



WEDNESDAY AGENDA

2019 Learning Engagement Conference / Hackathon

October 2, 2019

12:00 pm – 5:30 pm

12:00 pm – 1:00 pm	Lunch (optional) and Registration	Town Square
	Please register at the front desk and get your meeting materials prior to the opening session. Optional lunch provided for those who indicated they would like one on their registration.	
1:00 pm – 1:45 pm	Welcome Session	Town Square
	Welcome and introduction to the 2019 Learning Engagement Conference by Russ Waitman	
1:45 pm – 2:30 pm	Guest Speaker – Donna Cryer	Town Square
	Donna will share with us from her perspective with the People Centered Research Foundation	
2:30 pm – 2:45 pm	Break	Town Square
	Help yourself to some refreshments	
2:45 pm – 4:00 pm	Breakout Sessions – Participants are welcome to attend any session of interest	
	Engagement Bootcamp	Troost Room
	<ul style="list-style-type: none"> Targeted Attendees: Patient Advisors, Patient Engagement Officers, and anyone interested 	
	Site PIs & Hackathon	Brush Creek Room
	<ul style="list-style-type: none"> Targeted Attendees: Site PIs, Dev team members, and anyone interested 	
	IRB Group	Paseo Room
	<ul style="list-style-type: none"> IRB members 	

4:00 pm – 5:30 pm	Poster Walk	Breakout Rooms
	Posters will be hung in the breakout rooms so please take this time either individually or in small groups to walk around and view any posters you are interested in as well as discuss and ask questions of the presenter(s).	
5:30 pm – 6:30 pm	Break	Hotels
	Return to hotels and get ready for dinner.	
6:30 pm – 8:30 pm	Dinner	Brio Tuscan Grille
	Dinner will begin with drinks and socializing at 6:30 pm, followed by a buffet-style dinner starting at 7:00 pm.	



THURSDAY AGENDA

2019 Learning Engagement Conference / Hackathon

October 3, 2019

7:30 am – 4:30 pm

7:30 am – 8:00 am	Breakfast (Provided) Please sign in at the front desk, and then help yourself to some coffee, bagels and fruit, meet and greet other attendees, and get ready for day two!	Town Square
8:00 am – 9:15 am	Breakout Sessions – Participants are welcome to attend any session of interest Engagement from the Field #1 (UNMC, Iowa, UT Southwestern, Marshfield, Allina) <ul style="list-style-type: none">Targeted Attendees: Patient Advisors, Patient Engagement Officers, and anyone interested Cancer Tumor Registry Data Integration <ul style="list-style-type: none">Targeted Attendees: Dev team members and anyone interested IRB Group <ul style="list-style-type: none">Targeted Attendees: IRB members Sustainability of GPC in relation to PCORnet and NIH CTSA's and Funds Flow <ul style="list-style-type: none">Targeted Attendees: Site PIs and anyone interested	Troost Room Brookside Room Paseo Room Brush Creek Room
9:15 am – 10:00 am	Break & Table Topics <ul style="list-style-type: none">Help yourself to some refreshments and join a group at any table to learn more about their role in the GPC	Town Square

10:00 am – 12:00 am	Breakout Sessions – Participants are welcome to attend any session of interest	Troost Room
	Sharing Session with the People Centered Research Foundation	
	<ul style="list-style-type: none"> Targeted Attendees: Patient Advisors, Patient Engagement Officers, and anyone interested 	
	Honest Broker Tool and GROUSE	Brookside Room
	<ul style="list-style-type: none"> Targeted Attendees: Dev team members, Honest Brokers, and anyone interested 	
	IRB Group	Paseo Room
	<ul style="list-style-type: none"> Targeted Attendees: IRB members 	
	Proposal Development	Brush Creek Room
	<ul style="list-style-type: none"> Targeted Attendees: Site PIs and anyone interested 	
12:00 pm – 1:00 pm	Lunch	Town Square
1:00 pm – 2:15 pm	Breakout Sessions – Participants are welcome to attend any session of interest	
	Engagement from the Field #2 (MCW, Missouri, Indiana, Utah, KUMC)	Troost Room
	<ul style="list-style-type: none"> Targeted Attendees: Patient Advisors, Patient Engagement Officers, and anyone interested 	
	Hackathon	Brookside Room
	<ul style="list-style-type: none"> Targeted Attendees: Dev team members and anyone interested 	
	IRB Group	Paseo Room
	<ul style="list-style-type: none"> Targeted Attendees: IRB members 	
	Continuation of Proposal Development	Brush Creek Room
	<ul style="list-style-type: none"> Targeted Attendees: Site PIs and anyone interested 	
2:15 pm – 2:45 pm	Break & Walk with Group Leader	Town Square
	<ul style="list-style-type: none"> Help yourself to some refreshments & head outside for a walk with one of the group leaders to learn more about what they do with the GPC. 	

