

ARCC Round 5 Seed Grant Project Summaries

Partnership Building Grant

Building a Community-Academic Partnership to Identify and Eliminate Barriers to HPV Vaccination in African Americans

Tonya Roberson, Sisters Working It Out, and Rebecca Wurtz, Preventive Medicine, Feinberg School of Medicine

The human papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the U.S. and is associated with the vast majority of cases of cervical cancer. Black women have higher incidence rates and mortality rates from cervical cancer than any racial/ethnic group in the U.S., which may be partially due to lower HPV vaccination rates among this population. Although the HPV vaccine can prevent most cases of cervical cancer, many barriers and disincentives have been identified, including cost, the need for multiple injections, lack of a government mandate, and the beliefs and behavior of adolescent recipients, their parents, and healthcare providers.

Sisters Working It Out (SWIO) and Dr. Rebecca Wurtz from Northwestern University's Department of Preventive Medicine, propose developing a community-academic partnership that will work to build a coalition of stakeholders in adolescent African-American health to identify and eliminate barriers to HPV immunization. We anticipate gathering 11 organizations.

The goals of the coalition will be defined by the coalition, but as conveners, we anticipate that goals will include:

1. Educating each other about HPV, HPV-induced cancer, and the HPV vaccine.
2. Exploring members' experiences of barriers to HPV immunization.
3. Brainstorming about community-based research projects that would test novel ways to overcome barriers to immunization and result in the immunization of adolescents.
4. Working together to develop meaningful research proposals to submit for funding to national level funders.

CBPR Implementation Grants

Increasing Clinician Understanding Regarding the Needs of Children with Life-Limiting Illnesses and Their Families

Kimberly Downing, Greater Illinois Pediatric Palliative Care Coalition, and Kelly Michelson, Pediatrics, Feinberg School of Medicine

Community-based pediatric palliative care provides comprehensive, interdisciplinary age-appropriate medical, psychosocial, spiritual, and social support for children with life-limiting illnesses and their families. Palliative support has emerged within the past 20 years as a crucial partner to curative therapies for children with chronic/complex and life-limiting illnesses. Despite tremendous advancement in palliative services over the past decade, studies indicate that a significant gap continues to exist between the support families caring for children with life-limiting illnesses need and the services they receive. The challenge of identifying family needs is exacerbated by the absence of any practice-derived, theory based, empirically validated tool to assist pediatric palliative care teams with identifying

family needs. Such a tool would help community-based families communicate needs to multidisciplinary palliative teams who could then individually tailor care and resources, thus closing the gap between needs and services received. The Greater Illinois Pediatric Palliative Care Coalition (GIPPCC), in partnership with Dr. Kelly Michelson from Lurie Children's Hospital, seeks to utilize the community-based participatory research process to engage families caring for children with life-limiting illnesses, community-based interdisciplinary care providers, and research experts in the use and refinement of a comprehensive pediatric palliative care needs assessment tool. Specifically, we will 1) expand a previously developed academic-community partnership into a research capable relationship; 2) pilot test a collaboratively developed palliative care needs assessment tool in the community to obtain initial reliability and validity data; and 3) refine the tool for larger scale evaluation. We will then disseminate the results to research participants and the pediatric palliative care community; and plan for larger scale testing of the palliative needs assessment tool. Through this process, we will empower community-based families of children with life-limiting illnesses and palliative care teams to impact and improve patient and family care.

Improving Asthma Verification and Medication Access in the Chicago Public Schools

Lilliana DeSantiago-Cardenas, Chicago Public Schools, and Ruchi Gupta, Pediatrics, Feinberg School of Medicine

Our proposed project seeks to leverage the combined resources, expertise and longstanding research partnership between Northwestern University's Institute for Health Care Studies and the Chicago Public Schools (CPS) Office of Physical Health in collaboration with the Office of Special Education and Supports. This project will determine the prevalence and variability of asthma among Chicago public schoolchildren and assess barriers to adherence to new asthma management policies (including disease verification and medication, asthma action plan and 504 plan access) approved by CPS in January 2012. Additionally, we will solicit feedback from parents, CPS staff and a variety of asthma stakeholders on how to improve asthma verification, management and medication access for children with asthma in the nation's third largest school district.

To guide and support us in our efforts and to ensure the data we gather is relevant and that our policy recommendations reflect local concerns, we will create a community advisory board. In order to determine asthma prevalence and variability in CPS we will gather district-wide data through our partnership with the CPS OPH, which has access to student health data across Chicago. To better understand barriers to disease verification, management and medication access, we will gather school-specific data from three partner schools. After listening to the perspectives of parents and CPS staff through focus groups and cognitive interviews in the three schools, we will develop and launch a comprehensive survey to parents/caregivers of asthmatic students assessing knowledge and behaviors regarding current asthma management policies. The results of these surveys will help us identify areas of difficulty for parent/caregiver compliance with CPS' asthma verification and management policies as well as help us develop recommendations for interventions to improve asthma management across the district.

KARE- Korean American Alzheimer's Research and Education

Hyeyoung Lee, Korean American Community Services, and Darby Morhardt, Cognitive Neurology & Alzheimer's Disease Center, Feinberg School of Medicine

Studies show that the way ethnic minorities view dementia frequently diverges from the Western biomedical perspective, and misconceptions and a lack of knowledge can be barriers to early detection, timely intervention, and benefits of available treatments. Currently the fourth largest Asian American subpopulation and one of the largest growing immigrant population in the U.S., Korean Americans have a sizeable presence in the greater Chicago area, and the local aging population is projected to grow significantly, which also implies a significant number of Korean American families affected by Alzheimer's disease (AD).

Thus, after spending a year building a partnership based on CBPR principles, Korean American Community Services (KACS) and the Cognitive Neurology and Alzheimer's Disease Center (CNADC) of Northwestern University's Feinberg School of Medicine propose to implement a research project exploring the knowledge, perceptions, and awareness of AD- and AD-related services among Korean Americans. After conducting focus groups and individual interviews of stakeholders (Korean American Older adults, family caregivers of persons with cognitive impairment, and community personnel working with cognitively impaired adults), KACS and the CNADC aim to: 1) assess the needs, concerns, beliefs and attitudes of older adults, families, and community agency and medical/nursing personnel regarding dementia of help-seeking in the Chicago Korean community, and 2) develop a model for a community based intervention for cognitively impaired Korean Americans and their families, taking into consideration identified cultural perspectives. The results will be shared in the community, and the partnership will submit a written report to various scholarly journals, so that both our research process and intervention can be replicated in other areas of the country.