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PROMIS TRAINING WORKSHOP

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SPEAKER BIOS

Sara Ahmed, PT, PhD

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Sara Ahmed, PT, PhD, is a Professor in the School of Physical and Occupational Therapy, and Associate Member in Epidemiology and Biostatistics and Family Medicine, McGill University. She leads a research program in person-centered digital health research and is the scientific director of the BRILLIANT learning health community project. She conducts research aimed at improving health outcomes for individuals with chronic disease. Her research addresses the implementation of patient-reported outcomes (e.g. health-related quality of life, self-efficacy) and digital health solutions across trajectories of care to inform clinical and health system decision-making.

Susan Bartlett, PhD

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Dr. Susan Bartlett is a licensed clinical psychologist and Professor of Medicine at McGill University, Senior Scientist with the McGill University Health Center and Arthritis Research Canada, and Co-Founder of the McGill Centre for Health Measurement. She is a member of the PROMIS Health Organization Board of Directors and is Co-Director of the Canadian PROMIS National Center. Dr. Bartlett's research focuses on how behavior change such as diet, exercise, smoking, medication adherence and emotional wellbeing can help people with inflammatory arthritis and other chronic conditions feel and function better. She also evaluates ways to make medical care more patient-centered by collaborating with patient research partners, developing better patient reported outcome measures and improving doctor-patient communication.

Judith F. Baumhauer, MD, MPH

University of Rochester Medical Center, Rochester, New York

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Dr. Baumhauer is a tenured Professor and serves as Associate Chair of Academic Affairs and Professor, Department of Orthopaedics at the University of Rochester. In addition to providing clinical care, she holds the position as the Director of the Clinical Health Informatics Core for the UR Health Care System and is a board of director of Accountable Health Partners, ACS for the Rochester Region.

She received her Bachelor's degree from Springfield College, Master's degree in Biology from Middlebury College, and Doctorate of Medicine from the University of Vermont College of Medicine. She completed orthopaedic residency at the Medical Center Hospital of Vermont and a Fellowship in Foot and Ankle Surgery at the Medical College of Wisconsin. While working as an Attending at the University of Rochester, she obtained a Master in Public Health degree from the University of Rochester Department of Community and Preventative Health.

Dr. Baumhauer is the past president of the American Board of Orthopaedic Surgery, American Orthopaedic Foot and Ankle Society (AOFAS) and Eastern Orthopaedic Association. She currently is the president of the PROMIS Health Organization. Dr. Baumhauer has published over two hundred peer reviewed papers and book chapters. Her research interest focuses on the use of patient reported outcomes (PROs) in clinical decision-making to improve the care provided to patients. She has studied how collecting and sharing

PROs affect patient engagement, patient satisfaction and clinical efficiency. Dr. Baumhauer is a Board of Trustee for the *American Journal of Bone and Joint Surgery* and a reviewer for *Clinical Orthopaedics and Related Research*, *Foot & Ankle International*, *American Journal of Bone and Joint Surgery*, and the *Journal of Orthopaedic Research*

Clifton O. Bingham III, MD
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Clifton O. ("Bing") Bingham III, MD is Professor of Medicine in Rheumatology and Allergy and Clinical Immunology at Johns Hopkins University, where he directs the Johns Hopkins Arthritis Center, serves as Deputy Director for Research for the Division, and serves as Vice-Chair for Clinical Research in the Department of Medicine. He has a long-standing interest in rheumatoid arthritis (RA) spanning the continuum of bench to bedside investigation. He has been an investigator and led numerous RA clinical trials over the past 20 years and conducted a number of analyses of PROs from these studies. He has been a member of the Executive Leadership Committee for the international outcome measure development and validation group, OMERACT (Outcome Measures in Rheumatology), where many of his efforts have focused on PRO development and validation. He also serves as a member of the RA-PRO Working Group for the Critical Pathway Institute (C-Path).

Over more than a decade his work has focused on better understanding the patient's perspective of their disease experience and life impact, identifying and developing measures to reflect these aspects of HRQoL, piloting and validating the use of PROMIS measures in RA, and integrating this information into routine clinical care and clinical trials. He has been funded in this work by NIH, PCORI, the Jerome L. Greene Foundation, and the Stabler Foundation. He is author of more than 250 publications, reviews, and book chapters.

Patricia Franklin, MD, MPH, MBA
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Dr. Franklin serves as Professor, Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine where she leads research in methods for optimal patient-reported outcome (PRO) measure integration in clinical care and quality. Following a residency in Preventive Medicine, she completed a fellowship in Health Services Research emphasizing large database design and outcome measurement. This training laid the foundation for a career in quality improvement (Medical Director for Quality) and outcomes research. She serves as Principal Investigator of FORCE-TJR, a P50 (AHRQ) for comparative effectiveness research in total joint replacement (TJR) outcomes. Annual patient-reported outcomes (PROs) are collected on over 30,000 patients nationally. FORCE-TJR returns real-time scored, trended PRO and risk data to surgeons for individual patients and benchmarks aggregate outcomes. A PCORI-funded cluster randomized trial (6000 patients; 30 surgeons) is evaluating the role of PRO-based, tailored predictive data in a shared decision tool to guide TJR decisions. Other research includes co-directing a learning health system K12 program for junior faculty, evaluation of physical therapy and opioids in TJR, a trial of anti-thrombotic medications in TKR, and use of APPs to collect longitudinal PROs.

