

## PATIENT ADVISORS LEARN FROM HENRY FORD LEADERS ABOUT POPULATION HEALTH MANAGEMENT



Henry Ford Health System is partnering with patients and caregivers through a Patient and Family Advisory Council (PFAC) dedicated to Population Health Management which may help develop and deliver innovations in value based care. The work aligns with a new health care plan,

ConnectedCare, which aims to provide both affordable and exceptional health care to General Motors employees, among other initiatives.

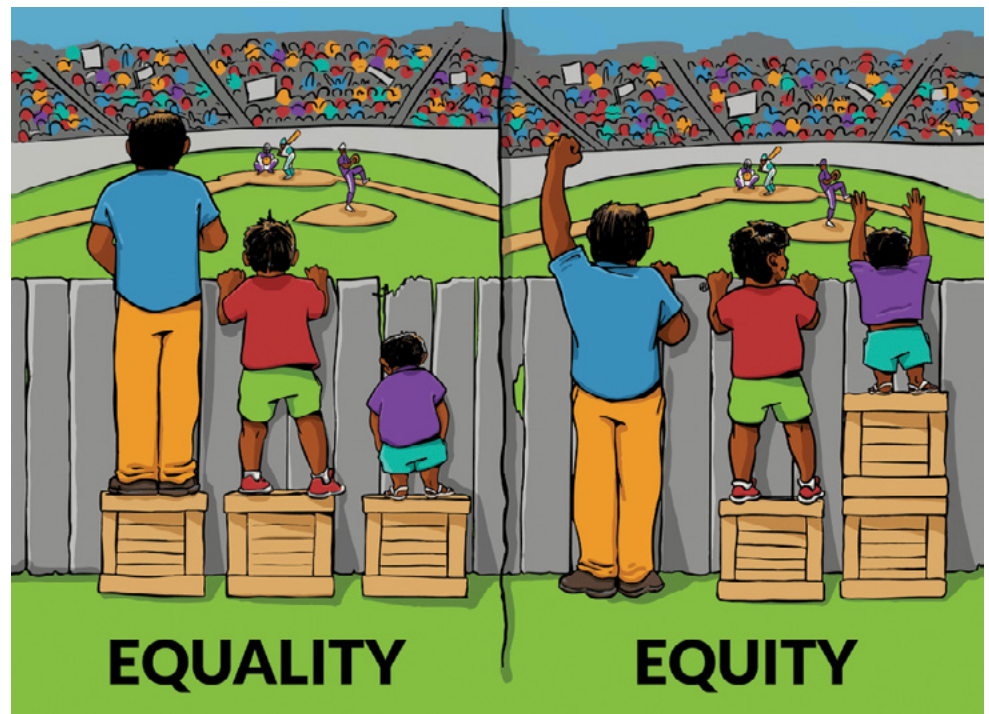
Katherine Scher, RN, Vice President, Clinical Integration and Ambulatory Care Management, Population Health is co-leading the council with Patient Advisors. Her broad experience on the provider side includes clinical work in a medical ICU, work as a case manager and implementation of the patient-centered medical home concept and patient-centered team care. She also has experience working on the payer side for Health Alliance Plan, the insurance arm of Henry Ford.

Kathy sees great potential for bi-directional learning leading to design enhancements and interventions to improve healthcare outcomes. The most exciting part of the monthly meetings and working with the patients and caregivers is “how engaged the group is and their willingness to give feedback”, says Ms. Scher.

Patient Advisor Chelsea Jackson has emerged as a leader in the Population

Health PFAC and has been voted as one of the Co-Chairs in the council. She states that “even though I am the youngest person in the room, I am ready to set up as a leader to bring focus to the group.” Chelsea is passionate about health and wellness within the community. She hopes to help the group focus on resources for the community; whether that means a resource library or going directly into the community to provide more information. She states that “another area for expansion would be women’s health, and even wants to host a women’s health focus group in the future.”

Launched in 2018, this PFAC has developed a plan and priorities related to Population Health Management. There is great interest in learning how to identify and address the social determinants of health barriers. The council has learned what population health management means and what health initiatives are currently in progress at Henry Ford.



# ADVISOR SPOTLIGHT

## MELINDA JANSON



Over 30 year ago, Melinda Janson was diagnosed with Stage IV Head & Neck Cancer. After surgery, Melinda struggled with harsh chemotherapy and radiation, but ultimately did very well through her treatments into survivorship, retaining her perfect speech, swallowing, and taste. Many years later, Melinda found a lump on the other side of her jaw and had another biopsy.

