

Agenda for Women's Health Research

Improving Women's Musculoskeletal Health

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Increased attention and resources focused on women's health during the past decade have resulted in new offices, policies, and programs of the Federal government. The Office of Research on Women's Health, established by the National Institutes of Health in 1990, is a focal point for all National Institutes of Health-supported efforts to improve women's health through biomedical and behavioral research. The Office of Research on Women's Health ensures women's appropriate inclusion in research studies supported by the National Institutes of Health. Through the development of a comprehensive agenda for research on women's health, the Office of Research on Women's Health encourages the consideration of gender issues and gender differences in health and disease in research sponsored by the National Institutes of Health. The importance of research to study and improve women's musculoskeletal health has become increasingly recognized. Clinicians, researchers, and representatives of professional and advocacy organizations concerned with women's musculoskeletal health participated in the development of the initial research agenda on women's health in 1991 and participated in the meetings to update and revise the agenda in 1996 and 1997. As

a result of meetings convened to review and revise the agenda on women's health for the twenty-first century, many recommendations for additional research on women's musculoskeletal health have been developed and now are being implemented across the National Institutes of Health.

... women's health issues are long on numbers, large in disability and suffering, and enormous in cost. To reduce suffering and disability, we need to prevent these disorders when we can, diagnose them early to minimize their impact, and provide interventions to maximize functioning in patients who have them. We want our daughters and their daughters to travel a different road than we have.⁹

—Laura L. Tosi, MD
American Academy
of Orthopaedic Surgeons

In recent decades, interest in and commitment to the improvement of women's health have flourished in the United States and around the world.⁴ In September 1990 the first Federal office dedicated to addressing women's health issues, the Office of Research on Women's Health, was established at the National Institutes of Health. During the past 9 years, new offices concerned with women's health have been established within virtually every agency of the United States Public

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Health Service to foster biomedical and behavioral research, healthcare, health policy studies, and other programs designed to address important issues related to the health of women and women's participation in research studies and careers in the biomedical and healthcare professions.¹⁵

Through the policies and programs of the Office of Research on Women's Health, the National Institutes of Health is committed to improving the health of women across the life span through biomedical and behavioral research and to ensuring gender equity in research. The Office of Research on Women's Health, which was established in law by the National Institutes of Health Revitalization Act of 1993 (PL 103-43),¹⁰ has a tripartite mission to: (1) strengthen, develop, and increase research into diseases, disorders, and conditions that affect women, determining gaps in knowledge about such conditions and diseases, and then establish a research agenda for the National Institutes of Health for future directions in women's health research; (2) ensure that women are appropriately represented in biomedical and biobehavioral research studies, especially clinical trials, that are supported by the National Institutes of Health; and (3) create direct initiatives to increase the number of women in biomedical careers and to facilitate their advancement and promotion.

The Office of Research on Women's Health is responsible for monitoring and ensuring the appropriate inclusion of women (and minorities) in all studies supported by the National Institutes of Health and fostering research on women's health issues undertaken and supported by all of the agency's constituent institutes and centers. National Institutes of Health policies promoting the inclusion of women in research studies and research careers help to ensure equity in the conduct of research. Research findings related to gender differences in health and disease foster greater equity in health by eliminating "avoidable differences between men and women in their potential for enjoying

good health and in their likelihood of becoming ill, disabled, or dying from preventable causes."¹¹

There is an increased awareness of the need for women's health and gender differences in health and disease to be addressed in the education and training of all healthcare professionals. The Office of Research on Women's Health, the Health Resources and Services Administration, the Public Health Service Office of Women's Health, and other Federal and non-Federal organizations supported the data analysis and publication of a 1994 survey conducted by the Association of American Medical Colleges with the American Association of Colleges of Osteopathic Medicine to determine the extent to which women's health issues are included in the standard curricula of all medical schools in the United States and Canada.²⁰ The report indicated that women's health issues across the life span have been incorporated into the required curricula of 68% of allopathic and osteopathic medical schools. The survey also showed that osteoporosis and rheumatoid arthritis are incorporated into the required courses of 82% and 64%, respectively, of medical schools. However, the survey also revealed that only 33% of medical schools covered temporomandibular joint disease in the courses required of all students. By contrast, in 1997 and 1998 when the American Association of Dental Schools conducted a similar survey of all dental schools in the United States and Canada, the resulting report, which was supported by the Office of Research on Women's Health and the Health Resources and Services Administration, indicated that "while dental schools do not address a broad range of health issues in their curricula,"¹⁸ only two schools failed to include temporomandibular joint disease in required courses. However, osteoporosis and rheumatoid arthritis are incorporated in only 47% and 49%, respectively, of dental schools' standard curricula. Unfortunately, neither of the two surveys queried medical or dental schools concerning the incorporation of sports medicine into their standard curricula. To improve

healthcare for women, competencies in women's health must be established for undergraduate and graduate health professional education and training. Research can provide the scientific foundation for developing such competencies.

