2024

# PERC ANNUAL SUMMARY



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## Introduction



## The Patient Engaged Research Center (PERC)

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 Patent 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.



- Responsible conduct in research
- Studies that are expertly designed, managed, and analyzed
- Responsible, effective and ethical use of HFH population-resources
- Patient confidentiality
- Public domain research
- Local, national and international collaborations
- Treating all patients, collaborators and staff with respect and dignity

## The PERC Flexible Engagement Model

Henry Ford Health's Patient Engaged Research Center (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.

**Publication:** Bridging the Patient Engagement Gap in Research and Quality Improvement Utilizing the Henry Ford Flexible Engagement Model (<u>link</u>)

## 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.

## **PERC Structure**

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



## Research/Project Design & Analysis

- 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
- Transcription
- Project Recruitment



# Patient Advisor <u>Program</u>

- 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



Number of Patient Advisors

## **Patient Advisor Demographics**

470

**Total Advisors** 

60%

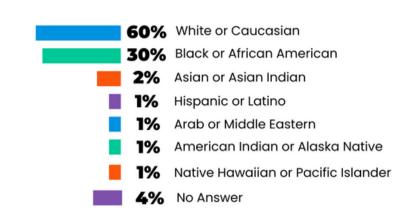
Percent of Advisors serving on a placement

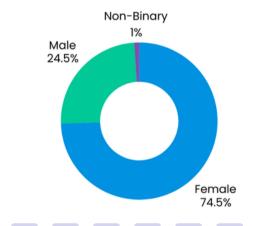
64

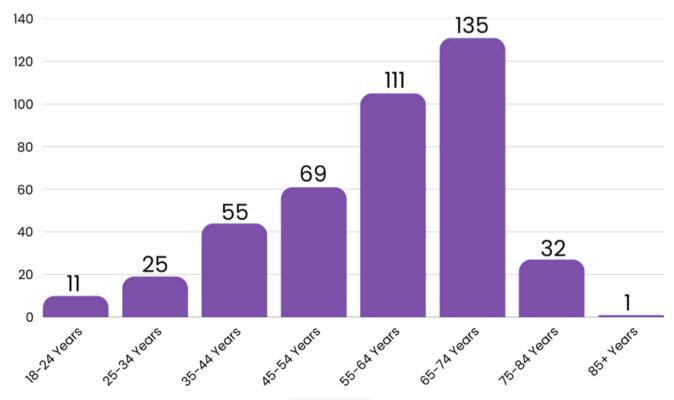
New Advisors joined the program in 2024

13%

Percent of Advisors that work for Henry Ford Health









## Recruitment & Training

The ability to communicate effectively is key to a successful experience for Patient Advisors and other team members. Before an Advisor is placed on a project, the Patient Engaged Research Center (PERC) team discovers the interests and skills of each individual through an informal screening and orientation training process.

Currently PERC has 470 trained and active Patient Advisors and 291 working on teams and committees throughout Henry Ford Health (HFH). The system currently has twelve (12) active Patient & Family Advisory Councils (PFACs) that have been developed to address specific issues important to both patients and providers. The PFACs are co-led by the Patient Advisors and HFH leadership who develop a charter that outlines specific initiatives and a workplan to fully address outcomes that are important to both patients and the organization. In order to support active participation for patients, families and HFH teams, educational workshops and webinars have been developed to meet the unique needs of each group. Patient Advisors also serve on existing and ongoing department committees throughout the health system.

For patients and caregivers, an easy application has been developed on PERC's website

(henryford.com/perc) as the first step to become involved. One of PERC's staff will initiate a call to talk about the opportunities and schedule the applicant for a Welcome Workshop (Orientation). The objectives of the workshop are to get to know the Patient Advisors and begin to understand their passions, priorities, and skill levels to find the most appropriate placement for engagement.





## Engagement & Retention

## 8th Annual Patient Advisor Retreat

For the past 8 years, PERC hosts an Annual Patient Advisor Retreat that is intended to bring Patient Advisors and Henry Ford staff together to celebrate accomplishments as well as provide advisors with meaningful speakers that remind them why their role is so important. We invite Henry Ford clinicians, researchers, and leadership to show them the true meaning of patient engagement and how valuable it is to partner with Patient Advisors. The retreat will feature Henry Ford Health senior leaders, skill building, informative speakers, networking/mingling, food, opportunities to learn about other councils & committees and more.

## Opening Remarks

PERC founders, Dr. Christine Cole Johnson and Karen Kippen, kicked off the event by sharing the center's journey since its inception in 2014.



## Patient Experience

Courtney Stevens shared updates on the Front Door Transformation Initiative, which is focused on transforming how patients access HFH's ambulatory healthcare services and optimizing the patient experience. We are excited to share new updates around this work.



## Panel Session

Aarolyn McCullough (Patient Advisor), John Doyle (Research Patient Advisor), Tammy Pink (Patient Advisor- Caregiver), and Julie Johns (Patient Advisor Liaison-Leadership).



## Lunch & Poster Session

Placements within the Patient Advisor Program shared projects and accomplishments from 2024. Attendees voted for their favorite poster, with the Wyandotte PFAC taking 1st place.



## Break Out Sessions

Patient Advisors attended one of four available sessions: Mindfulness for Self-Care and Burnout Prevention, Patient Empowerment Class, and Nutrition for Healthy Living and Disease Prevention









## **Engagement Events**

- Bingo at Henry Ford Macomb Hosptial
- >> Cooking Workshop at Henry Ford West Bloomfield Hospital
- >> Wellness + Yoga Workshop hosted virtually
- >>> Stop the Bleed (Emergency Preparedness Class) at One Ford Place in Detroit



## Recruitment & Engagement Taskforce

From time to time, PERC invites Patient Advisors to join virtual sessions aimed at enhancing the Patient Advisor Program. During these sessions, advisors share their insights on topics such as recruiting new members, improving engagement efforts, refining communication strategies, and more. Those who participate in the task force provide valuable input to program leaders on effectively communicating with other advisors.



