

# 2021 ANNUAL SUMMARY

## PATIENT ENGAGED RESEARCH CENTER



# TABLE OF CONTENTS

<b>03</b>	About PERC
<b>04</b>	PERC Flexible Engagement Model
<b>05</b>	Demographics
<b>06</b>	Recruitment, Training, Engagement & Retention
<b>07</b>	Welcome Workshop
<b>08</b>	Patient Advisor Buddy
<b>09</b>	5th Annual Patient Advisor Retreat
<b>10-27</b>	Patient & Family Advisory Councils and Committees
<b>28-30</b>	PFAC/Committee List Continued
<b>31-32</b>	PERC in Research
<b>33</b>	Quotes from Patient Advisors



## ABOUT PERC

In October 2013, Henry Ford Health System was one on seven organizations chosen from across the country to participate in a groundbreaking infrastructure development initiative to improve patient outcomes through engaging patients, families, community groups and healthcare providers in healthcare improvement and research. The Patient Engaged Research Center (PERC), led by Dr. Christine Johnson, has developed a flexible model to facilitate dialog 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.

### PATIENT ENGAGED RESEARCH CENTER



# THE PERC FLEXIBLE ENGAGEMENT MODEL

Henry Ford Health System'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.

<p><b><i>Health System Advisors</i></b></p> <p>Serve as a Patient Advisor representative on Patient/Family Advisory Council or healthcare committee focused on designing or improving a new or current program, service, policy or process.</p>	<p><b><i>Research Advisors</i></b></p> <p>Serve as Patient Advisor members of funded research projects giving input on study design, outcome measurement selection, data collection and dissemination of research findings.</p>
<p><b><i>E-Advisors</i></b></p> <p>Share feedback by participating in short online surveys. Topics may include: patient care experiences, new services and improvement ideas, and better ways to partner with patients.</p>	<p><b><i>Focus Group Advisors</i></b></p> <p>Participate in focus groups and provide feedback on own personal healthcare experiences, as well as other key healthcare delivery topics</p>



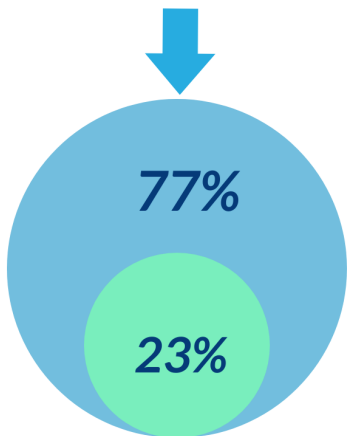
# PATIENT ADVISOR DEMOGRAPHICS

Total # of Active Patient Advisors:  
**476**

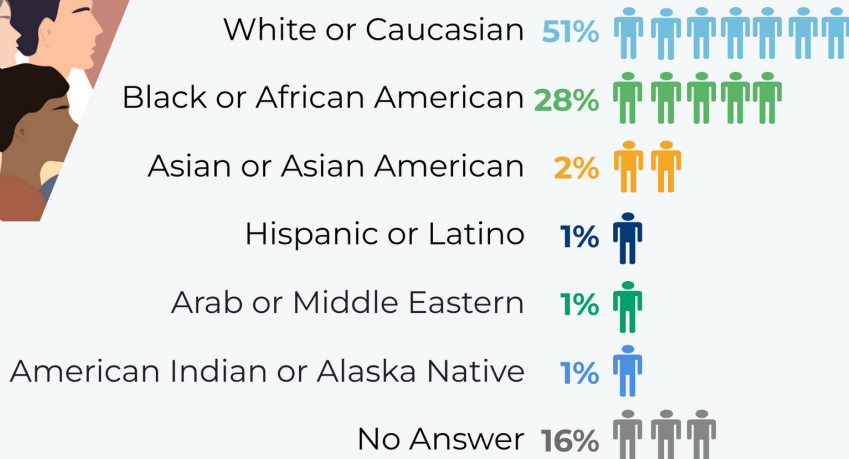
23% of Patient Advisors are employees

With Placement  
271

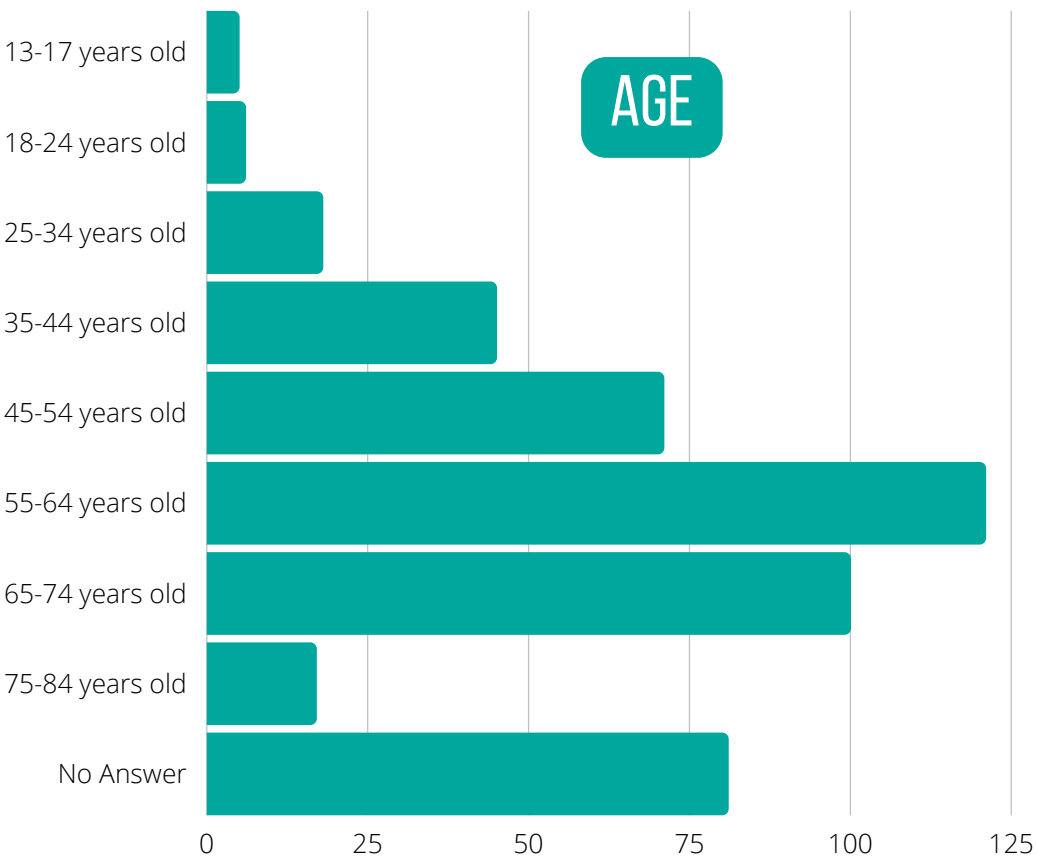
Without Placement  
205



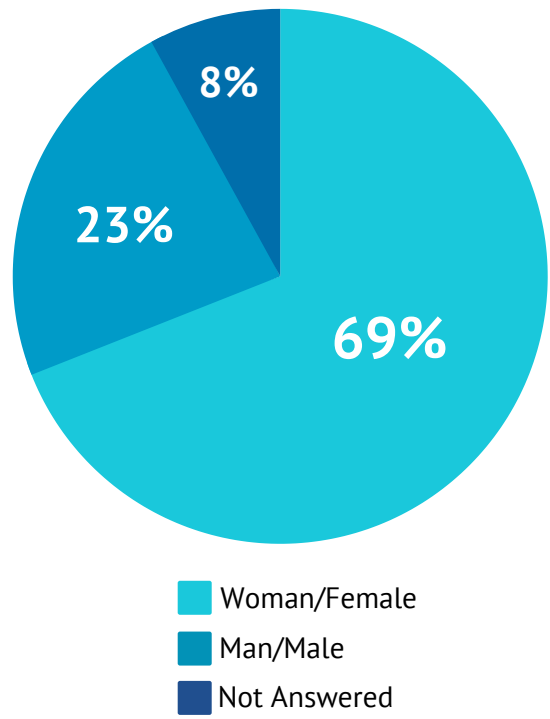
## Race



## AGE



## GENDER



Councils/Committee Members  
 Online Surveys

Woman/Female  
 Man/Male  
 Not Answered

# RECRUITMENT, TRAINING, ENGAGEMENT & RETENTION

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 provides training for each advisor.

