GPC
Greater Plains Collaborative

Welcome to the 2015 Learning Engagement Conference!

Introductions
Russ Waitman

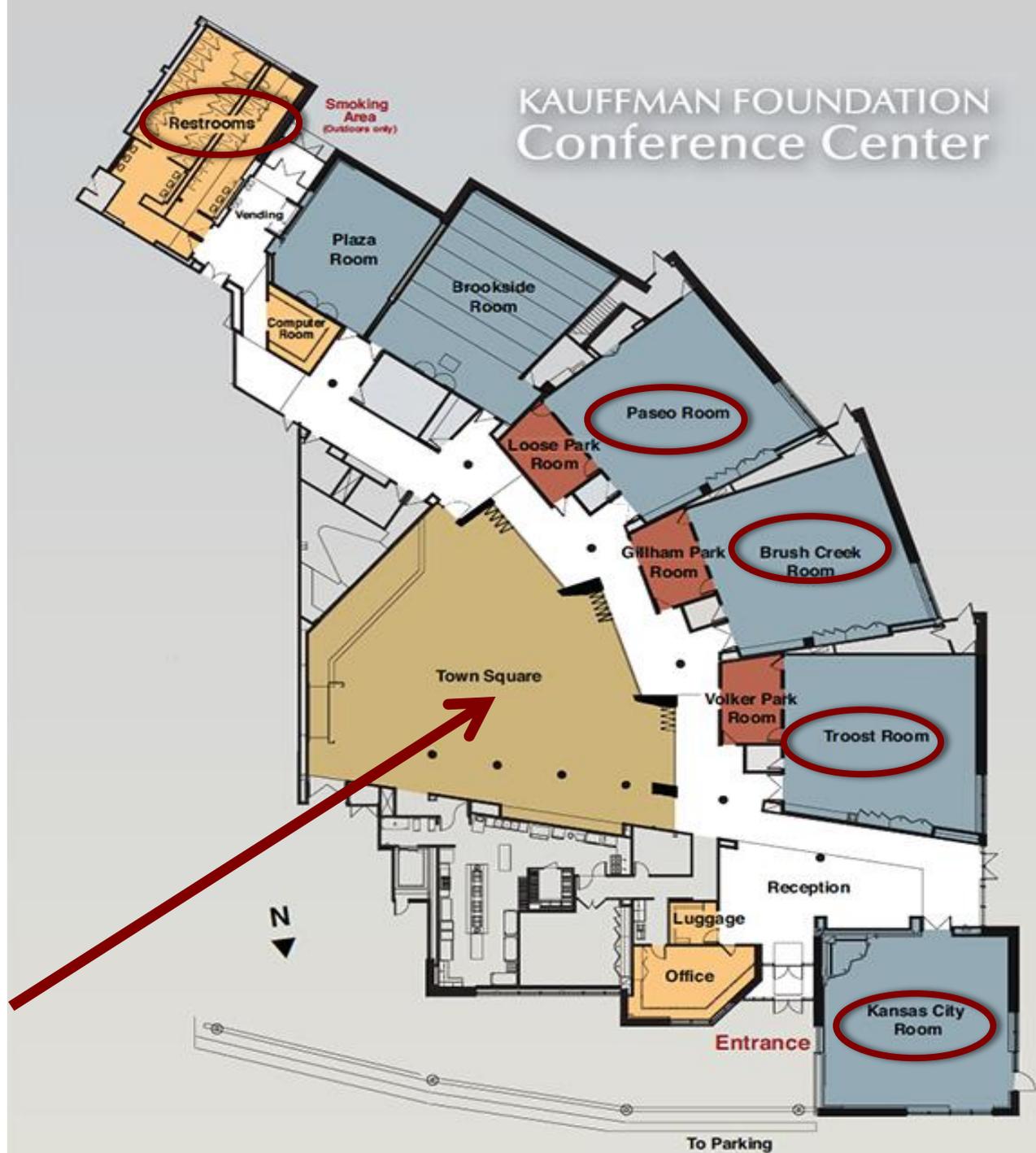# October 1-2, 2015

Housekeeping

- Business Casual, no ties!
- Friendly engagement
- Information is in your packet and prior emails.
- We'll post notes and summaries on the website
  - http://www.gpcnetwork.org/?q=LEK2015
- If you need help, KUMC team, Hillary, and Brittany are here
- Enjoy snacks and drinks

Thank you: for joining!

