

Patient Engaged Research Center

# Patient Engagement Playbook

**HENRY  
FORD  
HEALTH**<sup>®</sup>



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# PATIENT ENGAGED RESEARCH CENTER



## About this advisor toolkit

This Playbook will help you prepare to partner with Patient and Family Advisors on committees, councils, projects, etc. It is organized in a way that gives you background information about Henry Ford's Patient Advisor Program as well as step by step instructions on the process of engaging Patient and Family Advisors.

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## Patient Engaged Research Center (PERC)

### Background Information

In 2014, Henry Ford Health was one of only a handful of organizations across the country chosen to participate in a groundbreaking research study to improve the outcomes of patients.

Now, Henry Ford Patient Engaged Research Center (PERC) transforms research results into evidence based medicine with the patient's perspective at the center of this change. The program works with patient and clinical advisors to conduct research and clinical improvement that is meaningful to the community in which they reside to help transform the way Henry Ford provides care.

Working with patients and families as advisors at the organizational level is a critical part of improving the way Henry Ford delivers care and utilizes the perspectives of patients and families directly into the planning, delivery, and evaluation of care.

### Program Highlights

- PERC assesses the benefits and harms of preventive, diagnostic, therapeutic, palliative, or health delivery system interventions to inform decision making; highlighting comparisons and outcomes that matter to people
- PERC is inclusive of an individual's preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health related quality of life
- PERC incorporates a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination
- PERC investigates optimizing outcomes while addressing burden to individuals, availability of services, technology, and personnel, and other stakeholder perspectives

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# Patient Advisors

## Who are they?



Advisors are patients and their family members or care givers willing to contribute their own patient experience to the conversation. Their main goal is to improve the health care experience for themselves and others. The model for patient engagement shows in what ways Patient Advisors can be involved.

Advisors can participate in two formats:

1. Individual Advisor- Member of existing committee (with HFHS employees)
2. Patient and Family Advisory Councils (PFAC)- Member of Council (with other Advisors)

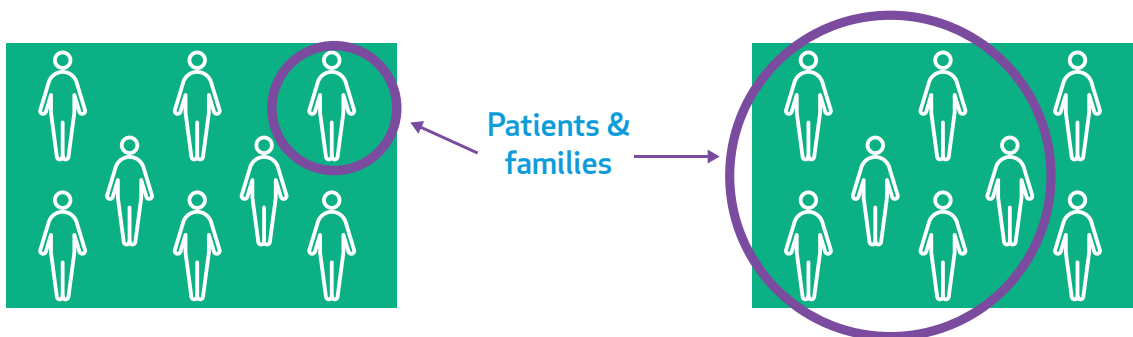
## Table 1: Models for Patient Engagement

### Individual Advisors

- 1-2 patients to join work team
- Henry Ford Health employees lead and set agendas
- Patients are active members of team

### Patient and Family Advisory Councils (PFAC)

- 15+ patient and family advisors create a new local or System team
- Patients lead team with Henry Ford Health Champion to set agendas for work



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Table 2: Patient Advisor Roles

## Focus Group Advisors

- Participate as a focus group participant and provide feedback on your own personal healthcare experience, as well as any topics that are brought to discuss
- Time investment is typically 1.5 to 2 hours per group meeting
- Required to sign confidentiality and photo release form
- Paid opportunity

## E-Advisors

- 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.
- Time commitment about 1-2 surveys a month
- Able to respond quickly and meet deadlines as requested
- Have access to email and internet to complete online surveys.
- Unpaid volunteer opportunity

## Research Project Advisors

- Participate as a valued member of the Research Team working on a project
- Share ideas and give feedback on patient reading materials, strategies to enroll people into studies, and other parts of the project.
- Have input on project design and execution
- Required to sign confidentiality form and photo release form
- Paid opportunity

## Health System Advisors

- Serve as a Patient Advisor representative on a hospital council or committee. You will be considered a valued member of the group and will attend regular meetings focused on designing or improving a new or current program, service, policy or process.
- Review materials and/or provide feedback outside of meeting times
- Work closely with different clinical and non-clinical staff
- Communicate ideas in a clear and succinct manner
- Required to sign confidentiality and photo release form
- Regular attendance and active participation is expected
- Unpaid volunteer opportunity

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## What do Patient Advisors do?

