2023 PERC ANNUAL SUMMARY

PATIENT ENGAGED RESEARCH CENTER



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Meet the PERC Team



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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

Values

- 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.

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

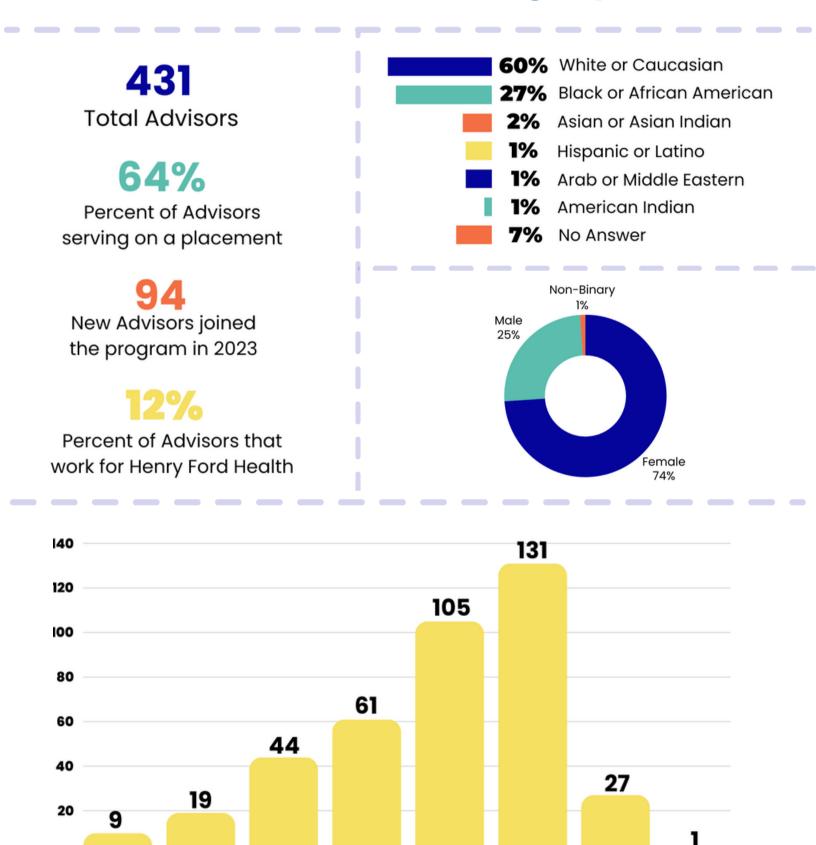
- PERC as Core Service within HFH Department of Public Health Sciences
- Principal Investigator on Grants
- Grant Writing
- Survey Development and Distribution
- Institutional Review Board (IRB) Support
- Research/Funded projects
- Data Analysis (Mixed Methods)
- Qualitative Research Design
- Facilitation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

Patient Advisor 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

18-24 Veens

Patient Advisor Demographics



A5-5A Vents

35-AA Veors

25-34 Veors

65-64 Vears

15-BAVeors

65-7A Vears

85*Vedrs

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 431 trained and active Patient Advisors and 276 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

Patient Advisor Retreat

Every year PERC hosts a Patient Advisor Retreat to celebrate the Patient Advisors and all the work they have done to make positive changes in research and healthcare improvements across the health system. This was a fully virtual event for the third year in a row. The virtual setting allows for the ease of offering breakout session selections to attendees. These sessions are separated by two groups, and attendees made their selection in advance. Full agenda is listed below.

Breakfast Mingle

Patient Advisors, PALs, and PERC staff discussed successes and challenges from the last year in the program.

Opening Remarks

Dr. Steven Kalkanis, Executive Director of Henry Ford Health and CEO of Henry Ford Hospital and Henry Ford Medical Group expressed gratitude for the contributions of the Patient Advisor Program and visions for the future of the health system.

A Look Into the Future

Barry Blackwell, Manager of Community Relations at HFH, gave a detailed look into the Destination Grand campus and its impact on the health system and surrounding community.

Break Out Sessions

Patient Advisors attended one of four available sessions: Healthy Living for Your Brain and Body, Literacy and Health Care, Emotional Intelligence, and the Value of Patient Engagement.

Lunch & Poster Session

Placements within the Patient Advisor Program shared projects and accomplishments from 2023. Attendees voted for their favorite poster, with the Wyandotte PFAC taking 1st place.

Panel Session

Maureen Bennett (HFH system perspective), Lynn Gaunt (patient perspective), Theresa Skwara (caregiver perspective), and Kate Itacy (patient perspective) shared their experiences, advocacy, and answers to audience questions.

