

Driving Inclusion in Clinical Research

Second Wednesday monthly
11AM – 12PM ET

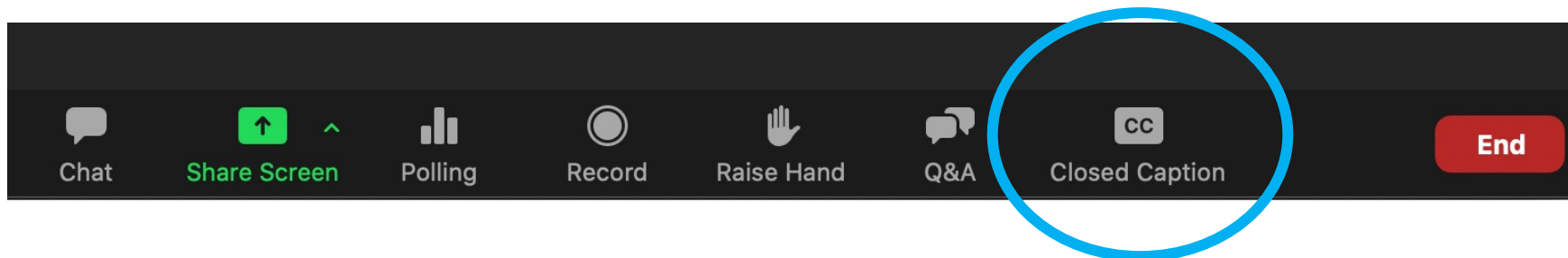


**MULTI-REGIONAL
CLINICAL TRIALS**

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

LEANING IN: A WEBINAR SERIES

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Disclaimer

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The MRCT Center is supported by voluntary contributions (www.MRCTCenter.org) and grants.

Practical Approaches to Improving Diversity in Clinical Trials

Wednesdays
11AM -12noon ET



LEANING IN: A WEBINAR SERIES

PREVIOUS WEBINAR
RECORDINGS AND SLIDES
AVAILABLE TO DOWNLOAD
[HERE](#)

Community Awareness, Access, Knowledge

Workforce Development

Study Design, Eligibility, Site Selection & Feasibility

Study Conduct (Recruitment, Retention)

Data Standards and Analysis

Stakeholder Roles and Responsibilities

Role of Data in Diversity: Genetics & Real World Data



Webinars in this series

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- + April 14, 2021: How to Begin
- + May 12, 2021: Inducement or Fair Compensation? Impact on Diverse Participation
- + June 9, 2021: Improving Inclusion of Persons with Disabilities in Clinical Research
- + July 14, 2021: Simplifying the Complexity of Translation in Clinical Research

Webinar recordings
and slides available



The Multi-Regional Clinical Trials Center (MRCT Center)

Our Vision

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

Our Mission

Engage diverse stakeholders to define emerging issues in global clinical trials and to create and implement ethical, actionable, and practical solutions.



Guidance Document and Online Resources

Outstanding Leadership and the invaluable contributions of >50 Workgroup members, representing:

- Patients, Patient Advocates
- Academia
- Pharmaceutical companies
- Medical device companies
- CROs
- Non-profit organizations
- Trade associations
- Government agencies
- Research institutes

Each serving in their individual capacity.



<https://mrctcenter.org/diversity-in-clinical-research>



Today's topic and guest speakers

Improving Inclusion of Persons with Disabilities in Clinical Research

June 9, 2021
11AM -12PM EDT



Barbara Bierer, MD
Moderator
Faculty Director,
MRCT Center



Tinamarie Duff
Guest Speaker
Global Lead: People and
Business Resource Group
for DAWN (Differently-Abled
Workplace Network)
at Bristol Myers Squibb



Julie Sowash
Guest Speaker
Executive Director,
Disability Solutions
Co-Host, Crazy and The
King Podcast
DEIB Lead, Ability Beyond



Michael Stein
Guest Speaker
Professor
Executive Director,
Harvard Law School
Project on Disability



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Individuals with disabilities



- ~60 million people in the US live with disabilities
- Definitions vary
 - WHO
 - US American Disabilities Act
 - US Department of Commerce Economics and Statistics Administration (US Census)
 - Centers for Disease Control and Prevention (CDC)

CDC Definition

- A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).
- There are many types of disabilities, such as those that affect a person's:
 - Vision
 - Hearing
 - Motor or physical movement (chronic, intermittent, or progressive)
 - Learning or comprehension
 - Emotional, intellectual, interpersonal, or social



Comfort – and discomfort – in the conversation

- Beginning conversations with an open question that allows an individual to respond, prior to more specific questioning, is often helpful, such as:
 - Do you have any limitations that I should know about?
 - Do you have any limitations or disabilities that might impact your participation in the research?
 - Can we help make your participation easier in any way?
- These types of questions can then be followed with more specific questions:
 - How are you going to get to your clinic visit, and are there barriers?
 - What are the accommodations that I should know about?
- Adopting the principle of “universal precautions,” asking everyone about their lived experience whether or not a disability is visible or evident, is the most equitable and considerate approach.



People (or person) first language (PFL)

Use This	Avoid This
Person(s) with disability	Handicapped person, the disabled
Person(s) without disability	Normal person, typical person
Person with quadriplegia	A quadriplegic
Persons who are blind or visually impaired	The blind
Person with a learning disability	Learning disabled
Person who receives special education services	Special ed student
Person who uses a wheelchair	Wheelchair-bound, confined to a wheelchair
Accessible parking, bathrooms, etc.	Handicapped accessible parking, bathrooms,

PFL is not without controversy: It is OK to ask



General recommendations

- Ask about, and provide information about, accommodations
- Include who to contact should accommodations be required
- Solicit advice and recommendations from organizations and people dedicated to access
- Offer telemedicine, video conferencing, and virtual visits as appropriate
 - Availability of large print format
 - Health literate and plain language materials, appropriately translated
 - Audible translation for individuals unable to read
- Use person-first language (until you can ask the person their preferences)
- Create and use multiple formats (visual, written, verbal, picture) for all communications
 - Visual: large (≥ 18) font, sans serif fonts, contrast, screen readers, Braille, alt text, voice over)
 - Hearing: complementary visual format, closed-captioned, transcripts, telecommunications relay services)
- Use assisted technologies whenever possible
- Remain flexible and be aware of personal bias



Technology resources for common applications

Web-based resources should be created with accessibility in mind from the outset:

- <https://www.w3.org/WAI/standards-guidelines/wcag/>

Google has resources for accessible web creation:

- <https://support.google.com/docs/answer/6199477>

Twitter has accessibility tools:

- https://blog.twitter.com/en_us/topics/company/2020/making-twitter-more-accessible.html

Microsoft has a commitment to accessibility:

- And dedicated accessibility resources:
 - <https://www.microsoft.com/en-us/accessibility>
 - https://www.microsoft.com/en-us/accessibility/resources?rtc=1&activetab=pivot_1%3aprimar3
 - <https://support.microsoft.com/en-us/windows/guide-for-people-who-are-blind-or-low-vision-11c8b979-f8cd-f65e-6406-6f03b613b94b> (for those who have low vision or are blind)
- And a shared list of resources from suppliers:
 - <https://www.microsoft.com/en-us/accessibility/supplier-toolkit-resources?rtc=1>



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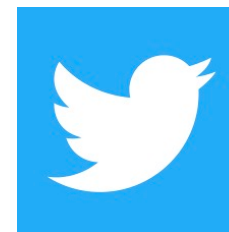


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Discussion and Questions