



**AGENDA FOR RESEARCH
ON WOMEN'S HEALTH
FOR THE 21ST CENTURY**

**NEW FRONTIERS IN
WOMEN'S HEALTH**

NATIONAL INSTITUTES
OF HEALTH
Office of the Director

7

V O L U M E

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INTRODUCTION

“The extensive focus on women’s health has brought forward new concepts and scientific questions.”

Vivian W. Pinn, M.D.
Associate Director for
Research on Women’s Health
Director, Office of Research
on Women’s Health
National Institutes of Health

Women live an average of 7 years longer than men and make up the majority of the population over 65. They suffer from different diseases, disorders, and conditions than men and, even when they have the same diseases, women often experience different symptoms and responses to treatment than do their male counterparts.

There is ample evidence of variations in health and disease between women and men. Research shows, for example, that more women than men are diagnosed with arthritis, depression, type 2 diabetes, osteoporosis, gallstone disease, and eating disorders. Women have a higher rate of lung cancer and spend twice as many years disabled. They suffer more serious consequences from drinking less alcohol; have a 2 to 3 times higher occurrence of irritable bowel syndrome and functional bowel disease; and are 9 times more likely to contract certain liver diseases. Older women tend to experience more reactions to medications than older men, and women of all ages have a higher prevalence of urinary incontinence. And, while women account for 52 percent of all deaths due to heart disease and 61 percent of all deaths due to stroke in the United States, they are less likely to have been treated by a doctor for heart problems prior to their deaths.

Sex and gender differences in disease rates, symptoms, and treatment outcomes have been recognized only recently. Earlier scientific studies sometimes excluded women for various reasons, including the desire to protect reproductive-age women from the unknown effects of unproven treatments, and the commonly held belief that what was true for men was also true for women.

Sex refers to the classification of living things, generally as male or female, according to their reproductive organs and functions assigned by their biological make-up.

Gender refers to a person’s self-representation as male or female, or how society responds to that person based on the individual’s gender presentation. Gender is rooted in biology and shaped by environment and experience.

Creating a National Agenda

In 1996-1997, more than 1,500 scientists, public policy makers, clinicians, advocates, and members of the general public came together at a series of meetings held across the United States to discuss the state of women's health research at the end of the 20th century. Their task was to contribute to a 21st century national research agenda that would address the changing requirements and opportunities for women's health. Meetings were sponsored by the Office of Research on Women's Health, National Institutes of Health (NIH), with the assistance of the Task Force on the NIH Women's Health Research Agenda for the 21st Century and the NIH Advisory Committee on Research on Women's Health.

Fortunately, in the last decade of the 20th century, science has made substantial progress in understanding the differences between women and men in health and disease. Supported by a federal mandate, women's health research is now an integral part of the fabric of research at the National Institutes of Health and in programs nationwide. Yet progress gives rise to new questions—critical questions that point the way into uncharted territory.

This report summarizes thousands of issues and questions raised by more than 1,500 women's health professionals and advocates throughout the United States. Their recommendations for addressing the major diseases and health risks affecting women create a comprehensive map for scientific inquiry in the 21st century. Their common concerns reflect emerging directions for women's health research as it explores new frontiers in women's unique experience of health and disease.

MAJOR DISEASES, CONDITIONS, AND HEALTH RISKS AMONG WOMEN

Women are at risk for numerous life-threatening diseases and chronic conditions that impact the length and quality of their lives. By addressing critical questions about each of these health risks, research can help improve the lives of generations of women.

H E A R T D I S E A S E

More than 960,000 Americans die each year from cardiovascular disease (CVD), about one person every 33 seconds. CVD, which includes heart and coronary artery diseases, congestive heart failure, and stroke, kills almost twice as many American women as all cancers combined, and more than 11 times as many women as does breast cancer. In fact, a postmenopausal woman is 10 times more likely to die from coronary artery disease than she is from breast cancer.

Heart disease has been the number one killer of women for nearly a century and accounts for 43 percent of all deaths among women.

Although women develop heart disease later in life than men do, heart attacks are more deadly for women. For example, older women who have heart attacks are nearly twice as likely as men to die from those attacks within a few weeks (about 44 percent of women compared to 27 percent of men). And, among the women who die suddenly of coronary heart disease, 64 percent have had no previous symptoms.

While dramatic progress has been achieved against heart disease in recent decades, the frequency of heart attacks and other cardiovascular diseases remains disturbingly high. Even though risk factors for heart disease in women and men have been known for years, heart attack, stroke, and

TABLE 1. Women's Perceived and Real Health Risks

Perception	Percent	Cause of Death	Percent
Breast cancer	46	Heart disease	34
Other cancer	19	Other cancer	21
Heart disease	4	Stroke	8
		Breast cancer	4

"As obesity is becoming more prevalent, particularly among women, and affects a number of risk factors, as well as risk for coronary heart disease itself, further research into its causes and treatment are needed."

Marian C. Limacher, M.D.
American College
of Cardiology

other cardiovascular diseases in women have not been recognized as serious problems until recently, especially by women themselves.

Recent scientific achievements include increased funding for cardiovascular research, including research into women's health services, the cost effectiveness of treatments, and the study of diverse populations and communities; greater participation of women in clinical studies; and new cardiovascular disease treatment regimens for women.

Continued research in the 21st century will help save women's lives with answers to critical questions related to heart disease, such as:

- How do hormones affect the cardiovascular system in women versus men? In premenopausal versus postmenopausal women? With or without hormone replacement therapy?
- What effects do diabetes and obesity have on the cardiovascular system? Why is obesity a greater problem for women than for men and what factors contribute to this difference?
- What differences in cardiovascular disease exist among elderly and disabled women, as well as racial and ethnic minorities? Among women living in different locations?
- How can cardiovascular disease in high-risk populations be prevented, detected, and managed?

C A N C E R

Cancer is the leading cause of death for American women aged 35 to 74. It is only after age 75 that heart disease claims the lives of women in sufficient numbers to become their number one killer. In 1997, an estimated 596,000 women were diagnosed with cancer, while 265,900 women died from the disease.

Breast cancer is the most common form of cancer in women, yet lung cancer is the leading cause of cancer deaths in women, followed by breast and colorectal (colon and rectal) cancers. The number of lung cancer

“The tragic and commanding fact about ovarian cancer is that more than 50 percent of the women who have it die within 5 years of diagnosis.”

Ann Kolker
 Ovarian Cancer National Alliance
 “Ovar’coming Together”

deaths in 1997 represented 25 percent of all cancer deaths among women, and an increase of more than 16,000 deaths since 1991.

While lung cancer among all women continues to rise (it is decreasing among men), scientific progress in the last decade has helped decrease the death rate from breast and colorectal cancers among white women. Fifty-six new drugs for treating breast cancer are now in various stages of development and factors decreasing the risk of colon and rectal cancers have been identified. In addition, major advances in genetics are improving the scientific understanding of cancer, although little progress has been made to improve women’s survival from ovarian, cervical, and uterine cancers.

Cancer researchers have observed differences in metabolism between women and men, between different racial and ethnic groups, and between older and younger persons; these differences influence individual responses to carcinogens (cancer-producing substances) and treatments. As a result of these findings, studies are now underway to investigate how factors such as age, ethnicity, genetics, the environment, and social and economic variables interact to determine whether an individual will develop cancer and whether that cancer will respond to treatment. Researchers hope to develop prevention strategies, diagnostic tests, and education and treatment programs that are effective, inexpensive, acceptable, and available to women of all income levels and cultural backgrounds.

