

THURSDAY BREAKOUT SESSION

DESCRIPTIONS:

10:00AM-12:00PM

- **Patient Engagement**
 - **Who:** Patients and Patient Engagement Officers
 - **What:** This session will discuss the role of patients, caregivers and coordinators in the work of the GPC. We will talk about different types of research and what kinds of research can best use the resources of the GPC to improve patient care and health.
- **Institutional Review Board (IRB) Meeting**
 - **Who:** IRB members
 - **What:** This session will work on the progress of sharing common reviews of projects to make sure patients and their health data are properly protected and that research is conducted in ethical ways.
- **Discussion of Trials/Studies**
 - **Who:** Site PIs
 - **What:** There are already a number of research studies being conducted across the GPC, and to make sure that all of the sites understand their responsibilities and have the opportunity to discuss institutional problems, the lead person from each site (called the Principal Investigator) will meet.
- **Fishing Trip**
 - **Who:** Medical Informatics teams, others who are interested
 - **What:** We call this a fishing trip because we are going to show everyone how they can “fish” for necessary information that is needed to answer their research questions. Tamara McMahon is going to demonstrate how the system works at KUMC.
- **Cohort Characterization**
 - **Who:** Cohort groups
 - **What:** A cohort is a name for a group of patients who share a common set of conditions and are part of a research study. In GPC 1.0, we focused on breast cancer, ALS (Lou Gehrig’s disease) and healthy weight in children. If you were involved in GPC 1.0 in one of these groups or are interested in hearing an update on surveys, patient engagement activities, etc., join in!

1:00PM-3:00PM

- **Patient Engagement**
 - **Who:** Patients and Patient Engagement Officers
 - **What:** We will start this session with hearing about patient engagement from two patient advocates at Children's Mercy Hospital, followed by comments from PPRN participants. Having their input will kick off our session to focus on 1) how to help describe the GPC in ways that will help get patients interested at the local level, and 2) how can we make sure patient perspectives are at every "table" in the GPC. If we can, we will also write a value statement together.
- **Institutional Review Board (IRB) Meeting**
 - **Who:** IRB members
 - **What:** Continuation from morning session.
- **Collaborator Identification Process / Collaborator Database**
 - **Who:** Site PIs
 - **What:** The PIs are going to discuss how to track and review the data integration and collaboration from current and future institutions interested in the GPC.
- **Fishing Trip**
 - **Who:** Medical Informatics teams, Investigators
 - **What:** Continuation from morning session adding a hands-on experience for participants.
- **Cohort Characterization**
 - **Who:** Cohort groups
 - **What:** Continuation from morning session.

3:15PM-4:45PM

- **World Café**
 - **Who:** Everyone
 - **What:** The purpose of the World Café time is to give everyone a chance to learn about what has happened in all of the other groups. Everyone will have about 10 minutes at various tables or stations to hear what was covered and to contribute to a list of questions and concerns or provide advice. Each group has a brief description, so you can go to (or stay at) any of the tables or stations you care to. We'll seek volunteers to describe the work of each group at each table/station.