



MULTI-REGIONAL CLINICAL TRIALS

THE MRCT CENTER of
BRIGHAM AND WOMEN'S HOSPITAL
and HARVARD

Accessibility 101: How to Write Alt Text and Map Participant Journeys

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Speakers



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The REACH Project

The REACH Project aims to curate, align, and disseminate tools to advance access to and inclusion in clinical research—for all potential participants--tailored for Institutional Review Boards (IRBs), Human Research Protection Programs (HRPPs), and the broader community.

REACH

Research **E**thics **A**ction **C**ollaborative for **H**RPPs



The Multi-Regional Clinical Trials Center (MRCT Center) of Brigham and Women's Hospital and Harvard

Our Vision

Improve the integrity, safety, and rigor of global clinical trials.

Our Mission

Engage diverse stakeholders to define emerging issues [across all stages of] global clinical trials and to create and implement ethical, actionable, and practical solutions.



Disability data

- 1 billion people and 240 million children globally have a disability.
- People with disabilities are the largest minority group in the US (1 in 4 adults; 1 in 3 Black and Hispanic adults).
- There are different kinds of disabilities such as visual, hearing, mobility, chronic conditions (like asthma), mental health, and cognitive, intellectual, or developmental disabilities. Mental health and cognitive/developmental disabilities are not the same.



Ableism: Definition

- Ableism is defined as:
 - “A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human (Fiona Kumari Campbell; <https://research-repository.griffith.edu.au/server/api/core/bitstreams/bdf45182-e5b6-59f6-8285-2c44ad749a65/content>).
 - “Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be ‘fixed’ in one form or the other (Leah Smith; Center for Disability Rights, <https://cdrnys.org/blog/uncategorized/ableism/>).



Ableism: In clinical care

- Data from the Health Affairs Special Issue on Disability and Health:
 - 82.4% of 714 surveyed physicians assumed that people with significant disability have worse quality of life than nondisabled people (Iezzoni et al.; <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2020.01452>).
 - ‘I am not the doctor for you’ (Legu et al.; <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00475>)



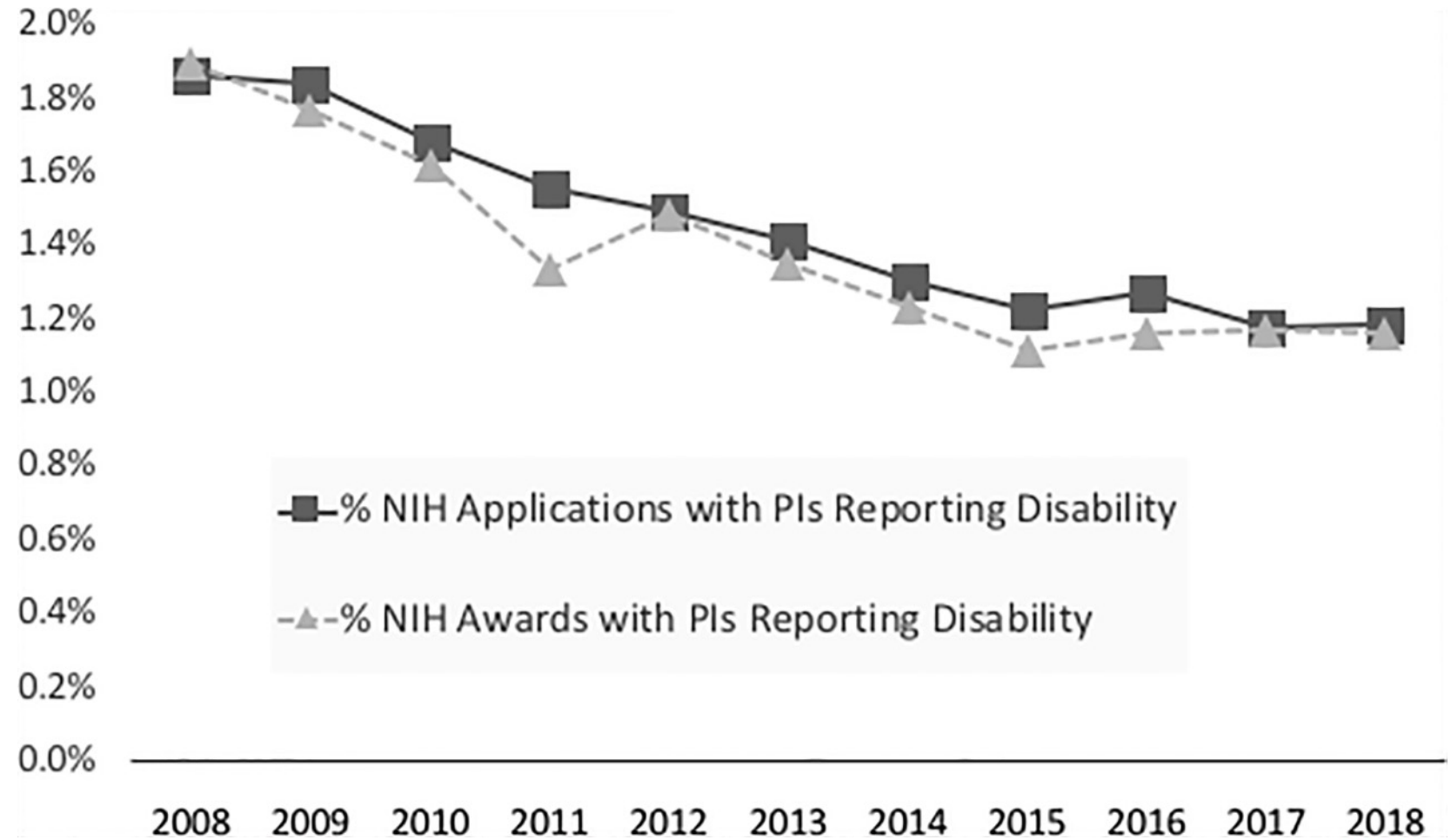
Ableism: In becoming a clinical provider



