

**HEALTH PARTNERSHIP PROGRAM:  
PROGRESS, OPPORTUNITIES, AND CHALLENGES**

**FEBRUARY 25-26, 2002  
BETHESDA, MD**

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Health Partnership Program (HPP) is a collaborative community-based effort directed at developing research programs to understand and address health disparities in rheumatic and musculoskeletal diseases. The NIAMS convened a meeting to foster interchange among NIAMS Community Partners, academic and community experts from a variety of settings, and NIAMS staff involved in the HPP. This meeting took place on February 25-26, 2002, in Bethesda, MD, 2 years after the initiation of the HPP. [See appendix A for the list of invited participants.]

The goals of the meeting were (1) to review the current state of the HPP, (2) to learn about other programs and experiences that are relevant to the HPP, and (3) to begin to articulate 5- to 10-year program goals addressing the HPP program areas: public health education, patient care, access to clinical studies, and recruitment to research careers, as well as plans whereby these aims can be achieved.

On the first day, Peter E. Lipsky, M.D., NIAMS, and Barbara B. Mittleman, M.D., NIAMS, charged the meeting attendees with the responsibility and opportunity to provide innovative and novel contributions to the HPP process over the coming years.

The program began by focusing on the current state of the HPP. The first speaker was Kelli Carrington, M.A., NIAMS. Ms. Carrington discussed the community outreach effort; the community-based activities and presentations; the large group meetings involving up to 60 partner organizations and individuals drawn from the greater Washington, D.C., African American and Hispanic/Latino communities; and the HPP document drafted in conjunction with the community partners and the NIAMS.

Dr. Mittleman discussed the NIAMS Community Health Center (CHC), which opened in July 2001 as (1) a rheumatology clinic; (2) a training site for fellows, residents and students; (3) a recruitment site for clinical protocol enrollment; and (4) a coordinating site for career development activities in biomedical research and health disparities. Data on the first 6 months of operation were presented. Patients attending the clinic were mainly African American and Hispanic/Latino. There were more women than men, and the average age of African American patients was significantly higher than that of the Hispanic/Latino patients. These data closely mirror the demographics of the community immediately surrounding the CHC. A wide variety of clinical symptoms and diagnoses were represented. Patients were most commonly referred by health care providers or community contacts.

Gwen Coleman, M.S., D.C. Family and Child Services and a member of the African American Community Partners Core Group, discussed the HPP from the perspective of a community member. She discussed initial concerns and mistrust in dealing with NIH/NIAMS,

and stated that the openness, the responsiveness, and the attention to issues of cultural differences and sensitivities of the NIAMS staff have been critical to the success of the program.

Maite Arce, Self Reliance Foundation ~ *Acceso Hispano* and a member of the Hispanic/Latino Community Partners Core Group, spoke about the process of working with the NIH/NIAMS on the HPP, the needs and concerns of the Hispanic/Latino community, and impressions of the CHC based on her personal experience and comments from community members. She, too, felt that the NIAMS has been successful in working with the Spanish-speaking community in a culturally sensitive manner.

Gregory Dennis, M.D., NIAMS, discussed the clinical activities at the CHC and the training of fellows in community rheumatology there. He saw the potential of the CHC as a recruitment site for patients to enroll in NIAMS and other NIH institute clinical protocols, and as a stimulus for community members to enter medicine and biomedical research in a variety of capacities.

Outside experts shared information and experiences about programs in other communities. Oretta Mae Todd, Ph.D., R.N., Arthritis Foundation – Detroit Chapter, described arthritis education and exercise programs in the African American community in Detroit. She spoke about the barriers to initiating and continuing such programs, the merits of academic affiliation (in this case with the University of Michigan), and the cultural aspects of their local community organizations and alliances. She emphasized the importance of the church as an entry to the African American community.

Kate Lorig, R.N., Dr.P.H., Stanford University, discussed outreach education efforts in arthritis and chronic disease self-management programs in the Hispanic/Latino community in California. She mentioned some of the specific cultural determinants influencing the success of their programs. She also emphasized the need to tailor programs to communities and to develop the means for programs to become self-sustaining.

The afternoon sessions focused on disparities in recruitment to research careers, disparities in access to health education, and more focused means for accomplishing HPP goals.