The type of procedure they chose for this biopsy was invasive and ultimately severed the nerves on half the tongue she had left. While the biopsy came back negative, the procedure left her with no taste, no feeling, and issues with swallowing and speech. After the damage had been done, Melinda realized there were less invasive options for her biopsy and it was in that moment she knew she needed to find a new physician.

Several years ago, Melinda's new doctor encouraged her to attend a support group to talk through her very emotional and painful experiences with health care. Because of Melinda's speech difficulties, she was discouraged and not eager to share her experiences with others who were in the same situation as her. While that resource works for others, she just knew in her heart that a support group would not give her the kind of support she needed. Her doctor listened to her concerns and offered another avenue that may help her. He suggested she join the Patient Advisor Program. Her hesitation toward the program at first soon went away when she realized the group

collaboration was focused on not just talking about health care struggles, but discussed ways to improve them. In the end, she says her "doctor was completely right". Melinda states, **"This PFAC [Patient & Family Advisory Council] was life changing for me, and it is in the top 4 most important things in my life."**

As a Patient Advisor and member of the Head & Neck Cancer Council, Melinda has learned about new resources available for head and neck cancer patients. She was able to share with the council information about her dental prosthesis that helps with speech. Melinda advocates for other head and neck cancer patients and urges everyone to do research about alternatives of care.

The Head & Neck Cancer Council received grant funding from the Patient Centered Outcomes Research Institute (PCORI) for a project called "What's the SCOOP? Discovering Quality-of-Life Outcomes That Matter to Squamous Cell Carcinoma of the Oropharynx (SCOOP) Patients and Their Families". This award funded Melinda and 4 other Patient Advisors to attend the 2018 Combined Otolaryngology Spring Meeting (COSM). This was one of Melinda's favorite experiences as a Patient Advisor and it left her feeling energized and truly valued. The Council has many accomplishments, some of which includes advocating for Henry Ford's Survivorship Clinic, helping to provide resources for Dental Oncologist services that were previously unavailable, and helping to create content for the new Head & Neck Cancer Patient Resource Guide Book.

Melinda is looking forward to continuing to provide resources for others who have been in her shoes, and she is thankful that she has found something that has given her difficulties in health care some purpose. She states that "this PFAC is so meaningful to me, because it shifts the bad feelings I had about everything into a more positive outlook."

## PATIENT ADVISORS HELP WITH HPV VACCINATIONS SURVEY

There are many ways that Patient Advisors can contribute to research, one of which is by participating in the grant proposal creation process. The Patient Engaged Research Center (PERC), in collaboration with health disparity researcher,

Dr. Christine Joseph and Otolaryngologist, Dr. Vivian Wu sent a survey to the Patient Advisor pool exploring ways of reaching out to parents of children 11-13 years of age about the HPV vaccination. The survey took approximately 2-3 minutes to complete was disseminated on May 21, 2018 and was closed on June 6, 2018 with 67 respondents.

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## HPV VACCINATIONS SURVEY *Continued.*

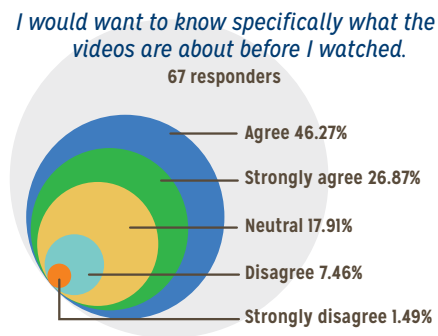
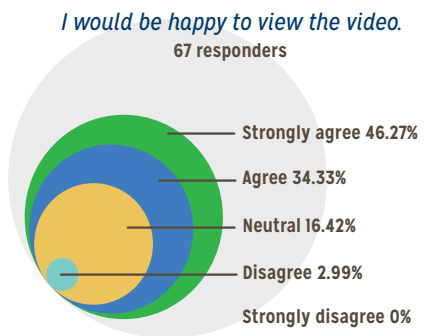
The survey began by presenting a scenario:

*You are at the doctor's office with your child age 11. The nurse calls your child's name and you and your child are led by the nurse to an exam room and asked to wait for the doctor. Before leaving the room, the nurse says "We have some videos that we would like you to view while waiting for the doctor (pointing to an Ipad). They cover important topics about your child's health and vaccines for pre-teens and adolescents. Would you like to see them?" Survey respondents were asked to share whether they agreed or disagreed with the presented statements.*

So what can we conclude from this data? Based on the data, respondents were generally receptive and eager to view the video, however respondents were split on whether they felt they could finish the video before the doctor comes in. For the most part, respondents would like to know the content of the videos beforehand, and

most would ask a few questions prior to viewing, but would still be willing to watch the video. Out of the 67 responders, close to 87 percent were females and 13 percent were males. Approximately 67 percent reported Caucasian/White as their ethnicity, 28 percent African American, and the remaining was split between Asian and Native American/Alaska Native.