Richard C. Gershon, PhD
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Dr. Gershon strives to find new ways to assess outcomes of treatment and methodologies and share this information with clinicians in a manner that can immediately impact treatment. In his former role as Principal Investigator for the PROMIS Technical Center, Dr. Gershon served as technology host for more than 2,000 researchers and clinicians who were registered users of AssessmentCenter.net, a test authoring and study administration portal that served as the host for web-based versions of numerous instrument systems. This work continues through his oversight of the Assessment Center API, which enables the delivery of PROMIS

measures for 50+ Epic hospitals, 20+ ePRO platforms, individual institutions worldwide. Dr. Gershon serves as PI for the NIH Toolbox for the Assessment of Neurological and Behavioral Function, where he coordinated a team of 235 researchers to create a battery of instruments for clinical investigators to assess areas within cognitive, motor, sensory, and emotional health, for longitudinal, clinical, and comparative effectiveness research. As MPI for the Environmental influences on Child Health Outcomes (ECHO) PRO Measurement Core, Dr. Gershon and his team recommend, develop, and curate assessment delivery for over 80 sites.

Janel Hanmer, MD, PhD
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Dr. Hanmer is a practicing general internist at the University of Pittsburgh Medical Center. She is the Medical Director of the Patient Reported Outcomes Center at UPMC which oversees the integration and use of patient reported outcomes in clinical settings. Her research focuses on the construction and use of preference-based summary scores (e.g., health utility scores) and was lead of the PROMIS-Preference (PROPr) scoring effort.

Dinesh Khanna, MD, MSc
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Dinesh Khanna, MD, MSc is Professor of Medicine and Director, University of Michigan Scleroderma Program. He holds the Frederick G.L. Huetwell Professorship in Rheumatology. Dr. Khanna has published over 450 peer-reviewed articles and book chapters. He is the Principal Investigator on National Institutes of Health and industry-sponsored clinical studies. He is the coordinating PI on investigator-initiated and pharmaceutical-sponsored clinical trials in scleroderma. His current research focus is on developing, validating, and refining outcome measures in rheumatic diseases and designing controlled trials. He received the prestigious 2015 Henry Kunkel Young Investigators Award from the American College of Rheumatology.

Michelle Langer, PhD
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Dr. Langer has over 15 years of experience contributing to psychometric research in assessment and patient-reported outcomes (PROs). Dr. Langer currently manages the Patient-Reported Outcomes Measurement Information System (PROMIS) API at Northwestern University and leads the Epic PROMIS Collaborative. Dr. Langer's PRO research spans the initial development of PROMIS pediatric measures, bookmarking studies to aid PRO score interpretation, and clinical implementation of PROMIS integrated into electronic data collection systems. In addition to the development and use of measurement instruments, her experience includes complex statistical analyses, ranging from biostatistics methods to latent variable methodology. Dr. Langer's work has been published in a wide range of journals including *Quality of Life Research*, *Health Psychology*, *Journal of Clinical Epidemiology*, *Multivariate Behavioral Research*, and *Medical Care*. She graduated with highest honors and highest distinction from the University of North Carolina at Chapel Hill, and continued her studies to complete a M.A. and Ph.D in Quantitative Psychology with Dr. David Thissen.

Jacob Lippa, MPH
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Jacob Lippa is Senior Manager of Clinical Analytics at Providence (formerly Providence St Joseph Health), a large non-profit health system in the western United States comprising 50 hospitals and more than a thousand clinics. In this role, he focuses primarily on value measurement and leads the organization's patient-reported outcomes program. His team is responsible for incorporating patient-reported outcomes into clinical practice and using these and other data on cost and quality to assess variation and drive higher value care across the enterprise.

Prior to joining Providence in 2017, Mr. Lipa held a dual appointment with Harvard Business School and the International Consortium for Health Outcomes Measurement (ICHOM), where he worked to advance value-based health care globally. During that time, he led several large-scale initiatives to measure and compare health outcomes in the US, Brazil, and Australia. He has worked at the intersection of health care policy and practice for more than 15 years. Originally from Denver, Colorado, he holds a postgraduate degree in health care policy and management from Columbia University and is a certified quality improvement advisor and patient safety officer.

Eric Makhni, MD, MBA
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Dr. Eric Makhni is a sports medicine orthopedic surgeon and Medical Director of the Center for Patient Reported Outcome Measures at the Henry Ford Health System in Detroit Metro, MI. He also serves as the Director of Quality and Informatics for the Orthopedic Service Line at Henry Ford. In these roles, Dr. Makhni has led the development and implementation of a fully integrated PROM platform delivered through the electronic medical record for numerous departments and service lines. His expertise is in PROM-driven patient care transformation and integration.