As active partners they:

- Share the patient viewpoint and ideas on ways to improve our process
- Give feedback on projects, HFHS initiatives, research, etc.
- Offer ideas on materials, surveys and participant recruitment
- Make suggestions on the methods and the way things are done at HFHS

**Table 3: Examples of Patient Advisor Projects**

<h3>Quality Improvement</h3> <ul style="list-style-type: none"><li>• Participate as active partners in decisions affecting future patients</li><li>• Listen to presentations and provide feedback</li><li>• Bring the patient voice to the table</li><li>• Consider innovative HFHS initiative</li></ul>	<h3>Research</h3> <ul style="list-style-type: none"><li>• Review surveys, project materials</li><li>• Help focus research on what matters to the patient</li><li>• Help with recruitment methods</li><li>• Make suggestions on how projects should be done</li></ul>
<h3>Design</h3> <ul style="list-style-type: none"><li>• Provide feedback and offer ideas to architects' drawing and designs</li><li>• Participate in virtual and in-person walkthroughs of new building</li><li>• Suggest additional features and amenities that would improve the patient and caregiver experience</li></ul>	<h3>Virtual Participation</h3> <ul style="list-style-type: none"><li>• Participate in surveys from HF Insights Community</li><li>• Participate in surveys from PERC</li><li>• Give feedback on patient education materials and other HFHS initiatives before they are seen by the public</li></ul>

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# Getting Started with patients and families as advisors

(After Review of this Playbook)

## Step 1: Are You Ready?

Is a Patient and Family Advisor Council right for you? It is important that the first step in implementing Patient Advisors within your group is to discuss if a PFAC is the right path. PERC can help talk you through your options if you are unsure. Open communication is key to a successful outcome. Once it is decided that you are ready to partner with Patient Advisors, you must then review the methods of engagement.

## Step 2: Identify a Patient Advisor Liaison

The Liaison will be the contact between the council and the Patient Advisors. This appointed person will be key to keeping the group in communication and engaged. The Liaison is responsible for and must commit to reporting meeting minutes, agendas, sign-in sheets and evaluations within the Liaison Portal to keep the PERC team up-to-date. This also includes attending the bi-monthly Patient Advisor Liaison meetings.

## Step 3: Intake Process

This is a two-step process that includes a formal online request form and a meeting with the PERC team. The HFHS Request for PHS Collaboration Form helps the PERC team understand how your team is interested in partnering with Patient Advisors. This form is completed and submitted online. Once the PERC team has received and reviewed the completed Request Form, a team member will then schedule an intake meeting to discuss next steps as a group.

## Step 4: Recruitment Process

Communication with the PERC team is important in achieving your goals to have Patient Advisors' contribution. Not just initial communication at the beginning process to help get your group up and running, but ongoing communication to ensure that the PFAC is running successfully and efficiently. The PERC Project Coordinator is here to support the PFACs and the Buddies for each council.

## Step 5: Preparing for the First Meeting with Patient Advisors

PERC will assist in preparing you and your team for your first meeting, and the first of couple meetings if needed. We will help with scheduling, invitation and reminder emails to Patient Advisors, agenda planning/strategic planning. PERC is dedicated to supporting the Liaison through this process.

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## Step 1: Are you ready?

### Are You Ready to Work With Patient Advisors?

As a leader, physician or staff member, I am ready to work with Patient Advisors when:

- I believe that patients, family members, staff and clinicians can look beyond their own experiences and issues to come up with useful ideas and solutions
- I feel comfortable listening and respectfully responding to both positive and negative care experiences that patients and caregivers may share
- I am comfortable requesting that Patient Advisors be invited to participate in improvement initiatives in which I am involved
- I believe in the importance of patient and caregiver participation in planning and decision-making at the program and policy level
- I am comfortable leading group discussions and making sure conversation does not stray from topic at hand
- I am committed to providing continuous updates on projects and topics that your Patient Advisor(s) provides feedback on
- I have the availability to communicate with Patient Advisors on meeting details and reminders
- I enjoy working with people who are different from me
- I can listen to and think about what others say, even when I disagree

The more boxes checked off, the more likely you and your team are ready to partner with Patient Advisors. If only one or two boxes are checked, it is likely that you and your team are not yet ready to work with Patient Advisors. Talk with the PERC team to discuss other possible options.

