

# Patient Engaged Partnership Research Pilot Awardees 2022-2024

Of Note: Previous to this year, this award was called the "Stakeholder and Patient Engaged Research (SPER)" Pilot Award. The name was changed to decolonize the language by removing the term "stakeholder," and to emphasize the engagement of patients and/or patient partners.

Year	Principal Investigator/s	Affiliation	Title
2024	KJ Hansmann	SMPH Department of Family Medicine and Community Health	Engaging Patients with Dementia and their Care Partners in Decisions about the Transition to Non-Driving
2024	Matthew Kalscheur	SMPH Department of Medicine	The Digital Living Well with Atrial Fibrillation Clinic
2024	Kristen Pecanac	School of Nursing	Co-developing a Communication-Training Intervention to Improve Surrogate Decision Making
2024	Zoua Vang	School of Human Ecology Department of Civil Society and Community Studies	mat-CHW: A Co-designed Community- based Intervention with WI Refugees to Improve Maternal Child Health & Wellness
2023	Megan Piper	SMPH Department of Medicine	Reducing Racial Disparities in Smoking: The Milwaukee Collaboration
2022	Malia Jones	College of Agricultural and Life Sciences Department of Community and Environmental Sociology	Community Co-design and Pilot Test of Public Health Messages Addressing Pediatric Vaccine Hesitancy in Rural America

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### 2024 Awards

## Engaging Patients with Dementia and their Care Partners in Decisions about the Transition to Non-Driving

KJ Hansmann, MD, MPH, PhD – SMPH, Department of Family Medicine and Community Health

Collaborators: UW Community Academic Aging Research Network (CAARN), UW Wisconsin Network for Research Support (WINRS), Metastar

Summary: The population of drivers ages 85 and older in Wisconsin is growing - projected to rise 140% by 2040. Despite driving being the primary mode of transportation for older adults, many older drivers will face age-related changes that decrease their driving safety and necessitate a transition to non-driving. Family and clinicians can facilitate planning for the transition to non-driving, but they often delay starting conversations about driving because this transition is logistically and emotionally complex. This represents a missed opportunity to engage older drivers in planning for this transition when they can still direct the timing and preparation. This is particularly problematic for adults with Alzheimer's disease and related dementias (ADRD). With progressive cognitive decline associated with ADRD, delays in care planning conversations can mean older adults with memory concerns no longer have the capacity to engage in shared decision-making about driving There is an urgent need for interventions that support older drivers with memory concerns to engage in shared decision-making about their transition to non-driving. The transition to non-driving is a unique life transition that spans a continuum from independence to complete cessation. Along this continuum, older drivers may value different approaches to maintain their safety and mobility. There is a critical need for decision support interventions that engage older drivers with memory concerns and their care partners in driving care planning discussions. Our long-term goal is to develop and implement a decision support intervention to help older drivers with memory concerns and their care partners navigate driving transitions. The overall objective of this pilot is to engage a diverse cohort of older drivers, care partners, and clinical team members to co-design a future study investigating driving care planning interventions.

### The Digital Living Well with Atrial Fibrillation Clinic

Matthew Kalscheur, MD – SMPH, Department of Medicine

**Collaborators:** CareEvolution, UW Health Cardiac Electrophysiology Clinics, UW Survey Center; UW Wisconsin Network for Research Support (WINRS), University of Massachusetts TH Chan School of Medicine

**Summary:** Atrial fibrillation (AF) represents a 21st-century cardiovascular disease epidemic. Addressing modifiable cardiovascular disease risk factors reduces the morbidity of AF. The American Heart Association recommends using Life's Essential 8 (LE8), a multi-faceted risk-factor assessment metric, to monitor individual progress on addressing modifiable risk factors and improve cardiovascular health (CVH). Cardiac rehabilitation programs use the LE8 framework to address individual modifiable risk factors to improve morbidity and mortality in coronary heart disease and heart failure. Despite strong evidence showing the benefits of addressing modifiable risk factors in AF, no such rehabilitation programs exist. Improving the LE8 metric requires a person-centered approach with a focus on understanding an individual's social needs while

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providing motivation to change behaviors. Currently, rural patients face increased barriers even when programs exist due to limited access to those programs. There is a critical need to deliver transformative programs that improve CVH in persons with AF from all communities, especially those in rural communities, a population known to have lower CVH.

