



NIH Office of Research on Women's Health

ORWH and Chronic Debilitating Conditions in Women- Catalyzing Change

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National Institutes of Health

May 31, 2023 – NASEM Committee on a Framework for the Consideration of Chronic Debilitating Conditions in Women



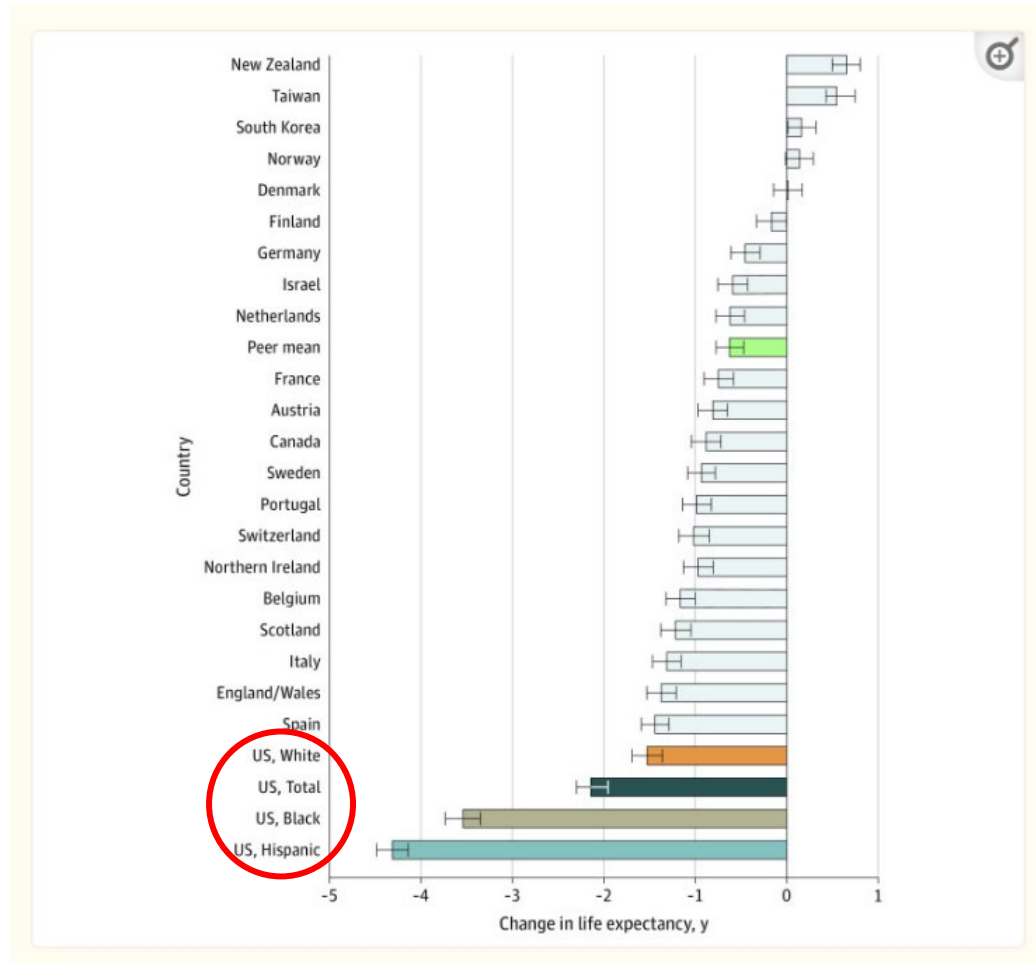
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www.nih.gov/women
[#ResearchForWomen](https://twitter.com/NIH_ORWH)

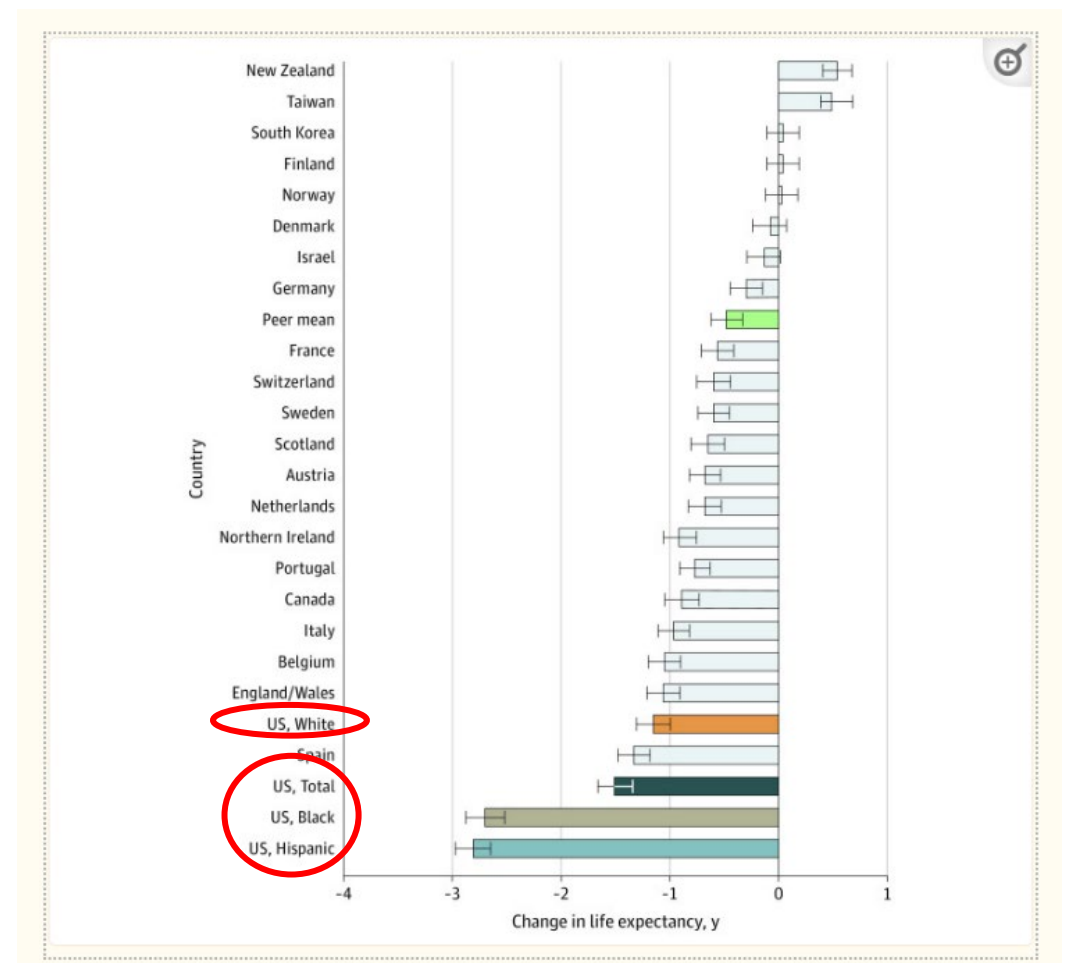
Changes in Life Expectancy in the U.S. & High-Income Countries, 2019-2020

