# CENTER FOR BIOMEDICAL RESEARCH TRANSPARENCY

# **2022 Biomedical Transparency Summit**

Enhancing communication of negative and inconclusive findings across biomedical research.

The 2022 Biomedical Transparency Summit is a virtual program of 2 webinars that brings together leaders in publishing, private and publicly funded research, policymakers and technology to share the latest transparency developments impacting research practice.

Executive Director (Vivli)

#### Webinar 1

7th September 2022

3pm EDT/NY 8pm BST/London

75 mins presentation 15 mins questions

## NIH Data Sharing Policy - What you need to know!

Chairs: Dr. Devon Crawford (NIH), Prof. Sandra Petty (CBMRT)

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Introduction to the NIH Data Sharing Policy

Dr. Lyric Jorgenson

Acting Director of the Office of Science Policy (NIH)



Implementation of the NIH Policy - FAIR-Data / TRUST-repositories Dr. Susan K. Gregurick Associate Director for Data Science (NIH)



Impact of the NIH Policy - what data users can expect Dr. Rebecca Li

## Webinar 2

14th September 2022

3pm EDT/NY 8pm BST/Lon

75 mins presentation 15 mins questions

## Transparency & Data Sharing: International Responses

Chairs: Dr. David Tovey (CBMRT), Dr. Luis-Gabriel Cuervo (PAHO/WHO)



Equity and transparency in clinical research: what can be done to improve it? Dr. Vivian Welch

Interim CEO & Editor-in-Chief, Campbell Collaboration



Null Hypothesis Update - What has been its impact? Where to from now? A/Prof Sandra Petty

CEO & Founder (CBMRT)



Biomedical Transparency: PAHO experience

Dr. Luis-Gabriel Cuervo Senior Advisor on Research for Health (PAHO/WHO)



The Inter-Academy Partnership call for a Global Health Data Sharing Framework for Global Health Emergencies: why it is important Prof. Zulfiqar Bhutta

Chair in Global Child Health, Hospital for Sick Children, Toronto

# ABOUT THE SPEAKERS

### Zulfiqar Bhutta, Director of the Institute for Global Health & Development, Aga Kahn University



Prof. Zulfiqar A. Bhutta is the Distinguished University Professor and Founding Director of the Institute for Global Health and Development and the Centre of Excellence in Women and Child Health, at the Aga Khan University. He also holds the Robert Harding Inaugural Chair in Global Child Health at the Hospital for Sick Children, Toronto, Co-Director of the SickKids Centre for Global Child Health, unique joint appointments. He also holds adjunct professorships at several leading Universities globally including the Schools of Public Health at Johns

Hopkins (Baltimore), George Washington University (DC), Boston University School of Public Health, University of Alberta as well as the London School of Hygiene & Tropical Medicine. He is a designated Distinguished National Professor of the Government of Pakistan and was the Founding Chair of the National Research Ethics Committee of the Government of Pakistan from 2003-2014.

#### Luis-Gabriel Cuervo, Senior Advisor on Research for Health, PAHO/WHO



Dr. Luis-Gabriel Cuervo is a clinical epidemiologist, a family physician, a public health professional, and a research policymaker. His career spans over three decades with a focus on bringing scientific evidence close to decisions for health, developing conducive ecosystems to advance research for health, and research governance. He is PAHO/WHO's Senior Advisor on Research for Health following his appointments as Senior Advisor on Health Systems Research and Unit Chief for Research Promotion and Development. He championed the development of PAHO's Policy on Research

for Health and now supports its implementation. He collaborates with the EQUATOR Network on increasing research value and reducing research waste, developing and promoting research reporting guidelines. He helped consolidate the International Clinical Trial Registry Platform and knowledge translation platforms such as WHO's EVIPNet.

Dr. Cuervo has been with the International Clinical Epidemiology Network, spearheaded the Cochrane Collaboration in Colombia, established partnerships to expand the influence of systematic reviews and overviews in decisions for health, and contributed to the Global Forum for Health Research.

### Susan K. Gregurick, Director of the Office of Data Science Strategy, NIH



Susan K. Gregurick, Ph.D., was appointed Associate Director for Data Science and Director of the Office of Data Science Strategy (ODSS) at the National Institutes of Health on Sept. 16, 2019. Under Dr. Gregurick's leadership, the ODSS leads the implementation of the NIH Strategic Plan for Data Science through scientific, technical, and operational collaboration with the institutes, centers, and offices that comprise NIH. Dr. Gregurick was instrumental in the creation of the ODSS in 2018 and served as a senior advisor to the office until being named to her current position.

