2022 ANNUAL SUMMARY The Patient Engaged **Research Center** (PERC)





HENRY FORD HEALTH

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About

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

Values

- 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.

Types of Patient Engagement



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 472 trained and active Patient Advisors and 252 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.

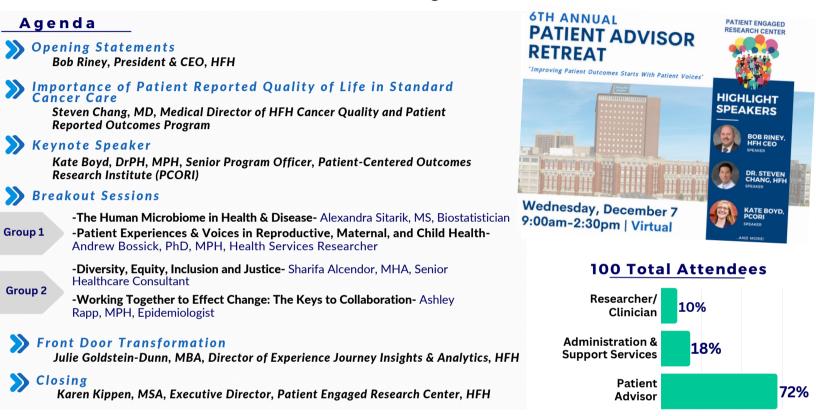
For patients and caregivers, an easy application has been developed on PERC's website (henryford.com/perc) as the first step to become involved. One of PERC's staff will initiate a call to talk about the opportunities and schedule the applicant for a Welcome Workshop (Orientation). The objectives of 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.



Placement Lunch & Learn

Starting in 2022, PERC began to host virtual 30-minute Lunch & Learn sessions. These sessions will include a short presentation from PALs on the council/committee that lead. The purpose of these sessions are 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 recruitment new Patient Advisors to join their placement.



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Patient & Family Advisor Council – Supportive Care

Marie Di Ponio-Hohl, MSN, AGPCNP-BC Katherine Stahl, DNP, AGPCNP-BC

Supportive Care Mission Utilizing an interdisciplinary team for the

Utilizing an interdisciplinary team for the identification of chronically complex patients with the goal of providing comprehensive support that: • Improves patient and family communication

- Relieves patient suffering
- Increases patient wellness and satisfaction

· Increases pacent weinless and substaction

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Future Goals









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Grow team & expand system-w

Patient Advisor Liaison (PAL)

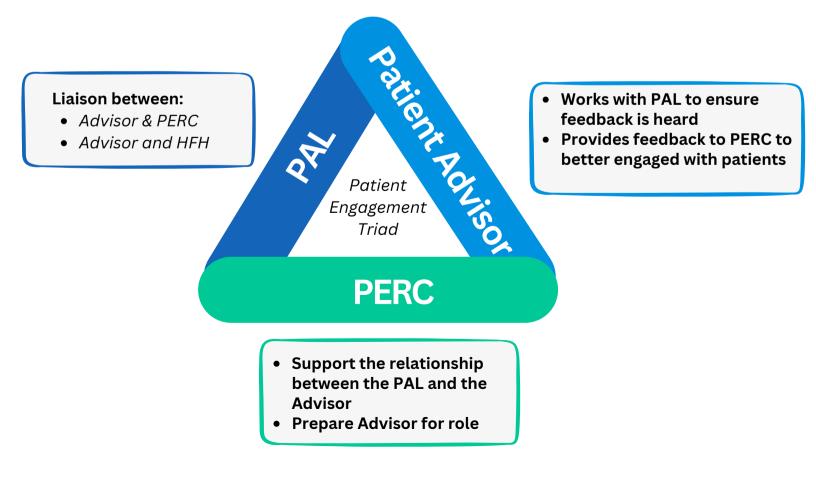
Providers and HFH Staff also need support including tools on effective ways to engage with patients as partners on teams. We call those in this role the Patient Advisor Liaison (PAL). To provide that support, PERC developed a HFH University online module for teams who partner with patient advisors. This 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



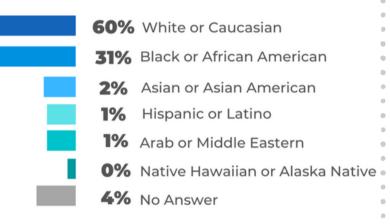
Patient Advisor Stats



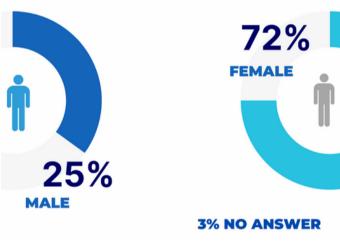


of Patient Advisors are Henry Ford Health Employees

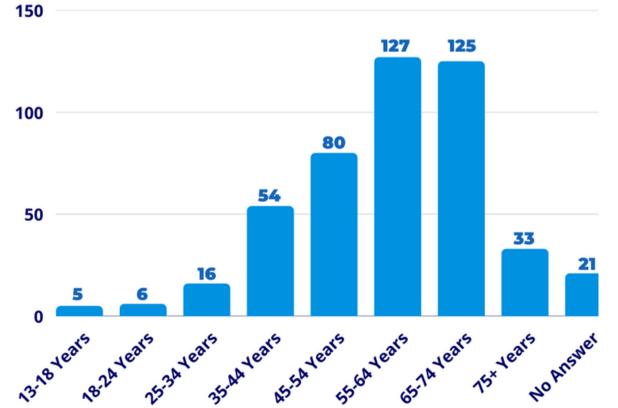
PATIENT ADVISOR RACE



PATIENT ADVISOR GENDER



PATIENT ADVISOR AGE



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.

PFACs

10-15 patient advisors placed on council led by HFH team member(s). 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.

Patient Involvement & Communication PFAC

All of Us Research Program PFAC

Perioperative Brain Health PFAC

STEPS PFAC Seniors using Technology to Engage in Pain Selfmanagement

Cancer Center PFAC

COVID PFAC

Experience Transformation PFAC

Hermelin Brain Tumor PFAC

- Hospital- based
- HF Allegiance PFAC
- **HF Macomb PFAC**
- HF West Bloomfield PFAC
- HF Wyandotte PFAC

Committees

Adding a patient and/or caregiver voice to existing department committee meetings. PERC will recruit and train patient advisor placed on department committee.

