



Greater Plains Collaborative Patient Advisory Council (PAC) Handbook

Version I, 9/5/2025

This handbook describes the policies, procedures, benefits, and practices of GPC PAC membership and engagement opportunities.

PAC OVERVIEW

The Greater Plains Collaborative is a Clinical Research Network in PCORnet® which has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®).

GPC is a network with a shared vision of improving healthcare delivery through ongoing learning, adopting evidence-based practices, and supporting active research. Our GPC network brings together a diverse population of over 38 million patients across 1,550 miles covering 10 states with a combined area of 783,907 square miles. The GPC supports a variety of collaboration options for investigators, researchers, patients and communities, to ensure opportunities for engagement throughout the research development process.

The Greater Plains Collaborative Patient Advisory Council (PAC) is a group of patients and caregivers, (i.e. people with lived experience as survivors, previvors and/or co-survivors), that work with researchers, policymakers, and care providers to make sure patient and caregiver voices are heard and included in the design, conduct, and sharing of primary care research in community health center settings for the Greater Plains Collaborative.

PAC FACILITATION TEAM (PAC TEAM)

The PAC is coordinated and facilitated by a team of GPC patient partners and academic engagement specialists. This group reports directly to GPC leadership. We are available for any questions, feedback, or other PAC related input.

GPC Patient Co-Investigator:

GPC PAC Chairperson:

GPC PAC Vice-Chairperson:

GPC Engagement Lead:



PURPOSE OF THE GPC PAC

The goal of including patient partners as key personnel during Phase 4 of PCORnet is to:

- acknowledge the importance of the patient experience to inform the network,
- formally recognize the expertise of patients advising on the project, and
- ensure that patient stakeholders have equitable representation on the project.

As such, patient partners will serve as content experts and work with the GPC in a consultant capacity to review and advise on key network activities. These may include governance, policies and processes.

PAC PARTICIPATION and EXPECTATIONS

- **Attend at least 80% of the scheduled monthly PAC meetings.** Other sessions, outside of those meetings, will be scheduled. These include meetings with other GPC engagement groups, such as **the Institutional Research Ambassadors (formerly the PEO group)**. It is expected that PAC members will attend as many of these additional sessions as possible.
 - You will be paid \$60/hr. for each hour you participate in these meetings.
 - The PAC meets monthly at **TBD** over Zoom.
 - You will be sent any meeting materials (agenda, slides, consultation materials) at least 48 hours before the meeting.
 - If a meeting needs to be canceled for any reason, the PAC Team will notify you at least 48 hours in advance.
 - All meetings are recorded. If you are unable to attend a meeting, please let us know and we will provide the recorded version for your review. You will be compensated for your time (calculated based on the length of the recording).
- Attend annual informal check-in meeting with PAC Team
 - Scheduled at the end of each calendar year
 - These are opportunities to connect on an individual level with the PAC Team to discuss your thoughts about the PAC and your role. It also allows the PAC Team to learn about and specifically discuss your insights and thoughts about the PAC.
- Provide input for the **Engagement Evaluation** annually (2 parts)
 - One is a Quantitative survey administered by the PCORnet Project Management Office (PMO)
 - The other is an annual targeted discussion with a non-aligned GPC representative to assess the performance of the GPC leadership, including the PAC Facilitation Team, in providing establishing and maintaining engagement practices within the network.
- Patient Partners will provide their areas of interest and/or lived experience for a patient repository to be shared with GPC Leadership, GPC Research Readiness, and GPC Engagement Leadership/PAC Team. This information will be used to enable inclusion in research study teams developing projects for submission through the GPC.



- Patient Partners and GPC staff are expected to maintain timely communications with each other.
 - Emails and virtual meetings (using Microsoft Teams or Zoom) will be the primary forms of communication.
 - Patient Partners and GPC staff will be asked to check their emails daily and respond to consultation and other time-sensitive requests within 48 hours of the email being sent.
- If poor communication practices (e.g., not responding to requests or regularly attending meetings) become the norm, the Patient Partner will be directed to Member Coaching (see below) to resolve the situation.