Patient Advisor Retreat Pictures



<u>Click here</u> to view more pictures & <u>Click here</u> to view the posters

Placement Lunch & Learn

Starting in 2022, PERC began to host virtual 30-minute Lunch & Learn sessions. These sessions included a short presentation from PALs on the council/committee that they lead. The purpose of these sessions was for Patient Advisors to learn more about placements and what other councils, committees, and projects are working on and have accomplished. These group sessions are a great way for PALs to communicate with and recruit new Patient Advisors to join their placement.

The following placements hosted a Lunch & Learn in 2023:

Experience Transformation PFAC COVID PFAC HF Wyandotte PFAC All of Us PFAC Patient Involvement & Communication PFAC HF West Bloomfield Volunteer Services

Patient Advisor Liaison (PAL)

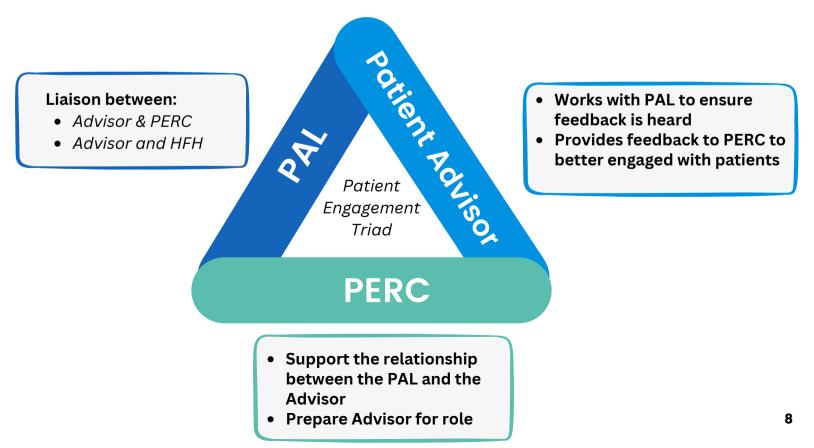
Providers and HFH Staff also need support, including tools on effective ways to engage with patients as partners on teams. We call those in this role the Patient Advisor Liaison (PAL). To provide that support, PERC developed a HFH University online module for teams who partner with patient advisors.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



<u>Click here</u> to view placement posters.

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 jump 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. **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.

Hospital-based	Individual Advisor Placements	
Allegiance Hospital PFAC	Stroke Transitions of Care Committee	
Macomb Hospital PFAC	Critical Care Committee	
West Bloomfield Hospital PFAC	Ethics Committee (HFH)	
Wyandotte Hospital PFAC	Henry Ford West Bloomfield Ethics	
Detroit Hospital PFAC New!	High Reliability/Care Experience/HR	
Department- specific	Palliative Care Committee	
Cancer PFAC	Patient Education Committee	
Patient Involvement & Communication PFAC	Pursuing Equity Patient Care Committee	
Experience Transformation PFAC	Quality and Safety Committee	
Hermelin Brain Tumor PFAC	Quality Safety & Reliability Council	
Recruitment & Engagement Taskforce	Readmissions Committee	
Research Funded	Supportive Care Committee	
All of Us Research Program PFAC	Radiology Customer Experience & Engagement Committee	
STEPS PFAC Seniors using Technology to Engage in Pain Self-management	Mental Health Research Network Project	
Shift Worker PFAC	SAMSHA Zero Suicide Project	
	PCORI Diabetes Project	

Allegiance Hospital PFAC

2022-2023 Key Topics

- Improving Patient Communication in the Emergency Room. Nicholas Dyc, MD, Director, Patient Experience for the ED requested input from the Patient and Family Advisory Council in how to improve communication between patients and family and their care givers.
- Feedback provided by PFAC
 - Explain the triage process to patients, the role of the intern, provide an opportunity for ER interns to be trained on communicating with patients, explain why a test is being ordered and how long before results are available
 - Make patient/family aware of patient's NPO status and why
- <u>Results:</u>
 - Press Ganey survey results in the Emergency Department patient satisfaction surveys showed some minor improvement.
 - Doctors treat with courtesy and respect went from 85.19 in the first quarter of 2023 to 86.60 in the fourth quarter of 2023 on the Emergency Department.
 - Nurses explain in a way I understand from 78.63 in the first quarter of 2023 to 79.08 in the fourth quarter of 2023.

