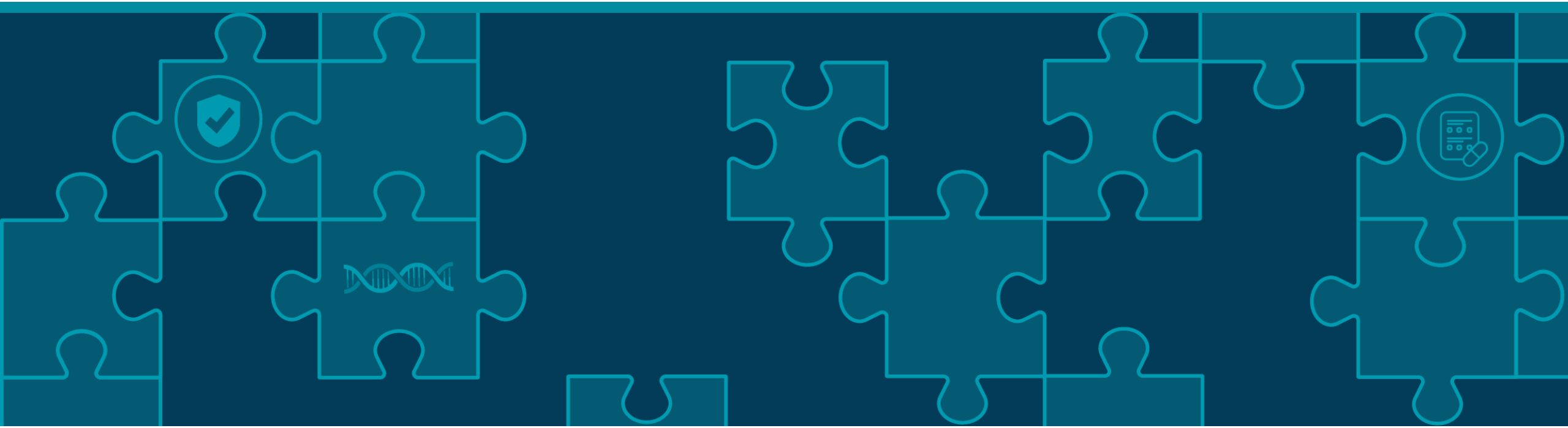

MULTI-REGIONAL
CLINICAL TRIALS
THE MRCT CENTER OF
BRIGHAM AND WOMEN'S HOSPITAL
and HARVARD
The Clinical Research Glossary Biannual Meeting
Adoption, Implementation, and Impact
building community around health literacy
LOCATION:
Virtual
DATE:
June 16, 2026
TIME:
12-1:30 pm EST
Welcome!

Welcome

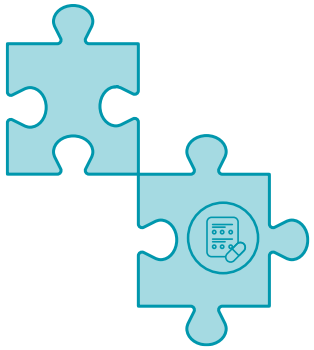


Disclaimer

The views and findings expressed today are ours, serving in our individual capacity, and do not imply endorsement or reflect the views or policies of Mass General Brigham, Harvard Medical School, or any affiliated organization or entity.

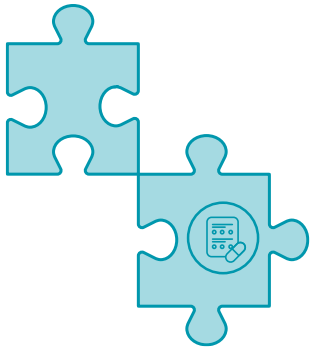
The MRCT Center is supported by voluntary contributions from foundations, corporations, international organizations, academic institutions, and government entities (see www.MRCTCenter.org) as well as by grants.

We are committed to autonomy in our research and to transparency in our relationships. The MRCT Center—and its directors—retain responsibility and final control of the content of any products, results and deliverables.



Webinar Logistics

- **This webinar is being recorded.**
  - The recording, slides and other resources will be made available on the MRCT Center website within the next week.
- **Please use the Q&A to ask questions**.
  - We will do our best to respond live – but will provide written responses to the questions we were unable to answer.
- **Please introduce yourself in the chat.**
  - We'd love to hear where you're joining from and why you decided to join this webinar today.



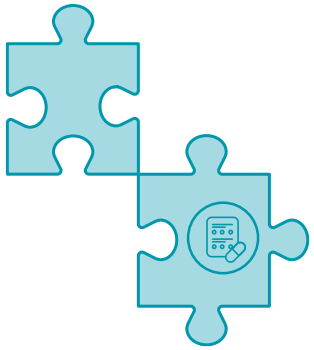
Overview of Today's Session

1) Introduction to the MRCT Center and the Clinical Research Glossary

2) Industry and Patient Partner Perspectives

3) Panel Discussion and Audience Questions

4) Closing



About the MRCT Center

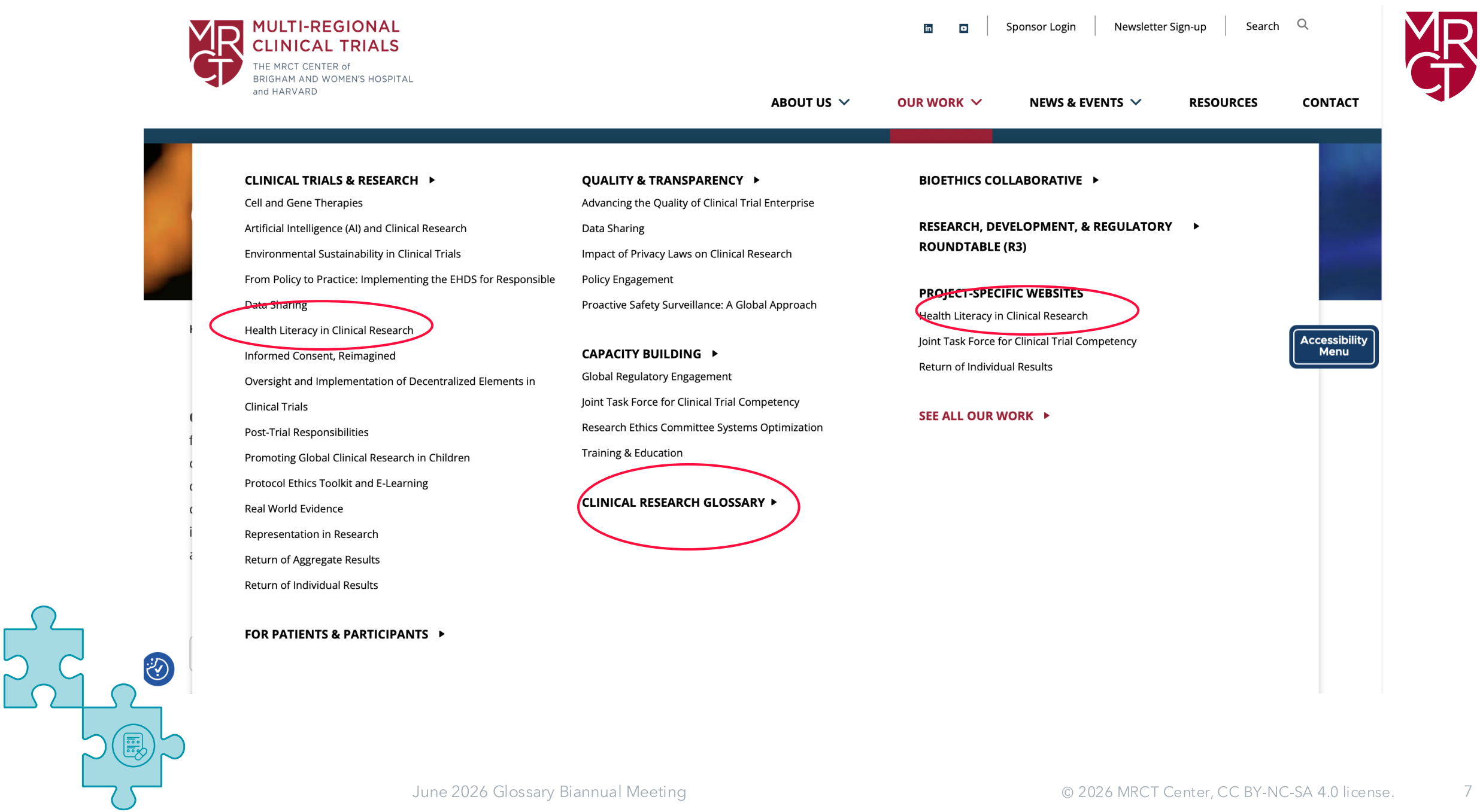
Our Vision

Improve the integrity, safety, and rigor of clinical trials around the world.

