

**Challenges in Advancing Women's Health in the 21st
Century: Perspectives From the
Office of Research on Women's Health**

Vivian W. Pinn, MD

Associate Director for Research on Women's Health,
Director, Office of Research on Women's Health, National Institutes of Health

The desire for good health is universal—common to men and women of all cultural and racial origins. Moreover, good health for all citizens is essential if the United States is to continue to prosper as a nation. As we have moved beyond the year 2000, it has become medically possible to preserve physical and mental health for a greater number of years than at any other time in history. Unfortunately, advancements in scientific knowledge are not sufficient to ensure that all Americans benefit. Those advances must, or should be, applicable to the variety of factors that influence the status of health of our nation's diverse populations. And such populations must have access to health care that incorporates these new advancements.

Until recently, inclusion of substantial representation of the sex or racial diversity of the US population could not be assured within the biomedical research arena. Today there are policies that require the inclusion of women and minority groups in NIH-funded research and there are many community and advocacy efforts to assist in information dissemination and recruitment for clinical trials. The health of women represents such an area that has received advocacy, medical, scientific and legislative attention during the past decade.

Lack of sex-specific therapies, access to medical care, and health insurance are among the barriers that explain many of the disparities in health status between women and men. The disparities are even more dramatic for poor women and women of color. For example, women of color are only about one-fourth of the female population in the United States, yet they are overly represented among the uninsured. In 1995, nearly half the 19 million uninsured women in the United States were women of color. It is not surprising, therefore, that "... sizable proportions of the sub-populations of women of color report that they do not avail themselves of preventive health tests such as pap smears and mammograms on a regular basis."¹

In contrast with the middle class, higher proportions of lower-income women seek care in hospital emergency departments,² turning the emergency room into fertile ground for health care providers and researchers to identify and study the cultural, economic, and other factors that contribute to women's and children's lack of access to the health care system. Empowering women to take better care of their own health and their families' health involves health education and programs to overcome cultural stigmas about disease and disability.

It must also include means of access to health care through improved health policies and strategies.

Lack of information about the differences in the effect of specific diseases (ie, diabetes, cervical cancer, breast cancer, HIV) among members of diverse groups also contributes to the health care community's inability to provide optimum care for many Americans. The findings of biomedical and behavioral research provide the scientific basis for improving standards of care, formulating public health policy, changing individuals' health-related behaviors and expectations of their health, modifying health care delivery systems, and creating strategies for overcoming cultural and economic barriers to health care.³ There are many challenges in addressing the disparities in health and health outcomes of all those individuals who lack the financial resources, cultural incentives, geographic mobility, and access to health information needed to seek and receive optimum health care. A concerted effort must be made to better define and understand the barriers to health promoting behaviors and wellness care of these individuals, in addition to increased knowledge about biological factors being incorporated into the health care so that we can formulate strategies, policies, and actions to improve the overall health of at-risk populations.

The need to understand more fully the disparities in health and health outcomes among diverse groups of Americans is an important issue for both researchers and those setting public health and health care policy. Fortunately, today there is a growing sensitivity and awareness concerning the need for research on health issues, health status and outcomes, and health care to be designed and conducted in such a way that the results are applicable to all affected groups—including women, minority members, the poor, and the elderly. These approaches have begun to mitigate the differing health effects and outcomes of some conditions, such as cancer and HIV, among many Americans. Over the past decade, partnerships among women as advocates for improved health, as spokespersons within the legislative, political, and scientific communities, and as key players within federal and local governmental agencies have resulted in an unprecedented focus of attention and resources on improving the health of women and their families.

The National Institutes of Health (NIH) has made important strides in meeting the challenge of improving the health of women and their families through research. In 1990, NIH established the Office of Research on Women's Health (ORWH), which seeks to redress inequities in prevention, detection, and treatment of illness among women of all races, cultures, and socioeconomic backgrounds through biomedical and biobehavioral research. The NIH recognizes that research must be an important element in any serious effort to improve the health of all Americans, especially those with health concerns that have not been addressed either specifically or historically by the biomedical research community.

