

The Patient Engaged  
Research Center (PERC)

# Annual Report 2025

PATIENT ENGAGED  
RESEARCH CENTER



Introduction

Patient Advisor  
Program

Councils &  
Committees

Special  
Achievements

Research &  
Services

PERC Grants

Dissemination

**HENRY  
FORD  
HEALTH** SM



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Introduction

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# Introduction

In 2014, Henry Ford Health was one of seven organizations chosen from across the country to participate in a groundbreaking infrastructure development initiative to improve patient outcomes through engaging patients, families, community groups and healthcare providers in healthcare improvement and research. The **Patient Engaged Research Center (PERC)**, led by HFH Public Health Sciences Department Chair, Dr. Christine Johnson, has developed a flexible model to facilitate dialogue and shared learning between all stakeholder groups by developing targeted training and support services for individual providers and patient advisors ensuring all voices are heard in the shared goals of providing safe, timely, efficient, effective, equitable, patient-centered care.

## Mission

To translate the patient voice into evidence-based care through community engagement and world-class research methods.

## Vision

To create a sustainable foundation and model to develop and disseminate world-class patient-centered outcomes research.

## Informational Videos

Click to watch videos



PATIENT ENGAGED RESEARCH CENTER



PERC - Center Overview



PERC - Patient Engagement in Research



PERC - Patient Advisor Program



# PERC Structure

PERC operates under an umbrella, which is split between two arms: 1) Research & Services, and 2) Patient Advisor Program. This structure allows PERC to offer services and apply for grant funding under the Research arm, which results in additional financial support for the Patient Advisor Program.

**Sara Santarossa, PhD**  
Scientific Director



**Ashley Redding, MPH**  
Researcher



**Dana Murphy, BS**  
Project Manager



**Melissa Paré, PhD**  
Researcher



**Maya Zreik, MPH**  
Researcher



**Leah Copeland, BA**  
Project Manager



PATIENT ENGAGED  
RESEARCH CENTER



## Research & Services

- PERC as Core Service within HFH Department of Public Health Sciences
- Principal Investigator on Grants
- Grant Writing
- Survey Development and Distribution
- Institutional Review Board (IRB) Support
- Research/Funded projects
- Data Analysis (Mixed Methods)
- Qualitative Research Design
- Facilitation
- Dissemination and Implementation of Research Findings
- Patient Centered Outcomes Research Design
- Participant Recruitment

## Patient Advisor Program

- Patient Advisors Placements & Opportunities
- Recruitment/Onboarding
- Patient Advisor Liaisons (PAL)
- Patient Advisor Engagement
- Events
- Surveys
- Strategic Planning
- Patient & Family Advisory Councils (PFAC)
- Committees
- Projects
- Process Improvement
- Community Engagement

**Publication:**

Coyne, P., Copeland, L., Murphy, D., Redding, A., Johnson, C. C., Kippen, K. E., & Santarossa, S. (2025). **The Patient Engaged Research Center's Sustainable Funding Framework: A Path Towards Sustainable Patient Engagement in Care and Research Within a Health System.** *Learning Health Systems*, e70047. ([link](#))



# Patient Advisor Program

Introduction

**Patient Advisor  
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Councils &  
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# PERC Flexible Engagement Model

PERC has created a unique flexible stakeholder engagement model that meets the needs of diverse stakeholders (patients, families, providers, payers, and industry), across platforms, (Integrated Health Systems, Academic Medical Centers and Community Medical Clinics) to support participation in a multitude of disciplines including clinical care and research, quality improvement, and patient experience work. The four types of Advisor roles are outlined below.

## Health System Advisors

Serves on a Patient/Family Advisory council or healthcare committee focused on designing or improving new or current processes.

## Research Advisors

Serves as a Patient Advisor on funded research projects, giving input and feedback about different elements of the study.

## E-Advisors

Shares feedback by participating in short, online surveys about patient care experience, new service ideas, etc.

## Focus Group Advisors

Participates in focus groups, provides feedback on own personal healthcare experience or other key healthcare delivery topics.

### **Publication:**

Olden, H. A., Santarossa, S., Murphy, D., Johnson, C. C., & Kippen, K. E. (2022). **Bridging the patient engagement gap in research and quality improvement utilizing the henry ford flexible engagement model.** *Journal of Patient-Centered Research and Reviews*, 9(1), 35.7 ([link](#))

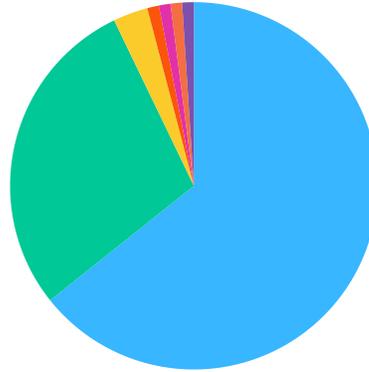
# Patient Advisor Demographics

\*as of December 2025

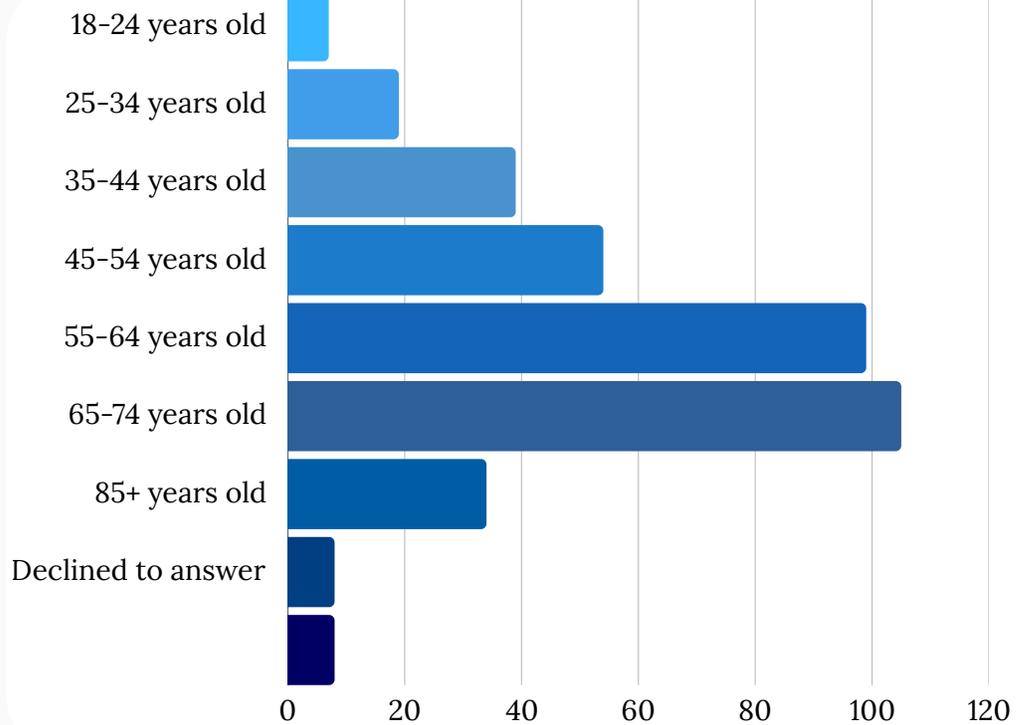
Total Active Patient Advisors

## 376 Advisors

- White or Caucasian **63%**
- Black or African American **28%**
- Asian or Asian Indian **3%**
- Hispanic or Latino **1%**
- Arab or Middle Eastern **1%**
- American Indian or Alaska Native **1%**
- Native Hawaiian or Pacific Islander **1%**



**158** Zip Codes Represented



**76% Female**

**22% Male**

**1% Non Binary**

**1% Transgender**



# Patient Advisor Recruitment & Training

PERC leads the recruitment, training, and onboarding of new Patient Advisors across Henry Ford Health. Our structured process ensures patients and caregivers are prepared, supported, and meaningfully engaged in both research and healthcare improvement efforts.

## Recruitment

PERC recruits Patient Advisors through multiple channels including word of mouth, website submissions, referrals, Press Ganey surveys, and targeted outreach. Patients and caregivers can easily begin the process by completing a short online application at [henryford.com/perc](https://henryford.com/perc) or by contacting the PERC team directly.

## Application

After applying, individuals are contacted within a few days to schedule a brief phone screen with PERC staff. This conversation allows our team to:

- Learn about the applicant's background, interests, and strengths
- Provide an overview of the Patient Advisor Program
- Ensure clarity on expectations and responsibilities
- Identify any potential concerns before placement

This step helps us understand each advisor's communication style, motivations, and lived experience so the right placement can be made.

## Welcome Workshop (Orientation)

New advisors complete a 1.5-hour virtual Welcome Workshop led by PERC staff and an experienced Patient Advisor. The session focuses on:

- Introduction to PERC and the Patient Advisor Program
- HFH system orientation
- Advisor roles and responsibilities
- Storytelling and communication skills (including the S.H.A.R.E. framework)
- Practice sharing their personal "elevator pitch"
- Next steps for engagement

To officially join the program, advisors complete required forms including consent, photo release, confidentiality, demographics, and code of conduct acknowledgment.



# Program Capacity and Reach

As of December 2025, PERC currently supports:

**376** Trained and active Patient Advisors

**266** Advisors serving on committees, projects, and workgroups

**32** Patient & Family Advisory Councils (PFACs) and Committees

PFACs develop charters, identify priority initiatives, and partner with HFH teams to address issues important to both patients and the health system.

Beyond PFACs, Patient Advisors contribute to department committees, research studies, and quality-improvement efforts across HFH.

## Ongoing Training and Support

To ensure meaningful engagement, PERC offers educational workshops, webinars, and tailored training opportunities for both Patient Advisors and HFH staff. These sessions strengthen communication, reinforce program expectations, and build skills needed for collaborative, patient-centered work.



# Annual Patient Advisor Retreat

Since 2017, PERC has hosted the Annual Patient Advisor Retreat to bring Patient Advisors and staff together to celebrate accomplishments and reinforce the importance of partnering with patients and families. Each Retreat offers meaningful speakers, participation from senior leaders, skill-building opportunities, networking and mingling, and chances to learn about councils, committees, and ongoing improvement efforts across the system.