- 3.1% of surveyed physicians self-identified as having a disability (178 of 6000). Only 9% of those identified as members of underrepresented racial groups (Nouri et al., <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7955270/>).
- Docs with Disabilities Initiative (led by Lisa Meeks) has great data and tools: <https://www.docswithdisabilities.org/>

Ableism: In becoming a clinical researcher

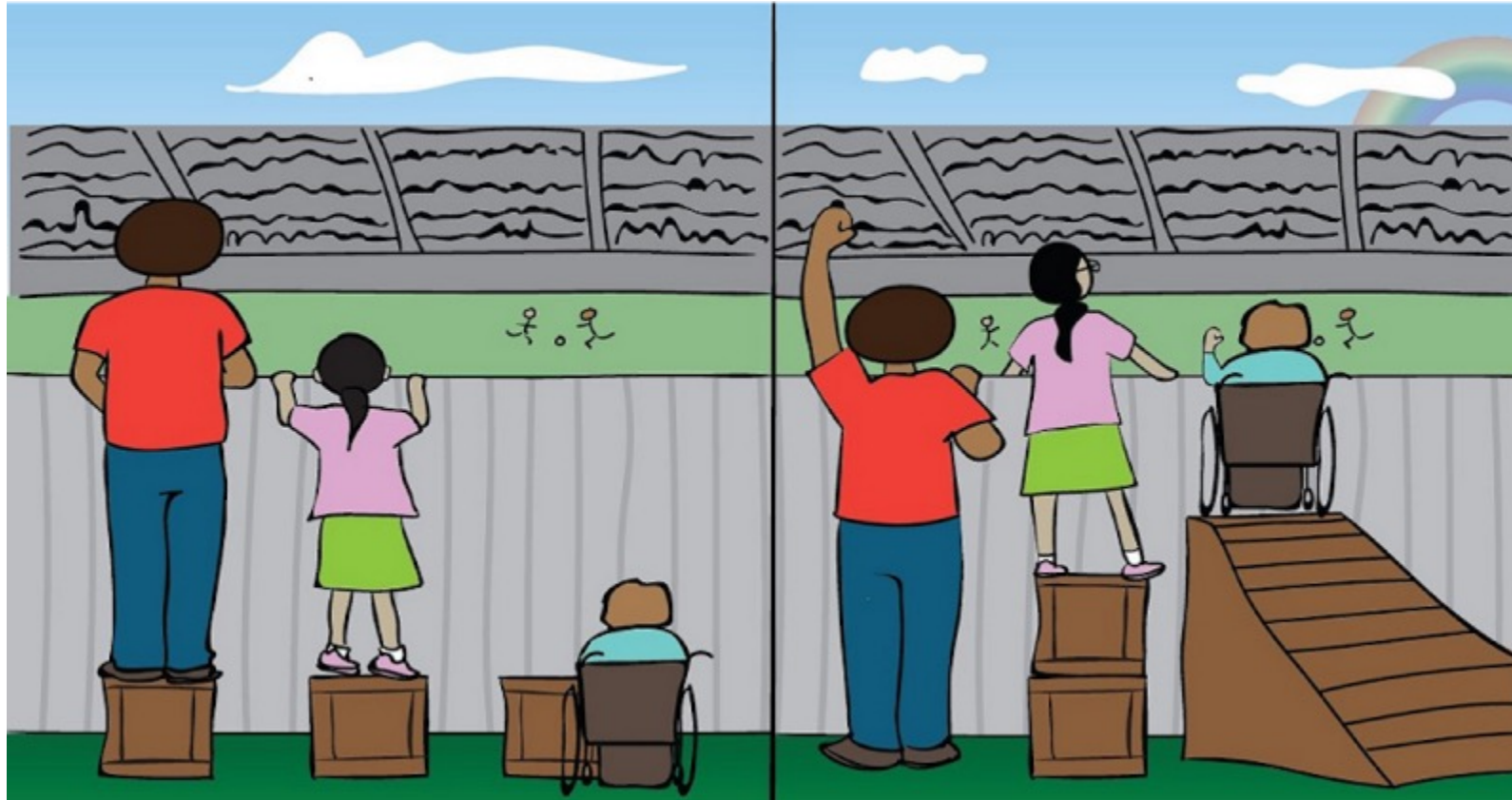
- NIH grant applicants with PIs reporting a disability declined from 1.9% in 2008, to 1.2% in 2018 (Swenor, Munoz, and Meeks; <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0228686>).



Equality-> Equity-> Justice

Equality

Equality is everyone getting the same support.



Equity

Equity is everyone getting the support that they need.

Image credit: Article by Beverly Ward, March 3, 2021. <https://quakerearthcare.org/equality-equity-justice-the-transportation-case-example/>

Disability laws

- International: Convention on the Rights of Persons With Disabilities (CRPD)
- Federal:
 - Americans with Disabilities Act (ADA)
 - Section 504 of the Rehabilitation Act
 - Notice of Proposed Rulemaking: <https://www.federalregister.gov/documents/2023/09/14/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities#:~:text=The%20proposed%20rule%20includes%20new,in%20or%20benefit%20from%20health>
 - MRCT Center response: <https://mrctcenter.org/wp-content/uploads/2023/11/MRCT-Center-OCR-504-comments.pdf>
 - Section 1557 of the Affordable Care Act (ACA) prohibits discrimination against people with disabilities and requires equal access to healthcare.