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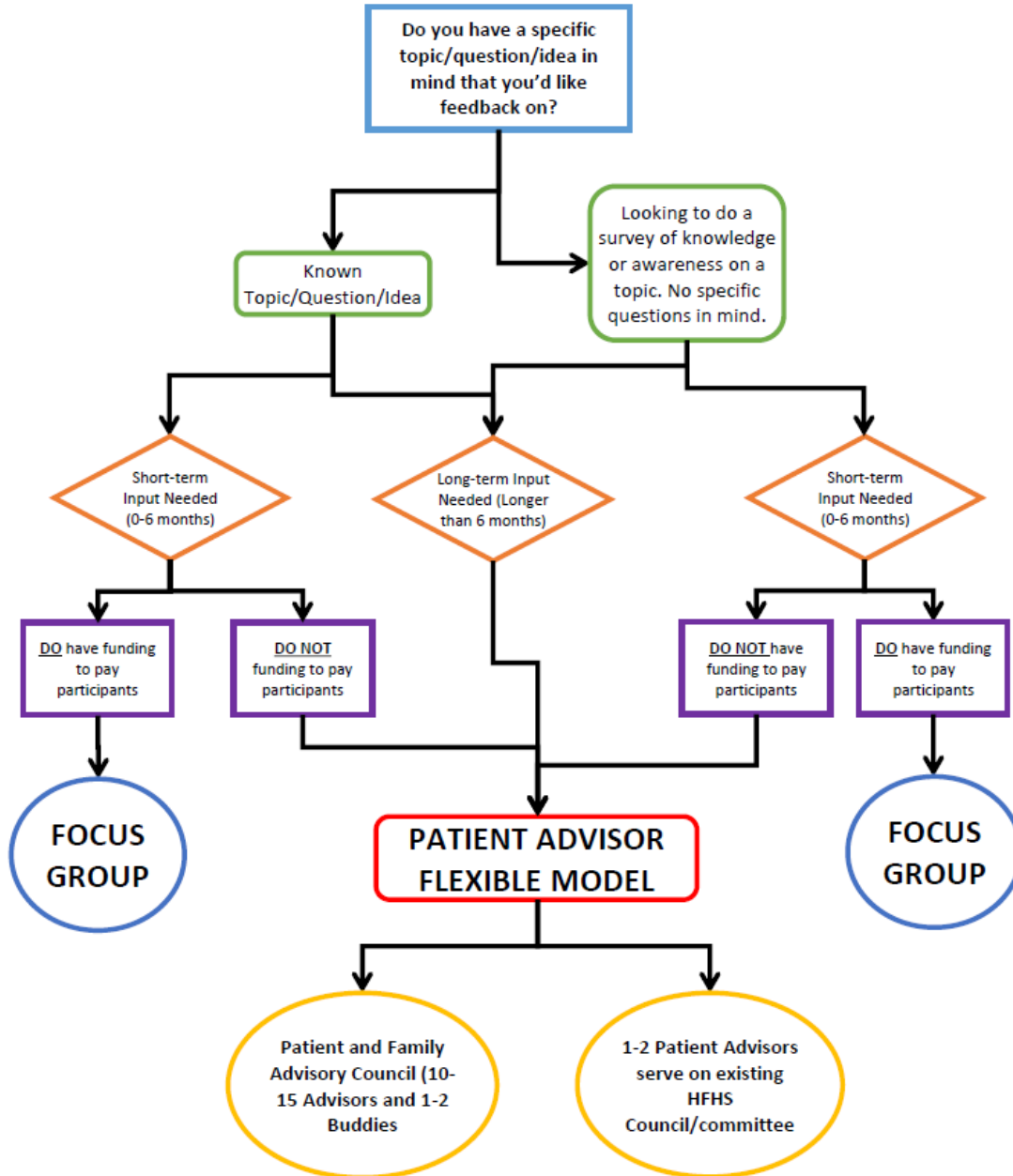


## Methods of Engagement

Now that you have decided that you and your team are ready to partner with Patient Advisors, it is time to decide how to integrate them. Use the flowchart below as a guide to help decide the best way to incorporate patient engagement.

Table 4: Flexible Model Flowchart

### Flexible Patient Advisor Model Flowchart



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## Step 2: Identify Patient Advisor Liaison

### What is a Liaison?

The Patient Family Advisor Liaison is the contact between the Patient Family Advisor and the team/committee.

The Liaison role:

- Successfully completes the Patient Advisor Liaison Module training (HFHS University)
- Ensures comfort working with Advisor(s)
- Builds a relationship with and supports Patient Advisor(s)
- Supports and guides the Advisor through the onboarding process and during team interactions

The Liaison's **main role** is to communicate important information to the Patient Family Advisor(s) and prepare the committee for the new team member.

### Responsibilities

The Liaison is responsible for:

- Inviting patient and family advisors to meetings and following up with meeting minutes
- Keeping advisors on distribution lists for emails regarding the project and future meetings
- Continuing to build a culture of **partnership** and keep **communication** channels open
- Being mindful when sending sensitive or confidential information
- Providing food/beverages at each meeting
- **Submitting meeting documentation** (agendas, minutes, sign-in sheets, evaluations, etc.) **to the Patient Advisor Liaison Portal**, which is managed by the PERC team
- Attending bi-monthly Patient Advisor Liaison meetings

Patient/Family Advisors are a full members of the team and should receive the same professional treatment and expectations as other committee members. It is important to remind committee members that this is a new environment and experience for Patient/Family Advisors. Some Advisors may be hesitant to first speak up/contribute or they may be very animated and contribute frequently.

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## Step 3: Intake PROCESS

The HFHS Request for PHS Collaboration Form below serves as a formal request and is submitted online. This is a shared form with the Department of Public Health Sciences. You may select any/all services that fit your needs. For Patient Engagement, you will select "PERC Services" as your collaboration request located in Section 3. You will then be prompted to complete a separate Patient Advisor Placement Form via email. It is important to be as detailed as possible in the Patient Advisor Engagement form so we can best understand your request. Once the forms are submitted, the PERC team will review and follow up to schedule an intake meeting to discuss next steps.

