Monitoring Disparities in Chronic Conditions

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CORT aims to increase community participation in all stages of research, foster research relevant to community needs, form and facilitate research network capabilities, and promote uptake of useful research findings in diverse health care settings. This quarterly newsletter is intended to serve communities in Washington, Wyoming, Alaska, Montana, and Idaho (WWAMI). The ITHS is supported by grants UL1 RR025014 from the NIH National Center for Research Resources.

Monitoring Disparities in Chronic Conditions

The WWAMI region Practice and Research Network (WPRN) has over 20 member practices across Washington, Wyoming, Alaska, Montana, and Idaho. On February 29th, 2012, the WPRN held its first annual meeting as an official network. Over thirty colleagues attended, representing WPRN member practices, ITHS collaborators, and regional partners. Dr. Wilson Pace of the University of Colorado delivered a keynote address about “Putting Practices into Research: Mixing Practices, Patients and Protocols.” Major topics of focus during the day were current and future WPRN projects, including opportunities for practice and quality improvement, and connecting electronic medical record data for research. Much of this latter discussion centered upon the LC Data QUEST collaboration with the ITHS Biomedical Informatics core and regional and national opportunities arising as a result of this effort. We also took the opportunity to recognize our member practices, research champions, and colleagues who played an integral role in the development of the WPRN, and wrapped up the day with reflection on future projects and direction, with input from Dr. Pace. We look forward to the WPRN’s upcoming work and to convening again next year! If you have questions or want to learn more about the WPRN, please contact Gina Keppel (gakeppel@uw.edu).
Partner Profile

Dr. David T. Takeuchi is a Professor in the University of Washington’s School of Social Work and Department of Sociology and serves as Associate Dean for Research in the School of Social Work. His research has focused on the social determinants of health with an emphasis on health disparities among racial and ethnic minorities and in particular persons of Asian and Pacific Islander heritage and Latinos. Dr. Takeuchi is leading efforts with CORT to identify research opportunities for faculty in the School of Social Work and other upper campus departments in the Evans School Public Affairs and the College of Arts and Sciences with investigators at the Group Health Research Institute. Working with Dr. Takeuchi, we will identify collaborative opportunities that bring together the diverse skills and knowledge of social and policy scientists, legal scholars, demographers, health services researchers and economists, epidemiologists and clinical investigators to address critical needs in public and social health.

Tools for Research
Enhancing the ITHS Research Toolkit

The Partnership-driven Resources to Improve and Enhance Research project web site, www.researchtoolkit.org, is a resource for health research in partnership with practices and communities. The Toolkit enhancement project and evaluation is funded through an ITHS Administrative Supplement and is underway. The enhancement team is assessing how to expand the resources for inclusion or adaptation. They are also developing novel ways to disseminate the Toolkit and its resources, and developing a sustainability plan to ensure that the Toolkit is an enduring resource for the research community.

The tools are indexed by:
- Building collaborations
- Developing proposals
- Starting a study
- Conducting and managing projects
- Disseminating research
- Resources for training
Dr. Leo Morales of the Group Health Research Institute and ITHS CORT is collaborating with the Institute for Health Metrics and Evaluation (IHME) at the University of Washington in a study that looks to better define and monitor health disparities experienced by people suffering from chronic disease in King County, in Washington. The primary aim of the Monitoring Disparities in Chronic Conditions (MDCC) Study is to design and test a population-based surveillance system that integrates multiple data sources to track disparities in chronic diseases at the local level. This system will capture information, from socioeconomic and health risk factors to disease incidence and the consequent cascade of hospitalizations, outpatient visits, and use of and adherence to interventions. This project is a pilot for a much larger, nationally relevant system. It is important to pilot this approach in a relatively data-rich environment with a heterogeneous population. The project focuses on three racial and ethnic groups for which there are demonstrated disparities in health outcomes nationally: white non-Hispanics, Hispanics, and black non-Hispanics. The study is intended to resolve a series of outstanding technical measurement issues, develop operational protocols, and produce results relevant to health policy formulation. Group Health members over 50 years of age with cerebral vascular disease, cardiovascular disease, congestive heart failure, atrial fibrillation, asthma, COPD, diabetes mellitus, and chronic renal failure will be approached for study participation. Approximately equal numbers of non-Hispanic white, non-Hispanic black and Hispanics from the Group Health population will be recruited for the study. This study is supported by the National Heart, Lung and Blood Institute which is part of NIH.
New Research and Collaborations
Understanding the Cancer Experience from Alaska Native Cancer Survivors

The Fairbanks Native Association (FNA) and The University of Alaska Fairbanks’ Center for Alaska Native Health Research (CANHR) have forged a partnership dedicated to improving quality of life. With funding from ITHS, the FNA-CANHR collaborative conducted the ‘Understanding the Cancer Experience from the Perspective of Alaska Native Cancer Survivors’ interview project. Findings revealed that participants experience cancer as a journey; a journey replete with consequences both negative and positive. A most positive effect of cancer is participants’ ambition to use their new “survivor” expertise to help others. For many, this type of support was desired, but was rarely available to them, as one breast cancer survivor explained: “Somebody. I wanted to talk to somebody who was going through what I was going through.” When asked about support resources available to them, participants indicated that they knew of no local support groups for Alaska Native people. Informed by these findings, and with funding from an ITHS/Native People for Cancer Control Community Grant, the FNA-CANHR partnership is pilot testing and evaluating an Alaska Native Cancer Support Group which directly responds to the strengths and needs identified by Alaska Native survivors, themselves. The aims of the support group project are to: 1) Provide the opportunity for Alaska Native cancer survivors to come together to give and receive knowledge, support, and develop “hopeful connections”; 2) Enhanced survivors’ trust in research by demonstrating the respectful collaborative research conducted within the FNA-CANHR partnership; and 3) Raise community awareness about the strengths and challenges of survivorship.

“I mean it’s frightening. I’ve never had to search my soul to try and understand something that’s so deep, you know, personal”
- Alaska Native Cancer Survivor

Photo (above): A support group meeting.
Photo (left): The building in which support groups are held.