Carole Tucker, PT, PhD
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Carole A Tucker, PT, PhD is the current Associate Dean for Research; Interim Chair, Department of Physical Therapy; and the Adoue Distinguished Professor of Cognitive Neuroscience, Department of Nutrition, Metabolism and Rehabilitation Sciences in the School of Health Professions at the University of Texas Medical Branch - Galveston. Dr Tucker's career objective is to improve the health of individuals, particularly children with disabilities, through two primary avenues of research: 1) the development of novel interventions and technology for natural environment and ecological assessment of health, function, activity, participation, and quality of life; and 2) advancing the science of person-reported outcome (PRO) measures using mixed methods and modern measurement approaches combined with data analytics suitable for pragmatic trials.

She is trained as a biomedical engineer and as a physical therapist with over 30 years of active clinical practice. Dr Tucker has a strong record of collaborative research with funding from NIH, DoD, NSF, PCORI and Shriners Hospitals for Children (SHC). Dr Tucker served as an NIH PROMIS network scientist and co-investigator on the Children's Hospital of Philadelphia (CHOP) site (PI: Forrest). Her roles in PROMIS include acting as the workgroup leader for the pediatric physical activity item bank, being appointed co-chair of the PROMIS network Standards Subcommittee, and as analytical co-lead for the CHOP site. In addition, she served as a Col on the NIH PEPR, Validation of Pediatric Patient Reported Outcomes in Chronic Diseases, grant(CHOP site/ Forrest PI. Her current research focuses on biomechanics and motor control of gait, development of patient-report outcome measures of health status in pediatric populations, clinical and health informatics, learning health systems, application of pattern recognition, machine learning and advanced statistical analytical approaches in large complex data sets of patient generated data.

Hedy van Oers, PhD
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Hedy van Oers is a postdoc researcher at the Amsterdam UMC, the Netherlands. She has a background in child psychology and obtained her PhD on Patient and Parent Reported Outcomes in clinical practice in 2019 (supervisors: prof. Martha Grootenhuis and dr. Lotte Haverman). In 2011, she started as a research/implementation assistant on the KLIK PROM portal (www.hetklikt.nu) at the Emma Children's Hospital Amsterdam UMC. KLIK has been implemented in many hospitals as part of standard care and continues to improve through scientific research, e.g., by adding the PROMIS measures to the portal, including research on

the visualization and collecting norm data, and on evaluating the implementation from different stakeholders' perspectives.

Ashley Wilder Smith, PhD, MPH
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Ashley Wilder Smith, PhD, MPH, is Chief of the [Outcomes Research Branch \(ORB\)](#) at the National Cancer Institute (NCI). ORB supports investigations to understand and improve health outcomes and quality care for cancer patients, survivors, and families. In addition to overseeing the entire portfolio of ORB grants, contracts and research activities, Dr. Smith collaborates on efforts across the NIH and the Department of Health and Human Services to study and improve the measurement and evaluation of patient-reported health outcomes in observational studies, clinical trials, and for use in clinical care. She is currently the NCI Chief Science Officer of [IMPACT: Improving the Management of symPtoms during And following Cancer Treatment](#), a Research Consortium designed to accelerate the use of systematic cancer symptom management systems integrated into electronic health record systems to collect patient-reported data and support clinical responses consistent with evidence-based guidelines. She also served as the National Institutes of Health (NIH) Chief Science Officer of a trans-NIH [initiative](#) to make four person-centered health outcome assessment systems available: PROMIS®, the NIH Toolbox®, Neuro-QOL, and ASCQ-Me™. These tools were transitioned to independence from NIH funding and are now offered through an integrated platform for automated use in one publicly available resource, [HealthMeasures](#).

Dr. Smith earned her MS and PhD degrees in Health Psychology from the University of Pittsburgh. She completed an NCI Cancer Prevention Fellowship, which included earning an MPH in Epidemiology, also from the University of Pittsburgh. Dr. Smith joined the ORB in 2006 and became Branch Chief in 2014.

Betina Yanez, PhD
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Dr. Yanez is an Associate Professor in the Department of Medical Social Sciences and a member of the Robert H. Lurie Comprehensive Cancer Center at the Northwestern University Feinberg School of Medicine. She received her undergraduate degree from New York University and her PhD in Clinical Psychology from the University of California, Los Angeles. Her research program falls within the areas of patient-centered outcomes and psychosocial issues pertinent to cancer control and survivorship. More specifically, her work bridges behavioral medicine and health equity research to investigate improvements in the patient-reported outcomes (PROs) and clinical outcomes of individuals diagnosed with cancer in order to translate evidence-based research into cancer care. To address the concerns faced by cancer patients, she has established an impactful and innovative research program that focuses on patient-centered care by engaging key stakeholders to address major public health problems facing cancer patients, optimize cancer-related outcomes, and enhance cancer care delivery. Her research program is organized into three distinct but overlapping research components: health equity and community-based research, evidence-based behavioral oncology research, and implementation of patient engagement and PROs in cancer care. Examples of her ongoing research projects include adherence to oral anticancer medications, outcomes among racial/ethnic minority cancer survivors, and the reach and scalability of evidence-based interventions for oncology patients that can be delivered via technology platforms.