Perhaps one of the most promising discoveries to date is that cancer may be a preventable disease. Diet, cigarette smoking, hormones, and the environment have been found to be potential contributing factors to various cancers. Decreased tobacco use has been shown to lower the occurrence of lung cancer, and some studies have shown that hormone replacement therapy may decrease the risk of colon cancer, although it may also increase the risk of breast and endometrial cancers.

TABLE 2. Estimated 1997 Prevalence of Cancer in Women

Type of Cancer	Number of Diagnoses	Number of Deaths
Lung	83,200	67,430
Breast	180,200	43,900
Colorectal	65,900	24,300
Ovarian	26,800	14,200
Cervical	14,500	8,000
Uterine	34,900	6,000

The women's health agenda for the 21st century contains important recommendations and leading questions for cancer research, such as those stated below.

- What are the long-term effects of different forms of estrogen on cancer risk?
- How does cancer start, grow, and spread?
- What medications are effective for various cancers, with minimal side effects?
- What are the effects of exercise and weight control on cancer risk?
- What strategies and methods help people quit smoking or refuse to start?

M E N T A L D I S O R D E R S

Mental disorders include anxiety disorders (panic disorder, posttraumatic stress syndrome, obsessive compulsive disorder, and phobias), depressive disorders, schizophrenia and other psychoses, and the eating disorders of anorexia and bulimia. Anxiety disorders are the most widespread forms of mental illness in the United States, affecting more than 20 million individuals. By comparison, an estimated 18.4 million Americans suffer each year from some form of depression, while another 2.3 million are considered manic depressive (experiencing alternating cycles of excessive excitement and depression).

Major mental disorders impact women and men to almost the same extent, although certain conditions are more common in women. Anxiety disorders, for example, are diagnosed approximately 2 to 3 times as often in women as in men. Major depression is diagnosed in about twice as many women as in men, while eating disorders occur 8 to 10 times more frequently in women. Plus, there is growing evidence that depression may express itself differently in women than in men.

Depression is becoming a global epidemic. At its current rate of increase, depression will be second only to heart disease as the reason people lose healthy years of life by the year 2020.

Research over the past decade has led to a new understanding of the burden of mental illness in women. Because women are often caregivers for both parents and children, their mental problems can influence two or three generations of family members. At the same time, women may

"Battered women are consistently found to have more depressive symptoms and significantly higher diagnoses of major depression than other women."

Jacquelyn Campbell, Ph.D., R.N., F.A.A.N.
The Johns Hopkins University
School of Nursing

"HIV infection is the third leading cause of death among women ages 25 to 44, and the leading cause of death among black women in this age group."

Betty B. Hambleton
Health Resources and
Services Administration

have multiple responsibilities creating stresses that amplify their mental illnesses. Women are also more likely to be the victims of violence, an experience that has been linked to the onset of various mental disorders.

Most mental disorders can be treated successfully. Nearly 85 percent of people with depression respond positively to one or more types of treatment, while recent therapies have provided relief to women with anxiety disorders. Progress is also being made in how to educate and help women and young girls suffering from eating disorders.

In addition to conducting research on the role of sex and gender in mental disorders, researchers are currently exploring how age, physical health, ethnicity and race, marital status, parental status, education, occupation, income, sexual orientation, geographic location, and work status influence the appearance, symptoms, and treatment of mental illnesses. As science enters the new century, it aims to answer additional questions about mental health in women, including those listed below.

- What factors contribute to the development of mental disorders in women across the life span? What makes some women susceptible and others resistant to mental disorders?
- What are the causes of depression in all its forms? What individual and interactive roles do genetics and environment play? How can depression be prevented and treated effectively in women?
- What are the long-term mental and physical consequences of sexual assault and domestic violence?
- What are the impacts of hormones on brain development, aging, behavior, and sex and gender differences in mental disorders? What are the long-term interactive effects of mood-altering drugs and hormones?

I N F E C T I O U S D I S E A S E S

Sexually transmitted diseases (STDs), including human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), are often the focus of discussions on infectious diseases in women, primarily because of their long-term potential for harm. Many STDs are more difficult to detect in women, often due to a lack of noticeable symptoms. Even so, these diseases tend to affect women, including a disproportionate number of minorities, more severely than they do men. An estimated 8 to 10 million women suffer from the chlamydia infection, while millions more live with genital herpes and human papilloma virus infections. As a result of sexually transmitted diseases, women often experience infertility, miscarriages, and genital cancer. In addition, STD infections have been shown to increase the risk of contracting or transmitting HIV.

Scientific studies of infectious diseases have led to new diagnostic tests and drugs for treating HIV/AIDS and other sexually transmitted diseases, and have reduced the spread of HIV to newborn infants. Research has also revealed a strong causal link between human papilloma virus (HPV) and cervical cancer, resulting in the consideration of cervical cancer as an STD. Additional findings have increased sensitivity to the importance of behavioral changes in preventing sexually transmitted diseases and HIV/AIDS, raised awareness about women's risk of HIV infection, and shown that the diagnosis and treatment of STDs can decrease the risk of HIV transmission.

Adolescents are at high risk of contracting sexually transmitted diseases, including HIV. An estimated 3 million STD cases occurred in teenagers in 1994.

"The need for woman-controlled methods of STD and HIV prevention has only recently been recognized as a priority, and much remains to be done to move this issue to the forefront of the women's health agenda."

Amy Allina
Reproductive Health
Technologies Project

Ongoing investigations of infectious diseases seek to (a) understand the development and natural history of STDs, including the influence of genetics; (b) develop and test methods for preventing infections and treating diseases and complications; (c) consider the impact of women's life cycle changes on the progression and treatment of infectious diseases; and (d) determine the range of related health issues important to women and their families and communities. For example, researchers hope to develop a catalog of sexual behaviors across the life span, and within and across communities, as a step toward preventing and treating STDs. They are studying the impact of popular culture and social standards on individual and group behavioral change, to guide the creation and use of public health messages. And they are creating new methods to diagnose and treat STDs that are reliable, inexpensive, rapid acting, accurate, and easy to use.

Leading questions for infectious disease and STD research in the 21st century include the following:

- How do environmental factors, genetics, and the immune system influence women's susceptibility to sexually transmitted diseases, including HIV?
- What are the potential effects of hormonal birth control methods on women's vulnerability to infections?
- What methods are effective in preventing STDs, including HIV, in women? In babies born to infected mothers?
- What are the long-term effects of vaccines, disease progression, and treatments for all sexually transmitted diseases and HIV?
- What factors influence women's incidence of urinary tract infections, tuberculosis, group B strep, and hepatitis B and C?

BONE AND MUSCULOSKELETAL DISEASES

Many bone and musculoskeletal conditions appear more often in women than in men, and have different causes, symptoms, effects, and treatment outcomes. *Arthritis*, which refers to more than 100 illnesses and conditions, is the most common chronic condition reported by American women (23 million in 1990). About 16 million Americans suffer from *osteoarthritis*, which affect 2 times as many women as it does men, while *rheumatoid arthritis* afflicts 2.1 million Americans, occurring in 3 times as many women as men. In all its forms, arthritis is the third leading cause of bed disability in the United States and contributes to individuals' inability to work or perform daily activities, as well as to adverse psychological effects.

Osteoporosis involves low bone mass, with continued bone loss leading to an increased risk of fracture. Low bone mass, or density, is found more often in women than men because women build up less bone as they mature and have increased bone loss at menopause, due to a drop off of estrogen. An estimated 4 to 6 million women over age 50 suffer from osteoporosis, while an additional 13 to 17 million have osteopenia (less severe bone loss). The percentage of women with osteoporosis increases with each decade of life after age 50.

