

Adoption of Health Literacy Best Practice to Enhance Clinical Research:

A Virtual Workshop

Participant Biosketch | October 28, 2021

I. The Patient Perspective

Elizabeth Cahn, PhD is a breast cancer survivor and BRCA1 mutation carrier, and has been a caregiver for family members with cancer and traumatic brain injury. She has extensive experience with clinical trial participation, informed consent, family decision-making, guardianship, complicated treatment decisions in collaborative treatment settings, and palliative care. Dr. Cahn has been involved in cancer research advocacy since 2007 and has been a patient advocate on many breast cancer research proposals and projects. She is a member of the Dana-Farber/Harvard Cancer Center Breast Cancer Advocacy Group and the Rays of Hope Center for Breast Cancer Research Advocacy Council. Dr. Cahn is employed as Program Director at Cancer Connection, a community-based non-profit in Northampton, MA, that provides support services for individuals with all types of cancer as well as their caregivers and families. Dr. Cahn has undergraduate degrees in Fine Arts and Architecture from the Rhode Island School of Design. She later earned master's degrees in Architectural History, Theory, and Criticism from the Massachusetts Institute of Technology and in Art Therapy from Seton Hill College. In 2014 she completed a PhD in Regional Planning at the University of Massachusetts Amherst, where she also earned a Certificate in Advanced Feminist Studies.

II. Tools to Improve the Health Literacy of Clinical Research Information

Sylvia Baedorf Kassis, MPH has had the pleasure of serving in the role of Program Manager at the Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard since January of 2018. With 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. In her position, Ms. Baedorf Kassis is focused predominantly on efforts that result in clinical research being more understandable and accessible to patients and participants through her work on [Health Literacy in Clinical Research](http://www.mrctcenter.org/health-literacy) (www.mrctcenter.org/health-literacy). Ms. Baedorf Kassis received 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).

Barbara Kress is the Executive Director of Clinical Data Disclosure and Transparency at Merck. She is responsible for registry and results disclosure, redaction operations, return of plain language summaries to patients and data sharing. She joined Merck 24 years ago as a clinical scientist working on the successful development and submission of several compounds. Barbara has worked in the transparency space exclusively since 2007. Prior to joining Merck, Barbara started her career as a critical care and emergency room nurse. She participates in several disclosure work streams, including PhRMA, EFPIA, TransCelerate, the Multi-Regional Clinical Trials (MRCT) Center at Brigham and Women's Hospital and Harvard and is a member of the NLM Board of Regents Public Service Working Group on

III. Integrating Clinical Research Information into Care & Community Settings

Rebekah SM Angove, PhD is a health services researcher and leader in patient engagement. She currently serves as the VP for Patient Experience and Program Evaluation at Patient Advocate Foundation. Her work is focused on mapping the patient experience and uncovering unmet needs, translating those needs to direct service and policy recommendations, and evaluating the impact of initiatives. She has led numerous projects focused on addressing health disparities and integrating the patient perspective into care and research. She is active in national committees and as an engaging speaker bridging the needs of the patient community with emerging issues in healthcare.

Monique Hill, MSW is an assistant professor in the department of Academic Affairs Faculty, program manager for Hands on Health SC, and serves as health literacy and program engagement advisor for the NNLM Region 2, at the Medical University of SC. In these roles, she applies her prior experience in social work and policy to her work in developing community-based programs, collaborating and engaging with the community, and championing disparities directly related to social and racial injustices. Ms. Hill believes that while these roles are what she does, impacting lives, amplifying the voices of those often under-heard and underserved, and fighting for equity, is the core of who she is. Ms. Hill has worked in the field of health literacy for over a decade, focusing on program development and implementation in South Carolina communities. She focuses on educating and empowering the community to actively participate in their personal and family healthcare experiences. Ms. Hill directs an inter-professional course on health literacy and is the founder of the Southeast Health Literacy Conference. She is currently serving on the advisory board for the National Conference on Health Disparities and Southeast Health Literacy Conference. Ms. Hill also serves on the City of Charleston (SC) Commission on Women and a member of other professional organizations. Ms. Hill earned her bachelor's degree from Benedict College, a master's in social work from Florida State University School of Social Work, with a concentration in social policy and administration. Additionally, Ms. Hill has completed advanced public health trainings from the University of Maryland-College Park and Tufts University.

Michael Paasche-Orlow, MD, MA, MPH is a Professor of Medicine in the department of General Internal Medicine at the Boston University School of Medicine and Boston Medical Center. As a primary care clinician and a nationally recognized expert in the field of health literacy, he has dedicated his career to improving the care of vulnerable populations. He is currently a PI on seven clinical studies that examine health literacy and doctor-patient communication, various modes of patient education, and empowerment. He has been the lead designer of nine patient-oriented interactive behavioral informatics programs and has helped create and evaluate a range of patient empowerment and decision support tools. With over 200 peer-reviewed papers, his work has brought attention to the role that health literacy plays in racial and ethnic disparities, improving informed consent, and improving advanced care planning, as well as to the fact that appropriately designed information technologies can be empowering for patients with low health literacy. He serves as the Editor-in-Chief for Health Literacy Research & Practice, as the Director of the Health Literacy Annual Research Conference (HARC), and as a member of the NASEM Health Literacy Round Table.

