# Rheumatic Disease Patients, Community Leaders, and Health Behavior Researchers: Partners in Research

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## COMMUNITY POLICY BRIEF

### What is the Purpose of This Study?

- The purpose of this study was to engage researchers, community leaders from a health partnership program, and predominantly Hispanic and African-American patients in purposeful dialogues focused on conducting health behavior research in an urban rheumatic disease clinic.

### What Is the Problem?

- Rheumatic diseases like arthritis are among the most common health problems in the United States, yet there are significant differences in the number of individuals with these diseases and their health outcomes based on race and ethnicity.

- Increasingly, attention is being focused on the identification of potentially modifiable environmental and social/behavioral factors behind racial and ethnic disparities in disease manifestations and outcome. Among these factors, health literacy, patient–provider trust, and shared decision making have become increasingly important variables to consider, particularly when it comes to disparities in the provision of care and in patient outcomes.

- Despite these differences, research is often not designed nor implemented in a manner that is easily translated into treatments and outcomes that benefit the individuals and communities that need it most.

### What Are the Findings?

- Focused discussions yielded five major themes by community members: trust, patient–provider relationship, study implementation suggestions, issues surrounding decreased functional capacity and access to care.

- Nine themes were generated by the patients: Trust, patient–provider relationship, study implementation suggestions, decreased functional capacity, access to healthcare, physical pain, emotional distress/depression, knowledge of disease, and complementary and alternative medicine use.

- One of the most important lessons learned during this process of community engagement through collaborations with community leaders and patients was that of community-research "fit."

- After reading the text and quotations in this paper, one cannot help but notice that both community leaders and patients expressed their views of research within the context of their health status and their access to healthcare.

- For this community, like many others who have experienced disparate health outcomes, particularly when it comes to the burdens of chronic disease, engaging in research must have more immediate applicability and translation into improved individual and community outcomes for it to be embraced as a true partnership.

- By meeting informally at "town hall"–type gatherings for updates followed by a more formal focus group process we were able to anticipate potential barriers and facilitators for the design and implementation of the third phase of our study.

- When specific elements of the study did not seem to "fit," our research team needed to be open to changing our approach.

- These changes toward a better fit ranged from how we structured the planned focus groups (the community members suggested that we include them in the first and last groups rather than including only patients) to what types of incentives would be appreciated by the research participants (they suggested jar openers and pens designed especially for individuals with functional disabilities).

- Including patients in the research partnership from the design phase of the study was instrumental to our success.

- Whereas the community leaders helped to guide our research implementation process with suggestions from how to approach the clinic patients to best methods for collecting data, the patients also offered us a "window" into their lives as individuals with a chronic illness and what was important to them such as having access to specialty care and understanding how to navigate complex health systems.

- Community leaders and patients were able to further partner with us in the design of the study by recommending the preferred format (face-to-face vs. paper-and-pencil or web-based surveys).

- Invaluable suggestions regarding the length and complexity of the questionnaires, particularly the inventory for complementary and alternative medicine practices, were incorporated in an effort to reduce respondent burden.

- In terms of implementation strategies, patient participants reminded the research team of the importance of being aware of patients' level of discomfort during the interview process based on their own pain and symptom experiences, which would make sitting for longer than a half hour nearly impossible without additional pain and stiffness.

- Interestingly the community leaders, particularly the African-American leaders, voiced more concerns about issues of trust and research participation than the patients did.

- Patients' readiness to provide suggestions and guidance for improving trust in research seemed to imply the fact that in this context research was recognized as having potential to improve health in their community.

- These underlying beliefs informed the community leaders' willingness to contribute to the success and value of the proposed research study.

- In addition to their strong belief that researchers need to be consistently engaged and visible in the community, our community and patient partners raised the importance of researcher and subject concordance in the context of building trust.

### Who Should Care Most?

- Conducting research that is relevant and applicable to the community members serving in these studies is important to individuals, families, and the community at large.

- Engaging community partners in informal and formal discussions from the early phases of research design through implementation, followed by systematic application of these insights, may serve to accelerate the potential for translation from findings into improved clinical practice and ultimately optimal patient and community outcomes.

### Recommendations for Action

- Clinical research partnerships between communities, providers and patients are fragile and require vigilance and ongoing communication as well as transparency.

- From the earliest stages, the research team must be willing to engage the community in a collaborative research design and work toward a community research "fit."