



2021 WOMEN'S HEALTH CONFERENCE

Updates and Next Steps

Samia Noursi, PhD

Sarah Temkin, MD

Judy Regensteiner, PhD



House and Senate “Significant Items” Request a Conference

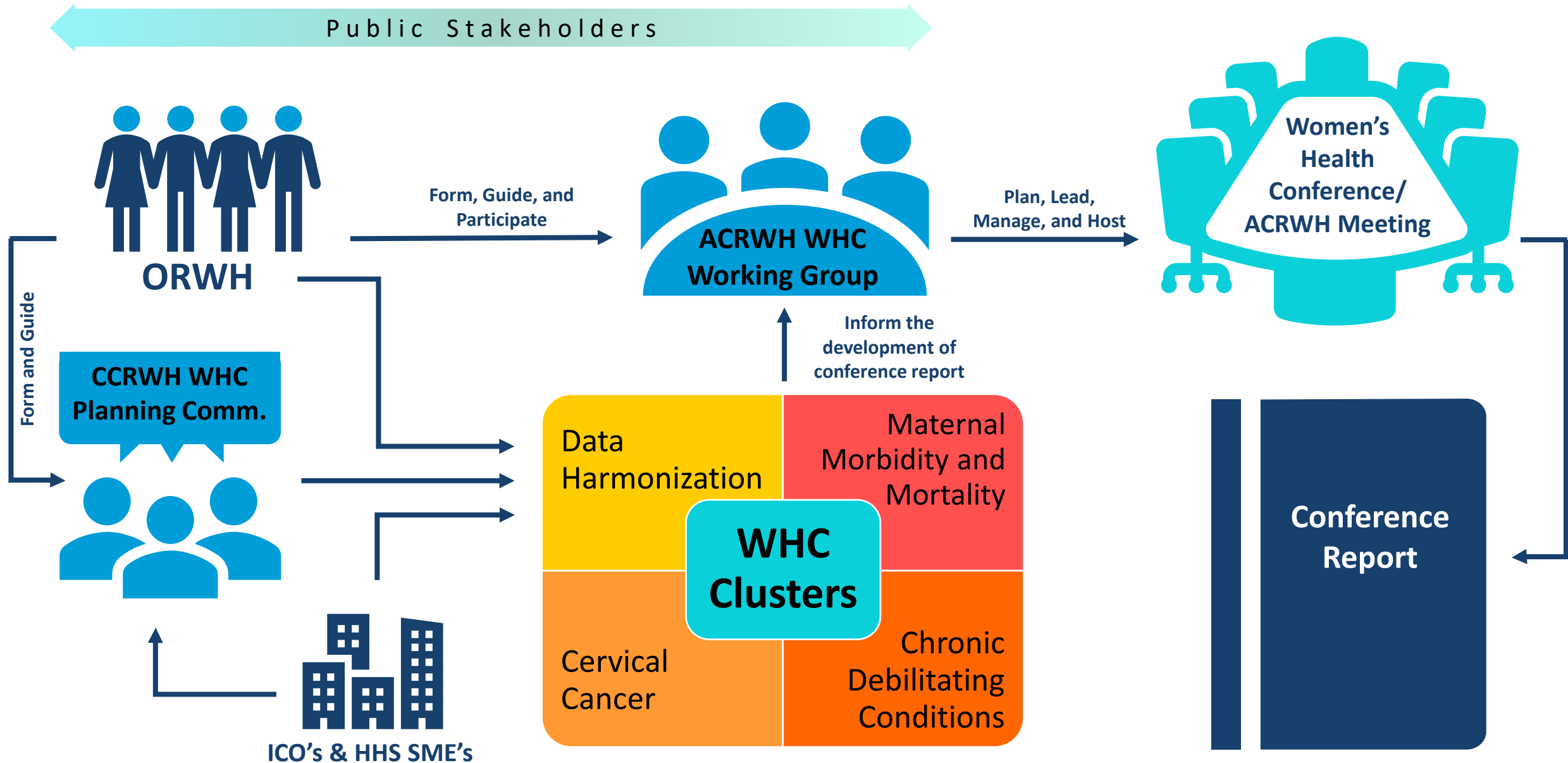
ORWH to hold the **Advancing NIH Research on the Health of Women: A 2021 Conference** on October 20, as part of the ACRWH Meeting.

- Must include representatives from ORWH, NICHD, NCI, NHLBI, NIDDK, & other relevant ICOs.
- **Evaluate research** and **identify priorities** to advance the study of women’s health, particularly:
 1. Rising rates of maternal morbidity and mortality;
 2. Rising rates of chronic debilitating conditions in women; and
 3. Stagnant survival rates among cervical cancer patients.

House: <https://www.congress.gov/116/crpt/hrpt450/CRPT-116hrpt450.pdf> (page 149)