Department Care Experience

Founded 2014

Meeting Frequency Every other month 2 hours

Patient Advisor Liaisons (PAL) Suzette Turpel, Director Care Experience

Amy Sayles, Manager Care Experience

- What Matters Most to Patients. To better understand the patient perspective when answering some patient satisfaction questions the PFAC broke into three groups to discuss. Those questions were:
 - Likelihood to recommend this hospital to friends and family. PFAC agreed that communication is key. Communicating the who, what, when, where, how and why and to do it with empathy.
 - Treated with courtesy and respect. PFAC members felt it was important that staff treat their patients like they would want to be treated.
 - Were the patient's preferences considered. The wording on this question was confusing to PFAC and they provided a variety of responses without consensus.
- <u>Results:</u>
 - Care Experience leadership was able to provide insight to service line leaders about improving results on the questions discussed.
- Survey Cover Letter Improvements. Henry Ford marketing was seeking input on the cover letters for surveys. They reviewed the current letter and two possible alternatives. The PFAC provided the following feedback.
 - Add the information for the Henry Ford Foundation so grateful patients can donate.
 - Add information about getting involved in the Patient and Family Advisory Council.
 - Bullet point information and keep it brief, rather than long paragraphs.
 - They liked the idea of the signature being Henry Ford Care Experience rather than the President of the organization.
- Results:
 - To date the survey cover letter has not been changed. Certain information is monitored and mandated by the Centers for Medicare and Medicaid and marketing was working around those.

Macomb Hospital PFAC

2023 Key Topics

- Project Title: Tower Project North Tower Furniture Choice
 - Description: Patient Advisors were asked to review furniture selections for the new Macomb Tower Project. They addressed the comfort, size, functionality and ease of use. These decisions will benefit 160 new beds in private rooms for our patients and families. Our PFAC took their role seriously and tested the Samples by following the instructions for fold outs, commenting on the comfort, and durability and produced a full page of recommendations to our Tower Build Committee.
 - **Results**: The Tower Build Committee reviewed the advisor's response, shared input on their questions, and have also approved the choices.

Project Title: Tower Project - North Tower Artwork

 Description: Artwork is essential in healing, Patient Advisors have been a part of the artwork project from the ground floor, and have worked with HFH creative project managers to choose the flavor of the artwork. Team has brought forward a project that partners with our advisors, front line team, community and therapy dogs.

Figure 1: PFAC group photo



Department Care Experience, North Market

> Founded 2014

Meeting Frequency Every other month 1.5 hours

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

Maureen Bennett, Director Care Experience

Project Title: New Menu

 Description: During the months of April 2023 through June, the Macomb PFAC was invited to taste testings on new menu and food items. The Patient Advisors met the Chefs, System-wide, and provided them surveys to share input. The menu was changed based on their input. Really nice partnership between our System, Site and our PFAC.

Project Title: Bedside Shift Report

• Description: Bedside shift report is a evidence based initiative that aids in communication between nursing and our patients. Patient Advisors were asked to consider the importance of bedside shift report, and the roll out of this program at Macomb. They shared their concerns of communication and setting expectations for the patient. They approved the coaching/observation training of staff to assist with continuity of the initiative

Figure 2: Bedside Shift Report trends



West Bloomfield Hospital PFAC

2023 Key Topics

- Project Title: ED Wait Time
 - Description: Patient Advisors partnered with our emergency department leadership on the increased volume of patients and wait times. Patient Advisors were tasked with input on how to change the perception of our patients and families and review of the process. Discussion ensured regarding volunteers rounding, more rooms, can there be a set up for urgent care and more.

• Project Title: Patient Experience Guide

- This was a true collaboration between our advisors and our Site. Our advisors went painstakingly through each page to look for changes, deletions and additions that would be an informational assistance to future patients and families.
- **Results**: The handbook was redesigned and multiple changes from our PFAC were utilized in the changes that occurred.
- The PFAC even noted on the back cover that this was reviewed by them. (See Figure 1)

Department Care Experience, North Market

Founded 2014

Meeting Frequency Every other month 1.5 hours

Patient Advisor Liaisons (PAL) Luke Sparkman, Manager Care Experience

Maureen Bennett, Director Care Experience

• Project Title: Bedside Shift Report

- Description: Bedside shift report is an evidence-based initiative that aids in communication between nursing and our patients. Patient Advisors were asked to consider the importance of bedside shift report, and the roll out of this program at West Bloomfield. They shared their concerns of communication and setting expectations for the patient.
- They approved the coaching/observation training of staff to assist with continuity of the initiative. See page 14
- **Project Revamp the menu and food tasting.** This occurred in April 2023, where all PFACs participated in a taste testing of the newly designed menu for our patients. (See Figure 2)

<image><section-header>

Figure 1: Patient Experience Guide

Henry Ford

6777 W. Maple Rd. West Bloomfield, Mi 48322 (248) 325-1000 Figure 2: Patient Advisor food tasting to revamp hospital menu



