The Johnston County Osteoarthritis Project:
An Illustration of a Community-University Partnership for Population-Based Research

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Community-based participatory research has been defined as "an approach to health and environmental research meant to increase the values of studies for both researchers and the community being studied."[1] This cooperative approach to research continues to gain recognition and popularity and has particular potential for the future of epidemiological studies.[2] Investigators from the University of North Carolina at Chapel Hill (UNC) and residents in Johnston County, North Carolina have worked together in and benefited from community-focused research for over 23 years. This partnership was an early adopter of the community-based approach to research through formation of the Rural Health Research collaboration, just the beginning of many "firsts" for this partnership.

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History of Rural Health Research

Rural Health Research is a community-based, university-affiliated research center in Johnston County, a mostly rural county in eastern North Carolina. Preliminary work in the community by UNC investigators began in the late 1970s. A multidisciplinary group of researchers came together with Johnston County residents to develop an ongoing research presence in the county. The participants included the directors of the Thurston Arthritis Research Center, the Center for Health Promotion and Disease Prevention, the Injury Prevention Research Center, and the Cecil G. Sheps Center for Health Services Research. The office of the Vice Chancellor for Health Affairs also provided vitally important input and support. Local

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advisers and participants have included lay and professional community leaders, state and national government officials, county managers, education superintendents, hospital and county health department personnel, and nonprofessional constituents with an interest in health issues.

A critical next step toward the establishment of this endeavor as a local entity came with an award from the Centers for Disease Control and Prevention to the UNC Health Promotion and Disease Prevention Center in 1987. This enabled Rural Health Research to incorporate and open a local research field office in Johnston County, directed and staffed by Johnston County residents. In order to determine the interests of the people in the county, 65 focus groups were held throughout the county with broad representation by race, gender, and age (ranging from 45 to 54 years, 55 to 64 years, and 65 years and older). The medical community was involved and kept informed through a local medical liaison, and awareness of Rural Health Research and its goals was increased through presentations given by the researchers to the county medical society in a meeting held at Johnston Memorial Hospital.

Over the years community-based research has flourished in Johnston County. Rural Health Research benefits from dedicated local volunteers who bring vitality and support to the studies. Local participants are involved in helping to map and enumerate streets for statistical sampling, assisting with project management duties both in and out of the Johnston County office, and serving as key study ambassadors to the county and other local organizations. In 2002 an adjoining research clinic was opened, including a fully-functional radiology suite, a bone density/body composition suite, facilities for phlebotomy and frozen storage of specimens, and multiple examination rooms.

Currently, the local staff includes 9 full-time employees, all Johnston County residents, including the director, administrative assistant, interviewers, data collectors, radiology technologist, and phlebotomist, and a cadre of fully-trained part-time and intermittent employees available for substudies and other tasks as necessary.

Over the years, Rural Health Research has been the site of studies in injury prevention, health care access and utilization, cardiovascular disease, nutrition, and dizziness and physical activity in frail elders. Arthritis and disability have been the primary focus of Rural Health Research since 1990, with over 25 studies conducted. (See Figure 1.) The first of these began in 1985 with an award from the National Institute of Arthritis and Musculoskeletal and Skin Diseases to the Thurston Arthritis Research Center to evaluate the reliability and validity of selected arthritis psychosocial measures used to assess arthritis beliefs, self-care practices, use of health services, and psychosocial health status of lower-income African American and white residents. This study provided the foundation for all subsequent research carried out in Johnston County.

A prospective cohort of osteoarthritis of the knee and hip in Johnston County, known as the Johnston County Osteoarthritis Project, has received continuous funding by the Centers for Disease Control and Prevention since 1990 (recently renewed through 2010) and by the National Institutes of Health since 1993. This study has facilitated the development of additional projects funded by multiple federal agencies, foundations, private philanthropic sources, and industry groups. (See Figure1.) The scope of these studies ranges from the biomedical (eg, development and validation of serum and urine biomarkers of joint metabolism, proteomics, metabolomics, and, most recently, genome-wide association studies) to the psychosocial (eg, the role of psychiatric comorbidity in the pain and disability of arthritis, individual and community social determinants of arthritis outcome, and spirituality). The Johnston County Osteoarthritis Project has been a part of research studies with investigators throughout the nation and the world. Collaboration has served not only to advance science but also to support the continued work of Rural Health Research which would be impossible without the financial backing of numerous investigations.

