



# MONDAY AGENDA

## 2017 Learning Engagement Conference

October 16, 2017

7:30 am – 8:30 pm

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<b>7:30 am – 8:00 am</b>	<b>Registration &amp; Breakfast (Provided)</b>	Town Square
	Help yourself to some coffee, bagels and fruit, meet and greet other attendees, and get ready for an exciting day!	
<b>8:00 am – 8:30 am</b>	<b>Introduction</b>	Town Square
	Welcome to the 2017 LEC!	
<b>8:40 am – 10:10 am</b>	<b>Poster Walk</b>	Breakout Rooms
	Pilots and existing PCORnet/GPC studies	
<b>10:10 am – 10:30 am</b>	<b>Break</b>	Town Square
	Help yourself to some refreshments	
<b>10:30 am – 12:00 pm</b>	<b>Pilot Breakout Sessions – Participants are welcome to attend any session of interest</b>	
	<b>GROUSE</b>	Paseo Room
	<b>Observational Studies</b>	Troost Room
	<b>Prospective Surveys</b>	Brush Creek Room
<b>12:00 pm – 1:00 pm</b>	<b>Working Lunch</b>	Town Square
	We will use this time to break into groups and give individualized attention to each pilot. Please note the location for discussion of each pilot marked by signs on the tables.	

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<b>1:00 pm – 2:00 pm</b>	<b>Breakout Sessions – Please discuss what we learned from the investigators. What do they want? What problems exist? When would CRGs play a role? If you do not fit into a targeted group please attend any session of interest.</b>	
	<b>IRB Group</b>	Town Square
	<ul style="list-style-type: none"> <li>Targeted Attendees: IRB members and anyone interested</li> </ul>	
	<b>Site PIs</b>	Paseo Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Site PIs and anyone interested</li> </ul>	
	<b>Patient Advisory Council and Engagement Officers</b>	Troost Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Patient Advisors, Engagement Officers, and anyone interested</li> </ul>	
	<b>Data Teams, Honest Brokers and Project Managers</b>	Brush Creek Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Data team members</li> </ul>	

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<b>2:10 pm – 3:10 pm</b>	<b>Breakout Sessions – Participants are welcome to attend any session of interest</b>	
	<b>ALS Cohort Meeting</b>	Paseo Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: ALS cohort members and others who are interested</li> </ul>	
	<b>Breast Cancer Cohort Meeting</b>	Troost Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Breast Cancer cohort members and others who are interested</li> </ul>	
	<b>Height/Weight Cohort Meeting</b>	Brush Creek Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Height/Weight cohort members and others who are interested</li> </ul>	

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<b>3:10 pm – 3:30 pm</b>	<b>Break</b>	Town Square
	Drinks (water and soda) and cookies	

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<b>3:30 pm – 4:30 pm</b>	<b>Breakout Sessions – Participants are welcome to attend any session of interest</b>	
	<b>Patient Advisory Council and IRB Meeting</b>	Paseo Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Patient Advisors, Engagement Officers, and IRB members</li> </ul>	
	<b>People Centered Research Foundation/GPC 3.0 and Transition Post-Contract (Sustainability)</b>	Troost Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: Site PIs</li> </ul>	
	<b>ADAPTABLE Meeting</b>	Brush Creek Room
	<ul style="list-style-type: none"> <li>Targeted Attendees: ADAPTABLE Team Members &amp; Data Teams</li> </ul>	

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<b>4:40 pm – 5:15 pm</b>	<b>Guest Speaker – Cherie Binns from Multiple Sclerosis Patient Powered Research Network</b>	Town Square
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<b>5:15 pm – 6:30 pm</b>	<b>Break</b>	Hotels
	Return to hotels and get ready for dinner.	

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<b>6:30 pm – 8:30 pm</b>	<b>Dinner</b>	Brio Tuscan Grill
	Dinner will begin with drinks and socializing, followed by a buffet-style dinner starting at 7:00 pm.	