Wyandotte Hospital PFAC

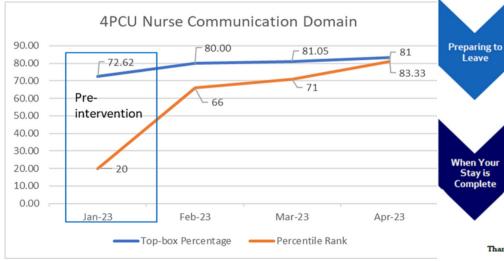
2023 Key Topics

- Patient Handbook: 1st Draft Completed
- **Ouietness Campaign:** Operations team is using direct feedback to create "Ouiet" Healing **Environment**
- Virtual ICU: Provided direct feedback to leaders on messaging to patients and families understand the consistent observation for improved care
- **CODE Help:** Assisted with development of easy to understand facilities poster
- Food Insecurity Assessment Program: Advised on messaging to patients and key phrases for staff
- Discharge Checklist: Implemented changes to improve patient understanding of admission. Created title "What to Expect". (See figures 2 & 3)

Figure 1: Group photo of Patient Advisors



Figure 3: Impact of Discharge Checklist on the pilot unit's Nursing Communication Domain



Department Care Experience, South Market

> Founded 2014

> > RD ALTH

Meeting Frequency Every other month 2 hours

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

John Chandler, Manager Care Experience

Figure 2:Discharge Checklist PFAC helped create

Inpatient Hospital Stay: What to Expect Henry Ford Wyandotte Hospital	HENRY FORD HEALTH
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Below are some things you can expect during your inpatient hospital stay, as you prepare to leave, and en your stay is complete. If you have questions or concerns, talk to a member of your care team at any

During Your Stay

- **During Your Stay** You will get a lot of information in a short amount of time while you are in the spital, especially right before you are discharged (go home). While you are in the hospital, you can expect to:
- Get education from your doctor or nurse about your condition and how to ca for yourself.
 - pose a caregiver or family member to include in your care plan. You will be asked to choose just 1 person so communication is clear arn what help or support you may need now and once you leave the hospital
 - Talk about how long you may need to stay in the hospital to get care for your ess or cond
- Consider where you will go when your hospital stay is complete

Preparing to Leave

- As you prepare to leave the hospital, you can expect: All play
 - ns and information to be clearly communicated to you and your caregiver.
 - To get instructions on any new medicines, your daily medicine routine, and a eating changes to support your health.
- understand symptoms to watch for and when to take actio You will know who to call if you have questions or need help
- ave information about any follow up appointments
- To know about any services you may need after you leave the hospital, such as home care, physical therapy, etc.

When Your Stay is Complete

Ask questions as often as you need to be sure you understand everything before

- The goal is to go home or wherever you will stay after the hospital around 12 p.m. or midday. This may be different for each person depending on your rituation
- . If a family member or friend is your ride, make sure they are at the hospital before discharge so they can hear the instructions we give you and they can ask questions
- You may be asked to give feedback about your stay. This helps make sure Henry Ford Wyandotte Hospital can provide the best care for future patients

Thank you for trusting Henry Ford Wyandotte Hospital with your care

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Cancer PFAC

2023 Key Topics

- Patient Reported Outcome Measures (PROMs) study with Dr. Sam Tam & Dr. Eric Boakye
 - Researchers noticed that the completion rate for Patient Reported Outcomes (PROMs), or a patients self-reported survey of their mental and physical health, was low. As such, they proposed intervention strategies to increase completion
 - PFAC members gave suggestions for rewording and alternate interventions such as MyChart messages and reminders on TV screens in the waiting room
- Cancer Service Line Goals with Madelyn Van Tassel
 - The Vice President of the Cancer Service Line presented to the PFAC to share the top 10 milestones for the next 3 years
 - Patient Advisors discussed the goals, ranked them by priority, and shared missing initiatives such as a survivorship clinic (See Figure 2)
- Cancer Navigation Process with Miles Schermerhorn and Laura Backer
 - The discussion around cancer navigation was a two-part series with this being a topic very close to Advisor's experience in cancer care
 - Advisors suggested that new patients receive a binder with information about their cancer journey and a notebook to journal symptoms and wellbeing. They also emphasized the importance of the accessibility, knowledge, compassion, and care of the navigation team
- Advancing Health Equity in Cancer Care Summit with Kristin Bodiford from Premier Inc
 - 4 Advisors were selected to attend the summit and collaborated with cancer leadership and industry partners from around the country
 - Prior to the summit, all Advisors participated in an interactive brainstorm to compile the most important considerations for each stage of the cancer journey (pre-diagnosis, diagnosis, care and treatment, and quality of life)
- OncoStat Clinic with Morgan Knies
 - The OncoStat Clinic provides medical care just for cancer patients where they can be treated for cancer related symptoms
 - Patient Advisors gave recommendations on the operating hours, the pamphlets and marketing around what the clinic offers, and the tag line for the clinic

Figure 1:. The PFAC members





Figure 2: Cancer Service Line Goals

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)