In recent years, the Retreat has grown to include patients, caregivers, researchers, and healthcare teams from across Henry Ford Health and Michigan State University Health Sciences. This expanded focus highlights the vital role of patient and family advisors not only in healthcare improvement but also in patient and community engaged research. Together, these annual gatherings continue to strengthen collaboration, celebrate engagement, and advance our shared mission of elevating patient and family voices.

[Click here to view all posters from the Retreat.](#)



**Panel Session:** Patient Advisors and a Community Advisor shared their personal experiences and the impact of their engagement.



**Breakout and Collaboration Sessions** provided an interactive component to the event. Attendees pre-selected the session they wished to attend.



**Research Collaboration Sessions** allowed HFH and MSU staff to learn more about patient and community engagement tools, techniques and lessons learned.



**Poster Session & Networking Lunch:** Attendees viewed research and quality improvement posters highlighting the work of HFH and MSU councils, committees, and investigators.

# Patient Advisor Liaison (PAL)

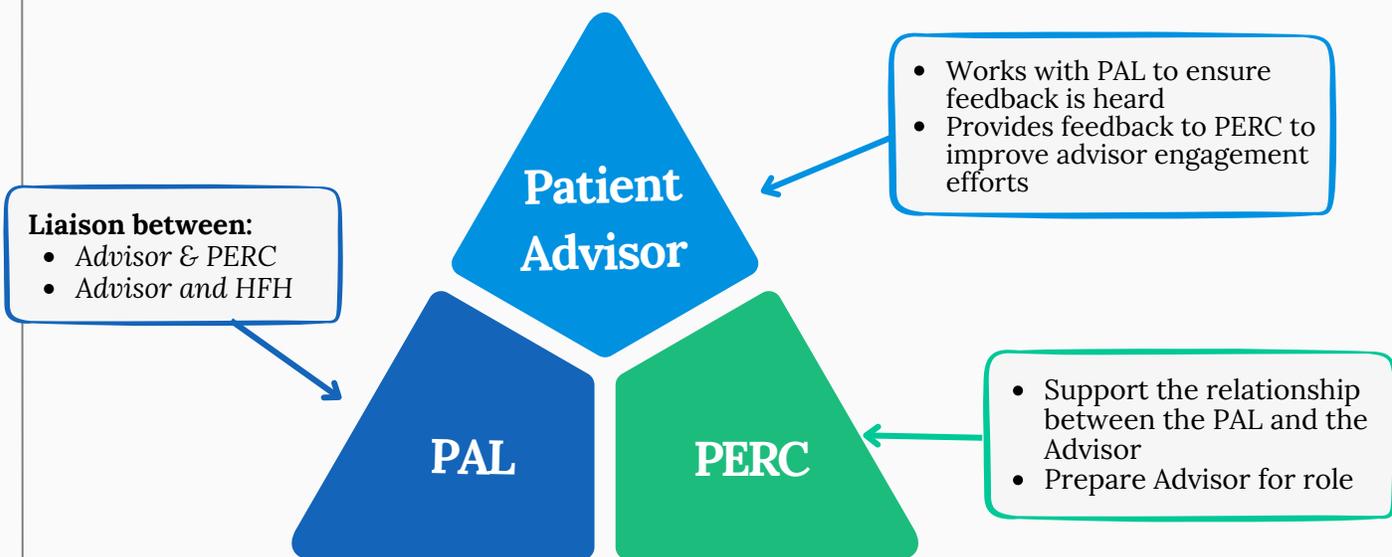
## Supporting Effective Patient Engagement Across Henry Ford Health

The PAL is the Henry Ford staff member who partners directly with Patient Advisors serving on committees, councils, and project teams. PALs play a critical role in ensuring Advisors are prepared, supported, and able to contribute meaningfully to improvement and research efforts. Their work helps ensure patient perspectives are heard, respected, and integrated into initiatives that strengthen the quality, safety, and overall care experience across the health system.

PALs serve as the primary point of contact for council/committee Patient Advisors and provide support before, during, and after meetings. Key responsibilities include:

- Preparing Advisors for meetings by sharing agendas, background materials, and expectations in advance
- Sending reminders and ensuring access to virtual links, documents, and pre-reading materials
- Clarifying the goals and purpose of meetings, projects, and discussions
- Sharing meeting notes or summaries within 1–3 days following meetings
- Communicating accomplishments, progress, and challenges to the PERC team
- Creating a supportive environment that encourages confident and meaningful participation

Through this work, PALs help create the conditions for strong partnerships and meaningful patient engagement that advance patient-centered efforts across the health system.



# Patient Advisor Placements

➡ **This is an interactive page.** Click on the placement you would like to read more about. By clicking on a placement, you will automatically navigate to that section of the summary.

## PATIENT & FAMILY ADVISORY COUNCILS (PFAC)

PFACs are groups of Patient Advisors on councils led by HFH team members (PALs). Council focuses on process improvement with feedback from patients/caregivers. PERC takes the lead on recruitment, strategic planning and development of council. PERC continuously supports council.

### Hospital based

Detroit Hospital PFAC ➡

Jackson Hospital PFAC

Macomb Hospital PFAC

West Bloomfield Hospital PFAC

Wyandotte Hospital PFAC

### Department specific

Cancer PFAC

Patient Involvement & Communication PFAC

Experience Transformation PFAC

Hermelin Brain Tumor PFAC

### Research

Seniors using Technology to Engage in Pain Self-management (STEPS) PFAC

Maternal Mental Health (MAMA) PFAC

## INDIVIDUAL ADVISOR PLACEMENTS

PERC facilitates the opportunity to a patient and/or caregiver voice to existing department committee meetings and/or research project teams. PERC will recruit and train patient advisor placed on department committee and teams.

In 2025 there were Patient Advisors that sat on twenty-two (22) department and leadership committees throughout the health system. [Click here to view the full list.](#) ➡

# Detroit Hospital PFAC

## SCOPE

The Detroit Hospital PFAC serves as a strategic partner to Henry Ford Hospital by embedding the voices, experiences, and priorities of patients and families into decision-making across departments and service lines. Members provide diverse perspectives to promote equity, inclusion, and patient-centered improvements. The PFAC advises leadership on major initiatives, operational changes, and patient-experience enhancements, and serves as a trusted resource for teams seeking authentic patient insight.

**Department**  
Care Experience

**Patient Advisor**  
**Liaisons (PAL)**

Joe Cafferty, Director  
Acute Care Services,  
Care Experience

Barbara Kuszak,  
Manager Care  
Experience

## KEY PROJECTS & ACCOMPLISHMENTS

### Emergency Department (ED) Redesign

- Reviewed signage, patient flow, and throughput to support a more efficient, patient-centered ED.
- Completed a tour of the redesigned ED and saw PFAC recommendations implemented.
- Post-Go Live data show a reduction in Door-to-Doc time, demonstrating measurable impact (**Figure 1**).

### Discharge Suite Development

- Assessed early design plans and provided recommendations to streamline patient transitions.
- Toured the completed suite and observed operational improvements.
- Data show a decrease in ED length of stay (**Figure 2**) for patients requiring inpatient beds.

### MyChart / Check-In Enhancements

- Provided input on check-in redesign features aimed at reducing wait times and increasing staff presence in waiting areas.

### Smoking Cessation Education Materials

- Reviewed educational resources and offered guidance to strengthen patient engagement.

### Public Submission Process Improvements

- Shared insights to help shape a more inclusive and user-friendly public submission pathway.

### Transplant Services Update

- Engaged in early conversations on evolving transplant criteria and community education needs.

### Community Comfort Item Initiative

- Partnered with Volunteer Services to explore community-supported comfort items (blankets, socks, etc.).

### Leadership Engagement with HFH President

- Met with Ronnie Hall, President of Henry Ford Hospital, for vision-setting and system updates; reinforced alignment between PFAC priorities and hospital strategy.



Figure 1: Post Go Live data shows decrease in Door to Doc time

	Pre-Go-Live	Post-Go-Live	On Hours	Off Hours
Median LOS: Admit/Obs.	973	962	1000	908

Figure 2: Post Discharge Suite Go Live data shows a decrease in ED length of stay



Pictured: Detroit PFAC Patient Advisors

# Jackson Hospital PFAC

## SCOPE

The Henry Ford Jackson Hospital PFAC brings together engaged community members to strengthen patient-centered care across the hospital. The council's scope includes learning about hospital services and challenges, offering real-time feedback on operations, and acting as ambassadors within the community. PFAC members collaborate with leadership to inform improvements in safety, quality, communication, and experience, while also participating on internal committees such as Patient Safety & Quality and the IRB. Their work centers on elevating patient and family voices to ensure care is safe, compassionate, and reflective of community needs.

Department  
Care Experience

Patient Advisor  
Liaisons (PAL)

Joe Cafferty, Director  
Acute Care Services,  
Care Experience

Amy Sayles, Manager  
Care Experience

## KEY PROJECTS & ACCOMPLISHMENTS

### Projects (New & Ongoing)

**Virtual Nursing Insights:** Provided patient and family feedback from pilot through hospital-wide rollout; advised on communication challenges and naming concerns; early data shows improving communication trends. **(Figure 1)**

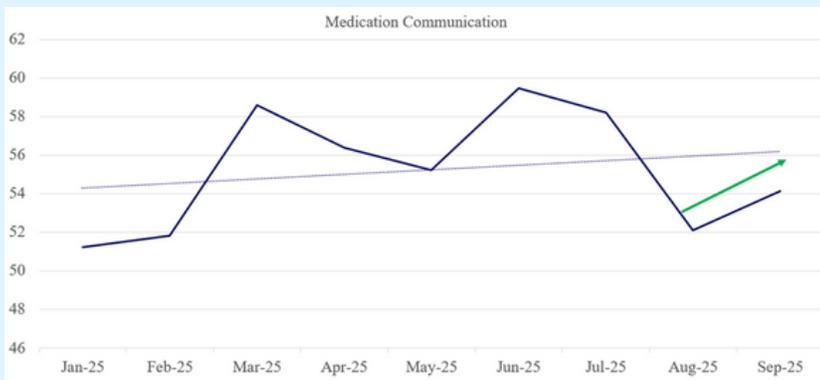


Figure 1: Adoption of Virtual Nurses for Admission, Discharge and Safety Checks

**Staff Appreciation Cart:** Continued rounding to recognize and support staff contributions.

**Compassionate Closet:** Supporting transition to a donation-based model; PFAC continues to monitor and stock inventory.