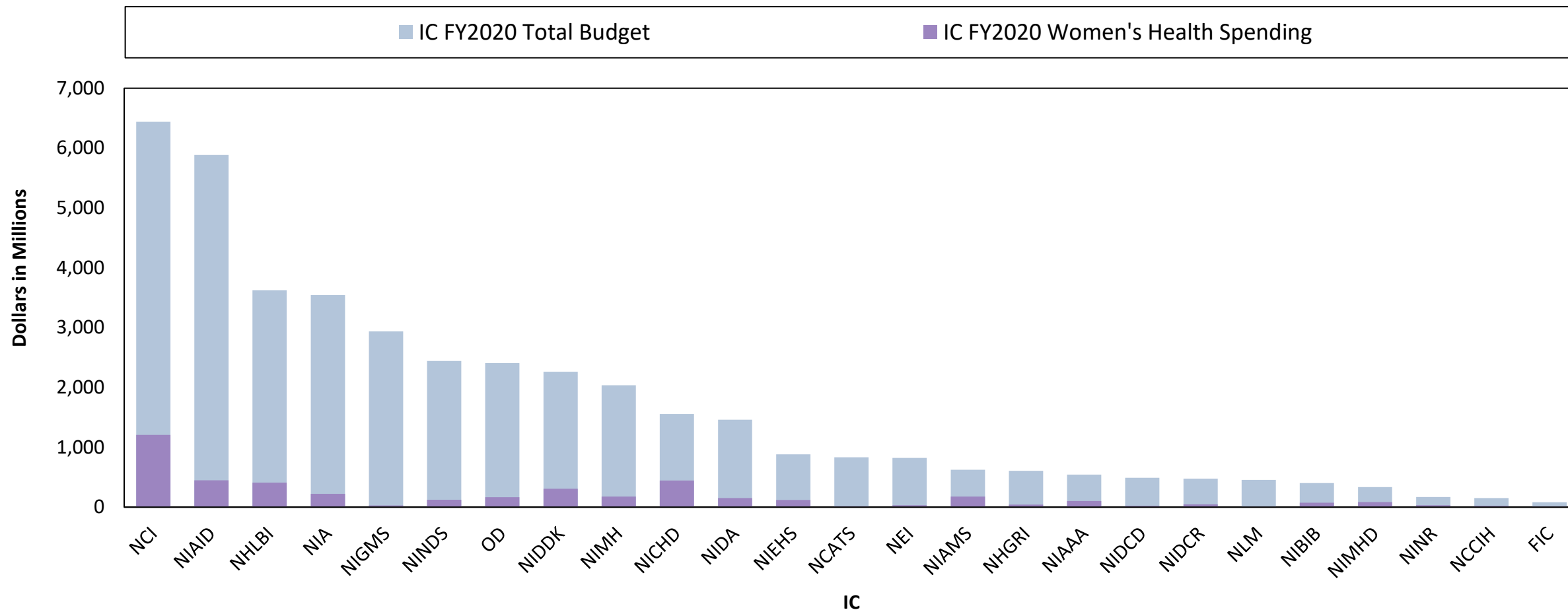
Senate: <https://www.appropriations.senate.gov/imo/media/doc/LHHSRept.pdf> (page 123)

»»» Broad Input Through Paths That Converge Along the Way



NIH Total Budget and Women's Health Research Spending by IC, FY 2020

(NIH Women's Health Research Total = \$4,466 Million)

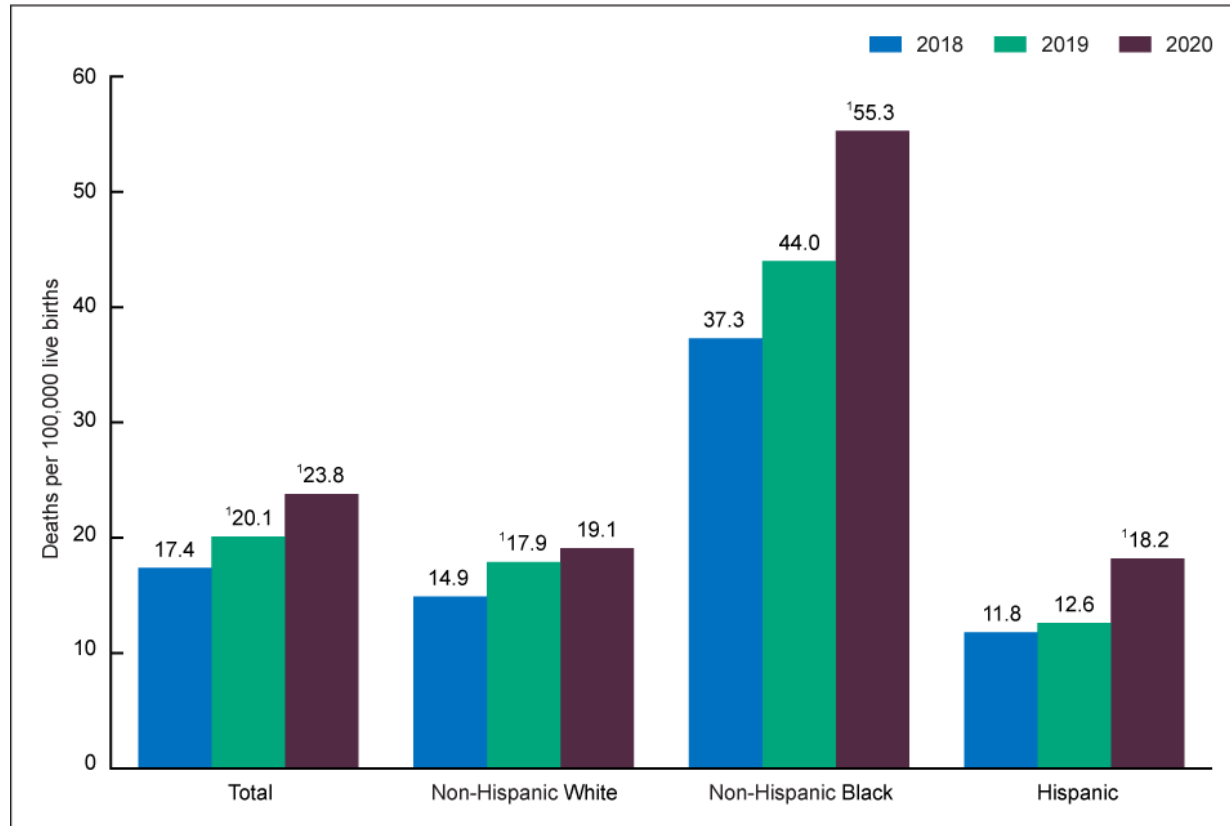


Data obtained from https://officeofbudget.od.nih.gov/approp_hist.html



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

Maternal Health and Maternal Morbidity and Mortality (MMM), 2020



¹Statistically significant increase in rate from previous year ($p < 0.05$).