## Patient Advisor Liaison (PAL)

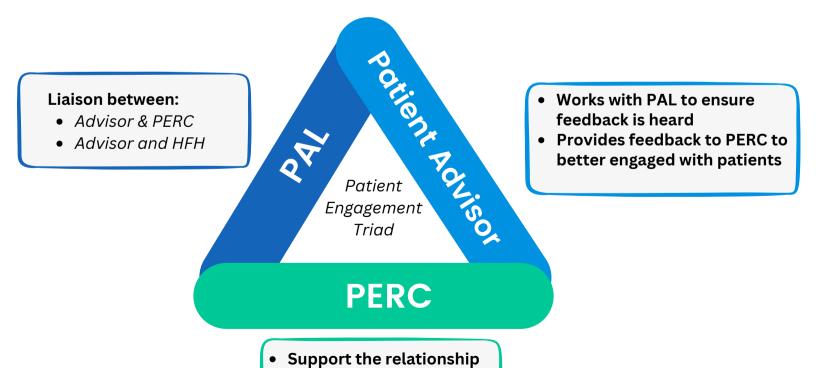
Providers and HFH Staff also need support, including tools on effective ways to engage with patients as partners on teams. We call those in this role the Patient Advisor Liaison (PAL). To provide that support, PERC developed a HFH University online module for teams who partner with patient advisors. This helpful module was developed jointly with the Office of Clinical Quality and Patient Education. As added support, PERC offers bi-monthly support calls for PALs to share successes, solve challenges and share knowledge.

## Role

- Builds a relationship with and supports PAs
- Creates a comfortable and safe environment for PAs
- Communicates important and appropriate information to the PA
- Prepares committee/council for PA as new team member

## Responsibility

- Invites PAs to council/committee meetings
- Follows up with meeting minutes
- Communicates project timelines, milestones, and updates with PAs
- Continues to build a culture of partnership and keep communication channels open
- Is mindful when sending sensitive or confidential information



between the PAL and the

**Prepare Advisor for role** 

Advisor



## **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)

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

All of Us Research Program PFAC

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

Maternal Mental Health (MAMA) PFAC

## INDIVIDUAL ADVISOR PLACEMENTS

Adding 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 2024 there were Patient Advisors that sat on twenty-four (24) department and leadership committees throughout the healthy system. Click here to view the full list.



## **Detroit Hospital PFAC**

In the PFAC's first year, the group engaged with leaders from multidisciplinary departments that are working on process improvements, ranging from marketing and messaging materials, physical plan changes, hardwiring best practices in communication and patient safety.

## 2024 Key Topics

- Inpatient White Board: Design Consultation (see images 2 and 3).
- **Mobility Matters Education**: PFAC provided essential feedback for in room educational materials and received follow up in a second meeting based on PFAC input.
- **Fall Prevention:** Discussed patient facing practices regarding patient safety including low, moderate, and high-risk patients and practices.
- **Discharge Suite:** PFAC reviewed plans for a discharge suite to facilitate throughout and create increased patient satisfaction. PFAC was in favor of discharge suite and provided their recommendation to institute it.
- Food and Nutrition Services: Advised on patient expectations around what to expect from food and nutrition, order process, and patient satisfaction around quality of food and courtesy of person who served the food.
- Destination Grand: Provided insights for visual components of the hospital including
  first impressions of environment. PFAC reviewed patient facing technology in patient
  rooms. PFAC provided insight regarding patients with vision, hearing, and language
  constraints.
- Discharge Readiness: Reviewed scripting to ready patients for next steps in their care.



Image 1. Kick-off PFAC meeting

Welcome to P6
Surgical Specialty Unit

Surgical Special Specia

Image 2. White Board prior to PFAC intervention

Image 3. Finished White Board Example reflective of PFAC input throughout two meetings with Department Leaders

**Department**Care Experience

Founded 2024

Meeting Frequency
Every month
2 hours

Patient Advisor Liaisons (PAL) Julie Johns, Director Care Experience

Barbara Kuszak, Manager Care Experience



## **Jackson Hospital PFAC**

## **2023-2024 Key Topics**

- Emergency Department (ED) Provider Warm Hand-off to Inpatient Provider to avoid the patient's feeling of being left in limbo during transition from ED patient to Inpatient care. (See figure 1)
- The **Compassionate Closet** provides free new gender-neutral clothing to discharging patients whose clothes were not salvageable upon admission and are unable to purchase their own clothing. Our goal is for all patients to feel respected and have dignity when discharging to home or elsewhere. The organization and inventory of the closet are maintained by the Jackson PFAC. (See figure 2)
- **Weapons Free Messaging** makes our patients and visitors aware we maintain a safe weapon free environment. The PFAC provided input on the 'what', 'how' and 'where' the Weapons Free messaging will be most impactful.
- **Public Patient Lockers** for day surgery patients to secure their belongings during their surgeries or procedures. This will allow the patient care giver to be free of the burden of several patient belonging bags that are often cumbersome and take up already limited space in the day surgery family waiting area.

## Department

Care Experience

Founded 2019

## Meeting Frequency Every other month

Every other month 2 hours

#### Patient Advisor Liaisons (PAL)

Julie Johns, Director Care Experience

Amy Sayles, Manager Care Experience

## Warm Hand-off ED to IP Provider HCAHPS Doctor Communication January 2023 – December 2023

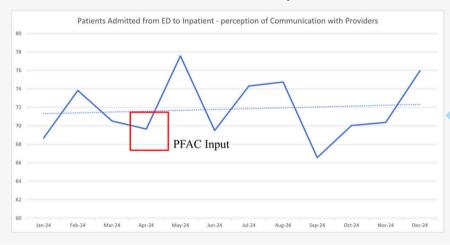


Figure 1

- •HCAHPS Doctor Communication Domain filtered by patients admitted from the ED
- •PFAC input in April 2023.
- Strong improvement in May
- •The practice sputters in June and September before the practice was hardwired
- •Improvement trend October through December

## Compassionate Closet Resources Impact on BH IP LTR Q1 2021 – Q3 2024



#### Figure 2

- •The data above reflects improvement for Inpatient Behavioral Health Likelihood to Recommend since the Compassionate Closet's inception. IP BH patients are the highest utilizers of the closet.
- •Several variables may influence the LTR but together those positive variables are influential.