2023 Key Topics

- Dialysis Patient Education Review new dialysis patient education material. (Figure 1)
 - Changed photos, changed wording, provided feedback
- Diabetes Education: Review diabetes management classes and education method.
 - Modified class structure, updated material, recommendations for virtual sessions
- Virtual ICU Pilot: Review of new virtual ICU pilot program and resources.
 - Updated patient info page, provide program feedback, recommendations for pilot
- Urgent Care Mailer: Provide guidance on patient mailer and Urgent Care.
 - Discussed attitudes towards urgent care, modified patient mailer
- Forms Standardization: Review new patient signature forms.
 - Modify templates, approved template layout, approved fonts

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

Rob Behrendt, Director-Service Line Quality & Safety

Laura Gooseberry, Patient Education Designer

Starting Your Dialysis Journey



Figure 1: Dialysis education material



Figure 2: PFAC members



Experience Transformation PFAC

2023 Key Topics

- Feedback from advisors has helped to inform the experience design strategy across the entire patient journey
- Improved scheduling pages to offer patients a better path to scheduling, in MyChart, on the phone, or using a form
- Patients in Wayne and Oakland County are now able to schedule their lab services online. Over 11,700 patients self-scheduled their appointment online through Find Lab Services this year
- Prescription refill requests/renewals through MyChart encouraging MyChart patients to utilize functionality via phone system
- As part of optimizing our front door, we are eliminating unnecessary phone numbers for our patients, starting with the removal of 15 numbers last fall
- Implemented eCheck-In for all; saw a 10% increase in eCheck-in usage; this team continues to give feedback to improve this feature
- Messaging expectations improved communications about how to change preferences in MyChart
- HenryFord.com user experience feedback from advisors has helped to inform the web design strategy
- Feedback helped develop content for Healthy Living seminars geared toward their peers
- New E-Visit patient satisfaction question development offered feedback and perspective on new E-Visit patient satisfaction survey questions
- Helped to redesign the virtual care webpages, creating patient-friendly, easy to navigate content
- Updated the patient satisfaction survey submission page
- Developed questions to measure patient satisfaction for virtual visit outreach
- Supported fast pass/wait list functionality design and communications; patient wait time to see a provider was significantly reduced as a result of automation of the wait list

Figure 1: The PFAC members



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

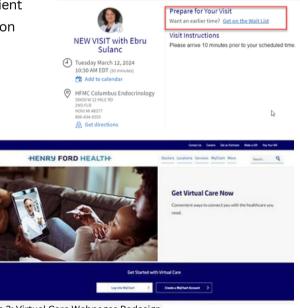


Figure 2: Fast Pass/Wait List Functionality

Figure 3: Virtual Care Webpages Redesign

Hermelin Brain Tumor PFAC

2023 Key Topics

- Published Patient Handbook Update (Volume 3)- Patient Advisor Input (See Figure 1)
- Developed an **informational patient handout** to be distributed in clinic that details the MRI process.
- Provided feedback that addresses the day and time for the **brain tumor support group** with the aim to increase attendance. These suggestions led to both a day and time change that is anticipated to better serve the HBTC patient population.
- Developed magnet so patient could readily access important phone numbers within reach.
- Hosted a roundtable meeting with Nurse Navigators and chemotherapy nurses to discuss **clinic patient experience.**
- Hosted a meeting with Dr. Mark Rosenblum, Chair Emeritus-Henry Ford Department of Neurosurgery to discuss the history and goals of the Hermelin Brain Tumor Center.
- Advised in the development of the surgical "pre-hab" module and new patient clinic handout.
- Several PFAC members traveled to the Lansing to sit in chamber for proclamation of Brain Tumor Awareness Month (See Figure 2)

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

Figure 1: Patient Handbook Volume 3

HENRY FORD HEALTH:

Hermelin Brain Tumor Center Patient Education Book



Figure 2: PFAC members trip to Lansing to sit in chamber for proclamation of Brain Tumor Awareness Month



henryford.com

Recruitment & Engagement Taskforce

2023 Key Topics

- Patient Advisor Onboarding Process
 - Patient Advisors took an in-depth look at the onboarding process to share feedback on how experience as a first time Advisor can be improved. Changes were made to the Welcome Workshop presentation, and a Patient Advisor representative now attends every monthly Welcome Workshop.
- Patient Advisor Engagement
 - Patient Advisors collaborated and brainstormed around the question: *How can we* engage Patient Advisors throughout the program?
 - Updates were made to the Placement Form and suggestions were given for future workshops, Lunch & Learns, and social events.
- Patient Advisor Communication
 - Patient Advisors reviewed the monthly E-Blast, the Patient Advisor Spotlight, frequency and quality of communication within the program
 - Suggestions were made around including a video instead of the Spotlight at times, so a video recap of the retreat was added to the December E-Blast

Patient Advisor Annual Survey & Retreat

- Together, members of the PERC team and task force reviewed past years feedback on the retreat and experience in the Patient Advisor Program
- As a result of the discussion, a Patient Advisor Panel was added to the retreat, and many felt the panel was a highlight of the 2023 Patient Advisor Retreat.

