

**5-YEAR PLAN
FOR THE
NIAMS HEALTH PARTNERSHIP PROGRAM
(2004-2008)**

REDUCING HEALTH DISPARITIES IN RHEUMATIC DISEASES

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES
NATIONAL INSTITUTES OF HEALTH
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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EXECUTIVE SUMMARY

In the last few years, we have witnessed an influx of scientific and medical advances leading to improvements in diagnosis and treatment for people with arthritis and other rheumatic diseases. While we celebrate these tremendous achievements with the research and patient communities, we remain diligently focused on the related health disparities. Marked differences in the incidence, prevalence, severity, process of care, and outcomes for people with rheumatic diseases, particularly minorities, remind us of the need to increase our understanding of these differences and ultimately to improve the health of all Americans.

Diseases such as systemic lupus erythematosus (lupus), which is characterized by an autoimmune response causing complications affecting the body's joints, skin, and vital organs, are more prevalent and severe in African Americans and Hispanics/Latinos. These groups also experience earlier disease onset and premature death resulting from lupus. Today, we know much more about the genetic links to lupus susceptibility, onset, and progression, and we have more effective treatments to reduce symptoms and increase life expectancy. Yet many questions remain about the nature and cause of lupus, as well as about preventive and treatment measures to reduce morbidity and mortality rates among minorities.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health, U.S. Department of Health and Human Services, established the Health Partnership Program (HPP) as part of its efforts to address these health disparities in rheumatic diseases. Through biomedical and behavioral research with under-represented patients affected by these diseases, the HPP aims to enhance our understanding of these disparities and their causes, and to provide direction for improving the health status and health outcomes of the minority communities affected.

This community-based research initiative operates through a collaborative effort between NIAMS and Washington, D.C. area community partners. Through this partnership, initiated in February 2000 with the program, the HPP has established the NIAMS Community Health Center, the site for many of the program's activities, including the clinical study, *The Natural History Study of Rheumatic Diseases in Minorities*.

The HPP now has the opportunity to take a multifaceted approach to address the multiple factors contributing to health disparities. Five areas have been identified. They are introduced below, and their objectives and strategies are explained in this 5-Year Plan.

I. Public Health Education

Goal: to increase the amount of comprehensive, culturally appropriate public health education materials and services that will inform and involve people affected by rheumatic diseases in the metropolitan Washington, D.C., area and improve their quality of life.

Objectives: to develop and disseminate public health information on (1) rheumatic diseases, (2) the impact of clinical studies on medical advances, and (3) opportunities for patients to participate in clinical studies.

II. Patient Care

Goals: (1) to increase access to rheumatology care to foster early detection and treatment of rheumatic diseases in preventing associated complications and chronic disabilities, and (2) to expand aspects of data collection that bear directly on patient care in rheumatology, including clinical, social, and psychological outcome measures; functional assessments; and patient satisfaction.

Objectives: (1) to provide access to quality health care for rheumatic diseases, and (2) to collect and analyze data to evaluate the impact of the HPP on the Washington, D.C. area community.

III. Health Disparities Research

Goals: (1) to increase access by under-represented Americans to clinical studies designed to understand, treat, and prevent complications, chronic disabilities, and health disparities associated with rheumatic diseases, and (2) to develop research approaches to understanding and eliminating health disparities related to these HPP areas of emphasis: public health education, patient care, and recruitment to research careers.

Objectives: (1) to increase access to clinical studies on health disparities; (2) to collect data on the process and outcome of HPP activities, such as clinical research, health education activities, and career development efforts; (3) to conduct community-based health disparities research; (4) to involve the Washington, D.C. area community in the research process; and (5) to practice research protections procedures.

IV. Recruitment to Research Careers

Goal: to increase the number of individuals from minority communities who have an opportunity to participate in biomedical research fields related to rheumatic diseases.

Objectives: (1) to provide science education, training, and mentoring for students and teachers; (2) to expand fellowship and intern programs; and (3) to provide employment opportunities.

V. Community Relations

Goal: to expand development of trusting, sustainable, and effective relationships between NIAMS/NIH and the metropolitan Washington, D.C., area community to facilitate and support the overall activities of the HPP.