Nigel E. Harris, M.D., Morehouse University School of Medicine, spoke about recruiting minority students to careers in medicine and research, and more specifically to careers in rheumatology. He underscored the value of personal mentoring relationships, exposure to specific occupations and scientific fields, and exposure to individuals who can be role models for minority students.

Leigh Callahan, Ph.D., University of North Carolina, spoke about the National Arthritis Action Plan, a multiagency, multiorganization national plan for arthritis assessment and education that has been implemented across the United States. Dr. Callahan emphasized the value of standardized methods of assessment of arthritis incidence and prevalence; the need to be able to assess disability, outcomes, and response in communities of differing ethnic backgrounds; and the need for arthritis education.

Gwenyth Wallen, R.N., Ph.D., NIH Clinical Center (CC), presented a preliminary plan for a research project to be conducted at the NIAMS CHC in collaboration with the CC. This project will examine acculturation, health beliefs, and behaviors regarding arthritis and complementary and alternative medicine (CAM) usage in the Hispanic/Latino and African American patients attending the CHC. She presented the rationale for the project and the methods planned. The discussion emphasized focus group input in the construction of the assessment instruments. Meeting participants suggested ways to gather and use the community's input on the proposed project.

The final presentations of the day were directed toward translating the HPP's current accomplishments into a long-term plan for the program and its related activities.

Matthew H. Liang, M.D., M.P.H., Harvard Medical School, spoke about the difficulties of community-based research, particularly with respect to funding, and establishing continuity between community contacts and institutions and the research team. Sustainability was seen as a major issue of any such program. He gave examples from the War on Poverty and the Office of Economic Opportunity, which started Neighborhood Health Centers in the 1960's, and the continued challenges they face. East Boston Health Center, a center that had become a successful model for community-based research, has had serious financial setbacks.

Lawren Daltroy, Dr.P.H., Harvard School of Public Health, discussed three evaluation methods and strategies: 1) formative evaluation is an iterative, bootstrapping kind of process of repetitive trial and error that happens in the practice of working out a program and is important to document; 2) process evaluation presupposes an established and operating program which serves as the base from which patient care, research questions, and community relations can be assessed; and 3) outcome evaluation generally requires a moderate to long period of time for assessment of the distal effects of a program or intervention. Examples would include improvements in health outcomes as a result of the clinic and the development of specific treatments or educational activities. A full evaluation program would include elements of all three modes and would encompass the setup or establishment phase, the operation of the program, and the long-term effects of the program.

A dinner session that included meeting attendees, as well as additional members of the HPP community partners, was held on February 25. Keynote speeches were presented by Carlos Ugarte, M.P.H., Deputy Vice President for Health, National Council of LaRaza, and Michael S. A. Richardson, M.D., Senior Deputy Director, D.C. Department of Health. Mr. Ugarte discussed ways in which the need to understand and reduce health disparities can be addressed synergistically through community-based research and the NIH-community partnerships, thereby meeting many shared goals. Dr. Richardson spoke about the significant health needs of District of Columbia residents and how the NIH and local agencies can work together to foster improvements in health disparities and better health outcomes for the local community.

The second morning of the meeting was directed at developing an intermediate and long-term set of directions in which the HPP can move, and to assess the resources needed to do so. Richard D. Brasington, M.D., Washington University School of Medicine, presented information

on an arthritis education and exercise program implemented in the state of Missouri, with state funding and commitment and with local academic and community support. Research activities have been added to the program, which constitutes a laboratory for evaluating community needs and for determining the effectiveness of programs, interventions, and treatment outcomes.

The final hours of the meeting were spent in work group sessions in which all participants had the opportunity to contribute to plans for future HPP programs and activities. The session facilitator, Marcia Carlyn, Ph.D., divided everyone into three working groups, each with a distinct focus and organizing questions to guide the discussions. The groups focused on issues relating to (1) clinical care and clinical research, (2) public health education, and (3) career development. [See appendix B for the conceptual framework used in the work groups. See appendix C for themes from group discussions and summary points from presentations and group discussions.]

The meeting concluded with thanks from the organizers to all of the participants for their thoughtful and insightful participation in the meeting. Plans for next steps include circulation of this summary to all of the HPP meeting participants and community partners, and development of a conceptual plan to guide the next phase of HPP activities. Plans are underway for the NIAMS CHC First Anniversary Celebration to be held in early summer 2002.