Cardiac Rehab Committee

Comprehensive Stroke Program

Critical Care Committee

High Reliability/Care Experience/HR Culture

Palliative Care Committee

Patient Education Committee

Quality and Safety Committee

Quality Safety & Reliability Council

Supportive Care Committee

Radiology

IMPACT CHF (Detroit & West Bloomfield) Integrated Michigan Patient-Centered Alliance in Care Transitions Congestive Heart Failure

Allegiance Hospital PFAC



The Henry Ford Allegiance Health Patient and Family Advisory Council (PFAC) is comprised of community members that have been recruited to provide input from a patient and family perspective to the health system. Our mission statement is to impact the delivery of healthcare at Henry Ford Allegiance Health by advocating for safe and compassionate care for every member of our diverse community.

Projects

Staff Appreciation Cart Rounding

Description: Patient Advisors conduct weekly staff rounding with the Staff Appreciation Cart. The PFAC members thank staff for their dedication and service and offer free items from the cart, including snacks and Henry Ford branded items.

Results: PFAC members rounding with the cart often share comments from the staff, including, "You made my day." They go to all main campus units and departments. "I've been to places I didn't know existed," stated one PFAC member. "It's eye-opening to see how many roles are required to keep our hospital going."

Role Playing Patients to Teach Soft Skills to ED Residents

Description: The Patient Advisors were asked by the HF Jackson Graduate Medical Education medical staff to help teach ED residents soft skills.

Results: PFAC members as well as first year Emergency Department (ED) residents were provided ED patient scenarios in which soft skills were recorded and reviewed with the PFAC members role playing patients, ED residents and GME Medical Staff. A collaborative discussion provided insight from a patient perspective as well as coaching in the moment.

Requested Leadership Input

Description: The HFJH PFAC is often called upon by senior leaders to provide community insight into new processes or services. This year HFJ senior leaders requested input on the following:

- Community perception on armed security guards
- Nursing recruitment
- Pharmacy communication to COVID positive ED patients filling prescriptions

Results:

- The President of HFJ asked PFAC members about their perception of having armed security guards on sight. Overall PFAC members were in favor.
- Nursing Administrator for Patient Care presented the current state of the nursing profession in healthcare. She asked PFAC members their suggestions for recruitment opportunities. PFAC members provided three suggestions, which were put in place.
- COVID positive patients were walking from ED to the pharmacy in the lobby to fill Plaxlovid prescriptions. PFAC members provided insight and suggestions to get patients to utilize the mobile pharmacy option.

Accomplishments

- Recruited two new members
- Added a new nurse representative
- Presentations and learnings from over 12 senior leaders
- Successful transition from virtual to in person meetings



2023 Goals

- 1. Project Driven Presentations
- **2023** 2. Update strategic plan for 2023
 - 3. Community Presentation
- **GOALS** 4. Recruitment of five new members
 - 5. Maintain and engage current members

Wyandotte Hospital PFAC



Henry Ford Wyandotte Hospital (HFWH) PFAC was founded in 2014 and is comprised of 9 highly engaged members including a Chair. This council meets every other month for 2 hours and have used a blended model of in-person and virtual formats. This team is engaged by leaders from multidisciplinary departments that are working on improvement projects that range from marketing and messaging materials, physical plant changes, hardwiring best practices in communication and patient engagement.

Projects

Employee Recognition

Description: We have a committee that is designated for managing excellence in nursing nominations called Daisy and Honeybee. These are very special nominations in which a patient, family member or team member observes a nurse or nurse assistant really going above and beyond in their caring, compassion and patient centered care. These are nationally recognized programs that we participate in. The leadership of this group felt we weren't getting enough submissions from patients and their families, and the goal was for PFAC to review any opportunities we may have to engage them more in the process of recognition. This is also very important to our Magnet journey at HFWH.

Results: PFAC team provided key clarifications to the explanation of the recognition and award process. They reviewed marketing materials and made recommendations for placement, awareness and wording. The team has noted in increase in nominations after implementing recommendations.

HFWH Patient Handbook

Description: Patient Advisors on the council wanted to choose a project that they could have direct impact on given the current state of competing priorities. We have a hardcopy of a patient handbook that is given to every Inpatient. These contain a great deal of information relevant to their stay and also some required information from a regulatory perspective. The HFWH Handbook is outdated and needed a refresh along with some requests for optimization on wording related to new project work at HFWH, like when a patient is going home or discharged.

Results: PFAC team did a complete tear out and reordering/revisions to the Patient Handbook. We are working with Marketing to complete the process changes, which were somewhat delayed with the New Branding requirements and with priorities of the triannual Joint Commission survey. They also created new wording recommendations to align with improved messaging that supports the early discharge process. This is still in progress, but with great success from our PFAC's input.

Remote Sitters

Description: This is a system wide initiative to create a safety solution given the staffing shortage of patient care sitters. The clinical team is using technology, when appropriate, to have cameras in the rooms for the staff to observe a patient remotely for their safety. There are many considerations to this on the clinical and operational end, however, nursing wanted to ensure our PFAC was involved to review our patient and family engagement while using this process and technology.

Results: PFAC members provided family introduction and overview approach for patient and family engagement to assist in explanation. Remote sitter program was launched and is having some success. We have had no complaints in the use of this from patients or families.

Early Discharge Process

Description: A multidisciplinary team is working on Early Discharge process. The average time of day for discharge is between 4-6 pm which presents operational challenges for our hospital throughput and patient satisfactions. The goal is to move the time to 12pm so we have adequate time and resources to get patient's home comfortably with all their needs met. They also want a more set time block for discharge so patients and families can plan transportation needs and/or having the caregiver/family available for the discharge teaching process.

Results: PFAC used this opportunity to talk about the language used in the process of "discharge" and made key recommendations to transition this to "When your hospital stay is complete". They revised the entire page of the patient handbook for more clear and inclusive language as well as importance of the end of stay process. We are still working with Care Experience Leadership to have a timeframe message pushed across the patient's TV as another part of this project, but it is it the works.

Population Health Food Insecurity

Description: The leadership team from Population Health is spearheading an initiative to increase identification of people who are experiencing hunger. When they recognized that the Downriver community was reporting significantly lower percentages they wanted to understand more about if this was an accurate representation or if they could improve their screening toll and process to better meet the community needs.