### Table 5: HFHS Request for PHS Collaboration Form

**\*\*Must be completed and submitted online**

SECTION 1: Request for Public Health Sciences (PHS) Collaboration.  
For information regarding the Public Health Sciences Department's overview and services, click on the following link; [Public Health Sciences](#)

Request Date  M-D-Y

Please enter requester information, this person will be contacted after this form is submitted.

First Name   
\* must provide value

Last Name   
\* must provide value

SECTION 3: PHS Collaboration Request  
Please select all applicable services.  
For more information on each option, click on the link.  
(At least ONE collaboration option must be selected.)

- Patient Engagement Research Center  
 Select Services

**PERC (Patient Engagement Research Center)**  
PERC services include: Focus Group Development, Patient/Caregiver Recruitment and Patient Centered Research with Patient Advisors. You will receive an additional PERC form which will include an intake meeting. A PERC Team Member will schedule an intake meeting.

Table 6: Patient Advisor Engagement Form. This form will come as a separate email for you to complete after the PHS form is submitted.

**Patient Advisor Engagement Form**  
*(To obtain PERC services complete the following questionnaire. Please note, all questions are NOT required. After the submission of this request form, a PERC Team Member will contact you. Thank you.)*

PERC (Patient Engagement Research Center)

**PERC Collaboration options**  
**What PERC Services are required?**

- Focus Group
- One-on-One Interviews
- PFAC Development
- Committee
- Survey
- PFAC Consult
- Recruitment
- Patient Centered Research Design
- Not sure yet

**What is your Project/Council/Committee called?**

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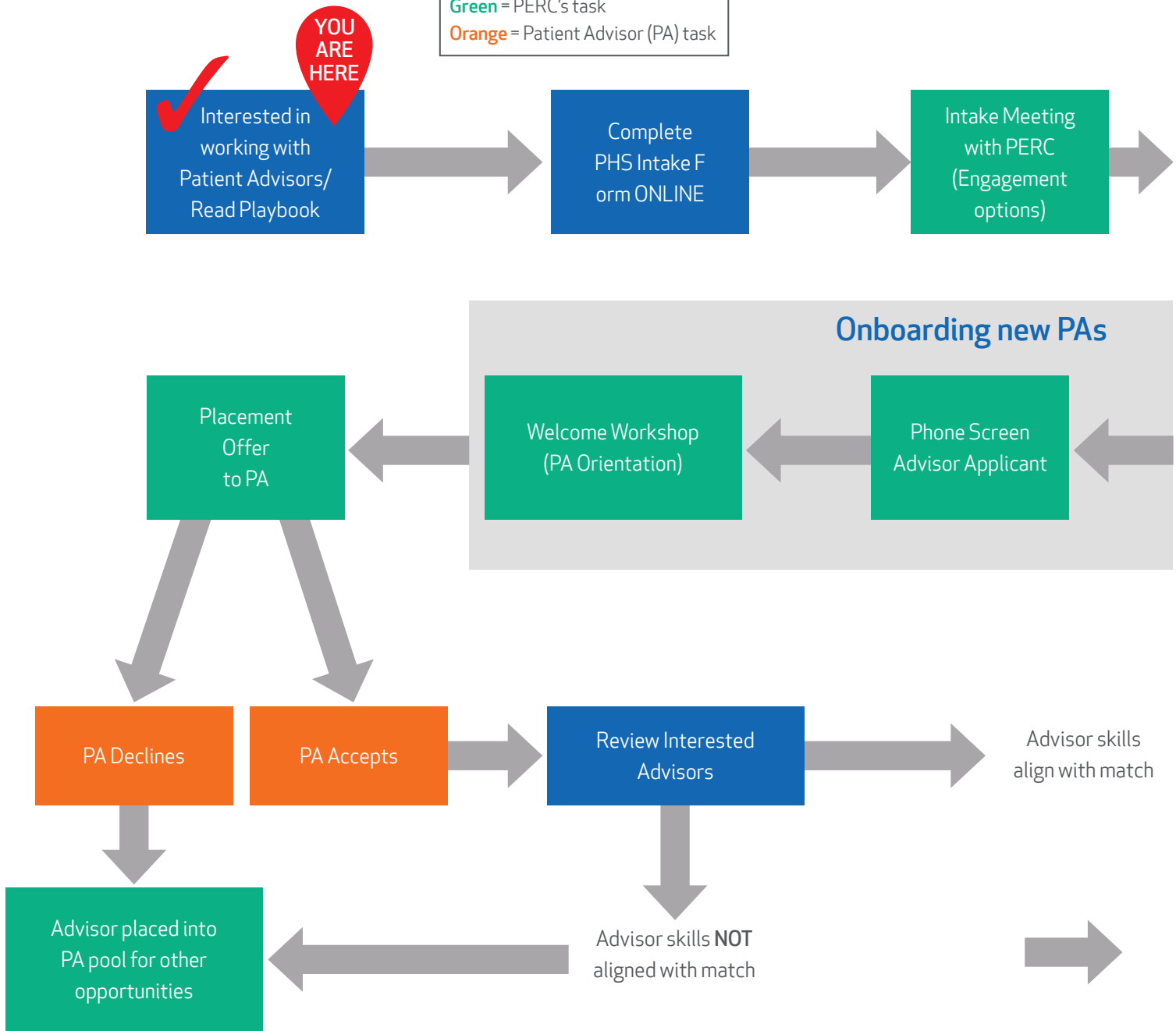
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# Step 4: Recruitment Process