Thank you: Kauffman Foundation

You're here

KAUFFMAN FOUNDATION
Conference Center

Restrooms

Smoking Area (Outdoors only)

Vending

Plaza Room

Brookside Room

Computer Room

Paseo Room

Loose Park Room

Gillham Park Room

Brush Creek Room

Town Square

Volker Park Room

Troost Room

N

Reception

Luggage

Office

Kansas City Room

Entrance

To Parking

Dinner tonight at 630
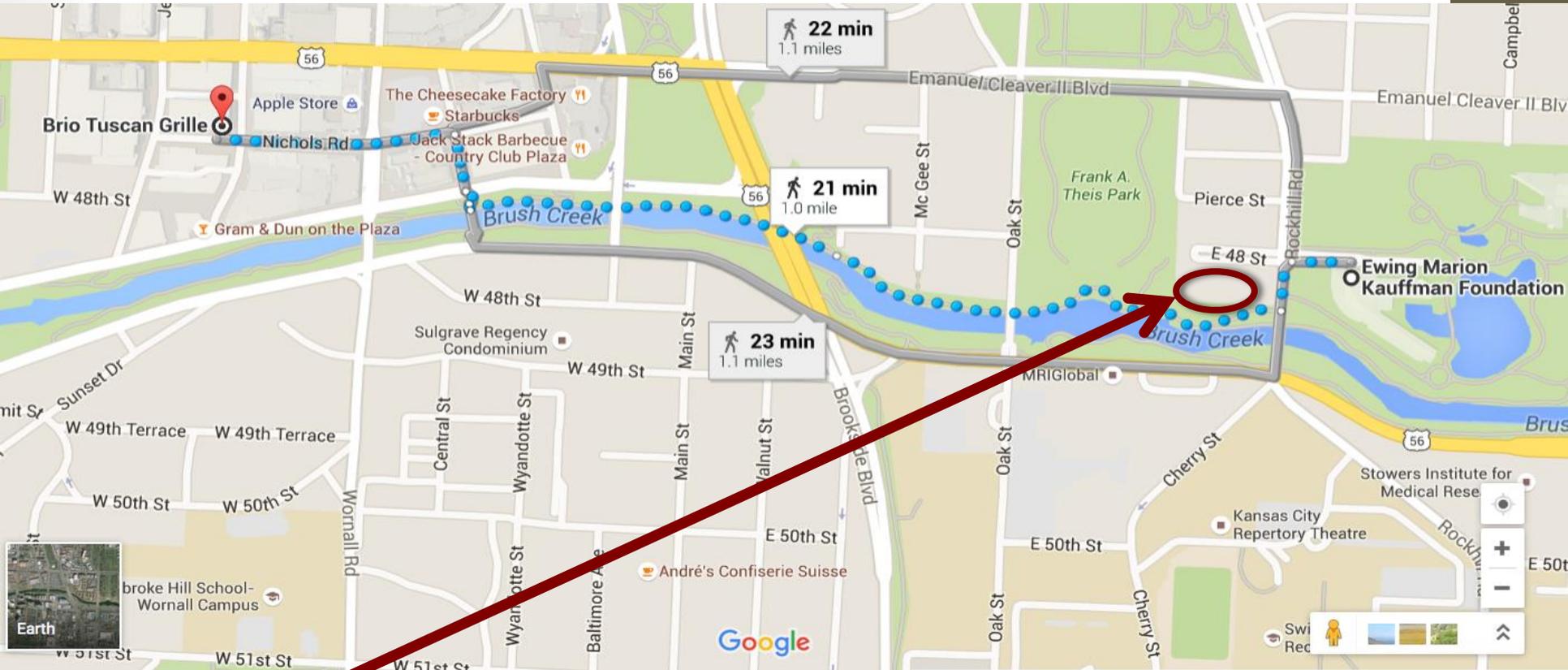
Beautiful small garden