**APPENDIX A**

**LIST OF INVITED PARTICIPANTS**

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PROGRESS, OPPORTUNITIES, AND CHALLENGES**  
*February 25-26, 2002*

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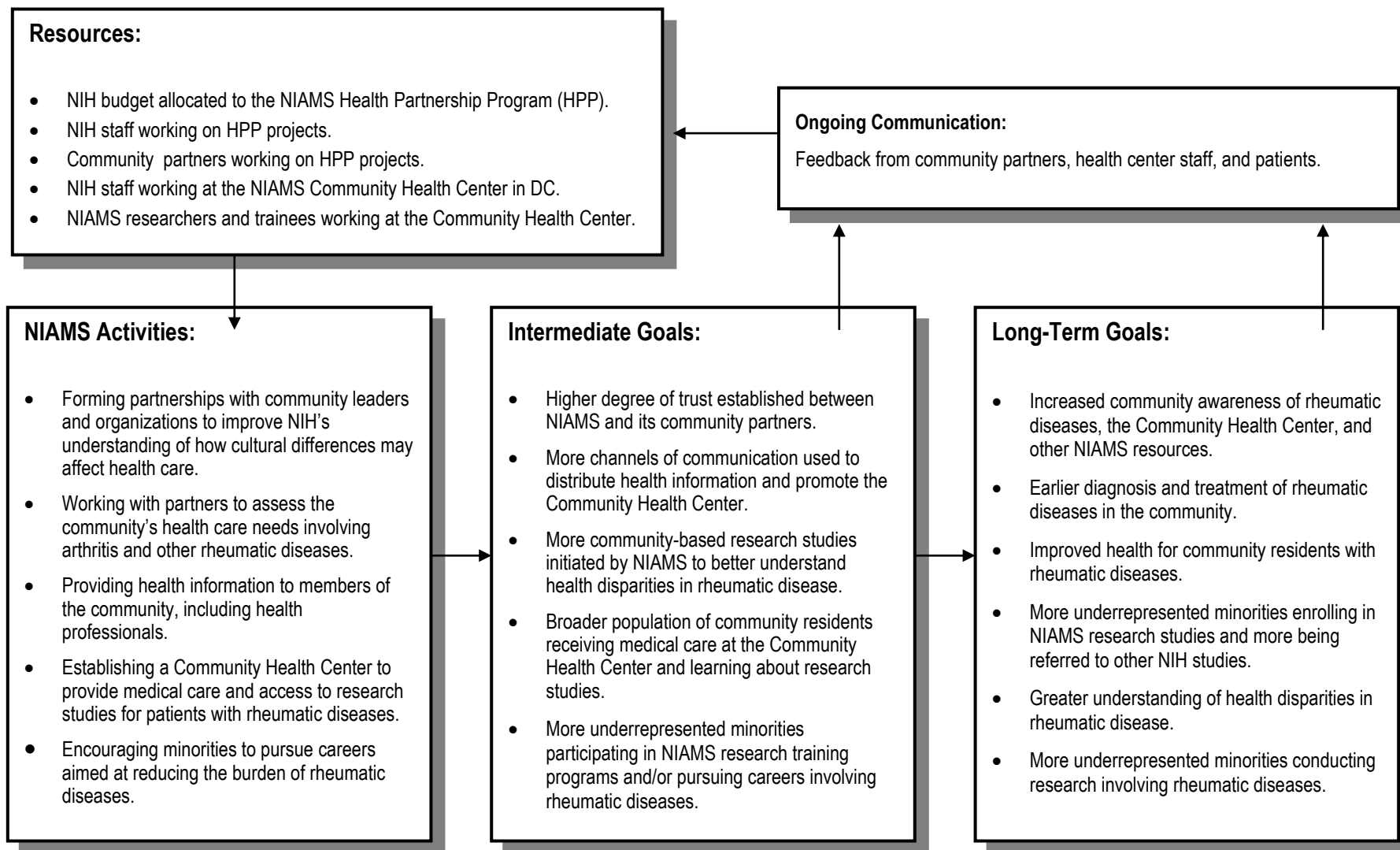
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## **APPENDIX B**

### **CONCEPTUAL FRAMEWORK FOR GROUP DISCUSSIONS**

**NIAMS HEALTH PARTNERSHIP PROGRAM**  
**PROPOSED CONCEPTUAL FRAMEWORK**  
FOR EVALUATING THE  
**MODEL COMMUNITY-BASED PROGRAM IN WASHINGTON, DC**