Currently PERC has 476 trained and active Patient Advisors and 226 working on teams and committees across the Healthcare System. The system currently has **eleven (11)** 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 patients and providers who develop a charter, specific initiatives and work plan facilitated by PERC, to fully address outcomes important to patients and the Health System. In order to support active participation for patients, families and providers educational workshops and webinars have been developed to meet the unique needs of each group. Patients and caregivers 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](http://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.

# WELCOME WORKSHOP

The 2-hour Welcome Workshop for Patient Advisors is built around the S.H.A.R.E acronym which outlines key attributes of a successful Patient Advisor. Each attribute is described, and each patient is coached and supported as they tell their patient story. This workshop is fully virtual and prepares applicants for their new role as a Patient Advisor.



Virtual Welcome Workshop

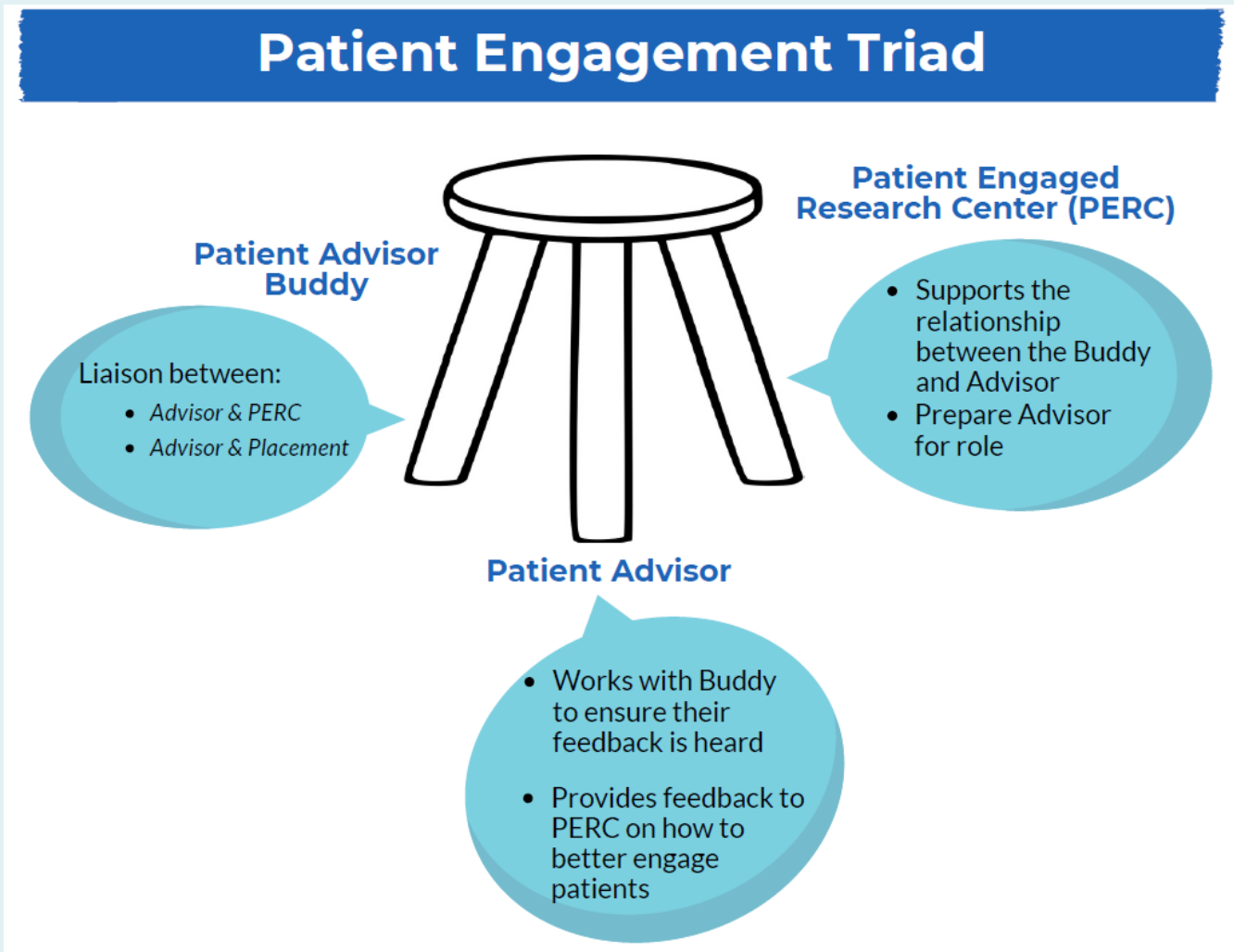


Slides from Welcome Workshop

# PATIENT ADVISOR BUDDY

Providers and HFHS Staff also need support including tools on effective ways to engage with patients as partners on teams. We call those in this role Patient Advisor Buddies\*. To provide that support, PERC developed HFHS University online module for staff who are asking for patient advisors to join their teams. This mandatory modules was developed jointly with the Office of Clinical Quality and Patient Education and PERC. PERC also offers bi-monthly support calls for Advisor Buddies to share successes, solve challenges and share knowledge.

**\*\*Buddy Role is undergoing a name change in 2022. Role will be titled "Patient Advisor Liaison (PAL)"**



# 5TH ANNUAL 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 second year in a row. For the first time, the retreat offered breakout sessions, including two session with three different speaker and topics. Participants were offered the choice to select their breakout sessions ahead of time. Full agenda is listed below.



**5th Annual Patient Advisor Retreat**  
 Wednesday, November 10, 2021  
 9:00 am- 2:30 pm

**PATIENT ENGAGED RESEARCH CENTER**

**PERC OPENING REMARKS**  
*Karen Kippen, Executive Director of the Patient Engaged Research Center*

**GUEST SPEAKER**  
*Heather Geisler, Executive Vice President & Chief Marketing, Communication & Experience Office*  
 Brand + Experience: Making the Impossible Possible

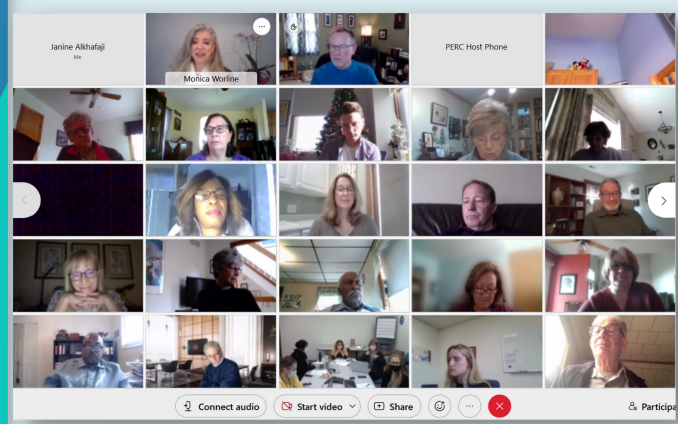
**KEYNOTE SPEAKER**  
*Bob Stocking & Monica Worline*  
 Reflected Best Self

**BREAKOUT SESSIONS**

<b>Improving Quality of Life in Older Adults</b> <i>Dr. Paula van Wyk</i>	<b>Compassion Fatigue: Caring for the Caregiver</b> <i>Dr. Lisa MacLean</i>
<b>All of Us Research Program</b> <i>Renee Williams</i>	<b>Patient Advisors in Research</b> <i>Dr. Sara Santarossa</i>
<b>Healthcare Equity 101: Disparities and Unconscious Bias</b> <i>Dr. Marla Rowe Gorosh</i>	<b>Health &amp; Wellness: A Holistic Approach to Living Well and Preventing Disease</b> <i>Paige Coyne</i>

**PATIENT ADVISOR PANEL**  
*Mike Sarokin Nestelynn Gay*  
*Kathy White Randee Bloom*

There were 90 participants (Patient Advisors and Buddies) in attendance and all attendees were offered a DoorDash or Grubhub food delivery voucher to order food to enjoy during the virtual retreat, just as they would have enjoyed at an in-person event.