**Patient Lockers (Day Surgery & Waiting Areas):** Project in final approval phases with Surgical Services leadership and Space Committee review underway.

### Community Insights & Advocacy

- Elevated concerns about inconsistent hygiene kits and daily bathing; partnered with nursing leadership to review protocols and options.
- Provided ongoing feedback to Emergency Department leadership on patient perceptions, care experience, and community needs.



Pictured: Jackson PFAC Meeting

### Leadership Integration

- PFAC member reported insights to the Patient Safety & Quality Committee. Jackson PFAC Poster 2025
- PFAC representative participated on the Institutional Review Board to review and approve research projects.

# Macomb Hospital PFAC

## SCOPE

The Henry Ford Macomb PFAC partners with hospital and Emergency Department leadership to elevate patient and family perspectives in care delivery, safety, communication, and overall experience. The council provides guidance on programs, educational efforts, operational initiatives, and research activities that directly impact patients and families. Its scope includes offering feedback, evaluation, and recommendations; strengthening respectful partnerships between patients, families, providers, and hospital administration; serving as a bridge to the community; providing patient/family insights for staff education; and offering recommendations on facility design and wayfinding. Members commit to active participation, accountability, collaboration, and creating a space where all voices are heard.



Pictured:  
Macomb PFAC

**Department**  
Care Experience

**Patient Advisor**  
**Liaisons (PAL)**

Joe Cafferty, Director  
Acute Care Services,  
Care Experience

Brooke Shankin,  
Manager Care  
Experience

## KEY PROJECTS & ACCOMPLISHMENTS

### Honoring the End of Life Initiatives

- **No Patient Dies Alone Program:** PFAC supported this compassionate initiative where trained volunteers or staff provide presence and comfort to patients nearing end-of-life without family present, ensuring dignity and emotional support.
- **Dove Door Sign:** Implementation of a subtle door sign symbolizing that a patient has passed, encouraging quiet, sensitive behavior from staff and honoring the space with care and compassion. (Figure 1)
- **The Pause:** Adoption of a practice allowing clinical teams to briefly pause and honor a patient's life after they pass; badge buddies were created to guide respectful dialogue. (Figure 2 & 3)



Figure 1: Dove Door Sign



Figure 2: The Pause badge buddies

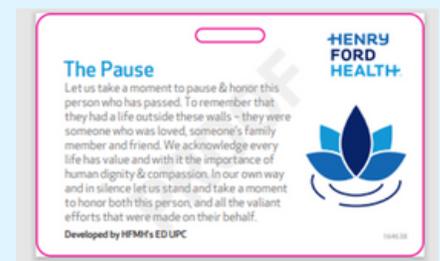


Figure 3: The Pause badge buddies

### Cancer Support Group Awareness Improvements

PFAC members identified that many patients were unaware of available cancer support groups. Recommendations were made to:

- **Increase visibility of support group** information on inpatient oncology units
- **Improve website accessibility** so patients can easily find support offerings

These actions aim to reduce information gaps and support patients earlier in their cancer journey.

### Emergency Department Partnership & Brochure Development

HFM Emergency Department (ED) brochure includes feedback provided by our advisors. The goal of the brochure was to provide patients with basic expectations on things like arrival, triage, wait times, decision making and visitors.

# West Bloomfield Hospital PFAC

## SCOPE

The Henry Ford West Bloomfield (HFWB) PFAC ensures that patient and family voices directly shape safety, quality, communication, and improvement priorities across the West Bloomfield campus. The PFAC partners closely with the Care Experience team to provide patient-centered insights on materials, processes, policies, and communication tools used across clinical areas. Their purpose is to elevate patient perspectives in improvement efforts, foster compassionate and comprehensive care, and strengthen patient-provider-family partnerships.

## KEY PROJECTS & ACCOMPLISHMENTS

### Bedside Shift Report (BSSR) Brochure

- Simplified language, clarified the patient/family role, and refined layout.
- Improved patient understanding of the bedside shift report, strengthening communication, transparency, and engagement during care transitions. (See page 17)

### Left Without Being Seen/Completing Service Letter (LWOBS)

- Redefined and redesigned the letter given to patients who leave the ED without treatment; launched September 2025.
- More empathetic, clearer communication improves trust and reduces frustration while supporting safe follow-up care decisions.

### Medication Education Pamphlet

- Revised content to reduce complexity and lessen anxiety for patients beginning new medications.
- Increased patient confidence in medication management, reduced anxiety, and strengthened safety through clearer instructions.

### Patient-Reported Outcomes (PRO) Questionnaire Improvements

- Provided feedback on ambulatory clinical questionnaires to enhance readability and patient usability.
- Made the tool more patient-friendly, added a progress bar, and enabled auto population of previously completed fields- reducing burden and improving completion accuracy.

### After-Hours Patients & Visitors Welcome Guide (Figure 1)

- Improved clarity and simplified content for after-hours navigation, safety, and directional information.
- Reduced confusion and improved wayfinding for patients and visitors entering the facility after hours.

**Department**  
Care Experience

**Patient Advisor**  
**Liaisons (PAL)**

Joe Cafferty, Director  
Acute Care Services,  
Care Experience

Jennifer Manciel,  
Manager Care  
Experience

Hannah Leinonen,  
Care Experience  
Consultant



Figure 1: After-Hours Patients & Visitors Welcome Guide

# Wyandotte Hospital PFAC

## SCOPE

The Henry Ford Wyandotte PFAC supports the hospital by strengthening communication between patients, families, and staff, ensuring that the patient voice remains central to all improvement efforts. The council partners with multidisciplinary leaders on a wide range of initiatives—from communication materials and patient-facing processes to environmental updates and engagement practices—helping shape projects that directly impact care quality and experience. The group is committed to broadening member diversity, maintaining strong relationships with operational leaders, and staying actively engaged with frontline teams to enhance the patient experience across the hospital.

## KEY PROJECTS & ACCOMPLISHMENTS

### Bedside Shift Report (BSSR)

- Provided ongoing guidance on the patient-facing handout explaining BSSR and its benefits. The collaboration contributed to strong systemwide BSSR recognition and measurable improvements shown in site data. (See page 17)

### Purposeful Hourly Rounding Program (Figure 1)

- Redefined and redesigned the letter given to patients who leave the ED without treatment; launched September 2025.
- More empathetic, clearer communication improves trust and reduces frustration while supporting safe follow-up care decisions.

### Leader Rounding Questions

- Requested to assist in development of questions for Leader Rounding operationalized at HFWH in 2025 with 52% of Leaders currently rounding to make a difference in patient care.

### ED Lobby Liaison Project

- Contributed feedback to enhance the experience for Emergency Department patients through improvements in communication and service during lobby wait times.

### Behavioral Emergency Response Team Review

- Reviewed and offered recommendations for processes in both ED and inpatient settings to support patient and staff safety.

### Relationship-Based Care Training (Figure 2)

- Partnered with the Chief Nursing Officer to review Relationship-Based Care and were invited to participate in staff trainings by sharing their personal patient journeys. Staff trainings called “Reigniting The Spirit of Caring Workshop”.

Figure 1: Responsiveness of Hospital Staff increased by 13% from previous year

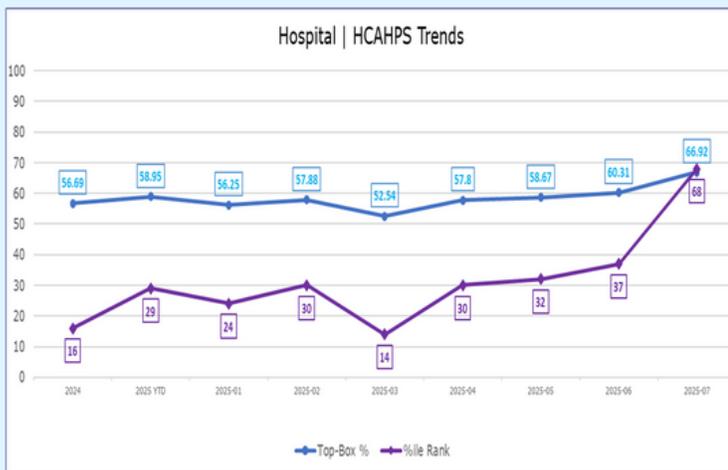


Figure 2: PFAC was asked to have a representative for Reigniting The Spirit of Caring initial kick off



Department  
Care Experience

Patient Advisor  
Liaisons (PAL)

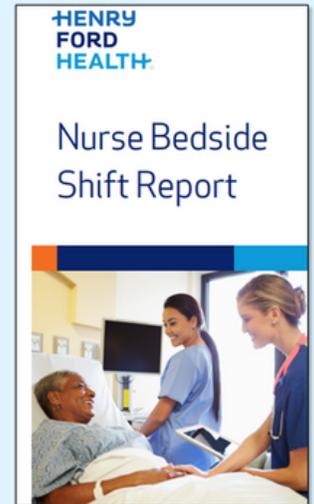
Joe Cafferty, Director  
Acute Care Services,  
Care Experience

Jennifer Manciel,  
Manager Care  
Experience

# Patient Advisor Feedback Highlight

## Bedside Shift Report (BSSR)

**Overview:** Bedside Shift Report (BSSR) is a patient-centered approach that brings key parts of the nursing shift handoff into the patient's room. This model ensures that patients and families understand the plan of care, can ask questions, and feel actively included in decision-making. Across Henry Ford Health, Patient Advisors have played an essential role in strengthening how BSSR is communicated and practiced.