In view of the aging of the population of the United States, preserving good health across the life span—particularly fostering physical fitness among girls, adolescents, and women to improve health and increase mobility during the mature years—constitute critical components of research efforts of the National Institutes of Health. The preservation of bone mass in women and prevention of bone loss and osteoporotic fractures are the focus of numerous investigations supported by the National Institutes of Health. Fortunately, some gains have been achieved: for example, in the United States, the prevalence of disabling conditions declined from 24.9% to 21.3% in the 12-year interval between 1982 and 1994.³ Nevertheless, women continue to be at higher risk than men for chronic conditions such as arthritis, which currently is the most prevalent chronic condition reported by American women.⁵ The prevalence of osteoporosis and the many forms of arthritis among women contributes to the high rates of activity limitation and disability in women, which are 1.5 times greater among women 65 to 74 years of age than those for men of the same ages. Orthopaedic disorders account for the majority of such limitations of activity; during a 10-year period, a woman 65 years of age has a 40% chance of being admitted to the hospital for a musculoskeletal condition.¹⁷

Health Across the Continuum of Women's Lives

One of the earliest efforts of the Office of Research on Women's Health and the National Institutes of Health was to convene a meeting held at Hunt Valley, MD, in September 1991, to formulate an agenda for science-driven research initiatives and priorities on women's health.^{11,12} At that meeting, Janet L. Walker,

MD, of the Ruth Jackson Orthopaedic Society, and Sandra C. Raymond, Executive Director of the Osteoporosis Foundation, presented testimony that showed the need for "More research . . . on the chronic conditions that predominantly affect women, such as osteoporosis, to learn the extent to which these conditions are unavoidable concomitants of aging versus the consequences of inheritance and health-related behaviors."⁶

The meeting in Hunt Valley was organized according to health issues across a woman's life span. Issues of women's musculoskeletal health were addressed by working groups on women's Perimenopausal to Mature Years and Mature Years. The resulting agenda, which was published in 1992,⁶ contained numerous recommendations for research to address women's musculoskeletal health across the life span, from childhood and adolescence to the later years of life. For example, the initial agenda on women's health research stated that "Research should determine whether the skeletal changes that occur during pregnancy predispose to musculoskeletal disorders in later life" and "studies should explore the gender-related differences in trauma-induced dysfunction in early life and their possible impact on age-related musculoskeletal disorders in later life."⁶ The agenda also showed that the role of estrogen and other endogenous and exogenous hormones in women is understood poorly, as are the effects of long-term hormone replacement therapy and its relative benefits in preventing osteoporosis and cardiovascular disease versus the potential increased risks of breast or endometrial cancer.

Since the formulation and publication of the first research agenda, progress has been made in establishing women's health research as an integral part of programs of the National Institutes of Health.¹⁴ During the 1990s, investigations have expanded the parameters of knowledge, which has given rise to additional questions and new scientific opportunities. These advances have created the need for the Office of Research on Women's Health to reassess the research agenda and to consider

new priorities and the formulation of a revised agenda for research on women's health issues.^{2,13,16}

A basic tenet of the process that led to the initial research agenda was that women's health research should encompass biomedical and behavioral research, ranging from laboratory to applied research, and including considerations of health and disease from the individual to the public health levels. In addition, expanded concepts of women's health were emphasized in research to encompass the life span of women and their total bodies, including but beyond reproductive issues, normal development and pathologic processes, and conditions unique to women. Although gender comparisons related to differences in maturation, aging, health, and disease continue to be important, the Office of Research on Women's Health is also addressing differences in health status and outcomes among diverse populations of women in the United States. These same tenets were integral to the Office of Research on Women's Health's most recent effort to review and update the research agenda on women's health for the twenty-first century.

Revitalizing the Agenda on Women's Health Research: A Collaborative Effort

To renew and revitalize the agenda for women's health research for the twenty-first century, the Office of Research on Women's Health launched a collaborative effort with the National Institutes of Health and the broader women's health scientific community, designed to: (1) identify priorities for the Office of Research on Women's Health to use to encourage and support new research; (2) identify priorities for investigators to consider for inquiry; (3) identify areas for public and private funders interested in women's health research to consider, and; (4) signal areas of scientific opportunity.