## **Macomb Hospital PFAC**

## **2024 Key Topics**

- **Project Title: First Impressions** (See images 1 and 2)
  - Description: PFAC was asked to participate in our First Impressions Committee and complete observations in thee following areas of HFM: Emergency Department, North & South lobby entrances, Labor & Delivery Unit, and Cafeteria.
  - The **goals** of the first impression committee are to:
    - Determine how patients/visitors perceive specific areas of our organization
    - Make Immediate Improvements
    - Move the needle in areas where there is 'low hanging fruit'
    - Provide an accurate and honest assessment of the current state
    - Prioritize observations and recommendations from committee to present to ELT
  - **Results**: The committee was able to influence each of these areas with their own observations. One of the immediate improvements made was removing the cluttered signage from the entrance of the ED.

#### • Project Title: Walking Path

o **Description**: Henry Ford Macomb is in the early stages of developing a walking path for patients and visitors. The indoor path that has been identified is ¾ of a mile and is indoors. Our PFAC was asked to walk the route to ensure path is clearly identified and easy to find. The walking path will have QR codes that patients/visitors can scan to get helpful information related to health/wellness. PFAC will help identify helpful topics that should be considered for the walking path QR codes.

## Department

Care Experience

Founded 2015

Meeting Frequency Every other month 1.5 hours

Patient Advisor Liaisons (PAL) Brooke Shankin, Manager Care Experience

Julie Johns, Director Care Experience

#### • Project Title: Cancer Support Groups

o **Description**: The Patient Advisors of this PFAC is passionate about understanding what cancer support groups are available to HFM patients. It is important to our PFAC that we treat the patients psychological & emotional adjustment through this difficult journey. Support groups are one way to support patients through this and we have partnered with HFCI to understand what support groups are currently being offered. Our next steps include looking at different avenues to better get this information in the hands of the patients who need the support the most.

Image 1: First Impressions
Project- BEFORE PFAC input



Image 2: First Impressions Project- AFTER PFAC input



Image 3: PFAC members





## West Bloomfield Hospital PFAC

## **2024 Key Topics**

- Project Title: First Impressions Committee (See Figure 1)
  - Description: This committee was formed with support of the HFWB President to provide a regular view of "fresh eyes" on all aspects of our environment including care areas. The committee created a tracking checklist with observations and recommendations that were then taken to the local operations leaders and Executive teams for review, prioritization and approval of recommended fixes. Observers in the committee initially included team members and then primarily became our PFAC team members this year.

#### • Project Title: Food and Nutrition Improvement Support

o **Description**: The PFAC continues to remain engaged with our Food and Nutrition team and provides support with seasonal menu changes, tastings, review of our process for delivery and accuracy of order. We also engage on how delivery occurs and ways to create a great first impression with courtesy when delivering meals. This is key work for our organization as we are looking to better meet the needs of our patients and improve the perception of Food Quality and Courtesy of our Servers on our Press Ganey patient feedback surveys.

Figure 1: First Impressions Project

PFAC Member Dave Shevrin	Date: 2/15/24	Time: 11:00- 11:45 a.m.	
Notes Category	Notes from Category	Additional Notes	Recommendations
Cleanliness	CLEAN /dirty/messy/organized		
Noise level	soft/ <b>Quiet</b> /loud/chatter	Not Very Crowded	
Team member behavior	INVTING /cold/tone of voice/actions		
Walls/Paint	CLEAN /scuff marks/chipped paint		
Carpet/Floors	clean/ dirty/ STAINS /new/ OLD /dar k/bright/		Replace Carpet
Atmosphere	bright/dark/happy/ GLOOMY	Room felt empty, lacked ambiance	See Resdesign comments below
Clear instructions	clear where to go what to do NOT CLEAR	Birthing Center desk tucked around corner	Combine 2 desks & set up like Surgical Lobby
Art/Signage	NEEDED (not needed/appropriate	Nice sculpture in outside of central window. But little else. Little Signage	Add"wait here" sign to give patients more privacy when at desk.
Entertainment offerings - Magazine, T.V. Etc.	magazine/ T.V ./nothing	No magazine, Info Leaflets. TV poorly placed	Add general magazines for mags new moms. More , bgger & better placed TVs.
Friendlessness/Inviting	friendly/ <b>NOT FRIENDLY</b>	Nor inviting. Very stark, empty, and lousy seating.	Redesign lobby. Combine desk in front of central window, add "Birthing Center" sign to "Emergency Obstetrics" sign. Add "Wait Here" signa and privcy booths. MORE & NEW CHAIRS & SOFAS for family/friends to sit together. Change layout of chairs/sofas and place TVs, art, info, etc accordingly.

**Department** 

Care Experience

Founded 2018

**Meeting Frequency** Every other month 1.5 hours

> **Patient Advisor** Liaisons (PAL)

Hannah Leinonen, Care **Experience Consultant** 

Jennifer Manciel, Manager Care Experience

> Julie Johns, Director Care Experience

Sample of a tracking form, opportunities identified, and feedback given. Many of the recommendations for the Labor and Delivery area were implemented based on this recommendation!!



## **Wyandotte Hospital PFAC**

## **2024 Key Topics**

- Bedside Shift Report (BSSR): PFAC advised in 3 meetings on BSSR related to Patient Recognition of Practice including Sonifi prompts. Target Unit Discussion with lower performers, and BSSR handout for patient recognition. (See figure 2)
  - Results: From PFAC involvement in key tactics, rate of 'Always' BSSR has increased by 5.5% from previous year with decrease in 'Never' by over 8%.
- Hospital Signage: Influential in development of staff facing signage for Quietness and assisted in Quietness Campaign work.
- Thank You Cards and treats to Leaders: PFAC wrote thank you cards to the entire leadership team during a time of crisis for recognition and support.
- Food and Nutrition Services work on menu items and delivery times.
- **CDU Handout:** Partnered with local leader of a new short stay unit to develop a handout for all patients.
- **Emergency Department (ED) Improvement Efforts** 
  - Safety Initiative: Provided direct feedback on safety processes including doing a walk-through of the department lobby, testing of metal detector, and identifying opportunity areas in the department.
  - ED Sensitive Exams: Advised on practice habits and messaging for ED patients undergoing sensitive exams to decrease trauma and proactively provide empathetic communication.
  - ED Messaging for Providers regarding MyChart results in real-time.
  - ED Signage: PFAC worked to improve external signage for patient awareness and safety.

