Summary of Previous Awards
ICTR-CAP Stakeholder and Patient Engaged Research (SPER) RFA

*Formerly the Patient-Centered Outcomes Research (PCOR) RFA*
2013-2019

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
<th>Principal Investigator</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019</td>
<td>Partnering with a WI Health System to Optimize Opioid Stewardship</td>
<td>Michelle Chui; David Mott Pharmacy</td>
</tr>
<tr>
<td></td>
<td>Across the Care Continuum</td>
<td></td>
</tr>
<tr>
<td>2018</td>
<td>Engaging Stakeholders to Improve the Quality of Breast Cancer Follow-</td>
<td>Heather Neuman SMPH, Surgery</td>
</tr>
<tr>
<td></td>
<td>up: Development of a Novel Approach to Breast Cancer Follow-up Care</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>Engaging Stakeholders to Develop a Patient-Centered Approach to Improve</td>
<td>Barb King Nursing</td>
</tr>
<tr>
<td></td>
<td>Older Adult Patient Ambulation during Hospitalization</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>Faith and Community in Action: Increasing Knowledge and Management of</td>
<td>Earlise Ward Nursing</td>
</tr>
<tr>
<td></td>
<td>Depression in African American Communities</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>Engaging Stakeholders in Reducing Overtreatment of Papillary Thyroid</td>
<td>Susan Pitt SMPH, Surgery</td>
</tr>
<tr>
<td></td>
<td>Microcarcinomas</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>Engaging Stakeholders in Integration of Preventive Care and Health</td>
<td>Christie Bartels SMPH, Med</td>
</tr>
<tr>
<td></td>
<td>Promotion in Rheumatology Clinics</td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>Improving the Care of Children with Spinal Muscular Atrophy</td>
<td>Matthew Halanski SMPH, Ortho</td>
</tr>
<tr>
<td>2014</td>
<td>Can Community Advisors Improve Recruitment of Underrepresented People?</td>
<td>Barbara Bowers, Nursing</td>
</tr>
<tr>
<td>2014</td>
<td>Engaging Stakeholders and Developing Partners in Mental Health and</td>
<td>Nancy Pandhi SMPH, Fam Med</td>
</tr>
<tr>
<td></td>
<td>Primary Care Integration Research</td>
<td></td>
</tr>
<tr>
<td>2014</td>
<td>Engaging Stakeholders to Develop a Patient Navigation Tool for High-</td>
<td>Gretchen Schwarze SMPH, Surgery</td>
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<td>risk Surgery</td>
<td></td>
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<tr>
<td>2013</td>
<td>Engaging Stakeholders to Deliver Family-Centered Diabetes Self-</td>
<td>Elizabeth Cox SMPH, Ped</td>
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<td></td>
<td>Management Resources</td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td>Expanding the Role of the Community Pharmacist in Falls Prevention</td>
<td>David Mott Pharmacy</td>
</tr>
<tr>
<td></td>
<td>and Systems Engineering Approach</td>
<td></td>
</tr>
</tbody>
</table>
Partnering with a WI Health System to Optimize Opioid Stewardship Across the Care Continuum

- **PIs:** Michelle Chui, PharmD, PhD and David Mott, PhD, FAPhA, RPh, School of Pharmacy
- **UW Program Partners:** Wisconsin Network for Research Support (WINRS), Pharmacy Practice Enhancement and Action Research Link (PEARLRx)
- **Community Collaborators:** Forth HealthCare

**Summary:** In 2017, over 900 Wisconsinites lost their lives to opioid-related overdoses, while another 15,000 were hospitalized due to overdose or poisoning. Many of these tragic events involved the unsafe use or abuse of prescription opioid medications (opioids), and efforts to reduce overdose and death require a broad-based approach matching the complex nature of today’s opioid crisis. An opioid stewardship program (OSP) involves coordinated activities designed to improve, monitor, and evaluate opioid use. This project will leverage our collective research experience and partner with a Wisconsin health system stakeholder (Fort HealthCare) to inform development of OSP interventions that cross the care continuum. We will engage multiple stakeholder groups including Fort HealthCare Providers, Community Providers, and Patient Partners to: (1) choose OSP goals that are important to the health system and the communities it serves, (2) describe how stakeholders decide on OSP activities needed to achieve these goals, and (3) begin deciding on OSP activity features, including objectives, resources, outcome measures, and success criteria. This project will inform development of a multi-year grant to implement, evaluate, and disseminate health system coordinated interventions to improve aspects of the opioid crisis that are most important for the health system and their communities.