Worldwide Changes in Life Expectancy- U.S. Hispanic & Black Populations Experience Largest Decreases

Males

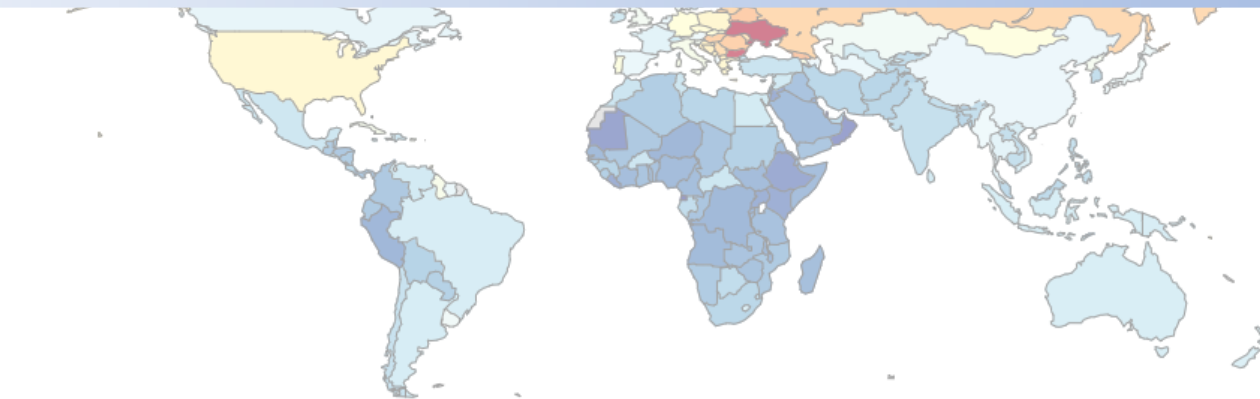
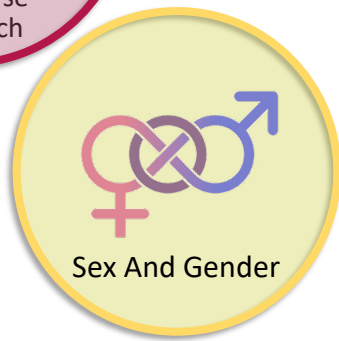


Females

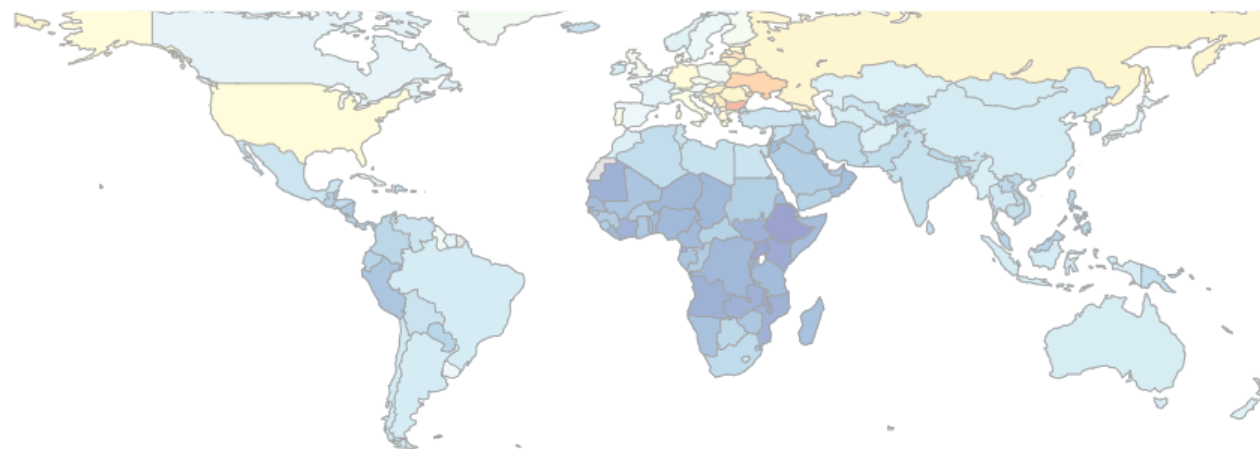


Women's Health AND The Health of Women

Population Health | Economic and Societal Impact



Non-communicable Diseases; Females, All ages, 2019, DALYs per 100,000



Health & Science Policy | Health Care | Careers & Education

House and Senate “Significant Items” Request a Conference

ORWH held the **Advancing NIH Research on the Health of Women: A 2021 Conference** in October concurrent with the ACRWH Meeting.