NOTE: Race groups are single race.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

- Maternal mortality rate in the U.S. continues to rise
- In 2020, 861 women were identified as having died of maternal causes in the United States, compared with 754 in 2019
- The maternal mortality rate for 2020 was 23.8 deaths per 100,000 live births compared with a rate of 20.1 in 2019

Hoyert DL. Maternal mortality rates in the United States, 2020. NCHS Health E-Stats. 2022.

<https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/maternal-mortality-rates-2020.htm>



FY20 NIH MMM Funding

**Maternal
Morbidity and
Mortality**
\$223,522,448



MMM Examples

(subset of Maternal Health)

- Diagnosing, treating, preventing pregnancy complications
- Epidemiological studies of pregnancy-associated mortality

**Maternal
Health**
\$406,679,474



Maternal Health Examples

(not in MMM)

- Healthy pregnancy weight gain
- Long-term health risks in women
- Healthy pregnancy intervals

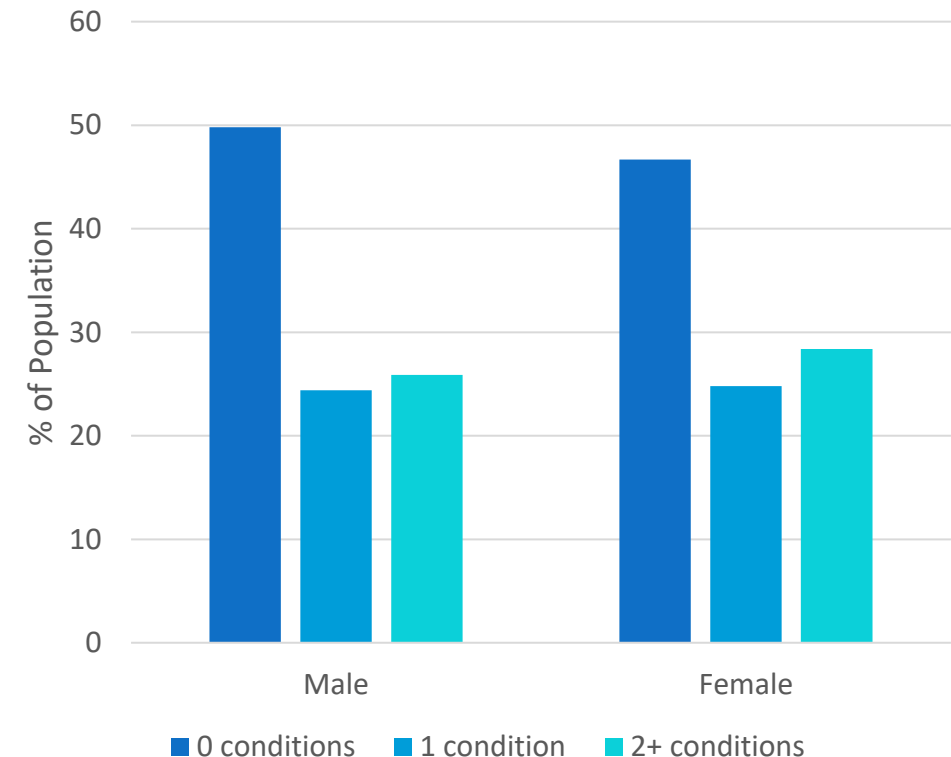
- Multiple IC initiatives on MMM
- Several NIH-wide Initiatives
 - Maternal Mortality Task Force
 - Implementing a Maternal health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative
 - Institutional Development Award (IDeA) Program

Data from <https://report.nih.gov/funding/categorical-spending/#>

<https://www.nih.gov/research-training/medical-research-initiatives/improve-initiative>
<https://www.nigms.nih.gov/Research/DRCB/IDeA/Pages/default.aspx>