Beginning in September 1996, the Office of Research on Women's Health convened a series of three regional public hearings and sci-

entific workshops, held in Philadelphia, New Orleans, and Santa Fe, and one national meeting held in Bethesda to examine and update the scientific agenda on women's health research to meet the challenges of a changing scientific and social world in the next millennium. More than 1500 individuals from the scientific community, the healthcare and health policy communities, advocacy organizations, and the general public participated in the meetings.

The public hearings and scientific workshops were designed to examine progress resulting from research, to identify continuing or new and emerging issues and gaps in knowledge, to recommend a new framework for research priorities, and to recommend how such research initiatives can best be accomplished in the current scientific environment.^{11,12} The workshops were conducted by working groups that focused on periods across the life span (from birth to adolescence, the reproductive years, the transitional years up to and including menopause, the postmenopausal years, and the later years of life and the health of elderly and frail, elderly women), or on scientific areas.

Plenary sessions at the four meetings addressed such issues as the role of hormones in gender differences, and considerations of the role of environmental, genetic, and sociocultural factors on women's health. Participants in the working groups examined aspects of the initial research agenda from the perspectives of gender (physiologic, psychosocial, and pharmacologic differences between women and men). The working groups moved beyond consideration of gender issues to examine knowledge about factors that contribute to differences in health status and health outcomes among diverse populations of women, including biology, genetics, race, culture and ethnicity, psychosocial and behavioral factors, educational influences, traditional and alternative practices, poverty and socioeconomic status, access to healthcare, and occupational exposures and stresses. The workshops also in-

cluded considerations of health issues for women with disabilities and the health-related needs of special populations of women, including frail, elderly women; women who traditionally have been underserved by the medical and research community; ethnic minorities; women with disabilities; adolescents; women with somatic and developmental illness; lesbians; and women with exogenous exposures; and women living in isolated geographic locations of the United States. As stated in the February 1998 issue of *Orthopedics Today*, "a philosophical difference between the initial women's health public hearing and workshop . . . in Hunt Valley, MD, and the meeting in November [1997] . . . was a lot more attention and emphasis [was] placed on orthopedic issues"¹⁹ in the later series of meetings.

Researchers, healthcare providers, and individuals representing various organizations concerned with musculoskeletal health participated in the public hearings and scientific workshops associated with this series of meetings to update the research agenda on women's health. At the meeting held in September 1996 in Philadelphia, Laura Tosi, MD, of the American Academy of Orthopaedic Surgeons presented public testimony on women's skeletal health and emphasized the need for all healthcare professionals to encourage young girls and women to increase their intake of calcium to safeguard the health of their bones during the life span.⁹ At the national meeting held in Bethesda, MD, in November 1997, Frances Cuomo, MD, of the American Shoulder and Elbow Surgeons, Laura Flawn, MD, of the Scoliosis Research Society, Letha Y. Griffin, MD, of the American Orthopaedic Society for Sports Medicine, Jo Hannifin, MD, PhD, of the Orthopaedic Research Society, Mary Lloyd Ireland, MD, of the Ruth Jackson Orthopaedic Society, Mary Lynn Newport, MD, of the American Society for Surgery of the Hand, Sally A. Rudicel, MD, of the American Foot and Ankle Society, and Laura Tosi, MD, of the American Academy of Orthopaedic Surgeons presented pub-

lic testimony concerning orthopedic issues for women ranging from the need for additional research on osteoporosis in younger women to women's footwear and the need for rehabilitation programs for women to be structured differently than those for men.⁸

A Task Force on Women's Health Research for the Twenty-First Century oversaw the meetings and reviewed the recommendations from each meeting, working in tandem with National Institutes of Health's Advisory Committee on Research on Women's Health to develop an updated research agenda. At the final meeting held in Bethesda in November 1997, Joan McGowan, PhD, of the National Institute of Arthritis and Musculoskeletal and Bone Diseases, Dr. Laura Tosi, of the American Academy of Orthopaedic Surgeons, and Barbara Drinkwater, PhD, of the Pacific Medical Center chaired a scientific working group on bone and musculoskeletal disorders in women. Recommendations resulting from the meeting can be divided into three general categories: arthritis and musculoskeletal disability, osteoporosis and fractures, and orthopaedics and physical activity.