- Included 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)

Condition Type	Condition (FY 2020 spending/2019 DALY)							
Female specific	Cancers of the female reproductive tract* \$372	Dys-menorrhea/ Abnormal menses	Fibroids* \$281	Endo-metriosi*s* and Adenomyosis \$260	Infertility*/ Early Pregnancy Loss \$6108	Polycystic Ovarian Syndrome	Pelvic floor disorders, Organ prolapse	Menopausal symptoms Pelvic Inflammatory Disease* Vulvodynia/Chronic gynecologic pain disorders – pelvic and vulvar Vaginosis
More common in women and/or morbidity is greater for women	Depressive Disorders \$353	Migraine/ Headache \$27	Breast cancer* \$568	Autoimmune diseases (*including RA) •SLE* •Sjögren's Syndrome* Scleroderma*	Rheumatoid Arthritis* \$463	Multiple Sclerosis \$866	Sexually transmitted infections	Temporomandibular Muscle/Joint Disorder (TMJD)* Chronic Fatigue Syndrome* Fibromyalgia* Candidiasis Chronic stress Irritable Bowel syndrome Interstitial Cystitis* UTI Infection* Depression* Anxiety disorders
Occur in both sexes/ Potentially understudied in women	Unintentional Injuries (including violence against women*)	Alzheimers/	Osteo-	Endocrine,	Recurrent UTI/ Interstitial Nephritis	HIV \$25,936	Exogenous hormone use- Neuropathy Overactive bladder/Incontinence Chronic pain including chronic pelvic pain	
High morbidity for women	Heart Disease \$472	Lower back pain \$17	COPD \$449	Drug Use Disorders \$967	Stroke \$210	Diabetes \$574	Obesity/metabolic disease Influenza and pneumonia	

HIV

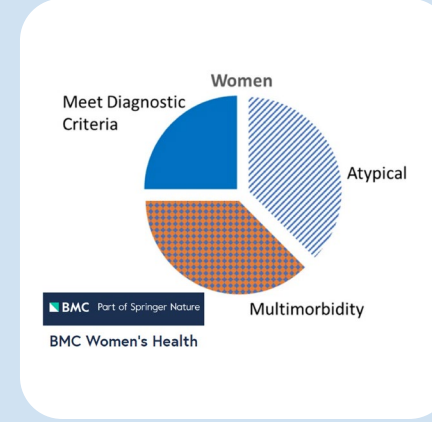
\$25,936

Lower back pain

\$17

*Per MCS-WH reporting guidance, the following RCDC disease categories are particularly relevant to women’s health

Chronic Diseases Among Women are Understudied and Require More Research



FY 2021:
Congressional
request to
address NIH
efforts related
to women's
health research

Advancing NIH
Research on
the Health of
Women: A
2021
Conference

*Increasing rates
of chronic
debilitating
conditions in
women*

Women's
Health
Research Lacks
Funding –
These Charts
Show How (The
Funding Gap)

*Kerri Smith,
2023. Nature.*

Chronic
Conditions in
Women: The
Development
of a National
Institutes of
Health
Framework