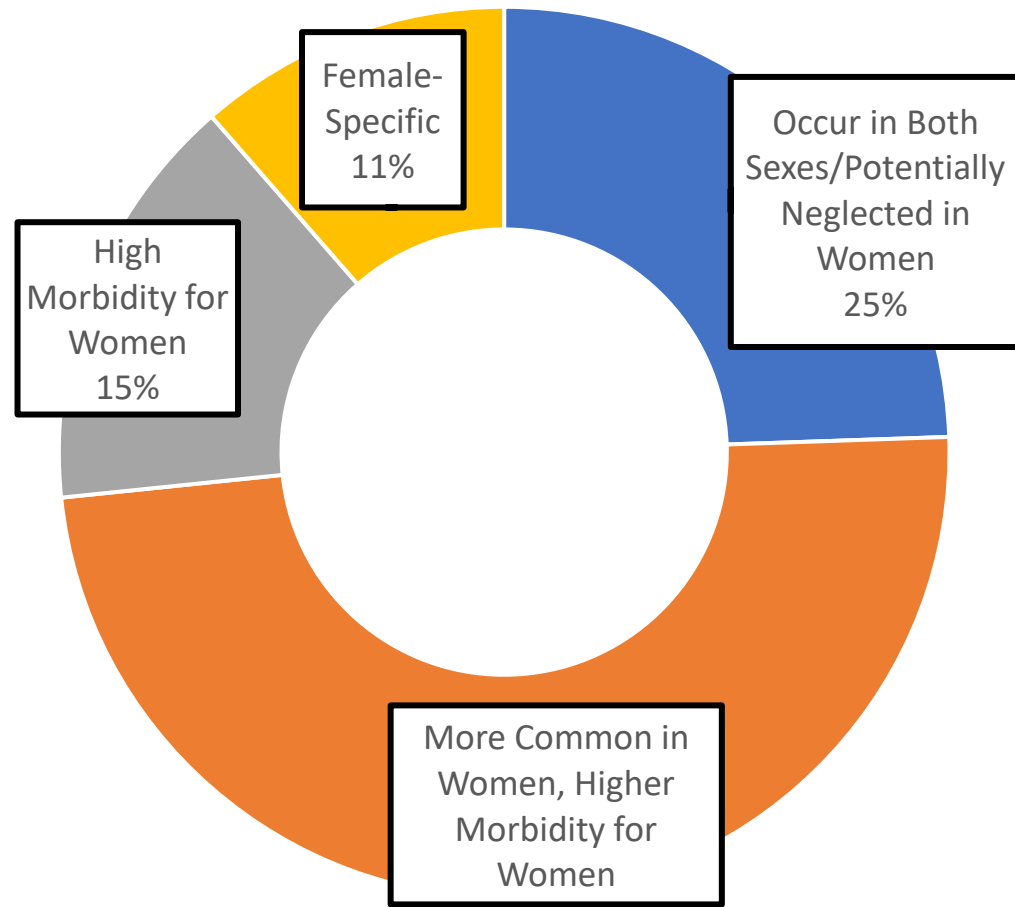
Chronic Debilitating Conditions in Women

- Rates of chronic conditions in women are increasing
- Chronic conditions and multiple chronic conditions are more common among women
- US Department of Health and Human Services (HHS) 2010: Chronic illnesses are “conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living”
- Centers for Medicare and Medicaid Services (CMS): Provides data on prevalence, utilization, and Medicare spending for specific chronic conditions and multiple chronic conditions



Institute of Medicine. 2012. *Living Well with Chronic Illness: A Call for Public Health Action*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/1327>
https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Downloads/Methods_Overview.pdf
Dana E. King, Jun Xiang, Courtney S. Pilkerton. JABFM 2018, 31 (4) 503-513. DOI: <https://doi.org/10.3122/jabfm.2018.04.180008>

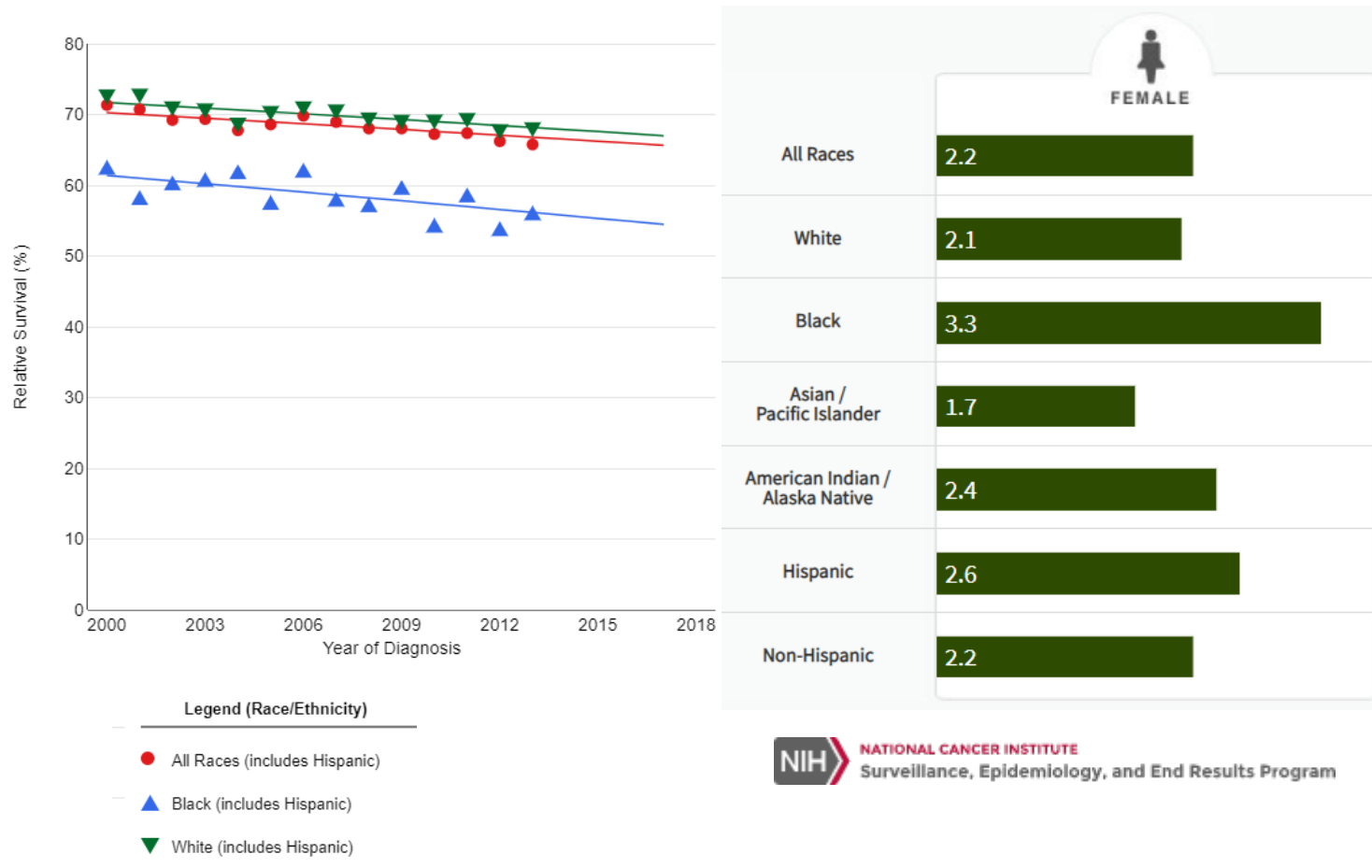
Chronic Debilitating Conditions Snapshot: Distribution of Projects Submitted by ICs