Because of the disparities that exist in health, it is vital that members of minority groups and those who are disadvantaged by socioeconomic status, geographic location, or other factors, participate in clinical research, not only as study subjects, but also as participants in the design, implementation, and interpretation of such studies. The inclusion of women and men of all racial,

ethnic, cultural, and socioeconomic backgrounds in clinical trials is crucial to determining whether women and men respond differently to an intervention, and whether a treatment or prevention strategy will work effectively for women of all races, circumstances, and cultural backgrounds.

During the past decade, evolving scientific, public, and political perspectives have led to policies that mandate broader inclusion of both women and men—and those of diverse racial, cultural, and ethnic origins, geographic locations, and economic backgrounds—in clinical research. The need for a better understanding of the ways in which sex, gender, cultural and racial differences may influence the pathobiology, etiology, diagnosis, progression, and treatment outcomes of diseases among various groups within the United States has also led to changes in requirements for research strategies.

That women and minorities have not been routinely included in human subject research is, to some degree, attributable to historical events. The tragic Public Health Service study of syphilis in Tuskegee, in which African-American men suffering from syphilis were denied treatment in order to allow researchers to document disease progression, has left a legacy of fear and distrust in the minority community about participation in research studies. Moreover, the fetal developmental abnormalities associated with thalidomide use and the recognition of the carcinogenic effects of DES in the offspring of pregnant women have given rise to clinical, ethical, and legal concerns about the inclusion of women who are pregnant or of childbearing age in clinical trials. Protectionist policies based upon such ethical concerns contributed to the exclusion of women and minorities from clinical research as a means of preventing their exploitation.⁴

While the shameful example of the syphilis study in Tuskegee understandably may have caused many African-American men and women to shun the biomedical establishment and participation in research, we should also remember that this study served as the catalyst for the federal government to establish policies for the protection of human subjects in research. We cannot improve the health of African Americans and members of other minority groups, women, and all those who have traditionally experienced disparities in health status unless we can overcome many barriers and replace fear and distrust with trust and knowledge of the positive, life-affirming outcomes of clinical research.

Although investigators are now required by public law to include women and minority groups as subjects in clinical research, there are other barriers to overcome in the recruitment and retention of volunteers representing diverse populations as research subjects. These include the need for increased representation of women and minorities as investigators, cultural diversity in research teams, and closer relationships between researchers and the communities they seek to study. As important, we must overcome logistical problems—including transportation, child care, and convenience of complying with study requirements—and sensitize investigators to differences in potential participants' cultural beliefs and social norms.

In this issue of *Ethnicity and Disease*, a special section on issues of women's health highlights some of the emerging advances in the women's healthcare. Issues such as post-term delivery, mammography use, and pre-eclampsia associated with chronic hypertension represent several of the areas of women's

health recognized as high priorities by the NIH. The ORWH looks forward to seeing a continued effort by *Ethnicity and Disease* to highlight investigative studies that expand the ORWH- and NIH-wide efforts to increase the participation of the richness of diversity of the American populace in clinical trials. We believe that, with a greater diversity of individuals who participate as study subjects and as investigators who design, conduct, and interpret biomedical research, we will achieve greater diversity of those who will benefit from the fruits of research through improved and appropriate health care services and public health policies.

References

1. Office of Research on Women's Health, National Institutes of Health (DHHS). *Women of Color Health Data Book*. 1998. Washington, DC: US Government Printing Office; 1998. NIH Pub. No. 98-4247.
2. Reisinger, AL. *Health insurance and access to care: issues for women*. A background paper prepared for the Commonwealth Fund Commission on Women's Health. New York, NY: The Commonwealth Fund; 1995.
3. Pinn VW. Equity in biomedical research. *Science*. 1995;269:739.
4. McCarthy CR. Historical background of clinical trials involving women and minorities. *Acad Med*. 1994;69:95-98.