KEY:  
Blue = HFHS Liaison task  
Green = PERC's task  
Orange = Patient Advisor (PA) task



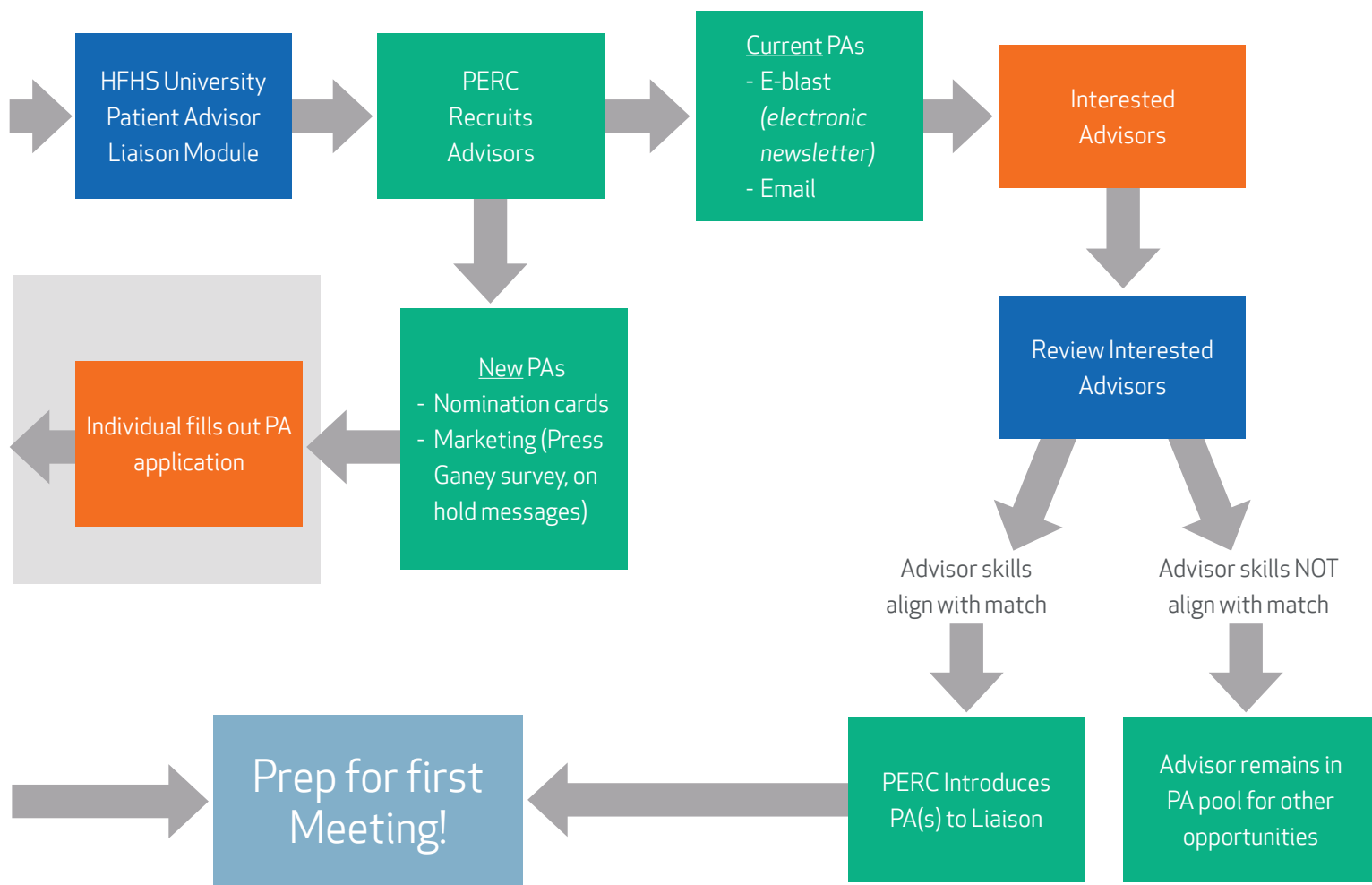
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## Step 5: Preparing for the First Meeting with Patient Advisors

You are ready to prepare for your first meeting when you have:

- Accepted the commitment of engaging Patient Advisors
- Identified a Patient Advisor Liaison
- Submitted the Patient Engagement Request Form
- Attended the Intake Meeting with PERC team
- Accepted recruited Patient Advisors

It is now time to start planning for the first kick-off meeting! PERC will partner with you to help plan your first couple of meetings. Continue reading through this Playbook to learn how PERC keeps Patient Advisors engaged, read about successes and testimonials, and resources that will help you in this journey.