*Virtual gallery view of Retreat Participants*

# HENRY FORD NORTH MARKET

## MACOMB PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

To enable Henry Ford Health System 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 Hospital. The Patient Advisory Council serves as a formal mechanism for involving patients and families in policy and program decision making. **Macomb and West Bloomfield PFAC often collaborate together on projects.**

### PROJECTS OF 2021

#### Tower Project

The Macomb PFAC has been working with the Macomb team on the Tower Project and providing input on room set up, patient needs/wants. This has been an interactive project with touring a mockup room and providing input through survey monkey. The PFAC also watched many presentations from the architects with the project as well.

#### Valuables Process

PFAC discussed the situations of our patients and families having valuables misplaced or lost from ED to inpatient. They were presented ideas on providing neon stickers for valuables at registration and on the units along with new signage. Continued with communication at desk/signage to take valuables home.

#### Whiteboard Review

Whiteboard (inpatient communication) changes were brought to the PFAC to review the questions that were being changed and adding the icons for valuables for input. The PFAC gave input on readability, where it will hang, the scope of the project.

#### Hand Hygiene

PFAC representatives were involved in the Macomb Hand Hygiene initiative. Many committee meetings were held to increase hand hygiene compliance. Patient Advisors weighed in on opportunities to involve patients in either surveying or filling out info on the TV.



#### Royal Oak Wayfinding

The Macomb PFAC was asked to participate in a multi-PFAC project of wayfinding at the newly established Royal Oak health center for Henry Ford. The transformational team reached out months prior to the actual event to discuss the project, scope, and time. In November, our PFAC were given scenarios to find the location, as well as patient scenarios for testing.

#### Other

Throughout 2021, our PFAC has been involved with many discussions and heard multiple presentations for input. They have shared their opinions and support for changes that have been requested by Henry Ford. Although not a project, we have had our Leadership discuss upcoming projects with our PFAC to make them aware of future builds and growth projects.



## ACCOMPLISHMENTS

- ✓ Decrease in Valuable Loss with input on Valuable process change
- ✓ Royal Oak Wayfinding
- ✓ Hand Hygiene

## CHALLENGES

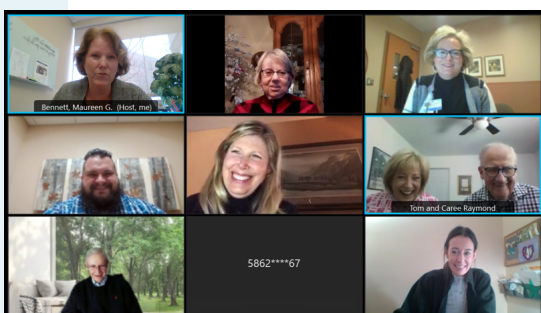
This year we continued to meet virtually due to the continuous surges. Although we have moved beyond technical issues and have had great turn out by our PFAC it still feels **distanced from our teams**.

During the **COVID-19 surges** many of the presentations or request for implementation of new practices were put on hold, therefore, we also saw the request for input lessen. As the surges would decrease, the opportunities for input from our PFAC would increase. This is a challenge as it stalls opportunities to enhance patient care, but was also an acknowledgement that patient care was being performed during a surge, therefore, other initiatives were paused.

We had challenges with the wayfinding project due to **delays** with the Royal Oak Wayfinding project. We were requested back in May for this project, yet it did not occur until November. We also felt that for a project the PFAC should be brought in at the beginning, not near the end. Regardless of the challenges, there was very good input from PFAC on wayfinding opportunities and barriers.

## 2022 GOALS

- Continue work on Tower
- Tower Artwork Project
- Discuss Magnet and stories based around patient experience
- Re-address initiatives from varying sources to receive input from our PFAC
- Request a 'System Stamp of Approval' for PFAC approved items



*Virtual PFAC Meeting*



*Future Macomb Tower with Patient Advisor input*



*Royal Oak Wayfinding with Patient Advisors*

# HENRY FORD NORTH MARKET

## WEST BLOOMFIELD PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

To enable Henry Ford Health System 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 West Bloomfield Hospital. The Patient Advisory Council serves as a formal mechanism for involving patients and families in policy and program decision making. **Macomb and West Bloomfield PFAC often collaborate together on projects.**

### PROJECTS OF 2021

#### Patient Handbook Review

Patient handbook reviewed yearly. PFAC reviewed for changes and input. PFAC found multiple needs for change and offered input for ease of review by patients/families. Final product presented to Executive Leadership and approved. Handbook was approved with changes and stamped that this booklet was Patient and Advisor approved. Looking to request a similar approach through out the Market.

#### Valuable Process

Our PFAC discussed the situations of our patients and families having valuables misplaced or lost from ED to inpatient. Presented ideas on providing cases for valuables at registration and new signage. Pilot of providing cases were put into place as well as new signage. Did see a slight decrease, yet patients did not want to take the cases – felt it was too big/bulky. Continued with communication at desk/signage to take valuables home.

#### Whiteboard Changes

Whiteboard changes were brought to the PFAC to review the questions that were being changed and adding the icons for valuables for input. The PFAC gave input on readability, where it will hang, the scope of the project.

#### Radiology Volume/Hours Change

The PFAC heard a presentation from Radiology on growing volume, staffing and hours for testing. They requested weigh in from the PFAC on change to hours to accommodate patient testing and staffing. They also requested the PFAC to share input on expectations of wait times.



#### Royal Oak Wayfinding

The West Bloomfield PFAC was asked to participate in a multi-PFAC project of wayfinding at the newly established Royal Oak health center for Henry Ford. The transformational team reached out months prior to the actual event to discuss the project, scope, and time. In November, our PFAC were given scenarios to find the location, as well as patient scenarios for testing.

#### Other

Throughout 2021, our PFAC has been involved with many discussions and heard multiple presentations for input. They have shared their opinions and support for changes that have been requested by Henry Ford. Although not a project, we have had our Leadership discuss upcoming projects with our PFAC to make them aware of future builds and growth projects.



## ACCOMPLISHMENTS

- ✓ PFAC Stamp of Approval on Patient Handbook
- ✓ Decrease in Valuable Loss with input on Valuable process change
- ✓ Royal Oak Wayfinding

## CHALLENGES

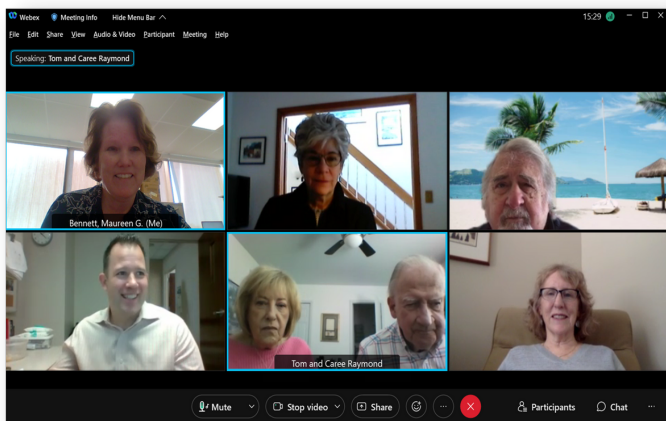
This year we continued to meet virtually due to the continuous surges. Although we have moved beyond technical issues and have had great turn out by our PFAC it still feels **distanced from our teams**.

During the **COVID-19 surges** many of the presentations or request for implementation of new practices were put on hold, therefore, we also saw the request for input lesson. As the surges would decrease the opportunities for input from our PFAC would be requested. This is a challenge as it stalls opportunities to enhance patient care but was also recognized as accepting patient care was being performed during a surge, therefore, other initiatives were paused.