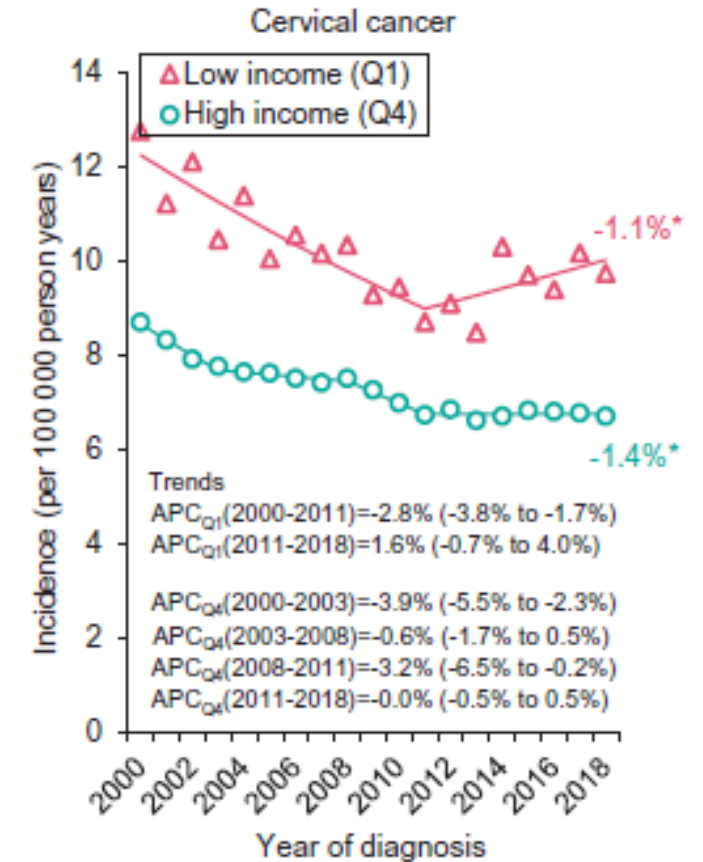
- Multiple IC-supported research on chronic debilitating conditions in women
- Few studies on multimorbidity
- As measured by Disability Adjusted Life Years (DALYS) among the US female population, NIH spending varies widely
 - \$17 per DALY for lower back pain to \$25,936 per DALY for HIV at either extreme

Stagnant Cervical Cancer Survival

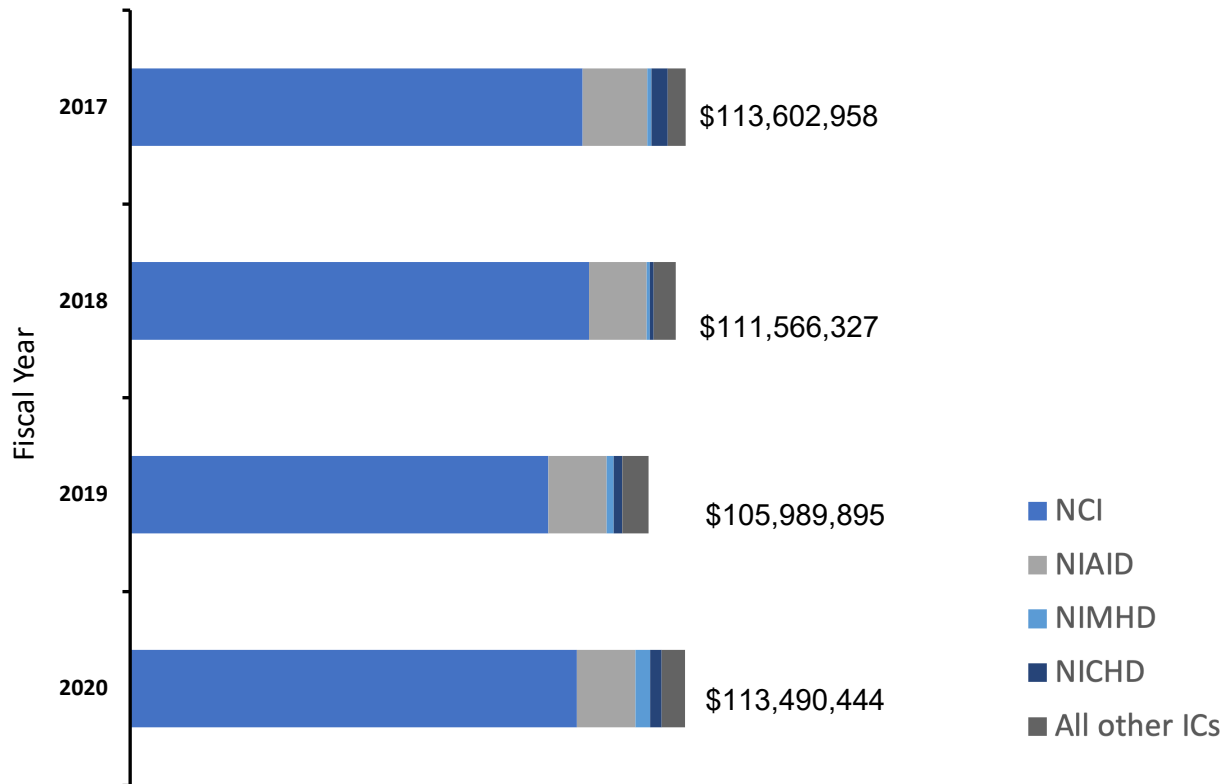
Cervix Uteri
Recent Trends in SEER Relative Survival Rates, 2000-2018
Female By Race/Ethnicity, 5-year Relative Survival, All Ages, All Stages