Results: Patient Advisors on this council made key recommendations for adjustments to the following:

- Timeline of when to engage about this issue during an encounter
- Key personnel that are best suited to inquire with the patient given discomfort to disclose at times to physicians
- How to approach the issue in terms of questions recommendation
- Resource follow up options
- Key moments or other triggers that could lead to re-asking a question for identification
- Project handed off to a new leader for implementation given staff turnover at Population Health.

Geriatric ED Certification and Clinical Decision Unit Pilot

Description: In effort to improve outcomes in the ED experience for our aging population HFWH is pursing certification as a Geriatric ED. This requires we take several improvement actions from physical design to improved inclusion of family members/caregivers. We also reviewed the pilot for having a small Clinical Decision/Observation unit near the ED to address throughput and to increase patient understanding/awareness of Observation process instead of moving them to an inpatient unit while still in Observation status.

Results: PFAC provided key feedback on family engagement methods, key moments and key messages for Geriatric ED. They also made recommendations to improve explanation of care and pross for CDU as this can be very confusing to patients. Addressed gaps in experience and options for how to mitigate these going forward. Will review results in Q1 of 2023.

2023 Goals

1. See end product of Patient Handbook

2. Be able to complete onsite walk through of physical space improvements in projects

3. Grow membership by 1-3 advisors

4. Take more pictures of our work and activities

5. Continue to learn more about patient surveys and public reporting of reviews and ratings

Belonging to PFAC gives me an opportunity to help make HFWH a better hospital, a leader within the HF system. The Council also has been a place to meet others with the same goals. We work well together in open, non-judgmental meetings conducted by wonderful leaders.

-HF Wyandotte Patient Advisor

Accomplishments

Greater participation in patient and family recognition of Daisey and Honeybee awards

Revisions to key moments, messages and implementation of Food Insecurity Screening

Created messaging for Early Discharge and revised entire Discharge page to Patient Handbook



Created introductions and patient/family engagement messaging for remote sitter project



Significant contributions to revision of Patient Handbook to make it more relevant and user friendly

Adv to 0

Advised on improvement to caregiver inclusion to Geriatric ED and patient understanding of CDU process for patient safety.

"I joined this group to help HFH become the go to hospital Downriver and being part of it is so satisfying on a personal level. While many obstacles have been placed in your way, I'm impressed with the changes that have been made and hope that my participation is a small part of that success" -HF Wyandotte Patient Advisor

North Market PFACs

West Bloomfield Hospital PFAC & Macomb Hospital PFAC

To enable Henry Ford Health to provide the highest standard of safe, comprehensive and compassionate healthcare while integrating the voice of the patients, families, caregivers and community of Henry Ford Macomb & West Bloomfield Hospitals. The Patient Advisory Council serves as a formal mechanism for the North Market in involving patients and families in policy and program decision making. Macomb and West Bloomfield PFAC often collaborate together on projects.

Projects

Bedside Shift Report West Bloomfield & Macomb PFACs

Description: Bedside shift report is an evidence based initiative that aids in communication between nursing and our patients. Our 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. They also shared that this would be a good partnership to the Sonifi question which was added for our patients to report out their satisfaction of care. The metrics of improvement will be shared with the advisors in 2023 to add input to the success or opportunities shown.

Results: This is a new strategy for Macomb to add observation/coaching to the docket, the advisors will review the data in 2023 for any support opportunities noted.

Patient Handbook Review West Bloomfield & Macomb PFACs

Description: Our Patient Handbook was up for review and our advisors' received copies of the current handbook for changes. They reviewed for content and ease of reading, The books were also updated with new branding and then supplied to the units. The work from our advisors was greatly appreciated as they found many areas that needed updating or clarification, i.e. uniform colors.

Results: We were able to update the handbook, but in August, 2022 we uploaded the handbook to the patient's television and to our website which allowed for a financial savings to the hospital and made the information more accessible to our patients. We do have a few hard copies on the units if needed, and still provide the patient rights/responsibilities in our Welcome Packets.

ED Wait Time West Bloomfield PFAC

Description: Our Advisors partnered with our emergency department leadership on the increased volume that they are seeing which has increased the wait times and is a patient dissatisfier. We heard from both our ED Nursing Lead, Deb Spencer, and our ED Director, Dr. Rockoff. Through the presentation our 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. This will be an ongoing discussion and all ideas are on the table for this team moving into 2023. This presentation took place in November 2022 and is ongoing.

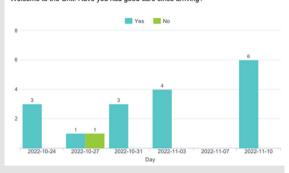
Results: This is a new project that our advisors have been requested to take part in and more information on results will be shared in 2023.

Sonifi Project West Bloomfield & Macomb PFACs

Description: Patient Advisors took part in a presentation from our System on adding a question to the TV for our patients to assess their satisfaction to the unit they were admitted to. This question would determine in real time if the patient was satisfied or not, and an alert would be sent to the care experience team if there was an opportunity to change the course of the experience for the patient. Our advisors collaborated with our System to clarify the question, expectation of the patient, and how it would in turn be a successful outcome. The concern of when the messaging would be shown, and for how long were also brought up to our System lead. Their input was taken into consideration with the roll out of this patient partnership in real time care.



West Bloomfield Hospital - Survey Reponses Welcome to the Unit. Have you had good care since arriving?



Results: Patients are answering the question, and when opportunities are found, the alerts hit the email of care experience. We have had a few false/negative responses, but it has allowed our team to follow up with our patients/families in real time.

Code Lavender West Bloomfield PFAC

Description: The PFAC heard a presentation on Code Lavender and were asked to weigh in on this project rollout at West Bloomfield. Great discussion was had on the communication of the plan, how leadership of the employee who a code lavender is called on will know and brought to the surface some opportunities to consider. The team that presented appreciated the input as this was at the ground level and took back the conversation to the Code Lavender committee. The committee also appreciated the information and will consider change to the program based around the PFAC discussion.

Results: PFAC input was taken into consideration for changes in roll out and discussion with staff.

First developed by the Cleveland Clinic and launched in 2008, Code Lavender is a holistic care rapid response program to help caregivers in need of calming influence after a stressful situation, such as a difficult diagnosis or the loss of a patient

Tower Project Macomb PFAC

Description: Our PFAC was 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. Advisors have been on the ground floor of the Macomb tower build, and this was one of many in the next' steps moving forward. Artwork is essential in healing, and the art work that will hand in the Lobby of the new Macomb tower is no exception.