*Temkin et al.,
2023. BMC
Women's Health.*

Framework for
the
Consideration
of Chronic
Debilitating
Conditions in
Women

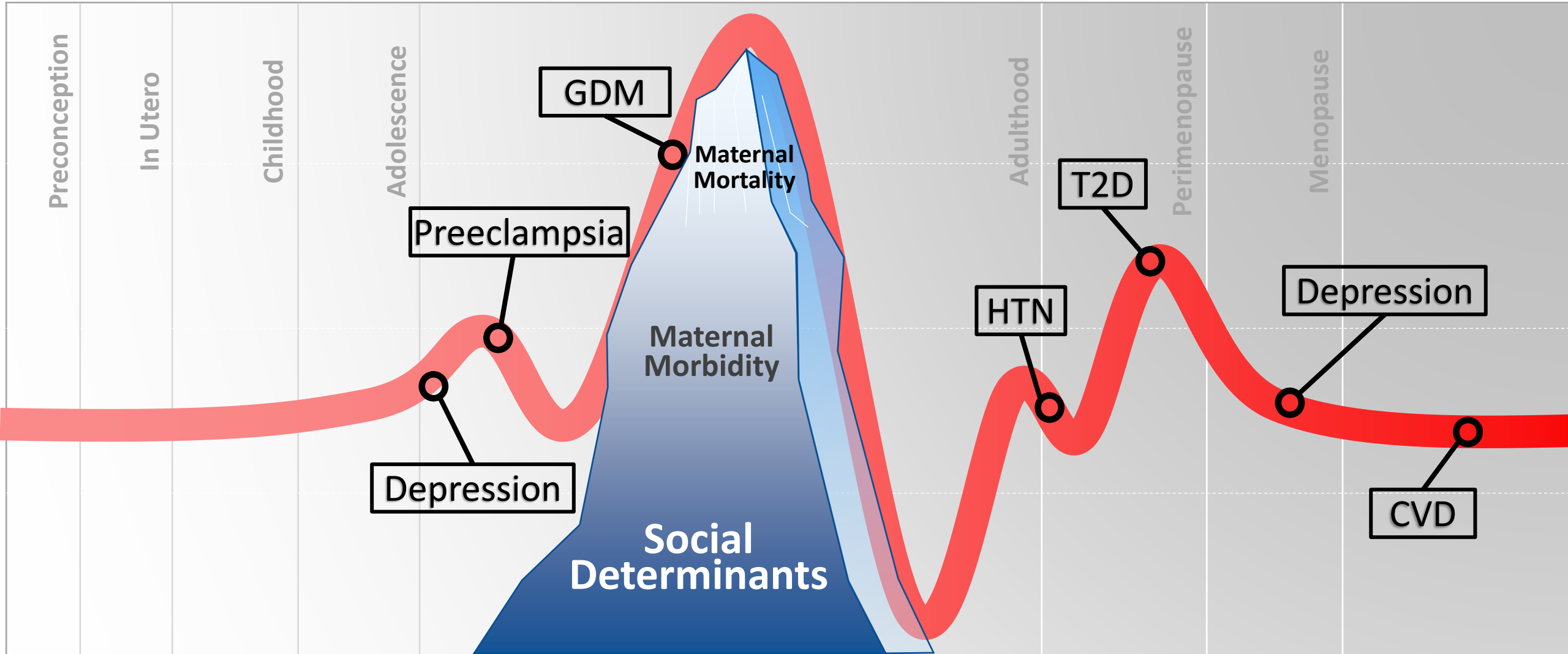
*Forthcoming
study supported
by ORWH*



ORWH Life Course Perspective

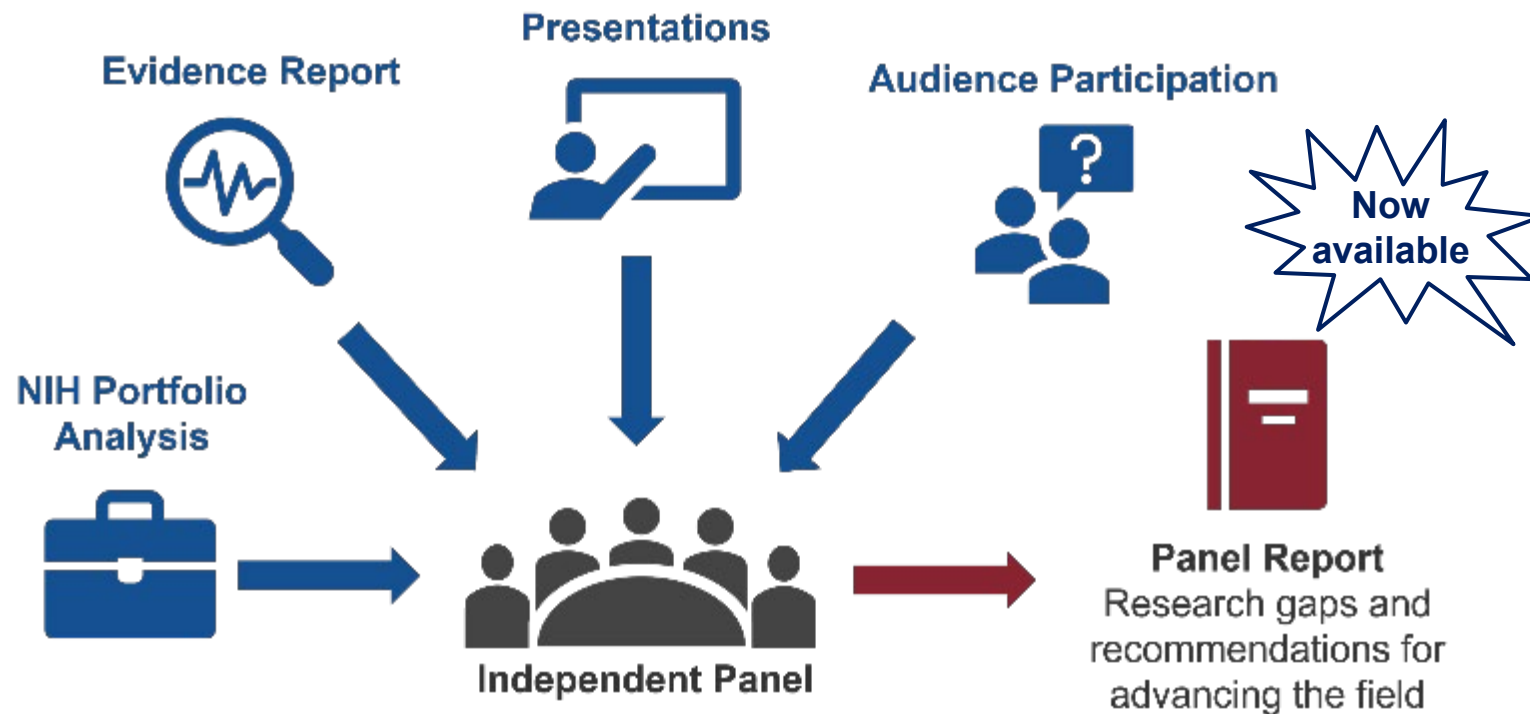
Connecting the dots

Pregnancy Is a Stress Test, and We Are Failing Women throughout the Life Course



Office of Disease Prevention: Pathways to Prevention Program (P2P)

Identifying Risks and Interventions to Optimize Postpartum Health



Workshop Components

Workshop Takeaways

- The “stress test” of pregnancy continues postpartum
- We need to bridge the chasm
- Take a life course perspective
- And importantly, listen to the patient and their families...
- Panel Report available and open for comment*

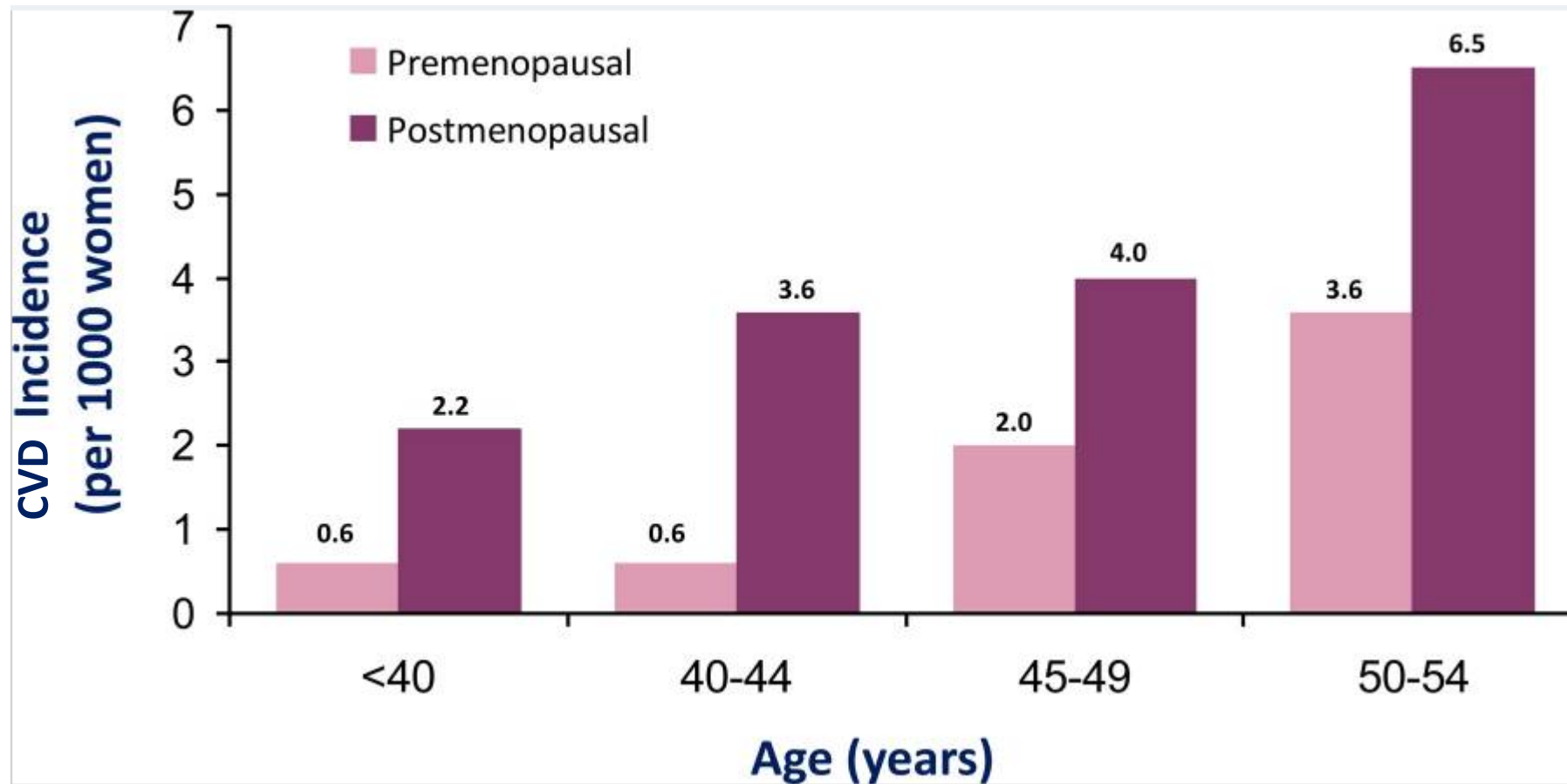
[Conference Recordings](#) are available on the ODP website