Our Community

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

www.mrctcenter.org



Ongoing Commitment to Health Literacy

2017 – Release of Return of Results toolkits and guidance that incorporated health literacy principles

2019 - Completed a multi-stakeholder initiative focused on health literacy and launched a publicly available website on Health Literacy in Clinical Research. www.mrctcenter.org/health-literacy

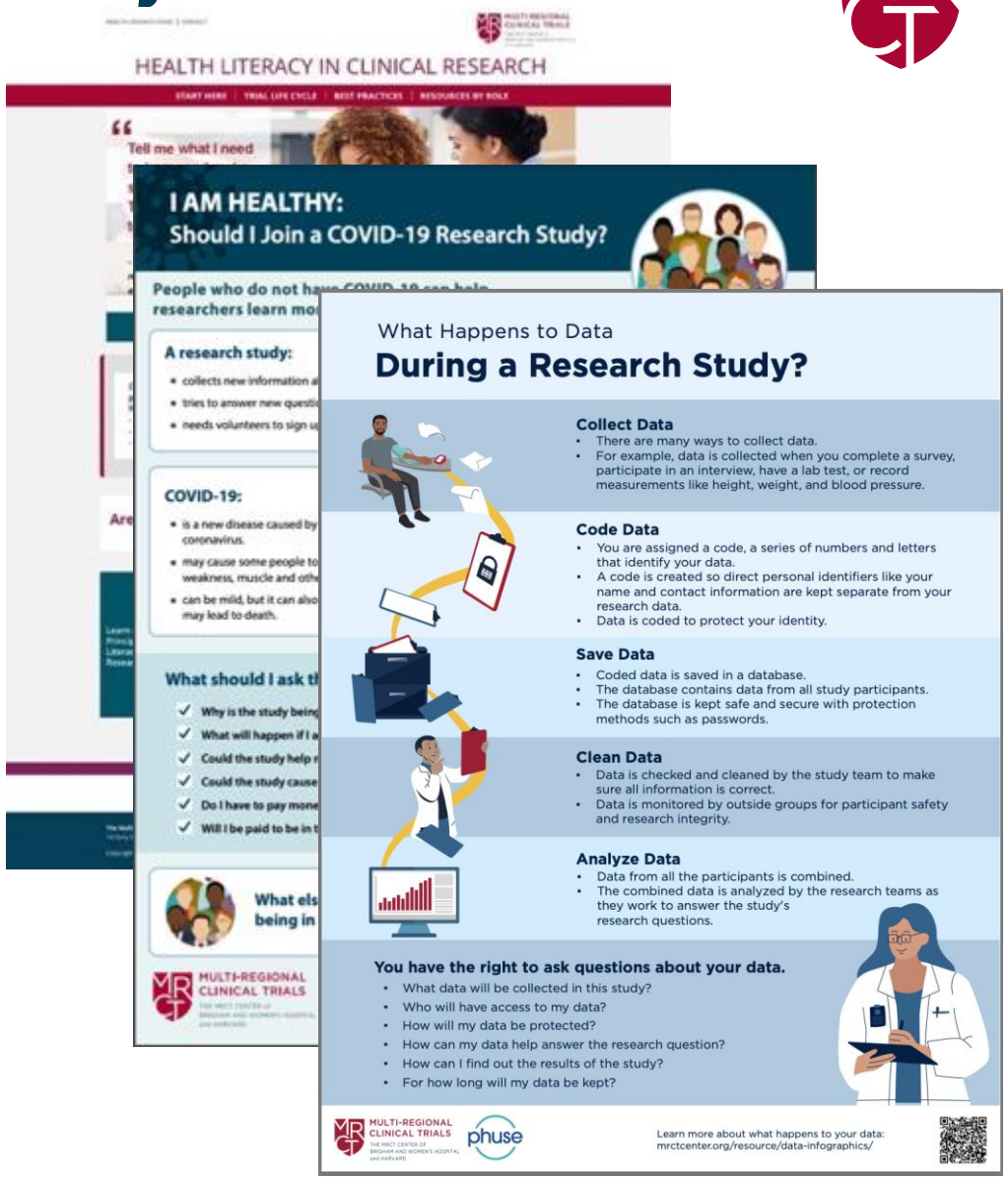
2020 - Developed COVID-19 pamphlets to support understanding of clinical research (in English & Spanish). https://mrctcenter.org/blog/resources/covid-19-clinical-research-flyers/

2020 to 2021 - Piloted and launched the first version of the Clinical Research Glossary! https://mrctcenter.org/glossary/

2025 - Developed and released a set of data literacy infographics.

2026 – health literacy in clinical research, patient engagement, and return of results updates!

Ongoing: glossary development, maintenance, and dissemination



Clinical Research Glossary

Helping you understand clinical research

The Clinical Research Glossary offers easy to understand clinical research definitions.

All definitions are developed by the MRCT Center and a committed team of patient advocates and other professionals in medicine and research. Before definitions are released, they are reviewed by members of the public.

The Clinical Research Glossary started as a pilot project in 2020 and is now a CDISC global standard for clear communication. This means that more and more groups are learning about and using this resource.

Welcome! We hope this resource is helpful to you.

LEARN MORE | GET INVOLVED | MEET THE TEAM | DOWNLOAD

Search glossary | SEARCH

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

A

additive effect -
The combined effect when two or more things are used together.

adherence -
Following the study directions and requirements.

adverse event -
Any health problem that happens during the study.

https://mrctcenter.org/glossary/

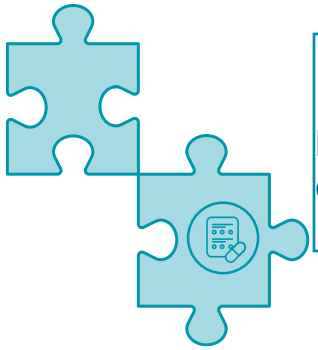
Thank you to the current team!

Development Team

Rebecca Baker, *CDISC*
Lisa Chamberlain James, *Trilogy Writing*
Sudipta Chakraborty, *Biogen*
R Bernard Coley, *Advocate*
Deborah Collyar, *PAIR/Advocate*
Scott Finger, *CISCRP*
Rick Galli, *CIHR Centre for REACH*
Kavita Garg, *Saliegral*
Helle Gawrylewski, *Hawkwood Consulting, LLC*
Art Gertel, *MedSciCom, LLC*
Julia Hild, *Boehringer-Ingelheim*
Maureen Kashuba, *Merck & Co.*
Rena Lubker, *Medical University of South Carolina*
Josh Mailman, *Advocate*
Erin Muhlbradt, *CDISC/NCI EVS*
Pavithra Mukunda, *Stanford*
Marilyn Neault (co-lead), *Advocate*
Harold Silverman, *Argenx*
Gloria Stone, *G Stone Connections*
Cornelia Weiss-Haljiti, *Boehringer-Ingelheim*
Peery White, *Strengthening Native Connections LLC*

Review Team

Roberta Albany, *Advocate*
Jessica Chaikof, *Advocate*
Maura Cummings, *Advocate*
Joseph Haddad, *Advocate*
Crystal Hendricks-Kretzer, *Advocate*
Sheila Polite, *Advocate*
TJ Sharpe, *Advocate*
Desiree Walker (co-lead), *Advocate*

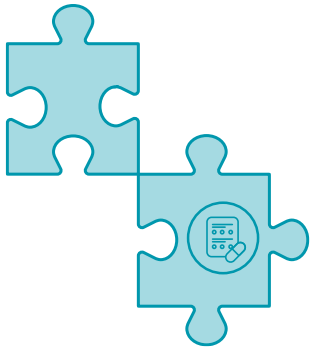


Expert Advisory Committee

Behtash Bahador *CISCRP*
Elizabeth Brown *Merck*
Jay Duhig *AbbVie*
Malgorzata Sztolsztener *Astra Zeneca*
Marian Ryan *Institute for Healthcare Advancement*
Nathalie Bohm *Pfizer*
Robert Weker *Advocate*