"They always ask the right questions to make me think out of the box and gain greater insight" - Leader, 5th floor General Medicine

"PFAC led us to look at the right survey question to see exactly where we could make an impact" -Leader, 5th floor General Medicine

> "On a day that was so tough for me, I received the card from PFAC, and it moved me to tears. Thank you, PFAC!" -Trauma Manager

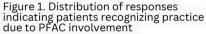
Department Care Experience

> **Founded** 2014

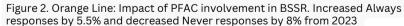
**Meeting Frequency** Every month 2 hours

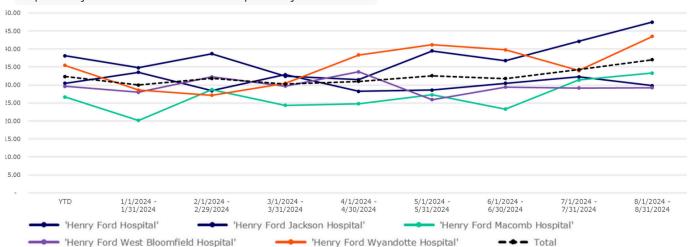
**Patient Advisor** Liaisons (PAL) Julie Johns, Director Care Experience

John Chandler, Manager Care Experience











## Cancer PFAC

## **2024 Key Topics**

#### • Financial Benefits Letter - Presenter: Danielle Nelson

 Patient Advisors met with financial benefits counselors and made suggestions about helping people who may face large medical bills with a new outreach letter for cancer patients that estimates treatment costs and explains help available from HFH's recently expanded financial resource team.

#### • Palliative Care - Presenter: Dr. David Henkin

 Patient Advisors learned about the difference between Palliative Care and Hospice Care and offered helpful tips on how to best explain this vital but often misunderstood and underutilized service to cancer patients.

#### • Social Support Teams - Presenter: Camille Romain

 Patient Advisors met with Community Health workers and made suggestions about how to expand this vital program that brings awareness about cancer prevention and screening, resources, and staff to work in under-served communities.

#### • Marketing - Presenter: Jennifer Day

 Patient Advisors learned about HFH marketing priorities and initiatives and gave their opinions about how to expand marketing and media relations strategies, particularly to promote HFH's nationally recognized excellence in cancer care.

## • Reflection Room - Presenter: Megan Winkel

- Patient Advisors visited the Cancer Institute's newly redesigned reflection space and offered feedback on several relaxation videos patients, caregivers and staff can use, along with ideas on how to best promote this unique space. (See image 1)
- Cancer Service Line Goals and Priorities Presenter: Dr. Shirish Gadgeel, Christopher Bissell
  - Patient Advisors collaborated with Cancer Leadership around goals and priorities for the Cancer Service Line.

## • "Pursuing Perfect Care" Campaign and the Cancer Service Line 3 Year Strategic Plan - Presenter: Danielle Nelson

- Patient Advisors reviewed the Cancer Service Line's new campaign, as well as their three-year strategic plan. Advisors gave feedback about the values, standards, and initiatives surrounding cancer care at HF, including the expansion of supportive oncology efforts.
- o Looking into the future, the Cancer Service Line and Advisors will be focused on:
  - Clinical trial collaboration & innovation
  - Continued building upgrades and services
  - Messaging and investment in HF as a destination for cancer care
  - Expansion of care with Ascension

Department Oncology

> Founded 2016

**Meeting Frequency** Every month 1.5 hours

**Patient Advisor** Liaisons (PAL) Danielle Nelson, Director Supportive Oncology Services







## Patient Involvement & Communication Council (PICC)

## **2024 Key Topics**

- Patient Billing Letters (see image 1)
  - Redesigned the system billing letters to be easily understood and actionable. This was presented at a national conference.
- Behavioral Health Transition to Community
  - Revised program process and marketing.
- Digital Literacy and Telehealth Access
  - o Provided feedback on training curriculum.
- Language Access Symbols
  - Submitted recommendations for a universal language access symbol to Office of Minority Health.
- Primary Care Advertising
  - Reviewed campaigns for social media and print advertisements.
- System Inpatient Guide
  - Updated the systemwide inpatient welcome and information book.
- Food and Nutrition Cards
  - Reviewed information cards and updated program to improve patient experience.

#### Department

Patient Education & Health Literacy, Care Experience

#### **Founded**

2017

#### **Meeting Frequency**

Monthly 1.5 hours

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

Angela Murphy, Manager -Organizational Health Literacy & Patient Education

Laura Gooseberry, Patient Education Designer

#### Image 1: Patient Billing Letters- Revised Version

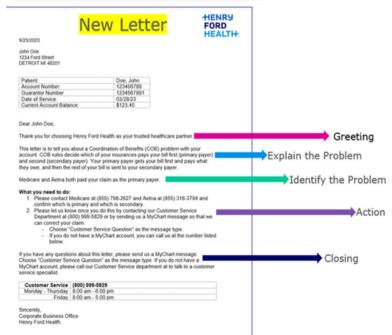




Image 2: PFAC members

## **Experience Transformation PFAC**

## 2024 Key Topics

#### • eCheck-In/Pre-Register Online

#### Use of Feedback:

Feedback from this session was used in Front Door Transformation work to develop our pre-visit patient messaging strategy. Updates to photo ID scanning were made based on council feedback that includes an explanation about why we require photo ID and now allows patients to skip this step in eCheck-in. Other work will be rolled out in early December when we update our texting features. (Image 2)

#### • Advertising (Images 3 and 4)

#### Use of Feedback:

- Eliminated some negative copy like "sketchy" "don't" and "can't."
- Made sure the use of the "H" element is clear but doesn't obscure image completely and is more limited to the bottom of the image.
- Images match copy (e.g., "palm of your hand" to show patient holding phone with virtual
- Made it easier to see laptop in images.
- Focused on only video visits and eliminated "virtual" language.
- Eliminated "healthy route" language because it was not clear and obvious.
- Ensuring same day ads are only shown during daytime operating hours.