*<https://prevention.nih.gov/sites/default/files/P2P/P2P-PostpartumHealth-DraftReport-FINAL-508.pdf>



Midlife Marks a Pivotal Moment with the Onset of Chronic Diseases among Women

Critical to address the role of menopause in the health of midlife women in the context of preventing, diagnosing, and treating chronic disease



Postmenopausal women are at significantly higher risk for cardiovascular disease than premenopausal women

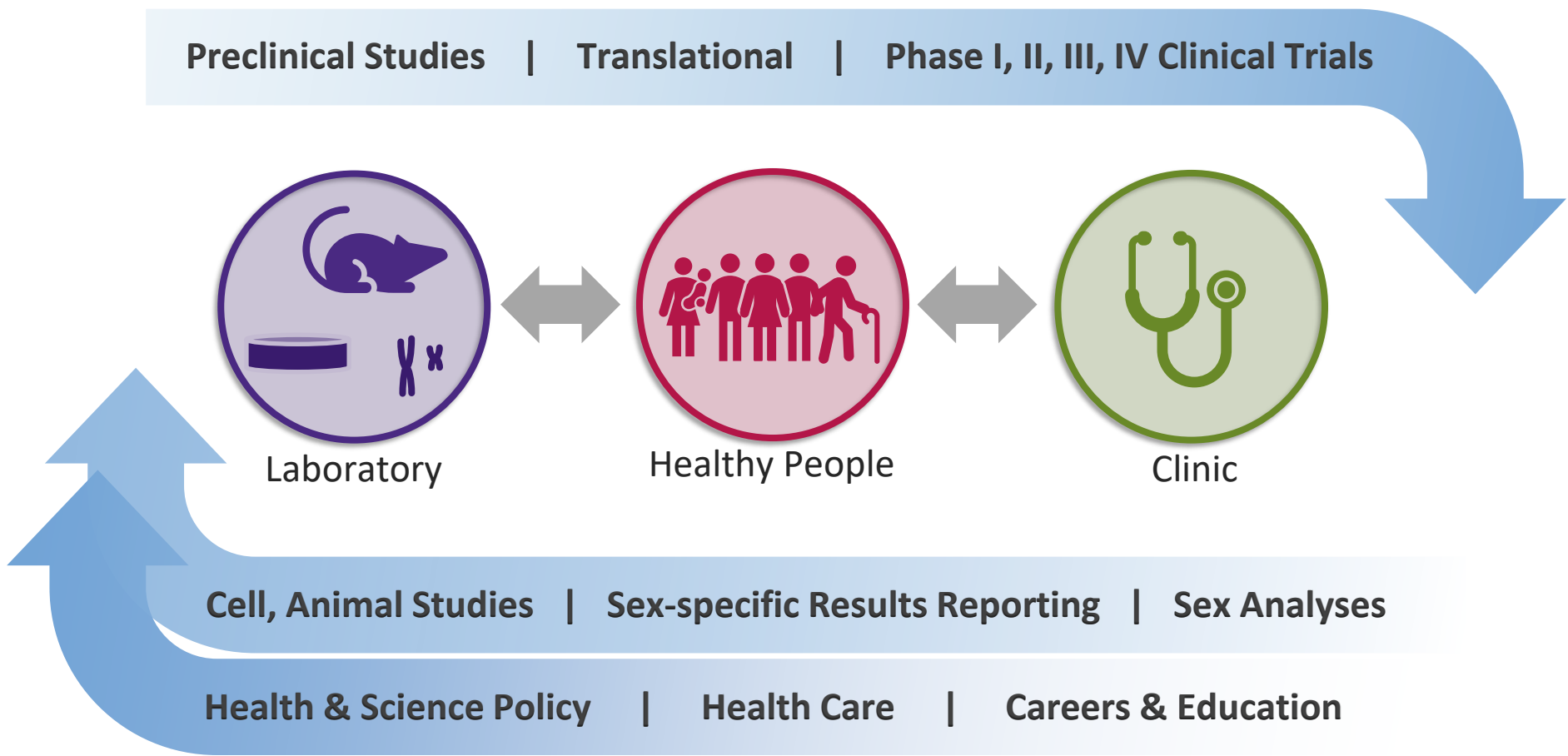


The ORWH Approach

Intentional integration



Incorporating Sex & Gender Across the Research Continuum Advances Rigor, Discovery, Innovation, and Equity



NIH Policy on Sex as a Biological Variable (SABV)

»» "NIH expects that [SABV] will be factored into research designs, analyses, and reporting in vertebrate animal and human studies.

the scientific literature, preliminary data, or other relevant considerations must be provided for applications proposing to study only one sex."

