# Defining Accessibility and Accessible Research

## Message from the VPR

Dear reader,

I am proud to introduce you to the Accessibility in Research Training Series.

This initiative aligns with Queen's vision to enrich research and scholarship through the lens and values of Indigenization – Equity, Diversity, Inclusion, Anti-Racism, and Accessibility (I-EDIAA) and with our commitment to the United Nations' Sustainable Development Goals (UN SDGs). Inclusive excellence in research means increasing our capacity to add a wider range of voices, perspectives and skillsets to the table.

This module on Accessibility in Research complements the Equity, Diversity and Inclusion in Research training modules we launched in 2022 and adds to our growing suite of resources to empower and equip researchers in implementing wise I-EDIAA practices throughout the research lifecycle, from project design and data collection to results analysis and dissemination of findings.

By taking this training, you will familiarize yourself with important concepts and practices that are intended to increase awareness of avenues for accessibility in our research activities. We appreciate your efforts in making research processes more inclusive and, in turn, outcomes more meaningful and impactful.

Nancy A. Ross, PhD Vice-Principal, Research Professor, Department of Public Health Sciences

### **Acknowledgment**

Thank you to the dedicated individuals whose commitment and collaboration played a pivotal role in developing this training course.

Contributors:

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Special thanks to:

Nicole Bobbette Claire Davies Getachew Gebeyaw Tadese Bekele Worku

Progress in this course cannot be bookmarked or saved. You will need to complete the course from start to finish in one sitting taking approximately 90 minutes.

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## Land acknowledgement

To begin, let us acknowledge that Queen's is situated on traditional Anishinaabe and Haudenosaunee territory. We are grateful to be able to live, learn and play on these lands.

To acknowledge this traditional territory is to recognize its longer history, one predating the establishment of the earliest European colonies. It is also to acknowledge this territory's significance for the Indigenous Peoples whose practices and spiritualities are tied to the land, and who have lived, and continue to live, in relationship to the territory and its other inhabitants today.

In acknowledging the land that Queen's University is situated upon, it is important for all of us to consider our own positionality, relationship and responsability to the land. It is also important to pause and reflect on what reconciliation, decolonization, and Indigenization look like for each of us.

Please view the video to learn more about the <u>significance and importance of land</u> <u>acknowledgments (opens in a new tab)</u>.

Lindsay Brant is an Educational Developer, in the Centre for Teaching and Learning at Queen's with a focus on Indigenous Pedagogies and Ways of Knowing.

VISIT: Office of Indigenous Initiatives (Land Acknowledgement) (opens in a new tab)

VISIT: Decolonizing and Indigenizing Teaching and Learning (opens in a new tab)

VISIT: <u>Find out more about local Indigenous territories and languages (opens in a new tab)</u>.

## **Accessibility statement**

Queen's is committed to an inclusive campus community with accessible goods, services, and facilities that respect the dignity and independence of people with disabilities. **Queen's University Accessibility Policy (opens in a new tab)** and its related procedures and guidelines facilitate the identification, removal, and prevention of barriers to persons with disabilities to enable better access to Queen's University goods, services, facilities, accommodation, employment, buildings, structures, and premises.

The modules in this course were developed using Articulate Rise 360 and adhere to Web Content Accessibility Guidelines (WCAG) 2.1 Level AA, you can review the complete Rise 360 Accessibility Conformance Report. Rise 360 is inherently responsive, so content scales and reflows as needed when you interact with your browser zoom features. Content reflows as you zoom in, so you never need to scroll horizontally. You can logically tab your way through the interface. The focus remains on the Next button in interactions, and screen readers announce the title for the current step. Much of the learning experience is keyboard accessible.

Follow the link **Keyboard-accessible navigation (opens in a new tab)** for further instructions on keyboard navigation. Built-in navigation elements always appear in the same location.

Additional accessibility features include:

Transcripts for audio clips. Captioning for video.

Meaningful text for hyperlinks.

Text sizes are set to 18pt or greater with a minimum 4.5:1contrast ratio.

The following screen readers are supported:

Windows: NVDA (latest version), JAWS (latest version). Mac: VoiceOver.

Mobile: VoiceOver in Apple iOS, VoiceOver in Apple iPadOS, TalkBack (latest version) for Android OS.

You can complete the training course on any devices that support these browsers. This includes mobile devices such as iPhones, iPads, and Android-enabled phones and tablets.

Windows: Google Chrome (latest version), Firefox (latest version), Microsoft Edge (Chromium-based, latest version).

Mac: Google Chrome (latest version), Safari (latest version), Firefox (latest version).

Mobile: Safari in Apple iOS/iPadOS (latest version), Google Chrome (latest version) in Apple iOS/iPadOS (latest version), Google Chrome (latest version) in Android OS 6 or later.

If you find any module content or functionality inaccessible, require materials in an accessible format or with appropriate communication supports, please contact <a href="mailto:research@queensu.ca">research@queensu.ca</a>.

## Welcome to the Accessibility in Research Training Series

Progress in this course cannot be bookmarked or saved. You will need to complete the course from start to finish in one sitting taking approximately 90 minutes.

If you are just getting started on your I-EDIAA journey, we suggest that you take the **EDI in Research Modules (opens in a new tab)** and the **Ableism Module (opens in a new tab)** prior to engaging in this training series.

Welcome to the Accessibility in Research online training series. The purpose of this training series is to equip researchers at Queen's University with the knowledge base necessary to incorporate accessibility considerations within their teams and at different stages of the research process.

The training series consists of two courses:

- 1. Understanding Disability and Ableism
- 2. Defining Accessibility and Accessible Research

The two courses are designed for all researchers, at different career stages and at different levels of engaging with equity, diversity, inclusion, and accessibility practices. The training recognizes engaging in disability visibility as central to the I-EDIAA initiatives across the university and brings a proactive consideration of accessibility when forming research teams and embedding equity in research design and practices. This approach addresses the underrepresentation of people with disabilities in the research ecosystem and conceptualizes accessibility as the baseline of equitable research.

### Introduction

Welcome to the course on accessibility and accessible research. In this course, you will learn what accessibility is and why it is important to embed accessibility in the research design and practice. We will also touch upon some of the barriers to participation in research and academia experienced by people with disabilities.

We will then discuss how to adopt an accessible and participatory approach in different stages of the research life cycle including design and planning, recruitment, obtaining consent, data collection and dissemination of research findings. This module will equip learners to design their research programs and projects with greater attention to accessibility so as to improve the experience of researchers and participants with disabilities.

You will work through this course at your own pace, completing formative knowledge checks along the way. These checks will give you an opportunity to synthesize important concepts. The course will take approximately 90min to complete.

## **Modes of learning**

In this course you will learn in the following ways:

- Self-paced learning Readings
- Videos
- Formative knowledge checks
- Case study with self-reflective activity

## **Learning goals**

After completing this course, you will have:

- Familiarized yourself with the concept of accessibility. Identified common barriers
  experienced by students, researchers and research participants as a result of
  systemic ableism in academia.
- Explored wise practices for including accessibility in research.
- Reflected on the accessibility considerations based on a research study scenario.

## **Module 1: Accessibility**

## What is accessibility?

Ontario Human Rights Commission (n.d.) defines accessibility as "a general term for the degree of ease that something (e.g., device, service, physical environment and information) can be accessed, used and enjoyed by people with disabilities. The term implies conscious planning, design and/or effort to make sure something is barrier-free to people with disabilities. Accessibility also benefits the general population, by making things more usable and practical for everyone, including older people and families with small children."

As articulated in the Ontario Human Rights Code, disability is a code protected ground. A commitment to accessibility requires society to address physical, attitudinal, structural and institutional barriers to full and equal participation.

Disability is an integral part of diversity. Inclusion of a wide range of perspectives and lived experiences (different ways of knowing and learning) is a crucial factor in achieving research excellence. A strong commitment to accessibility promotes and diversifies talent in research teams and amplifies the impact and outreach of the research findings.