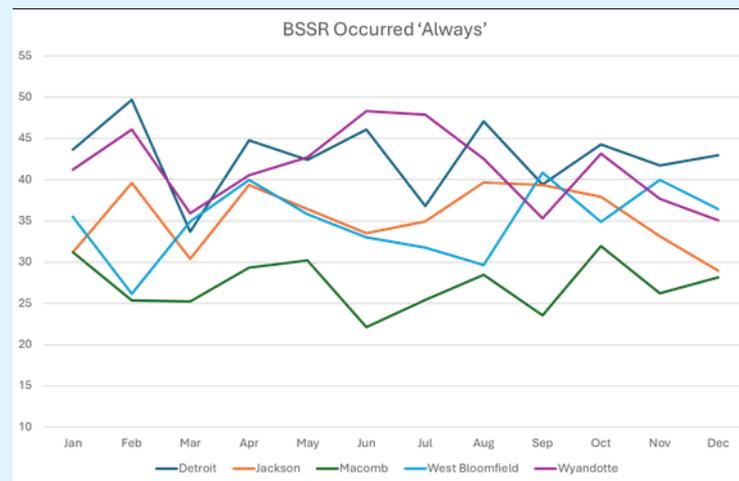
### PFAC Contributions Across Sites

- ✓ **Improved Patient-Facing Materials:** improved readability, expanded explanations of the patient's role, and ensured the content felt welcoming rather than clinical.
- ✓ **Supporting Engagement at the Bedside:** Advisors helped nursing teams shape clearer, more predictable shift-change communication.
- ✓ **Strengthening Consistency in Practice:** PFAC input supported measurable improvements in BSSR performance and highlighted the value of reliable, patient-centered communication. **(Wyandotte)**
- ✓ **Enhancing Patient Experience Education:** Patient Advisors helped clarify the BSSR brochure to better show how patients and families can participate, strengthening relationships with nursing teams. **(HFWB)**

### Data Highlights (2025)

\*Based on systemwide BSSR "Always" percentages

- Across all Henry Ford hospitals, BSSR "Always" scores ranged between **30-50% throughout 2025**, demonstrating stable and consistent adoption.
- **Wyandotte and Henry Ford Hospital (Detroit)** were the top performers, consistently reaching **45-50%** in several months.
- **West Bloomfield** maintained steady performance, averaging **35-40%** across the year.
- **Macomb** showed variable but improving performance, recovering from mid-year dips to **~26%-31%**.
- Many hospitals saw **noticeable improvements** in the late summer and fall, aligning with PFAC-driven communication refinements and staff education.



## Why BSSR Matters

Builds transparency and trust between patients, families, and care teams

Ensures patients can clarify information, ask questions, and understand their care plan

Contributes to improved satisfaction, safety, and patient confidence in their care

Reduces gaps in communication during one of the most critical handoff moments in healthcare

# Cancer PFAC

## SCOPE

The Cancer PFAC partners with Cancer Service Line leadership to elevate patient and caregiver perspectives across programs, communication, and care delivery. The council advises on initiatives such as nurse navigation, supportive oncology, palliative care, survivorship, financial support, research engagement, and patient education—helping ensure services are accessible, understandable, and responsive to patient needs. Through collaboration with clinical, research, and support teams, members help shape a more compassionate and patient-centered cancer experience at Henry Ford Health.

Department  
Oncology

Patient Advisor  
Liaisons (PAL)

Danielle Nelson,  
Director- Oncology

## KEY PROJECTS & ACCOMPLISHMENTS

### Cancer Biobanking

- Patient Advisors met with Dr. David Kwon and leaders of the Cancer Biobank initiative to learn about efforts to build a comprehensive biobank to support future research first in pancreatic cancer and then expanding to all tumor types. Advisors provided insight into patient-facing communication and engagement strategies.

### Art Therapy

- Advisors met with art therapist Calli Perry to learn more about the art therapy program and related support groups. Members offered feedback on program structure, accessibility, and opportunities to expand offerings.

### Patient Support Groups & Programming

- Advisors received updates from Sarah Shore (Resource & Education Coordinator) on patient support groups and programming across the cancer program. Members shared feedback based on their experiences and identified unmet needs to help strengthen offerings. They also provided input on the support group survey and feedback process.

### Research Feedback: “Testing Virtual Body Mapping to Meaningfully Engage Black & Hispanic/Latinx Adults with Cancer”

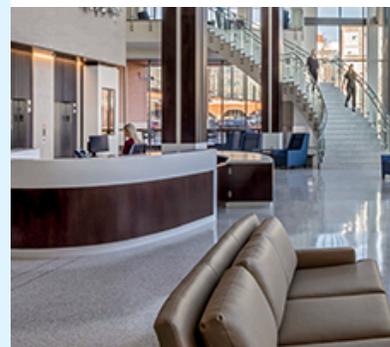
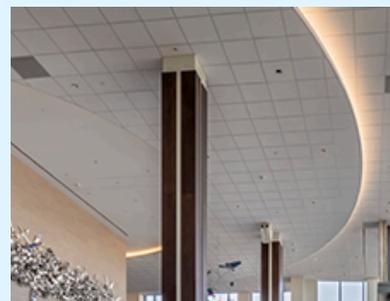
- Dr. Sara Santarossa (PHS Dept) met with the council to gather patient feedback on key elements of her research project. The discussion helped shape the proposal, with the goal of incorporating PFAC input and preparing a letter of support from the Patient Advisors.

### Nurse Navigation

- The nurse navigation leadership team provided updates on team structure, patient volumes, and progress related to the newly adopted intake process—an initiative previously reviewed by the PFAC. Advisors reviewed metrics, discussed patient experience impacts, and provided recommendations for future enhancements.

### Supportive Care Clinic & Survivorship

- Social Work Manager Camille Romain and Patient Programming & Education Manager Carey Papalekas shared preliminary plans to introduce supportive oncology services earlier in the care journey and strengthen survivorship support. Advisors offered input on communication strategies and patient education needs.



# Patient Involvement & Communication PFAC

## SCOPE

The Patient Involvement and Communication Council (PICC) works with teams across Henry Ford Health to ensure patient and caregiver perspectives shape systemwide communication, education, and care processes. The council helps improve patient-facing materials, identify communication gaps, and strengthen engagement in health care services. Through their insights and diverse experiences, members support clearer, more accessible information and contribute to a more patient-centered approach across the organization.

## KEY PROJECTS & ACCOMPLISHMENTS

### System Inpatient Guidebook (Figure 1)

- Combined all hospital guidebooks into one systemwide resource.
- Collaborated with departments to verify accurate location and service information.
- Reviewed formatting, images, language, and key information to ensure clarity, cultural inclusivity, and relevance for patients and caregivers.

### Making Decisions About Life Support Treatments Brochure

- Revised the emergency and life support information for clarity and plain language.

### Stay Home Safe Program (Habitat for Humanity)

- Offered feedback on program goals and advertisements to strengthen outreach and support home safety initiatives.

### Peer-to-Peer Digital Skills Training

- Evaluated digital training content, terminology, and methods to improve accessibility for patients with varying levels of digital literacy.

### Health Literacy & Patient Education Standards Review

- Analyzed system education standards and provided recommendations to improve clarity, consistency, and patient comprehension.

### Michigan Collaborative Patient Terminology Initiative

- Participated in discussions on respectful and appropriate terminology for “frail” individuals preparing for surgery.

Pictured: Patient Involvement & Communication PFAC



Department  
Patient Experience

Patient Advisor  
Liaisons (PAL)

Angela Murphy,  
Manager Health  
Literacy & Patient  
Education

Laura Gooseberry,  
Patient Education  
Designer

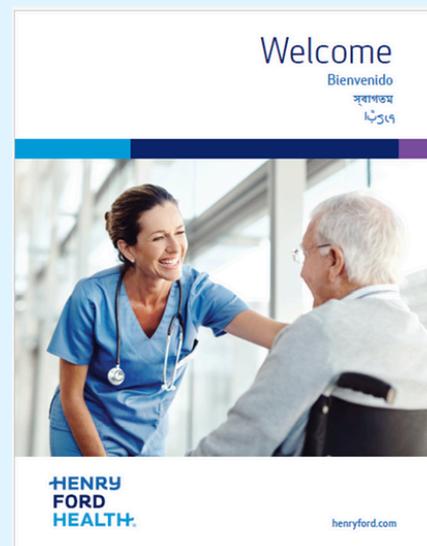


Figure 1: Updated System Inpatient Guidebook

# Experience Transformation PFAC

## SCOPE

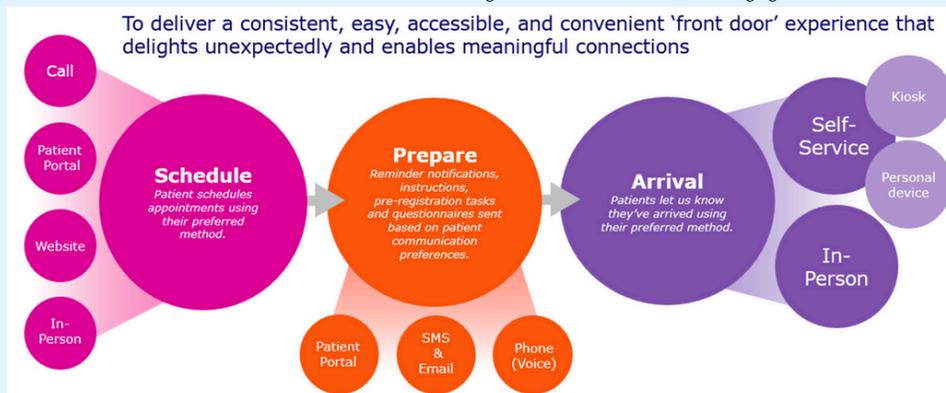
The Experience Transformation PFAC partners with Access Technology & Experience, Care Experience, Digital Experience & Web Strategy, Experience Insights & Analytics, and Virtual Care to help Henry Ford Health deliver consistent, easy, and accessible experiences across all patient touchpoints. The council tests new tools, reviews communication and web features, and identifies barriers in the “front door” experience, ensuring solutions are shaped by real patient needs. Through ongoing feedback and collaboration, members help create more seamless, convenient, and patient-centered experiences.

## KEY PROJECTS & ACCOMPLISHMENTS

### Pre-Visit Patient Engagement (Figure 1)

- Tested new tools to improve the Front Door Experience before launch.
- Reviewed Hello World messaging updates, including future email/voice features.
- Provided input on referral scheduling and questionnaire delivery improvements.
- Evaluated Self-Arrival (Hello Patient) to support mobile check-in and bypassing the front desk.

Figure 1: Pre-Visit Patient Engagement



### Provider Search Feedback

- Evaluated how patients use the Find a Doctor tool on henryford.com.
- Identified key search behaviors, including preferred attributes and locations.
- Emphasized need for clearer language, strong insurance filters, and complete provider profiles.
- Supported alignment of Ascension provider data into Epic for unified patient records.

