

Health Research Advisory Council

Meeting Notes

February 9, 2017

In attendance - council members: Helena Abrom, Carol Benson, Ashley Borgschatz, Marie Cano, Ken Caron, Angie Chafos, Bob Dimler, Jo Ericksen, Pete Kasper, Fatuma Omer, Jim Rodrick, Mary Rodrick, Joan Rose, Lori Scanlan-Hanson, Dee Servick, Barry Skolnick, Harold Stewart, and Denny Uthke (18 attendees)

In attendance – leadership: Walter Rocca, Joan Griffin, Lori Klein, and Robin Adams

The first meeting of the merged group with members from both the Center for the Science of Health Care Delivery (CSHCD) Patient and Family Advisory Council (PFAC) and the Rochester Epidemiology Project Community Advisory Board (REP CAB) kicked off with two ice breaker activities which allowed members a fun opportunity to interact briefly.

Dr. Walter Rocca, co-principal investigator (“Co-Director”) of the Rochester Epidemiology Project (REP) provided a description of the REP and the community advisory board (CAB). The REP is a collaboration of clinics, hospitals, and other medical facilities in SE Minnesota and SW Wisconsin and involves community members who have agreed to share their medical records for research. The REP collaboration includes medical records from Olmsted Medical Center, Mayo Clinic, Olmsted County Public Health Services, dental clinics, and other private practice physicians. The REP is a unique resource for researchers because of the ability to link a patient’s medical records across all the medical facilities where they have received care within the REP region. In 2016, the REP celebrated 50 years. The REP website (rochesterproject.org) has videos and an “about us” section which provides a wealth of information to help in understanding the REP.

The community advisory board was created after gathering feedback at a deliberative community engagement event held in Rochester in 2011. The primary purpose of the engagement event was to find out the level of awareness about the REP within the local community. The results of the event made it clear that there was a need to increase awareness and to educate the community about not only the REP, but also, research and the Minnesota research authorization law (MN law giving patients the right to authorize or deny access to their medical records for research). In response to the results of the event, the community advisory board (CAB) was formed to help increase awareness and to educate the community about the REP. The first CAB meeting was held in October 2012 then met 3 - 4 times per year through September 2016. The CAB brought a community perspective when making recommendations to the REP on topics they were requested to review, such as creation of a REP Facebook page, providing feedback on the REP logo and website, and the 50 year anniversary activities. The CAB also helped raise awareness and educate the community by representing the REP at events, such as Rochester Women’s Fall Expo, Good Life Expo, Rochester Fest, Thursdays on First and 3rd, and the Olmsted County Community Health Needs Assessment.

Next, an overview of the Patient and Family Advisory Council (PFAC) was delivered by Dr. Joan Griffin, Scientific Director of the Care Experiences Program at Mayo Clinic. The PFAC was

originally initiated by Dr. Jeanne Huddelston, a physician and health system engineer, when she was working on a study trying to predict when a hospitalized patient's health begins to show signs of deterioration. She was looking for feedback about this study and gathered together interested patients and their family members to discuss the work. The group has continued to meet and advise researchers on patient and family perspectives of proposed research projects. In Spring, 2016, Dr. Joan Griffin, on behalf of the Center for the Science of Healthcare Delivery, took the reins from Dr. Huddelston. The group has continued to provide their feedback on research from investigators across Mayo Clinic.

Next, Lori explained that the merged group will have two co-chair positions – one will be from the former CAB and one from the former PFAC. There is already a former CAB member in a co-chair role, Denny Uthke, but an election will be used to fill the other co-chair role. Anyone from the former PFAC group that is interested in being considered for the co-chair role should write a short paragraph explaining why they want to be the co-chair and what it is they hope to bring to the role. A role description is attached.

The full process will work as follows:

1. Submit paragraph to Lori by March 10
 - a. Lori will send reminder email on March 8
2. Lori will route to all council members by March 15
3. Council members vote by March 31
 - a. Lori will send reminder email on March 29
4. Co-chair announced at the April 27 meeting.

Next, the group held a discussion about naming the newly merged group. Using a list of potential group names as a starting point, the members engaged in a dynamic and respectful debate until a final vote could be taken. The group name winning the majority of votes was ["Health Research Advisory Council."](#)

The final topic discussed was the location and schedule for future council meetings. The overall consensus on location was that if the availability of Charter House allows, it would work well to schedule future meetings in the same room (Charter House room 1-158). Also, a group discussion helped determine a consensus about a recurring schedule for the council meetings. The final compromise by attendees was to meet the 4th Thursday of January, April, July and October at 5:30pm.

Due to time limitations, we were unable to discuss mission statement and training therefore those agenda items will be discussed at a later date.

NEXT MEETING: Thursday, **April 27, 2017** at **5:30pm** at the **Charter House room 1-158**.

2017-2018 Meeting Dates

- April 27, 2017
- July 27, 2017
- October 26, 2017
- January 25, 2018