Department Public Health Science, Patient Engaged Research Centers (PERC)

> Founded 2023

Meeting Frequency Every month 1 hour

Patient Advisor Liaison (PAL) Leah Copeland, Project Coordinator

Dana Murphy, Project Manager

Discussion points: all Advisors on the call wanted skill building to be a break out session, liked that the speakers were broken up in option 2, longer time for closing statement/prizes, panel of

<u>Tentative Agendas</u>

	rs instead of a patient advocate	101	Option 2
	Option 1	9:00 ar	n Breakfast Mingle (optional)
9:00 am 30 min	Breakfast Mingle (optional)	9:30 ar	m Opening Speaker- HF Senior Leader
9:30 am 30 min	Opening Speaker- HF Senior Leader	10:00 a	am Keynote Speaker- Patient Advocate
10:00 am 30 min	Guest Speaker- HF Senior Leader	10:45 a	am Skill building
10:30 am 60 min	Keynote Speaker- Patient Advocate	11:30 p	om Lunch/ Poster Session
11:30 am 90 min	Lunch/ Poster Session	1:00 pr	m Breakout Session (3-4)
1:00 pm 60 min	Breakout Session (3-4) • skill building	2:00 pr 20 min	m Guest Speaker- HF Senior Leader
2:00 pm 30 min	Closing Statements/Prizes	2:20 10 min	Closing Statements/Prizes
2:30	End	2:30	End

Figure 1: Tentative Patient Advisor Retreat Agenda for discussion and revising

Figure 2: Discussion topics for Patient Advisor Engagement

Why

- In the Patient Advisor survey, many advisors recommended that PERC improve the engagement of its members
- Additionally, the PERC team has a goal of recruiting more advisors, with a special focus on recruiting more of the following demographics:
 - Men 25% or other gender identities
 - African-Americans 31%
 - Asian or Asian-Americans 2%
 - Hispanic/Latino 1%
 - Native Hawaiian/Alaskan 0%
 - Advisors under 45 years old 32%



Within the Recruitment & Engagement Taskforce, Patient Advisors will give Community Partner suggestions, feedback on marketing materials (especially those that can be distributed to friends, family, and community), social media campaign ideas, and recruitment events ideas

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 and medical breakthroughs. 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.

2023 Key Topics

- In 2022, advisors participated in an All of Us National Communications photoshoot that took place in downtown Detroit. The areas and landmarks of the photoshoot were picked to showcase our thriving community.
 - Now in 2023, these photos are being utilized nationally and locally for marketing materials. Our new brochure featuring our advisor Tykesha Lewis Harper. (See Figure 2)
- In 2023, the program released Researcher Highlights on research being done with the program. Advisors learned about these projects & provided feedback on return of value.
 - The advisors' feedback on researcher highlights were escalated to the NIH and the program is planning for participants to be able to review these highlights on their account. (See Figure 1)
- Several members have been selected to also serve on National NIH workgroups:



Randee Bloom- as a Participant Advisor and Ambassador, she currently serves on the program's Participant Provided Information Committee (PPI) and is a member of the Program's Participant Ambassador Team.



Elizabeth Rubinstein- currently represents the participant voice on the Advisory Panel to drive value, enrollment, and retention with meaningful participant engagement strategies.

Figure 1: Program Research Highlights that advisors provided feedback on

Research Highlights

All of Us is shaping how we understand health and disease. Research Highlights showcase the recent research powered by All of Us data and tools.

Leer Investigaciones destacadas en español





Study Links Birthplace and Cancer Risk Among Hispanic *All of Us* Participants

Steps to Better Health With All of Us

A new study using All of Us participant Fitbit and electronic health record data

A new study using an or os participant Prox and vectorine neutrinecord due finds that taking at least 8,200 daily steps is linked with lower rates of certain health conditions—including depression, sleep apnea, acid reflux, high blood pressure, obesity, and diabetes.

Scientists used All of Us data to study cancer risk in participants who selfreport as Hispanic, Latino, or Spanish. Liver cancer rates were twice as high in Hispanic participants born outside of the United States, showing that place of birth is an important consideration for understanding cancer risk.



Figure 2: Brochure featuring Patient Advisor TyKesha **Department** Public Health Sciences

> **Funding Agency** 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



Stand out. Value your differences. We do.