2:45 pm – 4:00 pm

Breakout Sessions – Participants are welcome to attend any session of interest

The “Price is Right” for Engagement

Troost Room

- Targeted Attendees: Patient Advisors, Patient Engagement Officers, and anyone interested

Proposal / Business Development & Hackathon

Brush Creek Room

- Targeted Attendees: Site PIs, Dev team members, and anyone interested

IRB Group

Paseo Room

- Targeted Attendees: IRB members

4:00 pm – 4:30 pm

Closing Statement

Town Center

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

www.gpcnetwork.org

www.pcornet.org

BREAKOUT SESSION DESCRIPTIONS:

Wednesday 1:00PM-1:45PM

- **Introduction**
 - **Presenting:** Russ Waitman
 - **Who:** Everyone
 - **What:** Welcome and introduction to the 2019 Learning Engagement Conference by Russ Waitman

Wednesday 1:45PM-2:30PM

- **Guest Speaker – Donna Cryer with PCRFB**
 - **Presenting:** Donna Cryer
 - **Who:** Everyone
 - **What:** We are very excited to have Donna Cryer from the People Centered Research Foundation join us for the LEC this year. In this session Donna will share with us from her perspective with the PCRFB.

Wednesday 2:45PM-4:00PM

- **Engagement Bootcamp**
 - **Presenting:** Kim Kimminau
 - **Who:** Patient Advisors, Patient Engagement Officers, and anyone interested
 - **What:** This session will orient everyone to the engagement work we have done to date and what we plan for our future. To begin, we'll share a brief history of the Greater Plains Collaborative and we'll talk about how the roles of site engagement officers and patient advisors have evolved – basically, why we're organized the way we are today. Then, Dan Connoly, Biomedical Informatics Software Engineer, will join us to explain the Common Data Model and describe how all of the data from each of our sites gets organized for research. During this session, we'll be doing an exercise called "1-2-4 All" that will help us individually and collectively raise questions about the data and how and who is accessing the data. By the end of this session, everyone will have learned some important facts about health data and we will have raised important questions for us to plan and work on together.
- **Site PIs & Hackathon**

- **Presenting:** Russ Waitman & Dan Connolly
- **Who:** Site PIs, Dev team members, and anyone interested
- **What:** Review of current development activities and plans for the coming year as aligned with sustainability. For example, what key infrastructure components do we see as highly attractive to investigators to use the GPC that are not currently available, like notes and natural language processing.
- **IRB Group**
 - **Presenting:** Sarah Mumford
 - **Who:** IRB members
 - **What:** With the increase in multi-center EFIC trials, local institutions are expected to provide guidance and oversight for community consultation plans. In this session we will discuss the regulatory requirements and literature review and work together to develop ideas and requirements for local site community consultation plans.

Wednesday 4:00PM-5:30PM

- **Poster Walk**
 - **Presenting:** Various current GPC studies, capabilities, and groups
 - **Who:** Everyone
 - **What:** Various GPC studies, capabilities, and groups will present posters in the breakout rooms for review and discussion. Please feel free to move around and stop at any posters that interest you either individually or as a small group.
 - **For New Engagement Team Members:** If you have never been to a poster session, no worries! PAC and PEO members will go around to the posters as a group to encourage a facilitated discussion with the poster presenter(s). This is a chance to “translate” and share as well as to offer the presenter(s) a patient and community perspective on their GPC-related topic.