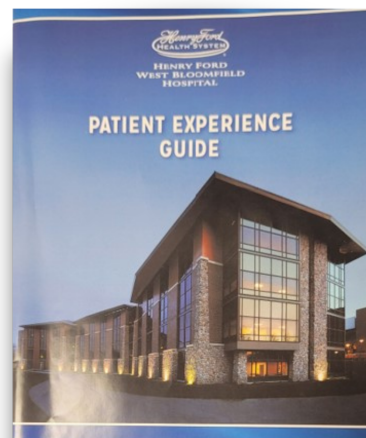
We had challenges with the way finding project due to **delays** with the Royal Oak Wayfinding project. We were requested back in May for this project, yet it did not occur until November. We also felt that for a project the PFAC should be brought in at the beginning, not near the end. Through the challenge though, there was very good input on what were seen as opportunities and barriers.

## 2022 GOALS

- Continue work around Valuables
- Discuss Magnet and stories based around patient experience
- Re-address initiatives from varying sources to receive input from our PFAC
- Request a 'System Stamp of Approval' for PFAC approved items



West Bloomfield PFAC meeting Virtually (not all members present)



Patient Experience Guide with PFAC Input

# HENRY FORD WYANDOTTE

## PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

HFWH PFAC was founded in 2014 and is comprised of 10 highly engaged members including a Chair. We meet bimonthly for 2 hours and have used a virtual format for all of 2021. Our team is engaged by leaders from multidisciplinary departments that are working on improvement projects that range from physical plant changes to care interactions.

### PROJECTS OF 2021

#### Vaccine Messaging

Discussion of vaccine mandate from perspective of community, employees and Health System. PFAC member concerned for health and well being of our teams, the conflict between any team members or loss of employees, and the community responses. We reviewed HFHS current stance, messaging and approach to support all team members and retain talent while maintaining public and workforce health and impact to community.

#### Leader Support Cards

In their desire to help support out leaders and team members the PFAC group inquired what actions steps they could do to engage our leaders while not being onsite given current restrictions.

#### Mindful Moments

This is a nursing led repacking of the Evidence Based Best Practice Purposeful Hourly Rounding. Our clinical teams were working with Care Experience to make this a primary initiative to improve our unit based HCAHPS. This practice includes the intentional checking in on each patient about every hour and asking them specific questions about Pain, Position, Potty (bathroom needs) and Possessions (is everything near you that is needed for comfort and safety)

#### Culture of Caring

Culture of Caring is our system Service Platform that drives our work and behaviors on how we interact with patients, family members and each other. At HFWH we refreshed and retrained all team members during 2020 and created a virtual format for 2021 to include all new employees. In 2021 we went back to the unit level accountability for validations of the AIDET+1 vital behaviors.



#### Project Title: IPASS+ Safety

Implementation of High Reliability Organization (HRO) Best Practice reviewed with PFAC for feedback. This is a clinical practice that aligns with Bedside Shift Report in which at times of shift change and rounding for handoff the clinical team follows a planned set of safety items for review (Illness, severity, etc) There is also a patient facing practice at bedside, so patient receives a Thank you from current RN and a transfer of care to the oncoming RN.

#### Discharge Lounge

Hospital Operations Committee engaged Care Experience in need to establish a Discharge Lounge for patients that are 1-3 hours post discharge but waiting for family arrival and transportation home. Team was presented with data to establish need, views of other lounges within and outside of the unit and key comfort and communications needs may be recommended for this space.

## ACCOMPLISHMENTS

- ✓ Implemented change in Vaccine Communication
- ✓ Leader Support and Engagement with personal thank you cards to all leaders
- ✓ Impacting renaming of Mindful Moments and how to validate/communicate and celebrate accomplishments
- ✓ Methodology for team member recognition and celebration of validation of Culture of Caring Vital Behaviors
- ✓ Discharge Lounge comfort and communication recommendations for implementation

## CHALLENGES

Leaders have **limited time** to bring back projects we have reviewed and/or bring new project to us. We also have many new leaders and have had to re-educate hospital leadership on the importance of the PFAC and role they play in our community.

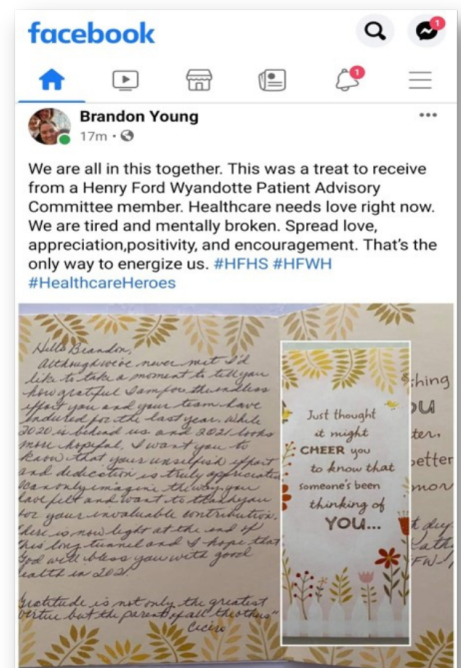
PFAC members continue to stress the **desire to be in person**. While they are understanding of current environment, they are truly deeply wanting that in-person connection. The Care Experience (CE) team works to maintain engagement with kind gestures, engaging activities etc., but it does get difficult to maintain same level of engagement with virtual only platform.

**Time constraints** have impacted the ability to be as consistently aligned with leaders and projects so we would like to complete something meaningful that the team can do on their own. Great pride, meaning and sense of purpose achieved in doing leader support cards for both members and employees and this was accomplished with group and Care Experience Leadership.

The PFAC team wants to be able to learn more about HCAHPS, Comments and Care Experience driven metrics. We want this to be meaningful and not distracting to them as it can provide some insight into more challenges we are facing with communication to patients. This can be **controversial data** to show and/or connect work with for this team if it is not tied to a specific goal.

## 2022 GOALS

- Better learn and understand data, comments and key indicators of care experience as regular part of agenda
- Return to In person opportunities
- Expand membership only for diversity enrichment as group size should not exceed 15
- Engage our unit based shared governance with PFAC
- Complete one self-directed project to support patients or team members



# HENRY FORD ALLEGIANCE

## PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

The Henry Ford Allegiance Health Patient and Family Advisory Council 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 OF 2021

#### Emergency Department Community Insights

HFAH PFAC wanted to learn and understand more about how the pandemic was impacting patients and family receiving care in the HFAH Emergency Department. Patient Advisors provided insights to leadership regarding department changes during COVID, providing a more positive experience, as well as input regarding the metal detector and having armed officers present.

#### Operations and Services

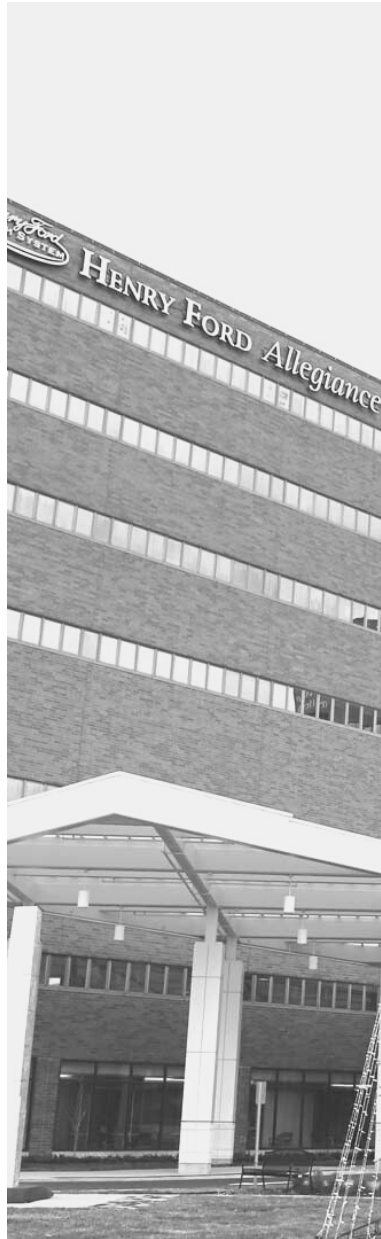
The Council wanted to learn more about how HFAH operates, and the various services offered to the community to be able to act as informed ambassadors. Twelve senior leaders presented to the HFAH PFAC over the course of the year. They heard from the leaders of Home Health and Hospice, Advanced Practice Professionals, Nursing, Patient Education Resources, the Chief Medical Officer, Graduate Medical Education, Diversity & Inclusion, Behavioral Health Services, Market Operations and Strategy, Compliance, Marketing, Oncology, and Operations Scope and Breadth.

