Methods for Assessing the Impact of Screening in Childhood on Health Outcomes

May 9–10, 2019 6710B Rockledge Drive, Bethesda, MD 20817

Agenda

Precis: The goal of this workshop is to stimulate methodological innovation in evaluating the impact of screening on childhood health outcomes. Workshop objectives include:

- Conceptualizing the universe of child health outcomes pertinent to screening
- Identifying methodological challenges in evaluating child health outcomes
- Discussing novel and rigorous approaches to evaluating child health outcomes
- Considering next steps for moving the research field forward

Products: In addition to identifying next steps that will inform future NIH activities, the issues addressed at this meeting will be summarized in a set of papers for a journal supplement in a relevant pediatric journal.

Day One: May 9, 2019

8:45 a.m.-9:00 a.m. Welcome and Introductions

• Tracy King, M.D., M.P.H.

Medical Officer

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Elizabeth Neilson, Ph.D., M.P.H., M.S.N.

Health Science Policy Analyst

NIH Office of Disease Prevention (ODP)

9:00 a.m.-9:15 a.m. NIH ODP Director's Remarks

<u>David M. Murray, Ph.D.</u>
 NIH Associate Director for Prevention
 Director, NIH ODP

9:15 a.m.-9:30 a.m. Presenting the Challenge

- Overview of the Challenges of Evaluating Outcomes from Screening in Childhood
 - Alex R. Kemper, M.D., M.P.H., M.S.
 Former Member, U.S. Preventive Services Task Force
 Pediatrician and Chief, Division of Ambulatory Pediatrics at Nationwide Children's Hospital

Session I

9:30 a.m.–10:10 a.m. Conceptual Frameworks for Assessing the Impact of Screening

- Beyond Morbidity and Mortality: Measuring Optimal Development
 - Childhood Screening: Considering the Importance of Social Context
 - Margaret Kuklinski, Ph.D.
 Research Scientist and Principal Investigator, School of Social Work, University of Washington

- Innovations in Measuring Optimal Development—Physiologic Aspects
 - Matthew Gillman, M.D.
 NIH Environmental influences on Child Health Outcomes (ECHO) Program Director

10:10 a.m.-11:00 a.m. Panel Discussion (to include speakers, moderator, and invited panel discussant)

- Discussant: <u>Stephen R. Daniels, M.D., Ph.D.</u>
 Professor of Pediatrics and Chairman, Department of Pediatrics University of Colorado Pediatrician-in-Chief, Children's Hospital Color
- Moderator: <u>Sharon J. Levy, M.D., M.P.H.</u>
 Director, Adolescent Substance Use and Addiction Program, Boston Children's Hospital Associate Professor in Pediatrics, Harvard Medical School

11:00 a.m.-11:15 a.m. Break

Session II

11:15 a.m.–12:15 p.m. Conceptual Frameworks for Assessing the Impact of Screening (continued)

- Beyond Considerations of Morbidity and Mortality: Measuring Well-Being, Quality of Life, and Other Childhood Health Outcomes Across Developmental Stages
 - Measuring Quality of Life—Approaches for Assessing the Child and Family
 - Katherine Bevans, Ph.D.
 Associate Professor, Temple University College of Public Health
 - Conceptual Frameworks for Assessing the Impact of Screening, Across Different Stages of Development, on Health Outcomes: Screening and Well-Being
 - Darwin Labarthe, M.D., Ph.D., M.P.H.
 Professor of Preventive Medicine, Northwestern University
 - Measuring Educational Outcomes in Community Settings: The Case of Early Screening for Dyslexia
 - Don L. Compton, Ph.D.
 Professor of Psychology at Florida State University
 Director, Florida Center for Reading Research

12:15 p.m.-1:00 p.m. Panel Discussion (to include speakers, moderator, and invited panel discussants)

- Discussant: <u>Jennifer Brooks, Ph.D.</u>
 Social Impact Adviser, Jennifer L. Brooks, LLC
- Discussant: Ned Calonge, M.D., M.P.H.
 President and CEO, The Colorado Trust
 Associate Professor of Family Medicine and Epidemiology, University of Colorado
 Vice Chair, Community Preventive Services Task Force
- Moderator: Kelly J. Kelleher, M.D.
 Principal Investigator for Center of Innovation in Pediatric Practice, Vice President for Community Health Nationwide Children's Hospital
 Professor of Pediatrics and Public Health, Ohio State University Colleges of Medicine and Public Health

1:00 p.m.-2:00 p.m. Lunch

Session III

2:00 p.m.–2:45 p.m. Conceptual Frameworks for Assessing the Impact of Screening (continued)

- Measuring Benefits and Harms of Screening to the Child, Family, and Community
 - The Family Life Project (FLP)
 - Lynne Vernon-Feagans, Ph.D.
 Senior Research Scientist, Frank Porter Graham Child Development Institute, The University of North Carolina at Chapel Hill
 - Childhood Screening: Benefits and Harms to Communities
 - Jennifer Lowry, M.D.
 Pediatrician, Children's Mercy Hospital

2:45 p.m.-3:25 p.m. Panel Discussion (to include speakers, moderator, and invited panel discussant)

- Discussant: Robert O. Wright, M.D., M.P.H.
 Professor and Ethel H. Wise Chair of the Department of Environmental Medicine and Public Health
 Professor of Pediatrics, Icahn School of Medicine at Mount Sinai
- Discussant: Michael Silverstein, M.D., M.P.H.
 Professor of Pediatrics; Chief, Division of General Academic Pediatrics; Vice Chair for Research,
 Department of Pediatrics at Boston University School of Medicine
 Associate Chief Medical Officer for Research and Population Health, Boston Medical Center
- Moderator: <u>Don Bailey, Ph.D.</u>
 Distinguished Fellow, Early Childhood Development, RTI International

3:25 p.m.–3:40 p.m. *Break*

Session IV

3:40 p.m.-4:40 p.m. Innovative Designs and Analytic Approaches

- Using Longitudinal and Linked Data Systems to Evaluate Screening in Clinical Settings
 - Shannon Gwin Mitchell, Ph.D.
 Senior Research Scientist, Friends Research Institute
- Using Longitudinal and Linked Data Systems to Evaluate Screening in Community Settings
 - <u>Corina Graif, Ph.D.</u>
 Assistant Professor of Sociology and Criminology; Research Associate, Population Research Institute at Pennsylvania State University
- Non-RCT Designs and Analytic Approaches for Evaluating Outcomes of Childhood Screening
 - o Thomas D. Cook, Ph.D.