PAC ENGAGEMENT OPPORTUNITIES

- Engagement opportunities that may arise through work within the GPC network may include:
 - Review network policies and provide guidance on both content and lay adaptations for the public when appropriate
 - Spearhead the development of multiple training initiatives for GPC stakeholders
 - Read and evaluate GPC research applications for patient-centeredness and patient engagement approaches
 - Participate in media and communication initiatives
- Externally funded project teams may seek PAC input outside of regularly scheduled PAC meetings, such as **Rapid Patient And Community Engagement (Rapid PACE)** sessions and/or additional engagement opportunities that may ask for patient input on various parts of a research project. (e.g., Letters of support, email consultation, focus group, or individual interviews).
 - GPC staff will send you additional engagement opportunities as our research partners request them.
 - The PAC team will send (email/mail) you any consultation materials 48 hours in advance of the meeting when available.
 - You decide whether to take part based on your availability or interest.
 - Your participation in these sessions will be compensated (\$60/hr.).
(Please see Addendum 1, PAC Consultation Activities, below.)



Greater Plains Collaborative

Engagement Meeting Norms

THE BASICS

Meeting Fundamentals:

- Start and end on time
 - Have an agenda and stick to it
 - Speak loudly and clearly; don't interrupt others
 - Trust one another
 - Maintain confidentiality
 - Use check-in introductions
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WHAT WE DO AND ASPIRE TO DO WELL

Respect and Communication

- **Treat each other with dignity and respect**
- **Practice transparency:** Avoid hidden agendas
- **Be genuine with each other** about ideas, challenges, and feelings
- **Trust each other:** Have and maintain the expectation that issues discussed will be kept in confidence
- **Practice open-mindedness**
- **Give colleagues the benefit of the doubt:** Rather than searching for fault, have a constructive mindset and assume positive intent

Leadership and Participation

- **Leaders are open, communicative, and authentic** with each other and the group
- **Leaders create safe spaces** where people have access to information and feel comfortable asking for what they need
- **Avoid territoriality:** Think of the overall good for the mutual cause(s) we have come together to advance

Problem-Solving and Decision-Making

- **Present problems constructively** in ways that promote mutual discussion and resolution
- **Practice thoughtful decision-making**
- **Recognize your role in the bigger picture:** Be responsible for understanding the whole picture, not just your individual part

Commitment and Accountability

- **Follow through on commitments:** If you commit to doing something, do it. Be accountable and responsible to the group
 - **Come prepared to meetings** to demonstrate value and respect for the time and convenience of others
 - **Strive to continuously improve** and achieve the group's strategic goals
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ACKNOWLEDGMENT

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MEMBER SUPPORT

GPC PAC leadership and staff value the unique perspectives, skills, expertise, and passion of each PAC member and will do all that we can to support your participation in our patient engagement. Members are encouraged to share their ideas, priority topics, or special interests with our PAC Team. Our goal is to collaborate with you on ways that we can help develop your research interests and skills in the GPC PAC or beyond. We also welcome member feedback on any aspect of the PAC and are open to ways we can continue to improve and innovate.

We encourage you to reach out to us (key contact information below) at any time by email, phone, Teams, Zoom call, or any other format you would prefer!

MEMBER COACHING

As part of our shared commitment to ensure our members, the PAC Team, and research partners can work together at their full potential, we have developed a coaching process to support PAC members through any areas of difficulty. Coaching is available either by member request or if the PAC Team determines whether a member would benefit from extra support in fulfilling their role. The PAC Team facilitators will work closely with any member through coaching to assess any issues and plan steps toward a solution. The overall process is:

1. **PAC member request for support:** You are welcome to reach out to any member of our PAC Team to request additional support at any time. We will meet with you individually to develop a plan, action items, and a timeline in order to establish a safe space for open dialogue about issues that may arise. Member requests could include, but are not limited to:
 - a. Language support for members whose primary language is not English or experiencing other language barriers
 - b. Cultural Sensitivity
 - c. Technology issues
 - d. Time commitment/schedule changes
2. **PAC Team request for coaching plan:** PAC Team members may recommend a coaching plan if they think it would benefit your ability to take part in the PAC meetings and engagement work. The PAC Team will reach out to you individually by email to set up a meeting time and initiate the coaching process as needed. They will identify any shared concerns or barriers to taking part in engagement work in the GPC and develop a plan with action items and a timeline to address them.
3. **Issues not resolved with a coaching plan:** If you or the PAC Team do not resolve issues or barriers through a coaching plan, we will:
 - a. Continue the coaching process to identify and eliminate any remaining barriers.
 - b. If this second time does not resolve the issue for all concerned, then one or more members of the PAC Team (your preference) will meet with you individually to discuss whether the PAC is still a good fit. If needed or desired, the contract between you, as the Patient Partner and the GPC may be terminated.