HENRY

FORD

PATIENT ADVISOR PROGRAM

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



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

We met with the PFAC team 5 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

Jessica Judson, Sr Project Coordinator, Community Health, Equity & Wellness Henry Ford Health

Shift Worker PFAC

<u>Goals</u>

- Offer a sleep wellness program for night shift workers to help improve health, job satisfaction, reduce burnout, and increase retention
- To create a tool that converts wearable data into circadian state, and from circadian state to personalized lighting recommendations used by night shift employees and their employers to improve health and performance. A long-term version of this app could interface with smart lighting in homes and in offices to automatically adjust lighting conditions to minimize circadian disruption
- Our long-term vision involves the seamless integration of this tool with smart lighting systems in homes and offices, facilitating automatic adjustments to lighting conditions to promote optimal circadian timing.
- With technological innovations, we aim to disseminate personalized light exposure interventions, providing tailored solutions for Shift Work Disorder (SWD).

Department Sleep Research

> Founded 2023

Meeting Frequency Every other month 2 hours

Patient Advisor Liaisons (PAL) Dr. Philip Cheng, Associate Scientist , Sleep Disorder

2023 Key Topics

- **SHIFT** Tests a mobile application to improve sleep and night shift worker's circadian rhythm in a controlled setting
- **SAIL** Tests the implementation of a mobile application we designed to improve sleep in night shift workers in the real world
- **REACT** Establishes sleep reactivity (aka 'stress') as a cause of Shift Work Disorder (SWD) in night shift workers [controlled setting]
- PFAC works with Arcascope CEO, Olivia Walch, to take feedback from SHIFT PFAC and apply changes to the Arcashift Application which is used in the SHIFT and SAIL study.

Cool evening, Carol

Varke 200ar

Arcashift, an innovative intervention to treat shift work disorder in night shift workers. The app was developed collaboratively by Arcascope and the HFH team.

<u>Click here</u> for app webpage.

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 Dr. Kimberlydawn Wisdom- Senior VP of Community Health & Equity Chief Wellness & Diversity Officer

Ethics Committee, Henry Ford Hospital *Karen Smith- Lead Ethicist, Safety & Reliability*

Ethics Committee, Henry Ford West Bloomfield Dr. Emily Hurst- Director, Residency Training Program



High Reliability/Care Experience/HR Culture Mary Voutt-Goos- Director, Quality Safety Initiative

Palliative Care Committee Dr. Kristen Chasteen- Division Head, Hospice Palliative Med

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



Special Projects

Patient Advisors as stakeholders on research team



Mental Health Research Network *Amy Loree - Assistant Scientist, Center for Health Services Research*



SAMHSA Zero Suicide Amy Loree - Assistant Scientist, Center for Health Services Research

PCORI Diabetes Project Lisa King - Project Manager



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.



2023 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**

All of Us Research Program

Funding Source: NIH PI: Christine C. Johnson/Brian Ahmedani Total Award Amount (including indirect costs) : \$55M to date **PERC Service(s): PFAC support**

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 Direct Funds: \$2,745 **PERC Service(s:) Focus Groups, Recruitment**



PERC RESEARCH

HFH-MSU CSRN ACCrual Enrollment and Screening Site

Funding Source: National Cancer Institute (NCI) PI: Christine Neslund-Dudas Direct Funds: \$4,503 PERC Service(s): Focus Groups, Recruitment

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**

Understanding Experiences of Pregnant and Postpartum Persons with Disabilities Navigating

Funding Source: NIH PI: Andrew S. Bossick, HFH; Hannah Bolder, MSU Total Award Amount: \$49,384 **PERC Service(s): Focus Groups, Recruitment**

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: Paige Coyne Source of Support: Genentech Direct Funds: \$62,690 **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 Direct Funds: \$4,503 **PERC Service(s): Focus Groups, Recruitment, Qualitative Analysis**

Tx fragmentation: Effect of Treatment Fragmentation on the Quality and Outcomes of

Funding Source

Funding Source: AAMC PI: Sam Tam Direct Funds: \$12,000 **PERC Service(s): Interviews, Recruitment, Preliminary Analysis**

2023 Funded Projects

PERC Led Awards



Using Body Mapping to Develop a Patient Centered Research Agenda About Long COVID-19

Principal Investigator: Sara Santarossa Source of Support: Patient Centered Outcomes Research Institute (PCORI) Total Award Amount (including Indirect Costs): \$160,000

Background: Post-acute sequala of COVID-19 (PASC) or "long COVID-19" is a crippling aftermath of the pandemic wherein 10-30 percent of patients diagnosed with COVID-19 continue to experience symptoms after their infection period is over. To date, there is no formal definition/consensus on terminology for PASC; risk factors for who will experience PASC are still emerging; and there is uncertainty regarding how to alleviate the symptoms of PASC. <u>Click here</u> to learn more.



