



Summaries of UW ICTR Funded Patient-Centered Outcomes Research Awards, 2014

1. PI: Barbara Bowers, PhD, RN, UW SON

Title: *Can Community Advisors Improve Recruitment of Underrepresented People?*

Academic Collaborators: Roger Brown, Nora Jacobson, UW SON

Community Collaborators: Goodman Community Center; Lussier Community Education Center; Community Advisors on Research Design and Strategy members

Summary

Some populations benefit from biomedical research much more than others—and research findings are most likely to help people who are similar to those who participate in research studies. Equitable access to research participation is fundamental to the goal of promoting research that can be used to benefit everyone, ultimately reducing health disparities; however, researchers have been generally unsuccessful in convincing people from underrepresented communities to participate in research studies. Several factors are known to discourage people from underrepresented groups from participating in research: materials that are difficult to understand, recruiting strategies that discourage or don't reach underrepresented groups, and lack of trust in researchers and health care providers. Researchers have tried to address these problems by including community stakeholders in planning or designing their research; however, these “stakeholders” are often chosen because they are community opinion leaders, people in positions of authority who may not adequately represent people living and working in the community—particularly low-income, ethnically diverse communities. This study will test how people from ethnically and economically diverse groups respond to research materials that are evaluated and revised by a community-based focus group comprised of individuals who are traditionally left out of the research process.

2. PI: Nancy Pandhi, MD, PhD, MPH, UW SMPH

Title: *Engaging Stakeholders and Developing Partners in Mental Health and Primary Care Integration Research*

Academic Collaborators: Sarah Davis, UW SOP and UW Law School; Nora Jacobson, UW SON

Community Collaborators: United Way of Dane County; WORT Community Radio; National Alliance on Mental Illness; Cornucopia, Inc.; Access Community Health Centers; Group Health Cooperative; UW Health

Summary

In Wisconsin, like the nation overall, approximately one out of four adults have mental illness. Mental illness is the leading cause of disability in the U.S., and can result in up to 25 years of reduced life expectancy. Delivering health care to this population is complicated by the separation of specialty mental health care and primary care into uncoordinated silos—despite the fact that two-thirds of individuals with mental illness have other chronic medical conditions. Consequently, there is growing national interest in integrating mental health care and primary care. Research about models that integrate mental health and primary care is identified as one of the top two areas for funding priority by the Patient-Centered Outcomes Research Institute. This project aims to (1) identify and prioritize outcomes important to the public from an integrated mental health and primary care model; (2) engage delivery system partners in helping to identify differences and similarities in the components of their integrated mental health and primary care models; and (3) recruit a patient/stakeholder research advisory board to support this effort. Our long-term goal is to improve health care delivery for individuals with mental illness through understanding the effectiveness of integrated mental health and primary care models on outcomes of interest to patients.



3. PI: Gretchen Schwarze, MD, MPP, UW SMPH

Title: *Engaging Stakeholders to Develop a Patient Navigation Tool for High-risk Surgery*

Academic Collaborators: Paul Rathouz, UW SMPH

Community Collaborators: UW Health Patient Relations & Patient/Family Partnerships; Patient-Family Advisors; Center for Patient Partnerships

Summary

Each year, approximately 500,000 Americans (including 10,000 Wisconsinites) age 65 and older will decide whether to undergo a high-risk operation, such as heart bypass or risky cancer surgery. Although many patients benefit from high-risk surgery, it carries significant likelihood of mortality and serious complications, including stroke, kidney, or respiratory failure. High-risk surgery can have other far-reaching consequences, including postoperative suffering, conflict about additional aggressive treatments, and receipt of unwanted care. Thus, there is much at stake for patients in the decision to proceed with surgery. Although surgeons use informed consent to disclose short-range operative risks, this process fails to communicate how patients might experience complications or anticipate expected downstream outcomes such as invasive postoperative treatments or predictable changes in functional status. We aim to close this gap by clarifying patients' preoperative decisional needs and developing a patient navigation tool for use in high-stakes surgical decision making.