## Accessibility is an essential component of research

Around 16% of the world's population (1 in 6 of us) experience significant disability (WHO, 2023). Accessibility is the baseline of equitable research and an essential component of a sound scientific strategy. People with disabilities shape the research agenda and contribute to scientific excellence in a variety of ways, e.g., as researchers, leaders, research participants, and disability justice advocates. Accessible research aims to create a barrier-free experience for all involved.

Research that's inclusive of the perspectives of people with disabilities leads to diverse outcomes, for example:

- Enhanced uptake and application of the research findings.
- Evidence base needed to address disability-related inequalities.
- Greater insight and understanding of the experiences of people with disabilities (Bailie et al., 2023).

## **Quick facts**

Over the past two decades, significant changes have taken place in Canada with respect to accessibility policy and legislation.

In 2005, the Accessibility for Ontarians with Disabilities Act (AODA) became the law, making Ontario the first province to pass legislation to improve accessibility.

The Integrated Accessibility Standards Regulation (IASR) was enacted into law in 2011. The Accessible Canada Act (ACA) came into force in 2019, with the goal of creating communities, workplaces, and services that enable all people, including people with disabilities, to participate fully in society without barriers. ACA applies to organizations under federal responsibility (Lau et al., 2020).

In addition to these milestones, many Canadian cities and communities have established rules and recommendations to address accessibility challenges Canadians encounter daily. These improvements are leading to changes in important areas, such as customer service, job opportunities, transportation, physical spaces, and communication.

## **Knowledge check question**

What is accessibility?
[Select the correct answer]

- 1. A wide range of perspectives that contribute to research excellence.
- 2. Only providing information in alternate formats.
- 3. Ensuring that services, spaces, information, products, and devices can be used by everyone regardless of disability.
- 4. Addressing legislation gaps to improve equity.

Answer: Ensuring that services, spaces, information, products, and devices can be used by everyone regardless of disability.

## Module 2: Barriers to participation in research and academia for people with disabilities

## Experiences of people with disabilities in the research ecosystem

Despite important achievements, many gaps still exist when it comes to participation of people with disabilities in research and academia.

Some of these barriers are listed below:

- The perspectives of researchers and research participants with disabilities are not adequately considered when discussing access needs due to systemic ableism and the underrepresentation of people with disabilities in the research ecosystem.
- Overly rigid inclusion and exclusion criteria in research studies.
- Transportation to and from research events is difficult to arrange or not available, and the study facility or spaces where data collection takes place are not fully accessible.
- Communication barriers including inaccessible language and documents; use of complicated, technical language or jargon that is difficult to understand.
- Not providing additional time and accommodations that may be needed to ensure full participation of people with disabilities (Honisch & Hill, 2022; St John et al., 2022).
- The perception that all people with disabilities are vulnerable and have a "limited capacity to consent."

As a result of systemic ableism, researchers and students with disabilities are likely to face many challenges in their academic environments, including ableist ideas around productivity and academic excellence, difficult process of obtaining accommodations as well as oppressive structures and attitudes. Their lived experiences highlight continued

exclusion from equitable participation in academia, as described by disability academic activist, Dr. Armineh Soorenian:

"One of the side effects of my medical condition is that I need more time to process information, reflect and prepare my responses, a situation not necessarily conducive to a traditional academic culture or typical interview situations. Everyday tasks take longer; I may require double or even triple the time of that taken by a non- disabled researcher to complete the same work. I also have a visual impairment, and converting standard print written materials to a format that I can access is a very time-consuming process. (...) Sadly, in academia, little accommodation is made for disabled academics who may need extra time for impairment-related reasons" (Olsen & Porter, 2020, p.268).

Furthermore, people with disabilities who pursue academic careers have disproportionately lower odds of success when applying for research grants as a result of systemic ableism in academia (CIHR, 2022). For example, the percentage of National Institute on Health (NIH) grant awardees with disabilities significantly declined from 1.9% of awards in 2008, to 1.2% in 2018. Grant success rates were lower for researchers reporting disabilities (27.2%) than for those not reporting disabilities (29.7%) (Swenor et al., 2020).

## Barriers to accessible research video (opens in a new tab)

[We sincerely thank our guest interviewees for their invaluable contributions to this course content. You can find their biographies at the end of this course]

Video transcript

### Lack of commitment to address accessibility needs

Getachew Gebeyaw Tadese

PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[0:11] - In those researches that I have been participated as a participant there is lack of commitment from the researchers about fully fulfilling the accessibility need of those researchers. Maybe this is unique for me because I am a person with disability, I am educated, I'm a university lecturer, I'm, I'm curious for everything when researchers come to me and I ask a lot of questions, how this research is to be conducted and how they are going to interview me. Even though my disability type doesn't require a complex accessibility needs, but I need to confirm that to what extent they are fulfilling those requirements. So, at the moment that I asked them a different question, is, they try to, do not interested to come back and interview me because they sometimes need the easiest way to complete that research. instead of go through all the detailed requirements for a person with disability that they should fulfil.

## Barriers vary depending on individual needs and the context of research

Bekele Worku, PhD

Queen's University Alumnus Assistant Professor, School of Law University of Gondar

[1:20] - Researchers, research barriers for persons with disabilities vary depending on the type of disability and extent of disability. Luckily, I am partially sighted, to a certain extent, I do have residual site. Therefore, moving around to find the research participants is one of the challenges of persons with visual impairment. That has not happened because I can move on my own because of my residual sight.

The other challenge which is faced for researchers like me, including me, is, you know, getting access to those materials in hardcopy. Those could be primary sources of data, for instance, cases, court cases. They could be archived documents. They could be documents which are not available in English, for instance.

We are doing our legal practice in our own language. There are different languages and we use handwritten... judgements are written in hand, they are not yet transformed into a computer or something like that, and which are not accessible to... assistive technologies like JAWS or screen readers.

## Attitudes and assumptions about disability

Claire Davies, PhD, P.Eng Professor Department of Mechanical and Materials Engineering Smith Engineering

[2:52] - I would have to say that ableism is quite prevalent within the community of persons who are in academia and research. There are a lot of assumptions about disabilities and persons who have disabilities, and those assumptions are as a result of past experience or just lack of knowledge, lack of understanding, not actually understanding what disabilities can affect people in different ways.

And so, one of the things that I find is hardest is, is people make the assumption that if a person has a disability, then they can't do what needs to be done. And it can be any disability, it can be a visible disability, it could be an invisible disability. But people just say if, if that person has a disability, then they don't know what needs to be accomplished, they don't know how to do it, they may not be able to communicate effectively with me.

And I think that's one of the other things that we find with respect to ableism, especially with communication, is there's an expectation that people can verbally communicate. And if you can't verbally communicate, then you don't know what's happening. And I think that is one of the hardest things that people have to get through their heads is that once you are actually in an environment with a person who has a disability, they may be just as

qualified as you are, they just have difficulty expressing themselves. And so you have to give them the opportunity to express themselves in different forms.

## **Recognizing ableism**

Nicole Bobbette, PhD Assistant Professor School of Rehabilitation Therapy Faculty of Health Sciences

[4:30] - I've had a number of different experiences where people have found it difficult to participate in research. And it could be that someone couldn't get on the web platform for a meeting, or didn't understand the meeting, went too, research activity went too fast, or they, they didn't feel like their voice was heard when we met as a team, or that their feedback was incorporated when we did ask them.

So, at different points along the... our research projects, I think I, we have learned and stumbled and experienced and, and maybe it wasn't... I would say in all of those cases wasn't intentional, but the ways in which we worked as a team... in a really ableist way we were... we ended up excluding our, our, our team members. And, and because of that, you know, we learned through experience and you learn through feedback. But those particular barriers around, access and participation...

I think are, are really... quite frequent and can and can occur quite easily without without intentionally thinking about accessibility.

## Attitudinal, structural, and systemic barriers

Stereotypes and lack of awareness often result in attitudinal, structural and systemic barriers to accessible funding which hinder the research endeavors of people with disabilities and limit their ability to contribute to the academic community.