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

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 seeks 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.

2023 Funded Projects

PERC Led Awards



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

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. <u>Click here</u> 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.



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

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.



PERC Publications

2022-2023 (†denotes Patient Partner author)

Santarossa S, Baber M, *Hussein J, Oley C, Slangerup K, Murphy D, & Kippen KE. (in press). Using Action Research and a community-academic partnership to understand clinical trial participation: a patient-centered perspective. Journal of Action Research.

Santarossa S, Rapp A, Murphy D, Hussein J. (2022). The patient perspective on COVID-19 restrictions lifting: a descriptive study of resuming in-person meetings. Journal of Covid Research and Treatment. 1(1). 10.58489/JCRT.002. Link

Olden HA, Santarossa S, Murphy D, Johnson CC, Kippen KE. Bridging the patient engagement gap in research and quality improvement utilizing the Henry Ford flexible engagement model. Journal of Patient-Centered Research and Reviews. 2022;9(1):35. in press. Link

Hecht, L.M., †Adams, R., †Dutkiewicz, D., †Radloff, D., †Wales, M.N., †Whitmer, J., Murphy, D. & Santarossa, S. (in press). "Healing can be a Very Jagged Line:" Patient Reflections on Life as a COVID-19 Long Hauler. Journal of Patient-Centered Research and Reviews. Link

Redding, A., Santarossa, S., Sagong, C., Kalmbach, D. A., Drake, C. L., Casement, M. D., & Cheng, P. (2023). "Life will never be the same": a qualitative analysis of the impact of COVID-19 on adults with a history of insomnia. Sleep Advances, 4(1), zpad046. Link

Santarossa S., Redding A., Murphy, D., (2023). Pioneering Virtual Body Mapping: A Methodological Guide for Researchers Using a Health-Affected Population as an Example. American Journal of Qualitative Research, 7(2), 73-88. <u>Link</u>

Ashley Redding, Sara Santarossa, Dana Murphy, Mary Priyanka Udumula, Adnan Munkarah, Miriana Hijaz, and Ramandeep Rattan. (2023). A patient perspective on applying intermittent fasting in gynecologic cancer. BMC Research Notes 16, 190 (2023). Link

PERC Conference Posters & Presentations 2023

Posters

Coyne, P., Susick, L., Schultz, L., Santarossa, S., Gough, P., Rice, S., Bilicki, V., Brewster, N., & Behrendt, R. (2023). Using care navigation to improve patient-reported outcomes amongst older adult patients: Preliminary results from a pilot study. WE-Spark Health Research Conference, Windsor, Canada.

Dana Murphy, Leah Copeland. The Patient Engaged Research Center's Annual Patient Advisor Retreat: Post-Evaluation Survey. Presenting at: Henry Ford Health Research Symposium, Detroit, MI 2023.

Sara Santarossa, Ashley Rapp, Dana Murphy, Janine Hussein. The patient perspective on COVID-19 restrictions lifting: a descriptive study of resuming in-person meetings. Presented at: American Public Health Association Meeting. Boston, MA; 2022.

Redding, A., Santarossa, S., Murphy, D., Udumula, M.P., Munkarah, A., Hijaz, M, & Rattan, R. (2023). A patient perspective on applying intermittent fasting in gynecologic cancer. Poster presented at the weSpark Health Research Conference, Windsor, ON, CAN.

Redding, A., Lava, J., Murphy, D., Sitarik, A., Johnson, C.C., Straughen, J.K., Santarossa, S. (2023). Activity tracking during pregnancy in the REACH-Fitbit cohort: Understanding the Participant Experience. Poster presented at the Henry Ford Medical Group 20th Annual Research Virtual Symposium, Detroit, MI.

Presentations

Sara Santarossa, PhD, Leah Copeland, BA; 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: WE Spark Health Research Conference. Windsor, Ontario, Canada. Nov. 4, 2023.

Dana Murphy, Leah Copeland. The Patient Engaged Research Center's Annual Patient Advisor Retreat: Post-Evaluation Survey. Presenting at: Henry Ford Health Research Symposium, Detroit, MI 2023.

Acknowledgements

Thank you to our **Patient Advisors** who selflessly dedicate their time on efforts to improve Henry Ford Health. The accomplishments of 2023 prove how meaningful patient and caregiver voices are in the delivery of health care and in research. The Patient Engaged Research Center (PERC) continues to advocate for patient and caregiver engagement throughout the health system and beyond.

The Patient Advisor Liaisons (PALs) also deserve recognition for understanding the importance of including Patient Advisors in their departments. These PFACs and committees could not be functional without the PALs who lead them. Thank you for advocating for patient and caregiver voices.

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



<u>*Click here to submit an intake form to collaborate with PERC!*</u>