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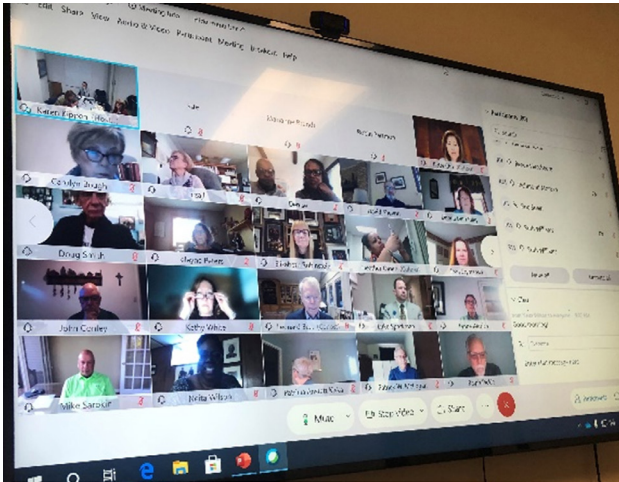
# Continued Engagement & Retention

## Annual Retreat

Each year the Patient Engaged Research Center 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. Patient Advisors, researchers, administrators and providers are all invited to attend this day long event. The Retreat gives PERC the opportunity to share accomplishments throughout all the councils and committees that Patient Advisors serve on as well as provides skill building activities and learning sessions. This event also offers a great networking opportunity among attendees. Take a look at some of the key agenda items of PERC's previous Patient Advisor Retreat's.

**2020** - The Program had its first ever fully virtual Retreat! Though the COVID-19 pandemic impacted our ability to engage in-person, the PERC team was determined to host a Retreat that was just as productive and fulfilling as previous years. We turned to WebEx to help us provide a large virtual event that was user-friendly and provided an interactive experience for attendees.

Turnout of 80+ attendees



Retreat Agenda

### 4<sup>th</sup> Annual Patient Advisor Retreat

**9:00-9:30 am - Opening Remarks**  
**Dr. Betty Chu, MD, MBA**  
*HFHS SVP, Associate Chief Clinical Officer/Chief Quality Office*

**9:40-10:30 am - "The Power of Proximity in Health Services Research"**  
**Dr. Leonard Berry, PhD**  
*Professor of Marketing at Mays Business School, Texas A&M University*

**10:30 -10:45 am - Break**

**10:45-11:45 am - Training Session**  
**Identifying and Addressing Stress Trauma**  
**Renee Verschure**  
*HFHS Organizational Effectiveness Consultant*

**11:45 am-12:00 pm - Closing & Final Thoughts**  
**Christine Johnson, PhD, MPH**  
*HFHS Department Chair of Public Health Sciences*





**2019** - Opening Remarks with Department Chair of Public Health Sciences, Dr. Christine Johnson, Patient Advisor Presentation by Beth Rubinstein, Keynote Speaker Best-selling Author Dr. Rana Awdish including a book signing, Patient Advisor Poster Session including Awards and Prizes, Research 101 Skill Building Session, All of Us Research Hub Presentation.



2018 - Patient Advisor Bingo, Opening Remarks with Dr. Michelle Schreiber, Keynote Speakers Dr. Daniel Mullins and Patient Advisor Gail Graham from University of Maryland, Caregiver Corner with Shawn Bennis, Emotional Intelligence Skill Building Session



2017 - Opening Remarks with Henry Ford Health CEO Wright Lassiter, Highlight of PFAC Accomplishments, Skill Building Session, Patient Advisor Keynote Speakers



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## Patient Advisor Social Events

Beginning in 2018 PERC began to host quarterly Social Events for Patient Advisors and Buddies. These events give Patient Advisors and Buddies a chance to have fun and mingle with individuals who they may not meet otherwise. The social events are meant to bring people together and enjoy themselves. Check out some of the Patient Advisor Socials we have hosted so far!

- **Coffee & Conversation** – A group of Patient Advisors gathering for an hour of coffee and ice breaker activities.
- **Painting with Patient Advisors** – PERC hosts a painting with a twist style activity that allows participants to tap into their creative side!
- **(Seasonal Events) Spring Fling, Winter Social** – Patient Advisors and Buddies get together for an afternoon of mingling and board games.
- **PERC Holiday Party** – PERC invites Buddies, Patient Advisors and their family members to come together for nice dinner and celebrate the accomplishments of the year.

*\*In-person social events have been put on hold since March 2019. We plan to resume these events in the near future (dependent on HFHS policies).*



## Newsletters

### PERC Newsletter

The Patient Engaged Research Center publishes a quarterly Newsletter for researchers, advisors, and community partners. Each issue contains information about projects, investigator spotlights as well as shares news of our research and important advances at the Patient Engaged Research Center. This Newsletter is printed and distributed at Patient Advisor meetings/events as well as to various departments and for marketing to potential new members.

### Patient Advisor Monthly E-blast

This electronic update is created and sent out monthly via email to the Patient Advisor pool as well as all Buddies. The E-blast contains Patient Advisor Program announcements, accomplishments, available placements, upcoming events, and Patient Advisor birthday shout outs. The E-blast is a way to keep the Patient Advisors and Buddies engaged and informed. The E-blast is how PERC recruits active Patient Advisors for open councils and committees.

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## Successes

As of December 2020

Since the launch of PERC, Henry Ford has engaged patients and caregivers for feedback on key topics and projects important to patients, health care systems and providers.

