



**PATIENT ENGAGED
RESEARCH CENTER**

Annual Summary 2018

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Henry Ford Health System
Public Health Sciences
Patient Engaged Research Center (PERC)

Overview:

In October 2013, Henry Ford Health System was one of seven organizations chosen from across the country to participate in a groundbreaking infrastructure development initiative to improve patient outcomes through engaging patients, families, community groups and healthcare providers in healthcare improvement and research. The 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.

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.

Health System Advisors: 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.

Research Advisors: Serve as Patient Advisor members of funded research projects giving input on study design, outcome measurement selection, data collection and dissemination of research findings.

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.

Focus Group Advisors: Participate in focus groups and provide feedback on own personal healthcare experiences, as well as other key healthcare delivery topics

Recruitment, Training, Engagement and 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 360+ trained and active Patient Advisors and 170+ working on teams and committees across the Healthcare System. Fourteen (14) Patient Family Advisory Councils (PFACs) 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 plans, 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.

For Patients and Caregivers, an easy application has been developed on [PERC's website](#) 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. 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.

S= Solution Oriented

H= Helpful

A= Active Listener

R= Respectful

E= Effective Communicator

Providers also need support including tools on effective ways to engage with patients as partners on teams. We call these providers Patient Advisor Buddies. To provide that support, a 30 minute HFHS University class was developed and is mandatory for providers who are asking for patient advisors to join their teams. This class was developed jointly with the Office of Clinical Quality and Patient Education and PERC. Bi-monthly support calls for Advisor Buddies to share successes, solve challenges and share knowledge are facilitated by PERC.

2nd Annual Patient Advisor Retreat

Continuous retention activities and training are key to maintaining and growing our Patient Advisor groups. In 2018, we held our retreat at the John Lewis Conference Center at Macomb Community College. Highlights included, a Welcome by Michelle Schreiber, a keynote by Dr. Daniel Mullins and Gail Graham (Patient Advisor) from the University of Maryland, Shawn Bennis shared her Caregiver



Resources and an Emotional Intelligence Skill Building Session by Doreen O'Donnell, Lori Velu, and Renee Verscheure. More than 80 attendees participated. The retreat was co-sponsored by Astra Zenac

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.

February 2018: ***"Coffee & Conversation"***- A group of Patient Advisors gathered for an hour of coffee and ice breaker activities.

July 2018: ***"Spring Fling"***- 10-15 Patient Advisors got together for an afternoon of mingling and board games.

October 2018: ***"Painting with Patient Advisors"***- 20+ Patient Advisors joined us for a painting with a twist style activities and created some fall themed art canvases.



Research Based Councils

1. All of Us Research Program

Members: Angeline McLamb, Bridget Knox, Caree & Tom Raymond, Cheryl Beamgard, Debra Fowlkes, Denise Hardaway, Donna-Lynn Riley, Doris Rowe, Edward Brzozowski, Ellen Stefanovich, Ellen Bowden, Ellen Kershenbaum, Gloria Myers, Howayda Messiha, Jeaneane Havstad, Jeremy Washburn, Khalia Hill, Kimberly Swift, Laura McCourt, Linda Stechison, Mary Griffin, Dr. Randee Bloom, Rhonda Baker-Levingston, Rhonda Hall, Rita Lockridge, Roseanne Horne, Stacy Mina, Tehra Verellen, TyKesha Lewis-Harper, Wendy Simpson-Paige, Elizabeth Rubinstein



*(All of Us Advisory Council
Kick-off Meeting 9-25-18)*

Buddy: Karen Kippen

Begun in June of 2017, these advisors work closely with the NIH and Henry Ford researchers on approaches for engagement and return of information to patients as part of the development of a million person cohort for precision medicine research.