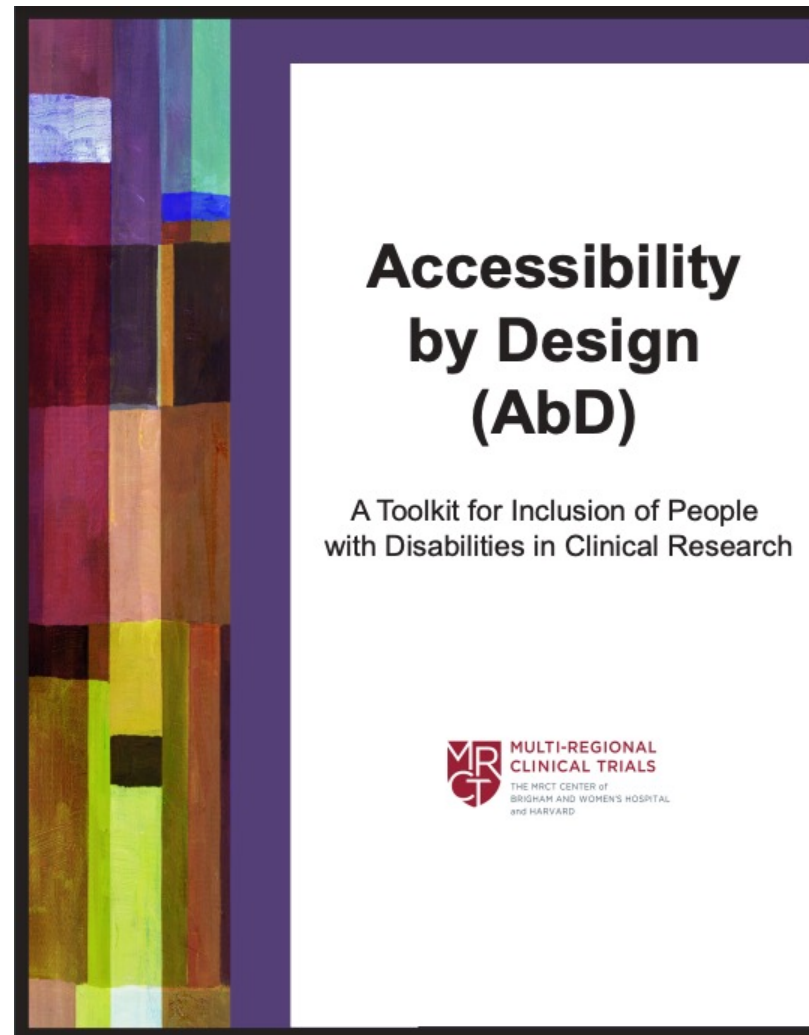
Disability laws, cont.

- State laws vary
- Clinical research guidelines
 - HHS: Protection of Human Subjects, 45 C.F.R. § 46
 - FDA: Diversity Action Plans are now required for Phase 3 and later trials.
 - NIH: People with disabilities recently declared to be a population with health disparities
 - HHS: The Secretary's Advisory Committee on Human Research Protections (SACHRP)



The Accessibility by Design (AbD) Toolkit

https://mrctcenter.org/diversity-in-clinical-research/tools/abd_toolkit/



The AbD Toolkit: Themes

- Preparing for AbD : General Considerations
- Implementing AbD: Communication Accessibility
- Implementing AbD: Physical Accessibility
- Innovating AbD: Newer Strategies for Inclusion
- Upholding AbD: Accountability and Advocacy



The AbD Toolkit: Key Points

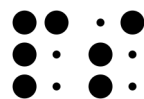
- Key points coded by skill level & feasibility:
 - Green circle (●) “easy”
 - Blue square (■) “moderate”
 - Black diamond (◆) “advanced”
- Links to complementary trainings, tools, and resources.

1. Be respectful



- Don't assume: Ask, and practice active listening. Provide the opportunity for participants to take time to think and to ask for something to be repeated, rephrased, or expressed visually.
- People with disabilities are capable adults. Respect autonomy and speak directly to the individual. When possible, keep your face and mouth visible. Treat physical aids as an individual's personal space. Do not pet or walk beside service animals.

2. Format communication materials for inclusive reading and mental processing





- Use appropriate font such as large print (minimum of 12-point; 16-point if possible) sans serif font (e.g., Ariel, Calibri, Helvetica, Verdana). Avoid justified text, use of *italics*, and ALL CAPS.
- Use contrasting colors and available tools to check that the degree of contrast is sufficient. Make key points and clickable items large and separated by white space.
- Refrain from animation, visuals that include flashing or spinning, pop-ups or auto-play audio (or allow for those setting options).



Example tool in the AbD Toolkit on eligibility criteria

- Revise eligibility criteria in study protocols. Provide justification for exclusions.
- Expect to provide reasonable accommodations, and clearly state they will be available.

 Problematic	 Preferred
Subject is judged by (or is in the opinion of) the Investigator inappropriate for the study.	Participant is documented by the Investigator to be inappropriate for the study due to the following specific scientific, safety, or ethical reasons: [Specify] (e.g., participant has a cochlear implant and cannot complete the required MRI for safety reasons).
Subject has any condition that confounds the ability to interpret data from the study.	Participant has a physical or mental condition, as determined by the study team, that is expected to significantly impact study data interpretation: [Specify] Determination of significant impact is due to the following specific scientific reasons: (e.g., participant is on an immune-suppressive and can't receive live vaccine; has a condition documented to be associated with atypical enzyme function).