### Intelligent (IVA) Systems

- Shared feedback on navigation challenges and need for easier access to live support.
- Highlighted patient dissatisfaction with the original IVR system.
- Helped drive improvements: keypad (DTMF) options restored, appointment confirmation added, and callback queues activated.

## OTHER PROJECTS

Clinical Questionnaires  
Same Day Care Web Design  
Hello Patient (Self-Arrival)  
E-Consult Feedback  
Provider Search Feedback  
Legacy Ascension Wave 1 Services

Hello World (Patient Messaging)  
Patient Portal Replacing MyChart on Web  
MyChart April Upgrade  
Referral Scheduling Process  
Real-Time Patient Feedback  
Local vs Toll-Free Numbers

### Department

CX Insights and Analytics

### Patient Advisor Liaisons (PAL)

Cailin Gauthier,  
Senior Analyst  
Experience Analytics

Julie Goldstein-Dunn,  
Director of Experience Insights & Analytics,

### Henry Ford Support Staff:

John Bollinger,  
Jessica Clarey,  
Missy Ewald,  
Laticia Miles,  
Ahlam Rizk,  
Stephanie Ryan,  
Keely Siciliano,  
Courtney Stevens

# Hermelin Brain Tumor Center PFAC

## SCOPE

The Hermelin Brain Tumor Center PFAC brings together patients, caregivers, and clinical leaders to strengthen education, communication, and patient-centered innovation across the Brain Tumor Center. The council provides insight on care experiences, supports development of patient- and caregiver-focused programming, and advises clinicians on sensitive discussions, consent processes, and research engagement. Through strategic planning, event co-design, and direct feedback, members help guide the continual improvement of services, resources, and patient support within the Brain Tumor Center.

## KEY PROJECTS & ACCOMPLISHMENTS

### HBTC Patient Activities Flyer

- Reviewed and made revisions to enhance clarity, relevance, and accessibility for patients and families.

### Strategic Planning with HBTC Leadership

- Participated in a planning session with the Center's co-director to establish priorities and guide improvement efforts for the remainder of 2025.

### Brain Tumor Patient & Caregiver Conference

- Co-designed focus areas and programming for the annual symposium, ensuring sessions reflected patient and caregiver priorities and included PFAC representation throughout.



*Pictured: Brain Tumor Patient & Caregiver Conference*

### Clinical Communication & Consent Guidance

- Provided ongoing feedback to physician leads on the timing of difficult conversations, best practices for patient consents, and approaches used in clinical trials.

### Statewide Brain Tumor Awareness Advocacy

- PFAC members attended the State of Michigan declaration recognizing May as Brain Tumor Awareness Month.

### Head for the Cure 5K Participation

- Joined the 12th Annual event, contributing to an effort that raised more than \$215,000 and engaged 1,800 participants.



*Pictured: Head for the Cure 5K*

Department  
Neurology

Patient Advisor  
Liaisons (PAL)

Nestelynn Gay,  
Patient Resource  
Coordinator

Lisa Scarpace,  
Project Manager

Dr. Tobias Walbert,  
Neuro-Oncologist

# Seniors using Technology to Engage in Pain Self-management (STEPS) PFAC

## SCOPE

The STEPS PFAC partners with the study team to ensure that the Seniors using Technology to Engage in Pain Self-management trial is shaped by real patient and caregiver experiences. The council provides ongoing guidance on study design, recruitment strategies, intervention content, communication materials, and participant engagement. By sharing insights on barriers, motivators, and usability, members help strengthen the effectiveness, clarity, and accessibility of the STEPS program for older adults living with chronic pain. **STEPS is a 5-year randomized controlled trial funded by the National Institute on Aging (NIA; R01AG071511).** [Link to website.](#)

**Department**  
University of Michigan School of Public Health in collaboration with Henry Ford Health

**Funding Source:**  
National Institute on Aging

## KEY TOPIC AREAS

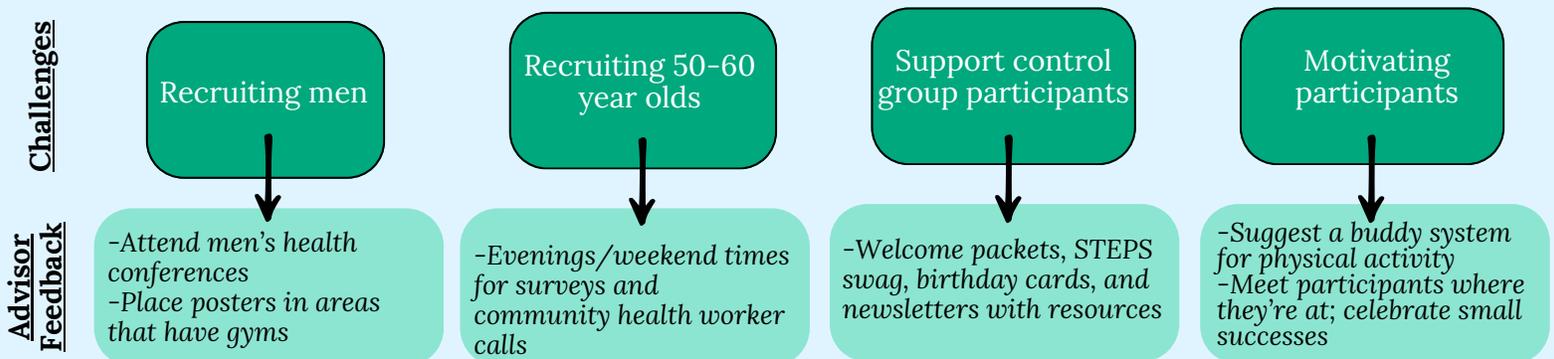
The Patient Advisors have been integral in designing and implementing the STEPS study. The research team met with the PFAC team nine times over Webex or Zoom. Some topics of discussion at meetings have been (but not limited to):



**Patient Advisor Liaisons (PAL)**

Rebecca Lindsay,  
Project Manager  
University of Michigan

Study challenges discussed with PFAC:



## NEXT STEPS:

- 2-month follow-up surveys are completed (378)
- 12-month follow-up surveys are in progress (325 completed)
- The study team is completing baseline and 2- month data analysis
- The PFAC is discussing dissemination strategies and opportunities, which include a 2- page summary of study results for study participants and to share at community-facing events

# MAternal Mental health (MAMA) PFAC

## SCOPE

The MAMA PFAC brings together patients, caregivers, researchers, providers, and community members to build capacity for patient-centered outcomes research in maternal mental health. The council works to create shared understanding across all stakeholders, strengthen patient-centered engagement practices, and expand PERC's advisor infrastructure. Through storytelling and other engagement tools, members collaboratively develop and prioritize a PCOR/CER research agenda, identify tailored dissemination strategies, and explore funding opportunities to advance this work. The council serves as a central space for co-creation, ensuring maternal mental health research is shaped directly by those with lived experience. **Using storytelling to build capacity for PCOR/CER in MAternal Mental health (MAMA, #EACB-29002).** [Link to website.](#)

## KEY TOPIC AREAS

In 2025, the council created the MAMA PCOR/CER Maternal Mental Health **Research Agenda** and developed a **dissemination plan** that incorporated insights from patients, caregivers, providers, and the broader community.

### Research Agenda

Through PFAC meetings, the group developed an agenda that includes PCOR/CER questions across four main domains:

#### Domain

#### Question 1

#### Expectation vs. Reality

*How does the sharing of lived experiences by a peer compare to the sharing of information by a provider in reducing adverse maternal mental health outcomes?*

#### Education & Awareness

*How do targeted educational strategies (e.g., considering learning style, literacy levels, etc.) compare to usual care for improving knowledge and awareness of perinatal mental health among patients?*

#### Grief & Trauma

*What are the comparative benefits of group-based cognitive behavioral therapy (CBT), interpersonal psychotherapy (IPT), and dialectical behavioral therapy (DBT) for pregnant and postpartum individuals with depression compared to patients that did not receive anything (standard of care)?*

#### Support

*In birthing people, how does perceived social support from online maternal communities compared to group peer support interventions (e.g., support groups, group prenatal care) influence prenatal and postnatal depression?*

### Dissemination Plan

**PFAC Contribution:** Used adapted PCORI Dissemination Toolkit worksheets, collaborated through breakout groups and an interactive Padlet board, and shared ideas both in real time and asynchronously.

- **Audience:** Maternal mental health organizations, clinicians, policymakers, researchers/students, partners/caregivers.
- **Messaging:** Scientific and public-friendly versions; emphasizes patient-centered development.
- **Visibility:** Website posts, open-access publication, conference presentations, social/visual media.
- **Outreach:** Storytelling, simple visual summaries, and stakeholder networks/listservs across local to national levels.

**Department**  
Public Health  
Sciences & Center  
for Health Services  
Research

**Funding Source:**  
Patient Centered  
Outcomes Research  
Institute (PCORI)

### Patient Advisor Liaisons (PAL)

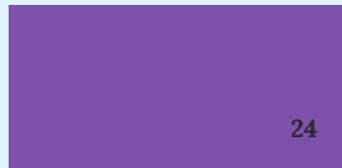
Dr. Sara Santarossa,  
Assistant Scientist,  
Public Health  
Sciences

Dr. Amy Loree,  
Associate Scientist,  
Center for Health  
Services Research

# Individual Placements

Incorporating 1-2 Patient Advisors into existing department committee meetings and/or research project teams.