We hypothesize that the Digital Living Well with Atrial Fibrillation Clinic – a person-centered, mobile health application (mHealth app) - will identify individual barriers and facilitators of social needs, provide tailored educational materials, and deliver just-in-time-adaptive-interventions (JITAIs) to facilitate behavior change that leads to improved CVH and reduces the morbidity of AF.

### Co-developing a Communication-Training Intervention to Improve Surrogate Decision Making Kristen Pecanac, PhD – School of Nursing

**Collaborators:** Wisconsin Network for Research Support (WINRS), Lussier Community Education Center

Summary: About 40% of surveyed Wisconsin residents have made a major medical treatment decision, of which 80% have made one for a loved one unable to make the decision themselves (as surrogate decision makers). Surrogate decision making is difficult, particularly decisions with life-ordeath implications for a patient in the hospital setting, such as the use of ventilators or feeding tubes. Surrogates experience high levels of decisional conflict and post-traumatic stress in making these decisions and patients do not always receive care that aligns with their values and preferences. Black surrogate decision makers are more likely to experience decisional regret and have higher levels of distrust and decisional conflict when they experience poor communication with providers during decision-making conversations. Improving provider communication, and in particular, improving surrogate involvement in the conversation, has led to positive outcomes such as reduced decisional conflict and a higher likelihood of patients receiving goal-concordant care. However, communication guidelines are inadeguate for offering providers communication strategies to improve surrogate involvement in conversations. Our prior work of audio-recorded providersurrogate conversations has shown that small nuances in provider communication strategies, such as how something is phrased, greatly influence surrogate involvement in the conversation. However, these findings are limited by including a mostly white sample of surrogates and the inability to discern how surrogates feel when providers use these strategies. Although not a formal hypothesis, we assert that by involving former surrogates who identify as Black in the development of a communication-training intervention, providers will be trained to meet the needs of racially diverse surrogates during decision-making conversations.

# *mat-CHW:* A Co-designed Community-based Intervention with WI Refugees to Improve Maternal Child Health & Wellness

Zoua Vang, PhD – School of Human Ecology, Department of Civil Society and Community Studies

**Collaborators:** World Relief Wisconsin – Fox Valley, Aurora Walker's Point Community Clinic, UW Division of Extension Health & Well-being Institute, WI Dept of Children & Families – Bureau of Refugee Programs, SSM Health Dean Medical Group, Madison Metropolitan School District

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### Previously Funded Proposals PEPR Pilot Award



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Summary: Globally, refugee women are at increased risk for poor maternal-child health, including pregnancy complications, adverse birth outcomes, perinatal depression, and postnatal unmet health needs. Refugees in the U.S. face multiple barriers to health care access, including language, culture, structural racism, and low socioeconomic status. As an evidence-based intervention strategy, community health workers (CHWs) have been shown to strengthen patient-provider relationships, reduce health risks in patients, and improve health care utilization among disadvantaged and underserved populations. The goal of the proposed study is to partner with stakeholders and refugee communities to co-design and pilot a specialty curriculum focused on maternal-child health for CHWs (hereafter, mat-CHW). Together with community partners, stakeholders, and refugee women/mothers, community leaders, and elders we will co-develop a CHW curriculum that covers key aspects of maternal-child health. The mat-CHW curriculum will also include training in prenatal and postnatal screening and will be tailored to the needs and priorities of our target refugee communities: Afghan, Congolese and Rohingya. These refugee populations were identified by our community partners as needing perinatal health services and/or constituting a large proportion of their current clientele. We will then recruit, hire and train three parttime perinatal community health workers (PCHWs) from the target communities and assess their health knowledge, self-efficacy and competencies using a mixed-methods pre/post training design. We expect that the mat-CHW curriculum will improve PCHWs' perinatal health knowledge, selfefficacy, and prenatal/postnatal screening competencies. Finally, we will deploy trained PCHWs to work with 60 pregnant and postpartum Afghan, Congolese and Rohingya refugee women in the Fox Valley, Madison and Milwaukee for a period of three months. The proposed study will fill important public health knowledge and CHW training gaps by developing and pilot testing a mat-CHW intervention for improving health care access and health outcomes among pregnant and postpartum refugee women in Wisconsin.

