

Patient Engagement Group (PEG) Roles and Responsibilities

Overview

The PEG plays an evolving and vital role in ensuring that the development of research resources within the Polycystic Kidney Disease Research Resource Consortium (PKD RRC) is aligned with the needs, priorities, and perspectives of individuals affected by PKD. As a PEG member, you will serve as a liaison between subcommittees of the RRC and the broader PEG, helping to shape patient-centered research and resource development. Your contributions are essential for ensuring patient perspectives are at the core of planning and decision-making.

General Expectations for PEG Members

- **Commitment:** PEG members should commit to attending monthly one-hour PEG meetings and 1 monthly subcommittee working-group meeting regularly and to being an active participant in discussions and projects. If life circumstances affect your ability to attend, please communicate with PEG facilitators and your subcommittee liaison partner in advance.
- **Ongoing Collaboration:** You are expected to participate in PEG meetings, share updates from subcommittee work, contribute to discussions, and collaborate with fellow PEG members. This includes listening to updates about subcommittee meetings, offering thoughts during discussions, participating in editing or commenting on documents between meetings, and providing your feedback on surveys in a timely manner. Beyond the scheduled meetings, it would be reasonable to expect to spend an additional 15-30 minutes per month on PEG activities.
- **Confidentiality:** Some subcommittee discussions may involve sensitive information. PEG members are expected to maintain confidentiality where necessary, only sharing information approved for dissemination. Training will be provided on what constitutes sensitive information and how to handle it appropriately.
- **Feedback and Inclusivity:** As part of the PEG, you are encouraged to provide verbal and written feedback on how the engagement process can be improved and to foster an inclusive environment where all members feel empowered to contribute. Constructive feedback helps us grow collectively.
- **Support and Empowerment:** If you require additional support or education to engage meaningfully in your role, please communicate this to the PEG facilitators. We are committed to providing resources, training, and peer support to ensure all members are comfortable and empowered in their roles.
- **Social Meetings:** In addition to regular PEG meetings, we encourage participation in a few social meetings each year. These informal gatherings will focus on getting to know each other better, fostering closer relationships, and encouraging a supportive environment. These meetings could include quick introductions, support group-style discussions on PKD experiences, and open conversations about any questions or challenges members are facing.

Key Responsibilities

1. Subcommittee Liaison Participation

- **Attend Subcommittee Meetings:** Each PEG member will serve as a liaison to a RRC subcommittee (Clinical Resources, In Vivo Models and Reagents, Cell Models, Antibodies and Vectors). You will attend subcommittee working group monthly meetings alongside your subcommittee liaison partner (another PEG member) to observe, take notes, and contribute to discussions. Your primary role is to ensure that the patient perspective is consistently

represented and integrated into the conversations and decision-making processes during these meetings. Please feel free to ask questions to subcommittee leads and/or PEG facilitators before or during meetings to ensure you are prepared and confident in your role.

- **Collaboration Between Liaisons:** If there are two PEG members attending a subcommittee meeting, you are encouraged to collaborate before and between meetings to decide on responsibilities, such as who will take notes and who will report back to the broader PEG. This collaboration helps ensure effective coverage and prevents overlap.
- **Summarize Subcommittee Activities:** After each subcommittee meeting, you will provide a summary of the subcommittee's activities, goals, and progress to the broader PEG during PEG meetings. These summaries can be brief highlights of key developments for the rest of the PEG. If you need assistance summarizing complex information, please reach out to subcommittee leads or other PEG members.
- **Relay Researcher Questions:** During subcommittee meetings, researchers may ask questions or seek input on how aspects of resource development affect patients. You can provide feedback based on your comfort or expertise, but you are also encouraged to gather questions posed by researchers to present to the PEG for collective input. This ensures that a broad range of perspectives is considered and communicated back to the subcommittees.

2. Communication with Subcommittee Leads

- **Facilitate Presentations and Panels:** You will work with subcommittee leads to arrange presentations or panels that provide an overview of subcommittee projects to the PEG. It is important that these presentations use clear language, properly define scientific jargon, and provide opportunities for PEG members to ask questions, thereby fostering deeper engagement with the research.
- **Proposing Patient Involvement:** Where appropriate, you can suggest areas where PEG members could become more directly involved in resource development, particularly in aspects that are patient-facing (e.g., informed consent summaries, patient education materials). Communicate potential projects, especially ideas formulated collaboratively during PEG meetings, to subcommittee leads. Remember, your suggestions are valued, even if you are uncertain about the implementation details.

3. Active Participation in Subcommittee Meetings

- **Offer Patient Perspective:** As a PEG liaison, you may offer your perspective as a person with PKD or caregiver for someone with PKD during subcommittee discussion. Your lived experience is invaluable in shaping how resources are developed, particularly in terms of usability, accessibility, and patient-friendliness. All contributions, no matter how small, are crucial to the success of our work.
- **Answer Questions from Researchers:** If researchers ask for input or clarification on patient-related issues during subcommittee meetings, you are encouraged to contribute your unique insights and feedback based on your experience. You are not obligated to speak on topics that make you uncomfortable, and you can always request clarification if needed.

Summary

Your role as a PEG liaison is crucial in ensuring that the voices of patients and caregivers are heard and considered throughout the research process. By fostering dialogue between patients and researchers, you will help shape research tools and resources that are not only scientifically robust but also patient-centered and accessible.

Thank you for your dedication and commitment to improving PKD research and patient outcomes through your involvement in the PKD RRC!