AbD tools respond to identified issues in clinical research practice



- 85% allowed for investigator discretion to exclude people.
- Only 24% of the exclusions had a listed justification. The listed justifications were often very broad.
- People with cognitive and intellectual disabilities were excluded in 42% of overall studies (dementia, depression, diabetes, lung cancer), and in approximately 90% of dementia studies.

<https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00520>

Current areas of discussion: Capacity assessment

- The AbD Toolkit does not include information of how to perform a capacity assessment or the assessment measures.
 - Tools like the INCLUDE Impaired Capacity to Consent Framework can be helpful
<https://www.capacityconsentresearch.com/include-impaired-capacity-to-consent-framework.html>
 - When to assess capacity? With whom? What about long-term decentralized trials like All of Us?
- Participation as researchers:
 - RE4ALL: Accessible Research Ethics Education for Community Research Partners. Available from:
<https://re4all.org/>



Image credit: Licensed under CC BY-NC-SA 4.0

Current areas of discussion: Decentralized trials

- There is a greater push for decentralized and more rapid trials. Will decentralized trials support or exclude people with disabilities?

**Communication
accessibility?**

**Physical
accessibility?**

**Financial
accessibility?**

Current areas of discussion: Data, financial neutrality

- Representation in data collection and differing definitions of disability.
 - Health Affairs Special Issue on Disability and Health: <https://www.healthaffairs.org/disability-and-health>
 - Census Bureau/American Community Survey; Washington City Question Set; [US] National Survey on Health and Disability
- Financial neutrality for participants with disabilities.
 - Tax law; Impact on benefits
 - Travel costs may be higher (See MRCT Center Response to DOJ Public Comment Request on Medical Diagnostic Equipment at: <https://mrctcenter.org/resource/comment-on-the-nprm-regarding-regulations-to-title-ii-of-the-americans-with-disabilities-act-accessibility-of-medical-diagnostic-equipment-of-state-and-local-government-entities/>)



Alt Text Exercise



Alt Text background information

Alt Text (or Alternative Text) are written statements that describe an image or graphic for a person who is not able to see it.

Alt Text can be read by screen readers. Screen readers are assistive technologies (software or hardware) that read information about images, menus, dialogue boxes, and files and then conveys that information through an audio or Braille format to the person using the screen reader.

Alt Text can be used for icons, pictures, graphics, illustrations, logos, and sometimes for charts (depending upon the complexity of the chart) and in Word documents, Powerpoint, social media, websites, apps, and some other participant-facing media. Alt Text can be displayed by websites if images do not load properly.



Alt Text background information, cont.

- Alt Text should convey the meaning of an image as it relates to the content/context.



A picture of a scale.



A scale, representing justice, that is equally balanced.

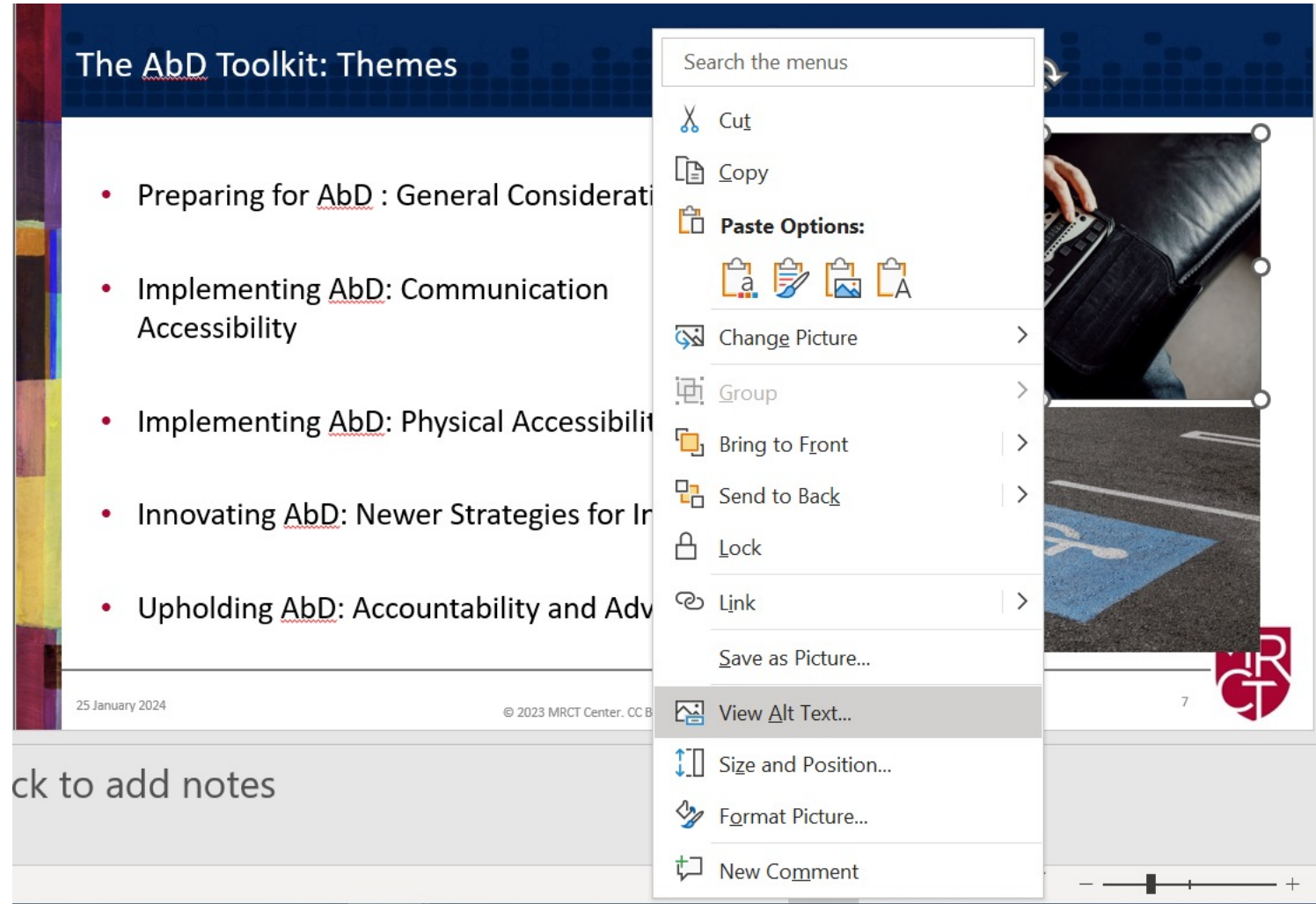
- For decorative objects (e.g., a border or a colored line that underlines text) write “null” in the Alt Text box or select “Mark as decorative” when you get to the Alt-Text screen.
- Do not insert emojis or personal opinions (e.g., a “disheveled” patient) in Alt Text.
- You should be able to clearly and concretely describe an image through Alt Text. Avoid using images that require abstract thinking.