Some of these barriers include:

- Inaccessible web-applications: Many funding agencies' application platforms are inaccessible to people with disabilities, especially to those relying on screen reading.
- **Inflexible deadlines**: Rigid or short deadlines may be inaccessible to researchers with disabilities depending on their specific requirements, e.g., time needed to organize access to equipment, software and/or assistants.
- **Attitudinal barriers**: Peer reviewers may perpetuate ableism and hold negative attitudes towards applications in which applicants self-identify as people with disabilities, including the belief that researchers with disabilities are not competent enough and lack the required research skills.
- **Insufficient funding for accommodations**: Grant and funding policies often do not consider funds for accommodations, resulting in the need to split grant funds between core research and accommodations (CIHR, 2022).

Establishing a research process that actively embraces accessibility principles goes beyond following institutional accessibility guidelines. Simply conforming to these policies without taking substantial action is not enough and researchers, educators, administrators, and peer reviewers are encouraged to translate these policies into tangible practices that impact different aspects of their work.

#### **Wise Practices**

The wise practices we will cover in the next section aim to offer clear guidance, enabling researchers to implement changes that foster an inclusive mindset and establish a research environment where everyone can flourish. These practices serve as a roadmap for transforming policy adherence into a tangible commitment to accessibility, thus ensuring that accessibility becomes an integral part of the research team's culture.

Insufficient awareness regarding disabilities can lead to negative attitudes and behaviors towards people with disabilities, perpetuating stereotypes, and social exclusion. Hence, understanding different types of disabilities and the barriers that people with disabilities experience becomes crucial when designing and conducting research that is inclusive and accessible.

[Pease review the follow video and/or video transcript (transcript available as DOC and PDF and the video is closed captioned). We sincerely thank our guest interviewees for their invaluable contributions to this course content. You can find their biographies at the end of this course]

## Supporting students with disabilities video (opens in a new tab)

[We sincerely thank our guest interviewees for their invaluable contributions to this course content. You can find their biographies at the end of this course]

Video transcript

## Start with assessing needs

Claire Davies, PhD, P.Eng Professor Department of Mechanical and Materials Engineering Smith Engineering

[0:08] - I think the first most important step is to actually ask people before they come, before they enter your laboratory environment. They may be persons who don't have visible disabilities, and you need to ask the question in order to get that answer. You shouldn't make it their obligation to advocate for themselves. You need to be welcoming right from the start. You need to enable them to offer their suggestions as to how they can best perform within your laboratory environment.

Most of the time, these things that they suggest are not expensive things that have to be done. Oftentimes it's just small things like a flexible work environment. If a person needs to work from 6 a.m. to noon rather than from 9 to 5, enable them to do that. If they need to be an environment where lighting is different or they need access to computers that have bigger displays.

Those are all different things that, not, don't necessarily cost a lot of money, but can provide them with that actual support that they need to excel.

#### **Accessible research environments**

Claire Davies, PhD, P.Eng Professor Department of Mechanical and Materials Engineering Smith Engineering

[1:23] - If the person needs to work on site, it's most important to ask them what their needs actually are. For example, a standing desk or a desk that can change from being a sitting desk to a standing desk can enable persons with, in a wheelchair, to access that environment. Screen readers are accessible by whatever means, including accessibility options within the Microsoft suites or the Apple suites. They're all giving you that opportunity to use a screen reading option. There are often times where we can provide switch access or alternative keyboards...It enables them to actually interact within the laboratory environment on a computer that may not necessarily be otherwise acceptable... accessible.

So, one of the biggest things is just to be aware of the different... plug-ins that can be used within a computing environment and enable them access to those sorts of plug-ins.

## Capacity building and the role of mentorship

**Getachew Gebeyaw Tadese** 

PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[2:32] - In, in, in my experience, in our, in our institution experience or based on the students that I have been provided mentorship for, so, I found that there is a gap on mentorship. So, we need them to involve in a research, but they have lack of capacity how they engage in that research and their skills and knowledge about research from the planning to the, the, the final stage of the research process.

So, this capacity building is very important that provide training for those... a student with disability, or a staff with disability to make sure that they have the capacity to, to conduct that research. If they don't have that capacity, it's also an opportunity to empower them about that research. And also, they need ongoing mentorships. So that ongoing mentorship is... providing them an opportunity to understand or to get skills and

knowledge in every stage. And... reasonable accommodation, this reasonable accommodation is based on the needs of each impairment, each disability.

## **Accessibility assistants**

Bekele Worku, PhD Queen's University Alumnus Assistant Professor, School of Law University of Gondar

[2:52] - What I suggest is, as I have told you, most of the challenges or barriers are because of our inability to access certain data. Therefore, it might increase some cost on the research fund, but give people, for instance, I'm talking about persons with visual impairment. If we have somebody, assistant, it is not a full- time assistant, but an assistant who can help, being paid because, you know, if he is not fully paid, he might be a volunteer and he might not be available at any time he's required.

Therefore, research, when they are planned, and if they plan to involve researchers with such disabilities, researchers must... think of including in their proposals some assistants to be hired in order to help the person access those inaccessible, inaccessible materials, inaccessible places and inaccessible communication tools.

## Accessibility expertise and adaptive technology

Bekele Worku, PhD

Queen's University Alumnus Assistant Professor, School of Law University of Gondar

[4:30] - These persons, people in the adaptive technology can help us, one, in changing different materials into an accessible version of the document. And, one, the other thing they helped me is, for instance, there was a room provided for me when I needed a silent to listen for something. There was a room provided by Adaptive Technology in, at Queen's. Therefore, these types of... and, they was... for instance, when I get an image document, they used to change it into a readable... also it is called optical character recognition, OCR. They change it into that. And the experts not only help persons with visual...disabilities, they used to help a lot of students with learning difficulties and persons with mental issues.

## Question

Can you think of three barriers to participation in research for people with disabilities?

### **Self-reflective activity**

Please read the following question and reflect on possible solutions. Reflect and check your knowledge of barriers to accessible research.

## **Examples of barriers**

- Not considering the perspectives and the access needs of researchers and participants with disabilities.
- Overly rigid inclusion and exclusion criteria in research.
- Inaccessible transportation and/or research locations.
- Communication barriers.
- Lack of accommodations.
- Ableist ideas around productivity and academic excellence.
- Oppressive structures and attitudes.

## **Knowledge check question**

What are the barriers to accessible research funding? [Select all that apply]

- 1. Lack of reviewers with expertise in accommodations.
- 2. Inaccessible web applications.
- 3. Inflexible merit review criteria.
- 4. Inflexible deadlines.
- 5. Attitudinal barriers.
- 6. Grant and funding policies often do not consider funds for accommodations.

Answer: Inaccessible web applications, inflexible deadlines, attitudinal barriers, grant and funding policies often do not consider funds for accommodations.

The wise practices we will cover in the next module aim to offer clear guidance, enabling researchers to implement changes that foster an inclusive mindset and establish a research environment where everyone can flourish.

## Module 3: Adopting an accessible & participatory approach throughout the research lifecycle

### Co-creation

Co-creation of research with diverse participants democratizes the research process. The Disability Innovation Institute at the University of New South Wales Sydney outlines six guiding principles for inclusive research (Strnadová, et al., 2020), which are adapted and presented below.

The primary goal of inclusive research is to actively contribute to the advancement of social change, which not only acknowledges but also actively promotes and communicates the importance of accessible knowledge coproduction and sharing. To achieve these aims, it is

crucial that the principles of inclusion are deeply integrated into the very design of the research process, consistently monitored and reflected upon throughout the research journey. These principles act as powerful drivers in rectifying and addressing power imbalances that can often persist in research and society at large.

## Six guiding principles for inclusive research

**Power sharing**: Acknowledge and manage any power differentials between individuals and groups: for example, ensure shared responsibility and ownership of the research process and recognition of the specific skills each person brings to the research.

**Accessibility**: Actively address barriers that may potentially prevent or discourage involvement of people with disabilities in the research process: for example, ensure accessibility of physical environments and all information relevant to the research project.

**Flexibility**: Identify how best to work together to achieve common goals in the context of each specific project: for example, understand the team's particular needs and their implications for the coproduction strategies to be put in place.