**APPENDIX C**

**THEMES FROM GROUP DISCUSSIONS**

**AND**

**SUMMARY POINTS FROM PRESENTATIONS AND**  
**GROUP DISCUSSIONS**

# **THEMES FROM GROUP DISCUSSIONS**

**Tuesday, February 26, 2002**

## **1) Overarching themes**

- a. Partnership
  - i. Trust
  - ii. Transparency
  - iii. Mutual respect
  - iv. Increasing the number and range of community partners
- b. Accessibility
  - i. Transportation
  - ii. Translation
  - iii. More sites
  - iv. More services
  - v. More non-weekday and non-daytime accessibility
- c. Representativeness
  - i. More partners
  - ii. More sources of partners
- d. Sustainability
  - i. Training community members to continue the work
  - ii. Enhancing partnerships with local government agencies and other Federal agencies
  - iii. Ensuring continuing commitment and funding

## **2) Clinical Research/Clinical Care**

- a. Community review of research proposals
  - i. Use focus groups to determine community opinions about proposed research topics and approaches
  - ii. Develop a community review board with power to veto a protocol
  - iii. Ensure community representation on NIH Institutional Review Boards (IRB)
  - iv. Establish mechanisms for community-generated research to be conducted through the HPP
- b. Dissemination of research results
  - i. To patients and participants
  - ii. To health care providers
- c. Ethical safeguards in clinical research
  - i. Make full information available to all parties
- d. Full representation in clinical research
  - i. Broad recruitment and outreach
  - ii. More community partners
- e. Communication of clinical care information to community care providers
  - i. Include health care professionals among partners
  - ii. Provide continuing education opportunities to providers

- f. Professional education for community health care providers about clinical research enrollment and collaboration opportunities
  - i. Wide availability of HPP literature and protocol information to health care providers

### **3) Career Recruitment**

- a. Generate training “pipelines” for a wide variety of careers
- b. Outreach and educational activities to students at all levels of age and education
- c. Make minority scientists and health care providers visible in the community as role models
- d. Encourage mentoring of community members by HPP and others
- e. Provide internships and training opportunities
- f. Collaborate with partners, other local and Federal agencies, and educational institutions to optimize contacts and opportunities and ensure the best use of resources

### **4) Public Health Education**

- a. Use wider variety of media for health education materials, given that some people gather information from written sources with difficulty: be aware of literacy level, use of illustrations, formality of language, etc.
- b. Use wider range of locations for making such materials available to the public
- c. Use wider variety of health-related activities
- d. Target populations in their language and with culturally appropriate materials and presentations

### **5) Evaluation Methods and Targets**

- a. Obtain general agreement with the need for intermediate and long-term goals and evaluation
- b. Use a variety of methods to accomplish this
- c. Use validated tools whenever possible, so results can be compared with other communities and programs
- d. Use information available from a wide variety of sources in assessing the impact of the HPP
- e. Assess impact in the NIH, in the community, and in the HPP



## **SUMMARY POINTS FROM PRESENTATIONS AND GROUP DISCUSSIONS**

### **PARTNERSHIP ISSUES**

#### **What has NIAMS already done to increase the level of trust between NIAMS and its community partners?**

- Coming to the inner city frequently to discuss the HPP project with community representatives and organizations.
- Listening to these individuals to better understand the community's health care needs and how they can be addressed.
- Selecting an established facility for the CHC that is trusted by the community and easily accessible (its location at a Metro station is ideal).
- Creating an attractive and comfortable clinic in a limited amount of space.
- Focusing on the two groups that are the most underserved (Hispanics/Latinos and African Americans) and understanding the diversity within each group.
- Initiating contact with organizations that represent these groups and treating them as real partners.
- Assuring that the NIAMS clinical staff involved are caring people who respect the residents of the community and understand their cultures.
- Ensuring that the clinic is run effectively by competent staff.
- Figuring out how to address language and literacy problems (e.g., hiring bilingual staff, using a translation telephone service, minimizing paperwork, asking intake questions orally).
- Providing a free service, recognizing that the uninsured in DC are unable to pay for clinic visits and medications.
- Assuring patients that they will not be asked about their immigration status or social security number.
- Assuring the community that identifying patient information will not be bought, sold, or shared.
- Assuring the community that the HPP is a long term project.