Thursday 8:00AM-9:15AM

- **Engagement from the Field #1 (UNMC, Iowa, UT Southwestern, Marshfield, and Allina)**
 - **Presenting:** Patient Engagement Officers
 - **Who:** Patient Advisors, Patient Engagement Officers, and anyone interested
 - **What:** What are GPC engagement members doing at their local site? Come to hear what five partner sites have to share with us! Each partner site has about 10 minutes to share highlights from their site for us all to learn what they do and how they accomplish engagement. Come prepared to learn, get access to shareable resources, and to ask questions.

- **Cancer Tumor Registry Data Integration**
 - **Presenting:** Dan Connolly
 - **Who:** Dev team and anyone interested
 - **What:** The NAACCR ETL process used at KUMC and other GPC sites to load cancer tumor registry data into i2b2 is **outdated by NAACCR version 18**. Addressing this issue presents an opportunity to reconsider our platform and approach, a goal since February 2014.
- **IRB Group**
 - **Presenting:** Sarah Mumford
 - **Who:** IRB members
 - **What:** During this session we will discuss lessons learned and best practices related to single IRB review. We will share the perspectives of both reviewing and relying institutions and discuss the operational processes for reviewing IRBs.
- **Sustainability of GPC in relation to PCORnet and NIH CTSA's and Funds Flow**
 - **Presenting:** Russ Waitman
 - **Who:** Site PIs and anyone interested
 - **What:** Review PCORnet business development status and funds flow at the national level relative to GPC pricing and funds flow recently developed by KUMC admin team. What do we propose we will change? What do we think the average project will be: query analysis, datasets for non-profit investigators, prospective trial recruitment, GROUSE use of integrated GPC claims and EHR environment? How will we manage the pricing model?

Thursday 9:15AM-10:00AM

- **Break & Table Topics**
 - **Presenting:** Group Representatives
 - **Who:** Everyone
 - **What:** Help yourself to some refreshments and join a group at any table to learn more about their role in the GPC. Feel free to move between tables and meet with multiple groups.

Thursday 10:00AM-12:00PM

- **Sharing Session with the People Centered Research Foundation**
 - **Presenting:** Donna Cryer and Kim Kimminau
 - **Who:** Patient Advisors, Patient Engagement Officers, and anyone interested

- **What:** We're very glad to have Donna Cryer from the PCRF joining us at the LEC. This session will begin with brief comments from our guests about the vision for PCORnet and the Foundation. We will then do a group exercise called "TRIZ" to generate and organize concerns and sources of inspiration that can inform the direction PCRF might consider taking to grow and deepen the value of engagement for PCORnet and beyond.
- **Honest Broker Tool and GROUSE**
 - **Presenting:** Dan Connolly
 - **Who:** Dev team members, Honest Brokers, and anyone interested
 - **What:** Demonstration of MCW Honest Broker tool. Then we'll discuss the annual GROUSE refresh where each site contributes data from their health system electronic health record (EHR) system for integration with claims data from Medicare and Medicaid, as well as plans to exploit the intergrated data to assess feasibility of research studies.
- **IRB Group**
 - **Presenting:** Sarah Mumford
 - **Who:** IRB members
 - **What:** During this session we will talk about IRB coordination services for single IRB review and what activities relying and reviewing IRBs should expect to be the responsibility of the IRB vs. the study team. During this "double session", we will also discuss IRB metrics and opportunities for collaboration.
- **Proposal Development**
 - **Presenting:** Russ Waitman and Site PIs – Collaborative Session
 - **Who:** Site PIs and anyone interested
 - **What:** Each Site PI is expected to bring 1-2 projects for discussion and development. Where do you need help and were are potential collaborators? It is highly encouraged to prepare a poster for the poster walk for your proposed project.