Patient Advisors have been a part of the artwork project from the ground floor, and have worked with Doug Jones and Meghan Winkel, our creative project managers to choose the flavor of the artwork. Doug has brought to the table a project that partners with our advisors, front line team, community and therapy dogs. Our advisors had the opportunity to participate in painting slides that will be fused together to create a beautiful picture which reflects areas of Macomb County.





Macomb PFAC

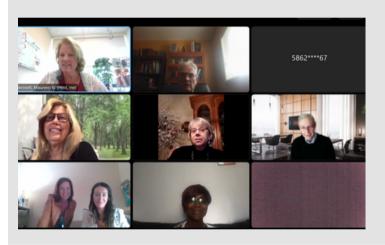
Accomplishment Highlights

- Decisions on Furniture for Tower Project
- Participation in Artwork for Tower Project
- Collaboration with System on Sonifi Project
- Collaboration with HF Macomb on Patient Handbook Review/Financial Change
- Partnership with Nursing/Care Experience Bedside Shift Report Rollout

2023 Goals

- 1. Continued work on Tower Project
- 2. Reviewing data on Bedside Shift Report
- 3. Reviewing data on Sonifi Project looking at change in questions.
- 4. Adding more Patient Advisors to PFAC roster
- 5. Continued work on supporting the frontline team on projects presented

"



Over the course of the 2022 operating year, I was impressed with the many chances offered to our group to become a part of active decision making regarding the addition of the new North Tower addition, and after becoming a patient at the hospital myself, the realization that decision makers do in fact act on our suggestions. It made me feel that our participation is actually changing and improving patient care.

-Macomb Patient Advisor

West Bloomfield PFAC

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Accomplishment Highlights

- 🗹 Patient feedback on Sonifi Project
- 🗹 Emergency Department Wait Time Discussion
- Bedside Shift Report Coaching/Observation and Auditing
- 🗹 Code Lavender Presentation Initiative

2023 Goals

- 1. Reviewing data on Bedside Shift Report
- 2. Reviewing data on Sonifi Project looking at change in questions.
- 3. Adding more PFA's to our roster
- 4. Continued work on supporting the frontline team on projects presented

Experience Transformation PFAC

This council works on initiatives and process improvement around pre-visit, onsite visit, and postvisit communication and delivery. Additional Henry Ford Health priorities are to leverage existing or new digital solutions that facilitate patient access, strengthen existing referral channels and growing new ones with potential future partners, assist patients with understanding and paying their health expenses, and better manage total per member per month cost through patient/member engagement in their wellness and care.

Projects

RECAP: Consumer & Digital Experience Topic

- MyChart Name
- Test Results Follow Up
- Same-Day Care
- Managing Patient and Family Feedback
- Messaging Expectations
- HenryFord.com User Experience
- Primary Care Navigation
- Front Door Transformation Project Introduction

RECAP: Access Technology Topic

- Open Scheduling on Henryford.com
- Bill Pay & Financial Assistance
- Ticket Scheduling Acceleration
- Phone Number Optimization & Cleanup
- Wait List (Fast Pass)
- MyChart Card
- eCheck-In for All
- Find Lab Services
- Prescription Refill Requests/Renewals through MyChart

RECAP: Virtual Care Topic

- Video Visit Custom Waiting Room
- Best Buy and Henry Ford Healthcare Digital Device Collaboration
- Video Visit Appointment Notifications and Usage
- MyChart Updates and Upgrades
- Video Visit Patient Satisfaction Survey New Question Proposal

Project Highlights

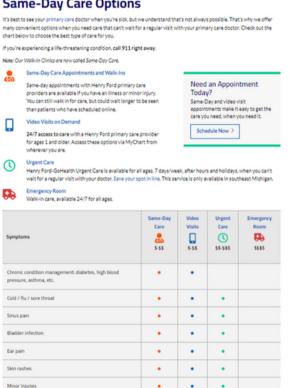
Same-Day Care

Description: Seek advisor feedback on understanding of new same-day care model on henryford.com

Results:

- Updated call to action to make "Schedule Now" more prominent
- Left "walk-in" terminology on the page
- Removed "same day with your PCP" to avoid confusion
- Page is focused on services available when you have an illness or injury and need CARE NOW
- Early feedback from patients and staff appreciate having scheduled time slots. Patient flow is improving.

Same-Day Care Options



Virtual Care

Description: Share and seek advisor feedback on custom Henry Ford virtual waiting room content and video for MyChart video visits to inform and enhance the customer experience.

Results: Based on insightful feedback and comments from advisors, HF launched and enhanced the virtual waiting room content to include useful and timely information as customers wait for their provider to join their video visit.



Key Accomplishments

- Implemented same-day care decision tree functionality on henryford.com to direct patients to appropriate care, leading to 27% of our patients scheduling online
- Piloted wait list (Fast Pass) optimization for Women's Health, with 1,500 patients being able to take advantage of a sooner appointment
- Piloted Find Lab Services at Henry Ford Hospital and West Bloomfield Hospital; 85% of our patients were able to schedule their lab appointment online

Key Accomplishments Cont..

- Prescription refill requests/renewals through MyChart Encouraging MyChart patients to utilize functionality via phone system
- Public Health Infections implementing name and/or placement change
 - Changing available appointment offer look-out for online scheduling from 60 days to 180 days; resulted in 1% increase in online scheduling to date
- Expanded digital scheduling to specialties such as Orthopedics, Podiatry, Rheumatology, Plastic Surgery, General Surgery, Dermatology, Endocrinology, and Vascular Surgery
- Implemented eCheck-In for all; saw a 10% increase in eCheck-in usage
 - Messaging Expectations improved communications about how to change preferences in MyChart
- HenryFord.com User Experience feedback from advisors will help inform web design strategy for 2023
- Open scheduling on henryford.com reviewed process for updating services on provider profiles

2023 Goals

- 1. Expand PFAC membership
- 2. Host a PFAC lunch & learn to share information about our PFAC and attract new members.
- 3. Find opportunities for PFAC members to engage in the Front Door Transformation.
- 4. Continue to gather patient-centric perspectives for varied topics.

Quotes from Experience Transformation Patient Advisors

What do you think was the biggest accomplishment for this group in 2022?

"That our suggestions on the various topics presented were taken seriously and where appropriate, implemented."

"Continuing to include patients in the conversation about their own care experiences."

What do you like most about serving on this Council?