### **How can we tell if the level of trust is increasing?**

- Consider analyzing the level of trust between NIAMS and its community partners using an analog scale.
- Ask CHC patients specific questions that indicate their level of trust (e.g., Would you come back to the clinic if the doctor recommends it? Would you feel comfortable recommending the clinic to a relative?) and track over time the percent of patients who respond favorably.
- Consider more indirect ways to measure trust, including tracking the percent of patients who return to the clinic, the percent who agree to enroll in clinical studies, and the number of requests for speaking engagements.
- Have clinic staff assess trust during telephone calls (e.g., routine followup calls to CHC patients).
- Use “free listing,” an anthropology technique involving free association, to better understand what NIAMS community partners think about NIAMS and the HPP [ref. Dr. Lawren Daltroy, Brigham and Women’s Hospital].
- Hand out postcards at each clinic visit that allow patients to provide feedback anonymously.

### **Should NIAMS form more partnerships?**

There was a strong consensus that the HPP should be expanded to include more partnerships. The following groups were recommended as potential partners:

#### Health-related groups

- Local physicians, including family physicians and rheumatologists who could refer patients to the CHC (especially those practicing in Southeast Washington and East of the River.
- DC Medical Society
- Black Nurses Association
- Visiting Nurses Association
- DC Department of Health
- Other public health organizations
- Clinics associated with Howard University
- Other public health clinics in DC, including those serving the homeless
- Nursing homes
- Meals on Wheels

### Faith-based groups

- Local churches (definitely focus on expanding this group). Ministers could be asked to identify a contact person “who really gets things done” at their church.
- National Council of Churches
- The Downtown Cluster (a group of DC congregations active in the community)
- Parish nurses
- Pastors’ organizations
- The Jewish Council on Aging

### Educational groups

- Schools at all levels (K through 12)
- DC colleges, especially community colleges and Howard University
- Local PTA groups

### Other groups

- National Center on Minority Health and Health Disparities, NIH
- NFL Players Association (which sponsors an arthritis program)
- AARP
- Other local organizations and agencies serving the elderly
- Advisory Neighborhood Committees (ANCs)
- Local housing units (especially low-income units)
- YMCA and YWCA
- Minority sororities and fraternities (e.g., Chi Eta Phi)
- Local soup kitchens
- Deaf community members
- CHC patients themselves (e.g., a patient advisory group could be formed.)

### **How can current partnerships be improved?**

- Categorize community partners by function.
- Prioritize the partnerships if possible.
- Develop a solid relationship with a contact person within each organization.
- Allow partner organizations to get more credit (e.g., use the organizations’ logos on HPP announcements).
- Design and conduct an enhanced needs assessment to understand partners’ current needs.
- Have more frequent partnership meetings with all HPP partners or specific subgroups.
- Increase the use of e-mail and other means of communication, keeping the messages short.
- Use the HPP Web site (or links to other Web sites) to communicate more frequently with partners, including information on ways to encourage earlier diagnosis and treatment for individuals with arthritis and other rheumatic diseases.

- Try to get all of the key opinion leaders in the community involved in the HPP. Ask HPP partners to identify individuals that community residents would go to for advice about health problems, and then ask these individuals the same question. Focus on the leaders who are mentioned more than once [ref. Dr. Oretta Mae Todd, Arthritis Foundation].
- Make sure all of the key stakeholders are involved as early as possible, including those who could obstruct the project.
- Discuss with partners the different evolutionary phases that the HPP may experience (e.g., the pilot, model, prototype, and institutionalized phases mentioned by Dr. Matthew Liang, Harvard Medical School). Try to identify community leaders who enjoy the process, not just better outcomes, since they are more likely to stay involved.