The combination of arthritis and orthopedic impairments limits the physical activity of 4.5 times as many people as do heart conditions.

"Today, no national system exists which can provide comprehensive information about injury and illness patterns in physically active women."

Marjorie J. Albohm,
M.D., A.T.C.
The National Athletic
Trainers Association

Orthopedic problems, such as fractures, foot problems, shoulder instability, scoliosis (curvature of the spine), and carpal tunnel syndrome (severe wrist pain) are the primary causes of bed disability in the United States. Women made an estimated 20 million visits to their physicians for these conditions in 1995. Although the lack of appropriate exercise throughout life may contribute to some of the physical impairments occurring in some women as they age, the increased participation of many women in sports and fitness activities makes the prevention of orthopedic sports injuries a high priority. In some cases, extreme physical activity can play a part in eating disorders and lead to amenorrhea (the absence of menstrual cycles) and osteoporosis.

Progress over the last few years in the science, treatment, and management of bone and musculoskeletal disorders has been remarkable. Arthritis research has led to improvements in joint replacement surgery, the discovery that self care works and enhances self-sufficiency, and an understanding of the benefits of exercise for pain relief. Studies of

osteoporosis have resulted in revised dietary guidelines for calcium intake, new ways to measure bone mass, and new drugs for disease prevention and treatment. In the field of orthopedics, scientists have improved techniques for treating fractures and soft tissue injuries, as well as for performing total joint replacements; developed less invasive surgery procedures; and identified factors that may make some women prone to carpal tunnel syndrome.

Over a 10-year period, a 65-year-old woman has a 40 percent chance of being hospitalized for a musculoskeletal condition.

Research in the next century promises to improve the bone and musculoskeletal health of women by addressing questions like those below.

- What factors influence the progression of arthritis and why do more women than men suffer from this disease?
- What factors contribute to the development of peak bone mass? What contributes to bone loss?
- What causes stress fractures?
- What is the role of physical activity in developing bones, tendons, ligaments, and muscles? In preserving muscular strength, balance, and coordination as a means of preventing falls in the elderly?

I M M U N I T Y A N D A U T O I M M U N E D I S E A S E S

The immune system protects the body from viruses, bacteria, and other health threats by identifying and destroying these foreign intruders. Autoimmune diseases, in which the immune response begins to attack the body's own tissues, affect three times as many women as men. Autoimmunity is the root cause of more than 80 serious, chronic diseases, including rheumatoid arthritis, type 1 diabetes, lupus (destructive tissue inflammation), multiple sclerosis, Graves' disease (hyperthyroidism), and scleroderma (thickening and hardening of the skin).

The most common autoimmune disease is arthritis, which currently afflicts 23 million women in the United States and is expected to afflict 36 million by the year 2020. A leading cause of disability in women, arthritis has also been linked to anxiety, depression, and changes in cognitive abilities (perception, memory, judgment, and reasoning). Asthma and chronic allergies, also immune-related diseases, account

“Basic research will yield information that benefits the treatment and diagnosis of all autoimmune diseases and represents the most promising approach to finding a cure.”

Virginia T. Ladd, R.T.
American Autoimmune
Related Diseases Association

for considerable illness among women, while atherosclerosis (hardening of the arteries) and Alzheimer’s disease are complicated by an immune or inflammatory component.

Many autoimmune diseases are considered rare, affecting fewer than 200,000 people. Taken together, however, they afflict 50 million Americans, including 3 times more women than men.

Notable scientific progress over recent years has expanded understanding of the immune system and its related diseases. For example, researchers have discovered that the immune function may be altered by external factors such as diet, vitamins, stress, infections, indoor and outdoor allergens, physical activity and exercise, sexual orientation, implants, hormone replacement therapy, and birth control pills. Study results have helped doctors improve bone marrow transplants and the rebuilding of the immune system after chemotherapy and radiation treatments.

At present, new research tools involving DNA are allowing researchers to conduct studies that were previously impossible, while important interactions between the immune system and the nervous and endocrine systems, as well as with hormones, are being studied and documented. These and other advances offer hope that autoimmune and allergic diseases can be prevented and effectively treated.

The women’s health agenda for the 21st century includes the following questions concerning immunity and autoimmune diseases.

- What genes are involved in autoimmune and allergic diseases?
- What are the specific effects of environmental factors, such as diet, stress, and allergen exposure on immune function?
- What are the effects of age and sex on normal and abnormal immune function?
- How do hormones affect the immune response? Is there a difference in effect between the body’s natural hormones and the hormones contained in birth control pills and hormone replacement therapy? Do women’s cyclical changes in hormones affect the immune response?
- What differences exist in various organs associated with inflammatory diseases—the brain in multiple sclerosis, the joints in rheumatoid arthritis, the beta cells in diabetes, the kidney and vasculature (blood vessels and lymph ducts) in lupus, the lung in asthma, and the skin in scleroderma?

KIDNEY AND UROLOGIC CONDITIONS

Diseases of the kidney and urinary system have a major impact on women's health. Permanent kidney failure, called end-stage renal disease, affects more than 120,000 women in the United States. And although treatment with dialysis or transplantation is necessary to sustain life, neither of these options restores normal, or even near-normal, life expectancy.

A person developing end-stage renal disease at age 50 has only a 20 percent chance of surviving for 10 years.

Kidney disease is on the rise among both men and women. The number of new patients requiring dialysis or a transplant nearly doubled from 1985 to 1995. Women, however, are more likely to suffer from renal failure as a result of type 2 diabetes or lupus (a type of autoimmune disease characterized by a destructive inflammation of connective tissue), or from the long-term use of painkillers; many also experience pregnancy-related kidney disorders.

Women's urological disorders, which afflict all women at some point in their lives, include urinary incontinence (uncontrollable urine flow), pelvic floor disorders, urinary tract infections, and interstitial cystitis (chronic bladder inflammation). Generally less serious than renal failure, these conditions still have a profound effect on women's quality of life. They are often chronic, misdiagnosed, and inadequately treated. Many women are too embarrassed to report these conditions to their doctors, often waiting years before getting treatment. Of the estimated 50 percent of childbearing women who lose pelvic floor support, resulting in urinary incontinence and severe pelvic pain, only 10 to 20 percent seek medical care.

Progress in renal health in recent years, which benefits many women, has included the development of new drugs for preventing organ rejection in kidney transplant patients. Advances in diabetes research have produced better ways to attempt to prevent and manage diabetic renal failure. In the field of urology, scientists have improved the design and increased the availability of adult continence products, while emphasizing patient training for the self-management of uncontrolled urine flow. Researchers have also enhanced their understanding of the link between childbirth and pelvic floor disorders, the use of folate supplements before and during pregnancy to help prevent bladder dysfunction, and the behavioral risk factors associated with urinary tract infections. And new drugs for treating interstitial cystitis now offer relief to millions of women.

"Interstitial cystitis (IC) was considered, and still is considered by some urologists, as an 'hysterical female condition.' Unfortunately, this blatantly incorrect label still haunts IC victims with the sufferer taking, on average, 4.5 years to get a correct diagnosis and often having to see an average of five physicians before IC is diagnosed."

Vicki Ratner, M.D.
Interstitial Cystitis
Association

TABLE 3. Frequency of Kidney and Urologic Conditions

Condition	Frequency
Urinary Incontinence	10-30 percent of women aged 15 to 64 and 10.4 million women over 65 (80 percent of all cases)
Pelvic Floor Disorder	400,000 related surgeries each year
Urinary Tract Infection	Half of all women have at least one infection by age 30
Interstitial Cystitis	405,000 women (90 percent of all cases)

Further progress in the prevention, diagnosis, and treatment of kidney and urologic conditions will come from answers to questions like those below.