#### Host of a Community Event

HFAH PFAC members desired to host a virtual community event to help community members better understand the role of the hospital as part of the health of the community. The event took place on Monday, October 25, 2021. The recorded live event can also be found on HFAH's Facebook page.



[Event Video Link](#)



#### Opportunities for Internal Involvement

The goal was to provide at least three opportunities for interested PFAC members to serve on committees or help with single events.

*One member serves on the HFAH Board Quality Committee*

*One member joined the IRB committee*

*Four committee members served at the Staff Appreciation Food Truck Extravaganza*

*Committee members attended the following community event:*

*NAACP Freedom Celebration with Central Market President and CEO Paula Autry*



## ACCOMPLISHMENTS

- ✓ Recruited five new PFAC members
- ✓ Embedded one PFAC member on an internal committee
- ✓ Hosted a virtual event, “It Takes a Community”
- ✓ Provided input to senior leadership on proposed process changes or new initiatives
- ✓ HFAH PFAC member attended the Brand Change Focus Group
- ✓ Learned about HFAH’s diversity and inclusion efforts
- ✓ Council members represented the PFAC at HFAH sponsored events

## CHALLENGES

The council has been meeting virtually since May of 2020. Some council members have dropped out due to **technical challenges** and **not feeling connected** to others and the work.

Interested council members have been **anxious to feel a sense of purpose** by serving in a volunteer capacity on internal committees or other opportunities that may open up.

## 2022 GOALS

- Goals are to be discussed during Strategic Planning at the February PFAC meeting.



*Staff Appreciation Food Truck Extravaganza. Patient Advisors helped at Event to direct staff, hand out beverages and meal tickets and thank staff for their service to our community.*



*PFAC members were given the opportunity to attend a Pistons Game by our executive team. Patient Advisor (right) enjoying a Pistons game for a Veterans Day Celebration.*

# ALL OF US RESEARCH PROGRAM

## PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

**All of Us**  
RESEARCH PROGRAM

The  
Precision  
Medicine  
Initiative

## SCOPE:

Call for Participation on the *All of Us* Research Program PFAC- "The Henry Ford All of Us Team wants to thank you for being our partner in this effort to speed up health research and medical breakthroughs. We invite you to share your ideas and suggestions about the program by becoming a member of the All of Us Advisory Council. The council meet (online) every other month for 90 minutes (5:00-6:30 pm) to discuss updates on the program and ask for your feedback and suggestions. Advisors receive a \$25 gift card for each online meeting they participate in."

## PROJECTS OF 2021

### Vaccine Clinic Outreach (*right*)

Advisors gave guidance on appropriate ways and messages to engage potential participants during the 15-minute wait times after receiving a vaccination at four HFHS clinics. Information about the All of Us Research Program was available to thousands of people in a safe environment. More than 150 potential participants shared their contact information and requested a follow up call from a recruiter.



### Communication Overview

An in-depth review of local communications was completed including the communication methods, timing, content. Email subject lines, postal mail formats and communication cadence that are most effective. WebEx Polling guided the program's local communications strategy for 2022. Key feedback was to use many different delivery formats and change to a Quarterly Newsletter that includes Research Study Overviews.

### Virtual Event Development

The COVID-19 pandemic required continued virtual meetings in 2021. A smaller group of advisors came together to help inform our efforts to develop content for virtual participant events. Advisors recommended health education topics on aging, mental health and stroke awareness and to make sure events were as interactive as possible.

### Genetic Return of Results (*right*)

The National All of Us Research Program is creating materials and content related to health-related return of results expected in late 2022. The group gave feedback on talking points, genetic counseling fact sheets, etc.. The advisor's feedback was shared with the National Institutes for Health (NIH) and several changes were made to proposed language, specifically related to requirements for sharing DNA results with life and long-term care insurance providers.

#### Health-related RoR fact sheets and talking points

##### Background

Once we the foundational content is created and IRB-approved, work will begin to design materials that the sites can cobrand and use. The fact sheets (which are meant to standalone) and talking points you are currently reviewing are part of that "foundational content."

##### Goals

Create materials and content that sites can use to recruit, inform/educate, and engage with participants.

##### Materials

- Talking points
- Health-related results from *All of Us* fact sheet
- DNA results and your privacy fact sheet
- DNA results and insurance fact sheet
- DNA results and your family fact sheet
- Genetic counseling fact sheet

##### Document Folder

##### Timeline

- Finalize the list of materials by **Friday, July 16**
- Deadline to create priority materials: **Friday, August 27**
- Material to be distributed: **March, 2022**

POLL: Let's discuss your ideas about materials

## ACCOMPLISHMENTS

- ✓ Guiding the reactivation of the All of Us Research Program in Detroit
- ✓ Design of outreach activities in Henry Ford Health System vaccination clinics
- ✓ Redesign of the local communication strategies for the program
- ✓ Providing feedback to the NIH on the return of health-related genetic results for All of Us
- ✓ Four Detroit advisors are working with NIH at the national level as ambassadors and committee members: Randee Bloom, Beth Rubinstein, TyKesha Lewis and Kylie Ryan
- ✓ Expansion of the PFAC membership to > 50 participant advisors

## CHALLENGES

**Technology challenges** continue to be a barrier for the council, although facilitators have strived to improve user skills throughout the year. This council participates in virtual polling, breakouts, and manages a long list of comments and questions in the WebEx chat box. Virtual aspect brings challenges, but also additional opportunity.

## 2022 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.



*Collage of PFAC Patient Advisors. Photos taken from Advisor Bios*

# EXPERIENCE TRANSFORMATION

## PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

Providing Patient-Centered Care (Nothing about me without me) is the best approach to improving outcomes and providing value to each patient. This council will work on initiatives and process improvement around pre-visit, onsite visit, and post-visit communication and delivery. Additional HFHS 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 cost through patient/member engagement in their wellness and care.

### PROJECTS OF 2021

#### **Combining and Rechartering Patient Facing Councils**

Combined Consumer Facing Digital Patient & Family Advisory Council and Patient Experience Patient & Family Advisory Council into one: Patient & Family Advisory Council (PFAC). Combining the councils has enhanced the overall patient experience and expanded the audience of both councils. The new charter provides better communication and support for patients both before and during their visit, as well as better assistance for patients with special needs.

#### **HenryFord.com COVID-19 Information Updates**

An effort to provide guidance and important information regarding Henry Ford's ongoing response to the pandemic, including Henry Ford website Coronavirus landing pages and banner, the COVID-19 assessment tool, and Henryford.com/blog. Both patients and employees are more easily able to determine how to proceed when entering Henry Ford facilities during the pandemic, as well as guidance for those who test positive for Coronavirus. The handy assessment tool makes it easier for individuals to assess their COVID status and report accordingly.

#### **Patient Satisfaction Survey Update**

Updating the methodology of the Patient Satisfaction Survey in order to better evaluate patient perception and address survey fatigue. Three modes of surveying were determined to be best: mail, text messaging, and emails. These methods will give us the best chance of getting an answer from patients.

#### **FindADoc (Open Scheduling)**

The FindADoc tool facilitates open scheduling through the Henry Ford website. Patients can search and book with a specialist after viewing available appointments. Patients are now able to schedule some specialty appointments on the Henry Ford website through FindADoc. More specialties will be onboarded in the future, in addition to primary care locations.