Clinical Research Glossary Collaboration Highlights

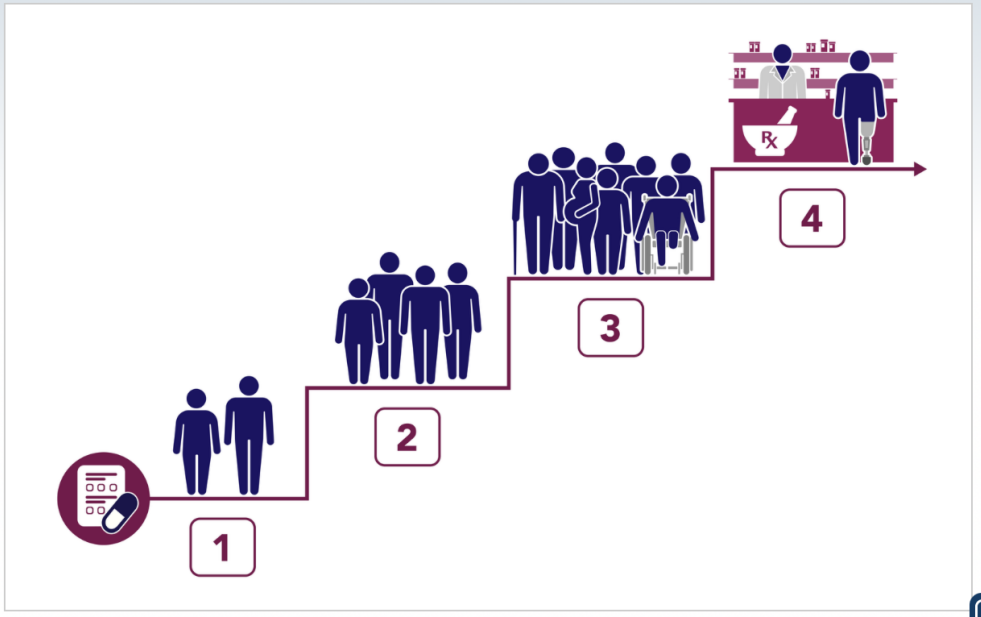
- Long-standing, diverse, multi-interest-holder team
- Monthly meetings for verbal feedback and discussion about content
- Opportunities for written feedback submission and one-on-one meetings to share comments
- Concurrent image development process with information designer
- Ongoing, active collaboration with the Clinical Data Interchange Standards Consortium (CDISC)
- Public Review every June
- Updated Clinical Research Glossary released every September



phase

cdisc

A step in the overall clinical research process to test a new drug or treatment.



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Accessibility Menu

Example of *phase* in a sentence

Research is done in *phase*s to make sure a study treatment is safe and then whether it works before it is approved.

More Info

A phase is a step in the research process. Phases of research studies build on each other and each phase has a separate goal.

Phase 1 studies are usually the first to enroll humans and test for safety.

Phase 2 studies test if the drug, or treatment works.

Phase 3 studies compare the study treatment to the usual, standard treatment.

Phase 4 studies continue to collect data after a study treatment is approved. These are sometimes called post-marketing studies.

Other info to think about when joining a study

You may see the term "phase" when you are reading about clinical trials.

Before you enroll in a clinical trial you may want to ask about what phase the study is in. You may also want to know more about the information the study team already has about the risks and benefits of the study treatment that is being tested.

Related Words

clinical research

clinical trial

preclinical study

Other Resources

NCI Thesaurus

FDA - The Drug Development Process, Step 3: Clinical Research

If you know of other resources we should link to to help explain this word, please contact us.

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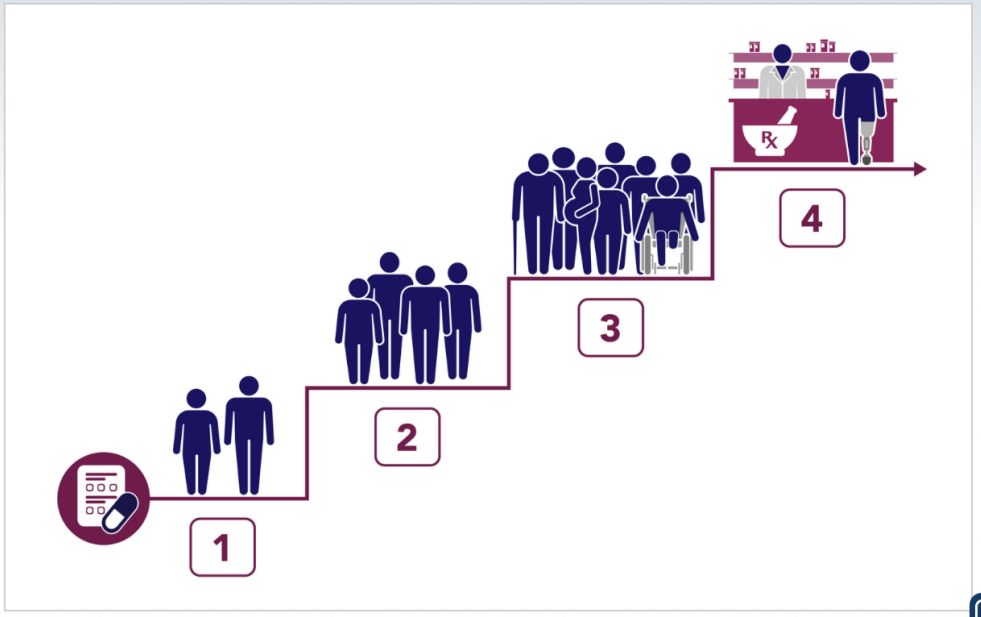

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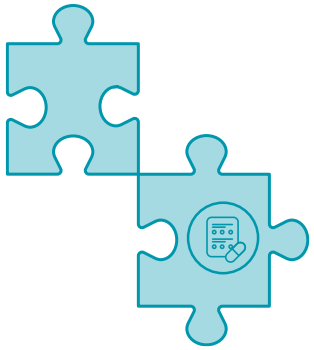
The MRCT Center Collaboration with CDISC

- Develops and advances data standards of the highest quality to transform incompatible formats, inconsistent methodologies, and diverse perspectives into a robust framework for generating accessible clinical research data.
- Convenes a global community of research experts representing a range of experiences and backgrounds to harness the collective power to drive more meaningful clinical research.
- Offers public review periods for new additions to its standards, when feedback can be collected from its users.

The plain language definitions developed by the MRCT Center Clinical Research Glossary Workgroup started being included in the CDISC standards in 2023.



https://www.cdisc.org/

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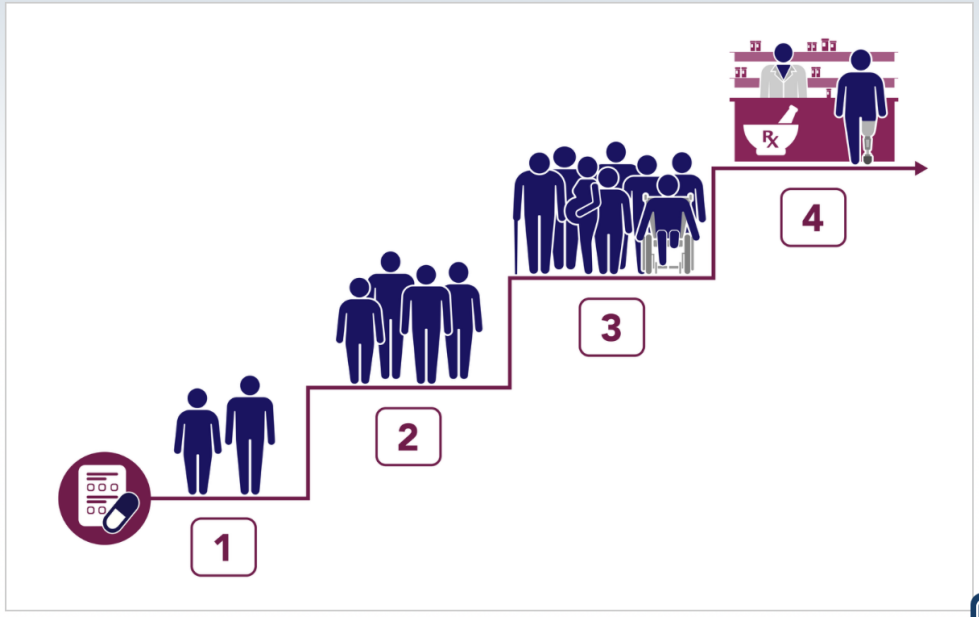