#### **Weapons Messaging**

#### Use of Feedback:

 Overwhelming consensus that messages create a sense of security and do not detract from a welcoming environment was positively received. We are now adding a MyChart banner message to remind patients that weapons are not permitted at Henry Ford Health facilitates. We are also adding messaging to the MyChart pre-registration page. These updates are live with the Epic Update as of 12/12/24.



Image 1: PFAC members

## Photo Identification For an upcoming appointment on 1/31/2024 Henry Ford Health requires verification of photo ID annually. If you don't have a current photo ID in MyChart you will be asked for photo identification when you arrive for your appointment. The front desk staff may upload your ID to save you time at registration in the future. \*Please accept to upload images of your current photo ID or decline to continue pre-registration. Accept Decline Continue Cancel

## **Departments**

Access Technology, Digital Experience & Web Strategy, Experience Insights & Analytics, and Virtual Care

> Founded 2020

**Meeting Frequency** 

Monthly 1.5 hours

**Patient Advisor** Liaisons (PAL)

Julie Goldstein-Dunn,

Director, Experience Insights & Analytics

Courtney Stevens,

VP, Front Door Experience Transformation

> Stephanie Ryan, Manager, Market Research







PFAC Feedback



## Hermelin Brain Tumor PFAC

## **2024 Key Topics**

- **Featured on henryford.com** in story about Patient and Family Advisory Councils: https://www.henryford.com/services/brain-tumors/patient-stories/pfac
- Patient Handbook was reformatted in collaboration with the Henry Ford Patient Education Team and made available on Patient Pass, allowing patients to receive the handbook via MyChart. (See image 1)
- The council advised the clinic team on the best day, time, and topics for the **patient** support group to meet to maximize attendance, leading to increased participation.
- Physician leads consistently turn to the council to offer advice and guidance including determining the best timing for difficult discussions and best practices for patient consents.
- Completed and **submitted journal article** for publication consideration.
  - Utilizing the perspectives and experiences of past patients/caregivers to develop a handbook for newly diagnosed patients with brain or spinal tumors and their caregivers. Manuscript submitted to editor. Sauer, S.., Gay, N., Langford, M.\*, Betman, M., Jackson, A., Bradac, A., Mackowski, D.\*, Leach, R., Marco, M., Coughlin, M., Salle, J., Scarpace, L., Snyder, J.
- Participated in the 11th Annual Head for the Cure 5k, which raised over \$172,000.
   Individual fundraising by the PFAC members provided sponsorship of the "bubble truck" during the event.

Department

Neuroscience

Founded 2018

Meeting Frequency
Monthly
1.5 hours

Patient Advisor Liaisons (PAL)

Nestelynn Gay, Patient Resource Coordinator

> Lisa Scarpace, Project Manager

Dr. Tobias Walbert, Neuro-Oncologist

Image 1: Patient Handbook Volume 3

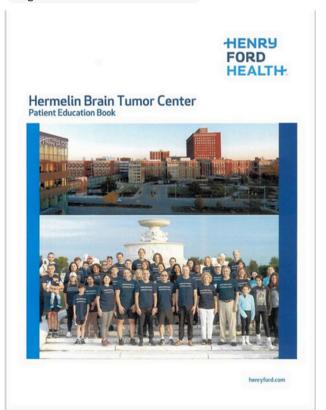


Image 2: PFAC members





## All of Us PFAC



The goal of the All of Us Research Program (AoURP) is to help improve the future of health by accelerating health research.. The AoURP is part of the National Institutes of Health (NIH) Precision Medicine Initiative and seeks to help researchers understand more about why people get sick or stay healthy.

Website: joinallofus.org/HenryFord

## **2024 Key Topics**

- In 2024, Patient Advisors were invited to share their "WHY" story and their program
  participation experiences. They took part in a photoshoot to highlight our Detroit &
  Dearborn communities. Patient Advisor images and stories were featured in newsletters
  and marketing materials. (See image 1)
- Our popular Lecture Series featuring researchers utilizing the *All of Us* Data continued with PERC's Dr. Paige Coyne's presentation on a new research project utilizing the *All of Us*Fitbit data.
- The PFAC was the first to hear about Henry Ford Health being one of five sites across the nation to be selected to enroll pediatrics participants in the program!
- Advisors were invited to provide feedback to the NIH *All of Us* Team for a national & local event called the **Participant Convening Event** during a monthly meeting in July.
  - The advisors' feedback was adopted in a local forum on October 9, 2024 that was hosted in Detroit. (See image 2)
  - Patient Advisors Randee Bloom & Tykesha Lewis participated on a panel during the event. They were able to detail their experiences as participants, their tenure as participant advisors & highlight why they participate in the All of Us Research Program!

## Department

**Public Health Sciences** 

## Funding Agency tional Institute of

National Institute of Health

## Founded 2017

Meeting Frequency Every other month 1.5 hours

#### Patient Advisor Liaison (PAL)

Janine Hussein, Project Manager

## **Principal Investigator**

Dr. Christine Johnson, Public Health Sciences Department Head







## STEPS PFAC



#### SENIORS USING TECHNOLOGY TO ENGAGE IN PAIN SELF-MANAGEMENT

## **Project Overview**

STEPS stands for **Seniors using Technology to Engage in Pain Self-management.** We are testing to see if a pain self-management program can help people live better with chronic pain and reduce pain's impact on their lives.

