



**Tier 1 Pilot Grant Application: Laying the Foundation
Autumn 2024 Cover Sheet**

Project Information

Project Title	Collaborative development of a community advisory board focused on serious cardiac illness in the Washington, Wyoming, Alaska, Montana, Idaho (WWAMI) region
Budget Request from Initiative	\$25,000
Budget Match (if applicable)	CSDE \$25,000
Total Project Budget	\$50,000

Applicant Information

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Jill Steiner, MD, MS (Co-Investigator): Assistant Professor, School of Medicine, Department of Medicine, University of Washington; jills8@uw.edu

Salpy Pamboukian, MD (Co-Investigator): Professor; School of Medicine, Department of Medicine, University of Washington; svpam@uw.edu

Jason Deen, MD (Advisor): Associate Professor; School of Medicine, Departments of Medicine and Pediatrics, University of Washington; jdeen@uw.edu

Maggie Ramirez, PhD (Advisor): Assistant Professor, Health Systems and Population Health, School of Public Health; maggiera@uw.edu

Research Assistant: TBD, School of Nursing, Department of Biobehavioral Nursing & Health Informatics

Abstract

Individuals with serious cardiac illness (SCI) such as advanced heart failure or adult congenital heart disease in the Washington, Wyoming, Alaska, Montana, and Idaho (WWAMI) region must travel to Seattle when they need advanced therapies. The University of Washington (UW) Medical Center is the only major hospital system to offer heart transplants and other advanced therapies in this region, which covers more than 1/5 of the land mass of the United States. This is a regional population health challenge because it presents major challenges to patients (and their family members/caregivers), and there is currently no forum to engage patients about their care experiences or to assess priorities for research regarding care delivery solutions. To address this challenge, we have assembled a multidisciplinary team of experts in clinical and community engaged research. This proposal aims to explore the needs, preferences, and priorities of patients, family members/caregivers, and health care team members about participating in community engaged research and to identify research priorities as a first step in developing a community advisory board focused on SCI in the WWAMI region. We will hold a series of workshops informed by user-centered design, then conduct a mixed-methods analysis of findings. Anticipated deliverables are 1) a coproduced structure for future community engaged WWAMI SCI research; 2) identification of priority research topics; and 3) determination of next steps (timeline and potential funding sources).



Tier 1 Project Research Plan

Problem:

The University of Washington (UW) is the only major hospital system providing care for serious cardiac illness (SCI) (e.g. advanced heart failure (AHF), adult congenital heart disease (ACHD)) in the WWAMI region (Washington, Wyoming, Alaska, Montana, Idaho). This is a regional population health challenge because it means many patients must travel to Seattle, sometimes for multiple days, weeks, or months at a time, to receive care. For example, in a sample of patients with AHF, 75% lived more than 1 hour away by car, and 21% needed to take a plane or ferry to reach UW [Blakeney, unpublished data]. This shared experience of the population of individuals living with SCI in the WWAMI region has logistical, financial, and equity implications and can affect well-being. Currently, there is no forum, such as a Community Advisory Board (CAB), to engage patients about their care experiences or to engage them in research regarding care delivery solutions. In fact, to our knowledge, no WWAMI-wide CABs exist in cardiology or other clinical or research areas, and there are few models in the literature or practice relevant to this unique regional challenge. Increasingly, the NIH and other sources of clinical and research funding favor, and sometimes require, community engagement in proposals and plans.¹⁻⁴

Aims:

1. Identify interests, needs, and barriers and facilitators to participating in a CAB among patients with SCI in the WWAMI region, their family members/caregivers, and health care teams.
2. Develop plans to establish a sustainable community advisory board (CAB) and research grant proposals to address needs, concerns, and priorities related to participation.
3. Elicit research topics regarding WWAMI SCI care delivery for which a future CAB may be convened.

Project Plan:

Participants: 5-7 patients with SCI who receive care at UW and reside in the WWAMI region (primarily outside of Seattle); 5-7 family members, caregivers, and/or 4-5 clinicians of such patients.

Design: Guided by the Assessing Community Engagement Conceptual Model,⁵ conduct a series of workshops leveraging user-centered design approaches.^{6,7}

Methods:

- Participants will be recruited via flyers, social media posts, email, and Epic messages.
- Following an introductory Zoom session (2 hours), we will conduct 3 rounds of virtual, interactive, facilitated small group workshops (2-3 hours each) focused on discovery, design, and prioritization⁶ of participants' needs, concerns, and priorities surrounding CAB and SCI research participation.
- Afterward, all participants will be invited to an in-person workshop (2 days) for team building, prioritization, and critique⁶. Here, synthesized findings will be presented and deliverables finalized, including 1) a coproduced structure for future community engaged WWAMI SCI research; 2) identification of priority research topics, and 3) determination of next steps (timeline and potential funding sources).