"The openness with which all comments [and] suggestions are listened to in a corporate setting is refreshing. Your dedication to improving the customer service experience for all who use HFH is great. I look forward to working on the PFAC in 2023."

"Knowing that the conversations are heard and make a difference."

How do you feel you have made the most impact this year?

"Even though I am not in an actual decision-making position, I still feel that my input was used in helping to formulate changes made to improve the customer's experience at HFH."

Patient Information & Involvement PFAC (PICC)

The Patient Advisory Council members are involved in some or all of following functions:

- Act as Champions of the ideal patient experience by bringing their ideas, thoughts, and opinions about various topics and processes.
- Review communications to patients and families to ensure engagement in health care services.
- Provide feedback to fill in communication gaps between patients and providers.
- Revise and improve patient education materials to be understandable by patients and their caregivers.

Projects

Becca Austin's Patient Story

Description: Our very own patient advisor liaison gave her story as a patient at Henry Ford Health. She wanted to tell everyone about her experience from beginning to end with the various departments she interacted with throughout her hospital stay.

Results:

- Great discussion from the advisors with suggestions for process improvements and care experience
- Had a whiteboard that had been updated in recent years from this advisor group that was of great use during her stay.

MyChart Layout and Usage

Description: The Chief Nursing Informatics Officer presented the MyChart app to the advisors and asked for feedback on the screener tools, usage, ease, the way they access MyChart, the features they use most and how to improve the app.

Results: The Chief Nursing Informatics Officer took feedback into consideration specifically around wording of screening tools.

Art Therapy and Music - The Connection of Relaxation

Description: The Caregiver Program's Art Therapist Kelly Darke had the group participate in a water color activity while listening to classical music. She discussed the connection between art and music and how it impacts people neurologically.

Results: People reported feeling less stressed and more relaxed and calm.

Dialysis Patient Education Booklet

Description: The patient education coordinator for outpatient dialysis presented the book to our advisors for feedback on the entire book. Specially, length, photos, language, information, purpose, and to determine if any information should be added.

Results: This group received plenty of feedback regarding the layout of the book, such as additional information that should be included and which information should be removed.

Accomplishment Highlights

Two (2) in-person meetings

Gave feedback on various MyChart access experiences and features.

Found new ways to relax through art therapy and music.

Provided feedback on dialysis education to make it easier for patients to understand and follow throughout the book and their dialysis journey.

2023 Goals

- 1. Resume in person monthly meetings.
- 2. Consistent topics for advisors through mandatory participation from population health program staff.
- 3. Have at least 8 advisors attend each meeting.
- 4. Include 1 education piece for review per month.
- 5. Invite at least 2 new members to join our group.

Quotes from Patient Information & Involvement Patient Advisors

"I greatly appreciate the expertise of the guests who come to our meetings to consult with us, as well as the respect that they show for the membership and the feedback that we provide. I also appreciate that they actually use the feedback." "The insights I have gained from my colleagues and its Henry Ford Health staff are terrific and fueled my passion for advocacy to bring the consumer viewpoint to healthcare. We've helped with seemingly small things like language in brochures and patient handbooks to bigger issues like improving ways health care staff communicate to patients. Thanks for letting me play a role in trying to put the consumer into the decision-making process."

"I like that HF health care providers continue to bring their concerns to our meetings. I continue to enjoy hearing the opinions of all participants on a wide range of topics, and appreciate my comments being heard as well."

"I believe that I made the most impact by listening to learn and not judge other's point of view."

Hermelin Brain Tumor Center PFAC

Mission: To leverage our combined experience as patients, caregivers and clinicians to guide the continual improvement and development of the Hermelin Brain Tumor Center. We believe our shared journey is invaluable. The goal is to drive innovation, research, and success to continue to be a center of excellence.



Projects

Journal Article

Description: The PFAC has expressed a longstanding interest in having an article published in a journal. To this end they began to write an outline for this article. Several members of the PFAC contributed content working as a team using a shared document

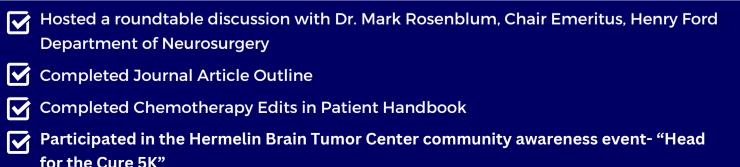
Results: We now have a strong outline that can be further developed into an article suited for publication.

Chemotherapy Edits to Patient Handbook

Description: Prior to Fall 2021, Neuro-Oncology patients who were prescribed chemotherapy as an element of their treatment plan were seen and followed by a Medical Oncologist. These patients are now followed by their Neuro-Oncologist in collaboration with a Physician Assistant. The PFAC updated the Patient handbook to reflect these changes.

Results: The edited document has been sent to Creative Services to be typeset and rebranded with the new HFH branding.

Accomplishment Highlights







Head for the Cure 5K

The PFAC participated in the Hermelin Brain Tumor Center community awareness event, "Head for the Cure 5K". Two PFAC members were awarded the **Keeping the Faith Award** by nomination from their friends and families. Other PFAC members brought their friends and family to host

teams and raise money for brain cancer

research.



2023 Goals

- 1. Host a focus group for patients on active treatment to learn if there are any ways that the process needs to be improved.
- 2. Consider resources for children of patients, i.e. C.L.I.M.B. program, support group topic.
- 3. Consult with radiology to ask if there are any gaps where patient input might be valuable.
- 4. Invite Supportive Oncology Services team to a meeting to see how we can get the word out better about the services they offer.
- 5. Review HBTC marketing and social media for opportunities.
- 6. Inquire about the opportunity to tour the Cancer Pavilion.
- 7. Revisit the HBTC PFACs mission statement.

Hermelin Brain Tumor Quotes Patient Advisors



What do you think was the biggest accomplishment for this group in 2022?

Megan L: "Being able to work on a publication to share group deliverables"

How do you feel you have made the most impact this year? Ron L: "Showing up and being available"

What do you like most about serving on this Council/Committee?

Mike C: "Giving Hope to future patients"

COVID Recovery Care PFAC

Patient population is emerging, needs specialized services for its specific needs, so little is known about COVID long haulers. Henry Ford Health has developed a COVID Recovery Care Service (Program) and formed a PFAC of long haulers to provide feedback on the new initiative. Along with providing feedback to HFH processes, Patient Advisors on this council also support the "Using Body Mapping to Develop a Patient Centered Research Agenda About Long COVID-19" PCORI funded project.