Objectives: (1) to communicate with the Washington, D.C. area community about the HPP; (2) to collaborate with community groups on HPP-related activities; (3) to develop and implement plans to operate the HPP with recognition, understanding, and respect for cultural aspects of focus communities; and (4) to measure partnership satisfaction with the process and progress of the HPP.

5-YEAR PLAN FOR THE NIAMS HEALTH PARTNERSHIP PROGRAM

INTRODUCTION

Improving daily life for all Americans is the driving force behind the research initiatives of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health, U.S. Department of Health and Human Services. Virtually every home in America is touched by diseases of the joints, muscles, bones, and skin. However, some of these diseases affect minority populations to a greater extent, both in increased frequency and increased severity of disease. As the country's leading research institution for these diseases, the NIAMS is committed to uncovering the bases of these racial and ethnic disparities and devising effective strategies to prevent and treat them.

Through a partnership with community leaders and representatives in the metropolitan Washington, D.C., area, the NIAMS has established the Health Partnership Program (HPP). The HPP is a community-based, biomedical research program that seeks to find answers to why the incidence, prevalence, morbidity, and mortality of certain forms of rheumatic disease are higher in some ethnic groups—such as lupus in African Americans and Hispanics/Latinos—and what prevention and treatment measures will help reduce these health disparities. The initial site of implementation for the HPP is the NIAMS Community Health Center, a medical facility that provides a platform for the program's research, education, and training activities.

As a model, the HPP concentrates on arthritis and other rheumatic diseases in the local African American and Hispanic/Latino communities. Future efforts may include other diseases within the Institute's mission, and additional minority groups and geographic locations may be involved.

This 5-year plan for the HPP sets forth the program's goals, evaluation objectives, and strategies to address health disparities in arthritis and other rheumatic diseases among minority populations.

CHARTING THE COURSE FOR THE HPP

In February 2000, the NIAMS initiated the HPP by forming relationships with individuals and organizations representing the African American and Hispanic/Latino communities in the metropolitan Washington, D.C., area. In December 2000, with input from these community partners, the NIAMS completed development of the program's Health Promotion Plan. This document describes the initial goals and objectives, as well as resources needed and available to expand arthritis care and research in the local community. The plan is available at <http://www.niams.nih.gov/hi/outreach/hppplan.htm>.

The NIAMS Community Health Center, a site for community-based research and clinical services for individuals with musculoskeletal complaints and rheumatic diseases, opened in July 2001.

Since initiating the program and opening the CHC, community participation in NIAMS-related activities has increased. From July 2001 to December 2003, more than 700 people had been enrolled and cared for under the program's current research study. Many more had attended educational and training activities or received health education material. In this first phase, we have begun evaluating partnership satisfaction, collecting data on clinical study enrollment and disease characteristics, and compiling statistics on community-based activities.

ADVANCING TO THE NEXT PHASE

The HPP is now ready to move from the initial phase of the program to the development and evaluation phases. During the initial phase, four areas of emphasis were defined: Public Health Education, Patient Care, Access to Clinical Investigations, and Recruitment to Research Careers. In the development phase, some of these areas have changed. Public Health Education, Patient Care, and Recruitment to Research Careers have remained the same. Access to Clinical Investigations, now called Health Disparities Research, has been expanded to include a community-based research agenda stemming from the HPP. The education efforts under this area have been incorporated into the Public Health Education and Patient Care areas. Additionally, a new area called Community Relations has been added to the program.

| Program Areas in the Initial Phase | Program Areas in the Development Phase |
|---|---|
| Public Health Education | Public Health Education |
| Patient Care | Patient Care |
| Access to Clinical Investigations | Health Disparities Research |
| Recruitment to Research Careers | Recruitment to Research Careers |
| | Community Relations |

Planning for this next phase of the HPP began in February 2002 when NIAMS staff and community partners met with academic and community experts from around the Nation to discuss intermediate and long-term plans for the program. Subcommittees were then convened to examine each area of emphasis in greater depth, and develop recommendations. This 5-year plan represents the compilation of the subcommittee reports and the synthesis of plans and benchmarks for the next phase of the HPP.

LOOKING AT HEALTH DISPARITIES IN RHEUMATIC DISEASES

The impact of health disparities in arthritis and other rheumatic diseases among minorities can be seen in many forms. The most striking disparities include early onset of disease, higher prevalence of serious and life-threatening complications, and premature death.