Analysis: Mixed methods analysis of workshop materials and products from facilitated open discussions, idea prioritization activities, and meeting transcripts.

Outcome: Community engaged guidance on format and structure of a CAB, research priorities, and insight into potential interventions to enhance SCI care delivery

Potential next steps: 1) Develop an ongoing, funding mechanism agnostic, virtual CAB. 2) Solidify plans to pursue one or more funding mechanisms (i.e. a palliative care NOSI (NOT-HL-23-117)⁸ from NHLBI).



Tier 1 Project Evaluation Plan

1. What are your measures of success for this project?

- Creation of a shareable compilation of needs, concerns, and priorities to inform future work
- Collection of necessary information to develop a sustainable virtual CAB
- Identification of at least 1 UW intramural and 1 extramural grant to apply to in the coming year

2. How are you planning to utilize the results of your work to pursue a future project to generate proof-of-concept once the eight-month project is complete?

This work is needed prior to pursuing funding for a proof-of concept study of a research intervention that could facilitate care for SCI in WWAMI. Currently, we do not know the needs, concerns, or priorities of this patient population; their input is required to ensure development of a compatible study design.

Project Timeline

Task	Jan	Feb	Mar	Apr	May	Jun	July	Aug
Start-up and Preparation	X							
Recruitment and Invitations	X	X						
Informational Zoom Session		X						
Small Group Workshops (Zoom)			X	X	X			
Large Group Workshop (In-Person)							X	
Analysis				X	X	X	X	
Deliverables Preparation						X	X	X
Summary Meeting (Zoom)								X

Biographies

Dr. Erin Blakeney is a nurse scientist whose research focuses on improving communication, safety, and experience in hospitals using methods and frameworks from implementation science, team science, and clinical research. She currently has a K23 Career Development Award from the NIH National Heart, Lung, and Blood Institute (NHLBI) which focuses on communication and experiences during hospital rounds.

Dr. Jill Steiner is an assistant professor of Medicine at UW. She is an ACHD cardiologist and physician scientist whose research focuses on palliative care in ACHD, specifically advance care planning and promotion of resilience. She holds a K23 Career Development Award from the NIH NHLBI and has experience with survey, interview, and administrative data and clinical trials.

Dr. Salpy Pamboukian is a professor of Medicine at UW. She is an AHF cardiologist who cares for patients in need of therapies like transplant. Her research incorporates the experiences of women with AHF and the impact of race on care. She has participated in a clinical trial of an early palliative care telehealth intervention for family caregivers and has experience reaching regional populations.

Dr. Jason Deen is an associate professor of Medicine and Pediatrics at UW. He is an ACHD cardiologist and the founding director of the Center for Indigenous Health at UW Medicine. He is also the Chair of the Committee on Native American Child Health through the American Academy of Pediatrics. His research focus is on improving the cardiovascular health of the Native population.

Dr. Maggie Ramirez is an assistant professor of health systems and population health in the UW School of Public Health. Her research focuses on the use of human centered design and health information technology to facilitate community engagement in improving health care delivery. She has a particular focus on Latino populations facing inequities in health status and health care delivery.



Tier 1 Project Budget

	Requested from Initiative	CSDE Funding Match
Salaries		
Faculty	\$10,914	
Staff	N/A	
Student	\$3,200	
Benefits Based on Payroll Load Rate in Effect	\$2,717	
Supplies and Materials Supplies, Equipment Under \$2,000, etc.	\$8,150	\$25,000
Equipment Equipment Over \$2,000	N/A	N/A
Tuition	N/A	N/A
Other	N/A	N/A
Total Direct Costs (PHI-requested funding cannot exceed \$25K)	\$25,000	\$25,000

Budget Justification [JMS1]

Faculty

Erin Blakeney, PhD, RN (2.5% FTE x 6 months; \$1745 salary, \$434 benefits); Dr. Blakeney will conduct staff training, plan/facilitate workshops, drive analyses, and participate in dissemination/publication efforts. She will also oversee fiscal management of the project.

Jill Steiner, MD, MS (2.5% FTE x 6 months; \$2937 salary, \$731 benefits); Dr. Steiner will conduct staff training, plan/facilitate workshops, drive analyses, and participate in dissemination/publication efforts.