#### **MyChart Redesign (Direct Scheduling)**

MyChart facilitates direct scheduling and has been better optimized for users. The message center and overall layout of MyChart has been redesigned with patient end-users in mind. Patients can sign up on MyChart without assistance. In addition, MyChart's improvements better facilitates direct scheduling with specialties and primary care providers.

#### **Scheduled Video Visits / Path Forward**

Patients are able to schedule video visits when an in-person visit is not possible, using the TytoCare Exam Kit. In order to facilitate these visits, there has been much thought put into bridging the 'digital divide' by promoting digital literacy, accessibility, and compatibility/technology support. Patients are able to efficiently participate in their video visits and with fewer technical frustrations.

#### **Cost Estimation and Billing / Centers for Medicare & Medicaid Services Price Transparency**

This provides patients much more transparency into their billing process. Bill pay optimization, Financial Assistance Module, and Price Transparency are the elements used to add transparency and understanding to the patient billing experience.

#### **Tech Check website**

Tech Check link allows users to verify proper functioning equipment for their video visits. Patients using either mobile or desktop browsers can test their audio and video before engaging in a scheduled virtual appointment. Patients are provided better tools to test their digital equipment before their appointment time. This saves time and hassle for both the patient and provider/resource.



## ACCOMPLISHMENTS

### ✓ Consumer and Digital Experience

- Implemented wizard (decision tree) functionality on henryford.com
- Implemented Next Available appointment functionality
- Improved LGBTQ content and tagged providers, making it easier for patients to find appropriate care
- Developed roadmap for Find a Doctor update for 2022

### ✓ Access Technology/Digital

- Patient Online Digital Self Scheduling rollout for Allergy, Gastro, Endocrinology, Plastic Surgery and Women's Health (Henryford.com (open) scheduling for generalists in 13 specialties)
- Sources of Truth data for Digital Self Scheduling including location, provider, departments, schedules etc.
- Transition/integrate current Remote Patient Monitoring vendor (HRS) to Epic
- Upgrade SMS Text platform with Epic Integration to enable patients to Opt-in/Opt-Out

### ✓ Virtual Care

- Established dedicated internal Virtual Care Online Training Webinars & Embed Virtual Care in RN/MA on-boarding & Skills Fair
- Enhanced Online Interactive Virtual Care Dashboard
- Managed, interpreted and applied Government and Commercial Payer Telehealth policy & licensure waiver updates
- Deployed Customer Support Strategies/Tools (Patient Video Visit Technical Risk Score calculated in Epic, HFHS Tech Check website, Dynamic Patient Video Visit Instruction Wizard on henryford.com, Patient Video Visit Step-by-Step Instructions in Spanish and Arabic)
- Updated Scheduling Decision Tree for all video visits to accommodate providers with Out-of-State Medical Licensure
- Refined Video Visit Type Options (Video Exam, Clinical Support, Post Op, Education Class)
- Executed MyChart Video Visit platform upgrade
- Released Primary Care Rapid Response (2hr Turn Around Time) E-Visit options
- Enabled TytoCare/Epic Integration for video exam visits

### ✓ MyChart | Contact Center

- "Not Yet Patient" (new patients to HFHS) online self enrollment/registration rollout for patient to automatically get a MyChart account/Medical Record Number (MRN)
- 9 Gold Stars from Epic for MyChart features (85th percentile)- 62.52% MyChart adoption rate as of 10/25/21
- Completed MyChart Homepage Redesign
- Epic-Salesforce API integration for real time patient demographics into Contact Center agent screen

## CHALLENGES

- **Online scheduling:** It still presents challenges for patients. Internally it has been challenging to figure out the best course of action to accurately display general provider information while not overwhelming patients looking for specific care. Striking a balance is a challenge.
- As we do more digital work, we accrue valuable data. The challenge is to understand how can we **better leverage decision-making** with this data being collected
- Both patient experience councils are still **learning how to best collaborate** since the merge of the teams. But there is a consensus that working together over time will help the councils work more efficiently together.

## 2022 GOALS

- Pre-Visit: Communication, technical support, virtual triage, and navigation
- Pre-Visit: Communication to patients of appointments running behind
- Onsite/Virtual Visit: More assistance ahead of time for patient with disabilities
- Improve eCheck-in (add or update insurance info in MyChart)
- Provider matching process
- Patient Satisfaction Surveys by text message
- Independent evaluation of new processes and/or tools
- Additional payment methods

# PATIENT INVOLVEMENT AND COMMUNICATION

## PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

Providing Patient-Centered Care (Nothing about me without me) is the best approach to improving outcomes and providing value to each patient.

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 OF 2021

#### Senior Navigator Project

A one stop shop for questions, help, and assistance for seniors at HF West Bloomfield and the surrounding community. The program helps connect seniors with additional resources in the community or within the system

##### **Results:**

- To duplicate this program at other HF sites. Advisors did not like that this was only for one site.
- Felt that this program was very important to seniors and could be very beneficial.

#### Heart Failure Transitions

Current discharge process for patients with heart failure is not optimal. Patients often are readmitted from home or skilled nursing facilities.

##### **Results:**

- Appropriate information needs to be discussed with patient/caregiver.
- There is significant room to improve the discharge process.
- There is a need to set up follow up appointments prior to leaving the hospital.

#### Antimicrobial Stewardship

Discuss the current documentation for HF pharmacist in MyChart, and how the language can be modified to improve patient understanding.

##### **Results:**

- The notes are not patient friendly.
- The purpose of the note needs to be made clear for the patient.
- Plain language must be used when the note is made available to the patient.

#### Documenting prognosis in medical record

Care team documenting prognosis in notes.

##### **Results:**

- The note must give warning about the information for those that do not want to read the note.
- The term prognosis must be defined.
- Give specific instructions in the prognosis note.
- The note must be understandable to both patients and caregivers.

#### Why Not Home program

Discussing how to market the program to patients and their caregivers.

##### **Results:**

- Beginning day one, talk about going home instead of to a facility at discharge.
- Discuss the patient/caregivers fears about going home provide solutions/resources to address fears.
- Focus on making the patient confident going directly home rather than a facility.

## ACCOMPLISHMENTS

- ✓ Created virtual environment for the group that allowed for safe and positive collaboration.
- ✓ Provided feedback on various MyChart provider notes to improve patient and provider communication.
- ✓ Focused on reasons and ways to communicate and ease the fear of going home after a hospital stay and improve readmission rates.

## CHALLENGES

**Virtual Environment-** Working with the equipment to access and attend bimonthly meetings. This can be challenging for advisors who are not able to work with the equipment or do not have equipment to log on to the meetings.

**Finding Informative Topics and Projects-** It can be difficult to find people to discuss the topics that are requested by the advisors. We also found it challenging to find topics for each meeting. Some months it was more difficult to find programs or material for the advisors to give feedback on.

**Mixed feedback on type of attendance for 2022-** The advisors are divided on the way we should meet. Some want this to be in person, virtual or hybrid.

## 2022 GOALS

- Have 2 in person meetings. This could be with art therapy or for a guest speaker to help with group bonding.
- Consistent and relatable topics for advisors.
- Finding people to speak on the topics suggested by the advisors.
- Have at least 7 team members call into each meeting.



*Art Therapy December 2021*

# HERMELIN BRAIN TUMOR CENTER

## PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

### SCOPE:

PFAC Mission Statement:

*"To leverage our combined experience as patients, caregivers and clinicians to guide the continual improvement and development of the Henry Ford 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 AND ACCOMPLISHMENTS OF 2021

### **Updated Patient Handbook**

Worked with Hermelin Brain Tumor Center physicians and staff to update patient handbook. Book has gone to print and is expected to be ready for the clinic in Spring 2022.

### **Craniotomy "Pre-Hab"**

Collaborated with surgical leadership to develop a pre-surgery "training" module to help alleviate the anxiety of the pre-surgical period.

### **One Page handout for New Patients**

Brochure that highlights the Hermelin Brain Tumor Center programs and support services. Currently being implemented in the clinic.

