NIH Perspective:
Collaborations on Research Related to Pregnant and Lactating Women

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Current Collaborations

• Committees, Advisory Groups, Working Groups
• Meetings, Conferences, and Workshops
• Health Surveys
• Research Initiatives and Resource Development
• Public Education Campaigns

NIH tracks collaborations with other HHS agencies and provides this info in a report and database: https://report.nih.gov/crs/. Collaborations within NIH are also tracked and described in a separate report located at https://dpcpsi.nih.gov/collaboration/index. Data on other trans-federal collaborations have also been collected on an ad hoc basis by the NIH Office of the Director.
Examples of Ongoing Committees and Working Groups

• Breastfeeding and Human Lactation Research Scientific Interest Group – NIH, FDA, OSG
• Advisory Committee for Immunization Practices (ACIP) – CDC, FDA, NIH
• Federal SUID/SIDS Work Group – CDC, NIH, ACF, CPSC, FDA, IHS, HRSA, DoD, OMH
Planning Research Initiatives: Meetings and Workshops

• Objective: Bring together researchers, federal agencies, international partners, professional societies and health care professionals to outline current research gaps and develop a research plan to answer important public health issues

• Recent examples:
  • Opioid Use in Pregnancy, Neonatal Abstinence Syndrome, and Childhood Outcomes – NIH, CDC, OASH, FDA, SAMHSA
  • Bridging Knowledge Gaps to Understand How ZIKV Exposure and Infection Affects Child Development – NIH, CDC

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Establishing an Information Base: Health Surveys

• The American Community Survey (ACS) – U.S. Census Bureau, CDC, NIH
  • Provides vital information on a yearly basis about our nation and its people
  • Generates data that help determine how more than $400 billion in federal and state funds are distributed each year

• The National Survey of Family Growth (NSFG) – CDC, NIH
  • Gathers information on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men’s and women’s health
  • Results are used by HHS and others to plan health services and education programs and to conduct statistical studies of families, fertility, and health
Examples of Research Collaborations and Resource Development

• Antiretroviral Pregnancy Registry – CDC, FDA, HRSA, NIH
• Federal Interagency Forum on Child and Family Statistics – CDC, HRSA, SAMHSA, NIH, AHRQ
• Zika Experimental Science Team (ZEST) data portal – FDA, HRSA, NIH
• USPSTF – AHRQ, CDC, NIH, OASH, SAMHSA, others
• PregSource™ – NIH, CDC, HRSA
Other PregSource™ Partners

NIH National Center for Complementary and Integrative Health

CDC Centers for Disease Control and Prevention

NIH National Institutes of Health Office of Research on Women’s Health

Society for Women’s Health Research

March of Dimes

NIH National Heart, Lung, and Blood Institute

NIH National Institute on Minority Health and Health Disparities

Genetic Alliance

American Academy of Pediatrics

Preeclampsia Foundation

AWHONN Promoting the Health of Women and Newborns

NIH National Institute of Nursing Research

NIH National Institutes of Health Office of Behavioral and Social Sciences Research

HRSA Health Resources and Services Administration

American College of Nurse-Midwives

American Society for Reproductive Medicine

American College of Obstetricians and Gynecologists
PregSource™: How it Works

• Each participant logs in periodically over the course of her pregnancy and afterwards
  • Receives monthly gestational-age and post-pregnancy questionnaires, including questions about her baby’s development
  • Enters data in online trackers (as often as daily)
  • Some women will receive specialized questionnaires targeted to their specific conditions (e.g., gestational diabetes, physical disabilities)

• Women provide information about common pregnancy experiences in near-real-time:
  • Sleep, Nausea, Exercise, Weight

• Answers to these topics will help researchers build a more complete picture of normal pregnancy and develop strategies for improving maternal care
Examples of Recent Collaborations Using NICHD Research Network Infrastructure

- Obstetric-Fetal Pharmacology Research Network
  - FDA
- Maternal Fetal Medicine Units Network
  - NHLBI, NINDS, FDA
- NuMOM2b study
  - NHLBI
- Neonatal Research Network
  - CDC, FDA, NHLBI
- Global Network for Women’s and Children’s Health Research
  - USAID
Examples of Applying Research: Public Education Campaigns

• Text4babySM – OASH (OWH, OMH), HRSA, CDC, NIH, ACF, OSTP, DoD, USDA, CPSC, SSA

• National Child and Maternal Health Education Program – NIH, CDC, IHS, HRSA, OASH (OMH, OWH)

• Safe to Sleep® – NIH, CDC, CPSC, HRSA, ACF, FDA, IHS, DoD, OASH (OMH)

• Treating for Two – NIH, FDA, NVPO, OASH (OMH, OWH)
Examples of Opportunities for Additional Collaborations

- **Global Coalition to Advance Preterm Birth Research (GCAPR)**
  - Reduce preterm birth and improve maternal and newborn health through expanded scientific knowledge, communications, and collaborations

- **Human Placenta Project**
  - Understand human placental development, structure, and function in real time

- **NIH Pregnancy Research Networks**
  - Obstetric-Fetal Pharmacology Research Units
  - Maternal Fetal Medicine Units
  - Neonatal Research Network
  - Global Network for Women’s and Children’s Health Research
THANK YOU!