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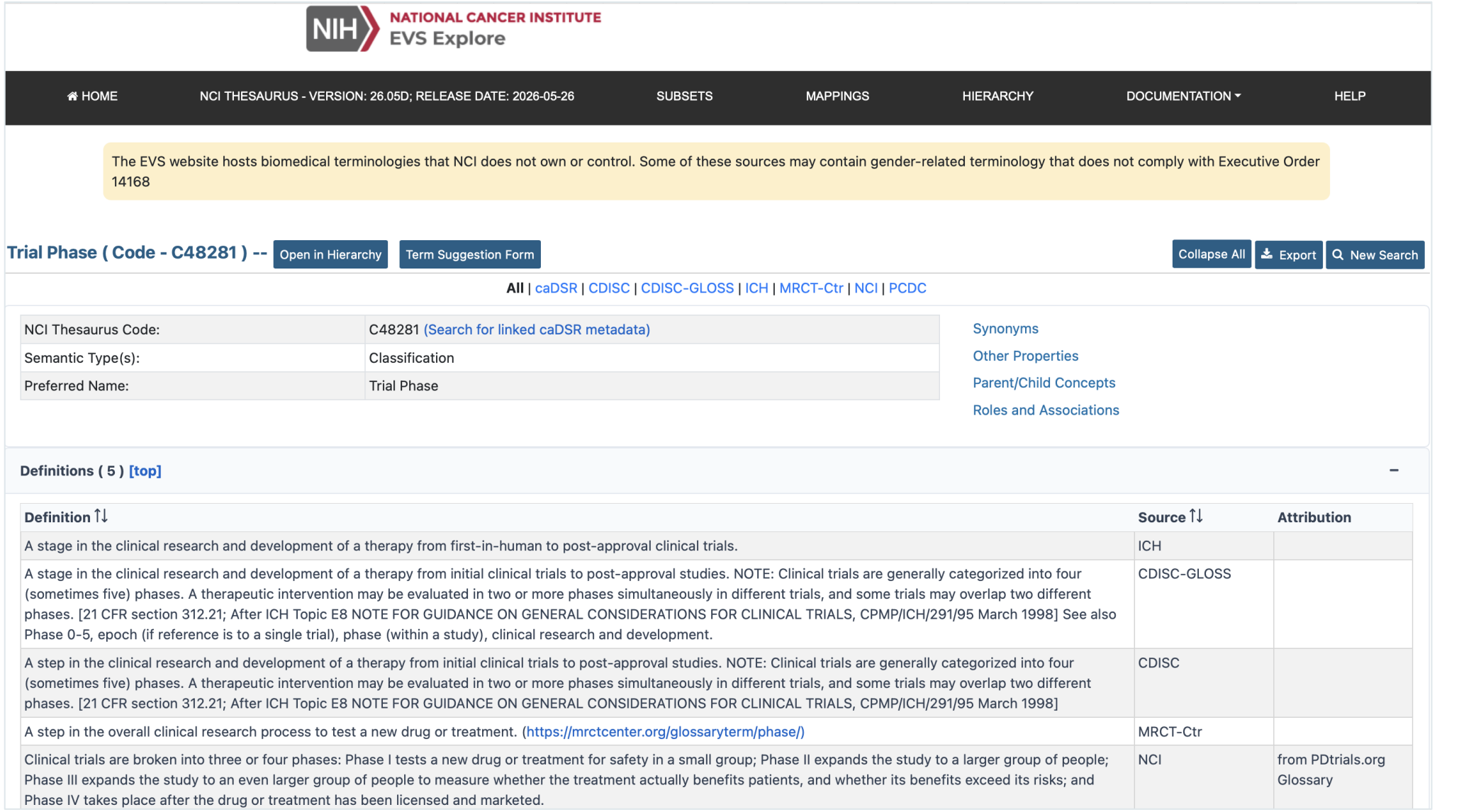


https://evsexplore.semantics.cancer.gov/evsexplore/concept/ncit/C48281

2026 Clinical Research Glossary Public Review with CDISC

June 12th through July 13th

Twenty-seven (27) definitions up for review:

- 24 new terms
- 3 updated terms

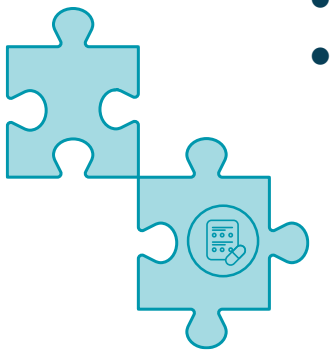
Access the feedback survey here:

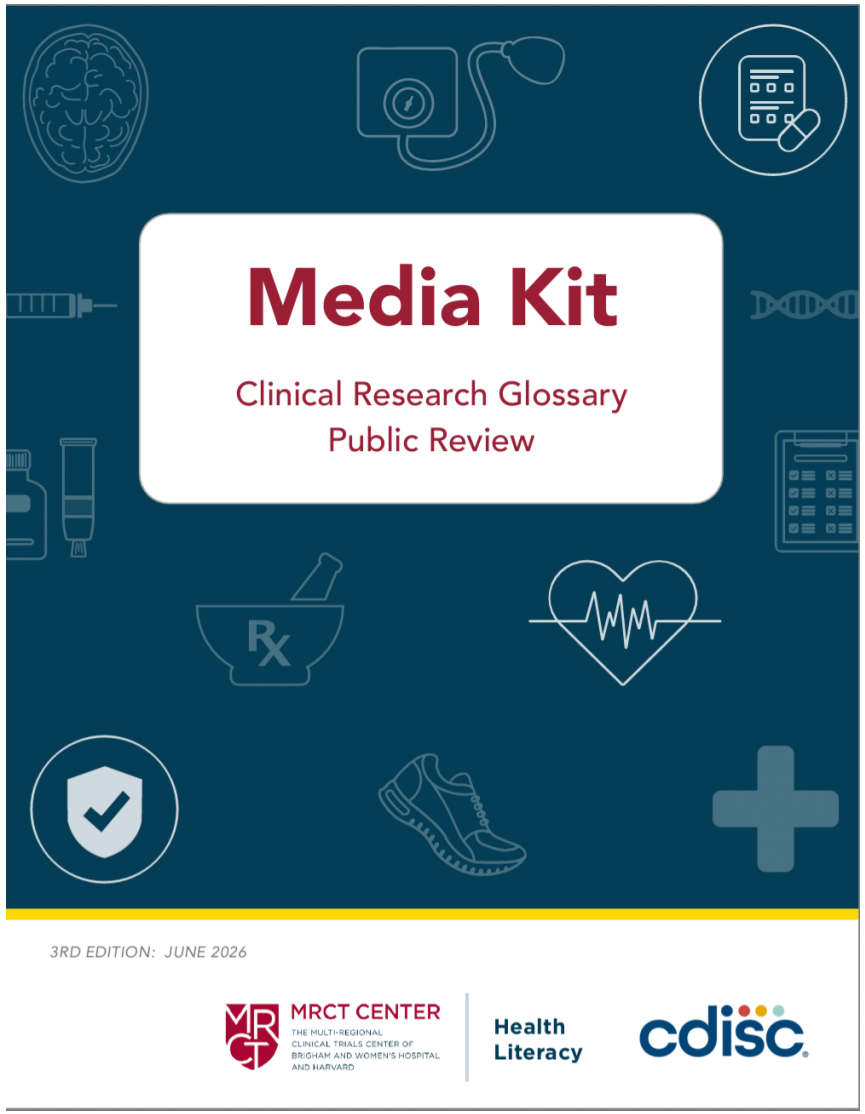
“Can I accept this definition?”