## **PUBLIC HEALTH EDUCATION**

### **In what ways can health information be packaged?**

- Develop a prepared announcement for publication in church newsletters and distribution to different types of community media.
- Ask students (particularly local college students) and other youth groups to develop ads for the HPP.
- Work with other public health clinics and nursing homes to educate patients and staff about rheumatic diseases and the CHC.
- Ask community organizations serving the elderly (Meals on Wheels, local soup kitchens, emergency rooms) to help distribute HPP information, integrating it into their own activities.
- Give partners a list of ways they could integrate HPP information into their groups' activities.
- Distribute brochures and other printed materials (as well as re-order forms) to churches, clinics, community centers sponsoring exercise programs, and other locations recommended by HPP partners.
- Distribute HPP information in nontraditional places, such as laundromats, beauty salons (hair and nail salons), and barber shops.
- Consider using the Arthritis Foundation's six-week course to train community leaders to help educate the community about arthritis; course materials should include information about the CHC as well as a list of local rheumatologists.
- When preparing materials in Spanish or a different language, write them initially in that language rather than translating documents written in English.
- When preparing media messages in Spanish, use "broadcast Spanish" (the standard used for radio and television media).

## **What factors should be considered when using different types of communication and distribution channels?**

- Identify your target audience (the group you want to address) and make sure your timing is appropriate for this audience.
- Pay special attention to the primary language and literacy/reading level of your audience (e.g., use of idioms, percent of nonreaders).
- Definitely use radio as a primary channel, especially during the workday.
- Also use print media and television (if funds permit).
- Carefully consider the gender and accent of the speaker.
- Use billboards.
- Use channels that permit free advertising (e.g., buses, the Metro, public service announcements on the radio).
- Use the CHC waiting room as a distribution channel for health information.
- Get advice from faculty and students enrolled in marketing and graphic design programs at local colleges.
- Use celebrities if possible.

## **In addition to conducting health education activities, how can the HPP promote earlier diagnosis and treatment of rheumatic diseases in the community?**

- Use the CHC to educate health professionals, emphasizing that arthritis is not a minor problem for many patients.
- Review the National Arthritis Action Plan (NAAP) for information on the disease distribution in different populations, communication and education strategies, and information on arthritis programs, policies, and systems [ref. Dr. Leigh Callahan, University of North Carolina].
- Conduct a literature review and sponsor studies on how arthritis and other rheumatic diseases affect people's roles (for example, arthritic women in Boston sought treatment earlier than men because it had a greater impact on their role within the family).
- Encourage college master's degree students to study these issues, as well as doctoral students in social work and nursing.
- Issue Requests for Applications (RFAs) to encourage researchers to develop instruments to measure treatment effects and investigate community-based strategies for encouraging earlier diagnosis and treatment of rheumatic diseases.

## **PATIENT CARE**

### **Do you have any suggestions for improving the Community Health Center?**

- Determine the clinic's capacity in terms of patient load and plan how to handle a large influx of patients in the near future. Be prepared for this situation since all the factors for a successful practice are present: ideal location, low cost to patients, and serving an unmet need.
- Consider alternatives to NIH's standard clinic intake process, which takes a long time to complete.
- Estimate the annual cost of providing the latest medications to uninsured patients and consider developing guidelines to stay within budget.
- For Medicaid patients, determine how their medication costs can be covered by Medicaid.
- Encourage DC rheumatologists in private practice to treat uninsured patients.
- Consider alternatives to shuttling two-thirds of CHC patients to the NIH Clinical Center for x rays.
- Consider using telephone intervention rather than a followup visit with a physician in certain cases [ref. Dr. Kate Lorig, Stanford University].
- Consider conducting "group visits" where patients meet in a group to discuss their problems with a physician and nurse; private patient exams can be done after the group session [ref. Kate Lorig, Stanford University].
- Consider broadening the CHC health care team to include medical and health-related professionals, with a rheumatologist serving as the team leader. This model of care is likely to be more cost-effective [ref. Dr. Matthew Liang, Harvard Medical School].
- Give patients options for providing information to clinic staff. For example, consider allowing patients to take home and mail back questionnaires that need to be completed so they can leave the clinic earlier and have their family help them answer the questionnaire.
- Consider offering a self-efficacy program for arthritis patients (perhaps modeled after Dr. Kate Lorig's generic self-help program). The program could focus on the key information patients need to know to manage their arthritis, using group processes, skills mastery, and action plans to change behavior.
- Review the Health Resources and Services Administration's Health Disparities Collaborative project which is being conducted with the Institute for Healthcare Improvement (IHI); their model involves using teams of clinical and administrative staff to improve patients' self-management skills.
- Be flexible in scheduling patient programs at the CHC (e.g., Saturday morning, Sunday afternoon, and evening programs may be best).
- Learn the key values of different cultures and incorporate them in clinic procedures [ref. Dr. Kate Lorig, Stanford University].
- To improve the clinic, talk as much as possible to patients and HPP partners who understand different cultures and listen to their recommendations.