ORWH Advances Study of Sex and Gender and the Health of Women through Collaborations across NIH

BIRCWH

Building
Interdisciplinary
Research
Careers in
Women's Health

8 ICOs

Mentored
Career
Development



SCORE

Specialized Centers
of Research
Excellence on Sex
Differences

5 ICOs

Disease-Agnostic
Research Centers



Administrative Supplements

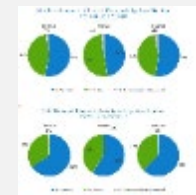
Sex and Gender

22 ICOs

Understudied,
Underrepresented, &
Underreported (U3)

16 ICOs

Funding Program to
Expand Sex &
Gender Data



R01

Intersection of
sex & gender
influences on
health & disease

11 ICOs

Sex & Gender
Influences on
Health &
Disease



RFA-OD-19-029

U3 Framework Interdisciplinary Research

- Bringing Women of Understudied, Underrepresented, and Underreported Populations into Focus
- Women of underrepresented groups have been historically excluded from and are often overlooked in biomedical research
- Until recently, many research populations consisted of mostly White and male participants
- U3 explores the ways in which socially determined categories, like gender, create different outcomes for individuals and communities
- Check out the **U3 Women's Health Lecture Series** on the ORWH website

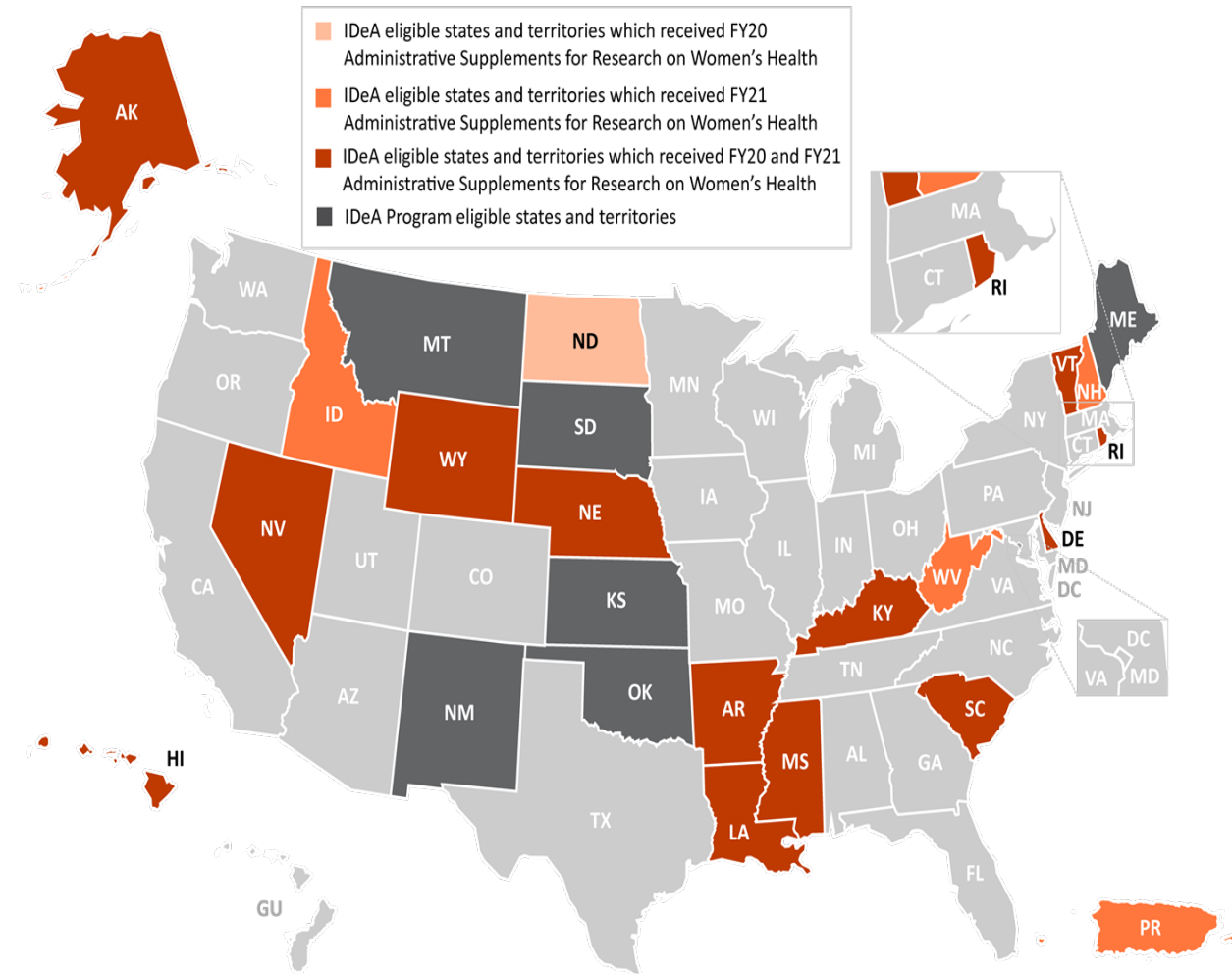


ORWH partners with NIGMS to grow women's health research in IDeA States

Administrative Supplements for Research in Women's Health

ORWH partners with NIGMS to expand research and research capacity in the IDeA states to address important issues of women's health across the lifespan.

- 23 IDeA states and Puerto Rico which are usually underserved states and historically have received lower levels of NIH funding.
- \$9 million dollars in funding to 34 grants in 18 IDeA states-ORWH co-funding 10.
- 75% of IDeA states received at least one award.
- 1 NOSI for **Administrative Supplements for FY23 (NOT-GM-22-005)**.