Engaging Stakeholders to Improve the Quality of Breast Cancer Follow-up: Development of a Novel Approach to Breast Cancer Follow-up Care

- **PI:** Heather Neuman, MD, School of Medicine & Public Health
- **Academic Collaborators:** Jessica Schumacher, SMPH; Amye Tevaarwerk, SMPH; Kristine Kwekkeboom, SON; Jennifer Tucholka, SMPH; Esra Alagoz, SMPH; Bret Hanlon, SMPH
- **UW Program Partners:** Wisconsin Network for Research Support
- **Community Collaborators:** Breast Cancer Research Advisory Network, UW Health, UW Carbone Cancer Center, Gilda’s Club of Madison, Swedish American Hospital

**Summary:** It is challenging and costly to provide the 3 million breast cancer survivors living in the United States with comprehensive follow-up care. Current guidelines recommend frequent follow-up to assess for recurrence, adherence to therapy, and post-treatment symptoms; these recommendations are standard regardless of an individual patient’s risk. For survivors, frequent follow-up visits create financial costs in the form of visit co-pays or time away from work or family, and logistic challenges related to travel. Since the majority of breast cancer survivors are at low risk of cancer recurrence, there is a critical need to develop a novel approach to follow-up that reduces the burden on survivors and their oncologists, while simultaneously delivering comprehensive care and maximizing quality of life. In prior research, our team identified remote assessments of patient-reported outcomes (PROs) for breast cancer survivors at low-risk of recurrence to be a potential opportunity to deliver more efficient and comprehensive follow-up. This approach substitutes one face-to-face visit each year with a remote assessment, a departure from the current standard of care. In collaboration with stakeholders, we will (1) Identify a cohort of survivors perceived to be low enough risk for recurrence that remote assessment using PROs would be acceptable; (2) Develop and pilot a PROs assessment that replicates the content of an ideal follow-up visit; and (3) Identify
outcomes that matter to stakeholders to use in assessing the overall effect of our follow-up intervention in a future trial. With this pilot award will establish our stakeholder advisory groups (Aim 1), collaborate with stakeholders to develop our deliverable products (Aim 2), and pilot test the products for comprehensiveness and acceptability (Aim 3).

Engaging Stakeholders to Develop a Patient-Centered Approach to Improve Older Adult Patient Ambulation during Hospitalization

- **PI**: Barbara King, PhD, APRN-BC, School of Nursing
- **UW Program Partners**: Wisconsin Network for Research Support
- **Community Collaborators**: UW Health Geriatric Clinics

**Summary**: Up to 65% of hospitalized older adults lose the ability to ambulate independently during hospitalization. Loss of independent ambulation is associated with negative outcomes including a 33% increase in new nursing home placement, increase in length of hospital stay, need for rehabilitation and home health services, falls, caregiver burden, decreased quality of life, and increased mortality. New conceptual frameworks provide a mechanism to explore how persons engage in “work” while patients in a healthcare system. The objective of this application is to collaborate with older adults to build a stronger intervention to improve patient ambulation during a hospital stay.

Faith and Community in Action: Increasing Knowledge and Management of Depression in African American Communities

- **PI**: Earlise Ward, PhD, School of Nursing
- **Academic Collaborators**: Elizabeth Cox, SMPH; Toni Ziegler, WNPRC, SOE
- **Community Collaborators**: Second Baptist Church

**Summary**: Major Depressive Disorder (MDD) is a major public health concern and is quickly approaching the status of a global public health crisis. In addition, health disparities research examining MDD show African Americans evidence higher prevalence of depression compared to Whites and African Americans report more chronic MDD and associated disability than do Whites. MDD and stress among African American women are of special concern because of multiple vulnerabilities including low SES, poverty, discrimination, and high rates of chronic illness, all of which are related to MDD being underdiagnosed, misdiagnosed, or dismissed as a normal part of aging among this group. Despite being burdened by MDD, older African American women are not seeking professional help. Instead, research suggests this population employs faith-based coping. This project will develop a faith-based community advisory board to offer input on adapting an existing intervention and future research design.
Engaging Stakeholders in Reducing Overtreatment of Papillary Thyroid Microcarcinomas