Patient Advisor Role:

- Give suggestions for the program design and services
- Feedback to COVID Recovery Care website
- Co-designing patient education and marketing
- Supporting in developing a research agenda that is patient-focused
- Patient perspective on research about Long COVID-19

Highlighted Projects

Patient Story Publication

Description: Patient Advisors are authors on a paper that tells their unique patient story with long COVID. Advisors participated in a writing exercise that helped them develop their stories.

Process:



Section 1- Life before COVID-19 (Day in a Life) Section 2- COVID-19 diagnosis Section 3- Life as a Long Hauler

- Symptoms
- Your "new normal"
- Biggest change that has impacted your life
 - Feeling/Emotions
 - Mental/Mind
 - Body
 - Relationships

• Struggles/Hardest part Sections 4- Hopes for future

2 Story Swap

Patient Advisors swapped stories and provided feedback as an editor:

- Highlight profound words, quotes. Things that move you or you can relate to
- Provide your overall feedback
- Ask any questions to the author

3 Publication Prep

Experienced professional to help compile stories into final publication draft. Patient Advisors reviewed draft and provided any edits before submission.

Results: Officially accepted for publication in Journal of Patient-Centered Research and Reviews. Article titled: *"Healing can be a Very Jagged Line:" Reflections on Life as a COVID-19 Long Hauler"*

Long COVID Body Mapping Project

Description: PFAC members give support to the "Using Body Mapping to Develop a Patient Centered Research Agenda About



Long COVID-19" PCORI research project. This funded project aims to pursue crucial work investigating long COVID-19, specially focusing on utilizing body mapping as an innovative approach to capture the patient's journey with long COVID-19. Patient Advisors provided feedback on varies parts of the project including participant materials, communication efforts, event feedback and more.

Results: Project in progress

Accomplishment Highlights

COVID Recovery Care Program started out as an idea, and with input and help from Patient Advisors the program is now up and running. Read the following accomplishments.

57 active long COVID patients

Full website development

2 Nurse Navigators

- 1 Clinic Day/Month
- Physician Awareness
- Community Awareness of Long COVID

COVID Patient Advisor in the news spreading awareness

Click here for news article

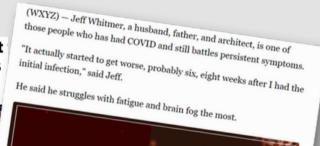
Michigan long COVID patients using art show struggle with lingering symptoms

'You would never know what I'm dealing with.'





and traffic f



"Overall, 1 in 13 adults in the U.S. (7.5%) have long COVID symptoms, defined as symptoms lasting three or more months after first contracting the virus, and that they didn't have prior to their COVID-19 infection."

2023 Goals

- 1. Long COVID Support Group
- 2. Published Paper
- 3. Continued learning and the hope of new treatments
- 4. Research findings
- 5. Hearing Patient Success Stories
- 6. More development of the COVID Recovery Care Service
- 7. More awareness for providers to understand long COVID

All of Us Research Program PFAC



Members are Participants in the All of Us Research Program.

The Henry Ford All of Us Team engages with the 50+Council members to discuss their ideas and suggestions about the program both locally and for the National Institutes of Health (NIH). We meet (online) every other month for 90 minutes (5:00-6:30 pm). Members also hear lectures related to the Program from research experts. Advisors receive a \$25 gift card for each online meeting they participate in. Several members have been selected to also serve on NIH workgroups and councils.

Projects

Social Media Expansion

Description: The council learned about how marketing professionals use demographics to target messages for specific generations (Gen X, Gen Z, Baby Boomers) and develop personas to create the messages. The group gave feedback on the most effective ways to reach those potential participants in the Detroit market. Members learned about Key Performance Indicators (KPI) in marketing campaigns and the KPIs we use locally to develop and monitor our marketing plan.

Results: Instagram site activated in June with expansion of Facebook and Twitter.

National Photo Shoot

Description: This summer we worked with the All of Us National Communications team on a photoshoot that took place in downtown Detroit. Our photographers and staff were local to the great mitten state. The areas and landmarks of the photoshoot were picked to showcase our thriving community. Some of those sites included the Detroit Riverwalk, Spirit of Detroit, Eastern Market, and Campus Martius.

<image>

Surge Week Brainstorming

Description: We explored the potential of coordinated all-hands-on-deck, collaborationfocused 'surge' weeks where we are laser-focused as a program on enrollment. The council shared their thoughts and opinions on the MOST EFFECTIVE outreach and enrollment strategies and what suggestions they had for these events.

Results: Enrollment increased by > 50%!

All of Us Lecture Series

Description: Based on council requests, we had 4 speakers to help educate members about the science potential of the All of Us Research Program.

- Risk Trajectories Suicidal Ideation During the COVID-19 Pandemic in the Diverse Sample of All of Us Research Program
- > Understanding Genomic Results
- Pediatric Enrollment
- > A Dirty Truth: Are We Too Clean?



Accomplishment Highlights

Successful Implementation of Instagram platform for #AllofUsMI

Support of National Photoshoot project in Detroit with member representation

- Surge Week goals of >50% increase in enrollment during Q4 2022 in Detroit
- Members were educated about the science potential of the All of Us Research Program

2023 Goals

The participant advisor voices will continue to guide the All of Us Research Program at both the local and national levels to support awareness, enrollment and retention in the program



Stroke Transitions of Care Committee

The purpose of the Stroke Transitions of Care Committee is to create pathways for stroke patients and their family/caregivers to transition from the inpatient care setting to other care settings and into survivorship in a seamless manner, by working with the patient and their caregivers to incorporate their unique needs into post-hospital planning.

The Patient Advisor on this committee offers first-hand perspective to the Comprehensive Stroke Program in order to improve care transitions for patients who experience stroke, by actively participating in our Stroke Transitions of Care (TOC) Committee meetings and lending their voice and ears for consideration in planning of projects, review of outcomes, and more.

Projects

2022 Metro Detroit Heart & Stroke Walk Table

Description: Provided an education table on stroke signs/symptoms, acting FAST, and reducing risk factors for stroke at the 2022 Metro Detroit Heart & Stroke Walk held at Ford Field. Designed an interactive, engaging stroke trivia board, offered give aways and prizes for participation, and disseminated take-away educational materials. Our patient advisor/stroke survivor assisted in the planning during committee meetings.

Results: Hundreds of people stopped by our table, and many participated in trivia and asked questions of our team. Great engagement!

