

Amplifying Participant Voices:

Crafting Respectful, Inclusive & Understandable Patient Materials

Panel to Celebrate Health Literacy Month

October 23, 12 - 1 PM ET, virtual



Moderator
SYLVIA BAEDORF KASSIS
Program Director
MRCT Center



MARTIE CARNIE
Senior Patient Experience Advisor
Brigham and Women's Hospital



MAUREEN KASHUBA
Health Literacy Projects Lead
Merck & Co, Inc



MARILYN NEAULT
Patient Advocate



**MULTI-REGIONAL
CLINICAL TRIALS**
THE MRCT CENTER OF
BRIGHAM AND WOMEN'S HOSPITAL
and HARVARD

October 23, 2023

Webinar Speaker Biographies



Sylvia Baedorf Kassis, MPH, first joined the MRCT Center as a Program Manager in January of 2018. She brought with her more than 20 years of clinical research-related experience in Canada and the United States of America. Her expertise includes ethical/regulatory review of research, clinical trial workforce training and capacity building, and study coordination, management, and oversight.

Sylvia assumed her role as MRCT Center Program Director in June 2022. Sylvia champions efforts to make clinical research more understandable and accessible to patients, participants, and caregivers through her work on Health Literacy in Clinical Research and the first-of-its-kind, plain language Clinical Research Glossary. In addition, she supports other MRCT Center initiatives in applying health literacy principles to their outputs. Sylvia is passionate about patient/participant engagement and, as such, strives for inclusivity in the programs she leads so that patient/participant voices are prioritized.

Sylvia's clinical research interests include: understanding study participants' experiences in research and incorporating their insights into study processes; supporting research coordinators through networks and training; and ensuring all research stakeholders have the resources they need to conduct ethical and compliant studies involving study participants and their data/samples.

Sylvia earned a Master of Public Health degree in Global Health from Boston University School of Public Health (2008) and a Bachelor of Science from the University of Toronto (2001).



Martie Carnie is a thirty-five-year survivor of breast and melanoma cancers, who learned how to navigate the healthcare system, and how to advocate for others and herself at Brigham and Women's Hospital. She has 50 years of communication, customer service, and management experience in her professional career. Martie became a leader in patient- and family-centered care 25 years ago bringing the Patient and Family voice into health care as Co- Chair of the first Adult Patient Family Advisory Council in the United States at Dana Farber Cancer Institute.

In 2014, Martie had the opportunity to be the lead patient on the Patient Centered Outcomes Research Institute (PCORI) Inaugural 10 site Falls Prevention 6-year grant, which opened the opportunity to bring the Patient, Family, Caregiver Voice, and Lived Experience to every aspect of the research process. This expanded her hospital-based theories to include Research. As a patient voice at the Brigham Research Institute, Martie serves as Co-Investigator to facilitate the Patient Family perspectives and voices to support and change the healthcare system from all avenues, resulting in publications to support these processes. She is also a PCORI Ambassador. Martie presents nationally and internationally on Patient Family Centered Care, Patient Experience and Engagement, Patient Safety, Health Literacy, and Design in Healthcare.



Maureen Kashuba is Health Literacy Projects Lead at Merck & Co, Inc. responsible for both Plain Language Summaries and Merck's Health Literate Glossary. She co-chairs the DIA Plain Language Summary Working Group and collaborates with a range of internal and external stakeholders to establish and implement best practices to improve public-facing communications. Maureen is a Nurse and passionate about working to ensure people feel empowered with the information they need to make health decisions and manage their overall health.



Marilyn Neault, PhD participates in a variety of patient advocacy activities under the umbrella of the Parkinson's Foundation. She serves as a working member of the Steering Committee of the Parkinson's Outcomes Project. She talks to groups of scientists and students regarding the experience of living with Parkinson's Disease. With a longstanding interest in health literacy, she serves on a task force to develop a clinical research glossary for the Multi-Regional Clinical Trial Center.

Dr. Neault retired in 2017 from a long career in pediatric audiology, during which she directed Audiology programs at Boston Children's Hospital, specializing in electrophysiological measures of hearing in infants and in programming cochlear implant devices. By 2004, she had developed symptoms diagnosed in 2009 as Parkinson's Disease. She now participates in clinical trials and in a variety of Parkinson's wellness activities. She enjoys composing music, a new interest. Fueled by her clinical experience with people who have limited ability to hear, she champions better communication along all avenues for people with Parkinson's Disease.