Dr. Gregurick was previously the Division Director for Biophysics, Biomedical Technology, and Computational Biosciences at the National Institute of General Medical Sciences. Prior to joining the NIH in 2013, Dr. Gregurick was a program director in the Office of Biological and Environmental Research at the Department of Energy. Before beginning a career of government service, Dr. Gregurick was a professor of computational chemistry at the University of Maryland, Baltimore County. Her research interests included dynamics of large biological macromolecules, and her areas of expertise are computational biology, high performance computing, neutron scattering and bioinformatics.

#### Lyric Jorgenson, Acting Director of the Office of Science Policy, NIH



Lyric Jorgenson, PhD, is the Acting Associate Director for Science Policy and the Acting Director of the Office of Science Policy at the NIH. In this position, she provides senior leadership in the development and oversight of cross-cutting biomedical research policies and programs considered to be of high-priority to NIH and the United States Government. Prior to this role, she served in numerous roles across the agency, including Deputy Director of the Office of Science Policy, and has led

the development of numerous high impact science and policy initiatives such as the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative and the National Center for Advancing Translational Sciences (NCATS). Dr. Jorgenson also served as the Deputy Executive Director of the White House Cancer Moonshot Task Force in the Office of the Vice President in the Obama administration, where she directed and coordinated cancer-related activities across the Federal government and worked to leverage investments across sectors to dramatically accelerate progress in cancer prevention.

Dr. Jorgenson earned a doctorate degree from the Graduate Program for Neuroscience at the University of Minnesota-Twin Cities where she conducted research in neurodevelopment with a focus on learning and memory systems. She earned a Bachelor's degree in Psychology from Denison University.

#### Rebecca Li, Executive Director, Vivli



Rebecca Li, PhD, is the Executive Director of Vivli and on faculty at the Center for Bioethics at the Harvard Medical School. Previous to her current role she was the Executive Director of the MRCT Center of Brigham and Women's Hospital and Harvard for over 5 years and remains a Senior Advisor at the Center. She has over 25 years of experience spanning the entire drug development process with experience in Biotech, Pharma and CRO environments. She completed a Fellowship in 2013 in

the Division of Medical Ethics at Harvard Medical School. She earned her PhD in Chemical and Biomolecular Engineering from Johns Hopkins University.

## Sandra Petty, CEO, Center for Biomedical Research Transparency



A/Prof. Sandra Petty MBBS FRACP PhD is an academic and clinical neurologist focussing on epilepsy and its co-morbidities. She undertook combined clinical and research training in neurology and in bone health. She was a Senior Lecturer at The University of Melbourne Medical School, involved in teaching and medical student curriculum development, particularly transition to medical practice and medical cognizance. She completed specialist training in Neurology in 2006 and currently

works in epilepsy at St Vincent's Hospital and at Alfred Health in Melbourne. Sandy was awarded her PhD 2009, examining bone health, body composition, falls and fracture risk in twins and siblings discordant for anti-epileptic medication use. Dr. Petty completed postdoctoral work utilising a mouse primary calvarial osteoblast model and patch clamping technique to examine effects of epilepsy medications on ion channels in osteoblasts.

Sandy is the founder of the Null Hypothesis initiative and is keen to facilitate transparent reporting of results in biomedical research - particularly regarding studies where there are negative or inconclusive results. This facilitates communication of results between scientists and clinicians, and will improve research efficiency and better inform research study design and ultimately, patient care.

#### Vivian Welch, Interim CEO & Editor in Chief, Campbell Collaboration

Vivian Welch is Interim CEO and Editor in Chief of Campbell, Director of the Methods Centre at

the Bruyère Research Institute, and Associate Professor at University of Ottawa School of Epidemiology and Public Health. She co-convenes the Campbell and Cochrane Equity Methods Group and is a co-director of Cochrane-Campbell Global Ageing. She obtained her PhD in Population health and epidemiology from the University of Ottawa in 2010.

Vivian's research interests include methods for reporting and conducting systematic reviews relevant to ageing and health equity. She has led international teams in the development of reporting guidelines for how to assess health equity in systematic reviews (PRISMA-Equity 2012), randomized controlled trials (CONSORT-Equity 2017) and public health guidelines. She has led and contributed to over 30 systematic reviews on global health. She led a new chapter on assessing health equity in the revised Cochrane Handbook, published in 2019.

She has published over 200 peer-reviewed papers on systematic review methods and health equity and led 33 research grants as a principal investigator or co-principal investigator. She was awarded a recognition as one of the top 100 women in Global Health 2018, The Lancet and Canadian Society for International Health and an Ontario Early Researcher Award (2014-2019).