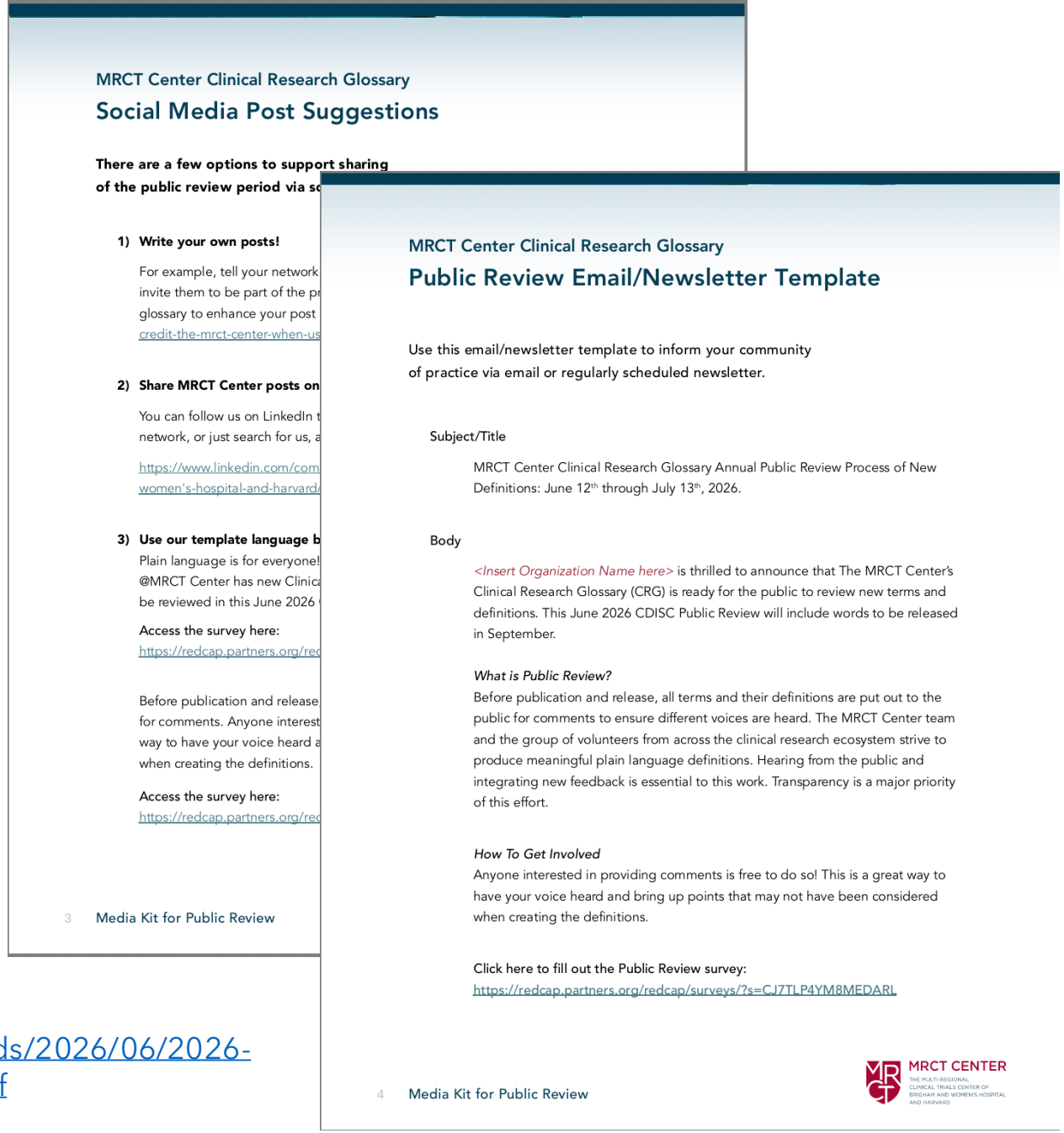
These definitions are meant to be in plain language for the general public.

These definitions do not have to be "perfect" but rather should be simple definitions that can help people who are learning more about clinical research.

- Consider: "**Is the change I am requesting really necessary? Can I accept the definition as written?"**
- Keep definitions as a single sentence.
- Avoid long, complex sentences with several pieces of information or commas within one sentence.
- Do not use brackets to separate ideas, or symbols, or abbreviations such as "e.g." and "i.e."
- Use short, simple words that don't have more than one meaning or connotation
- Use a tone that is more like how you might speak to someone.
- Be precise and concise while leaving out unnecessary words
- Use active voice when possible

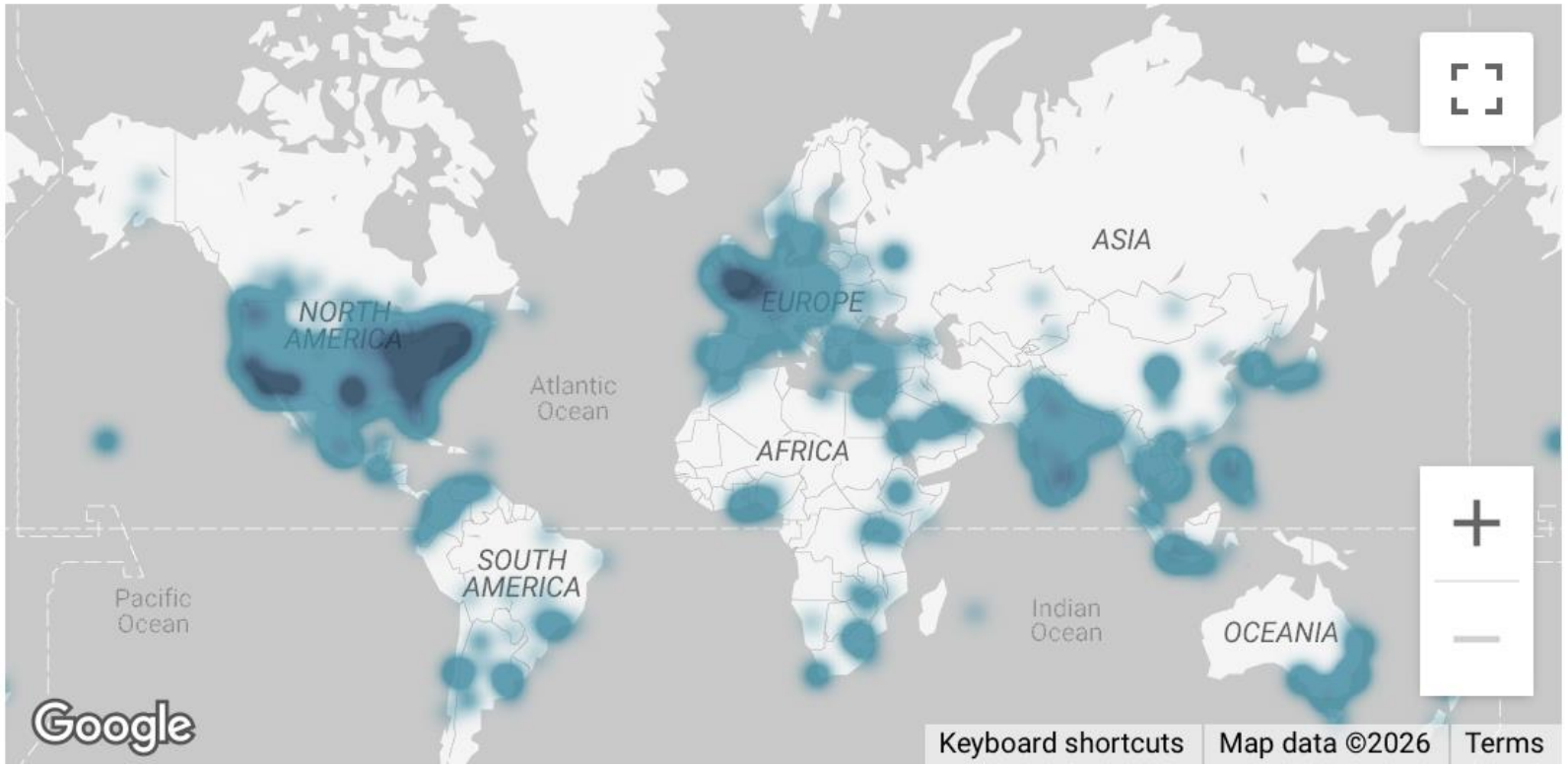






https://mrctcenter.org/wp-content/uploads/2026/06/2026-06_Glossary_Public-Review_Media-Kit.pdf

Glossary Analytics – Jan 1 to May 31, 2026

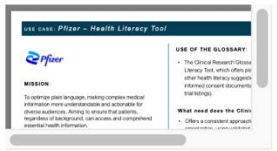


Country
United States
India
United Kingdom
Canada
Australia
France

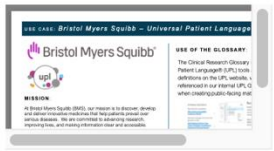
Language
Spanish; Castilian
English
French
Dutch; Flemish
German
Arabic

>2,200 users
83 PDF Downloads
47 Excel Downloads

Adoption, Implementation… … and Impact



Pfizer Glossary Use Case



Glossary Use Case – Bristol Myers Squibb

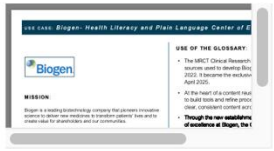
Glossary Case Use – Honor Health

Glossary Case Use – CureMito

Glossary Case Use – JSCDM

Glossary MGB Rally PDF

Glossary Case Use – TriCan Health



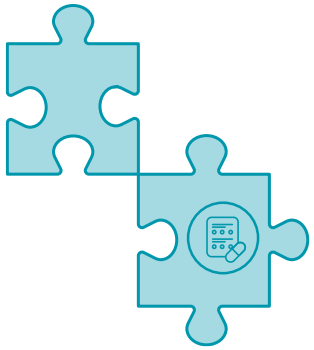
Biogen Glossary Use Case

Glossary Case Use – Special Interest – Black Diaspora

Your case could be here!