COMPENSATION

Our goal is to provide fair and consistent compensation while maintaining internal controls and compliance with Internal Revenue Service laws and grant funding regulations. Our standard rate for PAC activities is \$60/hour.

Compensation is provided through a reloadable bank card. We provide a “low risk”, annually renewable, plainly written contract that outlines what you (the patient partner) are required to do in the context of the Greater Plains Collaborative engagement work. That contract also clearly states the hourly remuneration and the process that is used for payment.

To improve timeliness and reduce paperwork, all patient partners are provided with a monthly log of the hours they have spent preparing for meetings, attending standing monthly meetings, attending Rapid PACE sessions, and completing assigned duties (i.e., sub-committees, gathering documents related to a particular topic, attending a training, etc.). The log is then sent by email and you are asked to check/modify/confirm and approve for payment.

With the contract, you will receive a short sign-up document to be issued a reloadable bank card. Once monthly hours are confirmed, the GPC administrative team authorizes a payment that is loaded directly into your bank card.

To track how much GPC is paying you each year, you will need to complete a W-9 IRS form when we set up your payments. If your compensation adds up to more than \$600 in a year (January-December), after the end of the year and before February 1st, you will receive a 1099-MISC IRS tax form confirming the income you received during the year. As required by law, GPC will report your total compensation to the IRS as taxable income

Note: If you have any questions or concerns about your total payments, compensation or if your situation changes at any time, please let us know.

ACKNOWLEDGEMENT

This handbook has been created in collaboration with GPC PAC members and the PAC Facilitation Team, with an acknowledgement to both OCHIN/ADVANCE and REACHnet (other PCORnet® CRNs) for their assistance. The purpose of this handbook is to foster a mutual understanding of the PAC’s policies, procedures, benefits, and practices to guide engagement matters.

I have read and understood the content and expectations, I understand that if I have questions at any time, I can contact the PAC Team.

PAC Member first and last name: _____

Signature: _____

Date: _____



PAC General Consultation Activities:

- **The Patient Partner** will work closely with the **GPC Patient Co-Investigator, Engagement Lead and Engagement Team** to support and further build patient engagement initiatives across the GPC. The ideal candidate will be able to work collaboratively with the patient community and organizations, researchers, and GPC staff to effectively incorporate the patient perspective into these initiatives.

With direction from the **GPC Project Management Office (PMO)**, patient consultants may be hired under formal contracts, with specified deliverables, as engagement specialists on outside research projects. Certain requests may be completed by one patient consultant, whereas other requests may be completed by all consultants working as a team.

This position will have the opportunity to provide consultation activities in this fashion. These include but are not limited to the duties and responsibilities listed below.

- Rapid PACE sessions and other work opportunities with GPC research applicants and Engagement Personnel to conceptualize and implement patient engagement plans. Activities may include:
 - Strategize approaches to overcome engagement challenges (time, resources, geography, trust)
 - Advice on recruitment and retention strategies and activities
 - Advise and co-develop patient facing materials
 - Provide feedback on study protocols and outcome measures.
 - Participate in development and review of study dissemination plans and materials
 - Support data interpretation analysis and patient centered messaging
 - Engage with outside groups to enhance study visibility and recruitment
 - Monitor and advise on equity and inclusion to minimize bias and enhance usefulness of study findings
- Participate in media and communication initiatives
- Review content of health information for patient-centeredness before dissemination
- **Desired Skills, Knowledge, and Abilities:**
 - Strong connection to patient experience or medically underserved population(s)
 - Able to generalize specific disease/patient experience to a more universal goal of patient centered research
 - Ability to help bridge the patient and research community
 - Active role in community (local, patient, or other- please specify in your personal statement)
 - Comfortable with public speaking & group facilitation
 - Understand policy and the ability to navigate systems
 - Confidence to actively participate in multi-stakeholder groups to communicate the patient perspective
 - Ability to use technology to collaborate and communicate (ex: email, Zoom, Microsoft word)