- What are the effects of the chronic use of pain relief medication on kidney function?
- In women with kidney disorders, what is the impact of pregnancy on renal function? The best approach to hormone replacement therapy?
- What strategies are effective in preventing kidney diseases among women with type 2 diabetes?
- What are the impacts of childbearing and aging on urinary incontinence, pelvic floor disorders, and urinary tract infections among diverse populations? Over long periods of time?

"Approximately 75 percent of individuals with irritable bowel syndrome (IBS) in the community are female, with the incidence being reported as high as 90 percent in some medical centers."

Nancy Norton
International Foundation
for Functional
Gastrointestinal Disorders

D I G E S T I V E D I S E A S E S

Women are at high risk for many digestive diseases. For example, 2 to 3 times more women than men are diagnosed with irritable bowel syndrome and functional bowel diseases, conditions that affect 15 to 20 percent of the U.S. population. Women also comprise two-thirds of the estimated 20 million Americans suffering from gallstones. More women than men develop peptic ulcers from high doses of nonsteroidal anti-inflammatory drugs, such as aspirin and ibuprofen. Nine times as many women suffer from biliary cirrhosis and 3 to 4 times as many women have autoimmune hepatitis (progressive inflammation of the liver). In addition, women with inflammatory bowel or chronic liver diseases have an increased chance of developing osteoporosis, while women diagnosed with colorectal cancer (also considered as a digestive disease) have a higher risk of experiencing cancer of the pancreas, small bowel, or endometrium.

Gallbladder removal is one of the most common surgeries performed on women.

Digestive problems during pregnancy include (a) chronic conditions present prior to pregnancy, such as ulcerative colitis, Crohn's disease, and biliary disease; and (b) symptoms and conditions generally associated with pregnancy, such as nausea, vomiting, and heartburn. Acute fatty liver disease can also occur during pregnancy and, although very rare, can be fatal.

Scientific advances over the past 10 to 15 years have expanded the understanding of gastrointestinal functions and diseases. For example, factors such as stress, physical and sexual abuse, and mental health have been shown to play important roles in the onset and treatment of irritable bowel syndrome, changes in the motility (ability to move) of the small intestines or colon, and an increased sensitivity to pain. The newly identified nonalcoholic liver disease, steatohepatitis, has been linked to obesity and non-insulin dependent diabetes. Plus, the development of less invasive surgical techniques now permit more rapid recovery rates for gallbladder patients, while recent genetic discoveries offer great promise for reducing the incidence of colorectal cancer and gallstone and acute fatty liver diseases.

Early screening for colorectal cancer is highly effective in preventing new cases of colon cancer because growths can be discovered and removed before they become cancerous.

The agenda for research on digestive diseases in women includes finding answers to questions such as:

- Why do irritable bowel syndrome and functional bowel diseases affect more women than men?
- What cost-effective methods are there for the early detection of colorectal cancer? How can women and health care providers be made more aware of the importance of screening for this disease?
- What causes gallstones during pregnancy and periods of rapid weight loss?
- What are safe and effective therapies for treating liver diseases in women? For treating chronic gastrointestinal conditions in pregnant women?
- How does calcium absorption in the intestines affect health and disease, and how does this change with age?

ALCOHOL, TOBACCO, AND ILLICIT DRUG USE

Women make up one-third of the estimated 14 million Americans who abuse or are dependent upon alcohol. While men drink alcohol in larger amounts than women do, alcohol-dependent women often experience greater psychological impairment sooner once they begin to drink heavily. Women alcoholics also develop alcohol-related liver disease, heart disease, and brain disorders earlier in their drinking careers than do men.

About half of the 48 million smokers in the United States are women, as are nearly a third of the 500,000 people who die from tobacco use each year. Even though tobacco is the most preventable cause of death in this country, smoking rates among women have declined only 21 percent in the past 30 years, compared to an 84 percent decline among men. In addition to risking lung cancer, women who smoke often experience early menopause, which may increase their risk for coronary artery disease.

“Women have a 1.4 to 2.9 times higher risk of developing lung cancer than men when the amount of tobacco exposure is controlled.”

Carolyn M. Dresler, M.D.
Thoracic Surgical Oncologist
American College of Chest Physicians

Cigarette ads have been linked to an increase in smoking rates among teenage girls.

A study conducted in 1990-1992 found that about 6 percent of American women between the ages of 15 and 54 met the criteria for lifetime drug dependence. In another study, more than 221,000 women admitted using drugs while pregnant. Such illicit drug use (as well as alcohol abuse) has been linked to mental disorders, especially depression; violence and sexual abuse; eating disorders; low self-esteem; and exposure to sexually transmitted diseases, including HIV/AIDS.

TABLE 4. Women's Alcohol, Tobacco, and Illicit Drug Use

Condition	Prevalence
Alcohol abuse and/or dependence	4.0 million
Alcohol use in past year of ≥ 12 drinks	32.7 million
Tobacco use at some time in life	73.6 million
Tobacco use in past year	32.5 million
Tobacco use in past month	29.5 million
Illicit drug use in past month among women of childbearing age	4.3 million

Recent scientific studies have demonstrated that (a) alcoholism risk can be transferred genetically from generation to generation; (b) women are more likely to begin or maintain cocaine use in order to develop more intimate relationships, while men are more likely to use the drug with

male friends and in relation to the drug trade; and (c) the presence of their children in residential treatment facilities increases women's length of time in treatment.

The following questions will help guide future research into alcohol, tobacco, and illicit drug use among women.

- What are the effects of a mother's alcohol and drug use on her children's use of alcohol and drugs?
- How is women's alcohol and drug use influenced by the presence of anxiety disorders? Eating disorders? Depression? Childhood sexual abuse? Violent victimization as an adult?
- How do the media and advertisements influence women's use of alcohol, tobacco, and illicit drugs?
- How do hormones and alcohol interact?
- What can be learned about effective treatment for alcohol and drug addictions from women who successfully recover?

ADDITIONAL CRITICAL ISSUES IN WOMEN'S HEALTH

"One of the greatest and most unfortunate gaps in the public's knowledge about women's health is a lack of understanding about human reproduction."

Mary Hammond, M.D.
American Society for
Reproductive Medicine

In addition to the major diseases and health risks just described, women face unique issues related to their reproductive and oral health. They also respond differently to medications and drug treatments than do men.

REPRODUCTIVE HEALTH

Historically, the term "women's health" has meant "reproductive health," with research in women's health generally limited to the study of obstetrics and gynecology. In the late 1970s, however, social pressures, especially feminist concerns about women's interactions with the medical system, resulted in a broader definition of women's health that included the treatment of all diseases and conditions in women. As the concept of women's health expanded, reproductive health research remained focused on issues related to pregnancy, fertility and infertility, contraception, benign reproductive tract diseases and disorders, and menopause.

In recent years, results from reproductive research have contributed to an increased knowledge of pregnancy, including the effects of infection and other external factors, such as diet, exercise, smoking, violence, and medications. In addition, physicians now have access to new birth control methods and more effective treatments for infertility, along with genetic and other diagnostic tests to help prevent birth defects. They also have a greater awareness of the occurrence and treatment of abnormal uterine bleeding, premenstrual syndrome, leiomyoma (uterine fibroids), pelvic pain, endometriosis, and pelvic floor relaxation.