**Diversity**: Create space for different perspectives and value and celebrate diverse skill sets: for example, encourage people to become involved in aspects of the research that best suit their interests, skills, and expertise.

**Reciprocity**: Ensure that everybody benefits from producing the research: for example, through financial compensation, learning from each other, building new relationships and skill sets and working towards social good.

**Transparency**: Openly communicate about the context, goals, scope and process, each person's role, and potential outcomes of the research: for example, ensure that everyone has a shared understanding of the parameters of the research project.

Applying these core principles in research leads to the integration of more than one way of thinking and working on a research project. These principles guide the ways in which your research is planned, research questions are framed, and how research is conducted and disseminated. Once you begin to apply the lens of inclusion, you will find that small changes allow yourself, your research team members, participants, and collaborators to have more than one point of access into the study.

#### Take a moment to reflect

Have you been actively applying the six guiding principles for inclusive research in your own research practice? What improvements can you make?

[Pease review the follow video and/or video transcript (transcript available as DOC and PDF and the video is closed captioned). We sincerely thank our guest interviewees for their

invaluable contributions to this course content. You can find their biographies at the end of this course]

## Research co-creation video (opens in a new tab)

[We sincerely thank our guest interviewees for their invaluable contributions to this course content. You can find their biographies at the end of this course]

Video transcript

## The importance of lived experiences

Getachew Gebeyaw Tadese

PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[0:08] - Listen to people with disabilities. Sometimes even accessibility is defined by those who are an outsider. And so, the perspective of those people with disabilities, those who have a lived experience, those who are insider perspective is very important, and it has very important nuances to that research quality or to ensure accessibility in research for people with disability. So... trying to listen those people with disabilities is important.

And the other one is... yeah, define accessibility in that research based on the perspective of those people with disabilities. So, if those people with disabilities define that accessibility in that research project, specific to that, we may have accessibility requirements as a larger... as institution level. But specifically to that project we need different details and nuances that we have to consider. So that is productive when we listen and understand the perspective of those people with disabilities. And, and, it, it is also productive for knowledge mobilization. So, those points are important for me we think about the inclusion of people with disabilities in those research.

## Co-creating research about brain health with adults with intellectual and developmental disabilities

Nicole Bobbette, PhD Assistant Professor School of Rehabilitation Therapy Faculty of Health Sciences

[1:20] - I am currently involved with a project I'm really excited about... It's around... brain health for adults labelled with an intellectual developmental disability, ...caregivers and service providers. And my role in the project is to lead the arm with... self-advocates.

So, co-researchers and researchers with... developmental disabilities or intellectual and developmental disabilities. And so... we had two... members of our research team... were

involved in, in actually... submitting the grant. So, have been involved since the start. And then they came over to help me build my, my team.

So, they are... part of... our team. And then we have clinician scientists as well... and as myself. And so, we, our, our primary research activity was... or has been those last few months is to co-create a six week virtual educational module for people over 40... with a intellectual developmental disability. And so, we decided on... on key topics. We built out the education together and we just finished our first six-week session. We all... members of our team co-facilitated and, and took the lead on different roles as a facilitator, as a teacher, as a leader of discussions. And then... and, and we all, I think... helped with the debrief of it and, and now we're planning for our fall session.

So, the... I think our main activity has been creating the content and running the education. And we're just doing some data collection now, but they'll... we'll kind of re-engage the team to ...make sense of what we're hearing from participants. Both from a program evaluation, how do we make our program better for the next round, but also then for a larger understanding the experiences of people taking the course and how it impacts their well-being, and their, their brain health.

## Co-creating engineering design

Claire Davies, PhD, P.Eng Professor

Department of Mechanical and Materials Engineering Smith Engineering

[2:52] - One of the examples that we can use with respect to good engagement with families is one that has happened most recently with designing a device for a head support system for a child with cerebral palsy.

This particular individual needed access to a device that would keep his head up while he was within an educational environment or an environment in which he could use to interact with others.

So, what we did is we actually met with the mother and the child on a regular basis. Now, this is one of my students that did this rather than me, but she met with the family once a week for a period of a year and they worked in a co-design process in that the mother provided feedback on a regular basis. The child, who didn't have any verbal communication but used expressions to... decide exactly how he felt with the design, was also important to understand.

So, my student actually got the opportunity to learn how to interact with persons who are completely non- verbal, as well as interacting with a mother who may or may not have different... the same... different or the same needs as the child. And so, it's really important that you get the student who is doing the research to be within that environment that allows the individual and the family to feel most comfortable.

## **Creating knowledge mobilization strategies**

Getachew Gebeyaw Tadese

PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[4:30] - So, the first thing is identify the audiences of knowledge mobilization. So... if we know clearly our audiences, how can we approach would be answered there. So, how can we, we... we, we practically provide to that community to make change on those people with disability.

And the second one is consult those disability organizations. Those disability organizations, I believe that they are an insider. So, they have insider perspective. How can we... approach the community and clearly... to implement knowledge mobilization stage also... to what extent this community events and gathering the communities and provide, and give them... understanding about that research, and we can collect information from those community members.

Next you will be introduced to some strategies that can be used for integration of accessibility in different stages of the research life cycle. Please note that they may not apply to all types of research in the same way. Learners are advised to adapt these strategies as per their individual research study or program.

## **Research planning**

## **Build inclusive research teams**

Forming inclusive research teams is vital for creating a research model that is accessible and welcoming to all. It is important to learn about the state of diversity within your current team and the gaps that exist.

- What steps can you take to address these gaps?
- Does your team have the expertise necessary to conduct accessible research?
- Can you include people and organizations from communities that are most impacted by your research?

For more information about developing inclusive research teams please visit **EDI in Research Modules (opens in a new tab)**.

## Consider barriers that may impact the research you are conducting

Take into account both the people engaged in the research and the locations where the research is being carried out. Evaluate how particular research methods or research settings might prevent or limit full participation of people with disabilities. Within your

research team, contemplate how each team member will address the accessibility requirements of research participants, collaborators, and co-researchers, including yourself (Honisch & Hill, 2022).

## Allocate time and resources for accessibility, accommodations, or modifications

Include provisions for the expenses related to accommodations for people with disabilities in all funding proposals and budgets, whether at the organizational level or for specific projects.

Dedicate a separate category in your budget plans, such as one for accessibility, accommodations, or modifications, and ensure that these costs are integrated into the overall funding request. This should encompass different expenses, e.g., hiring subject matter experts, providing sign language interpreting services and assistive technology, enhancing website accessibility or the use of accessible survey platforms that support Alt text and screen readers (Honisch & Hill, 2022, Rios et al., 2016).

## Center access needs when applying for ethics review

Accessibility should be prioritized in all research processes so that barriers can be reduced if not removed entirely. Unfortunately, some aspects of the ethics submission process, such as the need to navigate complex online application systems, may present accessibility challenges. Consider discussing your and your team's access needs with the research ethics office in advance of submitting an ethics application.

## Make accessibility explicit throughout ethics applications and in research materials and procedures

Consider the following when submitting an application to the ethics boards at Queen's University:

- Clearly articulating the important details about accessibility in your application and all research materials.
- Demonstrating that accessibility has been incorporated into all aspects of research (e.g., consent process, provision of supports and resources throughout the entire cycle of research, managing potential risks, securing the necessary approvals from the community research partners, etc.)

## **Knowledge check questions**

#### **Question 1**

Funding proposals and budgets should include expenses related to \_\_\_\_[blank]\_\_\_\_ for researchers and/or participants with disabilities.

[Select the correct answer to fill in the blank]

- 1. Online application systems
- 2. Research locations
- 3. Accommodations
- 4. Barriers to accessibility

Answer: Accommodations

## **Question 2**

During research planning, identify the potential barriers to inclusive research and consider how you will incorporate \_\_\_[blank]\_\_\_ of participants, collaborators, and co-researchers, including yourself.