For example, compared to the general population, the prevalence of systemic lupus erythematosus (SLE), an autoimmune disease whose symptoms can range from a mild skin rash to major organ failure, is higher among African Americans and Hispanics/Latinos. These groups also experience more complications of SLE, including kidney failure for both, neurologic problems for African Americans, and heart disease for Hispanics/Latinos.

Presently, the bases, effects, and outcomes of health disparities such as these are not well understood. Possible bases include genetic and environmental causes, differences in access to health care, and differences in utilization of services because of culturally determined health

beliefs and behaviors. Effects on disability, morbidity, and mortality may result from factors such as lack of health education, leading to failures to receive early diagnosis and treatment. Outcomes related to health disparities include economic effects such as lost wages and decreased occupational functioning, impaired social functioning, and depression.

The HPP provides a means to begin understanding health disparities in arthritis and other rheumatic diseases, and developing strategies and programs to diminish them. The five sections that follow lay out the goals, evaluation objectives, and strategies to address the coming 5 years of the HPP in the areas of Public Health Education, Patient Care, Health Disparities Research, Recruitment to Research Careers, and Community Relations. The goals and objectives provide a general direction for the program's focus and activities. The strategies provide examples of activities that may be undertaken to accomplish the objectives for each program area. They are not all-inclusive and will be revised as the needs of the community and program change.

PUBLIC HEALTH EDUCATION

Goal: By 2008, the NIAMS Health Partnership Program (HPP) will have increased the amount of comprehensive, culturally appropriate public health education materials and services that will inform and involve people affected by rheumatic diseases in the metropolitan Washington, D.C., area and improve their quality of life.

Information on Rheumatic Diseases

Objective 1: Develop and disseminate scientifically based public health and patient education information that is related to rheumatic diseases and tailored to the needs of the community, including information on definitions, symptoms, diagnosis, treatment, and prevention of complications and chronic disabilities associated with these diseases. This includes material designed for patients and members of their social network, including family and friends.

Strategies:

- Conduct research through focus groups and other means (e.g., online bulletin boards, videoconferences, teleconferences) to determine culturally appropriate messages, formats, and health communication priorities for public health and patient education material.
- Combine health education and patient support, when appropriate, throughout any expansion of the HPP's programs and services.
- Provide multilingual patient education materials on rheumatic diseases at a rate of five topics per year. These publications will be translated and/or adapted from English to other languages, such as Spanish.
- Coordinate and evaluate public health education efforts in conjunction with other HPP subcommittees to complement ongoing strategies.
- Identify relevant programs and services from existing sources for public health education efforts and, where appropriate, partner to collaborate on new publications and to distribute current materials (e.g. work with adult literacy programs, English as a second language programs, and local health voluntary groups).
- Coordinate with the HPP Community Relations Subcommittee to identify and collaborate with organizations that successfully communicate with and involve the community in the development and dissemination of health education materials.
- Coordinate with the HPP Community Relations Subcommittee in the training and education of NIAMS staff to incorporate culturally appropriate messages and graphics in all materials and communications.
- Develop a Steering Committee of NIAMS staff, Community Partners, and health voluntary group representatives to help facilitate and provide direction for HPP public health education programs and services.

Information on the Impact of Clinical Studies

Objective 2: Develop and disseminate public health education information on clinical studies and their impact on medical advances.

Strategies:

- Conduct research through focus groups and other means (e.g., online bulletin boards, videoconferences, teleconferences) to determine culturally appropriate messages, format, and health communication priorities for health education material.
- Expand distribution methods for disseminating health education information and materials to meet the audiences' needs.

Information on Clinical Study Recruitment

Objective 3: Develop and disseminate education material about current clinical studies that are seeking participation by members of the community.

Strategies:

- Refine existing and develop new materials to encourage participation in the natural history protocol at the CHC, as well as in future protocols (e.g., material on the nature of clinical studies, benefits and risks of participation, how science and medicine have benefited patients through results of clinical research).
- Combine health education and patient support when appropriate throughout any expansion of the HPP's programs and services.
- Develop a "Welcome to the NIH" booklet for new patients at the CHC.
- Develop a public health education training component for staff at the CHC.
- Finalize and implement the Patient Liaison Training Manual.
- Develop communication mechanisms to keep people affected by rheumatic diseases informed of and connected to the HPP (e.g., updates on the NIAMS Web site).
- Provide information on how to access and enroll in NIAMS and NIH clinical studies.