Scientific studies are now underway to address gaps in our understanding of normal and problem pregnancy. Hopefully, biological and behavioral research can come together to (a) identify contraceptives that are effective and acceptable to use and (b) improve the safety and cost-effectiveness of fertility treatments, while addressing ethical concerns in reproductive

medicine. Scientists can also explore the long-term effects of gynecological diseases and treatments, as well as the effects of hormonal changes over the life span, on fertility, behavior, menopause, and hormone-dependent diseases.

Reproductive health research in the 21st century will keep two considerations in mind: (a) educating health professionals and the general public on risk factors, diagnostic tests, and the pros and cons of available treatment options; and (b) attending to the individualized needs of specific populations, including the medically underserved, women of color, women with disabilities, adolescents, postmenopausal and elderly women, and lesbians. Within this context, some key research questions are stated below.

- What genetic tests, medical and surgical options, and other treatment alternatives can improve the monitoring and outcomes of pregnancy?
- How can contraceptives help prevent sexually transmitted diseases?
- Which infertility treatments are best for specific populations? How can the negative medical, social, and economic effects of multiple pregnancy and births be reduced?
- What are the critical factors in the development of gynecological diseases and disorders? How can these diseases be identified? What are the safe, effective, and less invasive treatment options?
- What are the effects of hormone changes at menopause? What is the safety and usefulness of hormone replacement therapy (HRT)? How can problems be detected and reduced? What effects does HRT have on the start-up, growth, or return of hormone-dependent diseases?

O R A L H E A L T H

Most oral problems are complex diseases involving genetic, behavioral, social, economic, and environmental factors. They affect women of all ages. Young women who smoke, engage in unprotected sexual activity, or suffer from eating disorders in which they invoke frequent vomiting are at risk for mouth and throat cancers, AIDS-related oral problems,

“Dental and oral diseases affect most older Americans; 99.5 percent of Americans 65 years and older have had cavities and 40 percent of these elderly Americans have lost all their teeth... 46 percent of women over 75 years of age have lost all their teeth.”

Susan Silverton, M.D., Ph.D.
American Association of
Dental Schools

and tooth erosion and decay. Uninsured single mothers living in poverty and many mothers, in general, who defer their own dental care in favor of other family members are susceptible to oral problems that repeat and multiply over time. Older women who have multiple chronic conditions, take numerous medicines, or experience reduced physical functioning and/or mental capacity encounter many disabling problems from oral diseases, disorders, and conditions.

Oral health refers to the status of the teeth, gums, salivary glands, bone and facial structures, nerves, taste buds, and mucous membranes (inner lining of the mouth).

In addition to providing new materials for dental and facial implants and jaw replacements, oral health advances in the latter part of the 20th century offer hope to women suffering from a variety of diseases. For example, oral health studies confirming differences in pain sensitivity between men and women may help to explain and treat women’s more frequent experience of migraine headaches, fibromyalgia, and temporomandibular joint (TMJ), or jaw, pain. Preliminary data pointing to links between oral and hipbone mineral densities, periodontal (gum) disease and diabetes, and gum disease and heart attacks may lead to new strategies for reducing these major health risks. Emerging evidence showing that poor maternal periodontal health increases a newborn infant’s potential for low birth weight, and for preterm or premature birth, may be an important key to effective prenatal care. And saliva, which is already being used to monitor levels of hormones and prescription drugs, as well as the presence of illicit drugs, may prove to be an effective diagnostic aid in diseases such as Alzheimer’s, cystic fibrosis, and diabetes.

Severe periodontal disease in pregnant women is linked to a sevenfold increase in the risk of delivering preterm, low-birthweight babies.

Additional research topics offering promise in the control of oral diseases and the improvement of the general health and quality of life for women in the 21st century are stated below.

- What is the relationship between variations in reproductive hormone levels and women's experience of pain? How do social and cultural factors influence women's responses to pain across the life span? In different cultural environments?
- What is the relationship between oral diseases in HIV-infected women and their children?
- How do stress, coping behaviors, and depression affect the relationship among oral bone loss, osteopenia, and osteoporosis? What are the effects of hormones and hormone replacement therapy on oral bone loss and tooth retention?
- What is the role of periodontal infection in diabetes? In cardiovascular disease? In premature birth?

D R U G T H E R A P Y

Women's bodies absorb and respond to therapeutic drugs differently than men's bodies do. As a result, women often experience negative side effects from drug doses established for men, and require higher or lower dosages to reap the same benefits. In addition, women's reactions to medications vary over the life span and may be influenced by hormonal changes during pregnancy and by hormone replacement therapy. There may also be differences in women's responses to medications or drug therapies across different racial and ethnic groups.

Therapeutic drugs are called "pharmacologic agents," as are dietary supplements (vitamins and minerals), and complementary and alternative medicines. Understanding how these therapies work in women, individually and in combination, can help doctors prescribe the correct amounts of the right medications and advise women on possible therapeutic drug interactions.

The most important advancement in drug therapy research in recent years is the progress made in promoting women's participation, including women of childbearing potential, in all phases of clinical trials. Results have contributed to an increased awareness of differences in medication-induced responses between men and women; the impact of hormones

“To provide optimal pharmaceutical care, pharmacists should be aware of the ethnic and racial composition of their patient population, and the distinctive characteristics that may elicit ethnic and racial differences in pharmacologic responses to medicines as well as the psychosocial and economic parameters that influence drug use or misuse.”

Gloria J. Nichols, M.Ed., Ph.D.
Catherine A. White, Ph.D.
University of Georgia
College of Pharmacy

and various enzymes on drug effectiveness; and the occurrence of problem side effects experienced by women during drug therapy and/or after taking dietary supplements.

While these and other findings will help ensure the safety and effectiveness of medications for women, complicated issues remain in the study of therapeutic drugs in women. Testing new medications on women of child-bearing age raises concerns about the potential harm to unborn infants. Not testing new medications on pregnant women leaves unanswered questions about the safety of the drugs, once they are approved, for the pregnant women themselves, as well as for their unborn and newborn children (who might take in the medication through a mother’s breast milk).

In 1994, the National Institutes of Health published the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research.

With these issues in mind, the agenda for research on women and drug therapy in the next century includes important questions, such as:

- What are the differences in how medications work in women and men? In women from different racial and ethnic groups?
- How do therapeutic drugs affect women across the life span? During pregnancy? During and after menopause?
- What therapeutic drug-to-drug interactions are important for women’s health? Drug-to-supplement interactions? Drug-to-food interactions?
- How can the effects of medications on pregnant women and their children be evaluated without risking the health of the women or the children? What effect will drug therapies, especially anti-depressants, taken by a pregnant mother have on the development of her unborn child? What are the effects of a mother’s medications on her breast-feeding infant?

EMERGING DIRECTIONS FOR IMPROVING WOMEN'S HEALTH IN THE 21ST CENTURY

"Gender differences of significant clinical relevance have already been discovered in the immune system, susceptibility to lung cancer, use of pain-killing drugs, and treatment of angina."

John C. Fletcher, Ph.D.
Professor of Biomedical Ethics
University of Virginia

Answers to critical questions in all areas of women's health research will pave the way for improvements in disease prevention, diagnosis, and treatment. Scientists can gain further ground, and enhance the quality of life for both women and men in the 21st century, by following the seven emerging directions in women's health research listed below and described on the following pages.