Thursday 1:00PM-2:15PM

- **Engagement from the Field #2 (MCW, Missouri, Indiana, Utah, KUMC)**
 - **Presenting:** Patient Engagement Officers
 - **Who:** Patient Advisors, Patient Engagement Officers, and anyone interested
 - **What:** What are GPC engagement members doing at their local site? Come to hear what five partner sites have to share with us! Each partner has about 10 minutes to share highlights from their site for us all to learn what they do and how they accomplish engagement. Come prepared to learn, get access to shareable resources, and to ask questions.
- **Hackathon**

- **Presenting:** Dan Connolly
- **Who:** Dev team members and anyone interested
- **What:** Refining the gpc-dev roadmap: negotiating schedules for informatics work. Discussion of maintaining a PCORnet CDM datamart at each site: challenges/gaps, wins, and lessons learned.
- **IRB Group**
 - **Presenting:** Sarah Mumford
 - **Who:** IRB members
 - **What:** This will be a session of “IRB Potpourri” with a focus on best practices and learning from each other. This will be an opportunity for participants to discuss specific cases and issues that have arisen at their IRB and describe how they handled or solved the issue or ask the group for advice.
- **Continuation of Proposal Development**
 - **Presenting:** Russ Waitman and Site PIs – Collaborative Session
 - **Who:** Site PIs and anyone interested
 - **What:** Continuation of previous session. Each Site PI is expected to bring 1-2 projects for discussion and development. Where do you need help and where are potential collaborators? It is highly encouraged to prepare a poster for the poster walk for your proposed project.

Thursday 2:15PM-2:45PM

- **Break & Walk with Group Leader**
 - **Presenting:** Group Representatives
 - **Who:** Everyone
 - **What:** Help yourself to some refreshments & head outside for a walk with one of the group leaders to learn more about what they do with the GPC. **(weather permitting)**

Thursday 2:45PM-4:00PM

- **The “Price is Right” for Engagement**
 - **Presenting:** Kim Kimminau
 - **Who:** Patient Advisors, Patient Engagement Officers, and anyone interested
 - **What:** We will focus on working together to build a concrete plan for pricing engagement and engagement services that can be considered as PCRf and the Network expands to include

new academic and business partners. In earlier sessions, we will have heard how different sites cover the costs for engagement with patients, families, community organizations, and others who can contribute to infusing lived experience into the work of PCORnet. We can take these ideas and shape approaches that we agree honor the time, commitment, and effort necessary for authentic and meaningful engagement.

- **Proposal / Business Development & Hackathon**

- **Presenting:** Russ Waitman & Dan Connolly
- **Who:** Site PIs, Dev teams, and anyone interested
- **What:** Review GPC business development and pricing model against proposals people are developing in GPC and how does that match with the infrastructure development activities of GPC dev teams. For example, are there certain activities or tempo or work we may want to adjust in a leaner funding model?

- **IRB Group**

- **Presenting:** Sarah Mumford
- **Who:** IRB members
- **What:** During this session we will discuss the Local Context Review process as a relying institution. We will consider regulatory and institutional requirements and ways to harmonize processes.

Thursday 4:00PM-4:30PM

- **Closing Session**

- **Presenting:** Russ Waitman
- **Who:** Everyone
- **What:** Take-aways, final thoughts, and next steps from the 2019 Learning Engagement Conference and Hackathon.

Cancer CRG Meeting Agenda

Time	Topic	Presenter(s)
7:30am	Registration	
8:00am	Welcome and introductions	Betsy Chrischilles and Betsy Shenkman
8:15am	<p>Informatics and the Cancer CRG</p> <p>Informatics resources will be reviewed, including a RXCUI-based computational phenotype for chemotherapy, PCORnet reusable tools, and specifications for an optional tumor table for the CDM.</p>	Ryan Carnahan, Keith Marsolo, and Brad McDowell
8:45am	<p>Identification of Rare Autoimmune Events following administration of Immunotherapy Drugs (IRAE-ID)</p> <p>A pilot study supported by the Cancer CRG</p>	Theresa Walunas
9:15am	Break	
9:30am	<p>Real-World Endpoints</p> <p>Friends of Cancer Research is evaluating how real-world evidence can be used to fill knowledge gaps in cancer treatments.</p>	Mark Stewart
10:00am	<p>Intersection of cardiovascular and cancer research</p> <p>A project to evaluate cardiotoxicities related to cancer therapies in real-world clinical practice settings and evaluate the adoption rate of clinical guidelines</p>	Yan Gong
10:30am	Discussion	
11:00am	<p>Break into small workgroups</p> <ul style="list-style-type: none"> • Immunotherapy • Cancer and cardiac health • Others? 	
11:50am	Next steps	
12:00pm	Lunch	
1:00pm and on	LEC sessions (see LEC agenda) and opportunities for side discussions	