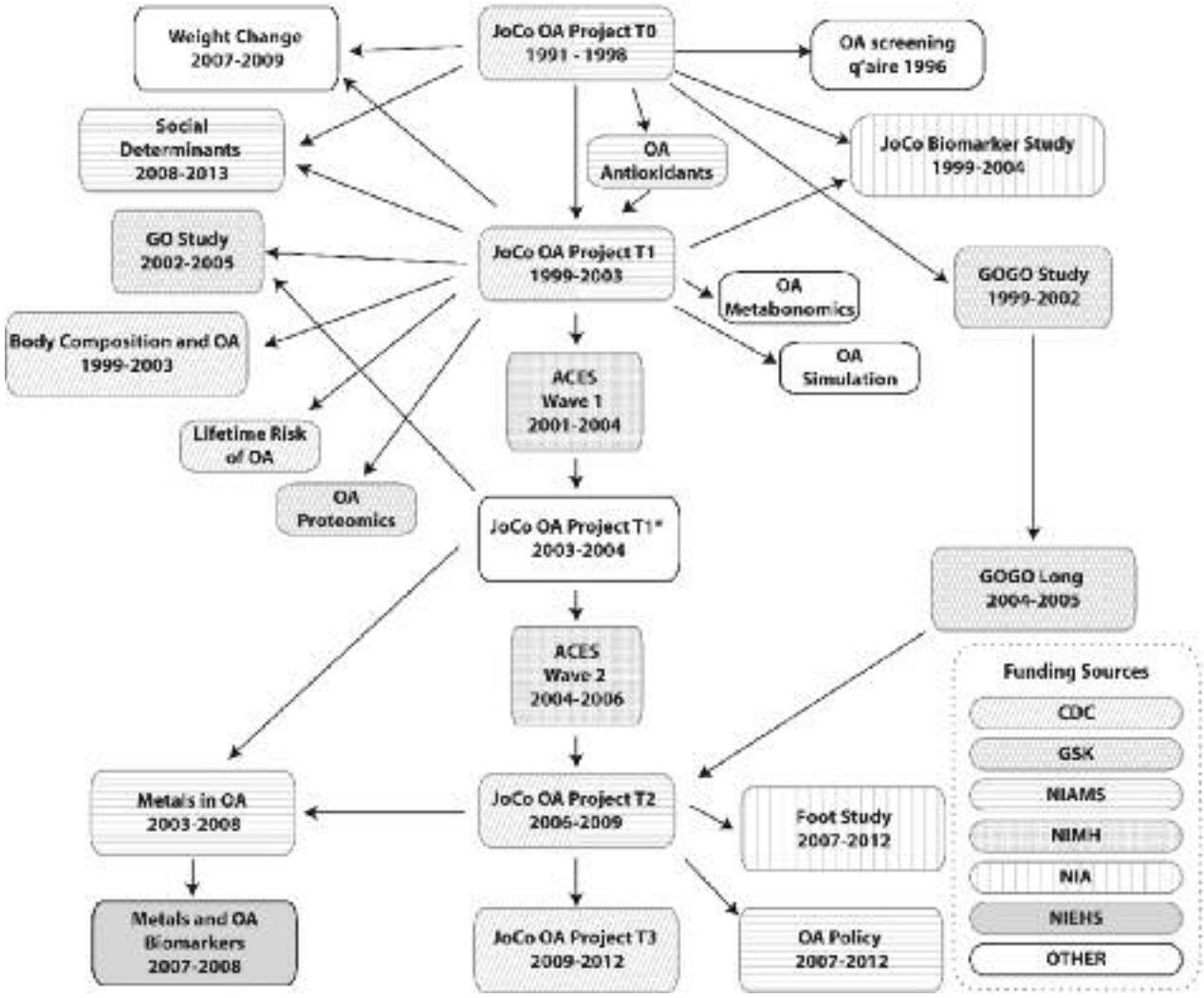
The Johnston County Osteoarthritis Project has contributed other notable "firsts." It was the first longitudinal study of osteoarthritis to include African Americans and it remains the only such study in a rural setting. The study revealed early on that osteoarthritis and its resultant disability were more common than expected.[3-6] Pursuing an explanation for this observation led to the examination of data on overweight and obesity in the study group.[7,8] The Johnston County Osteoarthritis Project also revealed that African Americans were not spared from hip osteoarthritis as had generally been thought.[9,10]