The report containing the National Institutes of Health's revised research agenda, *An Agenda for Research on Women's Health for the Twenty-First Century*,⁷ contains many recommendations for research on musculoskeletal and orthopaedic conditions in women. For example, the working group on bone and musculoskeletal health made the following recommendations, designed to enhance the medical community's knowledge of women's musculoskeletal health and ability to treat such disorders in women and men.

The report contains the following recommendations concerning arthritis: (1) investigate the greater prevalence of arthritis in women and its triggers; (2) explore the biologic and mechanical factors that influence the progression of arthritis; and (3) examine biologic repair processes and bioengineering approaches to tissue regeneration.

Research recommendations published in the report of the revised agenda encompass the

following issues concerning osteoporosis: (1) understand the factors that contribute to the development of peak bone mass (diet, exercise, puberty, pregnancy, smoking, and environment); (2) focus on clinical trials to develop treatment and prevention studies that will not be conducted by the private sector—combined drug therapies, exercise, and nutrition studies; (3) refine biologic markers and other assessment technology additionally; (4) focus on maintenance of bone mass throughout life—identify genetic and lifestyle factors associated with bone loss; (5) explore quality-of-life issues in women with osteoporotic fractures; (6) explore the role of physical activity in preserving muscular strength, balance, and coordination as a means of preventing falls in the elderly; and (7) develop specific exercise regimens that affect the bone at the major sites of fracture (hip, spine, and wrist).

Research recommendations for study of orthopaedics include the following: (1) investigate the role of women's footwear in pain, disability, and falls; (2) determine the prevalence and etiology of stress fractures and other overuse syndromes—repetitive stress injury; (3) investigate the molecular signals that control repair and growth in cells of the musculoskeletal system; (4) develop synthetic replacements for muscle, soft tissue, and bone damaged beyond repair; (5) explore knowledge of the interaction of the immune system and its role in transplantation of bone and ligaments; (6) study the relative influences of osseous anatomy, ligamentous laxity, and sex hormones on musculoskeletal disorders; and (7) explore gender variation in treatment outcomes.

Physical activity and sports medicine also were included in the report of the revised agenda, with the following recommendations for research: (1) improve measures of energy expenditure and its benefits to the musculoskeletal system—does leisure time exercise play a different role from household or occupational activities?; (2) determine the type, intensity, duration, and frequency of physical activity that is important for muscu-

loskeletal health; (3) investigate gender differences in sports injuries—endocrine, structural, and training factors that lead to injury; (4) explore the “female athlete triad,” including contributing factors such as nutrition, energy expenditure, and stress; and (5) understand the role of physical activity in the development of bone, tendon, ligament, and muscle.

Participants in the working groups recognized the need for improved gathering and dissemination of data and information concerning women's musculoskeletal health. The report of the agenda contains numerous recommendations pertaining to data needs and information dissemination, including recommendations to: (1) provide information from national data surveys and large cohorts on prevalence and treatment outcomes; (2) improve surveillance of injury patterns in physically active women of all ages; (3) improve, develop, and validate instruments that measure physical activity and relate it to health outcomes—improved performance measures; (4) develop effective information dissemination processes; and (5) develop methods for tracking and improving compliance with effective therapies.

Implementing the Agenda: A Partnership

As the focal point for women's health at the National Institutes of Health, the Office of Research on Women's Health is working with the institutes and centers of the National Institutes of Health and the scientific, advocacy, and healthcare communities to implement the research priorities identified through this collaborative process and published in the agenda. By addressing the continuum of health research, care, and information dissemination, the revised agenda on women's health research provides a blueprint for action on the part of researchers, clinicians, health policymakers, advocates, and all those dedicated to improving women's health in the twenty-first century. The success of the agenda depends on forging a collaborative, productive, and mutually beneficial

partnerships between the National Institutes of Health and the aforementioned groups and the professional organizations that serve them. The involvement of the healthcare community, including such an organization as the American Academy of Orthopaedic Surgeons, is vital to ensuring that the scientific research community addresses the gaps in knowledge and the recommendations published in *An Agenda for Research on Women's Health for the Twenty-first Century*.⁷ Health professional organizations also have a critical role to play in disseminating the results of research to their members and to the public at large.

Although research is central to the improvement of women's health, so too are improved standards of healthcare practice based on the findings of research. In addition to ensuring that women's health issues and new knowledge of women's musculoskeletal health are incorporated into the education and training of all physicians and other healthcare providers, orthopaedists and others concerned with improving women's health play important roles in educating the public about prevention of bone loss, osteoporosis, and osteoporotic fractures through diet, exercise, proper footwear, and other preventive strategies and interventions. Through scientific discovery and health professional and public education, the research and clinical communities can work together to help empower women and men to preserve their musculoskeletal health well into the advanced years of life.