[Select the correct answer to fill in the blank]

- 1. Different perspectives
- 2. The accessibility requirements
- 3. Creative thinking
- 4. Diverse skill sets

Answer: The accessibility requirements

Next, you will look at ways to frame research questions and research design.

## Framing research questions and research design

### Look beyond traditional research designs

Explore theoretical frameworks and methodological strategies that go beyond conventional approaches to research. Flexibility in research design may serve as a way to resist ableist structures and exclusionary practices (Fraser-Barbour, 2023). Encourage creative approaches and consider intersectional and disability-inclusive research methodologies such as mobilizing art and story (Croft et al., 2024). If necessary, offer and participate in training for everyone involved in the research process.

#### Have a dialogue

Choose the research topic and methodology through open discussions involving team members, research collaborators and participants to ensure that their input is appropriately incorporated. Consider how each aspect of your study, including questions, theoretical framework, data collection and analysis, and dissemination of results, can embrace diverse perspectives, approaches, and communication methods to process and share information effectively.

## Adopt universal design principles

The concept of Universal Design emphasizes "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (Centre for Universal Design, 1997).

## The seven principles of Universal Design

With examples of how they can be applied in research.

- **Equitable use**: For example, methods of data collection are designed to accommodate diverse users.
- **Flexibility in use**: For example, desks and chairs in spaces where research is conducted are height adjustable.
- **Simple and intuitive use**: For example, ensuring that instructions for research participants are easy to understand regardless of their level of knowledge, language skills or the current concentration level.
- **Perceptible information**: For example, using different methods of communication such as visual, auditory, and tactile to share research results.
- **Tolerance for error**: For example, allowing the survey takers to correct or edit their responses.
- **Low physical effort**: For example, designing your research space and equipment in a way that minimizes the physical strain of users.
- **Size and space for approach and use**: For example, lab equipment is arranged so that people of different statures, sizes and mobility levels can reach it.

Furthermore, The Universal Design for Learning (UDL) (CAST, 2018), is a framework that can be used or adapted to make research more accessible and to ensure that all participants and learners can engage in meaningful research and learning opportunities. The three UDL principles are:

- Provide multiple means of engagement: For example, if possible, choose a variety
  of research methodologies that create different opportunities for involvement in
  research.
- **Provide multiple means of representation**: For example, present research information in a way that acknowledges differences in learning and understanding. Use formats that allow for flexibility such as resizable text and adjustable volume.
- Provide multiple means of action and expression: For example, offer people different options to express themselves using:
  - verbal communication
  - o written communication
  - o technology tools (e.g., keyboards, touch screens)

- o multimedia
- o creative or arts-based approaches.

To learn more about these principles and how they can be operationalized please visit the <u>CAST website</u> (opens in a new tab). Please note that there is a strong connection between Indigenous Pedagogies and UDL. <u>This resource</u> (opens in a new tab) offers valuable insights on Indigenous approaches to learning.

## Collaborate and co-design with accessibility professionals and disability justicefocused organizations

Co-creating research with relevant communities, including your own, and fostering collaboration between research teams and disability justice-focused organizations pursuing similar objectives is vital to accessible research. It's important to secure funding to cover the costs associated with meaningful participation and expertise.

If you are new to participatory research and lack the necessary knowledge and skills, explore training resources to support you in building respectful and mutually beneficial partnerships that foster knowledge co-production, shared authorship, and equal recognition. Prioritize publicly available training opportunities and tools.

If you decide to approach an expert from an equity-deserving group, take steps to ensure reciprocity. Include measures to address the "equity tax" – a situation when members of underrepresented groups carry disproportionate amount of emotional burden, service, work and mentorship responsibilities while not being compensated or recognized for their efforts.

### Plan for making accommodations

Despite the implementation of universal design principles in the research process, there will still be situations where adaptations are necessary to ensure equitable participation for people with disabilities. Accommodations ensure an accessible experience by providing the necessary supports such as assistive technology, optimal lighting, access to quiet spaces that reduce sensory overload, and many other resources. In essence, accommodations serve to reduce or eliminate any potential barriers arising from the format of research, methodology and data collection. It's important to ask about potential accommodations in the early stages of research design.

#### Prioritize accessibility and evaluate your progress on a regular basis

Regularly evaluate accessibility by seeking feedback from your team and research participants and by assessing your own needs. Prioritize planning and open discussions regarding the balance between structure and flexibility. This involves considering various aspects of team meetings and research activities, such as their frequency, timing, location, agenda, social aspects, and the specific accommodations required for accessibility.

## **Conducting accessible research video (opens in a new tab)**

[We sincerely thank our guest interviewees for their invaluable contributions to this course content. You can find their biographies at the end of this course]

Video transcript

## Planning an inclusive research project

Nicole Bobbette, PhD Assistant Professor School of Rehabilitation Therapy Faculty of Health Sciences

[0:08] - So, when I think about a new and inclusive research project. I think about... who is on the team. And I would imagine most people do that when they think about starting a new project. Who do I want on the team? What expertise? And... I always want people who have... lived and living experience. I, I don't... that's... I want to do research with them... for them, to help amplify their voices. So, I think about who the people are first and I think about their, their motivations, their characteristics, their values. And we get to know each other... so it actually does take time.

And, and I would say that's... it... whether you identify or have been labelled as having a disability or not, you get to know the people that you work well with and your team. That's the first stage is actually who is the team and what do they need? And then I always think about access and accessibility. So, thinking about who is on my team and what do they need to participate.

## Distribution of tasks among the team members

Bekele Worku, PhD

Queen's University Alumnus Assistant Professor, School of Law University of Gondar

[1:20] - The research team members or leaders, if there are leaders, should apportion... type of job or task... that person with disability can do comfortably, with dignity, without being embarrassed. Because, if he's asked what he can do, participatory. Because, before you assign jobs or you assign tasks, you have to make some talks with persons with disability because many decisions are done without the inclusion of the person most impacted.

Therefore, nothing about us without us, this could be a motto even in a research team.

### Participatory research design

Getachew Gebeyaw Tadese

PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[2:26] - So, try to make the research participatory. Maybe, it, it doesn't mean that always every research could be participatory research, but we have been benefited from a participatory action research that we included students with disabilities from the very beginning to the end of, till the knowledge mobilization stage of a research. So, we have seen the capacity of the students with disability in that process. We have seen that to what extent their interest is reflected through the process of that research.

So, participatory approach is always, very, very important and... so, and examine always the implication of that research at the knowledge mobilization stage when we plan, the, the research. If that research really has a significant, will have a significant implication for people with disabilities, at the planning stage research team members should think about the inclusion of people with disabilities from organizations, or from advisory board members, or from other research participant team members. So, this is the most important points that I believe... think about in the planning stage.

#### **Accessible recruitment**

Claire Davies, PhD, P.Eng Professor

Department of Mechanical and Materials Engineering Smith Engineering

[3:49] - Recruitment of participants with disabilities can be difficult. You have to understand that a lot of these people have a lot going on within their lives. They may not be able to respond on a moment's notice. What I find, especially with people with complex disorders, is that they may not be able to engage at the time you have selected or an appointment that they've done. So, you have to be flexible. You have to make sure that you're flexible in returning to them and enabling them to tell you that it's not a good time today, we need something and we need another time, we need to set up another time.

Another way in which we can recruit persons with disabilities is enabling them to interact with the recruitment criteria as best they can. So, whether we use a video that includes sign language, closed captioning, an alternate means of communications or we use written communications such as... documents that are in word format. Word format is the best... format to use when using a screen reader, so it's often better to provide a word format document rather than a document in PDF form.

#### Participatory data collection and analysis

Getachew Gebeyaw Tadese

PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[5:18] - If, if we give a priority for a person with disability during the data collection stage, they understand that research area, that phenomena and they could be active participant in the analysis. And they can... they can analyze, they can approach those data, based on

their perspective, based on the disability perspective, and they can provide a unique... implication of that research based on lived experience of those individuals. So, that unique understanding is really helpful for knowledge mobilization stages.

So, we try to empower them, push them to figure out what the unique point is that we need from that research, based on the perspective of those who have a lived experience. And, also, it's, it's important those who have, do not have the lived experiences as well in that data analysis stage too.