- **PI:** Susan Pitt, MD, MPH, UW SMPH/Surgery
- **Academic Collaborators:** Caprice Greenberg, SMPH; Rebecca Sippel, SMPH; Margret Schwarze, SMPH
- **Community Collaborators:** Thyroid Cancer Survivor’s Association, Inc; Qualitative Healthcare Research Consultants; Patient stakeholders; Physician stakeholders from Dean/St.Mary’s Hospital, Medical College of Wisconsin, and Marshfield Clinic Health System

**Summary:** In the United States, 65,000 cases of thyroid cancer are diagnosed each year, and about 1,200 of these are in the state of Wisconsin. Patients with these microcancers can undergo total thyroidectomy, thyroid lobectomy (removal of half of the thyroid) or active surveillance with serial ultrasound studies. Currently, less than 1% of patients undergo active surveillance while 73% choose the riskiest option with the greatest potential for long-term adverse outcomes—total thyroidectomy. Treatment of these indolent tumors represents overtreatment because the risks of harm from therapy outweigh the potential benefits. In this project, we aim to engage stakeholders (patients, families, and doctors who treat thyroid cancer) in helping us study the factors that lead to overtreatment. We currently do not know (1) how stakeholders decide on treatments or (2) why they choose a risky treatment instead of active surveillance or less risky surgery. Knowing what causes overtreatment will allow our research team and stakeholder partners to develop, test, and put into practice interventions that decrease overtreatment, reduce healthcare costs, and improve the efficiency of healthcare delivery.

Engaging Stakeholders in Integration of Preventive Care and Health Promotion in Specialty Clinics

- **PI:** Christie Bartels, MD, MS, UW SMPH/Rheumatology
- **Academic Collaborators:** Elizabeth Cox, SMPH; Betty Chewning, School of Pharmacy; Megan Piper, SMPH; Edmond Ramley, College of Engineering; Ann Rosenthal, Medical College of Wisconsin
- **Community Collaborators:** WI Arthritis Foundation; WI Lupus Foundation of America; UW Health; Stakeholder Advisory Group

**Summary:** Patients with rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) experience premature cardiovascular disease (CVD) and lose on average 5 years of life. However, these CVD risk factors are rarely addressed in specialty clinics, where 73% of RA and SLE visits occur. This research team has created and pilot-tested a staff-protocol intervention to address high BP and smoking in RA and SLE patients, pilot studies indicate the intervention feasible and doubled timely primary care follow-up of high BPs. The specific aims of this study will lay the groundwork for a future PCORI application to compare the effectiveness of our rheumatology staff protocol approach versus evidence-based annual nurse management in a multisite comparative effectiveness trial. The aims of this study are to (1) Recruit, engage and sustain patient and blended multi-stakeholder advisory boards, (2) Engage stakeholders to identify and prioritize patient-centered outcomes for staff protocol interventions to reduce CVD risk factors, (3) Engage stakeholders to optimize our staff-protocol intervention for future implementation in diverse clinic settings including those serving hard-to-reach populations.
Improving the Care of Children with Spinal Muscular Atrophy

- **PI:** Matthew Halanski, MD, UW SMPH/Orthopedics
- **Academic Collaborators:** Mary Schroth, MD, UW SMPH; Karen Patterson, MS, UW SMPH
- **Community Collaborators:** Families of Spinal Muscular Atrophy, UW Hospitals and Clinics

**Summary:** Spinal Muscular Atrophy (SMA) is a deadly childhood disorder without a cure, and children with this disorder require 24/7 care. Due to the incidence of the disease (1/6,000-10,000), no single center cares for enough patients to develop evidence-based guidelines, and no system exists to compare the effectiveness of the various treatments being used to treat the SMA population. Our goal is to develop an electronic multicenter, multidisciplinary database containing validated outcome measures, and clinical data to allow comparisons between different treatments and outcomes to determine the optimal care for the complex children. In addition to medical data, we will gather patient/family-entered data and quality of life measures to evaluate how treatments affect patient and family life. With the data and lessons learned from this pilot project, we will submit a PCORI grant to expand the database allowing clinicians to compare the effectiveness of various interventions in the SMA population.

Can Community Advisors Improve Recruitment of Underrepresented People?