Help us grow our library and build our community.

Share your use cases!



https://mrctcenter.org/glossary/clinical-research-glossary-use-case-collection/

Meet the Speakers

Anna Subrizi

Senior Director, Patient Empowerment, Bristol Myers Squibb

Sudipta Chakraborty, PhD

Head, Health Literacy & Plain Language Center of Excellence, Biogen

R Bernard Coley

Co-Chair, Special Interest Group – Black Diaspora Care Partner, Research Advocate

2026 World Parkinson Coalition Robin A. Elliott Community Service Award

Moderated by:

Sylvia Baedorf Kassis

Program Director, MRCT Center

Meet the Speakers

Anna Subrizi

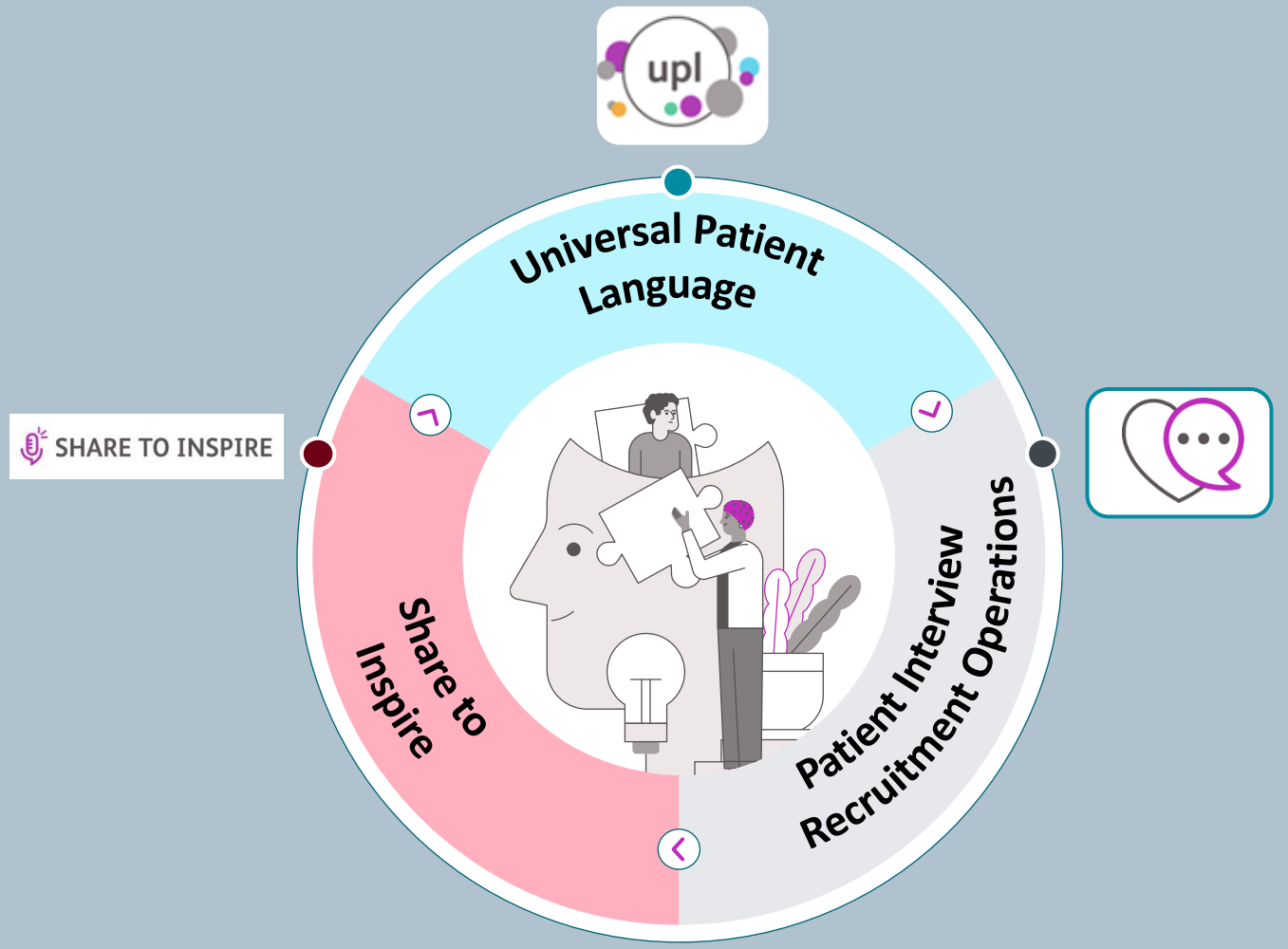
Senior Director, Patient Empowerment, Bristol Myers Squibb

Corporate Affairs

Global Purpose & Patient Experience

Patient Empowerment
Anna Subrizi

Vision: To shape a future where every patient and caregiver interaction is clear, empathetic, and trusted — where people feel heard, understood, and leave confident in what comes next



USE CASE: *Bristol Myers Squibb – Universal Patient Language*

Clinical Research GLOSSARY

Bristol Myers Squibb®

upl™

MISSION:

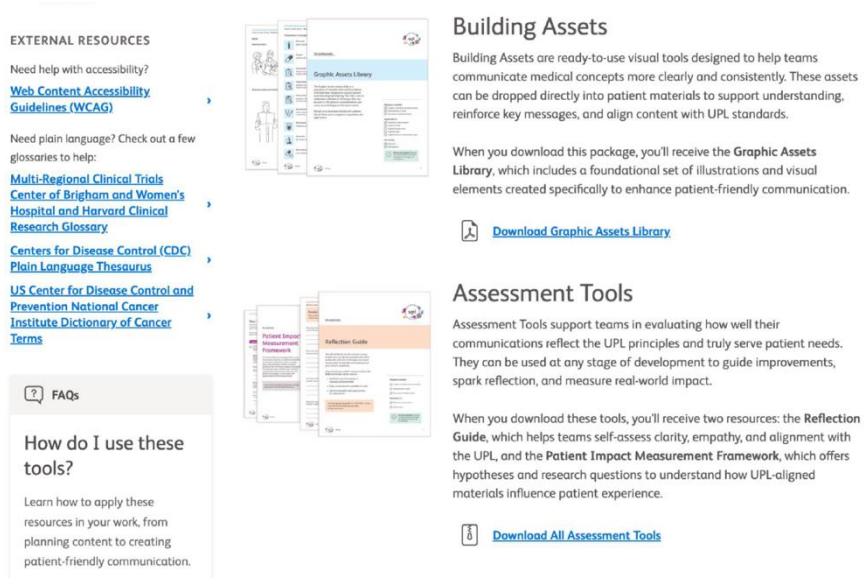
At Bristol Myers Squibb (BMS), our mission is to discover, develop and deliver innovative medicines that help patients prevail over serious diseases. We are committed to advancing research, improving lives, and making information clear and accessible. Through our Universal Patient Language® (UPL) program, we simplify complex medical terms and promote health literacy so patients and caregivers can make informed decisions. We also work to expand access to treatment and advocate for health equity.

POPULATION SERVED:

Teams across BMS leverage the Multi-Regional Clinical Trials (MRCT) Clinical Research Glossary when creating materials for patients, caregivers, and the general public. Examples include plain language summaries, informed consent forms, and branded or unbranded patient educational materials.

USE OF THE GLOSSARY:

The Clinical Research Glossary is included in our suite of Universal Patient Language® (UPL) tools as a source of patient-friendly definitions on the UPL website, www.UPL.org. Additionally, it is referenced in our internal UPL Glossary, which is used across BMS when creating public-facing materials.