Your participation in these sorts of surveys are extremely helpful for two major reasons. First, as researchers, we want to make sure we are putting time and resources into worthwhile ventures that are useful to patients and their caregivers, but the second and most important reason is that we want to make sure the patient voice is incorporated in EVERY aspect of research. From the study design creation to data collection, all the way to how we disseminate the study results, the patient voice is imperative in producing impactful patient-centered and engaged research. Thank you again to everyone who participated in the survey.



## A WORD FROM THE PERC DIRECTOR CHRISTINE JOHNSON, PhD



The year end hustle and bustle is starting to ramp up! I hope you can take a few minutes and read the great articles in this issue of the PERC Newsletter. You can learn about a new Patient Family Advisory Council (PFAC) called Population Health, which will focus their work on the patient's perspective of addressing various social determinates of health.

The champion of this PFAC, **Katherine Scher, RN** and co-leader Chelsea Jackson discusses their work on the council.

In our Patient Advisor Spotlight section, **Melinda Janson**, tells her story and talks about her work with the Head and Neck Cancer PFAC and her trip to the 2018 Combined Otolaryngology Spring Meeting (COSM). Another member of that group **Jennifer Menser**, talks about her new non-profit the Oral Cancer Awareness Network (OCAN).

Finally, find out how the 30 members of new All of Us Research Program PFAC are working to help develop appropriate messaging and marketing materials to educate and engage 1 million volunteers to change the future of health for everyone. You can go to [allofus@hfhs.org](mailto:allofus@hfhs.org) to find out more.

Wishing you and your family a happy healthy 2019. Happy Reading!

*Christine Cole Johnson*



## ADVISORY COUNCIL KICKS OFF SUCCESSFUL 2018 MEETINGS

The *All of Us* Research Program Advisory Council held their first meeting in late September serving as an open forum for addressing enrollment concerns, providing feedback on marketing materials, and learning about project updates. Heather Olden led the group in various skill building activities to prepare the new advisors for their upcoming role. Advisors are charged with evaluating and providing recommendations regarding *All of Us* Research Program activities.

The All of Us advisors were excited to share their feedback to help improve future meetings. One advisor said, *"I enjoyed*

*the meeting and liked that the members and facilitators showed willingness and enthusiasm about the project."*

At the November meeting, the leadership team shared an update on enrollment and recent accomplishments. Karen Kippen, Executive Director, Patient Centered Outcomes Research lead a discussion on barriers of enrollment listening to advisors suggestions for future enrollees. The advisors also shared marketing ideas to help spread the word about the *All of Us* Research Program, who will be beginning their second year of recruitment in 2019.

To learn more or become a member of the All of Us Advisory Council, please visit [HenryFord.com/PERC](http://HenryFord.com/PERC) and fill out the advisor application and select "All of Us" advisor.



## ORAL CANCER AWARENESS OF MICHIGAN (OCAM)

With almost 20 years in the dental industry, Oral Cancer Awareness of Michigan (OCAM) founder, Jennifer Menser, RDH started the non-profit recently to help people in Michigan with Oral/Oropharyngeal cancer.



Jennifer is a current Henry Ford patient advisor with the ENT Advisory Council and her work with Dr. Steven Chang has led her to do advocacy work with Michigan dentists to help early detection of oral cancer. In fact, her foundation *Oral Cancer Awareness of Michigan* was founded with that very same mission, to

improve patient outcomes for this devastating disease and help those impacted by oral/oropharyngeal cancer live longer, healthier, and fuller lives.

Oral cancer takes more lives than cancers we routinely hear about, such as cervical, Hodgkin's lymphoma, skin (malignant melanoma), testicular, and many others. In the efforts to reduce the death rate from cancers in the US, the most significant progress has been made through early detection.



Over the summer, OCAM, hosted a 5K race that raised money directly benefiting Michigan families' providing support while battling Oral/Oropharyngeal cancer. "The incredible strides we are making to bring awareness and support those

impacted by this disease would mean nothing if the people with oral/oropharyngeal cancer did not have the access to our support," said, Jennifer Menser, OCAM founder.

### SUPPORT

If you are interested to help support our mission or learn more about Oral Cancer Awareness of Michigan (OCAM), please contact us: [support@oralcancermi.org](mailto:support@oralcancermi.org).