Salpy Pamboukian, MD (2.5% FTE x 6 months; \$3826 salary, \$953 benefits); Dr. Pamboukian will plan/facilitate workshops and participate in analyses and dissemination/publication efforts.

Jason Deen, MD (1% FTE x 6 months; \$1646 salary, \$410 benefits); Dr. Deen will provide guidance on engaging with Indigenous communities and participate in dissemination efforts.

Maggie Ramirez, PhD (1% FTE x 6 months; \$760 salary, \$189 benefits); Dr. Ramirez will provide guidance on community engagement methods and participate in dissemination efforts.

Student

Research Assistant (\$20/hour x 12 hours/week x 8 months; work study student 60%/40% split with federal work study award, no benefits requested; cost to grant ~ \$3072 (40% of \$7680) This student will assist the co-Is in preparing documents for regulatory compliance and developing meeting materials. They will also lead recruitment of participants and oversee data management.

Supplies & Materials

Additional funds are requested from the Initiative for:

- Institutional Review Board application preparation assistance from ITHS (\$1500)
- Payment to participants attending virtual workshops (\$5000) (\$50 x 4 workshops x 20-25 people)
- Development of a CAB website (\$1650)

\$25,000 in CSDE Match funds are requested to support the 2-day in-person workshop for 25 people (5-6 study team members, 5-7 patients, 5-7 family members/caregivers, 4-5 clinicians). Costs detailed below:

- Meeting space and meals on Whitman College Campus (\$6000): Meeting space and meals for 2-day meeting (2 dinners, 2 lunches, 2 breakfasts) for 25 people.



- Supplies (\$250): to facilitate data collection. Includes flipcharts, markers, nametags, etc.
- Accommodation (\$7500): Hotel stay in Walla Walla for all meeting participants (either The Finch or Best Western Plus Walla Walla Suites Inn). (\$150 x 2 nights x 25 people)
- Transportation (\$6250): Round trip flights to/from Walla Walla (avg. Seattle to Walla Walla round trip = \$198) or mileage reimbursement for individuals who choose to drive. (\$250 x 25 people)
- Participant stipends (\$5000): To acknowledge participants' commitment and off-set the cost of time away. (\$250 x 20 people) (*note: study team members will not receive stipends).



References

1. National Academy of Medicine. Assessing Meaningful Community Engagement. Accessed September 18, 2024. <https://nam.edu/programs/value-science-driven-health-care/assessing-meaningful-community-engagement/>
2. National Institutes of Health. NOT-HL-23-119: Notice of NHLBI Participation in NOT-MD-23-002 Notice of Special Interest (NOSI): Addressing the Etiology of Health Disparities and Health Advantages Among Immigrant Populations. Accessed September 18, 2024. <https://grants.nih.gov/grants/guide/notice-files/NOT-HL-23-119.html>
3. National Institutes of Health. NOT-HL-23-110: Notice of Special Interest (NOSI): Data Informed, Place-Based Community-Engaged Research to Advance Health Equity. Accessed September 18, 2024. <https://grants.nih.gov/grants/guide/notice-files/NOT-HL-23-110.html>
4. National Institutes of Health. Strategic Goals and Objectives | NHLBI, NIH. Accessed September 18, 2024. <https://www.nhlbi.nih.gov/about/strategic-vision/goals-and-objectives>
5. Achieving Health Equity and Systems Transformation Through Community Engagement: A Conceptual Model - National Academy of Medicine. Accessed September 18, 2024. <https://nam.edu/programs/value-science-driven-health-care/achieving-health-equity-and-systems-transformation-through-community-engagement-a-conceptual-model/>
6. 5 UX Workshops Cheat Sheet. Accessed September 18, 2024. <https://www.nngroup.com/articles/5-ux-workshops/>
7. Cousino MK, Lord BT, Blume ED. State of the Science and Future Research Directions in Palliative and End-of-Life Care in Pediatric Cardiology: A Report from the Harvard Radcliffe Accelerator Workshop. *Cardiol Young*. 2022;32(3):431. doi:10.1017/S104795112100233X
8. National Institutes of Health. NOT-HL-23-117: Notice of Special Interest (NOSI): Palliative Care in the Care Continuum among Persons with Serious Heart, Lung, Blood and Sleep (HLBS) Diseases and their Caregivers. Accessed September 18, 2024. <https://grants.nih.gov/grants/guide/notice-files/NOT-HL-23-117.html>