Highlighted below are just a few of the many Patient Advisor accomplishments. PERC develops an Annual Summary that includes all council and committee accomplishments throughout the year.

Annual Summaries can be found on the main page of PERCs website at [henryford.com/perc](http://henryford.com/perc).

[PERC Annual Summary 2020](#)

[PERC Annual Summary 2019](#)

[PERC Annual Summary 2018](#)

All of Us PFAC-

- Assisted with submission of the grant proposal (\$64M in funding over 5 years)
- Participated in Feedback on All of Us Research Program marketing materials
- Identification of barriers to enrollment in the program
- Development of a Participant Ambassador Toolkit

Henry Ford Cancer Institute PFAC-

Cancer Center

- Created strategic planning priorities for what they as patients would want as amenities in the new Cancer Center.
- Working with Supportive Oncology Services to ensure the right services are available to patients and their caregivers.
- Provided feedback on the value and likelihood of use of The Experience Engine (TE2), a customer experience management and real-time interaction platform
- Participated in mock tours of the Cancer Center to provide feedback on colors, types of furniture and overall layout of various parts of the new building

Precision Medicine Award

- Hosted a successful Cancer Precision Medicine Symposium with about 100 attendees. Presentations were made by stakeholders from payors, researchers, IT, and pharma.
- Created video summarizing Cancer Precision Medicine Symposium
- Developed a comprehensive list of proposed comparative effectiveness research questions for future funding consideration

Perioperative Surgical Home PFAC-

- Created patient education materials for hip and knee replacement patients and their caregivers that address the following topics:
  - Preparing your home for surgery
  - Surgery Anxiety and Fear
- Developing a patient education portal for the Henry Ford website which will house all the patient and caregiver educational materials for the entire health system.
- Review and feedback of Hip and Knee Surgery on-line tools and phone apps for Force Therapeutics

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## Research

- In 2015, the Head and Neck Cancer PFAC acquired funding from the [Patient Centered Outcomes Research Institute PCORI](#) for “What’s the SCOOP? Discovering Quality of Life Outcomes that Matter to Squamous Cell Carcinoma of the Oropharynx Patients and their Families”:
- Participated in an activity that transforms the Advisor’s patient stories and converts them into research questions which helped guide direction of proposed research
- Conducted literature searches and reviews for research proposal
- Recruited and engaged 3 virtual Patient Advisors from California and Illinois
- Created engagement, communication and dissemination plans for proposed research
- Created a Letter of Support from the Council to support proposed research

## Transplant Living Community (TLC) PFAC-

- Edit review of patient education for Pharmacy booklet and COIIN consent documents
- Establishing ACES lifestyle classes for outreach units in Flint, Novi, and Macomb
- Group brainstorming for visual teaching aids for K16 clinic for medical, surgical, pharmacy, dietician, social work, and patient lifestyle coach use
- Establishing PCORI P2P stakeholder outreach and presenting an all stakeholder Breakfast Meeting December 2018.
- Development of CER questions and What I Wish I had Known survey for P2P project
- Collaborating with research staff in establishing 10% Kidney At Risk Clinic in with staff and TLC Lifestyle coaches with poster being accepted and presented at Society for Behavioral Medicine

## Hermelin Brain Tumor Center PFAC-

- Over several months, reviewed and updated the Hermelin Brain Tumor Center patient handbook.
- In June 2018, Nestelyn Gay attended the Institute for Patient and Family Centered Care (IPFCC) meeting to learn more about leading Patient Family Advisory Councils.

## Perioperative Surgical Home PFAC-

- Creating patient education materials for hip and knee replacement patients and their caregivers that address the following topics:
  - Preparing your home for surgery
  - Surgery Anxiety and Fear
- Developing a patient education portal for the Henry Ford website which will house all the patient and caregiver educational materials for the entire health system.
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## Testimonials

“My work as a patient advisor provides me with the opportunity to improve the health care experience for all patients who engage with Henry Ford Health. In addition, serving as a patient advisor allows me to navigate more efficiently through the Henry Ford Health and communicate more effectively with providers.”

**Jacquetta Hinton – Advisor**

“Being involved in the PERC advisor program has allowed me to have a deeper knowledge with what our patients expect from their care experience at Henry Ford. The program has been a parallel for departments such as marketing and web services to test campaigns and help shape our new patient promise.”

**Melissa Sampey, Marketing/PR**

“PERC is a valuable asset for Henry Ford Health because it adds a third dimension to the usual dichotomy of health care with the creation of the Patient Advisor role. Now, instead of a medical encounter ending once the provider delivers a prescribed health service to a patient, a Patient Advisor encourages the possibility of evolving and recurring services. Future patients are informed by health cohorts (Patient Advisors) who have just undergone and reported on the care they are considering. Patient Advisors are able to culminate their care with reflection and feedback. Medical practitioners can review the qualitative feedback to inform their delivery of future care.