### **Patient Focus Group**

Annual focus group to inform clinicians on what the most important topics are for newly diagnosed patients. The PFAC developed the questions in October 2021 and the focus group took place in November 2021. The PFAC found the feedback to be impactful and decided that it would be prudent to expand the reach of the focus group and gain more feedback from a larger pool of people.

### **Post-meeting Surveys**

PFAC members have made a concentrated effort to complete post meeting surveys. This will demonstrate engagement and make the PFAC more attractive candidates for grants.

### **Developed Executive Structure**

The PFAC has developed an executive structure with the intent of increasing engagement and providing leadership opportunities for PFAC members. This executive structure includes a Chair, Co-Chair, and sub-project leads.

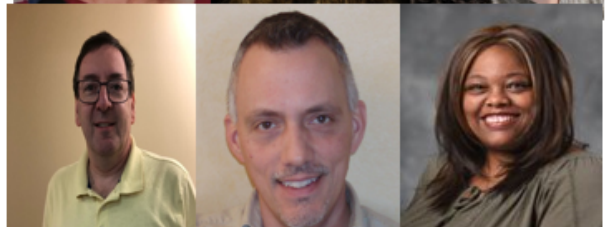
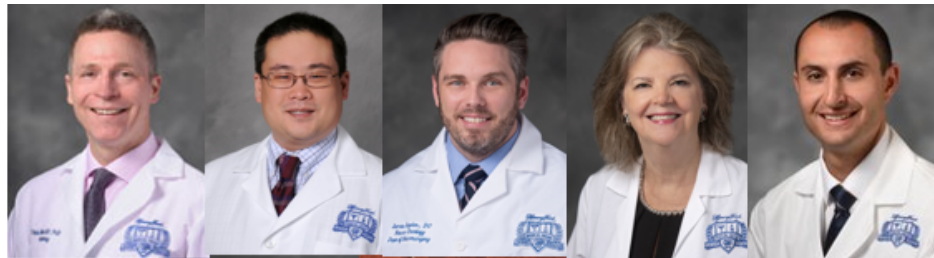


## CHALLENGES

- Missed being face-to-face
- No opportunity to bounce ideas off of each other
- Technology issues

## 2022 GOALS

- Publish a journal article
- Meeting with a national key opinion holder to share our success in building the model brain tumor center
- Meeting with marketing team to develop marketing strategies for the brain tumor center
- Continue to spread the word about the services offered at the Hermelin Brain Tumor Center
- Continue to grow council by engaging patients outside of metro Detroit area



*PFAC members*



# HENRY FORD HOME HEALTH AND HOSPICE PATIENT & FAMILY ADVISORY COUNCIL (PFAC)

## SCOPE

Henry Ford at Home, Michigan's largest home health group, offers a comprehensive network of home health products and services for people living in southeast and south-central Michigan. Patient Advisors on this Committee will help contribute in improving the quality and safety of home health, extended care, hospice, home infusion and e-home care services. The scope of this PFAC is to assist with improving Henry Ford at Home Patient Engagement scores (starting with Home Health Care and Hospice) as measured by a standard federal government survey.

## PROJECTS AND ACCOMPLISHMENTS OF 2021

### Patient/caregiver's knowledge about the Hospice satisfaction survey

Many Caregivers do not complete the survey after death because they do not realize the importance or that it is for Henry Ford Hospice (survey comes from outside vendor). Need to improve hospice patient/caregiver's knowledge about the satisfaction survey. Since there is a delay from when hospice services are provided and when surveys are sent out and data reported, data will be available June, 2022.

### Patient Rounding Hospice

HFHS initiative to round on patients to collect information about the patient's perception of their hospice care. December results reflected patient/caregiver verbalized satisfaction with all areas asked and no follow-up needed

### Patient Rounding Home Health

HFHS initiative to round on patients to collect information about the patient's perception of their hospice care. November & December results reflected follow-up was required after 25% of the rounding calls. Each question was positive over 94% except the current written schedule in the home met a 75% positivity rate. patient/caregiver verbalized satisfaction with hand hygiene.

### Increase communication touch points with hospice patients

Patient/caregiver's perception of their communication with Hospice staff is key to improving overall perception of the hospice care experience. Council developed to implement Patient Connect Mobile (PCM). Plan to evaluate Pilot (number of patient after calls, planned prn visits after 3 months and patient/caregiver satisfaction with PCM)

## CHALLENGES

- Maintaining Membership
- Good Attendance
- Virtual Meetings Only
- Projects not organized and well communicated
- Results/successes not clearly communicated

## 2022 GOALS

- Improve Attendance and Membership
- Communicate project goals, timelines regularly
- Improve one CAHPS measurement to meet national average/median

# HFH STROKE TRANSITIONS OF CARE COMMITTEE

## SCOPE:

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 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 OF 2021

### Inpatient Stroke Rounding Tool

Built a questionnaire specific to patients who are admitted for stroke to gather their feedback on understanding their diagnosis, risk factors, and other education as well as their patient experience. This questionnaire was embedded into an existing rounding tool used by the health system – Cipher – that the stroke coordinator uses to collect feedback when rounding on patients. The tool has been effective for obtaining information & feedback from patients who experience stroke. In 2022, data will be compiled to identify trends and opportunities for stroke program improvement. The tool will also be expanded to other HFHS hospital locations.

### Stroke Awareness Education

In recognition of World Stroke Day on October 29 each year, we held a stroke awareness event in the hospital atrium for patients, employees, and others which included a pop quiz on stroke awareness, education on risk factors, and some take-home reminders and health education material. We educated over 60 people on risk factors for stroke and stroke signs/symptoms, as well as how to reduce risk for stroke. Participants were engaged, surprised at what they learned, and took with them health education materials (flyers, badge buddies, tshirts, etc.).

## ACCOMPLISHMENTS

- ✓ Implementation of Stroke Rounding tool in Cipher
- ✓ Successful World Stroke Day event
- ✓ Also, our Patient Advisor was able to share his story on Fox2 and raise some awareness on stroke as well!



## CHALLENGES

- Ongoing pandemic making it difficult to meet as a team and also to initiate projects
- Competing clinical priorities that take team members away from our transitions of care team
- Regular team member turn over

## 2022 GOALS

- Identify an improvement to our Stroke Program based on stroke patient feedback and implement
- If pandemic allows, return to community stroke education outreach & stroke survivor in-person activities

# PATIENT & FAMILY ADVISORY COUNCILS CONTINUED...

## CANCER CENTER PFAC

Begun in early 2016, this group of cancer patient, survivors and their caregivers advised leaders on plans for the Henry Ford Cancer Institute to be built on Henry Ford's Downtown Campus which opened in 2021. They have given guidance to the architecture firm on specific building features and the most important cancer support services that are 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.

## COVID RECOVERY CARE PFAC

This council was formed in late 2021 and is made up of long hauler patients and caregivers (long COVID-19 sufferers). This group was formed to gather feedback from advisors on the new COVID-19 Recovery Care Service that is led by Dr. Eunice Yu. The advisors give feedback on design and services, patient education and marketing materials. They also support in developing research agendas that is patient-focused. They help to provide feedback on a PCORI funded research project "*Using Body Mapping to Develop a Patient Centered Research Agenda About Long COVID-19*". Some of the advisors on this council even signed up as participants of this research project.

## 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.



# EXISTING COMMITTEES/COUNCILS THAT PATIENT ADVISORS SERVE ON

## PREVENTATIVE CARDIOLOGY/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.

## IMPACT-CHF COMMITTEE

***Integrated Michigan Patient-centered Alliance in Care Transitions Congestive Heart Failure (HFH I-MPACT-CHF) (HFHB I-MPACT-CHF)***

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.