EMS Recognition for Stroke

Description: Participated with the Henry Ford Hospital ED to recognize and express our gratitude to Emergency Medical Services providers for their partnership in improving outcomes for patients with stroke. Provided them with lunch, giveaways items, and stroke education updates two days during EMS Appreciation Week. Our patient advisor/stroke survivor attended and helped to disseminate lunches and information.

Results: Disseminated lunches and provided recognition to at least 50 EMS crews, hopefully motivating them to continue to recognize stroke, pre-notify the ED, and act FAST for improved stroke outcomes.

Annual Stroke Survivor Picnic

Description: Organized our first Henry Ford Health Stroke Survivor Picnic, after taking off two years due to Covid-19 after our final Stroke Camp in 2019. Goal was to re-engage our Stroke Survivors in social and support activities. Our patient advisor/stroke survivor assisted in planning the event and also shared his story during the picnic.

Results: Attendance was light at this first event, but plan to offer it annually, as well as activities in between annual picnics to keep our survivors engaged and offer supportive activities to new stroke survivors. Feedback from attendees was extremely positive.



Accomplishments

- Return to in-person meetings and in-person events
- Successful stroke education table at the Metro Detroit Heart & Stroke Walk
- Appreciated our EMS partners during EMS Week which falls during Stroke Month (May)
- Re-engaged stroke survivors through an annual stroke picnic



Stroke Team members (L to R): Jake Maine, Lisa Cohen, Megan Brady, Taylor Pardo, Daniela Danese; and patient advisor, Dan Miller

Stroke Survivor Picnic Hemlock Park, Dearborn



2023 Goals

- $1.\ \mbox{Continue}$ to expand and enhance stroke survivor activities
- 2. Increase community stroke education outreach
- 3. Implement a stroke survivor support group in Detroit

Palliative Care Council

Engagement with the Palliative Care Council to provide feedback from a patient perspective on initiatives being presented by the council. This is an individual placement and currently has 1 Patient Advisor included on the Council.

Projects

Advance Care Planning

Description: Council discussion on how to best support Advance Care Planning across the system. The council has discussed, reviewed, and implemented systemwide changes to Advance Care Planning including educational needs (both physician and patient), standard documentation, and communication plans.

Results: Developed Standard Templates and education for Advance Care Planning in both the inpatient and ambulatory settings. Help physicians and patients navigate Advance Care Planning Discussions

Comfort Care

Description: Open discussion around comfort care protocols at a system level. Discussion from all disciplines on how to provide proper comfort care, including education (patient and physician), treatment options, and understanding of roles that different departments play in the care of patients who are at end of life. Respecting patient goals and wishes.

Results: Educational materials, treatment options and protocols developed. Council will return to this topic periodically to review and update.

MI-POST

Description: Michigan Physician Order for Scope of Treatment (MI-POST) is a two-sided medical order with a person's wishes for care in a crisis. This order is used for EMS and other non-acute care facilities, and can help guide wishes within an acute setting if confirmed. Project is to take State Educational materials and write HFH policy and education around order to educate staff who might encounter document. This applies to both inpatient for awareness and ambulatory on writing the orders.

Results: Developed educational materials for the Emergency Department. Have educational materials ready to roll out once final documentation is available from the state.

Accomplishments

1. Developed Education and Action Plan around

Advance Care Planning

2. Reviewed and Developed Plan for Educational

Material around MI-POST

3. Developed Education and Action Plan around

Comfort Care

Goal for 2023

Expand and educate on 2022 initiatives



Additional Councils & Committees

Cancer <u>Center PFAC</u>

Started in early 2016, this group of cancer patient, survivors and their caregivers advised leaders on early development plans for the Henry Ford Cancer Institute on Henry Ford's Downtown Campus which opened in 2021. They have given guidance to the architecture firm on specific building features and on cancer support services that are most important to patients and caregivers. Research support is part of their advisory work and the group was awarded \$250K in Patient Centered Outcomes Research Institute funding to develop precision medicine cancer research questions and are developing a research agenda and dissemination plan for their work. Their research questions are being developed for future funding opportunities. The HFCI and the Head and Neck Cancer PFACs were merged in 2020. Recently, this council received funding from AstraZeneca to continue their work on providing awareness to the community on clinical trials.

Perioperative Brain Health PFAC

This group participates in the creation of new patient and caregiver education materials and in the revision of existing patient and caregiver education materials as they relate to whole experience before, during and after surgery. They will also participate in improving the design of clinical pathways which guides all the healthcare providers to provide the same care to the right patient at the right time. Most recently this group focused on providing feedback to the "Speeding Up Your Recovery after Surgery" patient education booklet. PFAC meets as needed.

STEPS Advisory Council

Seniors using Technology to Engage in Pain Self-management

HFH is partnering with The University of Michigan to launch a 7-week program led by HFH community health workers that works with adults 50+ on how to live better with chronic pain. They will be comparing STEPS participants to a control group to see whether it can reduce pain's impact on daily life. Patient Advisors on this council will give input into all aspects of the study, including program development, recruitment, data collection, and interpreting and sharing study findings.

Supportive Care Committee

This committee focuses on best ways to connect patients to existing services within HFHS, improving communication between the care team and patients/family, as well as reducing readmissions and improving patient satisfaction. They are looking for patients and caregivers with experience in hospital readmissions.

Critical Care Committee

This is a system critical care collaboration with representation from all of our hospitals to help to make decisions for the system. Committee is a wide array of providers some examples are: critical care physicians, mid-levels, clinical nurse leaders, ICU nurse managers, pharmacists, Respiratory Therapists, administrators, quality people, supply chain representatives, and others.

Additional Councils & Committees

IMPACT-CHF Committee

Integrated Michigan Patient-Centered Alliance in Care Transitions Congestive Heart Failure (HFH & HFWB)

Integrated Michigan Patient-Centered Alliance in Care Transitions (I-MPACT) is a BCBS funded quality improvement initiative with the purpose of decreasing heart failure (HF) Patient Readmissions utilizing patient/caregiver involvement. The work of this group is important because involving the patient/ caregiver in HF education to improve disease management in the home is a key component in the project. Patients living with chronic disease often require support to manage their health and an appropriate, health condition educated and engaged caregiver is often required to manage one's health.

Patient Education Council

Henry Ford Health System provides health literate patient education that meets learning needs and literacy levels of all patients. Patient education is accessible to patients, caregivers, and employees through in person education, print, electronic, and audio-visual resources.