County-level household income



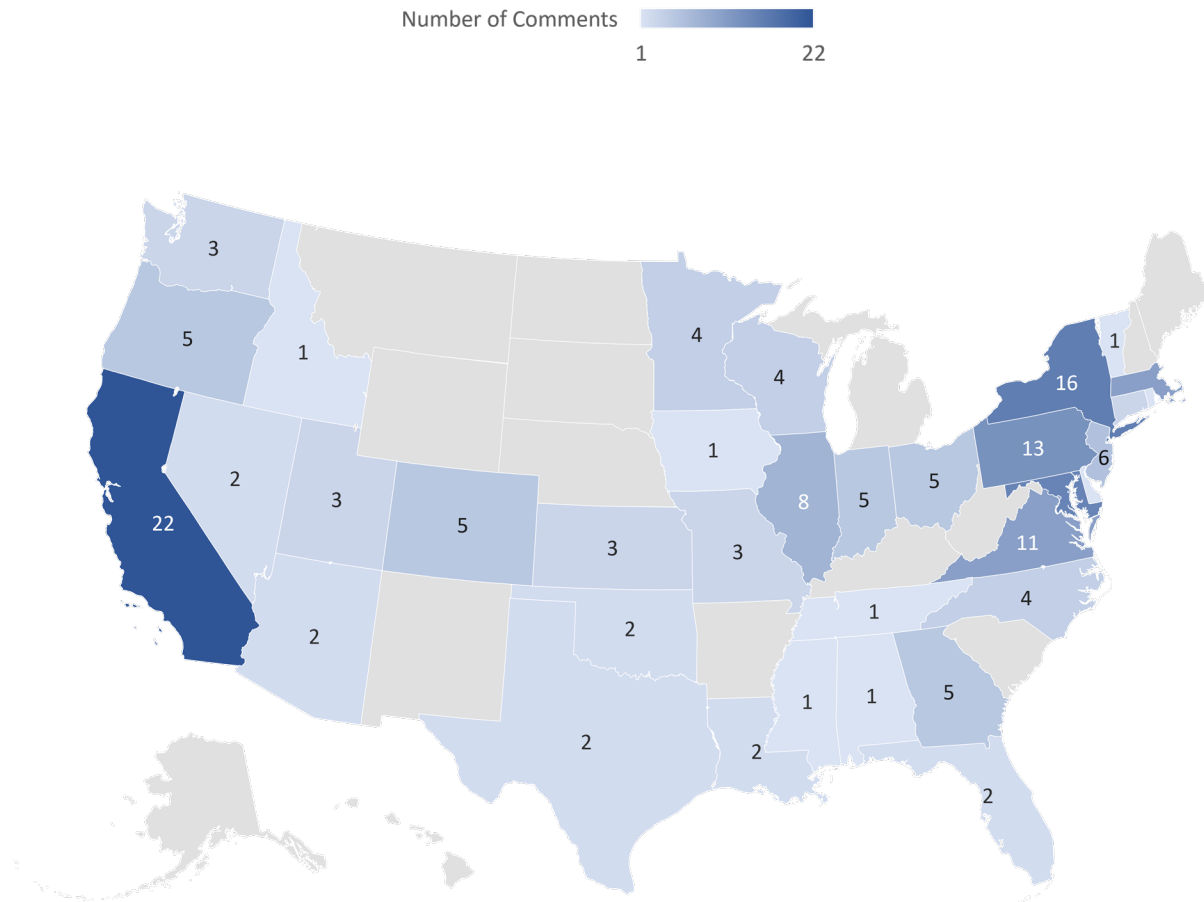
NIH Cervical Cancer Funding



- Most funding for research related to cervical cancer comes from the NCI
- The scope of research is broad and includes the following:
 - Basic science, translational, clinical and health services research
 - Pre-malignant and malignant HPV disease
 - Screening, prevention (primary and secondary) and treatment