Alt Text how-to: Step 1, find the Alt Text option

For a PC: Right-click (with the right-most button on your mouse) on any photo, chart, or image.

Select View Alt Text from the drop-down list.

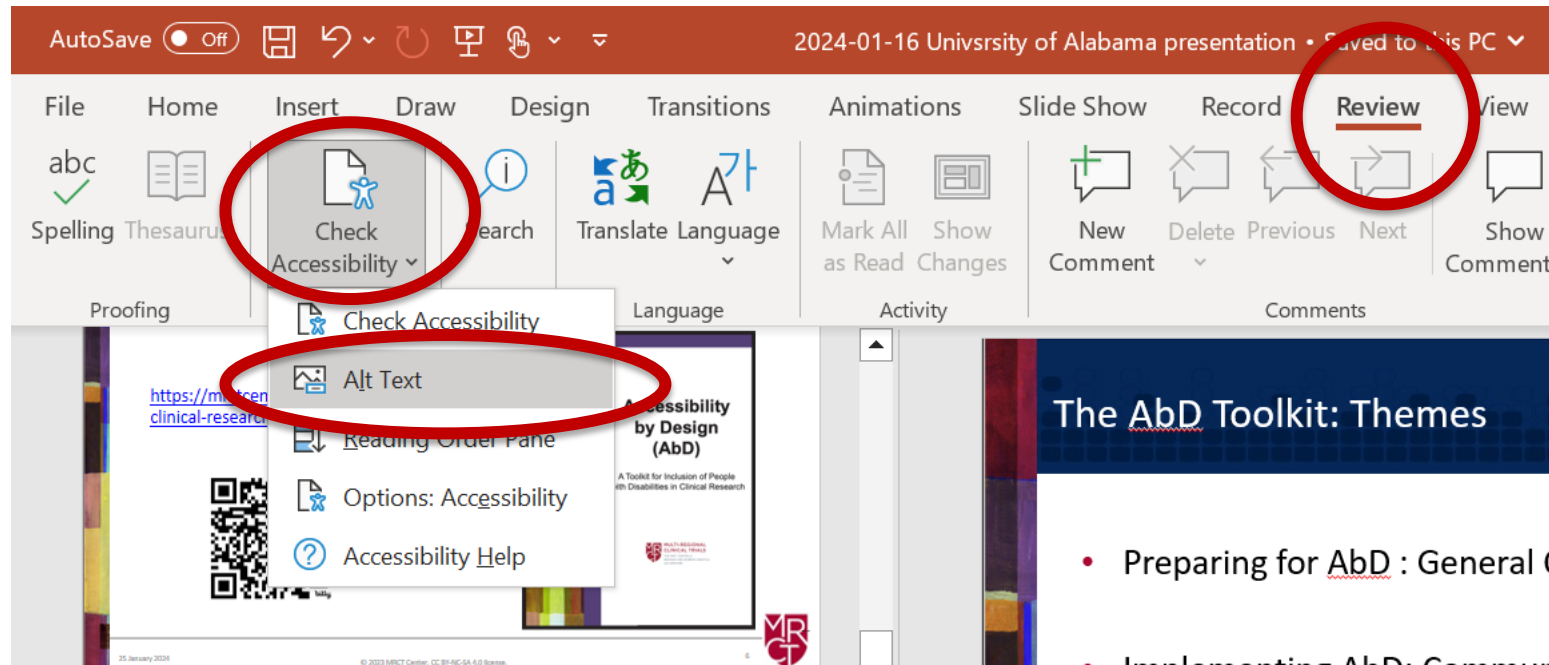
Please note: These instructions may differ on a Mac computer.