#### Participants will:

- •Complete three 60-minute telephone surveys
- -Baseline, 2-month follow-up, and 12-month follow-up
- •Be randomly placed into one of two groups (50/50 chance):

**Intervention Group:** A 7-week program with web-based videos and weekly telephone sessions led by a Community Health Worker

**Control Group:** A control group that receives program materials & a half-day workshop after the final survey

#### Update:

- 132 participants have completed the STEPS intervention!
- 20+ Recruitment Events Completed!

## STEPS

The Patient and Family Advisory Council (PFAC) has been integral in designing and implementing the STEPS study.

We met with the PFAC team 7 times over Webex since July 2022. Some topics of discussion at meetings have been (but not limited to):

## Department

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

Funding from the National Institute on Aging (NIA; R01AG071511)

Founded 2022

Meeting Frequency 2-3 meetings per year 1-1.5 hours

### Patient Advisor Liaisons (PAL)

Rebecca Lindsay, Project Manager University of Michigan School of Public Health





## MAMA PFAC

**MAternal MentAl health** 



## **Project Overview**

Project title: Using storytelling to build capacity for PCOR/CER in MAternal MentAl health (MAMA)

\*PCOR= Patient Centered Outcomes Research

#### **PFAC Purpose:**

- Convene a stakeholder team of 23 patients, caregivers, researchers, providers, and community members. (See image 2)
- Train all stakeholders to facilitate a shared understanding of patient-centeredness.
- Build off existing PERC infrastructure while identifying additional Patient Advisors.
- Utilize appropriate engagement tools.
- Use the results of this process to collaboratively generate and prioritize a PCOR/CER Research Agenda.
- Determine tailored dissemination strategies (including publications) for the PCOR/CER Research Agenda for each stakeholder group.
- Investigate and report on funding opportunities to pursue specific items from the PCOR/CER Research Agenda.

#### **Key Meeting Priorities- Complete**

- ② Review storytelling analysis (previous phase of project) (See image 1)
- ☑ Interactive research topic brainstorm
- PFAC members voted/prioritized topics
- OPFAC members learned how to write research questions
- O Developed research questions in breakout sessions

#### **Key Meeting Priorities**- Upcoming

O Finalize PCOR/CER Research Agenda

#### WHAT IT MEANS TO GRIEVE

"As the shock settles, you wake up from your nightmare and somehow reality feels worse."

> \*To this day, it's difficult for me to wrap my head around the fact that we loss parents often feel like we are simultaneously the elephant in the room, yet FEEL as small as a mouse."

"My grief has not softened with time, but I am continuing to grow stronger in carrying it."

Image 1: Slide shared at PFAC on storytelling analysis

"I felt an odd mix of joy and intense sorrow. My son felt ever-present, I couldn't help but feel joy for the magic of his short time with us. But my heart was broken, and I knew it could never be repaired. Losing a child is such a lonely and isolating experience. I felt trapped and suffocated in this

"I knew deep down in my heart, I could not handle any more grief any more loss. I needed to be a mother, not to carry a pregnancy.

#### **Department**

Public Health Sciences & Center for Health Services Research

Funding Source: Patient Centered Outcomes Research Institute (PCORI)

> **Founded** 2024

**Meeting Frequency** Monthly, 1 hour

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

Dr. Sara Santarossa.

Assistant Scientist, Public **Health Sciences** 

Dr. Amy Loree,

Associate Scientist, Center for Health Services Research

Scientist Stakeholders

Perinatal Mental

**Health Expertise** 

**Health Services &** 

**Health Equity** 

**Scholars** 

#### Patient Engaged **Research Center** (PERC)

- Science of Engagement
- **PCOR Expert**

#### **Patient Partners** Lived experience

MAMA -PFAC

#### Clinical Stakeholders Nurse Midwife

- Psychiatric Nurse Practitioner
  - Neonatology Physician

Community Stakeholders

Image 2: PFAC member makeup (as



<sup>\*</sup>CER= Comparative Effectiveness Research

## **Individual Placements**

1-2 Patient Advisors

	Henry Ford Hospital Stroke Transitions of Care Committee
	Megan Brady- Clinical Program Manager for Stroke

- Pursuing Equity Patient Care Committee

  Dr. Marla Rowe Gorosh- Family Practitioner
- Quality Committee, 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
- Critical Care Committee

  Alicia Wafer- Director of Respiratory Therapy
- 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

  Michelle Dolan, Director of Radiology Service Line

## **Individual Placements**

11	Supportive Care Committee  Maria Di Pania - Nursa Practitionar Supportive Care		
	Marie Di Ponio- Nurse Practitioner, Supportive Care		
	Natalie Hamadeh- Nurse Practitioner, Supportive Care		

- 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
- Michigan Hospital Medicine Safety

  Caitlin Tatarcuk, Quality Assurance Coordinator, Michigan Hospital Medicine Safety (HMS)

  Consortium
- Michigan Hospital Association Keystone Board
  Julie Johns, System Director Care Experience, HFH

#### **Other Contributions:**

Readmissions Journey Mapping, Telehealth Focus Groups, Diabetes Focus Groups, Patient Advisor Welcome Workshop Support, Henry Ford Health Website Redesign, Henry Ford+MSU Cancer Symposium, and more.



## **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 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 500 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.



# 2024 Active Grant Funded Projects

## **PERC Collaborator**

## Research Enterprise to Advance Children's Health (REACH/Star)

Funding Source: National Institute of Health (NIH)

PI: Christine C. Johnson/ Ownby, D. R.