## **Knowledge check questions**

## **Question 1**

\_\_[blank]\_\_ in research design can help address ableist structures and exclusionary practices.

[Select the correct answer to fill in the blank]

- 1. Flexibility
- 2. Conventional approaches
- 3. Interdisciplinary
- 4. Iteration

Answer: Flexibility

## **Question 2**

\_\_\_\_[blank]\_\_\_\_ is a framework that can be used to make research more accessible and ensure meaningful engagement.

[Select the correct answer to fill in the blank]

- 1. Participatory Action Research
- 2. The Universal Design for Learning (UDL)
- 3. Grounded Theory
- 4. The Medical Model of Disability

Answer: The Universal Design for Learning (UDL)

Next, you will look at the recruitment of participants with disabilities.

## Recruitment of participants with disabilities

## **Identify potential participants**

Consider the diversity, the range of experiences, and the intersecting identities of people with disabilities. Ensure that the inclusion and exclusion criteria for your research study are well justified. Strive to recruit people who represent a broad spectrum of backgrounds and varying degrees of disability. This approach enhances the probability of including voices that represent a wide array of perspectives.

## **Initial point of contact (IPC)**

The "initial point of contact" is a person or document, such as a recruitment advertisement, that alerts a potential participant to the occurrence of a research study. Ensure recruitment advertisements are widely circulated; share them through different media with diverse networks and special interest groups.

Consider collaborating with disability justice-focused organizations that pursue similar research interests to co-create research and recruitment plan. Use inclusive language and post recruitment materials in multiple formats such as large print, plain text, accessibility-enabled PDFs, HTML, Word documents and audio formats.

Consider including an accessibility statement and contact information for requesting accommodations in all recruitment materials. Plan for diverse response options to recruitment notices, e.g., the option to respond via phone.

## **Obtaining informed consent/assent**

Before engaging any participant in research, you must first fully and openly engage with them in discussions regarding the purpose of the research, objectives, timelines, risks and benefits, and expected outcomes.

Clearly outline the option to withdraw from participation at any time. Use plain language consent forms that are transparent about all aspects of research. Present information in accessible formats, such as large print with high contrast and ample white space, audio formats (in-person, video, or online), and ensure website compatibility with screen readers.

During the consent process be mindful of any signs of dissent, like discomfort or uncertainty; remember that consent must be given voluntarily, and with enough information to help make that decision.

To learn ethically correct recruitment and informed consent processes please consider taking courses that are part of the **Navigating the Ethical Landscape for Researchers Training Series**.

## **Knowledge check questions**

#### **Question 1**

Consider including \_\_\_\_[blank]\_\_\_ in all recruitment materials. [Select the correct answer to fill in the blank]

- 1. A short description of the study
- 2. Researcher's contact information
- 3. A recruitment script
- 4. An accessibility statement and contact information for requesting accommodation

Answer: An accessibility statement and contact information for requesting accommodation

#### **Question 2**

Ensure that the inclusion	and exclusion	criteria for your	research stuc	ly are
[blank]				

[Select the correct answer to fill in the blank]

- 1. Consistent and reliable
- 2. Well-justified
- 3. Regularly updated
- 4. Generalizable

Answer: Well-justified

Next, you will look at data collection and data analysis.

## Data collection and data analysis

## Individualize the research process

Select your methodology and data collection tools to resonate with a diverse group of participants. Consider this when developing, testing, or assessing the usability and user experience of any service or product such as a new software application or equipment. While research methods vary by discipline, data collection choices will also be impacted by your team's and participants' experiences of disability and accessibility.

Keep these experiences in mind when planning data collection activities (e.g., different types of fieldwork) that may potentially present access barriers to you, your co-researchers and research participants. As a starting point, consider conducting an analysis of context to identify barriers to accessible research in your specific field.

## Consider and analyze data from a variety of sources

Drawing from a range of sources yields more comprehensive data. Strive to appropriately balance quantitative, and qualitative approaches to create a complete picture. Looking at data through a lens of disaggregation and intersectionality is essential to accurately represent diverse perspectives including those of people with disabilities. Engage people with lived experiences to help make sense of the data.

## Adopt flexible scheduling

Keep in mind that flexible timing and scheduling accommodations may reduce people's levels of fatigue and help with research engagement. Schedule shorter research sessions on different days and include frequent breaks. Be flexible with scheduling to accommodate transportation requirements and personal routines.

## Plan for accessibility when choosing location for research activities

When selecting a venue for in-person interactions, take into account multiple modes of transportation, which may involve ensuring access to reliable public transit or allocating a portion of the research budget for transportation. Also, ensure that the chosen location adheres to accessibility standards, particularly those relevant to people using mobility aids.

## Be prepared to adapt research instruments if needed

You may need to modify research instruments and methodologies to meet diverse access needs.

These adaptations can include:

- Adjusting instructions or the way information is presented.
- Modifying how responses are recorded or presented.
- Allocating sufficient time for interviews, surveys, group discussions, testing, etc.
- Adjusting the physical setting in which the research takes place.
- Using a different method of data collection.

## **Knowledge check questions**

#### **Question 1**

Looking at data through a lens of \_\_\_\_[blank]\_\_\_\_ is essential to accurately represent diverse perspectives including those of people with disabilities.

[Select the correct answer to fill in the blank]

- 1. Accessibility and accommodation
- 2. Collaboration and improvement
- 3. Disaggregation and intersectionality

4. Ethics and accountability

Answer: Disaggregation and intersectionality

#### **Question 2**

One way to address physical barriers is to choose research locations that are equipped with \_\_\_[blank]\_\_\_\_ and accessible to people using mobility aids.

[Select the correct answer to fill in the blank]

- 1. Screen readers
- 2. Audible alarm systems
- 3. Route signage
- 4. Ramps or elevators

Answer: Ramps or elevators

Next, you will look at knowledge mobilization and dissemination.

## Knowledge mobilization and dissemination

## Practice accessible knowledge dissemination

Generate summaries of research findings that are accessible to a wide audience. Explore ways of sharing information that go beyond traditional academic publishing and can be easily accessed, such as newsletters, videos, social media posts, or blogs.

Seek out additional channels and methods for sharing research such as community presentations, creating accessible art exhibits from the research findings, social media content, and digital stories. Involve community partners, including your own community, in the dissemination process to enhance its effectiveness.

## Use plain language

Streamline the language used in all research documents and materials. Plain language emphasizes the presentation of complex or technical information in clear and concise ways that avoid technical terms. Ensure that materials consider diverse reading levels. According to Canadian accessibility standards, plain language is typically described as text that can be comprehended at an 8th-grade reading level or lower. To determine if a document is at an 8th grade reading level or lower please reference Microsoft's <u>Instructions for assessing reading level (opens a new tab).</u>

Some tips for achieving simple language:

- Write in short, clear sentences and paragraphs.
- Aoid using unnecessarily complex words and phrases.

- Avoid using technical and legal jargon.
- Expand acronyms on first use. For example, Accessibility for Ontarians with Disabilities Act (AODA).
- Use list formatting as applicable (i.e., numbers to show a process, bullets for all else).
- Consider using images, illustrations, and charts to help clarify meaning or organize schedule of events.

The example below shows a research study written at a very high reading level and also at a plain language reading level.

#### Very high reading level Plain language reading level The present investigation, denoted as We are doing a study called HAPPY to help improve healthcare in Rwanda. We want to 'HAPPY- 9213829387', endeavors to conceive and institute a health-financing find better ways to detect, prevent, and intervention imbued with evidence-based control diseases. To do this, we are going methodologies. The overarching objective to talk to different people and work together to check how well the health care of this study is to enhance disease detection, prevention, and control within system is working. We hope these things the Republic of Rwanda. The proposed will help us figure out how to make healthcare better in Rwanda. methodology involves the establishment of a stakeholder advisory board, the formation of a learning collaborative, and the execution of a comprehensive health system capacity and needs assessment. These multifaceted components collectively seek to discern the most efficacious strategies, thereby contributing to an informed decision-making process

## Wise practices and examples of accessibility features for research dissemination:

- Follow <u>Inclusive Language Guidelines (opens in a new tab)</u> to avoid ableist terminology. For more information, please review "A word on language" section from the <u>Ableism Module (opens in a new tab)</u> created by Queen's Human Rights and Equity Office.
- Pictures, videos, and graphics should have Alt-text. Alt-text is included in all social media postings.
- A transcript is provided for video and audio content.

for the subsequent effectiveness phase.