Alt Text how-to: [Alternate] Step 1, find the Alt Text option

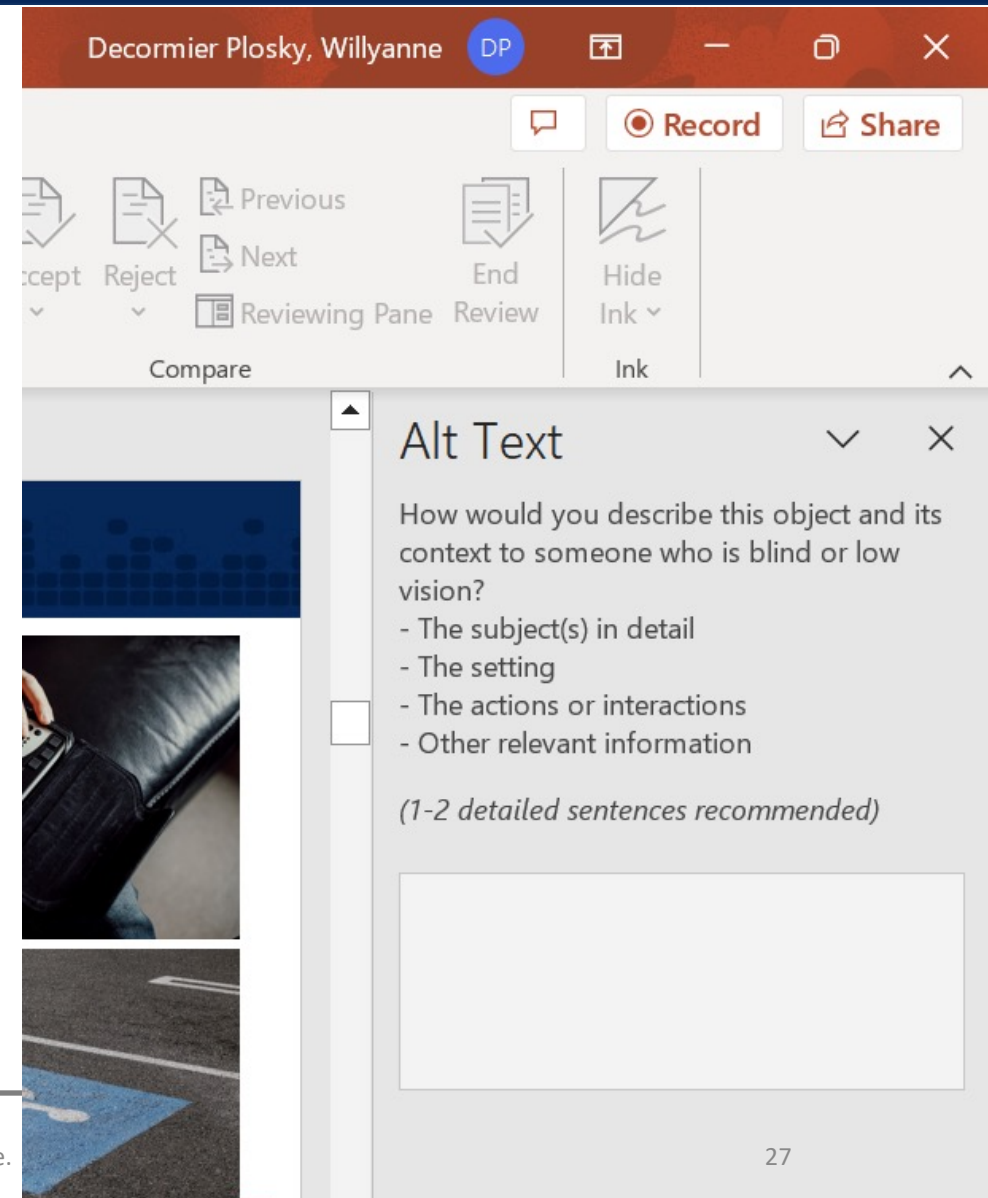
OR go to “Review” on the top ribbon, and then to “Check Accessibility.”
Select Alt Text from the drop-down list.

Please note the built-in Check Accessibility feature available in Microsoft programs like Powerpoint and Word. You can support accessibility on more ways than Alt Text!



Alt Text how- to: Step 2, enter image description into Alt Text window

Using either method, a box will appear on the right side of the screen. Enter in a brief description of what the image shows.



Alt Text exercise instructions

We will review each image (1-5) together. When prompted you can enter your proposed Alt Text for that image into the chat.

Context for images 2-5 has been provided, so that you may better convey the meaning for each image in your Alt Text.

At the end of this Alt Text exercise, we will summarize lessons learned.



Add Alt Text for an image (where you don't know context yet)



Image 1. Look closely at this image.

Then write your draft Alt Text in the chat. Be sure to start your draft text with the label: Image 1.

Add Alt Text for an image, where you know the context is about accessible medical equipment



Image 2. Now look again at this image.

Read the context: **You are discussing the accessibility of medical equipment, such as exam tables.**

Then write your draft Alt Text in the chat. Be sure to start your draft text with the label: Image 2.