- **PI:** Barbara Bowers, PhD, RN, UW SON
- **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

Engaging Stakeholders and Developing Partners in Mental Health and Primary Care Integration

- **PI:** Nancy Pandhi, MD, PhD, MPH, UW SMPH
- **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 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.

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

- **PI:** Gretchen Schwarze, MD, MPP, UW SMPH/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.

Engaging Stakeholders to Deliver Family-Centered Diabetes Self-Management Resources

- **PI:** Elizabeth Cox, MD, PhD, UW SMPH/Pediatrics
- **Academic Collaborators:** Nancy Pandhi, MD, MPH, PhD, UW SMPH
- **Community Collaborators:** American Family Children’s Hospital, Juvenile Diabetes Research Foundation Western Wisconsin Chapter

**UW ICTR Partners**

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Summary: Unlike type 2 diabetes, type 1 diabetes cannot be prevented or cured, nor treated solely with better diet and exercise. The only way for children with type 1 diabetes to survive is by enduring multiple insulin injections daily in order to control blood sugars; yet, taking too much insulin can cause seizures or even death. Controlling blood sugars requires “self-management,” carefully balancing the amount of insulin injected, the sugar consumed in food, and the fuel needed for activities. Each family faces unique barriers to self-management. Type 1 diabetes is nearly always cared for by a team of specialists, nurses, diabetes educators, nutritionists, and psychologists—who have no way to easily determine what barriers a family faces, so families often repeatedly visit resources not tailored to their needs, resulting in frustration and wasted time. To efficiently align resources to families’ needs, we will gather input directly from families and children which will then provide the basis for incorporating stakeholder perspectives into research on how to improve outcomes and provide self-management resources that address their unique barriers. Results can also be used to educate clinicians, guide policies for chronic disease care, and support future research in other chronic diseases.

Expanding the Role of the Community Pharmacist in Falls Prevention

- PI: David Mott, PhD, FAPhA, RPH, UW SOP
- Academic Collaborators: Jane Mahoney (SMPH), Beth Martin (Pharmacy), Bob Breslow (Pharmacy), Sarah Esmond (CCHE), Rachel Smedley (CAARN)
- Community Collaborators: LaCrosse County Aging Unit, Aging and Disability Resource Center (ADRC) of Calumet, Waupaca and Outagamie counties, Brown County ADRC

Summary: Falls are the number one cause of injury-related death for Wisconsin’s older adults and research shows that minority older adults have higher rates of falling. One contributor to loss of balance and falling is medication, classified as fall risk-increasing drugs (i.e. FRIDs); older fallers use these drugs regularly. Recent research shows that when a pharmacist works directly with a senior regarding FRIDs, the drugs are more often taken off the list of a senior’s medication regimen. This project will create a screening tool and referral process to link at-risk older adults with local pharmacists. This study will help community health organizations overcome health system structural and procedural barriers to promote older adults’ access to care. Understanding better how minority older adults can be served by local pharmacists may reduce disparities in access to pharmacists as well as disparities in outcomes such as reduced FRID use and reduced fall.

Reducing Readmission after Complex Cancer Surgery: A Human Factors and Systems Engineering

- PI: Sharon Weber, MD, FACS. UW SMPH/Surgery
- Academic Collaborators: Pascale Carayon (Engineering), Caprice Greenberg (SMPH), Emily Winslow
- (SMPH), Amy Kind (SMPH)
- Community Collaborators: UW Hospitals & Clinics, Pancreas Cancer Task Force, Carbone Cancer Center
Summary: Following an initial hospitalization for complex cancer surgery, the rate of return to the hospital—readmission—is very high, occurring in one of every five patients. The cost of all unplanned readmissions in Medicare patients is exorbitant, at over $17 billion. No study to date has looked at the human factors engineering reasons behind these readmissions — in other words, no one has looked at the intersection of people, technology, policy, and work across multiple disciplines to learn more about why these readmissions might be occurring at such high rates. Therefore, it is likely that there are missed opportunities to improve the quality of care for cancer patients by decreasing the readmission rate after surgery. This is particularly important since these operations are planned; resulting in a window of opportunity before surgery here an intervention could occur to decrease the risk of readmission. The goals of the project include assessing the cause of readmission from the patient and caregiver’s perspective and assessing the clinical risk factors associated with increased risk of readmission. With this information, we plan to test this surgery-specific, patient-centered readmission reduction tool in a follow-up study to evaluate whether it will decrease the readmission rates for these complex patients.