Research Professor, George Washington Institute of Public Policy, Trachtenberg School of Public Policy, George Washington University

Joan and Sarepta Harrison Emeritus Professor of Ethics and Justice; Professor Emeritus of Sociology and Institute for Policy Fellow Emeritus, Northwestern University

4:40 p.m.–5:30 p.m. Panel Discussion (to include speakers, moderator, and invited panel discussants)

- Discussant: <u>Thomas Newman, M.D., M.P.H.</u>
 Professor Emeritus of Epidemiology and Biostatistics, University of California, San Francisco
- Discussant: <u>Judith Shaw, Ed.D., M.P.H., R.N., FAAP</u>
 Executive Director, Vermont Child Health Improvement Program
 Professor of Nursing and Pediatrics, The University of Vermont
- Moderator: <u>Gary Slade, B.D.Sc., DipDPH, Ph.D.</u>
 John W. Stamm Distinguished Professor, Department of Dental Ecology and Director of Oral Epidemiology Ph.D. Program, UNC-Chapel Hill

5:30 p.m. Adjournment

6:00 p.m.–8:00 p.m. *Optional walk and group dinner* Darcy's Kitchen + Bar, Bethesda Marriott Suites

Day Two: May 10, 2019

8:15 a.m.-8:30 a.m. Welcome

Tracy King, M.D., M.P.H.
 Medical Officer
 NICHD

8:30 a.m.-8:45 a.m. NICHD Director's Remarks

<u>Diana W. Bianchi, M.D.</u>
 <u>Director, NICHD</u>

Session V

8:45 a.m.-9:30 a.m. Conceptual Frameworks for Assessing the Impact of Screening (continued)

- Economic/Cost-Benefit Analyses and Data Collection
 - Issues in Cost-Effectiveness Analysis and Cost-Benefit Analyses in the Case When Screening Is Likely to Most Benefit the Child
 - Clive Belfield, Ph.D.
 Professor in the Department of Economics, Queens College, City University of New York
 Principal Economist at the Center for Benefit-Cost Studies in Education, Teachers College,
 Columbia University.
 - Screening When the Benefits Accrue to Society: The Case of Childhood Blood Lead Screening
 - Mary Jean Brown Sc.D., R.N.
 Adjunct Assistant Professor of Social and Behavioral Sciences, Harvard T.H. Chan School of Public Health

9:30 a.m.-10:10 a.m. Panel Discussion (to include speakers, moderator, and invited panel discussants)

- Discussant: <u>Susan Griffin, Ph.D.</u>
 Health Economist, Centers for Disease Control and Prevention, Division of Oral Health
- Discussant: <u>Sara Kinsman, M.D., Ph.D.</u>
 Director, Division of Child, Adolescent and Family Health, Maternal and Child Health Bureau, Health Resources & Services Administration
- Moderator: <u>Phaedra Corso, Ph.D.</u>
 Vice President for Research, Kennesaw State University

10:10 a.m.-10:25 a.m. Break

Session VI

10:25 a.m.–11:50 a.m. *Innovative Designs and Analytic Approaches (continued)*

- Focus on Specific Designs or Analytic Approaches
 - o Natural Experiments and Linked Data to Assess Child Developmental Screening
 - John Meurer, M.D., M.B.A.
 Professor and Director, Institute for Health & Equity; Division Director, Community Health
 Professor, Medical College of Wisconsin; Pediatrician, Midtown Clinic, Children's Hospital of Wisconsin
 - Modeling Approaches to Enhance the Capacity for Causal Inference: Precision Medicine and Treatment (PreEMT) Model as an Example
 - Ann Wu, M.D., M.P.H.
 Associate Professor, Department of Population Medicine, Harvard Medical School Director of the PRecisiOn Medicine Translational Research (PROMoTeR) Center Director of the Center for Healthcare Research in Pediatrics (CHeRP)
 - o Screening in the Digital and Genomic Age
 - Kenneth D. Mandl, M.D., M.P.H.
 Donald A.B. Lindberg Professor of Pediatrics & Biomedical Informatics, Harvard University
 - Understanding the Context of Screening: How and Where Data Are Collected, and Who Is Present?
 - John Knight, M.D.
 Associate Professor of Pediatrics, Harvard Medical School

11:50 a.m.-12:30 p.m. Panel Discussion (to include speakers, moderator, and invited panel discussant)

- Discussant: <u>Margherita Fontana, D.D.S., Ph.D.</u>
 Professor, Cariology, Restorative Sciences and Endodontics, School of Dentistry, University of Michigan
- Moderator: <u>Elizabeth M. Ginexi, Ph.D.</u>
 Health Scientist Administrator, NIH Office of Behavioral and Social Sciences Research

12:30 p.m.–1:45 p.m. Bag Lunch and Discussion of Future Actions

1:45 p.m.-2:00 p.m. Wrap-Up

2:00 p.m. Adjournment