Add Alt Text for an image, where you know the context is about workforce diversity



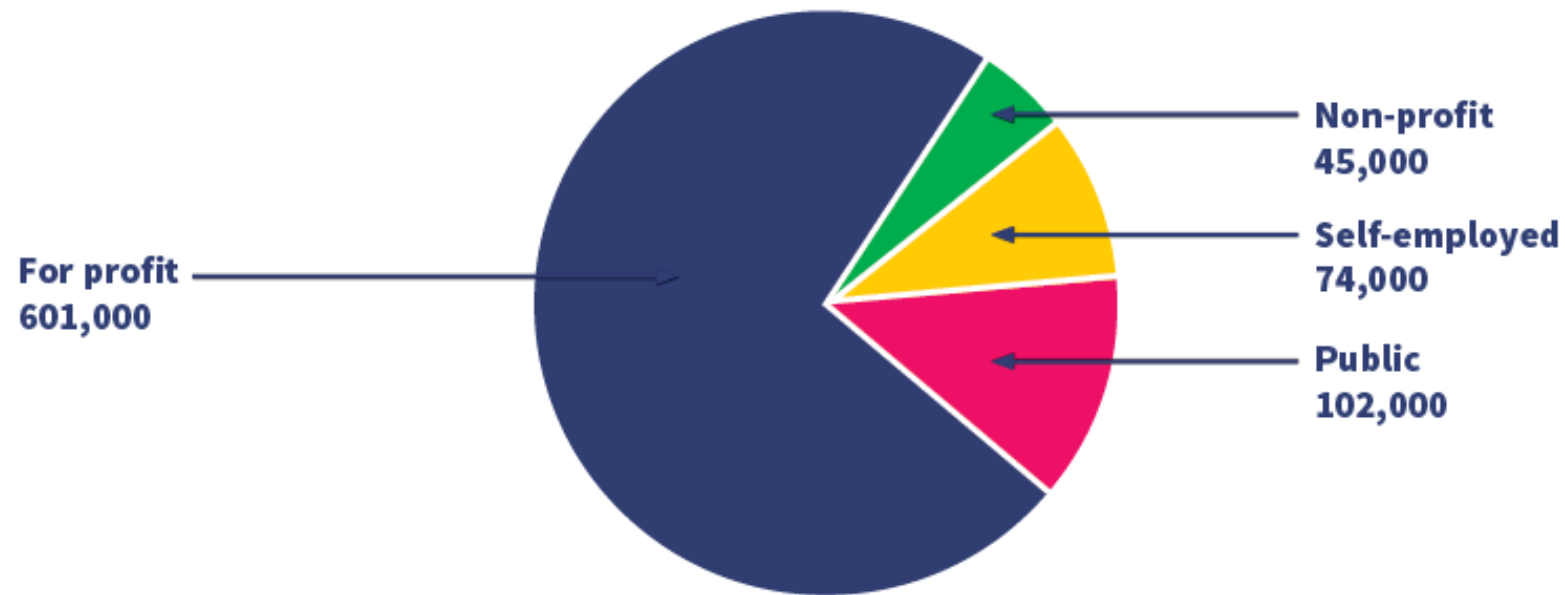
Image 3. Now look again at this image.

Read the context: **You are discussing the importance of workforce diversity.**

Then write your draft Alt Text in the chat. Be sure to start your draft text with the label: Image 3.

Add Alt Text to an image of a chart and data

Employment of Disabled Hispanic Workers (Age 16+) by Sector



Source: Authors' calculations using the Current Population Survey 2021, annual averages.

Image 4. Look at this image.

Read the context: **You are discussing the different sectors in which Hispanic people with disabilities are employed.**

Then write your draft Alt Text in the chat. Be sure to start your draft text with the label: Image 4.

Add Alt Text to more abstract images



Image 5. Look again at this image.

Read the context: **You are discussing the use of Artificial Intelligence (AI) to analyze clinical trial data.**

Then write your draft Alt Text in the chat. Be sure to start your draft text with the label: Image 5.

Lessons learned about Alt Text

1. Point 1: Context is very important.
2. Point 2: It can be difficult to get the right information in a succinct format. Focus on the key concepts that you are trying to convey with the image. If it takes more than three sentences to describe the image, it is likely too complex to serve as visual support. Select your images carefully.
3. Point 3: Describing physical features may be appropriate depending on context. In the disability community we describe ourself physically (e.g., I'm a white woman with long brown hair wearing glasses and a pink shirt), and therefore if physical attributes are important to the context, then it is ok to include those in the Alt Text description.
4. Point 4: Tailor images and Alt Text to your audience. If possible, review images and Alt Text with community members.
5. Point 5: If an image is only decorative, you may either mark it as decorative (under the Alt Text box), or you may write in the Alt Text box that it is a decorative image and give a brief description.



Physical Accessibility Exercise



Site accessibility background information

Attention to [physical or virtual] site accessibility requires a thorough understanding of the participant's (and family caregiver's or supporter's) journey to accessing trial components. This journey can start from a participant's home to transportation pick-up/drop-off, to the site location, getting into the site, navigating within the site to the different areas for appointments, interacting with different forms of medical equipment, and returning home.

The perspective of this journey and the barriers encountered will be different for people with different disabilities.

It is important to plan for this journey with people with disabilities (and family caregivers or supporters) who have lived experience. Please note that the following exercise, conducted with workshop participants who may not have lived experience with disability, is only meant to stimulate thinking. It is not intended to replace comprehensive inclusion of people with disabilities in the planning and conduct of trials.



Exercise 2: Mapping accessibility

Instructions for Exercise 2

We will review the following slides together, one at a time. The slides show different situations that may be part of a participant's journey at fixed sites, mobile sites, or through virtual applications.

For each slide we will ask you to consider where there may be challenges for people with disabilities and any people who accompany them (and enter your thoughts into the chat when prompted). You can consider the challenges from any disability perspective, for example, people with **visual, hearing, mobility, sensory, cognitive and intellectual**, or other disabilities.

At the end of this Mapping Accessibility exercise, we will summarize lessons learned.