- Understanding sex and gender differences in health/diseases and prevention/treatment
- Enhancing women's health across the life span
- Emphasizing prevention in women's health
- Recognizing the impact of behavior on women's health and diseases
- Employing a multidisciplinary (team) approach to fully understand women's health and provide women's health care
- Examining health disparities among diverse groups of women
- Exploring the role of genetics in women's health and disease

U N D E R S T A N D I N G S E X A N D G E N D E R D I F F E R E N C E S I N H E A L T H / D I S E A S E A N D P R E V E N T I O N / T R E A T M E N T

Women and men differ in their physiology and their behavior. While they suffer from diseases that are unique to their sex, they may also develop the same diseases at different rates with different symptoms. Variations in lifestyle choices (cigarette smoking, alcohol consumption, and exercising) often affect their health directly, while their distinct roles in society can contribute to their risk of disease. Their hormones, which affect many of their sex- and gender-dependent physical traits, have been shown to modify their ability to absorb and respond to certain medications; their biological

“Research on women’s health must include the full biological life cycle of the woman and the concomitant (related) physical, mental, and emotional changes that occur.”

Marianne Legato, M.D.

Donna Dean, Ph.D.

Task Force on the NIH Women’s Health Research Agenda for the 21st Century

differences in body composition, size, and metabolism may influence the required amount and effectiveness of therapeutic drugs. In addition, women go through hormonal stages that influence the development of diseases such as heart disease and osteoporosis, are more often the victims of domestic violence, and have higher rates of depression and eating disorders.

It is only in the last 10 years that the National Institutes of Health has implemented a policy requiring that women be included routinely in medical and behavioral research. Within NIH, the Office of Research on Women’s Health was established in 1990 to ensure the inclusion of women in clinical trials, as well as to ensure and enhance research on women’s health. Fortunately, such research is now providing information about sex and gender differences that can address the dangers of assuming that women and men are identical.

While the past decade of research into women’s health has raised awareness of sex and gender differences in diseases and treatments, there is more to be done. For example, the continued examination of differences in brain and nervous system development (neuroscience) between women and men, including sex- or gender-specific symptoms and treatment responses, can increase the scientific understanding of how diseases in women start, progress, and improve with treatment. Results of such research can hopefully shed light on conditions such as Alzheimer’s disease, chronic pain, anxiety disorders, depression, multiple sclerosis, Parkinson’s disease, stroke, schizophrenia, and epilepsy. Studies to determine the behavioral, social, cultural, and environmental factors that contribute to these diseases can round out the picture.

Additional areas of investigation offer considerable promise. Of special interest to women are studies on the role of hypertension (high blood pressure) in women’s heart disease; new and advanced technologies for the early diagnosis of lung and reproductive cancers; effective approaches for the treatment of infectious diseases in women; new categories of therapeutic drugs for depression; links between nutrition, obesity, and diabetes; gene studies related to heart disease, osteoporosis, and other conditions; and outreach to special populations of women (racial and ethnic minorities, women with disabilities, lesbians, and women living in poverty).

E N H A N C I N G W O M E N ’ S H E A L T H A C R O S S T H E L I F E S P A N

A woman faces specific health risks at each stage of her life. Studying these risks, along with other issues relevant to each stage of women’s development, is essential to understanding and improving women’s health in the 21st century.

“Issues for women who are 65 or 70 and 85 or 90 years of age are enormously different. Since this is the fastest-growing segment of our population, it can only be ignored at the peril of society as well as of the women whose problems we hope to address.”

Jeanne Carritt, M.A., M.Ed.

Lois Grey Long, R.N., M.S.N.

Research on the prenatal, infancy, and childhood years can focus on identifying the short- and long-term effects of drugs on unborn infants and young children; and normal physical, behavioral, and psychological development, including the influence of genes and the environment. Studies can also determine sex and gender differences in response to stress and nutrition, critical stress points, and the development of coping behaviors.

When studying the adolescent years, scientists can consider how girls develop physically, socially, emotionally, and mentally, as well as how the environment affects their physical growth. They can look at risk-taking behaviors related to sexual activity, substance use and abuse, violence, injury, runaways, suicide, homelessness, and girls in gangs. Other areas of focus include how teens learn to cope with chronic illness, family problems, life events, violence, and troubling emotions. In this area of research, investigators can also search for effective ways to promote healthy behaviors, such as good nutrition, physical activity, sexual health and hygiene, and oral health.

For women in their reproductive years, researchers in the new millennium can concentrate on issues related to contraception, pregnancy, and the prevention, diagnosis, and treatment of sexually transmitted diseases, including HIV/AIDS. They can investigate the effects of physical, chemical, atmospheric, and social exposures on women; and make an effort to reach special populations like minorities, prisoners, and the homeless. To study this stage in women's lives, scientists can also conduct tests to determine the effectiveness, safety, and possible complications and side effects of alternative therapies.

Diseases and conditions for which reproductive-age women are at risk include heart disease, autoimmune disorders, female cancers, infertility, endometriosis, uterine fibroids, mental health disorders, substance abuse, stress-related digestive disorders, and obesity.

Research into women's health during the perimenopausal and postmenopausal years can aim to clarify the menopausal process and explore environmental, cultural, and lifestyle influences on menopause, including what comprises the best health care for women in this stage of life. Other studies can focus on the effects of hormones, including hormone replacement therapy, on the body; the psychological aspects of menopause, including possible links between menopause, care giving responsibilities, and the loss of loved ones; and the attitudes of women, doctors, and society toward menopause and aging.

“Prevention can add more to the quality and length of life than the best treatment.”

William R. Harlan, M.D.
Director, Disease Prevention
National Institutes of Health

Scientific studies of the elderly and frail elderly years can examine how changes in family and social structures, caregiving roles, and new work-force services affect women’s well being; and how managed health care, living arrangements, and fear of death and dying impact women’s mental and physical health. Research can also determine what empowers older women to use available health care, including mammograms, second opinions, and clinical breast exams.

Diseases and issues often affecting elderly women include heart disease and stroke, osteoporosis and osteoarthritis, impaired vision, and urinary incontinence, along with chronic pain, physical fitness, surgery options and recovery times, and toxic drug reactions.

EMPHASIZING PREVENTION IN WOMEN’S HEALTH

Until recently, most doctors and researchers were more concerned with detecting and treating illnesses than they were on maintaining overall health or preventing disease; many still are. Prevention involves limiting the actual occurrence of diseases and supporting the body’s systems for maintaining health. It relies on an understanding of how illnesses start, grow, and spread, as well as what biological, psychological, social, cultural, and environmental factors contribute to diseases. Prevention depends on individuals avoiding the identified risk factors, while making healthy lifestyle choices.

Preventive health measures, which often involve recommended behavioral changes related to diet, exercise, and routine health examinations, are meant to promote wellness, a concept that has gained acceptance over the past 10 years. Even so, significant numbers of Americans continue to lead unhealthy lives, including many women who seem to be ignoring life-saving information on how to prevent diseases.

Lung cancer is the most rapidly increasing cancer in U.S. women, despite the fact that it can be reduced or prevented in women who voluntarily quit smoking or never start.

Hopefully, research in the 21st century can help doctors focus on prevention, while encouraging women to act in their own best interests, by answering the following: Why do women resist life-preserving change? Why do young women continue to smoke and engage in unsafe sex? Why

"Areas that significantly impact women's health, their family, and the economy all deserve greater attention as we work to help prevent many of the conditions that today we can only incompletely treat."

Mary Lynn Newport, M.D.
American Society for Surgery
of the Hand

"Research has not adequately addressed psychosocial and behavioral factors that contribute to health status."

Gwendolyn Puryear Keita, Ph.D.
American Psychological Association

do older women fail to get mammograms and Pap smears? Why do so many women lead inactive lives? What methods are effective in helping young girls, teens, and adult women adopt healthy lifestyles?