- » **Henry Ford Hospital Stroke Transitions of Care Committee**  
Megan Brady, Clinical Program Manager for Stroke
- » **Pursuing Equity Patient Care Committee**  
Shiny Isaac, Project Manager of Community Health, Equity & Wellness (CHEW)
- » **Quality Improvement Patient Safety, HF Macomb Hospital**  
Brooke Shankin, Care Experience Director
- » **Ethics Committee, Henry Ford Hospital**  
Hesham Shaban, Nephrologist & Lead Ethicist
- » **Ethics Committee, Henry Ford West Bloomfield**  
Dr. Emily Hurst, Director, Residency Training Program
- » **Board of Trustees, Quality, Henry Ford Hospital**  
Mary Voutt-Goos, Director, Quality Safety Initiative
- » **Palliative Care Committee**  
Rashonda (Shon) Mcgee, Group Practice Director
- » **Patient Education Committee**  
Angela Murphy, Manager, Organizational Health Literacy & Patient Education
- » **Quality and Safety Committee**  
Bonnie Calcaterra, Lead, Governance Specialist
- » **Quality Safety & Reliability Council**  
Dr. Edward Pollak, Chief Quality Officer, Henry Ford Hospital  
Eric Wallis, Senior Vice President, Chief Nursing Officer
- » **Readmissions Committee**  
Sue Piatak, Manager, Clinical and Quality Transform

- 
- » **Radiology Committee**  
Robyn McDermaid, Director of Radiology Product Line  
Corey Parrett, Management Engineer
  - » **Henry Ford Allegiance Board Quality Committee**  
Amy Sayles, Care Experience Manager
  - » **Henry Ford Allegiance Community Engagement Committee**  
Amy Sayles, Care Experience Manager
  - » **Henry Ford Allegiance IRB Board**  
Amy Sayles, Care Experience Manager
  - » **Mental Health Research Network**  
Amy Loree, Assistant Scientist, Center for Health Services Research, HFH
  - » **SAMHSA Zero Suicide**  
Amy Loree, Assistant Scientist, Center for Health Services Research, HFH
  - » **Cancer Screening Research Network (CSRN) Board**  
Christine Neslund-Dudas, Associate Scientist, Public Health Sciences, HFH
  - » **Cancer Screening Research Network (CSRN) Advisory Taskforce**  
Christine Neslund-Dudas, Associate Scientist, Public Health Sciences, HFH
  - » **Population-based, Embedded, and Personalized Research in Real-World Settings (PEPRRS) Center**  
Jordan Braciszewski, Senior Scientist, Center for Health Services Research, HFH
- 
- 
- 

# Special Achievements & Initiatives

## Re-Igniting the Spirit of Caring Workshops

This two-day learning experience at Henry Ford Health Wyandotte Hospital supports staff in strengthening relationship-based care. Through guided reflection and discussion, participants explore their relationships with themselves, colleagues, and patients and caregivers. The **workshop features a patient or caregiver story** that highlights what matters most in care, helping teams recognize, honor, and integrate patient and family voices into everyday practice while sustaining compassion in today's healthcare environment.

**23 Patient Advisors participated in the workshops in 2025**

*"It was an empowering and meaningful experience to be able to share my story with people who were genuinely interested in the lived experiences of their patients and learning more about where there might be gaps in their care."*

*-Patient Advisor*



## Conferences

Patient Centered Outcomes Research Institute (PCORI) Learning Network in Washington, DC

**1 Patient Advisor attended**

2025 Health Care Systems Research Network (HCSRN) Annual Conference in St. Louis, MO

**1 Patient Advisor attended, 2 Patient Advisors presented on a Panel**



Panel titled "Empowering Patient Partners: Training for Meaningful Engagement in Research"

## External Placements

### Michigan Hospital Association Keystone Board

Collaborative of Michigan community hospitals focused on achieving better care for individuals, better health for populations and lower per-capita costs across Michigan.

**1 Patient Advisor serving on Board**

### Michigan Hospital Medicine Safety Consortium (HMS) Council

A collaborative dedicated to enhancing patient safety and quality of care across the state of Michigan.

**10 Patient Advisor serving on Council**

## Digital Skills Training Program for Detroit Residents

Henry Ford Health partnered with a digital literacy program to offer free technology education for participants of all skill levels. The program provided devices, a Google Chromebook, one year of home internet, and instruction focused on essential digital, healthcare access, and career skills.



**5 Patient Advisors completed the Program**

## System Surveys

### Celebrating Legacy Survey

Henry Ford Health developed an engaging, interactive digital display highlighting key achievements of Henry Ford Hospital and Henry Ford Medical Group clinicians, researchers, and team members. The display was installed near the cafeteria at Henry Ford Hospital, adjacent to the Bigby Coffee stand.

### Community Needs Assessment Survey

Every three years, Henry Ford completes a Community Health Needs Assessment (CHNA) to better understand the health of the people we serve. This survey is for people who live in Genesee, Jackson, Livingston, Macomb, Oakland, St. Clair, and Wayne counties. In this year's survey, we want to focus on 3 areas which we know greatly impact our communities: mental and behavioral health, chronic disease, and maternal and infant health.

### Destination Grand Logo Survey

The Destination Grand team invited Patient Advisors to complete a survey that collected feedback on parking garage design preferences. The results of the survey will be used to help develop patient-friendly wayfinding signage in the new build.

## 2025 Patient Advisor Research Forum

PERC hosted this virtual Forum to provide investigators and research teams with structured feedback from Patient Advisors. The sessions supported grant applications and letters of intent by incorporating early patient input to strengthen research design, feasibility, and impact. PERC coordinated advisor recruitment, logistics, and investigator preparation. Research teams presented their projects during 30–60 minute virtual sessions to receive direct Patient Advisor feedback.

**4 Investigators participated** and gathered feedback from advisors to help with their grant submissions. *(2 grants were funded, 1 received a high score, and 1 is still waiting for the funding announcement)*

**30 Patient Advisors participated**

*"The researcher seemed genuinely interested in our feedback. He was so open to our input and listened attentively. I felt like our input was really helping him to better frame his study moving forward."*  
**-Patient Advisor**

*"The most valuable feedback I received was on the scope of the project. It really helped to have the patient advisors bring up topics that I hadn't considered as potentially being important to the study. I also appreciated some validation that they were interested in the long-term goal of the work."*  
**-Researcher**



# Research & Services

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# PERC Services

## Core Service within the Department of Public Health Sciences

### GRANT FUNDED PFAC

10-15 Patient Advisors placed on council led by HFH team member(s). Council focuses on process improvement with feedback from patients/caregivers. PERC can take the lead on recruitment, strategic planning and development of council. PERC continuously supports the councils.

### FOCUS GROUPS

Small group interview with patients/caregivers to gather thoughts and feedback on certain topics. PERC can help develop a moderator guide of questions to ask participants. We also will note take and/or record conversation and have transcribed.

### INTERVIEWS

In depth one-on-one conversation with patient/caregiver. PERC can help develop a guide of questions to ask participants. We also will note take and/or record conversation and have transcribed.

### SURVEYS

A great tool for quick and easy responses from the patient advisor pool. PERC will develop the survey, distribute to targeted audience and pull response results.

### RECRUITMENT

The Patient Advisor pool consists of near 400 patients and caregivers. This diverse group of participants are very receptive and engaged. PERC utilizes this pool for all forms of patient engagement. If desired audience does not exist within the patient advisor pool, PERC can help identify specific demographics outside of the pool. We will develop recruitment marketing materials, conduct outreach, and schedule participant interaction.

### PATIENT CENTERED RESEARCH DESIGN

Research studies designed to increase collaborative efforts between researchers and the participants (patients). Engagement, knowledge exchange and dissemination, as well as action and reflection are key components of these types of designs. Examples include: photo-voice, body-mapping, social network analysis, social media analysis, community-academic partnerships, participatory action research. PERC can assist in all aspects of study design and execution.

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[Click here to submit an intake form to collaborate with PERC!](#)

# 2025 PERC Funded Projects

PERC is a Core Service within the Department of Public Health Sciences, partnering with internal and external teams on grant-funded research and quality improvement projects. PERC provides consultation, stakeholder engagement, qualitative and mixed-methods support, and project management across a diverse portfolio. The following list highlights 2025 projects that reflect our commitment to patient-engaged research and improved care delivery across the system.

In addition to collaborating on projects across the system, PERC also leads its own funded grants with PERC investigators serving as Principal Investigators. (PAGE 23)

PERC Service Categories

- Engagement** – Patient Advisor/participant recruitment, coordination
- Facilitation**– Interview, focus groups, advisory committees
- Methods**– Patient-centered study design
- Data** – Preliminary or full qualitative analysis

## PERC Collaborator Projects

Project	Funder	PI	PERC Role
Cancer Screening Research Network (CSRN) ACCrual, Enrollment, and Screening Site (ACCESS)	NCI	Christine Neslund-Dudas	Engagement + Facilitation
Epidemiology of multimorbid pediatric atopic and airway diseases and the impact of prenatal maternal environmental exposures and placental epigenetics (ECHO-CANOE)	NIH	Jennifer Straughen, Amy Eapen	Engagement + Facilitation + Data
Enhancing digital CBT-I to improve adherence and reduce disparities	NIH/NHLBL	Philip Cheng	Facilitation + Methods + Data
A multi-sensor machine learning approach to precision sleep tracking for nightshift workers (SENSE)	NIH/NHLBL	Philip Cheng	Facilitation + Methods + Data
A pilot of a personalized circadian mHealth to improve sleep in night shift workers (SAIL)	NIH/NHLBL	Philip Cheng	Facilitation + Methods + Data
Pediatric hereditary angioedema – the Body Mapping in HAE (BOMAH)	US Hereditary Angioedema Association	Alan Baptist	Engagement + Facilitation + Methods
A Nursing Program for Advancing Training in Health and Social Determinants (N-PATHS)	NIH	Ashlee Vance	Engagement + Facilitation + Methods
Quality Improvement Project for Diagnosis and Treatment of Obesity	Eli Lilly	Suki Singh	Engagement + Facilitation + Methods + Data