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# TUESDAY AGENDA

## 2017 Learning Engagement Conference

October 17, 2017

7:30 am – 12:00 pm

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<b>7:30 am – 8:00 am</b>	<b>Breakfast (Provided)</b>	Town Square
	Help yourself to some coffee, bagels and fruit, meet and greet other attendees, and get ready for day two!	
<b>8:00 am – 9:30 am</b>	<b>Breakout Sessions – Participants are welcome to attend any session of interest</b>	
	<b>IRB Group Meeting</b>	Paseo Room
	<ul style="list-style-type: none"><li>Targeted Attendees: IRB Members</li></ul>	
	<b>Patient Advisory Council and Engagement Officer / Site PI Meeting</b>	Troost Room
	<ul style="list-style-type: none"><li>Targeted Attendees: Patient Advisors, Engagement Officers, and Site PIs</li></ul>	
<b>9:30 am – 10:00 am</b>	<b>Break</b>	Town Square
	Help yourself to some refreshments	
<b>10:00 am – 11:15 am</b>	<b>Breakout Sessions – Participants are welcome to attend any session of interest</b>	
	<b>Site PI and IRB Meeting</b>	Paseo Room
	<ul style="list-style-type: none"><li>Targeted Attendees: Site PIs and IRB members</li></ul>	
	<b>Patient Engagement Meeting</b>	Troost Room
	<ul style="list-style-type: none"><li>Targeted Attendees: Patient Advisors and Engagement Officers</li></ul>	
	<b>Supporting Pilots, CRGs and Other Opportunities</b>	Brush Creek Room
	<ul style="list-style-type: none"><li>Targeted Attendees: Those currently involved with the CRGs or who would like to be involved, Pilot awardees, and anyone interested</li></ul>	

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**Thank you to all of our GPC Patient Partners and Patient  
Representatives!**

We could not do this work or hold this event without you! Your hard work and dedication to Patient-Centered Outcomes Research are greatly appreciated, and we are looking forward to all of the exciting things to come in the rest of Phase II of the Greater Plains Collaborative!

**Another thank you to our host – the Kauffman Foundation!**

Ewing Marion

**KAUFFMAN**  
Foundation

[www.kauffman.org](http://www.kauffman.org)

[www.gpcnetwork.org](http://www.gpcnetwork.org)

[www.pcornet.org](http://www.pcornet.org)

## BREAKOUT SESSION DESCRIPTIONS:

### Monday 8:00AM-8:30AM

- **Introduction**
  - **Presenting:** Russ Waitman
  - **Who:** Everyone
  - **What:** This session will provide an overview of the conference, and also recent accomplishments of the GPC. Our goal this year is to make the pilots successful and pave the way for future researchers using the GPC.

### Monday 8:40AM-10:10AM

- **Poster Walk**
  - **Presenting:** Pilot Program awardees, along with leaders of cohorts and various current GPC studies
  - **Who:** Everyone
  - **What:** The GPC has recently awarded six pilots across our institutions to use the network to create stronger national proposals. This poster walk is an opportunity to interact with these investigators and for the investigators to interact with patients and GPC site team members, including regulatory officials, to strengthen their proposals. There will also be posters on other GPC study activities and capabilities.

### Monday 10:30AM-12:00PM

- **GROUSE**
  - **Presenting:** Russ Waitman and Dan Connolly
  - **Who:** Anyone who is interested
  - **What:** GROUSE is the GPC reusable study environment that includes MC, MA and claims data along with data from each site's tumor register, EHR, and billing systems. Several pilots have been awarded that will make use of GROUSE. This session will look at the status of the infrastructure and how we can make sure the infrastructure and data can support these pilots and larger studies.
- **Observational Studies**
  - **Presenting:** Elizabeth Chrischilles, Bradley Taylor, and Tamara McMahon
  - **Who:** Anyone who is interested
  - **What:** Other studies seek to use information from other sites and supplement them with additional data such as provider information, clinical

service departments, nursing observations, and free text notes. This session will explore how to support these studies.