Evaluation: As we move forward in implementing these objectives and strategies, we will regularly evaluate both the processes and the products of our efforts. If needed, we will bring in outside evaluators to systematically assess our activities and identify opportunities to further enhance our successes.

PATIENT CARE

Goal 1: By 2008, the NIAMS Health Partnership Program (HPP) will have increased access to rheumatology care to foster early detection and treatment of rheumatic diseases in preventing associated complications and chronic disabilities.

Access to Quality Health Care

Objective 1: Develop a model community-based rheumatology clinic (i.e., the NIAMS Community Health Center) to provide increased access to quality health care services for people with rheumatic diseases, including screening, referral, and health information.

Strategies:

- Collaborate with an established community-based medical facility that will provide space to operate the rheumatology clinic in a setting that is accessible and familiar to community members.
- Monitor and enhance operations of the rheumatology clinic.
 - Provide adequate staff who are culturally competent and bilingual in English and Spanish.
 - Establish professional relationships with primary care physicians in the local referral network.
 - Increase the number of patients evaluated.
 - Monitor and improve services (e.g., patient scheduling, pharmacy, phlebotomy)
 - Expand services such as infusion therapy, when needed.
 - Make interpreters available, when needed.

Objective 2: Provide access to rheumatology evaluations for people who suspect they have, or have been diagnosed with, a rheumatic disease.

Strategies:

- Maintain direct access to a rheumatologist for all consultations in the rheumatology clinic during every scheduled evaluation.
- Expand rheumatology clinic services by providing rheumatology consultation through additional collaborations with community-based medical facilities.
 - Make a physician available for rheumatology consultation in southeast Washington, D.C., when possible.
- Implement clinical evaluations in other locations.
 - Make clinical services available from a broad range of referral sources to patients who have rheumatic diseases and the need for a source of ongoing care and/or clinical consultation. Referral sources may include the NIH Clinical center, university hospitals and clinics, community clinics and wellness centers (e.g., D.C. Department of Aging Wellness programs, Montgomery County African American Health Initiative).

Goal 2: By 2008, the NIAMS HPP will have expanded aspects of data collection that bear directly on patient care in rheumatology. Clinical, social, and psychological outcome measures, functional assessments, and patient satisfaction are among areas of interest in evaluating the impact of the HPP in the community.

Data Collection and Analysis

Objective 1: Collect and analyze patient care data on topics such as clinical, social, and psychological outcome measures, functional assessments, and patient satisfaction to evaluate the impact of the HPP in the Washington, D.C., metropolitan area.

Strategy:

- Implement the following in the routine management of patients:
 - Patient satisfaction questionnaires
 - Physician global assessments
 - Health-related quality of life surveys to assess patients' satisfaction with their overall well-being.

Evaluation: To evaluate the impact of providing care to individuals with rheumatic conditions, we will implement outcome measures into the routine management of patients.

HEALTH DISPARITIES RESEARCH

Goal 1: By 2008, the NIAMS Health Partnership Program (HPP) will have increased access to clinical studies designed to understand, treat, and prevent complications, chronic disabilities, and health disparities associated with rheumatic diseases, including the incidence, prevalence, morbidity, and mortality of these conditions.

Access to Clinical Studies

Objective 1: Use the NIAMS CHC and other venues to provide increased access to clinical studies designed to understand, treat, and prevent complications and chronic disabilities associated with rheumatic diseases.

Strategy:

- Expand community access to clinical studies to additional locations beyond the NIAMS CHC at the Upper Cardozo Neighborhood Health Center; for example, into the southeast Washington area.

Goal 2: By 2008, the NIAMS HPP will have developed research approaches to understanding and eliminating health disparities related to these HPP areas of emphasis: Public Health Education, Patient Care, and Recruitment to Research Careers.

Data Collection

Objective 1: Initiate database development for information generated through HPP activities.

