



## Greater Plains Collaborative Rapid Community and Patient Engagement (GPC Rapid PACE) Resource

### **Purpose and Background:**

The GPC Rapid Community and Engagement (Rapid PACE) Resource consists of trained *patient research advocates* from diverse communities across all participating GPC sites (visit <http://www.gpcnetwork.org/?q=AboutUs> for a list of participating organizations and institutions). The term “*patient research advocate*” means these individuals have experience as patients, caregivers and community leaders. They bring their patient experiences and insights into the research process. They are familiar with research approaches and methods and value research that advances evidence-based medicine to improve people’s health. They understand research advocacy is not about patient care *today* – it’s about supporting research to improve care for patients in the future. Their lived experience and network with other patients and caregivers provide unique perspectives and insights to better inform research and collaborate with researchers. These individuals are members of GPC’s Patient Advisory Council (PAC).

The GPC Rapid PACE resource was created to provide easy access to patient input during all stages of research. This multi-site, novel approach is a quick way for researchers to get patient research advocates’ perspectives on their project’s development, implementation, and/or dissemination. The GPC Rapid PACE is valuable to all researchers at any stage in their career or at any point during a research project. This service is available to those using GPC informatics resources. As a PCORnet-funded project and because it’s the “right thing to do”, the GPC expects all investigators to engage with stakeholders. Whether this is accomplished through local engagement or through the GPC Rapid PACE resource is the prerogative of the investigator and/or their local site/institutional sponsor.

The GPC Rapid PACE is a way to receive immediate, real-time feedback with patient research advocates who can offer their lived experiences and community perspectives. Summary notes of the conversation will be sent approximately 5-8 workdays following the session.



Meeting with the GPC Rapid PACE team may occur:

- before a research project is submitted for consideration.
- if local patient/family/caregiver/community engagement resources are unavailable before an approved study begins.
- during a study when feedback could be informative in achieving a study's aims.  
For example, if recruitment is lagging, Rapid PACE can brainstorm possible approaches to improve outreach and retention.
- prior to disseminating study findings.  
For example, the Rapid PACE team can review lay abstracts, or react to a draft poster or oral presentation to improve accessibility and understanding for diverse audiences.

To access the GPC Rapid PACE resource, the researcher/research team must schedule a time to present their study using a prescribed, formatted set of PowerPoint slides. The Rapid PACE session is conducted online using video conferencing (with cameras activated). This improves communication by allowing everyone to be connected visually, as well as by voice. Rapid PACE patient research advocates may participate by telephone only if they do not have computer access. Video conferencing is always preferred.

The GPC Rapid PACE process can help provide the following:

- prioritize research topics
- recommend and/or assist in selecting patient-reported outcomes
- inform research strategy to increase acceptability of methods and requirements needed to engage stakeholders
- increase the relevance of the study to patients and their communities
- strengthen recruitment and retention efforts
- provide input to enhance dissemination materials' relevance and interest to patients and communities, thereby increasing dissemination and acceptance of study results



The GPC Rapid PACE also can respond to a variety of patient research and engagement requests including providing a letter of support for an application, identifying individual research advocate partners, mentoring opportunities, or other support as needed.

**GPC Rapid PACE Participants:**

A minimum of three and maximum of eight GPC Patient Advisory Council (PAC) members must be available to participate in a GPC Rapid PACE session. It is anticipated there will be approximately one to two meetings per month (The frequency of meetings is based on the number of requests received.) All GPC PAC members will receive an email describing the study topic and inviting them to volunteer for a scheduled session. Virtual “seats” will be filled on a first-come basis up to the maximum of eight participants.

GPC Rapid PACE members who are scheduled to participate must give the GPC project manager 24-hours’ notice if they are unable to attend a session. This allows time to find an alternate, or to cancel and reschedule the session. Members of the GPC Patient Engagement Officer (PEO) group will be courtesy copied when one of their site’s PAC members agrees to participate on a GPC Rapid PACE panel.

The University of Kansas Medical Center GPC engagement core will be provided a \$25 remuneration to each GPC Rapid PACE member participant per session. Payments will be made to participants on a quarterly basis.

Each GPC Rapid PACE member agrees to the following:

1. Be mentored by GPC leadership, assigned mentors and/or local engagement support (PEO) staff, as needed.
2. Has a desire to learn about research and the use of big data.
3. Has good listening and verbal communication skills.
4. Is willing to share his or her lived experiences that inform the research study.
5. Attend annual Learning Engagement Conference trainings to develop, maintain and strengthen their engagement skills.