Thank you: Cerner

Schedule Overview

Non-lecture as much as we can; break things up.

Thursday
- Kickoff
- Breakout
- Lunch
- Breakout
- 3:15 World Café Mixer
- Summarize
- 6:30 Dinner

Friday
- Introduction
- Breakout
- Breakout
- Lunch
- Breakout
- 2:30 Close out, summarize next steps
- http://kccrossroads.org/this-first-friday/

Thursday Sessions

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 are interested in hearing an update on surveys, patient engagement activities, etc., join in!

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.

Friday Sessions

Patient Engagement

Who: PPRNs, Patients, Investigators and Cohorts

What: We are going to role play all of the various aspects of a GPC project and put into action what was talked about on Thursday

Institutional Review Board (IRB) Meeting

Who: IRB members

What: Continuation of discussion from Thursday

Data Sharing and Record Linkage

Who: Site PIs

What: A central issue for the GPC is to make sure that all of data "line up" for true comparison, so they have to be mapped properly. It may sound simple, but even knowing whether a person has a specific diagnosis can be challenging.

Data Request Oversight Committee (DROC)

Who: DROC members, Honest Brokers, Patients

What: We want to make sure that we think of everyone's perspectives when we review projects. This session will discuss how we can ensure this happens.

Project Management Meeting

Who: Project Managers

What: This will be a live version of the Project Management Call which normally occurs every other Friday morning by phone.

10:45AM-12:00PM

Patient Engagement: How can the GPC support PPRNs and PPRNs support GPC patients and investigators?

Who: PPRNs, Patients, Patient Engagement Officers, Investigators

What: At the same time the GPC has developed, Patient-Powered Research Networks have also developed. How we can best work together will be the topic for this session.

Institutional Review Board (IRB) Meeting

Who: IRB members

What: Continuation from morning session (if needed).

Sustainability and Terms for Commercial Use for Data Access & Data Use

Who: Patient Engagement Officers, Patients, Cohorts

What: Brad will describe some of the ideas and directions the GPC may take with the data that has accumulated.

Process for Approaching/Approving Projects

Who: Site PIs, Patients

What: We need to make sure that there is a clear process and a relevant check-list to approve projects. Come with ideas to contribute or to listen and react.

Patient Engagement

Who: PPRNs, Patients, Investigators

What: Reflections and Feedback: everyone is invited to share and express observations and concerns. We hope to build a roadmap of the cares and concerns we have about any/all aspects of the GPC. The purpose is to make sure the issues brought up get attention down the road.

Record Linkage Continuation

Who: Site PIs

What: A continuation of the discussion from the morning session.

Sustainability and Terms for Commercial Use for Data Access & Data Use

Who: Patients, DROC members, Honest Brokers

What: A continuation of the discussion from the morning session.

Process for Approaching/Approving Projects

Who: Site PIs

What: We will discuss how Site PIs will manage to work across their institutions in support of new projects.

How we work and Why we're here

- Bring everyone along in the conversation
  - All roles critically important
  - Please ask questions
  - Prairie Chickens for jargon police
- Get/give energy with others
- Seek answers and solutions

- Actively engage and learn from each another
  - PCORnet vision back home to engage your teams
- Plan and design with patients
  - We are moving from Building to Operating
  - Agility and Improvement: Just in time design/redesign at times
- Practice/Test for future meetings for investigators

Questions?