Today’s Health Literacy Month Webinar Will Begin Shortly...
Amplifying Participant Voices: Crafting Respectful, Inclusive & Understandable Patient Materials

Panel to Celebrate Health Literacy Month

October 23, 12 - 1 PM ET, virtual

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

• None of the speakers have personal conflicts of interest relevant to this presentation.
Welcome!

You are part of a community of people who care about amplifying participant voices in research!

To limit disruptions, please keep yourself muted.

Questions can be submitted via the Q&A function.

Closed Captioning is available, via a real-time transcriptionist.

The recording will be available within a few days of this session.
Overview

• Welcome
• Introduction to the MRCT Center and Health Literacy
• Panelist Presentations
  – Marilyn Neault
  – Martie Carnie
  – Maureen Kashuba
• Discussion/Q&A
Introduction to the MRCT Center and Health Literacy
The MRCT Center is a research and policy center focused on addressing the conduct, oversight, ethics, and regulatory environment of clinical trials.

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.
What is Health Literacy?

From Healthy People 2030:

**Personal health literacy** is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

**Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Marilyn Neault
Communication goes ‘round and ‘round

- Patient / Participant
- Health Care Provider
- Research Investigator
What the Participant Wants

- Put yourself in my shoes.
- Ask what is important to me.
- Tell me what I NEED to know.
- Tell me again.
- Explain it in a different way.
- Show me with pictures.
- Ask me to tell it back to you.

- Information when and where we need it (just in time, just in place).
- Information we don’t need to strain to see, hear, understand, or find again.
- Information that is relevant.
- To be listened to.
- A sense of community in the process.
- To take away information that can be remembered, rephrased, explained, and even pronounced when talking with a neighbor or relative.
Patient Advocacy can grow out of good and bad experiences.

Typical font size for patient-facing printouts at a health center: too small to read with cataracts

An ophthalmologist went to great lengths to have patient-facing materials about cataracts in large font
A participant had difficulty using the form provided to record her physical status every 30 min. An “X” often landed in the wrong cell because the small rows and columns were difficult to track. In addition, the paper became mangled from carrying it around all day with a pen.

Participant made her own form which was easier to fold and carry, and which reduced the chance of wrong-cell entries.

TAKE-HOME MESSAGE: ASK PEOPLE WHO WOULD QUALIFY AS PARTICIPANTS TO TRY USING FORMS, DEVICES ETC. IN THE REAL WORLD, BEFORE THE STUDY PROTOCOL IS COMPLETE.
Overview of the BWH PFAC Review Process

1. Receive documents from research staff
2. Assess documents with Readability Software
3. Review with Health Literacy PFAC
4. Communicate results with research staff
5. Meet with research staff to improve Readability score
6. Research staff sends back edited document
Building a Partnership with Researchers and Patient Family Advisors

• All patient-facing materials should be vetted by patient advisors and contain valid contact information for questions or concerns.
• Know your audience understanding they are your teachers.
  – Both parties share perspectives for bidirectional learning and understanding
• Value patient stories and narratives of lived experiences
  – Patients have a PHD - Personal History of their Disease - and the lived experience of what works and what matters to THEM!

If we don't understand, how can we trust or participate in research?

You are talking WITH them not to or for them regarding your research goals and aims.
Recruiting Patient Family Advisors

**Sources**
- Patient Satisfaction Surveys
- Patient Relations Department
- Patient Experiences Office
- Clinical Staff Recommendations

**Candidates**
- Call to discuss expectations and commitment.
- Ask them to share an experience in healthcare/research
  - What went well?
  - What did not and how would you change it?

**Getting Started**
- Hospital process, including occupational health
- PFAC Training Program
- Offer opportunities for them to recruit others within their communities as well

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Universal Precautions Approach to Health Literacy

• How can we ensure that our communications are clear?
  • Making health communication understandable and actionable is both an art and a science.
  • It involves expertise in plain language, design, cultural awareness, and more

  ❖ Reading Level, Reading ease, Short sentences
  ❖ Explain complex concepts in simple text
  ❖ HL formatting – white space, bulleted text, bolded text
  ❖ Ask for feedback
  ❖ Take feedback seriously, not personally
Cultural Humility:
Recognizing our individual perspectives are shaped by our experiences and may not reflect the experiences and perspectives of others.

Cultural Competency:
The ability to provide effective, equitable, understandable, and respectful quality care and services.
Cultural Competency Review Model – Engaging Employees

Objectives
- Model developed to assess cultural relevance and sensitivity of internal Glossary definitions.

Purpose
- Understand how material aligns with lived experiences

Key Findings
- Engagement of Internal Employees from diverse cultures and communities
- Review material offline and at workshops
- 100% of participants willing to participate in future Workshops

Feedback from workshop attendees
- “A great initiative, and I am glad to have been a part of the work”
- “A great experience which gave me insight into other’s perspectives”
- “Happy to be a part of this work and would love to participate in future workshops. Time flew by”

- All company volunteers
- Open discussion of personal and professional cultural insights which can build respect and community across the organization
- Helps ensure inclusive language in patient and public facing materials

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Additional Resources
Patients & Participants Resources

The MRCT Center has developed resources with, and for, patients and participants.

Resources for the community of patients, participants and caregivers include:

- A Participant Bill of Rights

[https://mrctcenter.org/project/resources-for-patients-and-participants/](https://mrctcenter.org/project/resources-for-patients-and-participants/)
Two Highlights: Toolkits for Including Young People and AbD

https://mrctcenter.org/resource/including-young-people-in-research-toolkit/

https://mrctcenter.org/diversity-in-clinical-research/tools/abd_toolkit/
2023 Annual Meeting

Wednesday, December 13th
8:00 AM: Breakfast
8:30 AM - 12:30 PM: Keynote: Peter Arlett, Head of Data Analytics and Methods (EMA); Detailed programmatic discussions and updates (agenda forthcoming)
Lunch
1:30-4:45 PM: Research, Development, and Regulatory Roundtable (R3) Topics: Update on the GDPR, including discussion of the EU/US data privacy framework; Considerations in Ensuring Accurate Clinical Trials Data
5:00-6:15 PM: Cocktails and Appetizers

Thursday, December 14th
8:30 AM: Breakfast
9:00 - 11:45: Bioethics Collaborative (BC) Topic: Cell and Gene Therapy: Probing the Ethics (open to all)
Clear Communications Benefit Everyone

www.mrctcenter.org/health-literacy

HAPPY HEALTH LITERACY MONTH!

Thank you!

Questions?