- **Prospective Surveys**

- **Presenting:** Alex Bokov, Jim McClay, and Cheryl Jernigan
- **Who:** Anyone who is interested
- **What:** Several pilots seek to build upon the work the GPC did in Phase 1 with surveying our patients for ALS, Breast Cancer, and Height/Weight. This session will focus on how to support the pilots that seek to survey our patients (and/or providers) again.

### Monday, 12:00PM-1:00PM

- **Working Lunch**

- **Presenting:** Pilot Awardees
- **Who:** Everyone
- **What:** We will use this time to break into groups and give individualized attention to each pilot. Please note the location for discussion of each pilot marked by signs on the tables. We would like each pilot to have people from a variety of teams at their table.

### Monday 1:00PM-2:00PM

- **IRB Group**

- **Presenting:** Mike Bingham
- **Who:** IRB members and anyone interested
- **What:** This session will be to discuss what has been learned from the Pilot Program investigators. What do they want? What problems exist? When would CRGs play a role? Common rule updates will also be discussed

- **Site PIs**

- **Presenting:** Russ Waitman and Jim McClay
- **Who:** Site PIs and anyone interested
- **What:** This session will be to discuss what has been learned from the Pilot Program investigators. What do they want? What problems exist? When would CRGs play a role?

- **Patient Advisory Council and Engagement Officers**

- **Presenting:** Kim Kimminau and Cheryl Jernigan
- **Who:** Patient Advisors, Engagement Officers, and anyone interested
- **What:** This session will be to discuss what has been learned from the Pilot Program investigators. What do they want? What problems exist? When would CRGs play a role? Do you see opportunities to help enhance engagement for the pilots?

- **Data Teams, Honest Brokers, and Project Managers**

- **Presenting:** Dan Connolly and Tamara McMahon
- **Who:** Data Teams, Honest Brokers, Project Managers, and anyone interested
- **What:** This session will be to discuss what has been learned from the Pilot Program investigators. What do they want? What problems exist? When would CRGs play a role? Of the pilots that have been awarded, how many are well within scope versus ambitious?

## **Monday 2:10PM-3:10PM**

- **ALS Cohort Meeting**

- **Presenting:** Richard Barohn and Laura Herbelin
- **Who:** ALS Cohort members and anyone interested
- **What:** This session will be to discuss updates and plans for the ALS Cohort in Year 3, as well as proposed ALS studies with the National Institutes of Health

- **Breast Cancer Cohort Meeting**

- **Presenting:** Betsy Chrischilles
- **Who:** Breast Cancer Cohort members and anyone interested
- **What:** This session will be to discuss updates and plans for the Breast Cancer Cohort in Year 3 including goals, specific steps, and timeline for future work, as well as grant ideas and the status of manuscripts. There will also be a Rapid-Cycle Research study update.

- **Height/Weight Cohort Meeting**

- **Presenting:** Ann Davis
- **Who:** Height/Weight Cohort Meeting and anyone interested
- **What:** This session will be to discuss the ongoing work in the Height/Weight Cohort. There will be a review of missing data, site by site, and answers for any questions IT experts have to help them to enter the remaining missing/incomplete data. The team also has two papers in progress (a protocol paper and an outcomes paper), and the remaining time will be spent discussing the two papers and moving them closer to submission.

## **Monday 3:30PM-4:30PM**

- **Patient Advisory Council and IRB Meeting**

- **Presenting:** Kim Kimminau, Cheryl Jernigan, and Mike Bingham
- **Who:** Patient Advisors, Patient Engagement Officers, and IRB members
- **What:** Patient Advisors and IRB representatives will discuss ideas for making consent templates more patient-centered. Specifically, the group will talk about the new “concise



summary” requirement of the updated common rule. Common IRB definitions will also be discussed.