Disclaimer: Bristol Myers Squibb (BMS) is not responsible for third-party content on this website. We do not review or verify materials posted by other users, and their views do not represent Bristol Myers Squibb.

Challenges – Opportunities for Growth

SHIFTING LANGUAGE TAKES TIME

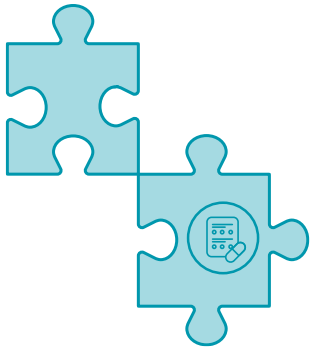
- Moving teams away from familiar scientific or regulatory terminology requires patience and sustained effort
- Building comfort with simpler, clearer alternatives to deeply ingrained technical language is an ongoing process

LEARNING NEW WAYS TO SOCIALIZE

- Adapting IT systems and finding effective ways to share the Clinical Research Glossary across a large enterprise
- These were viewed as opportunities rather than barriers – each step forward strengthened adoption and team buy-in

THE REFRAME

- No true barriers – each challenge was an opportunity to grow and strengthen the program
- Cross-communication between R&D and Commercial teams opened doors to new collaborations and broader glossary adoption
- The Clinical Research Glossary itself became a bridge – a trusted, science-backed resource that helped teams align around consistent plain language
- When patients don't understand the language, they can't fully engage – this principle kept the team motivated through every adjustment



What Comes Next

SCALING HEALTH LITERACY

- Embedding health literacy principles and tools more systematically into enterprise-wide processes
- Continuing to evaluate new and innovative ways to drive organizational and individual health literacy
- Continuing to leverage and share the Clinical Research Glossary as a reliable source of information for teams and patients alike

TECHNOLOGY & INNOVATION

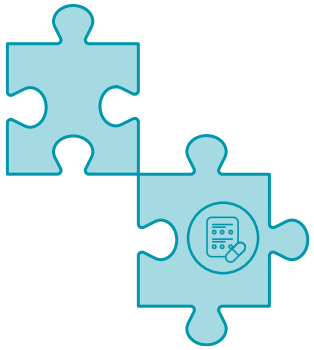
- Exploring how technology – including AI – can support and accelerate plain language adoption

PARTNERING WITH PATIENTS

- Working more closely with patients to co-create language that truly works for them
- Driving consistent, uniform plain language definitions across the healthcare system to empower patients in their care

SHARING BROADLY

- Continuing to offer UPL as a free resource on UPL.org and sharing the glossary to meet patients where they are in their journey
- Actively recommending the Clinical Research Glossary in trainings and conversations as a go-to source for meaningful plain language terms



Meet the Speakers

Sudipta Chakraborty, PhD

Head, Health Literacy &
Plain Language Center of
Excellence, Biogen

Biogen – Center of Excellence under R&D

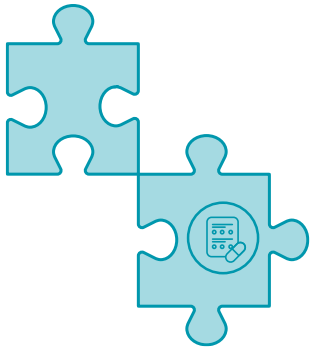
Research & Development

Global Clinical Operations

Clinical Trial Accelerator Unit

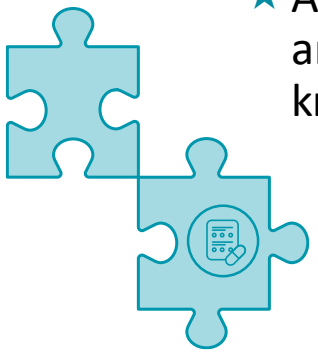
Clinical Trial Transparency

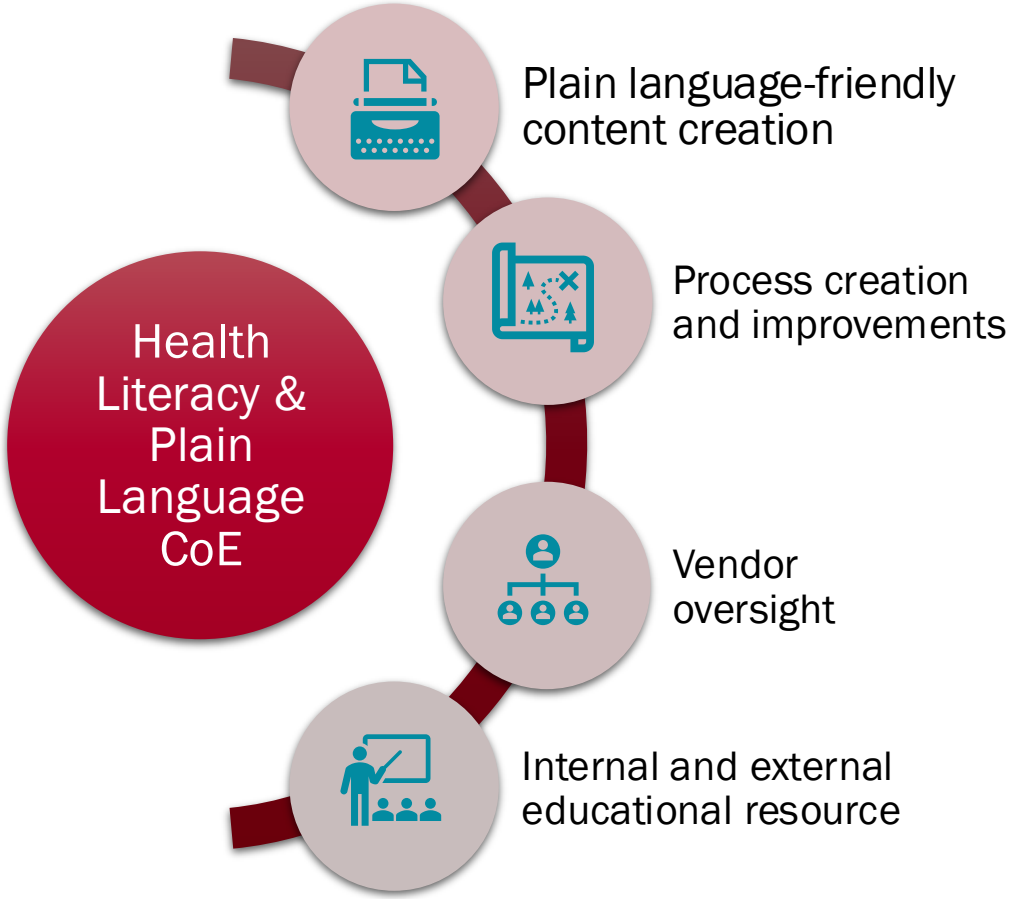
Health Literacy & Plain Language
Center of Excellence
Sudipta Chakraborty



Centralized resource spreading the health literacy gospel

- ★ Arose out of a **growing need** for non-promotional, inclusive, and plain-language friendly content beyond those required for transparency regulations
- ★ Specialized and dedicated support for producing **plain language-friendly content** that will create efficiencies and ensure consistent messaging to patients and the public
- ★ A dedicated unit to support **cross-functional needs**
- ★ Opportunities for **additional collaborations** beyond R&D
- ★ A **training/educational resource** on health literacy principles and plain language best practices based on SME domain knowledge and industry standards





USE CASE: *Biogen*

Clinical Research GLOSSARY

Biogen

MISSION:

Biogen is a leading biotechnology company that pioneers innovative science to deliver new medicines to transform patients' lives and to create value for shareholders and our communities.

We apply deep understanding of human biology and leverage different modalities to advance first-in-class treatments or therapies that deliver superior outcomes. Our approach is to take bold risks, balanced with return on investment to deliver long-term growth.

