

Innovative Approaches to Social and Behavioral Research in Rare Genetic Diseases

Participants' List

Barbara Bowles Biesecker, M.S., Social and Behavioral Research Branch, National Human Genome Research Institute, NIH

Ms. Biesecker conducts social and behavioral rare disease research at NHGRI and is initiating efforts to foster innovative new approaches to address limitations in this type of research.

Thomas Eng, V.M.D., M.P.H., EvaluMetrix LLC.

Dr. Eng's areas of expertise include the application of emerging technologies, especially the Internet, to health communication, health care, public health, evaluation, and research.

Bill Gahl, M.D., Ph.D., Office of the Clinical Director, National Human Genome Research Institute, NIH

Dr. Gahl studies rare inborn errors of metabolism through the observation and treatment of patients in the clinic and through biochemical, molecular biological, and cell biological investigations in the laboratory.

Steve Groft, Pharm.D., Office of Rare Diseases, NIH

Dr. Groft is the Director of the Office of Rare Diseases at NIH, and is dedicated to improving research on rare diseases.

Scott D. Halpern, M.D., Ph.D., Center for Clinical Epidemiology and Biostatistics, University of Pennsylvania School of Medicine.

Dr. Halpern has written extensively on the topic of ethical issues in underpowered clinical trials.

Janine E. Janosky, Ph.D., Department of Family Medicine and Clinical Epidemiology, University of Pittsburgh

Dr. Janosky is an expert in biomedical research designs, biostatistics and the use of statistical power.

Johanna Loewenstein, MPH, Social and Behavioral Research Branch, National Human Genome Research Institute, NIH

Ms. Loewenstein is a research fellow interested in the application of genomics to public health, and in the clinical application of genetic tests.

Colleen McBride, Ph.D., Social and Behavioral Research Branch, National Human Genome Research Institute, NIH

As the Chief of the Social and Behavioral Research Branch at NHGRI, Dr. McBride provides leadership to the branch in developing quality, innovative research to address a variety of populations.

Gurvaneet Randhawa, M.D., M.P.H., Center for Outcomes and Evidence, Agency for Healthcare Research & Quality

Dr. Randhawa is an expert on the principles and process of evidence-based decision-making and the need for outcomes data.

Bryce Reeve, Ph.D., National Cancer Institute, NIH

Dr. Reeve directs an active program to enhance the use of patient-reported outcomes (including health-related quality of life (HRQOL) and patient satisfaction with healthcare) in clinical research and practice to improve quality of care.

Sharon Terry, Genetic Alliance

Mrs. Terry is at the forefront of consumer participation in genetics research, services and policy and serves as a member of many of the major governmental advisory committees on medical research.

David Abrams, Office of Behavioral and Social Science Research, NIH (invited)

Raynard Kington, M.D., Ph.D, Deputy NIH Director (Offered to consult on the follow-up to the meeting)