With this history of pioneering into new areas, this study is the largest biracial population-based study to describe associations between radiographic osteoarthritis and osteoarthritis biomarkers and blood and urine markers of the osteoarthritis disease process. It also is the first to recognize that values of these markers, and factors associated with them, varied by gender and racial groups.[11-14] Recognizing that the experience of osteoarthritis has significant psychosocial consequences, the Johnston County Osteoarthritis Project partnered with the Arthritis, Coping and Emotions study to generate one of the largest psychosocial databases for an osteoarthritis cohort of African Americans and Caucasians in the world.[15,16]

Research into the role common environmental exposures play in osteoarthritis over a lifetime produced preliminary results showing that higher blood lead levels are associated with more severe osteoarthritis,[17] and low selenium levels are also associated with osteoarthritis presence and severity.[18,19] The examination of selenium and osteoarthritis was suggested by studies of Kashin-Beck Disease, an endemic osteoarthropathy in China associated with low selenium levels in the soil among other things.[20] The Johnston County analysis was the first large epidemiologic investigation into this relationship in a Western population. These observations have given birth to a new interdisciplinary field of "environmental rheumatology" currently being developed at the Thurston Arthritis Research Center at UNC.

Today, the community connection for the Johnston County Osteoarthritis Project and Rural Health Research remains alive and strong. As one county staff person said, "What impressed me the most about this study was that it came to the community. It

Figure 1.
The Johnston County Osteoarthritis Project and Related Studies



Legend:

JoCo OA Project = Johnston County Osteoarthritis Project
OA screening q'aire = Osteoarthritis screening questionnaire
GO Study = Genetics of Osteoarthritis Study
ACES = Arthritis, Coping, and Emotions Study
GOGO = Genetics of Generalized Osteoarthritis Study
GOGO Long = Genetics of Generalized Osteoarthritis Study, Longitudinal Follow-up
CDC = Centers for Disease Control and Prevention
GSK = GlaxoSmithKline
NIAMS = National Institute of Arthritis, Musculoskeletal, and Skin Diseases
NIMH = National Institute of Mental Health
NIA = National Institute on Aging
NIEHS = National Institute of Environmental Health Science

was more accessible to people who would not have had such an opportunity if they were required to travel. As an interviewer I see how participants begin to think about their arthritis perhaps in new ways as they have the chance to talk about their experiences with us. I think it has to make a positive difference for these people in our community." As the concept of community-based research has evolved to embrace more of the social impact of disease and public health, the Johnston County Osteoarthritis Project has collaborated with other researchers interested in the individual and community social determinants of health and disease.

Giving Back to the Community

In order to foster and maintain long-standing grassroots support for the work of Rural Health Research, it is critical for residents to feel that Rural Health Research is serving the interests and needs of the county. In keeping with this, it has been our long-standing philosophy and policy to give back to the community. This takes many forms. For example, all local employees receive considerable and continuing education in methods of field research, and full-time employees become permanent employees of UNC with its attendant benefits. As

much as is possible, we utilize and support local businesses for the work of the center. In addition, the Thurston Arthritis Research Center publishes an annual newsletter in Johnston County (*Johnston County Osteoarthritis Project Update*), and UNC and local colleagues give talks to local groups (eg, Smithfield Veterans of Foreign Wars, Kiwanis, Rotary, Lions Club, Civitan, Johnston Memorial Hospital) to keep the 2-way flow of information active. Project participants receive regular study updates and are invited to open houses in which they have an opportunity to meet with research staff and UNC faculty to learn about arthritis and the progress of the many studies ongoing in the center.

Rural Health Research is a member of the Chamber of Commerce, the Human Services Council, and other local groups. Each year for the past 20 years, the Rural Health Research director has attended the Chamber of Commerce Washington Issues Seminar in Washington, DC. This meeting is sponsored by North Carolina's US senators and representatives and is attended by state representatives, mayors, town managers, other Chambers of Commerce members throughout the state, national representatives and senators, and other national government officials. It is a highly effective forum for bringing local issues to the attention of elected officials in Congress. We have been able to increase awareness of arthritis and disability issues, inform officials about research studies underway in the county, and advance the mission of Rural Health Research as well as the community-based research role of UNC among these representatives and other government officials. **NCMJ**

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