Prevention is the best strategy for avoiding a lifetime of medical treatments and financial burdens. Fortunately, research in many critical areas of scientific inquiry promises to provide the information necessary to develop effective prevention measures. For example, researchers can determine (a) how hormones, diet, and exercise can prevent various cancers; (b) what early childhood developmental factors can point to the possible onset of mental illness; (c) which methods and vaccines are effective in preventing sexually transmitted diseases, including HIV; (d) what women can do to prevent osteoporosis and hip fractures; and (e) what medical options prevent or delay kidney failure in women with diabetes. Scientists can also help prevent many cancers, reproductive disorders, and infertility, as well as some chronic diseases in women, by understanding the risks of environmental exposures.

Prevention is both simple and complex. Finding ways to prevent diseases across the life span of women requires that women of all ages participate in clinical research trials. Once results are known, informing the general public, as well as doctors and other health care professionals, requires effective public service messages and educational programs. Physicians can play an important role in helping prevent diseases and promoting healthy behaviors in women. Yet, for this to occur, women of all ethnic and cultural backgrounds and income levels must have equal access to health care, especially to culturally appropriate preventive services.

R E C O G N I Z I N G T H E I M P A C T O F B E H A V I O R O N W O M E N ' S H E A L T H A N D D I S E A S E S

As noted in the discussion on prevention, a woman's health depends on her behavior as well as on the condition of her body. In fact, her individual experience of health and disease involves her attitudes, beliefs, emotions, and lifestyle choices and actions—all influenced, in turn, by her race, ethnicity, age, education, employment status, income level, social roles and support system, and sexual preference. Her health is also affected by where she lives, her access to quality healthcare, and whether or not she is the victim of violence or physical/sexual abuse. The combination of these factors, and their interaction with her genetic makeup and current physical condition, contribute to a woman's overall health and her susceptibility to disease.

“Behavioral research is important for it enables us to use effectively the continually emerging research knowledge—as individuals and as a nation.”

*Judith H. LaRosa, Ph.D.,
R.N., F.A.A.N.*
Professor and Chair
Tulane University School of Public
Health and Tropical Medicine

Studies that explore how these elements impact women’s health are referred to as behavioral research or social science. Discoveries in these fields complement the results of biomedical research, which investigates the physical causes, progression, and treatment of specific diseases. Biomedical research, for example, seeks to understand the benefits of physical activity in reducing the risk of heart disease, while behavioral research focuses on the factors that motivate women to exercise.

To help translate the results of biomedical research into improvements in women’s health, behavioral science in the 21st century can answer questions such as, “How do women make decisions about their health, including whether to adopt or maintain healthy behaviors? More specifically, investigators can look at the social influences on women’s reproductive and oral health choices and at the cultural factors, including race and ethnicity, that contribute to women’s behavior regarding alcohol, tobacco, and illegal drugs. They can explore the effects of income, housing, employment, education, and self-esteem on women’s choices related to nutrition, exercise, and sexual activity; investigate possible links between poverty, stress, and heart disease; and clarify the relationship between violence and depression. Social scientists can identify which specific medical, behavioral, and social interventions work, with whom, and why—to prevent and treat illnesses as diverse as cancer, infectious diseases, mental disorders, digestive and autoimmune diseases, and osteoporosis. They can also determine who benefits the most from genetic testing and counseling; and what factors are involved in assuring that women will follow medical advice, including taking prescribed medications. And, perhaps most importantly, behavioral researchers can address how the knowledge gained about women’s health choices and actions can be used to encourage women to make health-promoting changes.

The results of behavioral research can be especially effective in helping young girls adopt healthy behaviors related to nutrition, exercise, and sexual activities.

Together, biomedical and social sciences can offer guidance to women of all ages on how to prevent disease and maintain wellness. Equipped with this information, women can make positive lifestyle choices and take charge of their own health.

EMPLOYING A MULTIDISCIPLINARY (TEAM) APPROACH TO FULLY UNDERSTAND WOMEN'S HEALTH AND PROVIDE WOMEN'S HEALTH CARE

"True multidisciplinary research will bring together professionals involved in all levels of care, from prevention to diagnosis to treatment to education, to ensure a whole-person exploration of women's health."

Charlotte (Barney) Sanborne, Ph.D.
Texas Women's University

Each field of scientific inquiry captures key information on important aspects of women's health. Psychosocial research, including behavioral studies, explores how culture, lifestyle, personality, motivation, and social support affect women's choices related to health. Socioeconomic research examines the links between women's health, employment status, and income. Biomedical research, which is the most common type of women's health research, focuses on the physical causes of diseases and how they develop in women. Yet each of these focal points, by its very nature, provides just a single snapshot of the bigger picture that includes all three views.

Some scientists recognize that women's health is a unique, multidisciplinary research realm. It offers opportunities to supplement discipline-specific research by combining biomedical, psychosocial, and socioeconomic points of view and/or collaborating across various disciplines within biomedical research. Current research on chronic fatigue syndrome, for example, involves scientists from different biomedical and behavioral disciplines who are examining (a) a wide range of infectious agents as possible causal factors, (b) the roles played in the disease by the neuroendocrine function and the immune system, and (c) the use of antidepressants to relieve symptoms of fatigue, sleep disturbance, and chronic aches and pains.

At the beginning of the new century, scientists who collaborate or weave multiple views together can contribute significantly to the overall knowledge of women's health, especially with regard to prevention and treatment. For instance, they can determine the psychological, social, and cultural factors that influence women's and doctor's attitudes about the risks of cancer and the benefits of prevention and routine screening. They can explore the importance of developmental influences, environmental stressors, and biological, psychological, and social factors in digestive and autoimmune diseases, heart disease, and mental disorders.

Research teams might often include members from the basic sciences, nursing, psychology, sociology, pharmacology, anthropology, health education, social work, or economics.

Multidisciplinary research can be especially helpful in the investigation of HIV/AIDS, physical and sexual abuse, posttraumatic stress disorder, and depression. By conducting community-based studies of the risk

“It is really important that the affected population be part of all phases of research.”

Byllye Avery, M.Ed.

Founder, National Black Women's Health Project

factors for these conditions, along with the impact of popular culture on individual and group behavioral changes, scientists can design effective and culturally appropriate interventions and treatments.

To become more widely practiced, this relatively new approach to scientific study requires new and appropriate funding mechanisms, incentives and rewards, and training for researchers, as well as advocates who can develop multidisciplinary research opportunities.

EXAMINING HEALTH DISPARITIES AMONG DIVERSE GROUPS OF WOMEN

A woman's health may hinge upon the groups or subgroups to which she belongs. Her risk of getting and surviving certain diseases may depend on where she lives, how much money she has, and whether or not she is disabled, an immigrant, or a lesbian. A woman may face higher or lower risks of illness, and better or worse medical treatment, based on whether she is a black, white, Hispanic, American Indian, Asian, Pacific Islander, or Alaskan Native woman.

Health disparities abound in the United States. For example, while heart disease is the leading cause of death for all American women, cancer is the number one killer of Asian-American women. Black women, who have a lower frequency of breast cancer, are more likely than other women to die from the disease. The death rate due to all cancers among black women is more than 3 times higher than it is for American Indian women in New Mexico. High blood pressure, diabetes, and obesity are more common among black women than white women, while women of all races living below the poverty line are more likely to be obese than their higher income counterparts.

In 1993, a white woman was expected to reach 79.5 years of age; a black woman, 73.7 years.