\$1M+

\$500K-\$999k



\$100K - \$499K

Under \$100K

Project	Funder	PI	PERC Role
Identifying Multi-Level Barriers & Facilitators of Lung Cancer & Cardiovascular Disease Preventive Services in Patients Undergoing Lung Screening	HFH + MSU Cancer Pilot Grantv	Christine Neslund-Dudas	Engagement + Facilitation + Methods
Assessing how multilevel factors shape disparities in lung cancer screening	NIH	Natalie Del Vecchio*	Engagement + Facilitation
Genentech/Premier Annual Eye Screening for Black Adults with Diabetes	Genentech	Denise White Perkins	Engagement + Facilitation + Methods + Data
Building capacity with homeless-experienced veterans to shape patient-centered CER in Los Angeles, CA	PCORI	Melissa Chinchilla*, Matthew McCoy*	Methods
Trust and Vulnerability in Patients with Head and Neck Cancer	MSU	Sam Tam, Joseph Hamm*	Engagement + Facilitation + Methods + Data
Surveying the landscape of tobacco treatment practice in the state of Michigan	MDHHS	Amanda Holm	Engagement + Facilitation
Identifying Multi-Level Barriers & Facilitators of Lung Cancer & Cardiovascular Disease Preventive Services in Patients Undergoing Lung Screening	HFH + MSU Cancer Pilot Grantv	Christine Neslund-Dudas	Engagement + Facilitation + Methods
THRIVE Rewards Program	Internal HFH	Beth Thayer	Engagement + Facilitation + Methods + Data
CHASS Cervical dysplasia task force	Internal HFH	Lindsay Martin-Engel	Data
IMAGEN II: Improving Access to Genetic Testing and Considering Advanced Prostate Cancer Patient Opinions on Barriers and Decision-Making Factors	Internal HFH	Clara Hwang	Engagement + Facilitation + Methods
A Multiphase Optimization Strategy to Reduce Delays in Management of Chronic Nephrostomy Tubes	Urology Cares Foundation	Nabeel Shakir	Engagement + Facilitation + Methods + Data
Interventions to Increase Health Equity and Utilization of Patient Reported Outcomes (PROs) among Cancer Patients	NCI	Sam Tam, Eric Adjei Boakye	Engagement + Facilitation + Methods + Data
THRIVE Rewards Program	Internal HFH	Beth Thayer	Engagement + Facilitation + Methods + Data

\*denotes non-Henry Ford Health employee

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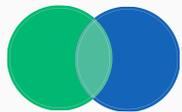
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# PERC Led Awards

1. **HFH + MSU Patient Engaged Research Conference-** Community Building Funding Mechanism (Henry Ford Health + Michigan State University Health Science partnership)
2. **Using storytelling to build capacity for PCOR/CER in MAternal Mental health (MAMA)-** Engagement Award from Patient Centered Outcomes Research Institute (PCORI)
3. **Patient Engaged Validation of the PEIR Survey by Inclusion, Diversity, Equity, Acceptance and Safety (IDEAS)-** Science of Engagement Award from Patient Centered Outcomes Research Institute (PCORI)



## HFH + MSU Patient Engaged Research Conference

Principal Investigators: Sara Santarossa (HFH), Krista Walker (MSU)  
 Source of Support: Community Building Funding Mechanism (Henry Ford Health + Michigan State University Health Science partnership)  
 Total Award Amount (including Indirect Costs): \$8,825  
 Funding Timeline: May 2025- May 2026

**Background:** This project launched the first annual HFH+MSU Patient Engaged Research Conference, bringing together investigators, staff, and patient/community advisors to strengthen collaboration, share findings, and spark new patient-centered research efforts. Building on HFH’s existing Patient Advisor Retreat, the expanded conference promoted community building, dissemination of patient and community engagement research, and the development of joint HFH+MSU grant ideas and partnerships. A Patient Advisor served on the planning team, ensuring patient perspectives informed event planning.

**Project aims:**

1. Build community among HFH and MSU investigators, staff, and patient/community advisors engaged in patient and community engagement research
2. Increase dissemination of patient- and community-engaged research projects and findings
3. Provide training and capacity building in engagement methods and patient and community engagement research funding opportunities
4. Create tangible patient and community engagement research ideas and collaborations that lead to future joint grant submissions



## Using storytelling to build capacity for PCOR/CER in Maternal Mental health (MAMA)

Principal Investigator: Sara Santarossa/Amy Loree

Source of Support: Patient Centered Outcomes Research Institute (PCORI)

Total Award Amount (including Indirect Costs): \$246,619

Funding Timeline: May 2023- May 2025

**Background:** Mental health conditions are a top medical complication of pregnancy and childbirth and are associated with a range of adverse maternal and child outcomes. Approximately 1 in 7 to 1 in 4 birthing people experience symptoms of a mental health condition during pregnancy or postpartum, yet few are diagnosed or treated. There remain critical knowledge gaps and significant challenges to adequately addressing maternal mental health. [Click here](#) to learn more about this project.

### Project aims:

1. Use storytelling to share diverse perspectives on Maternal Mental health (MAMA),
2. Build capacity and engagement for patient-centered research by sharing these stories in a Storytelling Symposium, and
3. With the aid of a diverse stakeholder team, develop a MAMA-focused research agenda.



Visit the [MAMA Website](#) to view live stories and experience the Storytelling Symposium.

### Publications

Santarossa, S., Blake, R. A., Buchanan, H., Price, M., Guzzardo, R., Guzzardo, C., ... & Loree, A. (2025). Beyond the Status of Health: A Collection of Stories Representing Diverse Maternal Mental Health Perspectives. *Journal of Patient-Centered Research and Reviews*, 12(1), 35.

Santarossa, S., Austin, B., Bell, M. A., Henry, S. C., Inclima, A., Maddox, H., ... & Loree, A. (2025). The Art of Resiliency: Patient Stories of Maternal Mental Health Experiences. *Journal of Patient-Centered Research and Reviews*, 12(2), 87.



# PEIR-IDEAS (Patients Engaged In Research - Inclusion, Diversity, Equity, Acceptance, and Safety)

Principal Investigator: Sara Santarossa

Source of Support: Patient Centered Outcomes Research Institute (PCORI)

Total Award Amount (including Indirect Costs): \$664,948

Funding Timeline: July 2023-July 2025

**Aims:** The PEIR-IDEAS project aimed to adapt and validate the Patient Engagement in Research Scale (PEIRS) in a diverse population of patients, centering inclusion, diversity, equity, acceptance, and safety (IDEAS). [Click here](#) to learn more.

**Partners:** The Science of Engagement Team (SEAT), which was comprised of diverse patient partners, researchers, and community members, were deeply embedded in every phase of the research process.

This is the first **Science of Engagement (SoE)** award HFH has received from PCORI.



[CLICK HERE TO ACCESS SCALE](#)

Figure: PEIR IDEAS Framework



Image: Patient Partner Karen Clemmens Lloyd and Principal Investigator Dr. Sara Santarossa at a PCORI meeting in Washington, DC

## Publications

Redding, A., Copeland, L., Murphy, D., Clemmons-Lloyd, K., Cummings, K., Doyle, J., Kesavan, S., Mitchell, V., Riley, D., Stechison, L., & Santarossa, S. (2025). Bridging the gap: empowering patients as research partners through a structured training program. *Research Involvement and Engagement*, 11(1), 17.

Zreik, M., Redding, A., & Santarossa, S. (2025). From engagement to evidence: a scoping review of qualitative and quantitative measures of adult patient engagement in research. *Research Involvement and Engagement*, 11(1), 136

# PERC Publications

## 2025

**PERC Staff**

**Patient Partner**

Pflaum-Carlson, J., **Redding, A., Murphy, D.**, MacLean, L., Hamilton, J., & **Santarossa, S.** (2025). Recruitment, retention and recouperation: lessons learned from a study aimed at assessing burnout mitigation in physician learners. *BMC Research Notes*, 18(1), Article 376.

**Santarossa, S.**, Haley, E. N., **Coyne, P.**, Pappas, C., Braciszewski, J. M., Miller-Maturo, L. R., **Zreik, M.** & Loree, A. M. (2025). Equity-focused barriers and facilitators to implementing a prenatal yoga intervention in a healthcare system: patient and provider perspectives. *BMC Pregnancy and Childbirth*, 25(1), 1197.

**Coyne, P., Copeland, L., Murphy, D., Redding, A., Johnson, C. C., Kippen, K. E., & Santarossa, S.** (2025). The Patient Engaged Research Center's Sustainable Funding Framework: A Path Towards Sustainable Patient Engagement in Care and Research Within a Health System. *Learning Health Systems*, e70047.

**Redding, A.**, Coates, D., Cassidy-Bushrow, A. E., Straughen, J. K., & **Santarossa, S.** (2025). Activity tracking devices in pregnancy: Understanding the participant experience in a longitudinal birth cohort. *Women's Health*, 21, 17455057251344388.

**Santarossa, S., Blake, R. A., Buchanan, H., Price, M., Guzzardo, R., Guzzardo, C., Johnson, L. M., Morshall, J., Bate, A., Bate, W., Copeland, L., Redding, A., Murphy, D.**, Loree, A. (2025). Beyond the Status of Health: A Collection of Stories Representing Diverse Maternal Mental Health Perspectives. *Journal of Patient-Centered Research and Reviews*, 12(1), 35.

**Santarossa, S., Austin, B., Bell, M. A., Henry, S. C., Inclima, A., Maddox, H., Smith, T. G., Copeland, L., Redding, A., Murphy, D.**, Loree, A. (2025). The Art of Resiliency: Patient Stories of Maternal Mental Health Experiences. *Journal of Patient-Centered Research and Reviews*, 12(2), 87.

**Redding, A., Copeland, L., Murphy, D., Clemmons-Lloyd, K., Cummings, K., Doyle, J., Kesavan, S., Mitchell, V., Riley, D., Stechison, L., & Santarossa, S.** (2025). Bridging the gap: empowering patients as research partners through a structured training program. *Research Involvement and Engagement*, 11(1), 17.

**Santarossa, S., Redding, A., & Murphy, D.** (2025). Living with Long COVID-19: A Virtual Body Mapping Study. *American Journal of Qualitative Research*, 9(2), 42-61

**Zreik, M., Redding, A., & Santarossa, S.** (2025). From engagement to evidence: a scoping review of qualitative and quantitative measures of adult patient engagement in research. *Research Involvement and Engagement*, 11(1), 136.