Strategies:

- Develop a platform capable of secure data storage and recovery for HPP-related activities including:
 - Educational activities undertaken, population served, content conveyed, evaluation by participants and staff, and information transferred.
 - Patient population characteristics, including basic intake information, demographic characteristics, and diagnoses of patients referred to and enrolled in NIAMS and other NIH protocols.
 - Career development activities undertaken, audience served, subject matter conveyed, evaluation by participants and staff, and outcome information regarding educational and career choices.

Community-based Research Studies

Objective 2: Enhance community-based research conducted through the HPP.

Strategies:

- Increase HPP/CHC-based protocols beyond the current Natural History Protocol 01-AR-0227 (see protocol at www.clinicaltrials.gov).
- Involve more NIAMS investigators in community-based research.

- Develop focused and interdisciplinary research programs in the community involving NIAMS and other investigators.
- Assess motivational factors that can influence participation in medical research to understand and address issues and barriers to participation by minority communities.

Community Involvement in Research

Objective 3: Ensure community involvement in the research process.

Strategies:

- Conduct meetings with HPP Core Groups regarding ongoing and proposed HPP-based research on a regular basis.
- Involve community members in the review of community-based research through focus groups, requests for comments, and meetings.
- Involve community members in NIAMS Institutional Review Board (IRB).

Research Participant Protections

Objective 4: Ensure optimal human subjects protection for all volunteers, participants, and subjects in NIAMS HPP community-based research.

Strategies:

- Ensure training in ethics of research and scientific conduct for NIAMS researchers working on HPP.
- Provide educational materials and programs to acquaint community members with Federal regulations and NIH policies regarding human subjects protections.
- Review consent documents with patients on a regular basis to ensure thorough understanding of participation in clinical research studies.

Evaluation: Evaluation of the Health Disparities Research effort will have several components. The research agenda and plan will be evaluated by the Scientific Director, NIAMS, for priority, scientific merit, and use of resources. Clinical protocols will be evaluated at their inception and at yearly intervals by the NIAMS IRB, with input from community members, with regard to human research participant protections, risk and benefit, and appropriateness. Data will be presented in oral and written forms, and will be subject to approval by the Scientific Director as well as peer review. Other aspects of the research agenda such as breadth, depth, productivity, novelty, and significance will be evaluated by a compilation of the above.

RECRUITMENT TO RESEARCH CAREERS

Goal: By 2008, The NIAMS Health Partnership Program will increase the number of individuals from minority communities who have an opportunity to participate in biomedical research fields related to rheumatic diseases.

Science Education

Objective 1: Develop and provide science education materials focused on the NIAMS disease areas to students and teachers in middle and senior high schools by working with organizations that have direct access to these audiences.

Strategies:

- Develop a science program that includes a hands-on curriculum to engage students in science (e.g., science projects).
- Schedule visits to the NIAMS labs and the CHC for teachers and students to provide hands-on experiences in science education.
- Explore opportunities to incorporate a rheumatic disease curriculum into existing programs (e.g., the Catholic University science education program for D.C. area high school teachers and students).
- Develop and disseminate careers in science material for parents and guardians of students in minority populations.
- Participate in Career Day events at local schools to promote careers in science.

Training and Mentoring for Students and Teachers

Objective 2: Provide research training and mentoring opportunities for students and teachers.

Strategies:

- Develop opportunities for parents and children to learn what scientists do, such as the Take Your Child To Work Day program at NIH.
- Develop information and training opportunities at high schools (e.g., Science Career Centers).
- Generate and promote opportunities for NIH/NIAMS speakers to talk to students at schools and universities in order to reach a large student audience and attract them to a career in science.
- Foster communications between NIAMS staff and the directors of the Minority Access to Research Careers (MARC) program, which awards undergraduate research training grants.
- Develop a learning program with local schools to provide an opportunity for students to volunteer at the CHC.

Fellowship and Intern Programs

Objective 3: Develop a model community-based rheumatology clinic to provide research and patient care opportunities for under-represented minority investigators.

Strategy:

- Expand fellowship and nursing training to be held at the clinic.
- Provide orientation tours for medical and health care students and staff interested in rheumatology (e.g., provide tours to interns of the Montgomery County African American Health Initiative and Latino Health Initiative and Unity Health Care, Inc.).