Total Award Amount (including indirect costs): \$17,790.585

PERC Service(s): Patient Centered Research Design

## Research Enterprise to Advance Children's Health (REACH) – Fitbit: Exploring effects of physical activity during pregnancy

Funding Source: HFH and Michigan State University (MSU) PD/PI: Sara Santarossa/ Jennifer Straughen/ Sascha Drewlo Total Award Amount (including indirect costs): \$50,000

PERC Service(s): Patient Centered Research Design

## Enhancing digital CBT-I to improve adherence and reduce disparities

Funding Source: NIH/National Heart, Lung, and Blood Institute (NHLBL)

PD/PI: Cheng, Phillip

Total Award Amount (including indirect costs): \$3,035,622

PERC Service(s:) Patient Centered Research Design, Interviews, Qualitative Analysis

## Assessment of mobile application-delivered lighting interventions for reducing circadian disruption in shift workers

Funding Source: NIH/NHLBI

PD/PI: Olivia Walch/Phillip Cheng

Total Award Amount (including indirect costs): \$254,877

PERC Service(s:) Patient Centered Research Design, Interviews, Focus Groups, Qualitative Analysis

## A Multilevel, Multiphase Optimization Strategy for PrEP: Patients and Providers in Primary Care

Funding Source: NIH PI: Elizabeth Lockhart

Total Award Amount (including indirect costs): \$788,126

PERC Service(s:) Focus Groups- Recruitment, Coordination, Facilitation



# 2024 Active Grant Funded Projects - PERC Collaborator



#### Addressing Health Equity for Older Adults in On-demand Virtual Care Access

Funding Source: Association of American Medical Colleges (AAMC)

PD/PI: Denise White Perkins

Direct Funds: \$4,503

PERC Service(s): Focus Groups, Recruitment, Preliminary Analysis



## Cancer Screening Research Network (CSRN) ACCrual, Enrollment, and Screening Site (ACCESS)

Funding Source: National Cancer Institute (NCI)

PI: Christine Neslund-Dudas

Total Award Amount (including indirect costs): \$3,200,000

PERC Service(s): Recruitment, Advisory Council



#### Prenatal Yoga to Prevent Postpartum Depression (PRY-D)

PI: Sara Santarossa, Amy Loree

Source of Support: NIH / National Institute of Mental Health (NIMH)

Total Award Amount (including indirect costs): \$698,773

PERC Service(s): Focus Groups, Recruitment, Qualitative Analysis



## Genentech Annual Eye Screening for Black Adults with Diabetes

Project owner: Premier PI: Denise White Perkins

Source of Support: Genentech

Total Award Amount (including indirect costs): \$165,939

PERC Service(s): Focus Groups, Recruitment, Qualitative Analysis



## IMPROVE pilot/PROMs: Interventions to Increase Health Equity and Utilization of Patient Reported Outcomes (PROs) Among Cancer Patients

**Funding Source: NCI** 

PI: Sam Tam, Eric Adjei Boakye

Total Award Amount (including indirect costs): \$10,000

PERC Service(s): Focus Groups-Recruitment, Qualitative Analysis



## Epidemiology of multimorbid pediatric atopic and airway diseases and the impact of prenatal maternal environmental exposures and placental epigenetics (ECHO-CANOE)

Funding Source: NIH

PI: Jennifer Straughen, Amy Eapen

Total Award Amount (including Indirect Costs): \$4,915,175

PERC Service(s): Patient Advisor Coordination, Qualitative Analysis



# 2024 Active Grant Funded Projects - PERC Collaborator



### CHASS cervical dysplasia task force

Funding Source: Internal Funding

PI: Lindsay Martin-Engel Direct Funds: \$2,632

PERC Service(s): Survey, IRB consultant, Qualitative Analysis



## Pediatric hereditary angioedema – the Body Mapping in HAE (BOMAH) study

Funding Source: US Hereditary Angioedema Association (HAEA)

PI: Baptist, Alan M.D.

Total Award Amount (including indirect costs): \$120,414

PERC Service(s:) Body Mapping methodology



## A Nursing Program for Advancing Training in Health and Social Determinants (N-PATHS)

Funding Source: NIH PI: Ashlee Vance

Total Award Amount (including indirect costs): \$804,977.00

PERC Service(s): Advisory Board- Recruitment, Coordination, Facilitation



#### THRIVE Rewards Program

Funding Source: Internal (HFH)

PI: N/A (quality improvement project, IRB exempt)

Direct Funds: \$11,217

PERC Service(s): Focus Groups- Recruitment, Coordination, Analysis



## Identifying Multi-Level Barriers and Facilitators of Lung Cancer and Cardiovascular Disease Preventive Services in Patients Undergoing Lung Screening

PI: Christine Neslund-Dudas

Source of Support: HFH + MSU Cancer Pilot Grant

Total Award Amount (including indirect costs): \$50,000

PERC Service(s): Focus Groups/Interviews- Recruitment, Coordination, Facilitation, Analysis



## Quality Improvement Project for Diagnosis and Treatment of Obesity

PI: Suki Singh

Source of Support: Lilly Endowment Fund

Total Award Amount (including indirect costs): \$467,253

PERC Service(s): Survey, Focus Groups/Interviews- Recruitment, Coordination, Facilitation, Analysis



## **PERC Led Awards**

- **1. Burnout Mitigation in Physician Trainees (BuMP)** Blue Cross Blue Shield of Michigan
- 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)



## **BuMP - Burnout Mitigation in Physician Trainees**

Principal Investigator: Sara Santarossa/Jacqueline Pflaum-Carlson

Source of Support: Blue Cross Blue Shield Michigan

Total Award Amount (including Indirect Costs): \$10,000

Funding Timeline: Jan 2023 - May 2024

**Background**: Physician burnout affects healthcare organizations at every level and has been associated with higher self-reported errors, increased turnover, and has a negative impact on patient care; it is estimated that tens of thousands of Americans die each year as a result of preventable medical errors.

This project aimed to reduce the symptoms of physician burnout by exploring Acceptance Commitment Therapy (ACT) compared to Body Mapping as effective interventions in preventing and mitigating burnout in physician trainees.





## 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 to:

- 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 <u>MAMA Website</u> to view live stories and experience the Storytelling Symposium.







# Patient Engaged Validation of the PEIR Survey by Inclusion, Diversity, Equity, Acceptance and Safety (IDEAS)

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

**Background**: This project involves long-, mid-, and short-term objectives to address gaps in the science of engagement in research focused on development and/or assessment of instruments that measure meaningful patient engagement in research (PEIR). PEIR involves patients undertaking roles beyond those of traditional study participants by including them throughout the entire research process. <u>Click here</u> to learn more.