Differences in health status and health outcomes among these special populations relate to cultural, educational, and behavioral variables, as well as the availability of services, individual preferences, and differences in supplementary services and the treatment of diseases. Physiological differences, including predispositions to certain disorders and different rates of drug absorption may also contribute to some variations.

“We want to be assured that diseases and ailments that so disproportionately affect minorities and women—diabetes, hypertension, teenage pregnancy, low-birthweight babies, heart attacks, strokes, sickle cell anemia, kidney failure—are given adequate attention and funding.”

Jann Primus, Ph.D.

Spelman College

In addition, physicians' attitudes and practices have been shown to influence women's health outcomes. Lesbians, women of color, and women with disabilities, for instance, are more likely to avoid routine medical care and screening procedures due to their fear of discrimination and the cultural insensitivity of health care professionals.

Despite the evidence of health disparities among various subgroups of women, most clinical research that has included women has focused on white, middle-class, heterosexual, able-bodied women. This attention to the majority group limits scientific understanding of the biomedical, behavioral, and cultural factors operating in the minority groups that make up more than 25 percent of the U.S. population.

To develop the knowledge base that will benefit all women, 21st century researchers can explore the reasons for existing disparities. They can also ensure diversity in all aspects of research, by (a) designing studies that include minority women and that accurately evaluate differences among population groups; (b) training minority researchers; (c) working with minority communities to define research goals, gather data, and analyze results; (d) making sure findings reach and help people in affected neighborhoods; and (e) widely disseminating results to health care professionals and the general public.

E X P L O R I N G T H E R O L E O F G E N E T I C S I N W O M E N ' S H E A L T H A N D D I S E A S E

"Genomic technology, in particular, holds the potential for uncovering the mechanisms of disease that underlie many women's health disorders."

Michael J. Gast, M.D., Ph.D.
Vice President for Women's
Healthcare
Clinical Research and Development
Wyeth-Ayerst Research

Not long ago, most people viewed the study of human genetics (DNA codes that determine physical traits) as a way of dealing only with rare diseases. Now, with the growing evidence of genetic influences in diseases as common as heart disease, cancer, osteoporosis, diabetes, manic depression, alcoholism, and some forms of mental retardation, genetic testing is becoming a routine part of mainstream medicine.

We are engaged in a genetic revolution.

Advances in genetics have improved doctors' ability to diagnose many diseases, through the widespread use of screening procedures and the specific testing of high-risk individuals. Prenatal genetic tests, for example, already help to prevent birth defects; ongoing genetic research will likely lead to new treatment options for many diseases, even helping to determine the drugs that work best for each patient, thus eliminating negative drug reactions.

"Bipartisan efforts are currently underway on issues such as...banning discrimination based on genetic testing."

Constance A. Morella, M.A.
Representative
U.S. House of Representatives

As research continues to identify the genes that predispose individuals to certain illnesses, many scientists suspect that most diseases, even those with proven genetic links, also involve environmental and socioeconomic risk factors. Therefore, scientific studies like the human genome project, which is mapping the genetic code for all three billion pairs of the human genome (the full set of inheritable human traits), can be balanced by studies of the social, cultural, familial, chemical, behavioral, and other factors that contribute to diseases. After all, explaining everything in terms of genetics would take away individuals' personal choices.

The primary purposes of genetic research are first, to understand diseases and second, to use the information to develop better diagnostic methods and treatment options. In some cases, genetic research may also lead to strategies for preventing disease. To this end, every area of medical research in the 21st century can focus on genetic factors to some degree. Scientists, for example, can (a) define the role of genetics in the onset, progression, and spread of cancer; (b) find ways to reduce the influence of genes on alcohol and drug use, abuse, and dependence; (c) identify the genes that cause or resist multiple sclerosis, lupus, rheumatoid arthritis, type 1 diabetes, scleroderma, and asthma; and (d) develop genetic-based methods for the improved monitoring of pregnancy.

The study of human genes raises many ethical, legal, and social questions: How can genetic tests be made available to everyone? What should doctors do with the information gained from genetic testing? If medical science offers a genetic test for an incurable disease, does a patient have meaningful reasons for undergoing that test? How can patient privacy and confidentiality be assured? How might genetic information change family relationships? Could the misuse of information result in discrimination against the carriers of genes for specific diseases? Hopefully, science in the 21st century will provide insight into these issues.

THE ROAD AHEAD

"The women's health movement is a movement that I think can and will bring benefits to all members of our society."

Vivian W. Pinn, M.D.
Associate Director for Research on Women's Health
Director, Office of Research on Women's Health
National Institutes of Health

There is no doubt that research provides the scientific foundation for making positive changes in women's health practices and policies. The enhanced understanding of normal and abnormal biologic processes and behavior contributes significantly to the improved prevention, diagnosis, and treatment of diseases, disabilities, and other conditions that affect the health of women and their families and communities.

The women's health research agenda for the 21st century sets the course for the further understanding of sex and gender differences in health and disease. It also seeks to learn more about disparities in the health needs and healthcare of diverse populations of women. The agenda emphasizes prevention, patient education, and the role of women in maintaining their own wellness. Encompassing behavioral and social research, as well as biomedical studies, this comprehensive plan calls for multidisciplinary collaboration to address relevant health issues across women's life span—from the prenatal stage to the frail elderly. And it highlights the importance of both genetics and the environment in determining how diseases start, grow, and spread.

Women's health is not just about
the health of one woman.
It is about the health of our families
and the health of this country.

At the dawn of the new millennium, women's health research offers hope to millions of women suffering from heart disease, cancer, mental disorders, infectious and autoimmune diseases, bone and musculoskeletal diseases, kidney and urologic conditions, digestive

“We want our daughters and their daughters to travel a different road than we have.”

Laura Tosi, M.D.

American Academy
of Orthopedic Surgeons

diseases, and alcohol, tobacco, and illicit drug abuse or dependence. Results can also enhance women’s reproductive and oral health and ensure the benefits of drug therapies. Yet, beyond improving the length and quality of women’s lives, such research promises to expand and enrich the practice of medicine to the benefit of all. As a result of scientific exploration, doctors will be better able to prevent, diagnose, and treat diseases in both women and men based on differences in biology, genetics, ethnicity, psychological make-up, cultural influences, social and environmental conditions, and economic status.

To reach this desired end, the Office of Research on Women’s Health will continue to maintain its close collaboration with scientists, health care providers, policy makers, and women’s health advocates across the United States and beyond. Together, they will lead the way for scientific advances into the ever-expanding frontier of women’s health.

Office of Research on Women’s Health

Established in 1990, ORWH is the focal point for women’s health research at the National Institutes of Health. The office has a threefold mandate to

- Strengthen and enhance biomedical research related to diseases, disorders, and conditions that affect women; ensure that research conducted and supported by NIH adequately addresses issues regarding women’s health; and establish a national research agenda for future directions in women’s health;
- Ensure that women are appropriately represented in biomedical and behavioral research studies supported by NIH; and
- Develop opportunities and support for the recruitment, retention, re-entry, and advancement of women in biomedical careers.

RESOURCES

For additional information, contact the appropriate National Institutes of Health office(s) shown below.

National Institutes of Health (NIH)

9000 Rockville Pike
Bethesda, MD 20892
<http://www.nih.gov/>

Clinical Center (CC)

6100 Executive Boulevard, Room 3C01
Bethesda, MD 20892
<http://www.cc.nih.gov/>

(301) 496-2563

National Cancer Institute (NCI)

31 Center Drive, Room 10A03
Bethesda, MD 20892
<http://www.nci.nih.gov/>

(301) 435-3848

(800) 422-6237

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