Employment Opportunities

Objective 4: Promote/ encourage research employment opportunities for under-represented investigators.

Strategies:

- Facilitate opportunities to make NIH employees visible in the community (e.g., public lectures, health fairs, career fairs).
- Promote research careers by advertising through posters, flyers, Web, TV, and local newspapers.
- Foster interactions with scientific and professional societies.

Evaluation: We will assess several activities to determine the success of our outreach efforts, including development, distribution, and impact of career-oriented publications, recruitment of minorities into scientific, clinical, and other positions, the number of student volunteers and trainees at the CHC, and the number of lectures and presentations in schools and in the community.

COMMUNITY RELATIONS

GOAL: By 2008, the Health Partnership Program (HPP) will expand on the development of trusting, sustainable, and effective relationships between NIAMS/NIH and the metropolitan Washington, D.C., area community to facilitate and support the overall activities of the HPP.

Communication

Objective 1: Increase understanding of the community's needs and concerns regarding care and research of rheumatic diseases through established communication mechanisms.

Strategy:

- Provide opportunities for community organizations and members to discuss needs and concerns and give input on plans (e.g., meetings, focus groups, community forums, and individual interviews).

Objective 2: Increase awareness of the HPP, NIAMS, and NIH.

Strategy:

- Provide information to increase awareness of HPP, NIAMS, NIH, and biomedical and behavioral research to community members and organizations.

Objective 3: Increase communication of HPP plans and activities to community members and organizations.

Strategies:

- Provide information such as progress reports to community organizations and members on a regularly scheduled basis through appropriate venues and in appropriate languages (e.g., e-mail, Web, videos, newspapers, radio, community forums/meetings).
- Provide information on the HPP, including study results, to the health, medical, and scientific communities (e.g., through professional journals, presentations, posters, abstracts).

Collaborations

Objective 4: Establish and increase collaborations with community members and organizations to generate and enhance support for the HPP and its activities.

Strategies:

- Develop and strengthen cooperative relationships with a variety of organizations and community members.

- Form additional partnerships with a variety of organizations whose missions and/or goals are relevant to the HPP (e.g., local medical societies; community-based physicians; faith-based organizations; fraternities and sororities; media, including talk radio, tv, and print; and NIH employee-based organizations such as the NIH Black Scientists and Hispanic Scientists organizations, and the Hispanic Employee organization speakers' bureau).
- Create and maintain mechanisms for exchange of ideas, knowledge, and resources among NIAMS/NIH and community organizations and members (NIH learns about community needs and concerns; community learns about NIH resources and services).
- Assess and build on strengths and resources within the community to create and enhance HPP activities.
- Provide opportunities for mutual support of shared program activities.
- Provide HPP-related information about NIAMS/NIH grants and contracts, and opportunities for training, seminars, and lectures to community members and organizations.
- Provide training opportunities relevant to rheumatic disease care and research for community organizations and members.
- Provide recognition of contributions to the HPP activities.

Cultural Recognition and Understanding

Objective 5: Develop and implement plans to ensure that HPP operates in a manner that expresses recognition, understanding, and respect for cultural aspects of focus communities.

Strategies:

- Ensure broad representation among NIAMS staff and community members participating in HPP activities.
- Ensure training of NIAMS staff to enhance recognition, understanding, and respect of diverse cultures.
- Promote dialogue regarding cultural issues as they relate to medical care and research.

Satisfaction

Objective 6: Increase and maintain a high level of satisfaction with the process and progress of the HPP among community organizations and members.

Strategies:

- Involve community organizations and members in the planning, implementation, and evaluation phases of the HPP.
- Create and maintain communication mechanisms to (1) obtain input from the community, (2) disseminate information to the community, and (3) exchange ideas and knowledge among the program participants.
- Ensure agreement with HPP goals and objectives on a frequent and regular basis to confirm that the program is responsive to the community's needs about arthritis care and research.
- Assess the level of importance of rheumatic diseases in the community on a frequent and regular basis.
- Conduct periodic satisfaction assessments, including areas outside of Community Relations objectives.

Evaluation: We will assess the effectiveness of activities related to community relations on a regular basis and revise plans as needed. Areas of assessment include (1) communications, (2) collaborations, (3) cultural awareness and understanding, and (4) satisfaction.