**Coyne P,** Jennings MB, **Santarossa S, Murphy D, Zreik M,** Bryans H, Drake C, Walch O, and Cheng P. Using night shift worker and employee health stakeholder perspectives to inform the development of Arcashift(tm), a digital precision circadian medicine intervention for shift work disorder. *BMC Digit Health* 2025; 3(1):25. PMID: 40740477. doi.org/10.1186/s44247-025-00167-3

# PERC Conference Posters & Presentations

## 2025

**Copeland, L.**, Loree, A., **Murphy, D.**, **Redding, A.**, Latimer, C. Gilbertson, S., Corriveau, W., **Maddox, H.**, (Patient Partner), **Santarossa, S.** (2025). Using Storytelling to Build Capacity for Patient-Centered Comparative Clinical Effectiveness Research in MAternal Mental Health (MAMA): Training, Community Engagement, and Research Agenda Development. 2025 PCORI Annual Meeting. Washington DC

**Redding, A.**, Chang, C., Wilson, C., **Copeland, L.**, **Murphy, D.**, **Clemmons-Lloyd, K.**, **Cummings, K.**, **Doyle, J.**, **Kesavan, S.**, **Mitchell, V.**, **Riley, D.**, **Stechison, L.**, & **Santarossa, S.** (2025) Co-Development and Co-Validation of the Patient Engagement in Research Scale enhanced by Inclusion, Diversity, Equity, Acceptance and Safety. 2025 PCORI Annual Meeting, Washington DC.

**Redding, A.**, **Copeland, L.**, **Murphy, D.**, **Clemmons-Lloyd, K.**, **Cummings, K.**, **Doyle, J.**, **Kesavan, S.**, **Mitchell, V.**, **Riley, D.**, **Stechison, L.**, & **Santarossa, S.** (2025) Centering Equity in the Science of Engagement: Best Practices from the PEIR-IDEAS Co-Leadership Model. 2025 PCORI Annual Meeting, Washington DC.

**Copeland, L.**, **Murphy, D.**, **Santarossa, S.**, **Coyne, P.**, **Redding, A.**, **Zreik, M.** (2025). Advancing Healthcare with Patient-Centered Collaboration: The Patient Advisor Program at Henry Ford Health. HF+MSU Innovation Symposium, East Lansing, MI

**Murphy, D.**, **Copeland, L.**, **Redding, A.**, **Zreik, M.**, **Coyne, P.**, **Santarossa, S.** (2025). The Patient Engaged Research Center (PERC) at HFH: Transforming Research through Patient Engagement. HF+MSU Innovation Symposium, East Lansing, MI

**Murphy, D.**, **Copeland, L.**, **Redding, A.**, **Zreik, M.**, **Coyne, P.**, **Santarossa, S.** (2025). The Patient Engaged Research Center (PERC) at HFH: Transforming Research through Patient Engagement. Henry Ford Health Research Symposium, Detroit, MI

**Murphy, D.**, **Copeland, L.**, **Redding, A.**, **Santarossa, S.** (2025). A Practical Guide and Detailed Case Study of Knowledge Translation Events in Research. Health Care Systems Research Network (HCSRN) Conference, St. Louis, MO

**Santarossa, S.**, **Redding, A.**, **Copeland, L.**, **Murphy, D.**, **Maddox, H.**, **Clemmons-Lloyd, L.**, **Cummings, L.**, **Doyle, J.**, **Kesavan, S.**, **Mitchell, V.**, **Riley, D.**, **Stechison, L.**, Loree, A. (2025). Empowering Patient Partners: Training for Meaningful Engagement in Research. Health Care Systems Research Network (HCSRN) Conference, St. Louis, MO.

**Zreik, M.**, **Redding, A.**, **Santarossa, S.** (2025). From Engagement to Evidence: A Scoping Review of Qualitative and Quantitative Measures of Adult Patient Engagement in Research. Health Care Systems Research Network (HCSRN) Conference. St. Louis, MO.

**Coyne, P.**, Jennings, M.B., **Santarossa, S.**, **Murphy, D.**, **Zreik, M.**, Bryans, H., Drake, C., Walch, O., & Cheng, P. Using Night Shift Worker and Employee Health Stakeholder Perspectives to Inform the Development of Arcashift™, a Digital Behavioral Circadian Medicine Intervention for Shift Work Disorder. Health Care Systems Research Network (HCSRN) Conference. St. Louis, MO.

# PERC Conference Posters & Presentations

## 2025

Sragi, Z., Elsis, F., Adjei Boakye, E., **Coyne, P.**, **Zreik, M.**, Springer, K., Nair, M., **Murphy, D.**, **Copeland, L.**, **Redding, A.**, Choi, E., Hart, L., Chang, S., Hirko, K., Tam, S. (2025) Enhancing PROM engagement: A mixed methods approach to reminder interventions and patient preferences in head and neck cancer. American Head and Neck Society (AHNS) Annual Meeting at Combined Otolaryngology Spring Meetings (COSM), New Orleans, LA

**Redding, A.**, **Copeland, L.**, **Murphy, D.**, **Clemmons-Lloyd, K.**, **Cummings, K.**, **Doyle, J.**, **Kesavan, S.**, **Mitchell, V.**, **Riley, D.**, **Stechison, L.**, & **Santarossa, S.** (2025). Enhancing Research Impact Through Inclusive Patient Engagement: Lessons from the PEIR-IDEAS Project. weSpark Health Research Conference, Windsor, ON, Canada.

**Coyne, P.**, **Zreik, M.**, Kramer, T., Pegoraro, A., **Santarossa, S.** (2025) Black Maternal Mortality and Social Media: Using Instagram to Examine Reactions to American Track Athlete Tori Bowie's Death. weSpark Health Research Conference. Windsor, ON, Canada.

**Coyne, P.**, Haley, E.N., Pappas, C., **Santarossa, S.**, Loree, A., Hicks, L.M., Braciszewski, J.M., Miller-Matero, L.R., **Zreik, M.** (2025). Equity-focused barriers and facilitators to implementing a prenatal yoga intervention in a health system: Patient and provider perspectives. weSpark Health Research Conference. Windsor, ON, Canada.

Crimson, M., Urquhart, A., Chaudhry, M., **Zreik, M.**, Eapen, A., Zoratti, E., Johnson, C., **Santarossa, S.**, Straughen, J. (2025). Enhancing participant engagement and retention through the development of the ECHO-CANOE mom opportunity meetings. 9th Annual Patient Advisor Retreat. Detroit, MI.

Hussein, L., Peltz, C., Cole Johnson, C., Ahmedani, B., **Santarossa, S.** (2025). Secret Shopper Program: Enhancing the Quality of Participant-Centered Recruitment in the All of Us Research Program. 9th Annual Patient Advisor Retreat. Detroit, MI.

**Coyne, P.**, Haley, E.N., Pappas, C., **Santarossa, S.**, Loree, A., Hicks, L.M., Braciszewski, J.M., Miller-Matero, L.R., **Zreik, M.** (2025). Equity-focused barriers and facilitators to implementing a prenatal yoga intervention in a health system: Patient and provider perspectives. Marcé of North America (MONA) Biannual Conference. Toronto, ON, Canada.

**Zreik, M.**, **Redding, A.**, **Santarossa, S.** (2025). From Engagement to Evidence: A Scoping Review of Qualitative and Quantitative Measures of Adult Patient Engagement in Research. Henry Ford Health Annual Research Symposium. Detroit, MI.

Hussein, J., Sherley, J., Autio, K., **Zreik, M.**, **Santarossa, S.**, Rybicki B., Neslund-Dudas, C. (2025). Enhancing Cancer Epidemiology Research Through Patient-Reported Insights on Study Participation Barriers. HFH+MSU Cancer Symposium. Lansing, MI.

Hussein, L., Peltz, C., Cole Johnson, C., Ahmedani, B., **Santarossa, S.** (2025). Secret Shopper Program: Enhancing the Quality of Participant-Centered Recruitment in the All of Us Research Program. Quality Expo. Detroit, MI.

# Testimonials

## Patient Advisors & Henry Ford Leadership

*"I have seen our suggestions put into action. It makes me feel my time and input is appreciated by HFH. The virtual meeting format allow us the ability to participate regardless of the weather, traffic, road construction or personal issues that would prevent meeting in person."* **-Experience Transformation PFAC Advisor**

*"Someone that experiences the disease/condition may have insight that researchers may not have."*

**-Research Patient Advisor**

*"Serving as a Patient Advisor ensures that patient voices are considered in the ongoing process of improving the health system."*

**-Detroit Hospital PFAC Advisor**

*"The feedback they provide significantly contributes to developing optimal procedures for safe and quality patient care"* **-Administration**

*"Just because patients are not officially labeled as "researchers," doesn't mean they don't know how to do research."* **-Research Patient Advisor**

*"They give us a direct line into what our patients and their families are feeling. It is like having a window into the patient experience."*

**-Leader Rehab Services**

*"They [patients] can do more than just fill a requirement to researchers...especially one who has the disease or condition that is being researched, truly brings the first person perspective to the discussion table."*

**-Research Patient Advisor**

# Acknowledgements

We are deeply grateful to our **Patient Advisors** for their generosity, insight, and ongoing commitment to strengthening Henry Ford Health. The accomplishments of 2025 underscore the essential role that patient and caregiver perspectives play in advancing meaningful research and shaping care experiences. The Patient Engaged Research Center (PERC) remains steadfast in its mission to elevate and embed patient and caregiver engagement throughout the health system and beyond.

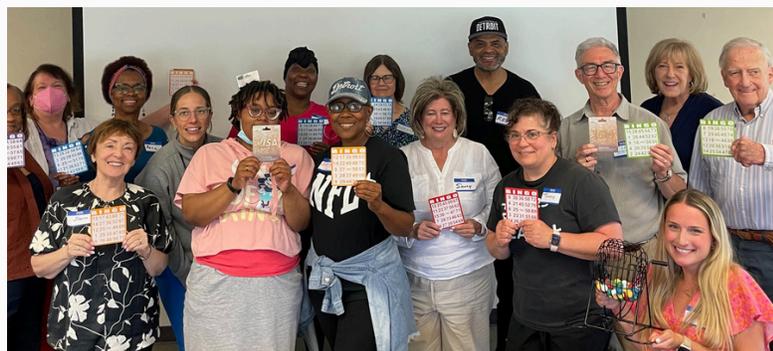
We also extend our sincere appreciation to the **Patient Advisor Liaisons (PALs)** whose leadership and partnership make this work possible. By championing the integration of Patient Advisors within their departments, PALs help ensure that PFACs and committees thrive. Your dedication to amplifying patient and caregiver voices continues to have a lasting and meaningful impact.

**Henry Ford Health Leadership and Research Administration: We thank you for your continued support in patient engagement efforts.**

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PATIENT ENGAGED RESEARCH CENTER