Research results are summarized using accessible vocabulary.

- Avoid the use of jargon and acronyms.
- Alternate formats are available when needed such as Braille, large print or sign language.
- Use a font size of 12 points or larger for accessible documents.
- Limit the use of italics and text in all capital letters in emails and documents.
- Use headings to format document. People who use screen readers or other
  assistive devices use headings to navigate documents. Learn how to <u>add a</u>
  heading style (opens in a new tab).
- Ensure there is sufficient contrast between text and its background (colour contrast ratio of at least 4.5:1).
- Captioning services, simultaneous interpretation, and sign language are provided at events.
- Illustrations and photos are reflective of diverse populations.
- Hyperlinks are created using meaningful text instead of URL strings.
  - Accessible: <u>Inclusive Language Guidelines (opens in a new tab)</u>
  - Not accessible: <a href="https://www.queensu.ca/brand-central/writing-style/inclusive">https://www.queensu.ca/brand-central/writing-style/inclusive</a> (opens in a new tab)
- Use the accessibility checker in Word, Outlook, PowerPoint, Excel and other Microsoft products. Check online support resources for updates. Improve accessibility with the <u>Accessibility Checker (opens in a new tab)</u>.
- Ensure that rows and columns in spreadsheets and tables have headers. Eliminate
  any merged or split cells in spreadsheets. <u>Make your Excel documents accessible</u>
  to people with disabilities (opens in a new tab).
- Refer to the <u>Web Content Accessibility Guidelines 2.1 (opens in a new</u>
   <u>tab)</u> (WCAG 2.1) if you are interested in learning more about making web content
   more accessible. Please be mindful that these standards change overtime and
   updated versions may become available.

## <u>Institutional support video (opens in a new tab)</u>

[We sincerely thank our guest interviewees for their invaluable contributions to this course content. You can find their biographies at the end of this course]

Video transcript

## Changes at a structural level

Nicole Bobbette, PhD Assistant Professor School of Rehabilitation Therapy Faculty of Health Sciences [0:09] - I do think there's a responsibility at a structural level and at these larger organizational bodies, the REBs – the research ethics boards, the university, to actually, if the intention is accessibility, then let's walk through all the, all the ways that we can, can create or enhance accessibility. And if you map it, you can also see where the blocks can come and, and... if nothing changes, then we need to resource that to make sure that people do feel seen and valued equally to an academic researcher that can just give me their email and their CV and, you know, their burden of time to participate on this project is much less than a community member with a disability that now I'm asking, okay, well, let's get you signed up for an email and let's create a resume for you, and let's go through this ethics training. But, and ultimately, you know, I can't pay you until we get a grant. So, my other team members are, you know, getting paid to contribute to this through their jobs and their responsibilities, but, you know, I don't have money yet for you until we get this.

So... I think both at the university level, but also at our, our larger, kind of funding body level we need to look at some of these things. If that's what we, if we want this kind of research, which I think we, we need from a social justice and rights-based perspective. But the enactment of it is still in process, I think.

## **Accessible publications**

Bekele Worku, PhD

Queen's University Alumnus Assistant Professor, School of Law University of Gondar

[2:00] - Universities must think about developing policies or... publishers requiring to produce their books in soft copies in case they need it for their students or their faculty, or staff with disabilities. Therefore, such types of agreements might be... because as far as I have seen most human beings are willing to help persons with disabilities. The only thing is, there is no one to remind them that they can help by doing a certain very easy task.

For instance, producing their products both in hard copies and soft copies. So soft copies must be protected because, you know, they might create a certain impact on their economic interests. I understand that, but some sort of controlled use for persons with disabilities must be facilitated. Therefore, that might help a lot for persons with disabilities, I think.

#### Well-staffed accessible services

Bekele Worku, PhD

Queen's University Alumnus Assistant Professor, School of Law University of Gondar

[3:12] - The disability centres or disability directorate, it could be disability adaptive technology, just like Queen's. Those have to be staffed to address different disability needs – hearing disability or physical disability, learning disability and sensory disability, that of like mine. If there are institutions or experts staffed very well in those capacities, problems

will be more good. And when I come to research teams, research teams must understand and know members of their teams.

## Funding for researchers with disabilities

Getachew Gebeyaw Tadese PhD Candidate in Rehabilitation Science School of Rehabilitation Therapy Faculty of Health Sciences

[4:30] - Maybe this is my personal interest, but I always look, a special funds for people with disability researchers. When we see scholarships, they may see a criteria that they give for people with disabilities, woman or other groups of the community. But, to what extent the institutions are ready to provide a special funds for people with disability researchers?

That, if, if those people with disabilities have a challenge to participate in a team members and that kind of approach might be helpful to empower them to work research independently by their own capacity and by their own understanding and the procedure that they should, they could follow.

So, this special funding, is, is, really important for, to, to empower those researchers.

## **Knowledge check question**

## **Question 1**

Avoid using \_\_\_[blank]\_\_\_ to make your research findings clear and accessible to diverse audiences.

[Select the correct answer to fill in the blank]

- 1. Accessibility checker
- 2. Complex language and jargon
- 3. Plain language
- 4. Lack of assistive technology
- 5. Alt-text

Answer: Complex language and jargon

#### **Question 2**

Inclusive research materials are available in alternate formats such as \_\_\_[blank]\_\_\_. [Select the correct answer to fill in the blank]

- 1. Standard PDFs
- 2. Print documents in hardcopy
- 3. URL strings
- 4. Braille, large print or sign language

Answer: Braille, large print or sign language

Let's summarize what you have learnt in this course.

## **Summary**

In this course you have learnt about the key concepts and tips for planning accessible research. You have covered:

- Accessibility as an essential component of research.
- The impact of systemic ableism on research design and practice.
- Wise practices for creating an accessible research project, including strategies for research planning and design, participant recruitment, data collection and analysis, and knowledge mobilization.

To conclude this course, review a Case Study and reflect on the discussion questions provided.

## **Case Study**

## Case title: Investigating the Impact of Online Education on Academic Performance

## Instructions for case study activity

Please read the following case study and discussion questions. Think about possible answers. You can work alone or with the members of your team/lab to come up with ideas and draw on your collective knowledge and experience. When you are ready, click on the hints/answers to learn more about potential solutions.

## Investigating the Impact of Online Education on Academic Performance

### **Scenario overview**

A research institution is conducting a study on the impact of online education on academic performance. The research team, comprised of seasoned academics and experts in education, aims to draw conclusions that can inform future educational practices.

Unfortunately, the team hasn't considered how ableism and lack of accessibility features can potentially impact the study. As the case unfolds, you will be asked to explore the consequences of these decisions.

#### **Characters**

Principal Investigator: Dr. Thompson, experienced researcher leading the study. Well-versed in education research but lacks knowledge about accessibility.

Graduate Research Assistant: Chris, graduate student responsible for data collection and analysis. Eager to learn and follow Dr. Thompson's instructions.

Online student with a visual impairment: Maria, participant in the online education system under study. Experiences accessibility challenges caused by the inadequate design of the online education system.

## **Case Developments**

## Research design

Dr. Thompson designs the study, opting for online surveys and self-reported data, assuming this is the most convenient approach for the participants.

Chris is tasked with creating the survey questions without any instructions or guidelines related to accessibility.

#### Recruitment

The team recruits participants through online platforms without specifying the need for diverse representation.

Maria, a student with a visual impairment, comes across the study but is hesitant to participate because there is no information about accessibility considerations.

#### **Data collection**

Chris sends out the online surveys without considering screen reader compatibility or alternate formats.