## ACCESS TO CLINICAL INVESTIGATIONS

### Do you have recommendations for future community-based research studies?

- Encourage both community-initiated and investigator-initiated studies.
- Ask HPP partners and patients what they think should be studied (i.e., what they want to learn more about).
- Design studies that focus on the more prevalent rheumatic diseases (e.g., arthritis rather than lupus).
- Ask HPP partners to play a key role in recruiting patients for HPP research studies, using the CHC to help with the recruitment process.
- Avoid certain language, such as “recruiting subjects for clinical trials,” “experimental drugs,” and “placebos.” For example, use “participant” instead of “human subject.” By being willing to fight IRB battles on the use of these terms, NIAMS will gain the respect of the community.
- Form a patient council or community advisory group (with IRB-like functions) to advise on administrative issues involving the CHC and review new proposals for research studies, including proposed consent forms. This group would not replace the official Institutional Review Board.
- Provide a process for researchers who have advised the HPP to have an opportunity to collaborate on HPP research studies in their areas of expertise.
- Conduct a literature review of research studies on arthritis and other rheumatic diseases, especially community-based studies involving minority populations and the use of complementary/alternative medicine.
- Conduct a needs assessment to better understand how clinical research is perceived by the patient community (e.g., a common fear of being a “guinea pig” ), how their concerns could be addressed, and which recruitment strategies are likely to be most effective (for example, many patients may be motivated by the idea of helping others).
- Seek advice from HPP partners and patients on the best ways to collect patient data, including the type of person who should obtain information from patients. Focus groups may be especially useful in identifying strategies for collecting data on complementary and alternative medicine practices [ref. Dr. Leigh Callahan, University of North Carolina].
- Consider involving an anthropologist to study cultural differences.
- Develop a process that encourages patients to participate in clinical trials but does not pressure them to do so. They need to feel in control of the decision.
- Talk with private-practice rheumatologists who have enrolled minority patients in clinical trials and ask them to share their experiences [ref. Dr. Nigel Harris, Morehouse School of Medicine].
- Develop informed consent documents that can be clearly understood by the patient population and be concrete in explaining to patients how their confidentiality will be maintained. For example, consider using sidebars to highlight key points in the consent form [ref. Dr. Lawren Daltroy, Brigham and Women’s Hospital and Dr. Kate Lorig, Stanford University].

- Ask patients and HPP partners to review draft consent forms and explain what they think each paragraph means. Tape-record these sessions and use them to improve consent forms.
- Consider conducting feasibility studies to see if proposed interventions are actually possible with the CHC population and the small clinic setting.
- Reassess all CHC patients at standard intervals (e.g., at 6 months, 1 year, and 2 years after their initial visit or intervention). Be sure to get adequate information on how to contact them in the future.
- Whenever possible, encourage researchers to use instruments that have been shown to be reliable and valid with similar populations. For example, consider using Dr. Kate Lorig's instrument (which includes self-efficacy scales) or the Health Assessment Questionnaire (HAQ). Dr. Richard Maisiak, University of Alabama, has found that the HAQ may need to be modified for certain populations.
- Consider using incentives to encourage enrollment and/or questionnaire completion (e.g., paying patients \$15-20 after completing a pretest, after completing a posttest, and 6 months later).

## **RECRUITMENT TO RESEARCH CAREERS**

### **In what ways can minorities be encouraged to pursue careers involving rheumatic diseases?**

- Develop an HPP "pipeline" program with different career tracks to encourage minorities at all levels of education to pursue health-related and research-related careers.
- Include a variety of careers, such as allied health professionals (physical therapists, dietitians), as well as physicians, nurses, and biostatisticians.
- Increase the visibility of minority scientists and health professions in the community (e.g., through radio shows aimed at minority communities, minority colleges, churches, social organizations).
- Consider using the slogans: "Look in the mirror. That's what a scientist looks like" and "There's a job for everyone in medical research."
- Promote the idea that scientists are "cool" (e.g., develop and distribute a poster with a rheumatologist researcher investigating an athlete's knee).
- In promoting scientific careers, try to communicate the passion and self-confidence of successful researchers.
- Talk to directors of rheumatology fellowship programs about how they got into the field and ask them to encourage minorities in internal medicine residencies to become rheumatologists.
- Invite minority medical students to the CHC and give them opportunities to work on rheumatology projects involving patients and the community.
- Identify "best practices" for recruiting minorities to health careers and fostering career development (e.g., contact Dr. Moses Williams at Temple University to learn about his longitudinal "distance learning" study in Philadelphia, which provides students at different



stages of the pipeline with mentoring, lab work, and clinical contact). Also assess the outcomes of different recruitment strategies.