Accomplishments:

- 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

Health System Based Councils

2. Care Transitions

Members: Ellen Stefanovich (Lead Patient Advisor), Linda Ali, Patrick Ferguson, Mary Gomez, Anita Hall, Toni Haddad, Sophia Hue, Sandra Perez, Joann Kok, Gary Ladd, Lorraine Mayberry, Sandra Perez, Dee Pitian, Valerie Scott, Susan Wautelet, Edward Weidenback

Buddies: Sue Craft, Rob Behrendt, Angela Murphy

Begun in November 2015, this group's mission is to improve transitions between care settings. One approach is to leverage electronic documents such as the "after visit summary" to make information about care and medications clear and easy to understand in a format that is designed to be patient centered. These efforts have resulted in changes that have been implemented in the most recent

Epic upgrades. Recently, the U.S. Patent & Trademark Office has officially registered the name C.A.R.E. Program Caregiver Assistance Resources and Education Program®, which included input from the patient advisors on a caregiver binder.

Accomplishments:

- Directed Helios to make the OPD/IPD AVS more patient friendly.
- Provided feedback on multiple caregiver resources: webpage, binder, Caregiver College.
- Assisted pharmacy in creating a more user friendly website and educational videos.
- Directed HFHS in the how patient education material should look.
- Provided feedback to smoking cessation, colonoscopy education, behavioral health integration, and the cancer institute.

3. Care Experience

Members: Linda Ali, Bonnie Bodart, Toni Bowker, Linda Czajka, Linda Doolittle, John Doyle, Lynette Gilmore, Jacquetta Hinton, Pamela Koch, Sharon Sigler, Sue Small, Avia Warmack, Nathaniel Warshay, Diana Wiebusch, A. Ruth Williams.

Buddies: Anna Marcantonio, Michelle Turylo (administrative support)



(Patient Advisors serving on Panel at Caregiver Symposium April 2018)

Begun in March 2016, this group's focus is on how to improve communication between patients and providers to support better outcomes for patients. Their work enables HFHS to provide the highest standard of safe comprehensive and compassionate healthcare through integrating the voices of the patients, families and their caregivers as partners with the Care Experience team.

Accomplishments:

- Sonifi Education/Entertainment System
- Rounding Embraced by All Leaders (REAL)
- Physician Communication (CLEAR Conversations)
- Billing Statement Redesign
- Parking/Security Training
- Cipher Orchid Rounding Questions
- Inpatient Skills Communication (HFH)
- MyChart Mobile Video
- HFMG Thank you Cards
- Complaint/Grievance Letter Templates
- Infection Control Signs
- Activity Packs

- HCAHPS Survey
- ED and ICU Surveys

4. Henry Ford Cancer Institute

Members: Joyce Gant, Molly Marco, Bud Howell, Michelle Solomon, Christina Pitts, Nestelynn Gay, Deidra Moody, Roxann Ellens-Dickson, Doug Smith, Sandra Keller, Gary Ladd, Speed Gant, Julie Bates, Steven Waski, Keith White, Yalonda Jackson, Kimberly Brown, Linda Czajka, Linda Stechison, Lynne Aldrich, Fred Lavery



(Patient Advisors attending the Brigitte Harris Cancer Pavilion VIP Beam Signing Event- April 2018)

Buddies: Rebecca Blanken and Karen Kippen

Begun in early 2016, this group of cancer patient, survivors and their caregivers advise leaders on plans for a destination cancer center to be built on Henry Ford's Downtown Campus. They have given guidance to the architecture firm on specific building features and the most important cancer support services that are important to patients. They have been awarded \$250K in PCORI funding to develop [precision medicine cancer research](#) questions and are developing a research agenda and dissemination plan for their work.

Accomplishments:

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

5. Henry Ford Population Health

Members: Audrey Byars, Carolyn Bough, Catherine Sanders, Chelsea Jackson, Gloria Myers, Miles Barnett, Naila Usmani, Nathaniel Warshay, Susan Hengesbaugh

Buddies: Suma Varma, Kathy Scher, Susan Hawkins

Begun in 2018, to support the System's Population Health Team and one of their early agenda items will be exploring opportunities in addressing the Social Determinates of Health.

Hospital Based Councils

6. Henry Ford Wyandotte

Members: Ann Achinger, Beverly Jager, Bonnie Bodart, Carole Bell-Duolos, Cindy McGrath, Deborah Edwards, Debra Page, Denise Bywater, Diana Wiebusch, Donald Massey, Kathy White, Laura Lieb, Loreleen Hyden, Lynn Ward, Mary Novak , Nancy Alberts, Pamela Cook, Pat Dolan, Paulette Slawski

Buddy: Julie Johns

Begun in January 2015 to address the specific needs of the Wyandotte Community, this group has been active in ED redesign as well as improvement in patient billing statements. This council provides advice, consultation, evaluation and recommendations regarding programs, educational efforts, selected research activities and operational initiatives that affect patients and families. They continue to be a vital link between Henry Ford Wyandotte Hospital and the community.