### 2023 Awards

Reducing Racial Disparities in Smoking: The Milwaukee Collaboration Megan Piper, PhD – SMPH, Department of Medicine, Center for Tobacco Research and Intervention

**Collaborators:** Wisconsin Network for Research Support (WINRS), Center for Community Engagement and Health Partnership (CCEAHP), Wisconsin Tobacco Prevention and Control Program (TPCP), Jump at the Sun Consultants, Wisconsin Women's Health Foundation (WWHF)

**Summary:** Smoking commercial tobacco cigarettes is the leading preventable cause of death and disease in the United States. Tragically, due to especially high smoking rates among some populations, the smoking-disease burden is not born equally across all communities in this country. In the state of Wisconsin, African American adults smoke at more than twice the rate of white adults (30% vs. 12%). African American people who smoke are motivated to quit, but they are less likely to use evidence-based smoking cessation treatment, even though there are many such treatments that have been shown to be effective for African American people. Thus, there is a clear need to identify smoking cessation treatments that are effective, acceptable, and sustainable within African American communities as well as effective strategies to engage people in African American communities with such treatments. To address this need, the proposed research will use community-engaged research strategies and expertise from a Community Advisory Board (CAB;

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including public health officials, community leaders, community members, and community adopters including a representative from the Wisconsin Tobacco Prevention and Control Program), scientists with expertise in tobacco cessation treatment interventions and health messaging, and tobacco control outreach specialists with expertise in training and implementation. Specifically, the research team (scientists and outreach specialists) will work collaboratively with the CAB and the support of community engagement experts from the University of Wisconsin Institute for Clinical and Translational Research (ICTR) to achieve the proposed aims.

### 2022 Awards

# *Community Co-design and Pilot Test of Public Health Messages Addressing Pediatric Vaccine Hesitancy in Rural America*

**Malia Jones, MPH, PhD** – College of Agricultural and Life Sciences, Department of Community and Environmental Sociology

**Collaborators:** Wisconsin Head Start Association, Wisconsin Council of Churches, Southwestern Wisconsin Community Action Program

**Summary:** Rural residents of the United States, including children, face significant structural barriers and challenges around social determinants of health, leading to rural health disparities. Routine vaccination was relatively low in rural areas before the COVID-19 pandemic, including for routine pediatric vaccinations. Over the last two years, many children missed routine immunization appointments and routine pediatric vaccination coverage has dropped precipitously. During the pandemic, profound COVID-19 vaccine hesitancy emerged in rural communities. Uptake of pediatric COVID-19 vaccines remains considerably lower than for adults and is especially low in rural Wisconsin. Evidence-based strategies for addressing vaccine hesitancy include culturally competent, tailored messaging. However, little is known about the ideological frames, barriers, and context of vaccine-hesitant, rural Wisconsin parents.

Throughout the project, we will use a community-driven, iterative co-design process to develop vaccine promotion messages tailored to rural-living parents in Wisconsin. A coalition of community partner organizations will be members of our project team. We will recruit three small co-design working groups made up of community members. Each group will iteratively develop vaccine promotion messages. We will pilot test co-designed messages in a national panel of rural-living parents. We will use a randomized study design to identify which messages are effective at changing vaccination attitudes and intentions.

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