It has been an interesting endeavor to participate in PERC as a Patient Advisor. I felt that I could not find all of the information I needed before a recent procedure and I couldn't figure out if I was asking the wrong questions or just not looking in the right places. It occurred to me that perhaps my questions didn't resonate with my physicians because they already knew everything would be fine and there wasn't need to worry or over analyze. While it is reassuring to feel like your doctors will take care of everything, natural curiosity compels our need to ask questions and gather data to the many unknowns peppering our minds before a medical experience. So, I would like to think that I and my fellow Patient Advisors add valuable voices bearing the “expertise” of being patients. Patient Advisors can help to reinterpret medical information so that it informs and assures someone without an M.D. or R.N. who is looking for concrete, clear, and useful information to inform their health choices and options.”

**Kate Bongiorno – Patient Advisor**

“Engaging patients and members of their personal support networks in conversation about the optimal healthcare experience offers us the opportunity to redefine our everyday routines to best meet the unique needs of the individuals we serve. The differing viewpoints the patient advisors bring to the table better positions us to deliver our customer promise, All for You, where each and every patient receives a personalized healthcare experience.

**Anna Marcantonio, Director of Performance Excellence, CCS Administration**

“The Patient Family Advisory Council has been an extremely beneficial partner to our nursing team. We had the pleasure of having numerous patient advisors attend our recent unit meetings. They openly shared their healthcare experiences with our team and the impact these experiences had on their healing.”

**Ryan Liddy, Nurse Manager – Wyandotte Hospital**

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"The patient advisors have been a valuable forum for development of new ideas and enhancement of dormant projects. They provide the much-needed patient perspective for making changes that will ultimately impact all of us at some point when we are a patient or caregiver of HFHS."

**Shawn Bennis, Family Caregiver Coordinator**

"When I originally became involved with HFHW PFAC, I was excited with all the changes that were taking place within the hospital and believed PFAC was the next logical step.

As a member of the council, it is a pleasure participating in the quarterly meetings/discussions, but more importantly it is very rewarding to see that our comments/suggestions/points of view are being carefully considered by administration and in many instances implemented. As a consumer, not a health care professional, it is important to me that the hospital is engaged in understanding how I/my family perceive the care being provided. Keep up the good work!"

**Kathy White – Wyandotte Hospital PFAC Advisor**

"It is exciting to see how HFHS has empowered patients to be advocates for their care and to witness the growth of this critical groups efforts and how they have collectively influenced our organization's receptiveness and responsiveness to patient needs. They express the vulnerable needs of the communities we serve.

The enthusiasm and commitment that each of the members is so inviting. I love their questions and opinions as well as their thirst for knowledge."

**Mary Alice Annecharico, Sr VP- Chief Info Officer**

"PFAC partners are essential to engineering high quality care that is patient centered. Through the unique perspectives of our patients and families, they give input on issues that impact care, ensuring that the next patient or family member's journey is easier and an overall better experience. From a healthcare provider perspective our PFAC partners help to guide us in more efficient planning to ensure that services really meet the needs of our patients and families, it provided a deeper understanding into what is really valued from a patient and family perspective, and it promotes a respectful mutual relationship allowing our patients and families to truly be partners in their care."

**Tracy Garland, Director, Wyandotte Hospital Cardiovascular Services & Health Center – Brownstown**

"I have worked with the PFAC on several initiatives for Women and Child Health Services. They were easy to work with and provided valuable and constructive feedback that we were able to incorporate into our work. Their insight and advice was not only helpful but clearly communicated and thought-provoking."

**Rebecca Gensler, Clinical Nurse Specialist**

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## Resources

For more information on Patient Advisors and Patient Engagement, visit the Institute for Patient- and Family-Centered Care's website: <http://ipfcc.org/>

To learn more about the Agency for Healthcare Research and Quality (AHRQ), visit <https://www.ahrq.gov/>. To learn more about the Patient Engaged Research Center (PERC) funding, visit <https://www.ahrq.gov/ncepcr/primary-care-research/workforce-financing/case-example6.html>

For information about patient-centered research funding, visit the Patient Centered Outcomes Research Institute (PCORI) at <https://www.pcori.org/>

### PERC's Past and Current PCORI Funded Research:

#### PCORI Pipeline to Proposal Awards:

**"What's the SCOOP? Discovering Quality-of-Life Outcomes That Matter to Squamous Cell Carcinoma of the Oropharynx (SCOOP) Patients and Their Families"** Principal Investigator- Dr. Steven Chang: <https://www.pcori.org/research-results/2015/whats-scoop-discovering-quality-life-outcomes-matter-squamous-cell-carcinoma>

**"Transforming the Gift of Life into a Transplant Living Community (TLC)"** Principal Investigator- Dr. Kelly Collins: <https://www.pcori.org/research-results/2017/transforming-gift-life-transplant-living-community-tlc-tier-ii>

#### PCORI Eugene Washington Awards:

**"Engaging Patients and Other Stakeholders to Develop a Patient-Centered Research Agenda for Cancer Precision Medicine"** Principal Investigator- Karen Kippen, MS: <https://www.pcori.org/research-results/2016/engaging-patients-and-other-stakeholders-develop-patient-centered-research>

**"Focus on the Rainbow"** Principal Investigator- Dr. Maureen Connolly: <https://www.pcori.org/research-results/2016/focus-rainbow>

**"Motor City School Health Collaborative"** Principal Investigator- Dr. Maureen Connolly: <https://www.pcori.org/research-results/2017/motor-city-school-health-collaborative>

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