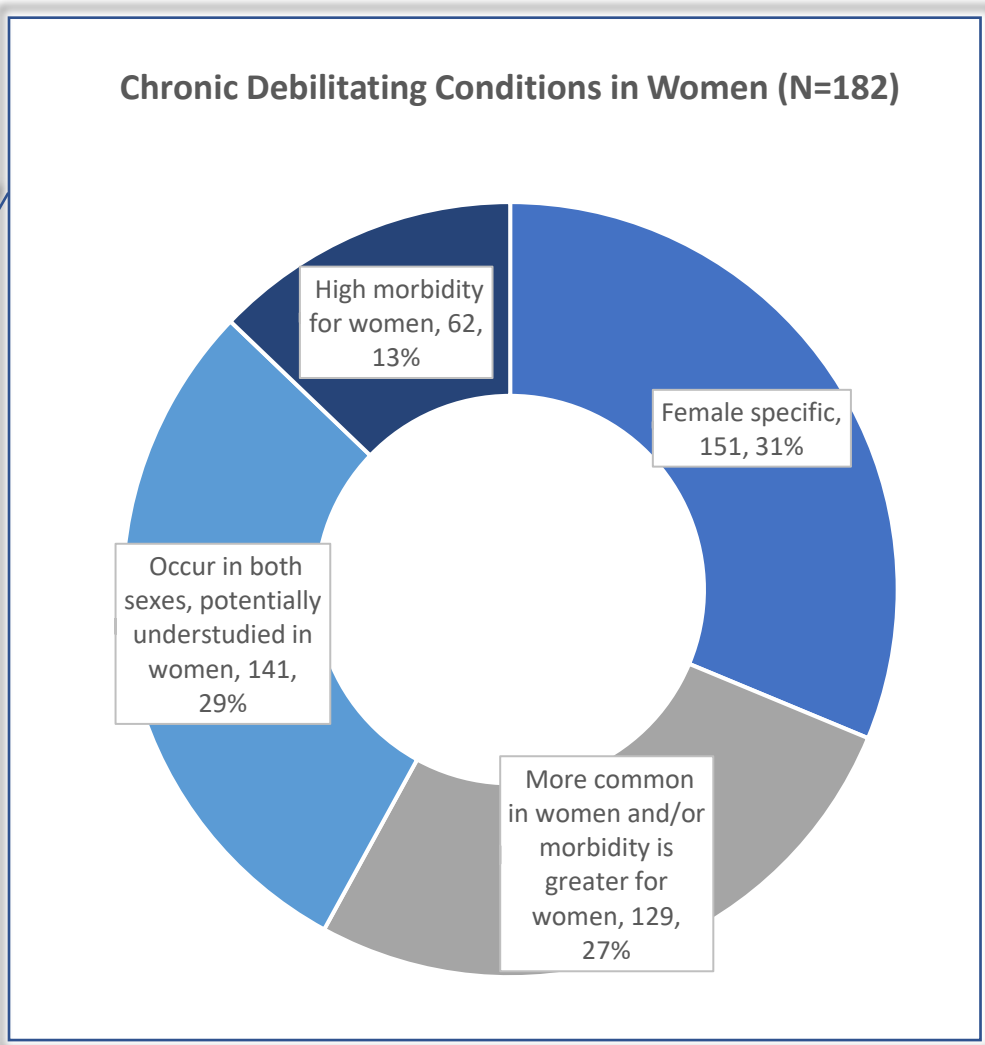
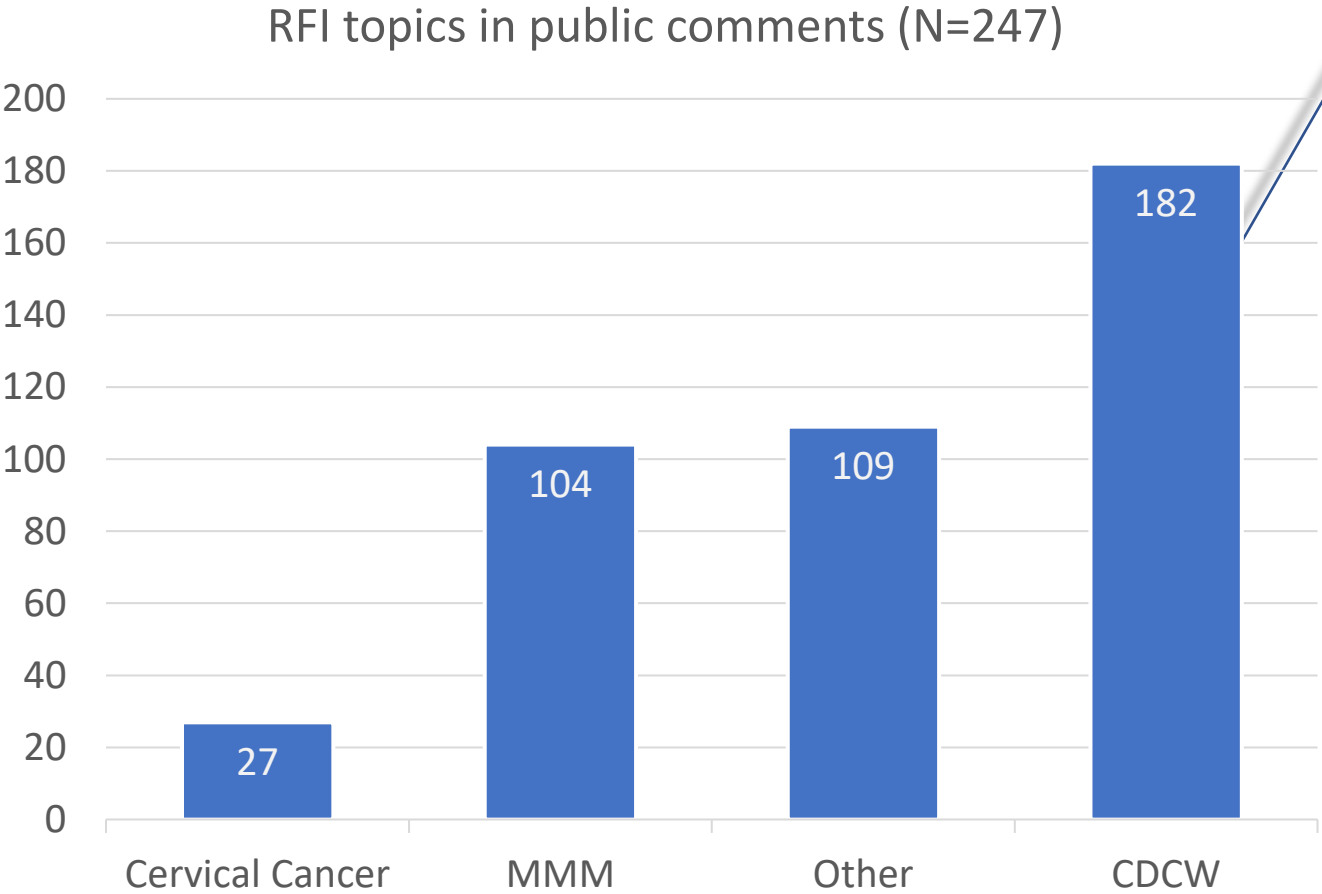
Public Comments