## IMPACT-SNF COMMITTEE

***HF Wyandotte Hospital Integrated Michigan Patient-centered Alliance in Care Transitions - Skilled Nursing Facility***

The IMPACT team works to reduce readmissions and improve transitions for patients that are transferred from the hospital to Skilled Nursing Facilities (SNFs)

## 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.

## 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.

# EXISTING COMMITTEES/COUNCILS THAT PATIENT ADVISORS SERVE ON

## 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 patient experience throughout the system.

## RADIOLOGY CUSTOMER EXPERIENCE & ENGAGEMENT COMMITTEE

This committee is important because radiology is always seeking ways to improve the customer experience using data from multiple methods. It relates to HFHS patient satisfaction scores and overall engagement of patients and staff. The patient advisor on this committee offers feedback from the survey recipient's end, such as preferred methods, time of contact, how many times they are contacted, etc.

## SUPPORTIVE CARE COMMITTEE

The Supportive Care Committee has been meeting for the last few years and has recently added a patient advisor to their 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.

### *currently seeking Patient Advisors*

## COPD COMMITTEE

Henry Ford and Wyandotte hospitals experience higher than expected chronic obstructive pulmonary disease (COPD) patients so HFHS considers COPD a priority for overall health of our patients. This existing Committee meets to focus on COPD patient outcomes. Discussions included but not limited to treatment options, medications, education

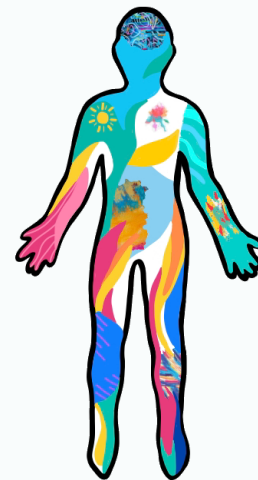
# PERC IN RESEARCH

## PERC RESEARCH PROJECTS

**Project name:** Using Body Mapping to Develop a Patient Centered Research Agenda About Long COVID-19

**Funded** (yes/no/pending): Yes, PCORI

**Description:** This Research Project seeks to utilize the voices, lived experiences, and narratives of those patients who had or are still suffering from Long COVID-19 using an innovative Body Mapping approach. Body maps can be broadly defined as life-size human body images created through drawing, painting, or other art-based techniques to visually represent aspects of people's lives, their bodies, and the world they live in. Body maps will also be used to co-design a virtual knowledge exchange opportunity and ultimately, with the aid of PASC caregivers and other stakeholders, develop a high-quality, patient-centered, PASC-focused Patient-Centered Outcomes Research/ Comparative Effectiveness Research (PCOR/CER) Research Agenda for dissemination.



**Project name:** Faces of Clinical Trials Video Initiative

**Funded** (yes/no/pending): Yes, AstraZeneca

**Description:** The Cancer Center Patient & Family Advisory Council has partnered with AstraZeneca to develop a promotional/informative video to inform the community on clinical trials as a treatment option. Patient Advisors take part in monthly meetings to help strategize the best approach in developing this video.

**Project name:** Developing Narrative Medicine Programming in U. S. Healthcare Settings: A Preliminary Study

**Funded** (yes/no/pending): Yes, Internal HFHS

**Description:** Patient Engaged Research Center has partnered with Dr. Rana Awdish, the Director of the Pulmonary Hypertension Program at Henry Ford Hospital to identify emerging and promising practices for starting Narrative Medicine programming in healthcare settings and to provide a valuable resource for individuals and institutions that are considering developing and implementing such programming. Narrative Medicine is both an interdisciplinary, international field of study using concepts and methodologies informed by the disciplines of literary studies, narrative theory, psychoanalysis, and phenomenology.

## PERC PUBLICATIONS

### **"Bridging the Patient Engagement Gap in Research and Quality Improvement Utilizing the Henry Ford Flexible Engagement Model"**

**Authors:** Heather Olden, Sara Santarossa, Dana Murphy, Christine Johnson, Karen Kippen

**Publication:** Journal of Patient-Centered Research and Reviews (JPCRR)

[Link to article](#)

### **"A multi-methods design to understand the #longCOVID and #longhaulers conversation on Twitter"**

**Authors:** Sara Santarossa, Ashley Rapp, Saily Sardinias, Janine Hussein, Alex Ramirez, Andrea Cassidy-Bushrow, Philip Cheng, Eunice Yu

**Publication:** Journal of Medical Internet Research (JMIR)

[Link to article](#)

### **"Social distancing during the COVID-19 pandemic: quantifying the practice in Michigan – a "hotspot state" early in the pandemic – using a volunteer-based online survey"**

**Authors:** Andrea E. Cassidy-Bushrow\*, Mohammed Baseer, Karen Kippen, Albert M. Levin, Jia Li, Ian Loveless, Laila M. Poisson, Lonni Schultz, Ganesa Wegienka, Yueren Zhou and Christine Cole Johnson

**Publication:** BMC Public Health

[Link to article](#)

## PATIENT ADVISORS PARTICIPATING IN RESEARCH

### All of Us Research Program

Henry Ford Health is one of 10 prestigious health provider organizations across the country supporting the [All of Us Research Program](#), which is run by the National Institutes of Health (NIH). The > 50 Patient Advisors participating on the PFAC are true partners and contributing to longitudinal research that may improve health for everyone (refer to page 18 for PFAC information).

### Telehealth Advisory Board

Henry Ford Health System, The University of North Carolina at Chapel Hill, and UNC Health are partnering to launch a research study to better understand patients' perceptions and use of virtual visits during cancer care. Virtual visits are real-time telephone or video appointments with a doctor or other health care provider. Prior to the COVID-19 pandemic, these types of appointments were rarely used in cancer care. This study is specifically interested in perceptions and use of virtual visits among African American/Black adults diagnosed with cancer.

### ASPIRE Project

One-time opportunity available for several parents of children between the ages of 3-to-17-years-old to participate in a "read-aloud" of several possible questions that are being considered in a research study on firearm safety. Your participation in this activity is not considered research and no personal or identifying data will be collected from you during this opportunity. This project is hoping to identify several parents who would be willing to read-through and discuss several research questions we are considering including in a firearm safety research study. Seeking parents' perspectives to ensure that we word all of our research questions clearly.

### PCORI Diabetes Project

Participants of this research project will provide feedback from a type 2 patient and/or caregiver. They will likely be asked to provide feedback on recruitment strategies, research participant materials, review surveys, and other project materials. The goal of the patient advisor on this project is to help focus research on what matters to the patient/caregiver.

### Asthma Allergy- Mom & Baby Research Project (SURVEY)

Women between the ages of 18-40 are invited to fill out this short survey pertaining to [Mom and Baby Research Studies](#) at HFHS. The Mom and Baby Research Studies need help with recruitment. We will be creating a button that clinical staff members at many prenatal care centers in the system will wear.

# QUOTES FROM PATIENT ADVISORS

*Over the last year, as we have lived with and contended with the pandemic, I have come to better understand the corporate culture of the Henry Ford Health System. That understanding has provided me with a respect for the authenticity of what is being attempted at improving patient experience. It means a lot to me because on the whole it is still very difficult and sometimes overwhelmingly intimidating to be a patient in most medical systems.*

-Patrick, Macomb PFAC

*"It's very rewarding to see our suggestions turn into positive action."*

-Experience Transformation Advisor

*"I have always loved science and I realized that because each person is so unique, medicines and treatments don't work the same for each person. By helping to collect more data that ties genetics and other factors together, it will help healthcare get better."*

- AOU Patient Advisor

*Having this team and these meetings has really helped me stay grounded and connected to another purpose during this time*

-HF Wyandotte Patient Advisor

*"I love the comradery of this team, we all help each other and even meet up if we can outside of the group"*

-HF Wyandotte Patient Advisor

*"Love serving on this [HF Macomb] committee because of the input from the community making a difference in how we shape our care and environment."*

-Wanda Francisco

*"As patients and caregivers, we collaborate together, while sharing our own experiences, with the goal of continuously improving the patient care experience."*

-Megan Sauer, Hermelin PFAC

*Favorite part about being a patient advisor: "Staying connected to current trends within the healthcare system. Feeling that we make a difference by offering suggestions and feedback, regardless of how small they may seem."*

- Patient Advisor