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

Figure: PEIR IDEAS Framework





Image: Patient Study Team members Linda Stechison and Kimberly Cummings proudly stand by PEIRS Poster



## **PERC Publications**

2024

(†denotes Patient Partner author)

Sara Santarossa, Ruth A. Blake, Heather Buchanan, Mercedes Price, Rachael Guzzardo, Craig Guzzardo, LaKenya M Johnson, Jacobeth M Morshall, Andrea Bate, Wayne Bate, Riziki Bakari, Leah Copeland, Dana Murphy, Ashley Redding, and Amy Loree. (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), 35-49. doi: 10.17294/2330-0698.2107 Link

Coyne, P., Susick, L., Schultz, L., Santarossa, S., Gough, P., Rice, S., ... & Bilicki, V. (2024). Using Care Navigation to Improve Patient-Reported Outcomes Among Older Adult Patients: Preliminary Results From a Pilot Study. Journal of Patient Experience, 11, <u>Link</u>

Santarossa, S., Baber, M., \*Hussein, J. et al. Using action research and a community-academic partnership to understand clinical trial participation: a patient-centered perspective. Res Involv Engagem 10, 61 (2024). <u>Link</u>

## <u>in press</u>

Sara Santarossa, †Becca Austin, †Molly A. Bell, †Samantha C. Henry, †Ashley Inclima, †Hailey Maddox, †Tara G. Smith, Leah Copeland, Dana Murphy, Ashley Redding, and Amy Loree. (in press). The Art of Resiliency: Patient Stories of Maternal Mental Health Experiences. Journal of Patient Centered Research Reviews.

Ashley Redding1; Leah Copeland1; Dana Murphy1; †Karen Clemmons-Lloyd2; †Kimberly Cummings2; †John Doyle2; †Sandy Kesavan2; †VeRonica Mitchell2; †Deyal Riley2; †Linda Stechison2; Sara Santarossa1,3 (in press) Bridging the Gap: Empowering Patients as Research Partners through a Structured Training Program. Research Involvement and Engagement.

Liz Lockhart, PhD, Jordan Gootee, BA, Leah Copeland, BA, DeAnne Turner PhD. Willingness to be contacted via the patient portal for health screening, research recruitment, and at home self-test kits for health monitoring: A Pilot Quantitative Survey.



# PERC Conference Posters & Presentations

2024

### **Posters**

Coyne, P., Copeland, L., Murphy, D., Redding, A., Kippen, K., Santarossa, S. (2024). The Patient Engaged Research Center (PERC): A path towards self-sustainable patient engagement in care and research. HCSRN 2024 Annual Conference, Milwaukee, WI, United States of America

Coyne, P., Susick, L., Schultz, L., Santarossa, S., Gough, P., Rice, S., Bilicki, V., Brewster, N., & Behrendt, R. (2024). Using care navigation to improve patient-reported outcomes amongst older adult patients: Preliminary results from a pilot study. Henry Ford Health's 2024 Quality Expo, Detroit, MI, United States of America.

Redding, A., Copeland, L., Murphy, D., Bossick, A., Clemmons-Lloyd, K., Cummings, K., Doyle, J., Kesavan, S., Mitchell, V., Riley, D., Stechison, L., Santarossa, S. (2024). Empowering patients as co-researchers: Training in psychometric assessment techniques. Poster accepted for presentation at the 2024 PCORI Annual Meeting, Washington, D.C.

Redding, A., Zreik, M., Leydet, E., Straughen, J.K., Cassidy-Bushrow, A.E., Santarossa, S. (2024). Perspectives from Arab Birth Cohort Study Participants: Implications for Recruitment and Retention. Poster accepted for presentation at the ACCESS 10th Arab Health Summit: Advancing Health Amidst Conflict and Crisis, Dearborn, MI.

Redding, A., Copeland, L.., Murphy, D., Bossick, A., Santarossa, S. (2024). Empowering patients as coresearchers: Training in psychometric assessment techniques. Poster presented at the Henry Ford Medical Group 21st Annual Research Symposium, Detroit, MI.

Leah Copeland, BA; Sara Santarossa, PhD; Dana Murphy, BS; Ashley Redding, MPH; Hailey Maddox (Patient Partner); Courtney Latimer, MS; Sara Gilbertson, MS, CNM; Wendy Corriveau, RN, MS; Amy Loree, PhD. Using storytelling to build capacity for patient centered outcomes research in MAternal MentAl health (MAMA): Storyteller training development and preliminary data. Presented at: Henry Ford Health Research Symposium, Detroit, MI 2024.

Redding, A, Zreik, M, Leydet, E, Straughen, JK, Cassidy-Bushrow, AE, Santarossa, S. Perspectives from Arab Birth Cohort Study Participants: Implications for Recruitment and Retention. Poster presented at: ACCESS 10th Arab Health Summit: Advancing Health Amidst Conflict and Crisis. Dearborn, MI, USA; 2024

## **Oral Presentations**

Coyne, P., Copeland, L., Murphy, D., Redding, A., Kippen, K., Santarossa, S. (2024). The Patient Engaged Research Center (PERC): A path towards self-sustainable patient engagement in care and research. Henry Ford Health's 2024 Research Symposium, Detroit, MI, United States.

## Acknowledgements

We extend our heartfelt gratitude to our **Patient Advisors** for their selfless dedication to improving Henry Ford Health. The achievements of 2024 highlight the vital role that patient and caregiver voices play in shaping healthcare delivery and research. The Patient Engaged Research Center (PERC) remains committed to championing patient and caregiver engagement across the health system and beyond.

A special thanks also goes to the **Patient Advisor Liaisons (PALs)** for recognizing the importance of integrating Patient Advisors into their departments. The success of PFACs and committees would not be possible without the leadership and commitment of the PALs who guide them. Your advocacy for patient and caregiver voices is truly invaluable.

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



## **Contact**

- PERCPTAdvisors@hfhs.org
- (313-874-6243

<u>Henry Ford Health PERC Website</u>