6. Complete the after-panel evaluation.
7. Quickly (within 2-3 business days) review and share their feedback on the session's summary notes to allow the notes to be shared quickly with the research team.

New GPC PAC members (those who have served for less than one year and/or have not attended an annual GPC Learning Engagement Conference) may attend one Rapid PACE session in listen-only mode to learn and observe how sessions are conducted before volunteering to actively participate in a session.

**GPC Rapid PACE Researcher's Presentation and Format:**

Each Rapid PACE session will not exceed one hour. If the team needs more time for discussion, an additional Rapid PACE session will be scheduled.

The GPC Rapid PACE session will be facilitated by one or more members of the KUMC GPC engagement team to ensure the allocated time for each session is adhered to and all participants have a chance to respond and provide input. The KUMC GPC engagement team:

- will provide guidance to the research team and review their slides prior to a scheduled GPC Rapid PACE session and
- will moderate sessions and take notes that will be shared with all participants and presenting research team.

The researcher/research team will give a brief oral presentation (no more than 10 minutes) about their project augmented by PowerPoint slides. This will outline the specific request they have for the GPC Rapid PACE participants. The researcher will use plain language, avoiding acronyms and research jargon. After the presentation, the researcher will hear the advocates' reactions, answer questions and discuss the project, as needed.

Directions for scheduling a GPC Rapid PACE session can be found at:

<http://www.gpcnetwork.org/?q=ResearcherResources>.



Investigators are required to submit PowerPoint slides to the KUMC GPC engagement coordinator at least three business days in advance of their scheduled Rapid PACE session. The slides will be shared electronically with the research advocates participating in the session. A model slide deck is available at <http://www.gpcnetwork.org/?q=ResearcherResources>.

**Slides:**

*Slide 1: Title*

This slide should include the title of study (with a lay title, if needed), researcher name, researcher/department/institution, and date.

*Slide 2: Research Proposal*

A brief statement describing the research study. Specifically state why the research is needed and how it could impact patients. For instance, how may it increase understanding and advance care for those with a specific condition or disease, etc.

*Slide 3: The Request or Focus for the Session*

Discuss what the researcher/research team is specifically requesting from GPC Rapid PACE session. If the request concerns a new project/proposal, include a statement about what are you trying to study and why it is important. If the request concerns some aspect of a current project, describe the feedback you seek (i.e., feedback on a newsletter format or survey questions). Use plain language and define terms likely to be unfamiliar with the audience of stakeholders participating in the Rapid PACE session.

Be specific about your “ask” for this session...what input you desire; and when or if you need any additional input following the session. For example, if the request concerns a new project/proposal, what aspect of the project are you seeking input on? For example, do you want clarification about the relevance of the research question? Do you want input into the various methods that could be used to answer the question? Do you want feedback on the protocol or design aspects of the study? If there is some current project phase or item you want the group to respond to, be sure to provide relevant documents separately or clearly describe the issue on this slide.



*Slide 4: What I Need Going Forward from GPC Related to Engagement*

Anticipate what your engagement needs from the project might be. For example:

- Will there be an additional request related to engagement at the local level or across the GPC?
- Do you need a letter of support from the Rapid PACE team?
- Are you asking for ongoing input from an individual patient(s) as a collaborator on your project?
- Include any other requests you would like the group to consider.

*Slide 5: Discussion (optional slide)*

If you need decisions or other information from the participants, discuss them on this slide. For example, if there are additional opportunities for the GPC Patient Advisory Council members to engage with the research team, include those here. Include a timeline reflecting those opportunities and any other requests you may have (for example, if you require a letter of support, who it should be sent to and a due date).

**What the Research Team Receives from GPC Rapid PACE Resource**

Beyond the patient-focused conversation, insights and reaction from the GPC Rapid PACE participants, the GPC engagement facilitator will take notes during the discussion for the research team. Notes will be emailed to the GPC Rapid PACE participants for any additional input prior to sending them on to the research team. This will be accomplished within 5-8 business days of the GPC Rapid PACE session.

Researchers will be asked to fill out a short, online evaluation immediately after each session to ensure the outcomes of the sessions meet expectations and can be continuously improved.

**How to request the GPC Rapid PACE Resource**

Complete a “GPC Rapid PACE Request Form” found at <http://www.gpcnetwork.org/?q=Collaboration>. Be sure to note when ideally you would like to schedule the Rapid PACE session. Completing the request will trigger a follow-up email from the GPC engagement coordinator to coordinate and confirm scheduling, and provide login and other logistics for the Rapid PACE appointment.