- **People Centered Research Foundation/GPC 3.0 and Transition Post-Contract (Sustainability)**
  - **Presenting:** Russ Waitman and Steve Fennel
  - **Who:** Site PIs
  - **What:** PCORnet funding ends in September, 2018, and PCORI has funded the creation of the People Centered Research Foundation (PCRF) which was initiated in 2017. We will discuss how the GPC and its member institutions will complete their applications to the Foundation, and how we transition as a network after the end of the contract in September 2018.
- **ADAPTABLE Meeting**
  - **Presenting:** Danielle Riley, Sravani Chandaka, and Michele Countryman
  - **Who:** ADAPTABLE Team Members and Data Teams
  - **What:** This session will discuss current work on ADAPTABLE including Data Team work as well as some relevant IRB topics.

### Monday 4:40PM-5:15PM

- **Guest Speaker – Cherie Binns from Multiple Sclerosis Patient Powered Research Network**
  - **Presenting:** Cherie Binns
  - **Who:** Everyone
  - **What:** “The Engagement Talk” – Cherie will speak about how the iConquerMS Patient Powered Research Network (PPRN) engages their members, what they have to offer to the research community, and how they do research differently. She will also talk about the benefits of partnering with a PPRN to meet our engagement goals.

### Tuesday 8:00AM-9:30AM

- **IRB Group Meeting**
  - **Presenting:** Mike Bingham
  - **Who:** IRB members
  - **What:** This session will be a continuation of the discussion from Monday’s 1:00PM meeting regarding the Pilot Program. Strategies moving forward will also be discussed.
- **Patient Advisory Council and Engagement Officer / Site PI Meeting**
  - **Presenting:** Kim Kimminau, Cheryl Jernigan, Russ Waitman, and Jim McClay

- **Who:** Patient Advisors, Engagement Officers, and Site PIs
- **What:** This session will discuss GPC structure and sustainability going forward, including cultivating projects with our investigators working with CTSA's and potentially adding new partners. Maureen Smith will also be giving a brief presentation on the quantitative results of the PCORI Health System Demonstration Project and possible next steps.

## Tuesday 10:00AM-11:15AM

- **Site PI and IRB Meeting**

- **Presenting:** Mike Bingham
- **Who:** Site PIs and IRB members
- **What:** The focus on this session will revolve around the use of SMART IRB and tools that have been developed by the SMART IRB team to assist study teams.

- **Patient Engagement Meeting**

- **Presenting:** Kim Kimminau, Cheryl Jernigan, and Maureen Smith
- **Who:** Patient Advisors and Patient Engagement Officers
- **What:** In the first half of this meeting, Maureen Smith will be presenting to obtain feedback on the results of a survey of case management programs across all GPC and SCILHS sites. These data were collected as part of Dr. Smith's PCORnet Health System Demonstration project, "Variation in case management programs and their effectiveness in managing high-risk patients for Medicare ACOs." The second half of the session will be used to brainstorm strategies and suggestions as follow-up to the "concise summary" IRB discussion from Monday's joint PEO/PAC/IRB session.

- **Supporting Pilots, CRGs, and Other Opportunities**

- **Presenting:** Brad McDowell, Dan Connolly, Tamara McMahon, Mei Liu, and others involved in the Collaborative Research Groups
- **Who:** Those currently involved with the CRGs or who would like to be involved, Pilot awardees, and anyone interested
- **What:** This will be a working session for Pilot awardees, CRGs, and other groups. The discussion will center around questions such as: How will we accomplish what they are asking for? What will we need? What are some barriers and solutions to being able to support pilot studies and rapid-cycle research? What is achievable for us?

## Tuesday 11:30AM-12:00PM

- **Closing Session with Comments from PCORI**

- **Presenting:** Russ Waitman and Maryan Zirkle
- **Who:** Everyone

- **What:** The closing session will provide a recap of what has been accomplished during this conference, as well as provide some feedback and comments from Maryan Zirkle of PCORI.