Henry Ford Hospital Quality Committee

The HFH Quality Committee is responsible for the oversight of patient and employee safety, infection control, quality projects and initiatives, regulatory readiness, risk, public reporting, quality measures and process improvements. This committee reports to the Clinical Operations Team and to the Board of Governors. This team also develops the quality strategic plan on an annual basis and monitors the hospital's quality performance through the Quality dashboard.

Quality, Safety & Reliability Council (QSRC)

This system council functions to drive execution and goal accountability within the quality enterprise to ensure safe and reliable care and also ensures patient and employee safety. This council makes decisions on the prioritization of quality and safety initiatives and utilizations of quality resources across the enterprise.

Pursuing Equity Patient Care Committee (PEPC)

PEPC provides strategic guidance for the organization to align equity strategies, review their health care equity dashboard, identify inequities, and sponsor equity improvement efforts to improve equity in patient care and patient experience throughout Henry Ford Health System. Patient Advisors on this committee help contribute to the discussions on strategic guidance for the system to align equity strategies, reviewing our health care equity dashboard, and efforts moved forward to improve equity in patient care and patience experience throughout the system.

Cardiac Rehab Committee

Patient Advisors on this committee provide patient perspective to the operations of HFHS cardiac rehab. Patient Advisors on this committee have gone through Phase II Cardiac Rehab Program.

Funded Projects Partnered with PERC

Research Enterprise to Advance Children's Health (REACH)

Funding Source: National Institute of Health Grant #: 5P01AI089473 PI: Johnson, C.C. / Ownby, D. R.

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

Funding Source: Henry Ford Health System and Michigan State University Grant #: N/A Name of PD/PI: Santarossa, Sara/ Straughen, Jennifer/ Drewlo, Sascha

iFIRE-C Focus Group: Intermittent Fasting to Restrict Cancer: A Pilot Randomized Trial to Investigate Intermittent Fasting (IF) in Gynecologic and Breast Cancer Patients

Funding Source: N/A Grant #: N/A Name of PI: Ramandeep Rattan, PhD

Faces of Clinical Trials Video Initiative

Funding Source: AstraZeneca Grant #: N/A Name of PI: Santarossa, Sara

Enhancing digital CBT-I to improve adherence and reduce disparities

Funding Source: National Institute of Health/National Heart, Lung, and Blood Institute Project Number: R01HL159180 Name of PD/PI: Cheng, Phillip

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

Funding Source: NIH/NHLBI Project Number: R41HL163783 Name of PD/PI: Walch, Olivia/Cheng, Phillip

Grants Awarded to PERC

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

Funding Source: Patient Centered Outcomes Research Institute Project Number: EASC-COVID-00231 Principle Investigator (PI): Dr. Sara Santarossa

Link to PCORI webpage

Objectives: The work will begin at Henry Ford Health System (HFHS) in Detroit, Michigan with a mid-term goal to create the sustained engagement of patients with PASC and HFHS's COVID Recovery Care Service, clinical staff, and researchers in the design, implementation, and dissemination of PCOR/CER research in PASC. The long-term objective is to develop a national knowledge base to encourage PCOR/CER research in PASC. The team's mid- and long-term goals will be pursued after the period of the proposed project and thus, to accomplish these goals, the team will focus on the following short-term objectives:

- Establish a collaborative comprising COVID-19 long haulers and caregivers, HFHS's COVID Recovery Care Service, clinical staff, and researchers focused on the unique needs of this PASC population
- Train all stakeholders to facilitate a shared understanding of patient-centeredness
- Through visual storytelling and a body mapping process as well as nominal group processes, identify issues that matter to these stakeholders
- Use the results of this process to collaboratively generate and prioritize a PCOR/CER research agenda
- Determine tailored dissemination strategies 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

<u>Gallery</u>

The body map artwork was displayed in-person at the Henry Ford Cancer Institute during the month of September (2022). A Gallery Reception Event was held to promote and showcase this artwork and the participants.

- Watch Video from the Event
- Photos from Event
- <u>Click here</u> to view Virtual Gallery



Media Coverage

- <u>https://www.wlns.com/news/haslett-woman-shares-story-of-long-term-covid-19-battle/</u>
- <u>https://www.secondwavemedia.com/features/covidlong10272022.aspx</u>
- Long COVID patients using art to show struggle with lingering symptoms (wxyz.com)
- Long COVID patients, dismissed by doctors, turn to art to show their pain | Bridge Michigan

Grants Awarded to PERC Cont..

Body Mapping COVID-19: Crisis Management in Frontline Healthcare Providers

Funding Source: Blue Cross Blue Shield of Michigan Foundation Project Number: TBD

Principle Investigator (PI): Dr. Sara Santarossa , Dr. Jacqueline Pflaum-Carlson

The project seeks to leverage the lived experiences of resident-physicians (physician learners) who care for COVID-19 patients using an innovative Body Mapping approach. Body maps are life-size human body images created through art-based techniques to visually represent aspects of people's lives and the world they live in. Body mapping will allow physicians to describe their journey with caring for COVID-19; connecting in their narratives and supporting their visualization of problems faced and sources of strengths. Body maps will be used in a virtual knowledge exchange opportunity for the broader community and to draw comparisons from COVID-19 patient perspectives. Bringing together stories from physician learners and patients will create an opportunity to improve patient-centered healthcare practices and may reduce burnout in frontline workers. Physician burnout affects the entire healthcare system; it is associated with increased rates of medical errors, higher cost via increased turnover, and worse patient outcomes due to physician irritability and decreased attentiveness.

PERC Publications

(*denotes student author, +denotes Patient Partner author)

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.

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.

 Santarossa S, Rapp A, *Sardinas S, Hussein J, *Ramirez A, Cassidy-Bushrow AE, Cheng P, Yu E.
Understanding the #longCOVID and #longhaulers Conversation on Twitter: Multimethod Study. JMIR Infodemiology. 2022 Feb 22;2(1):e31259. doi: 10.2196/31259. PMID: 35229074; PMCID: PMC8867393

Olden HA, Santarossa S, Murphy D, Johnson CC, Kippen KE. 2022 Bridging the Patient Engagement Gap in Research and Quality Improvement utilizing the Henry Ford Flexible Engagement Model. Journal of Patient Centered Research and Reviews, 9(1), 35-45. doi: 10.17294/2330-0698.1828