Accomplishments:

- Participated in Emergency Room Redesign
- Emergency Room Process Changes
- Based on Advisor's feedback, Brownstown implemented a marketing campaign around women services and the ER
- Participated in discussions around making Wyandotte a "Baby Friendly" designation
- Participated in discussions regarding Safe Patient Handling and significantly impacted hospital metrics related to nurses to always have back and shoulder pain
- Based on feedback from this group, a tabulated educational booklet was created for patients in the Breast Oncology Department

7. Henry Ford Macomb Hospital

Members: Andrea Wulf, Lois Barney, Brittany Brown, Dennis Grebur, Gary Jamerino, Janice Robichaud, JoAnna Sheen, Laurie Thiel, Marcy Lumetta, Patrick McLogan, Patty Rozanelli, Sandra Leonard, Terry Seewald, Wanda Francisco

Buddy: Maureen Bennett

Begun October 2016, this group's focus is to provide feedback and recommendations on our Patients Satisfaction Scores and the care and amenities we offer to families, friends and staff. Additionally, the PFAC will make recommendations on directional signs, new builds and renovations.

Accomplishments:

- Reviewed Patient handbook and changes made from suggestions
- MyChart verbiage discussed and changed
- Anesthesia patient cards discussed with a few changes
- Housekeeping card for patients rooms approved
- Discussed discharge instructions and made suggestions for in a few areas
- Reviewed patient satisfaction scores for Macomb
- Registration process explained and suggestions made.
- Informational presentations – Family Caregiver Resources, way finding, Geriatric specialist

8. Henry Ford West Bloomfield Hospital

Members: Caree Raymond, Teresa Bowers, Tom Raymond, Michael Simon, Chuck Pokriefka, Clarence Mills, Dennis Allgeier, Janet Smith, Kelly Tate, Linda Ali, Linda LaLonde, Lynda Shaw, Mary Drouillard, Peggy Simon

Buddy: Lori Wendt

Begun in early 2018, to address the specific needs of the West Bloomfield Community, this group is actively advising on key patient experience items.

Accomplishments:

- A PFAC Consult Request Form was developed to ensure clear communication for presentations
- Recommended rules for Sleep Room assignments, and creation of a list of local hotels for families
- Feedback on Ambulatory site planning including the importance of open green spaces at entry way
- Recommendation that a newsletter and HFHS marketing materials are given to any new resident that moves into West Bloomfield Township by the Township Supervisor

9. Henry Ford Hospital

Members: Brenda Allen, David Grudzinski, Deidra Moody, Doug Smith, Lorraine Mayberry, Lynette Gilmore, Mary (Molly) Marco, Michelle Solomon, Roxann Ellens-Dickson, Steven Wasko, Tasha Grays, Yalonda Jackson

Buddies: Jack Jordan, Vanessa Mona

Begun in 2018, this unique group was formed from all patient advisors that already had a placement on a different PFAC. This will bring the work of many teams together in one place.

10. Henry Ford Allegiance Health

Members: Actively recruiting members for a Q1 2019 kick-off

Buddies: Suzy Turpel, Amy Sayles

Clinical Care Based Councils

11. Head and Neck Cancer

Members: Bill Adams, David Grudzinski, Doug Smith, Erik Hanby, Gail Paskind (Virtual Advisor), Gary Ladd, Jennifer Menser, John Skovranko, Linda Stechison, Mary Solowski, Maryrose Pharo, Melinda Janson, Patrick Coughlin, Ralph Picklo, Sam Gachupin

Buddy: Steven Chang, MD

Begun in December 2014 to proactively address the needs of cancer patients and families before, during and after treatment. Key successes have been implementation of a survivorship clinic and improvement of clinic workflow to better meet patient service needs. This group is also interested in patient centered outcomes research and has received \$90K in funding to develop comparative effectiveness research questions related to head and neck cancer therapies and quality of life impacts of those therapies.



