about and how does it affect me?

The Westchester Institute for Human Development (WIHD) is doing research on technology for people with disabilities. Research is a process used in seeking new knowledge. In this study we want to learn how to develop survey technology to ensure that people with disabilities can use it effectively to communicate their wants and needs. We are asking you to participate in this study so that we can develop a way to do surveys that will allow people with all different abilities the best possible way to share their own opinions about the services and supports they receive.

What will happen to me?

If you choose to participate in this study, you will be asked to complete a survey in two different ways. One will be someone asking you questions and writing down your answers and the other one where you will use a tablet to answer the questions.

Will I get anything for being in this study?

No

Can being in this study hurt me?

No – you will only be completing the surveys. Your privacy is also protected by only allowing the research team access to the information.

Do I have to be in this study?

No – you can choose to be in the study or not.

Will I learn new things from this study?

I hope you will learn how to share your own opinions and ideas about your services so that you can have a say in how these services are done.

Will you tell anyone what I did in this study?

Not by using your name, but we will publish the results of the study so that we can share with other people how to use technology so that people with disabilities can give their own opinions.

By signing your name below, you agree to be video recorded for this study.

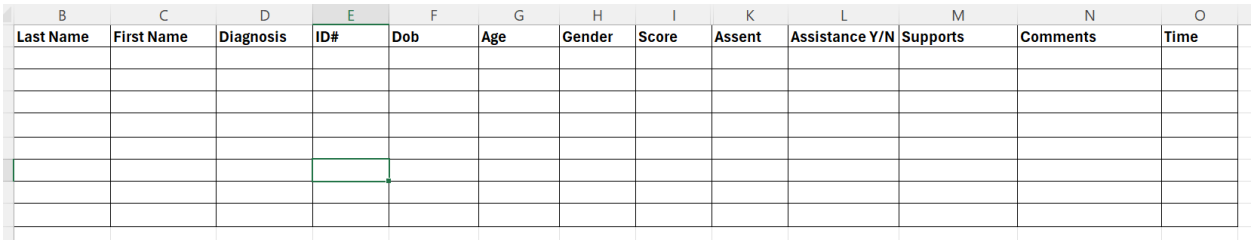
Name of Subject (please print): _____

Subject to sign or print the name: _____ Date:_____

Investigator Obtaining assent (printed name): _____

Signature: _____ Date: _____

Appendix Q: Excel spreadsheet for data collection phase 3



B	C	D	E	F	G	H	I	K	L	M	N	O
Last Name	First Name	Diagnosis	ID#	Dob	Age	Gender	Score	Assent	Assistance Y/N	Supports	Comments	Time

Appendix R: Turnitin Report

DEVELOPING AND EVALUATING A MULTIMEDIA TECHNOLOGY APPROACH TO SURVEYING INDIVIDUALS WITH COGNITIVE DISABILITIES TO PROMOTE PERSON CENTERED PRACTICE

by Izel Obermeyer

Submission date: 27-Feb-2025 11:31AM (UTC+0200)
Submission ID: 2600169812
File name: DEVELOPING_AND_EVALUATING_A_MULTIMEDIA_TECHNOLOGY_APPROACH_TO_SURVEYING_INDIVIDUALS_WITH_COGNITIVE_DISABILITIES_TO_PROMOTE_PERSON_CENTE (7.84M)
Word count: 51030
Character count: 284579

DEVELOPING AND EVALUATING A MULTIMEDIA TECHNOLOGY APPROACH TO SURVEYING INDIVIDUALS WITH COGNITIVE DISABILITIES TO PROMOTE PERSON CENTERED PRACTICE

ORIGINALITY REPORT

6%	3%	5%	1%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Franzsen, Denise. "The Development of a Handwriting Screening Assessment for Academic Accommodations at the University of Witwatersrand", University of the Witwatersrand, Johannesburg (South Africa), 2025 Publication	<1%
2	Submitted to Touro College Student Paper	<1%
3	www.wihd.org Internet Source	<1%
4	Submitted to University of Witwatersrand Student Paper	<1%
5	"Health Care for People with Intellectual and Developmental Disabilities across the Lifespan", Springer Nature, 2016 Publication	<1%
6	Constantine Stephanidis, Gavriel Salvendy. "Designing for Usability, Inclusion and Sustainability in Human-Computer Interaction", CRC Press, 2024 Publication	<1%
7	Katherine Walton, Gloria L. Krahn, Andrew Buck, Rebecca Andridge et al. "Putting “ME” into measurement: Adapting self-report health measures for use with individuals with	<1%