Federal Register Notice (FRN 2021-14151)



- 247 comments received
- Comments were submitted by researchers or research groups (N=56), members of the public (N=49), awareness and advocacy groups (N=36), patients (N=40), and healthcare professionals (N=34).
- The 10 most frequently identified keywords were as follows: (1) maternal morbidity and mortality, (2) racial disparities, (3) access to care, (4) healthcare professional training, (5) mental health, (6) Black or African American women, (7) screening, (8) quality of care, (9) time to diagnosis, and (10) social determinants of health.

Request for Information (RFI) Topics in Public Comments (N=247)

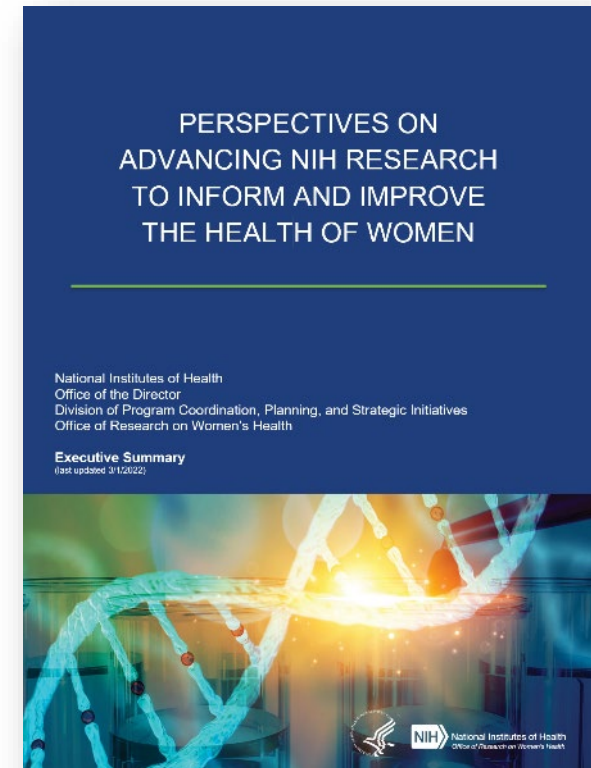


Crosscutting Themes Identified Where Research Is “Urgently Needed”

1. **Implementing best practices** – evidence-based and more holistic, patient-centered care

Examples include the following:

- MMM: Safety bundles
- Chronic Debilitating Conditions: Data to provide sex-specific guidelines are inadequate
- Cervical Cancer Survival: HPV vaccines available since 2006, yet only half of U.S. adolescents have completed this vaccine series



Crosscutting Themes Identified Where Research Is “Urgently Needed”

1. **Implementing best practices** – evidence-based and more holistic, patient-centered patient
2. **Addressing care inequities**, especially among populations of women with overlapping identities

Examples include the following:

- Pregnancy-related deaths occur at rates almost three times higher for Black, Alaska Native, and American Indian patients compared to White patients
- Lower socioeconomic status and lower educational attainment are additional risk factors for multimorbidity
- Despite equivalent screening rates, Black cervical cancer patients are more likely to be diagnosed with advanced and/or metastatic

Crosscutting Themes Identified Where Research Is “Urgently Needed”

1. **Implementing best practices** – evidence-based and more holistic, patient-centered patient
2. **Addressing care inequities**, especially among populations with overlapping identities
3. **Intentional research** – two components:
 - Historic overreliance on male clinical research subjects left significant gaps regarding disorders and diseases that occur in women
 - Many female-specific chronic and debilitating conditions – including menopause, endometriosis, and fibroids – fall under the purview of multiple ICOs and have few standing funding opportunities compared to other NIH-supported research topics
 - **Needed:** Studies that provide detailed sex-disaggregated clinical outcomes data—tied to critical life course windows, such as menarche and menopause—from a diverse population of women
 - Despite Sex as a Biological Variable (SABV) policy, gaps remain in basic and translational understanding of sex differences
 - Continued application and enforcement of SABV policy will allow further understanding of how sex influences physiology and pathophysiology
 - Will pave way for improved disease prevention and treatment strategies in the multitude of conditions that present differently and require different treatment in women and men

Questions? And answers...