(Four Patient Advisors from the Head and Neck Cancer Patient Advisory Council accompanied Dr. Steven Chang to the Combined Otolaryngology Spring Meetings (COSM) held in National Harbor, MD)

Accomplishments:

Clinical Focus

- Revamped the New Patient Resource Folder
- Revised the clinic flow for new patients
- Provided feedback on American Head and Neck Society patient education materials
- Provided feedback on a Universal Consent Form for the HFHS biorepository
- 6 Advisors have traveled to academic conferences
- 3 Advisors have presented at HFHS Head and Neck Cancer Symposium

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

12. Transplant Living Community (TLC)

Members: Cheryl Cushingberry, Terrence Jones, Aarolyn McCullough, Tim Davidson, Sarita Leak, Johnnie Miller, Ron Orzell, Ed Gizowski, Tom Smith, Jay Warner, Kristen Wimberly, Cassandra Allen, Dorothy Wise.

Buddies: Elizabeth Rubinstein, Kelly Collins, MD

This group reconvened in March of 2016, to focus on standardizing and care integration of patient and family lifestyle education through a patient developed tool call ACESSM. A key focus is establishing ACES Lifestyle classes for all organ transplant categories pre and post-transplant and incorporating ACES curriculum with medical staff through in-service presentations for in patient units and ambulatory clinic.

They have also received \$40K in PCORI funding for their PCORI Pipeline to Proposal Project (P2P), [Transforming the Gift of Life into a Transplant Living Community](#) and continue to be engaged in development of comparative effectiveness research questions through a nationwide survey tool.



(Patient Advisor/Buddy presenting at the All Leaders Meeting on March 29, 2016)

Accomplishments:

- 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

13. Hermelin Brain Tumor Center

Members: Tiffany Crowe, Adele Demchik, Fallon Hall, Kim Richardson-Hippler, Angela Jackson, Joan Redenbaugh, Lynda Shaw, Dave Ehlen, Matthew Beck, Bill Ayers, Carly Beck, Marc Betman

Buddies: Dr. Tobias Walbert, M.D., Dr. James M. Snyder, D.O., Lisa Scarpace, Nestelynn Gay

This group started in March 2018 with a goal to enhance the patient experience at the Hermelin Brain Tumor Center by implementing ideas based on feedback from patients, families and caregivers.

Accomplishments:

- 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.

14. The HUB /Patient Surgical Home

Members: Caree Raymond, Tom Raymond, Ellen Stefanovich, Joann Kok, Michelle Solomon, Pat Dempsey-Klott, Terry Jones

Buddy: Gary Loyd, MD

Begun in 2017 and led by Dr. Gary Loyd, this group is currently reviewing patient education for orthopedic surgery including hip and knee surgery to create understandable education modules for patients and caregivers. This group has been awarded a Sinai Medical Staff Foundation award for \$120K.

Accomplishments:

- 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.
- Review and feedback of an Hip and Knee Surgery on-line tools and phone apps for Force Therapeutics

Individual Placements

Ethics Committee

Member: Pastor Deborah Smith-Satterwhite

Buddy: Karen Smith

IMPACT- Congestive Heart Failure HFWB

(Integrated Michigan Patient-centered Alliance in Care Transitions)

Member: *currently recruiting*

Buddy: Rob Behrendt and Inna Beim

IMPACT- Congestive Heart Failure HF Main

Member: Jay Warner, Greg Heilman, Wendy Simpson-Paige

Buddy: Susan Holmes-Walker, PhD, RN and Rob Behrendt

IMPACT- Skilled Nursing Facility Committee

Member: Currently Recruiting

Buddy: Katie Biringer, RN

System Patient Education Council

Members: Beth Rubinstein, Christianne Sims, Neita Wilson, Tasha Grays, Toni Bowker

Buddy: Angela Murphy

HFH Stroke Transitions of Care Committee

Members: Denise Poplack and Katrina Smith

Buddy: Megan Brady

Radiology Customer Service

Member: Dennis Allgeier

Buddy: Jessica Zadorozny

Spinal Fusion Perioperative Surgical Home

Members: Beverly Jager and Michael & Peggy Simon

Buddy: Gary Loyd, MD