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Women's Health Research

Progress, Pitfalls, and Promise



Even though slightly over half of the U.S. population is female, apart from reproductive concerns, medical research historically has neglected the health needs of women. However, over the past two decades, there have been major changes in government support of women's health research—in policies, regulations, and the organization of research efforts. To assess the impact of these changes, in 2008, Congress directed the Department of Health and Human Services (HHS) to ask the Institute of Medicine (IOM) to examine what has been learned from that research and how well it has been put into practice and communicated to both providers and women.

An IOM committee defined women's health broadly, encompassing health conditions that are specific to women; are more common or more serious in women; have distinct causes or manifestations in women; have different outcomes or treatments in women; or have high morbidity or mortality in women. Although the committee could not review all such conditions, it finds that women's health research has contributed to significant progress in addressing some conditions, while other conditions have seen only moderate progress or even little or no progress over the past 20 years. Gaps remain, both in research areas and in the application of results to benefit women in general and across multiple population groups.

The IOM committee developed six overarching questions to guide its deliberations.

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Is Women's Health Research Studying the Most Appropriate and Relevant Determinants of Health?

Viewing women's health exclusively as a function of sex differences is too narrow. It frames women's health and well-being as a function only of biological factors and how they differ in men and women and ignores the role of gender, which is affected by broader social and community factors. The committee finds that there has been inadequate attention paid to the social and environmental factors that, along with biologic risk factors, influence women's health. Although progress has been made in identifying behavioral determinants of women's health, such as smoking, diet, and physical activity, few studies have tested ways to modify these determinants in women or examined the effects of social and community factors in specific groups of women. To advance this area of research, the committee recommends that the National Institutes of Health (NIH) support research on common determinants and risk factors that underlie multiple diseases.

Is Women's Health Research Focused on the Most Appropriate and Relevant Conditions and Endpoints?

The committee finds that major progress has been made in reducing mortality for women from breast cancer, cardiovascular disease, and cervical cancer. This can be attributed in part to increased consumer demand and awareness, which has resulted in additional funding and research; improved diagnosis; screening and treatment; and, in the case of cervical cancer, a vaccine.

More limited advances have been made in depression, HIV/AIDS, and osteoporosis, the committee finds. Few advances have been made in reducing unintended pregnancy, autoimmune diseases, maternal morbidity and mortality, alcohol and drug addiction, lung cancer, gynecological cancers other than cervical cancer, non-malignant gynecological disorders, and Alzheimer's disease.

The committee observed that there have been fewer advances in research investigating non-fatal diseases that result in major morbidity for women, despite the high value women place on quality of life as well as longevity. Therefore, the committee recommends that research include greater attention to assessing quality of life—for example, functional status or functionality, mobility, or pain—and promoting wellness. As part of this effort, research should include the development of better measures to compare effects of health conditions, interventions, and treatments on quality of life for women.

Is Women's Health Research Studying the Most Relevant Groups of Women?

While investments in women's health research have led to decreased rates of female mortality from some diseases, that progress has not been enjoyed equally by women from all population groups in the U.S. Large disparities in disease burden remain among groups of women. Women who are socially disadvantaged because of their race or ethnicity, income level, or educational attainment have been underrepresented in many studies and have not benefited as much from the progress in women's health research.

The IOM committee recommends that NIH, the Agency for Healthcare Research and Quality, and the Centers for Disease Control and Prevention develop targeted initiatives to increase research on the populations of women with the highest risks and burdens of disease.

Are the Most Appropriate Research Methods Being Employed to Study Women's Health?

Basic, observational, and clinical research, and studies of health systems all have contributed to progress in women's health. Multi-faceted research approaches that tackle a condition

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from several fronts have yielded important findings which have improved prevention and treatment of breast cancer, cardiovascular disease, and cervical cancer. At the same time, limitations in the design, analysis, and scientific reporting of health research have impeded progress on these and many other conditions. A lack of analysis and reporting of data separately for males and females continues to limit researchers' ability to identify potentially important sex and gender differences.

In addition to conducting women-only research as appropriate, the research community should strive to integrate women's health considerations into all health research, such that sexand gender-based differences between men and women are routinely and consistently assessed. The committee recommends that government and other funding agencies ensure adequate participation of women and reporting of sex-stratified analyses in health research. The committee also recommends that all medical product evaluations by the Food and Drug Administration present efficacy and safety data separately for men and women and that peer-reviewed journals require sex-stratified analysis for publication.

Are the Research Findings Being Translated in a Way that Affects Practice?

It can take 15–20 years for research findings to be incorporated into practice. Barriers to translation range from communication challenges to social or political opposition, to consumer confusion. Many of these barriers exist for research in general, but some are more specific to women's health. For example, women more often see different providers for different health concerns, exacerbating problems of fragmented care. A lack of health-care quality measures for many conditions that are specific to women also is problematic, as is failure to analyze sex- and gender-based differences in care.

To reduce these barriers, research should be conducted on how best to rapidly translate the research findings in women's health into clinical practice and public health policies. Research findings should be incorporated from the practitioner level to the overall public health systems level. Such changes may be achieved, for example, through the use of targeted education programs to practitioners and development of guidelines. As those programs and guidelines are developed and implemented, they should be evaluated to ensure effectiveness.

Are the Research Findings Being Communicated Effectively to Women?

The public often is confused by conflicting findings and opposing recommendations emerging from health research, including women's health research. Poor communication has in many cases led to substantial confusion and may adversely affect the care of women.

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To ensure that messages are clearly conveyed and understood by the public, the committee recommends that HHS appoint a task force to develop strategies to effectively communicate researchbased health messages to women. The messages should reach a diverse audience of women; increase awareness of women's health issues and treatments, including preventive and intervention strategies; and decrease confusion regarding complex and sometimes conflicting findings. The committee suggests including the requirement for all federally funded studies to develop and incorporate a plan for disseminating findings to the public, providers, and policymakers, and establishing a national media advisory panel whose experts would be readily available to provide context to reporters, scientists, clinicians, and policymakers when new women's health research reports findings are released.

Conclusion

This report finds that the considerable investment in women's health research of the past two decades has yielded much to improve the health and wellbeing of women in the U.S. Despite this important investment, much work remains in all aspects of research. Given the multiple and significant roles women play in our society, maintaining support for women's health research and enhancing its impact are not only in the interest of women, they are in the interest of us all. To

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