Maria attempts to complete the survey but faces barriers, leading to incomplete responses.

#### **Analysis**

Chris and Dr. Thompson analyze the data, overlooking the potential biases introduced by the lack of accessibility considerations in the survey design.

### **Results and reporting**

The team, satisfied with the implementation and the results of the study, plans to present the findings.

Maria's experiences and challenges are not incorporated in the final report.

## **Discussion questions**

1. Identify the potential issues in this research study and discuss the instances of ableism in the study design, recruitment, data collection, analysis, and reporting phase.

Please take this opportunity to reflect before you continue.

You can record your thoughts in a manner most suitable to you.

#### Hints/answers

Potential issues and instances of ableism:

- Failure to anticipate and address potential barriers for people with disabilities.
- Lack of information about accessibility measures in recruitment materials.
- Exclusion of researchers and participants with disabilities due to the failure to consider and accommodate diverse needs and preferences.
- Failure to explicitly mention the need for diverse representation, including people with disabilities.
- Overlooking the challenges and perspectives of students with disabilities, resulting in a skewed representation of the impact of online education on academic performance.
- Presenting findings without acknowledging potential biases or limitations related to accessibility.
- Overlooking the experiences of students with disabilities in the final report.
- 2. Explore how the lack of consideration for accessibility might impact the study's findings.

Please take this opportunity to reflect before you continue.

You can record your thoughts in a manner most suitable to you.

Take a moment to reflect before you continue

#### Hints/answers

Potential impacts:

- Without explicitly addressing accessibility concerns in recruitment, the study may exclude people with disabilities. The sample may not accurately represent the diversity of the student population, leading to a skewed understanding of how online education impacts the students.
- The data collected may not accurately reflect the experiences, challenges, and perspectives of students with disabilities, introducing a selection bias into the study.
- The findings may only be applicable to a limited subset of the population, hindering the broader applicability and relevance of the study.

• The study may draw conclusions that do not accurately reflect the impact of online education on the academic performance of students with disabilities, potentially leading to misguided recommendations.

#### Question for further discussion

3. Discuss ways the research team could have designed the study to be more inclusive and accessible from the outset.

Please take this opportunity to reflect before you continue.

You can record your thoughts in a manner most suitable to you.

Take a moment to reflect before you continue

#### Hints/answers

Designing an accessible study:

- If recruiting a research team, follow an employment equity process that specifically targets recruitment of federally recognized equity deserving groups. Ensure accessibility in the hiring process and on the job.
- Collaborate with accessibility experts during the study design to identify potential barriers and find appropriate solutions.
- Acknowledge the potential biases introduced by the lack of accessibility features in the survey and data collection process.
- Integrate accessibility considerations into the research design phase, ensuring that surveys, data collection tools, and recruitment strategies are inclusive.
- Consider applying an intersectional approach to the analysis to include the experiences of students with disabilities.
- Include a section on the experiences of people with disabilities in the findings report, emphasizing their specific challenges and contributions to the study.
- Disseminate the study findings with accessibility in mind. Explore different ways of sharing information that can be easily accessed.

## Thank you for completing Defining Accessibility and Accessible Research

You have completed Defining Accessibility and Accessible Research.

#### **Resources and Definitions information sheet**

You can reference this handy information containing helpful contact information and a list of key terms, provided in both doc and pdf formats.

#### **Resources and Definitions**

#### Resources

Contact information for accessibility concerns.

Manager, Accessibility and Inclusion Services, Human Rights & Equity Office: <a href="mailto:accessibility.hub@queensu.ca">accessibility.hub@queensu.ca</a>

You can request a consultation and/or report an accessibility issue that may involve different types of barriers using the **Accessibility Feedback Form (opens in a new tab)** available on the **Accessibility Hub (opens in a new tab)** website.

You may also submit your feedback about accessibility using any one of the following methods:

By e-mail: equity@queensu.ca

By phone: 613-533-2563

By fax: 613-533-2031

By mail: Equity Office, Mackintosh-Corry Hall, Room 513, Queen's University, Kingston, ON

K7L 3N6

<u>Queen's Student Accessibility Services (opens in a new tab)</u>, in collaboration with instructors and staff, is committed to supporting students with disabilities as they pursue their academic goals: <u>qsas.intake@queensu.ca</u>

**Queen's University Accessibility Policy (opens in a new tab)** and its related procedures and guidelines facilitate the identification, removal, and prevention of barriers to persons with disabilities to enable better access to Queen's University goods, services, facilities, accommodation, employment, buildings, structures, and premises.

## **Definitions**

**Ableism**: A belief system, analogous to racism, sexism or ageism, that sees people with disabilities as being less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others (Law Commission of Ontario, n.d.).

**Barrier**: Anything that hinders the full and equal participation in society of persons with an impairment (Accessible Canada Act, 2019).

**Disability**: Any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment – or a functional limitation – whether permanent,

temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person's full and equal participation in society (Accessible Canada Act, 2019).

**Intersectionality**: Intersectional approach recognizes that people may face multiple forms of discrimination or disadvantage, based on different identity factors such as disability, race and gender, simultaneously. The term was coined by lawyer, civil rights advocate, and critical race theory scholar Kimberlé Crenshaw.

**Medical model**: This model emphasizes people's impairments or medical conditions, often treating them as a personal problem that needs to be fixed. The medical model tends to overlook the broader social, cultural, and environmental factors that contribute to disability.

"Nothing about us without us": This principle gained prominence as a response to the historical exclusion and marginalization of people with disabilities. It recognizes the right of people with disabilities to control their own lives and have a say in matters that directly affect them.

**Person-first language**: Language that emphasizes the person as the primary reference, e.g., "a person with a disability" instead of "a disabled person."

**Social model**: This model makes a clear distinction between impairment and disability. It acknowledges the social barriers that prevent people with impairments from fully participating in activities and accessing opportunities. This model views disability as a social problem and not an individual characteristic.

## **Contact information**

If you find any module content or functionality inaccessible, require materials in an accessible format or with appropriate communication supports, or would like to receive further guidance around this course's content, please contact <a href="mailto:research@queensu.ca">research@queensu.ca</a>.

#### **Guest interviewee bios**

Nicole Bobbette, PhD is an Assistant Professor in the School of Rehabilitation Therapy at Queen's Faculty of Health Sciences. Her research focuses on supporting the health and wellbeing of adults and older adults with intellectual and/or developmental disabilities, as well as their caregivers. She supports interprofessional health providers' education and practice and investigates global examples of effective community supports for people with disabilities.

Claire Davies, PhD is a Professor in the Department of Mechanical and Materials Engineering at Queen's Smith Engineering. Her research focuses on increasing independence of people with disabilities. With an interdisciplinary approach, Dr. Davies combines input from clinicians and engineers to develop new medical technologies, including prosthetic devices, assistive technologies, and interface design.

Getachew Gebeyaw Tadese is a Ph.D. student in the School of Rehabilitation Therapy at Queen's University, a Mastercard Foundation Fellow, and a faculty member in the Department of Social Work at the University of Gondar in Ethiopia. His current research explores the role of community-based rehabilitation in formal and natural support for people with disabilities and their families. As a scholar and an activist, Getachew aims to empower people with disabilities to advocate for inclusion.

Bekele Worku, PhD is a Queen's Alumnus and an Assistant Professor in the School of Law at the University of Gondar, Ethiopia. He completed his doctorate at Queen's Faculty of Law as a Mastercard Foundation Fellow. His thesis explored the implementation of international human rights instruments in Ethiopia, particularly related to the right of education among people with disabilities.

#### **Feedback**

We would greatly appreciate your feedback, please consider completing the survey by clicking the button below. This survey consists of 11 questions. Providing feedback will help us improve this course for future learners. It is estimated that the survey will take 2 - 5 minutes to complete. Your participation is voluntary, responses are anonymous and will be used to guide improvements to this course.

By clicking the link to the survey, you are self-identifying your interest and by completing the survey you are giving implied consent.

Thank you for your help!

Open a link to complete the **feedback survey**.

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