- Conduct a literature review to determine trends in the number of minorities pursuing research careers and the number who become rheumatologists, identifying major barriers and incentives.
- Use NIAMS curriculum supplements to spark interest among K-12 students in careers involving rheumatic diseases.
- Develop summer research programs for high school students.
- Distribute to local schools some of the videos produced by the NIH Office of Science Education, such as “Women in Science” video.
- Promote the Web-based live chat sessions sponsored by the NIH Office of Science Education in which students can ask researchers questions about pursuing careers involving rheumatic diseases.
- Arrange for NIH scientists to visit the CHC.
- Recruit individuals to be mentors and role models for students at different stages of the pipeline, working with HPP partners; NIAMS fellows working at the CHC could serve as mentors, but there should be funding provided for mentoring.
- Ask local high schools, colleges, and the community to identify students at all levels who might be interested in participating in research projects at the CHC. Use these projects and mentors at the CHC to get the students “hooked” on research.
- Allow high school students to do voluntary community service projects at the CHC, getting the DC Department of Health involved if possible.
- Work with the National Area Health Education Center (AHEC) and its network of local AHECs and Health Education Training Centers (HETCs), which are community-based programs working with community and academic partners to address the health workforce needs and disease prevention information needs of medically underserved communities.
- Keep track of the number of students who have been contacted and who have been successfully recruited into health-related and research-related careers.

## **STRATEGIC PLANNING AND EVALUATION**

**Should any items in the Conceptual Framework be revised [See Conceptual Framework in appendix B]?**

- Consider dropping Intermediate Goal #1 (Higher degree of trust established between NIAMS and its community partners) because it is too hard to measure trust directly.
- Consider adding the long-term goal: Improved attitude of NIH scientists toward community-based research.
- Consider adding the long-term goal: More patients attending the Community Health Center (Note: This goal is similar to Intermediate Goal #4)
- Consider developing a more user-friendly conceptual framework and changing its name. The current approach seems too academic.

**How can we measure our progress toward achieving increased community awareness of rheumatic diseases, the CHC, and other NIAMS resources (Long-Term Goal #1 of the Conceptual Framework)?**

- Use telephone and personal interviews, polling non-CHC patients at the Upper Cardoza Health Center, patients and staff at other clinics, and community residents being served in beauty salons, barber shops, etc.

**How can we measure our progress toward achieving earlier diagnosis and treatment of rheumatic diseases in the community (Long-Term Goal #2 of the Conceptual Framework)?**

- To assess NIH's impact on health disparities, collect patient information on system-based factors (e.g., insurance status, other measures of access to care) as well as biologically based factors.
- Review *Healthy People 2010* statistics on arthritis in order to improve understanding of current health disparities and ensure that the same data are collected on CHC patients so that CHC statistics can be compared to national averages.
- Stay in contact with the National Center for Health Statistics (NCHS) to know which Behavior Risk Factor Surveillance Survey (BRFSS) questions (and other questions) on arthritis and other rheumatic conditions are being considered for national NCHS surveys.
- Compare CHC patients with other patients in the U.S. who have answered the same BRFSS questions [ref. Dr. Leigh Callahan, University of North Carolina].
- Ask CHC patients how long they have had arthritis and track the data through time to see if patients are presenting earlier in the course of their disease.
- Compare the average time-to-initial-treatment for CHC patients with averages reported in the literature for similar types of patients.
- Consider comparing CHC patients with similar patients at other DC clinics, at least in terms of demographics.
- Compare the self-rated behavior of CHC patients attending a self-efficacy program with a control group, such as patients on the waiting list [ref. Dr. Kate Lorig, Stanford University].
- In identifying comparison groups, consider the advantages and disadvantages of using historical standards, theoretical standards, and normative standards [ref. Dr. Lawren Daltroy, Brigham and Women's Hospital].