Intimate Partner Violence during Pandemic is Associated with Adverse Mental Health Outcomes Among Women

3 prospective, population-based, longitudinal U.S. cohort studies:

- Nurses' Health Study II
- Growing Up Today Study
- Nurses' Health Study 3

IPV experiences at the start of the pandemic associated with higher endorsement of:

- Depression
- Anxiety
- Posttraumatic stress symptoms

IPV also associated with:

- Poorer sleep quality
- Shorter sleep duration
- Increased use of alcohol
- Use of alcohol or other substances to cope with stress



JAMA
Network | **Open**™

**New RFI: Future Directions
in Violence Against Women
Research ([NOT-NR-23-008](#))**

**Issued by: NINR, NICHD,
NIMHD, SGMRO, ODP,
OBSSR, ORWH**

Innovation Equity Forum

Global R&D Opportunity Map

(July 2023)

BILL & MELINDA
GATES foundation

NIH National Institutes of Health
Office of Research on Women's Health
Putting science to work for the health of women

1 Potential for impact

Would exhibit high return on investment (ROI) – meaning a measurable reduction in morbidity/mortality, economic benefits to society, and/or improvement in the quality of life for women

2 Readiness

Can scale sustainably to reach desired impact – considering technical, social/political, and economic factors

3 Innovation

Is scientifically feasible – meaning the science and/or technology are able to advance within 1-3 years

4 Matters to women

Addresses women's unmet health needs – as defined by women and uniquely tailored based on lived experiences

5 Equity

Improves health equity, addresses the needs of diverse populations, and avoids exacerbating, sustaining, or creating additional health inequities among all women with different lived experiences

- *E.g., across different geographies and intersectional factors such as gender identity, age, nationality, race/ethnicity, caste, ableism, etc.*

Galvanizing Health Equity Through Novel and Diverse Educational Resources = ***GENDER***

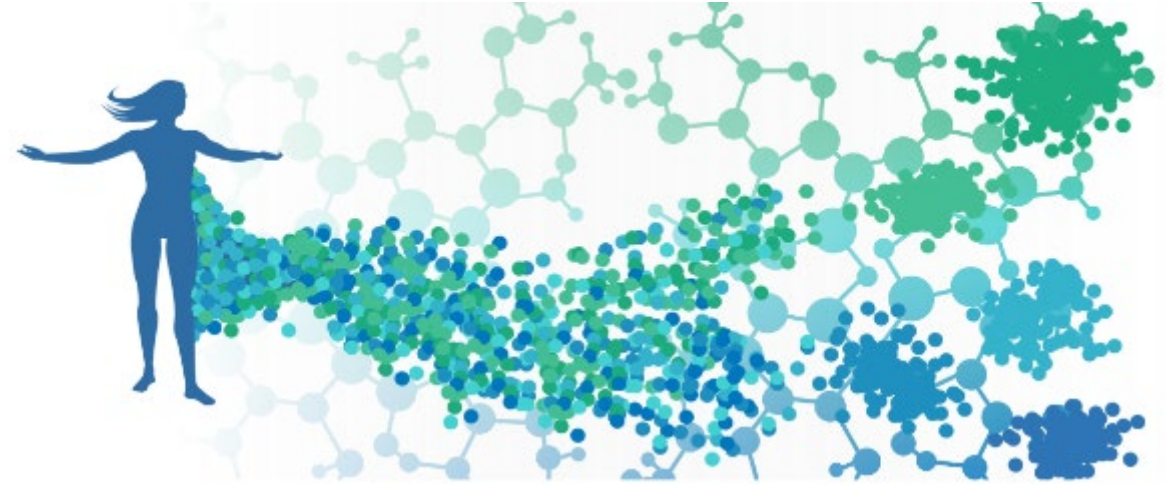


- GENDER R25 (RFA-OD-22-015)
- Help meet the need for gender-specific training in science, medicine, and allied health professions
- Supports development of gender-focused courses, curricula, and methods for extramural community
- **Application due date: June 27, 2023**
- Partner ICOs: NIA, NIAMS, NIDA, NIMHD, NLM, NIDCR, OBSSR, OAR, SGMRO
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-OD-22-015.html>

Team Science Leadership Scholar Program (LSP) in Women's Health, Autoimmune and Immune-Mediated Diseases

A pilot program to support and train women's health scholars by helping them acquire and hone team science leadership and mentoring skills

An immersive, cross-sectoral, collaborative experience that will enable women's health scholars to become large consortium team leaders

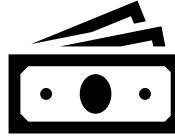




NEW ORWH Office of Autoimmune Disease Research



**2022 NASEM
report
recommendation
to establish OADR**



**FY 2023 Congress allocated \$10 million
to establish OADR within ORWH**



**ORWH-OADR offers
new opportunities
for interdisciplinary
research on
autoimmune disease
in the context of a
woman's life course**



**NOSI: EXposome in Autoimmune
Disease Collaborating Teams
PLANning Awards (EXACT-PLAN)**

(NOT-OD-23-112)

Due date: June 16, 2023

**Issued by: NIAMS, NEI, NIA,
NICHD, NIDCR, NIEHS, NCCIH,
ORWH**



Important Barriers To Success



NIH Has Funded Menopause Research for 30+ Years



Women's Health Initiative

Began in 1991
Funded by NHLBI



Study of Women's Health Across the Nation

Began in 1994
Funded by NIA



Menopause Strategies: Finding Lasting Answers for Symptoms and Health Trials

Began in 2008
Funded by NIA, NICHD, NCCIH, ORWH



Menopausal Vasomotor Symptoms and Brain Aging in Women

Funded in 2016 by NIA

NIH is developing a research, condition, and disease categorization (RCDC) code for menopause research which will allow accurate measurements of investments in future menopause research.