Karriem Watson, DHSc, MS, MPH is the new chief engagement officer with the All of Us Research Program at the National Institutes of Health. He leads the program's efforts to foster relationships with

participants, communities, researchers, and providers across the U.S. to help build one of the largest, most diverse health databases of its kind to study health and illness. Prior to working with All of Us, Dr. Watson served as the associate executive director of the Mile Square Health Center, a group of Federally Qualified Health Centers in Chicago affiliated with the University of Illinois Hospital and Health Sciences System. He also served as the associate director of community outreach and engagement for the University of Illinois Cancer Center and as a research assistant professor in the University of Illinois Chicago (UIC) School of Public Health. Beyond his work with UIC, he has served as co-lead of the All of Us Engagement Core at the Meharry-Vanderbilt Alliance, cultivating positive relationships with the program's participant ambassadors. He has served as a principal investigator on multiple projects including those funded by the National Cancer Institute, the National Institute on Minority Health and Health Disparities, and the All of Us Research Program. His expertise in community-academic partnerships is also supported in his role as board chair of the Community Campus Partnerships for Health. His contributions have earned him recognition by the Chicago Urban League, American Heart Association, LUNgevity Foundation, and others. Dr. Watson has a Doctorate in Health Science (Global Health), a Master of Science in Basic Medical Research, and a Master's in Public Health (Community Health Sciences).

Planning Committee

Barbara E. Bierer, M.D. is a hematologist-oncologist, is Professor of Medicine at Harvard Medical School (HMS) and the Brigham and Women's Hospital (BWH). Dr. Bierer co-founded and now leads the Multi-Regional Clinical Trials Center of BWH and Harvard (MRCT Center, www.mrctcenter.org), a collaborative effort to improve standards for the planning and conduct of international clinical trials. In this capacity, she works with regulators around the world, pharmaceutical companies, CROs, academia and patients/patient advocates to harmonize policies for and approaches to clinical trial regulation. She is a co-founder of COVID-19 Collaboration Platform (www.COVIDcp.org), a platform for cooperation in research. In 2017, the MRCT Center launched the non-profit Vivli (www.vivli.org), a global clinical research data sharing platform. She is also the Director of the Regulatory Foundations, Ethics, and Law program at the Harvard Catalyst, and Director of Regulatory Policy for SMART IRB (www.SMARTIRB.org). She serves as Faculty in the Center for Bioethics, HMS, and Affiliate Faculty in the Petrie-Flom Center for Health Law at Harvard Law School. From 2003 – 2014, Dr. Bierer served as Senior Vice-President, Research, BWH. She is a past chair of SACHRP and has served or serves on the Board of Directors of AAHRPP, PRIMR, MSH, Vivli, North Star IRB, and the Edward P. Evans Foundation. She served on the NASEM Committee on Science, Technology, and the Law. She received a BS from Yale University and an MD from Harvard Medical School, and she has authored over 250 publications.

Silas Buchanan is an experienced underserved-community outreach and engagement strategist. He is the Founding CEO of the Institute for eHealth Equity where he leads partnerships with healthcare payer, providers, government and academic stakeholders. Silas has expertise in crafting web-based ecosystems that solve for known, underserved-community outreach and engagement failure points. He co-developed AMEHealth.org as the official health information-sharing channel for the AME Church, the largest mainline, historically Black Denomination in the world (2000 congregations/2 million members). He is currently developing OurHealthyCommunity.com to better engage underserved communities both secularly and non-secularly. Silas is a member of the Milken Institute, FasterCures Health Equity and Clinical Trials Diversity Working Group; Digital Medicine Society, Digital Inclusion Steering Committee;

American Telemedicine Association Disparities and Inequities CEO Roundtable. He has been a KOL with Duke Clinical Research Institute, and has testified before the HHS, HIT Policy Committee. He was selected as a member of the White House Summit to Achieve eHealth Equity. Selected as Co-Chair of Region V of the HHS National Partnership for Action to End Health Disparities. He was also selected as an inaugural member of the National eHealth Collaborative Consumer Committee.

Catina O’Leary, PhD, LMSW is President and CEO at Health Literacy Media (HLM). Catina oversees HLM’s core activities and works to set and maintain the strategic vision for the organization, including HLM’s Clearly Communicating Clinical Trials program (c3t) that aims to help our partners make complex science and clinical trials accessible to everyone. Before joining HLM in 2012, Catina led research at Washington University School of Medicine focused on connecting people with chronic health conditions with medical and social resources aimed at improving health behaviors, preventing illness, and improving overall health and well-being. Over the course of a decade, Catina led multi-site research trials in the U.S. and internationally. Catina is a member of many boards and committees, including the International Health Literacy Association’s Standing Committee on Strategic Planning and Implementation and the National Academies of Sciences, Engineering, and Medicine’s Roundtable on Health Literacy.

Amanda J. Wilson, M.S. is Chief, Office of Engagement and Training (OET) at the National Library of Medicine (NLM). OET brings together the general engagement, training, capacity-building, and other outreach staff from across the library whose primary focus has been on the Library's presence across the U.S. and internationally. OET also coordinates the Network of the National Library of Medicine (NNLM), the field force for NLM. The NNLM’s main goals are to work through libraries and other members to support a highly trained workforce for biomedical and health information resources and data, improve health literacy, and advance health equity through information. She joins NLM from the U.S. Department of Transportation, where from Dec 2006-Jan 2017 she served as Director, National Transportation Library. Ms. Wilson's professional experience and service include assistant professor and metadata librarian at The Ohio State University Libraries; adjunct professor in the Department of Library and Information Science at the Catholic University of America; and the American Library Association Committee on Accreditation External Review Panels. Ms. Wilson has a M.S. in library science from the University of North Carolina–Chapel Hill.