Fixed sites: Getting into the facility



Fixed sites: Check-in kiosk

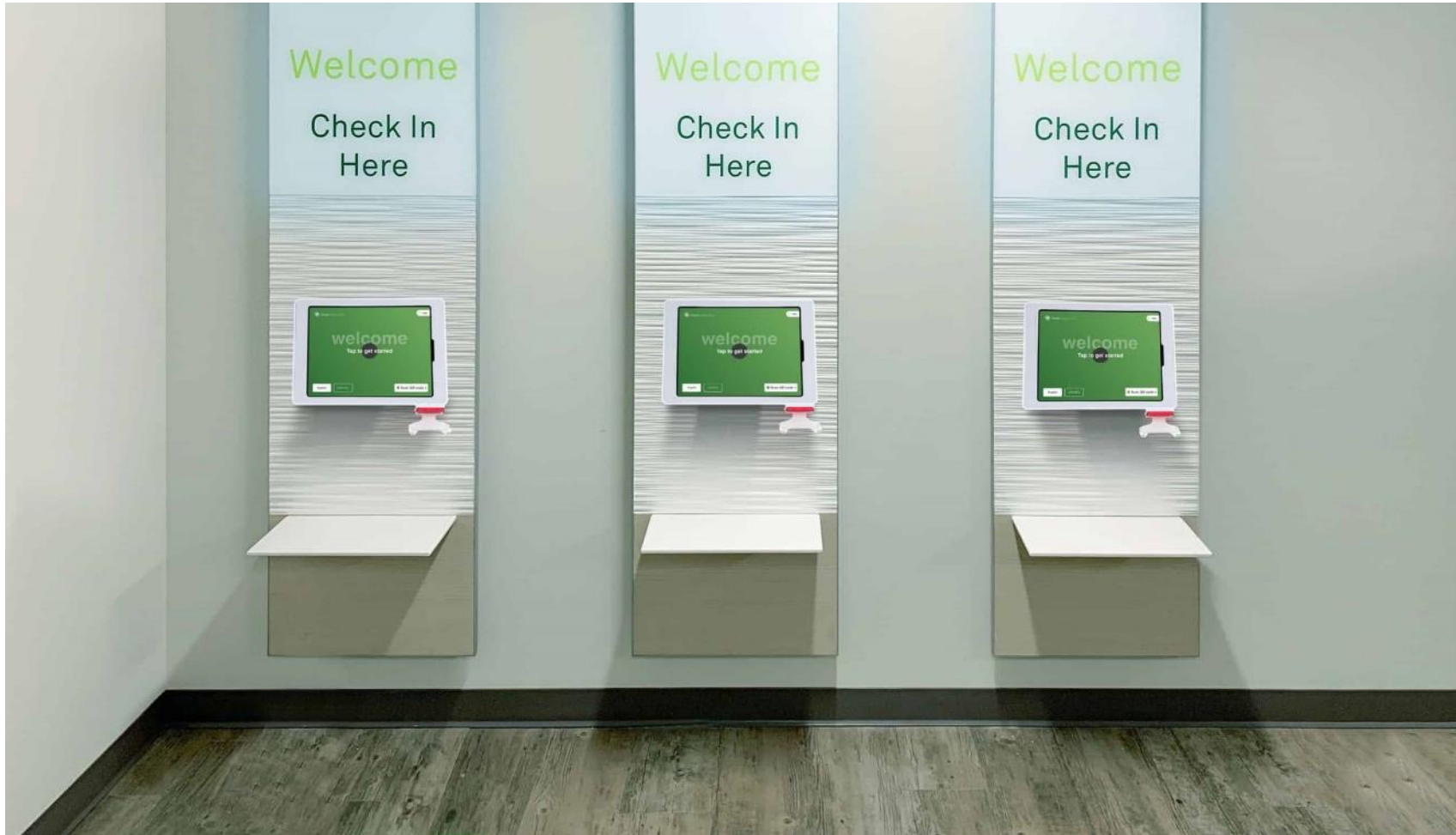


Image credit: <https://www.ailatech.com/blog/quest-diagnostics-saving-phlebotomists-time-and-streamlining-the-patient-experience-with-self-service-kiosks/>



Fixed sites: Waiting area



Fixed sites: Diagnostic exam room (CT scan)



Mobile sites: Unit under a tent



Mobile sites: [Ophthalmology] unit on a train (similar to the interiors of mobile units in vans or container trucks)



Image credit: Wikimedia Commons. [https://commons.wikimedia.org/wiki/File:Interior_of_Lifeline_Express_20080808-3_\(20230422130951\).jpg](https://commons.wikimedia.org/wiki/File:Interior_of_Lifeline_Express_20080808-3_(20230422130951).jpg)

Virtual applications: Self-measuring and reporting diagnostics (e.g., for a fitness test)



Lessons learned about physical accessibility

1. Point 1: Use appropriate color contrast, audio options to complement visual tools, font size adjustment options, and data labels for charts. Avoid very bright (e.g., all white, all glass) walls and signage.
2. Point 2: Remove obstacles in hallways, waiting areas, parking lots, and other spaces. Make sure that spaces are not too narrow and there is room to navigate for people that use wheelchairs. Make sure that medical equipment is accessible (e.g., adjustable height tables, lifts, patient-transfer equipment, railings) and provide storybooks or other sensitization options when participants will be interacting with equipment or other situations that may be scary.
3. Point 3: Post clear signage/directions. Where possible, make clearly identifiable staff available to help.
4. Point 4: For mobile devices and apps consider if these devices will be accessible for people with limited dexterity or with limb differences. Also, do the devices require expenditure for the participant (e.g., internet). Can they be used by people who speak languages other than English? Can they be used by people with cognitive and intellectual disabilities?



Thank you



<https://mrctcenter.org>