Additional RCDC Categories That Characterize Chronic Conditions in Women



RePORT

Research Portfolio Online Reporting Tools

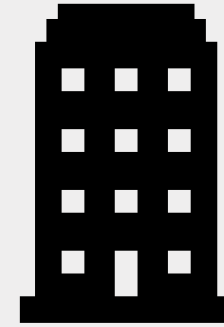
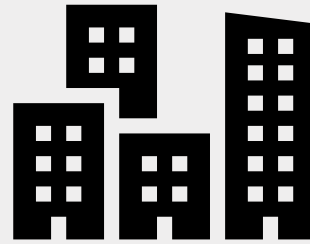
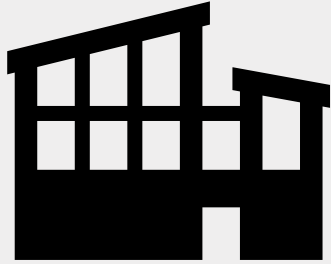


RCDC: Categorization Process

The Research, Condition, and Disease Categorization (RCDC) System

RCDC - How the Process Works

The RCDC computer-based process sorts NIH-funded projects into categories of research area, disease, or condition. The four main steps in the RCDC categorization process are outlined below.



**Federated Structure of the NIH
Impact on Research Specific to
Women's Health**

ORWH leads 1st NIH Funding Opportunity on:

Understanding Chronic Conditions Understudied Among Women R01 & R21

Partnering ICOs:

**NHLBI, NIA, NIAMS,
NICHD, NCI, ORWH**

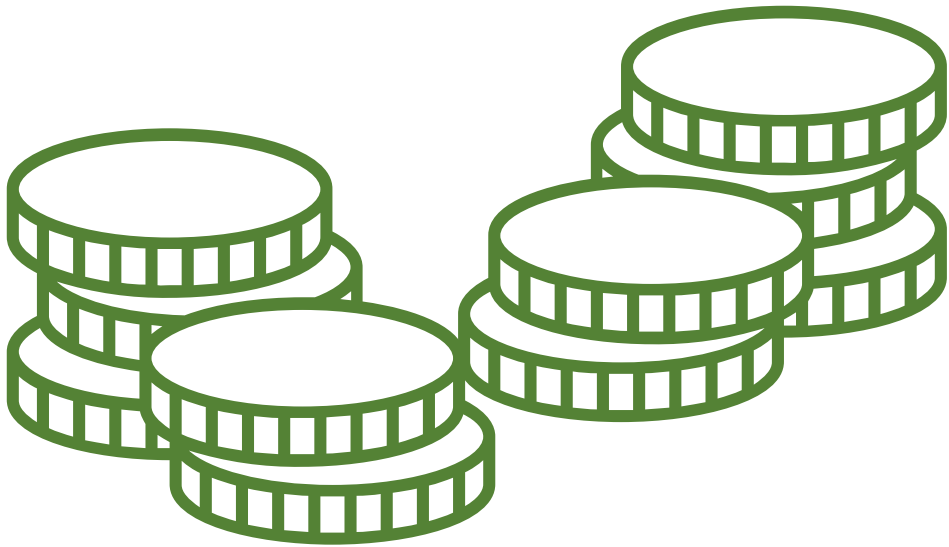
[RFA-OD-23-014](#)

[RFA-OD-23-013](#)



What about the other diseases?

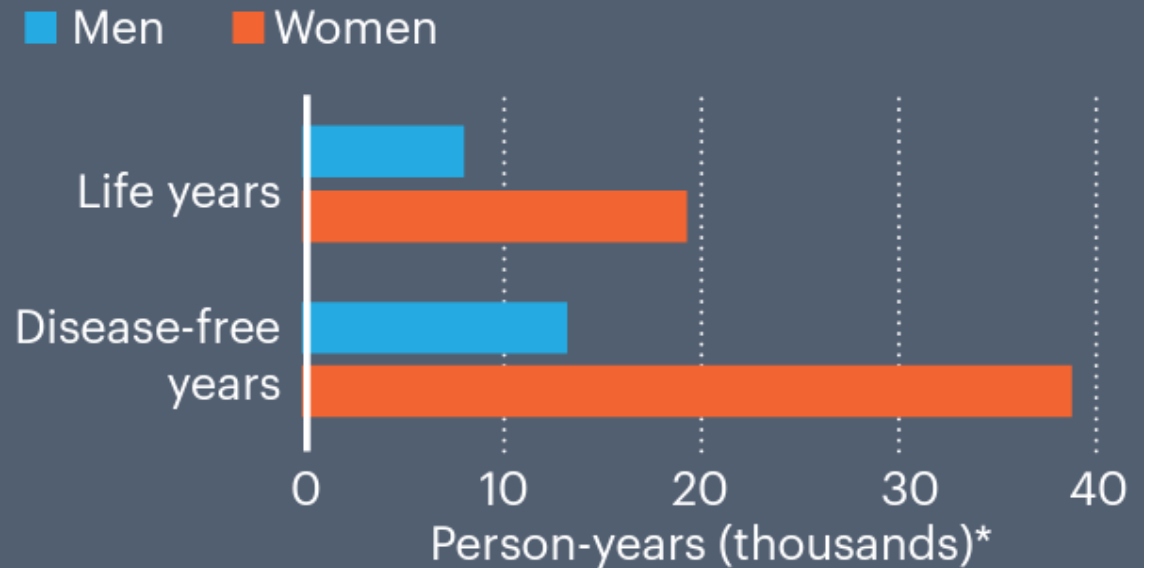
The Funding Gap: The Lack of Investment in Women's Health Research, *Nature* 2023



FY22 NIH investment in women's health research → \$4,592,531,730 (10.8% of NIH total)

How more funding would help

A separate study modelled how doubling US funding for women's health could yield health and economic improvements over a 30-year period. In coronary artery disease, for example, more funding increased life expectancy and disease-free years for men and women — with the model assuming a larger benefit for women.



*Person-years: years saved or added across the modelled group of one million people in the span of 30 years.

This is our why...



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EVENTS

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Women, Science, and the Impact of COVID-19

bit.ly/ORWHcovid

WOMEN'S HEALTH *In Focus* AT NIH
A QUARTERLY PUBLICATION OF THE NIH OFFICE OF RESEARCH ON WOMEN'S HEALTH



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**All Bitly addresses are case-sensitive*

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E-LEARNING



- Bench to Bedside: Integrating Sex & Gender to Improve Human Health
- SABV Primer
- SABV Primer Instructor Guide
- Intro. to Scientific Basis of Sex- & Gender-Related Differences

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