References

1. Ashworth G: *Gendered Governance: An Agenda for Change*. New York, United Nations Development Program. Gender in Development. Monograph Series No 3. 10, 1996.
2. Chunko MT, Hayunga EG, Rothenberg K, Rudick J, Pinn VW: Update: Office of Research on Women's Health, National Institutes of Health. *J Women's Health* 5:317-323, 1996.
3. Manton K: *The Threshold of Discovery: Future Directions for Research on Aging*, Report of the Task Force on Aging Research. Washington, DC, United States Department of Health and Human Services 1995.
4. Mongella G: Global approaches to the promotion of women's health. *Science* 269:789-790, 1995.
5. National Center for Health Statistics, National Health Interview Survey: National Heart, Lung, and Blood Institute, NHLBI FY 1996 Fact Book. Bethesda, MD, National Heart, Lung, and Blood Institute 1997.
6. National Institutes of Health, Office of Research on Women's Health: *Report of the National Institutes of Health: Opportunities for Research on Women's Health*. NIH Pub. No. 923457. Washington, DC, United States Government Printing Office 165, 1992.
7. National Institutes of Health, Office of Research on Women's Health: *An Agenda for Research on Women's Health for the 21st Century. A Report of the Task Force on the NIH Women's Health Research Agenda for the 21st Century. Vol 2*. NIH Pub. No. 99-4386. Bethesda, MD, National Institutes of Health 1999.
8. National Institutes of Health, Office of Research on Women's Health: *An Agenda for Research on Women's Health for the 21st Century. A Report of the Task Force on the NIH Women's Health Research Agenda for the 21st Century. Vol 3. Public Testimony*. Bethesda, MD, November 1997. NIH Pub. No. 99-4387. Bethesda, MD, National Institutes of Health 1999.
9. National Institutes of Health, Office of Research on Women's Health: *An Agenda for Research on Women's Health for the 21st Century. A Report of the Task Force on the NIH Women's Health Research Agenda for the 21st Century. Vol 4. Influences of Sex and Gender on Health. Scientific Meeting and Public Hearing*. Philadelphia, September 1996. NIH Pub. No. 99-4388. Bethesda, MD, National Institutes of Health 1999.
10. National Institutes of Health Revitalization Act of 1993 (Public Law 103-43), 107, Stat. 22 (codified at 42 United States Constitution 289.a-1), June 10, 1993, at 486 (d) (4) (D).
11. Pinn VW: Women's health research: Prescribing change and addressing the issues. *JAMA* 268:1921-1922, 1992.
12. Pinn VW: The role of the NIH's Office of Research on Women's Health. *Acad Med* 69:698-702, 1994.
13. Pinn VW: *Women's Health and Research: Defining the National Agenda*. 1996 Women's Health and Research Conference: Applying the National Agenda. Proceedings of the Inaugural Meeting of the National Leaders in Women's Health. February 16-17, 1996. Gainesville, FL, University of Florida 9-23, 1996.
14. Pinn VW: The NIH Office of Research on Women's Health: Goals and recent activities. *J Am Med Women's Assoc* 53:35-37, 1998.
15. Pinn VW, Chunko MT: The NIH office of research on women's health and its DHHS Partners: Meeting challenges in women's health. *J Am Med Women's Assoc* 54:15-19, 1999.
16. Pinn VW, Chunko MT, Cooper Z: Setting the research agenda for the 21st Century. *J Women Health* 6:517-520, 1997.
17. Praemer A, Furner S, Rice D (eds): *Musculoskeletal Conditions in the United States*. Park Ridge, IL, American Academy of Orthopaedic Surgeons 1992.

18. Silverton SS, Sinkford J, Inglehart M, et al: Women's Health in the Dental Curriculum: Report of a Survey and Recommendations. NIH Pub. No. 99-43-99. Washington, DC, United States Department of Health and Human Services, Health Resources and Services Administration, National Institutes of Health 1999.
19. Trace R: Orthopedists seek greater federal support for gender-specific research initiatives. *Orthop Today* 18:50-51, 1998.
20. United States Department of Health and Human Services; Health Resources and Services Administration, National Institutes of Health, Public Health Service Office on Women's Health: Women's Health in the Medical School Curriculum: Report of a Survey and Recommendations. HRSA Pub. No. HRSA-A-OEA-96-1. Washington, DC, United States Department of Health and Human Services, Health Resources and Services Administration 1996.