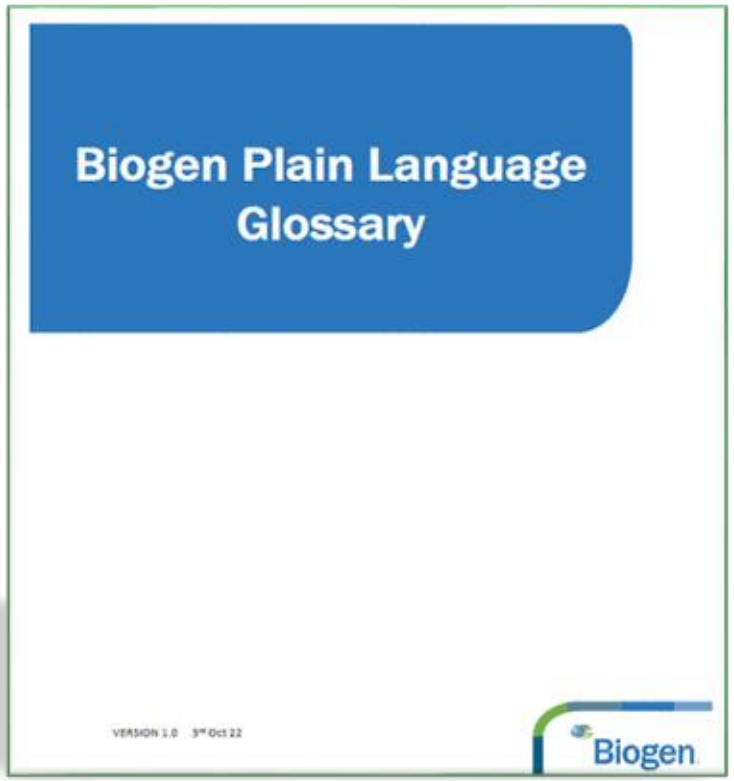
POPULATION SERVED:

Internal use for functions creating patient- and public-facing materials (currently transparency, informed consent, and patient engagement)

USE OF THE GLOSSARY:

- The MRCT glossary was one of several sources used to develop Biogen's initial Plain Language Glossary in 2022. It became the exclusive reference for Version 2.0, released in April 2025.
- At the heart of a content reuse initiative, the MRCT glossary supports efforts to build tools and refine processes that drive efficiency and ensure clear, consistent content across teams.
- Our ultimate goal is to enhance patient centricity throughout the organization by delivering consistent, readable messaging to study participants and the public at every stage of drug development.

Creating a cross-functional plain language glossary



Collaboration between the ICM, PCE, and CTT functions at Biogen

Referenced **established glossaries** in addition to internal ones:

- University of Michigan Plain Language Medical Dictionary
- EMA Medical Terms Simplifier
- **MRCT Clinical Research Glossary**

Initial version launched in **2022**

Version 2.0 launched in 2025; featuring updates solely based on internal feedback + **MRCT alignment**

Ongoing and Future Initiatives

Meet the Speakers

R Bernard Coley

Co-Chair, Special Interest Group – Black Diaspora Care Partner, Research Advocate

2026 World Parkinson Coalition Robin A. Elliott Community Service Award

Glossary use case – Special Interest Group – Black Diaspora

I am a member of the MRCT Center Clinical Research Glossary development team.

- Experienced firsthand the meticulous detail and in-depth effort that goes into the development of definitions, additional information, where used examples, and graphics to assist literacy that go into each clinical research term in the glossary.
- Proceeded with confidence to use this plain language glossary in my community service work in educating under-engaged health community members.

Glossary use case – The Black Parkinson's Disease Summit

Annually, I produce many of the educational sessions designed to reach this under-engaged community impacted by Parkinson's Disease to increase participation in clinical research.

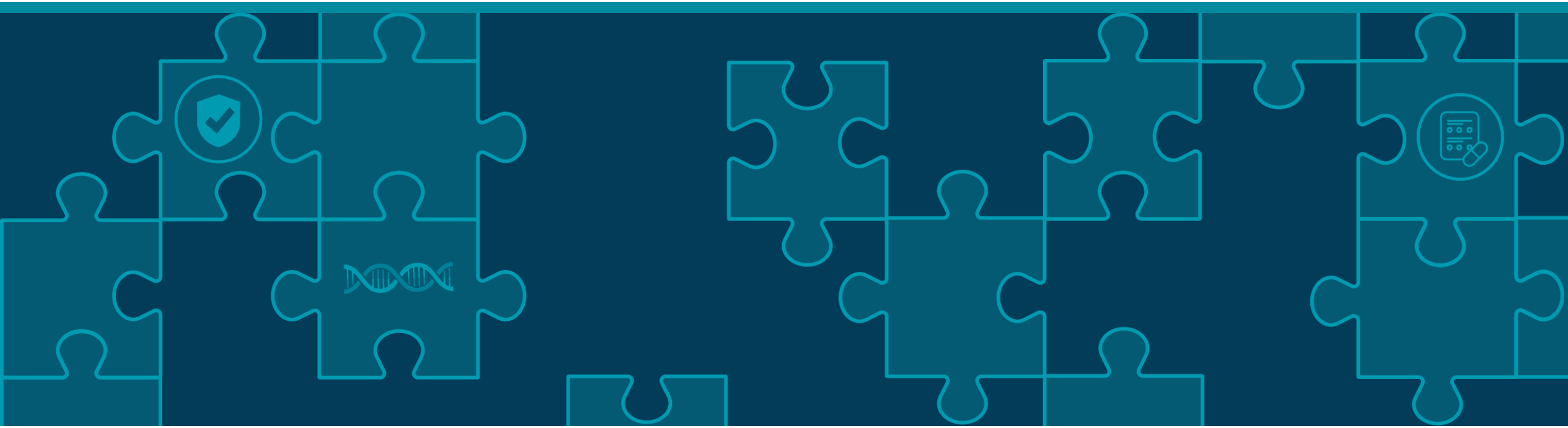
- Dedicated one entire day to providing an educational overview of clinical research and especially the clinical trials process and protocols.
- Utilized the Clinical Research Glossary to guide the plain language communications of descriptions of participant encountered aspects of clinical trials, e.g., informed consent contents.
- Onboarded our audience to essential terminology and an intelligible reference source.
- Feedback and reviews were outstanding.

Glossary use case – Challenges and the Future

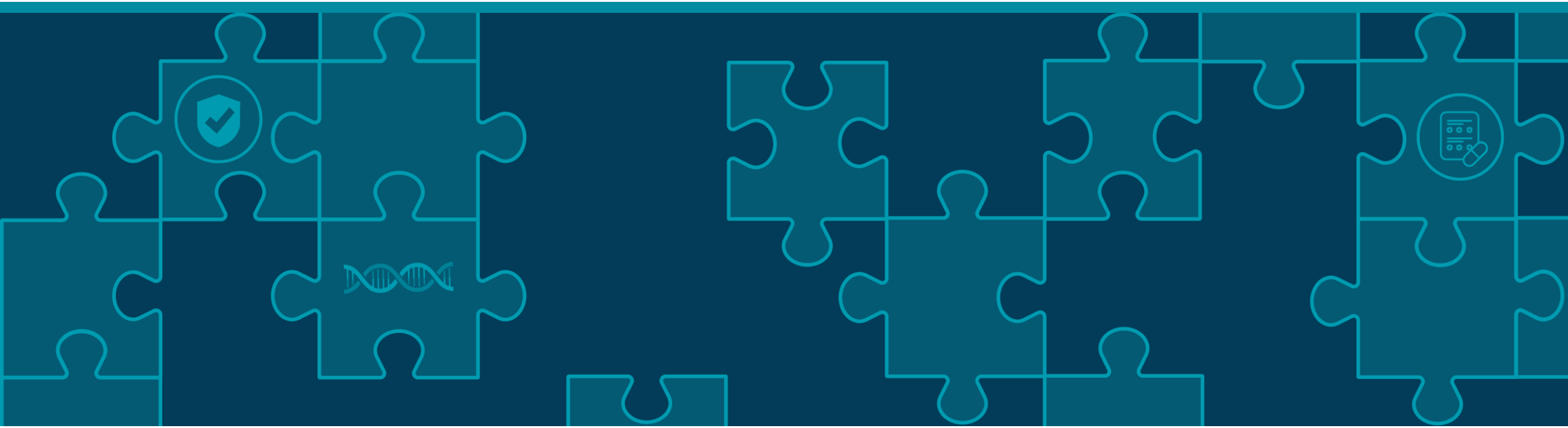
The MRCT Center Clinical Research Glossary is a work in progress.

- Challenge: Not every term or category of needed terms were released in the public version of the glossary at the time of our summit session.
- Challenge: Participants had to be left on their own for additional exploration with personally encountered terms found in patient materials.
- Challenge: Spent time explaining that plain language does not imply reduced accuracy or a dumbed down glossary product.
- Future: Based on the responses, we will repeat the summit session utilizing the MRCT Center Clinical Research Glossary again.

Panel Discussion and Questions



Closing



THINK + DO

THANK YOU!