



Interactions Core

*Collaborating for the Advancement of
Interdisciplinary Research in Benign Urology*

This meeting was organized to introduce Ajinkya Limkar, an MD-PhD student from the Ricke Lab at the University of Wisconsin–Madison, to the Interactions Core's efforts in conceptualizing a patient engagement initiative. The discussion also aimed to define his role in refining and implementing a Patient Engagement Logic Model for the CAIRIBU Community.

Attendance: Ajinkya Limkar (UW-Madison, U54 O'Brien Center), Mariana Coughlin (UW-Madison, U24 CAIRIBU Interactions Core), Kristina Penniston (UW-Madison, U24 CAIRIBU Interactions Core)

Transcript

<https://otter.ai/u/8xu0PBIXgkpAEAKhbFnSchYd9H4?view=transcript>

The meeting focused on establishing a systematic approach to patient engagement in research within the CAIRIBU Community. Key points included the need for training materials for basic scientists and patients, forming a community advisory board, and creating a culture of patient engagement. Metrics for success were outlined, such as the number of trained researchers and patients, regular advisory board meetings, and increased patient input in research proposals. The team discussed the importance of closing the gap between scientists and patients, enhancing research quality, and making research more accessible to the public. Next steps involve reviewing the logic model, creating a plan of action, and identifying key players to help implement these initiatives.

Action Items

- [] Review the logic model and provide feedback.
- [] Create a page on the CAIRIBU Connect website to host materials related to this initiative.
- [] Schedule a follow-up meeting on Thursday, February 20th at 9:30 AM.

Outline

CAIRIBU Community and Resources

- Mariana discusses the CAIRIBU network as a valuable resource, mentioning an outreach list of over 1000 people.
- The network includes clinical researchers, patient advocacy groups, and individuals involved in research interest groups.
- Mariana highlights the importance of information from PCORI (Patient-Centered Outcomes Research Institute) for the CAIRIBU Patient Engagement Initiative.
- The need for Research Fundamentals training materials for basic scientists is mentioned, with Mariana seeking feedback on their usefulness.

Training and Advisory Board Framework

- Mariana mentions patient-facing CITI training materials from UW and the potential use of these for advisory boards.

- The community advisory board toolkit from WINRS is considered as a framework, but with adjustments for the CAIRIBU network's larger and more diverse group.
- Funding for training and the possibility of using CAIRIBU Collaboration Awards to fund patient participation are discussed.
- Mariana outlines the need for capacity building for both patients and researchers, including establishing the community advisory board and facilitating patient feedback.

Goals and Outcomes of Patient Engagement

- Mariana emphasizes the importance of patient-engaged research and the need for basic scientists to engage with patients early and often.
- The goal is to strengthen partnerships between patients, researchers, and healthcare providers, and to increase the incorporation of patient perspectives in research.
- Mariana lists specific outcomes, including increased awareness among researchers, improved patient confidence, and enhanced transparency in the research process.
- The long-term goal is to embed sustainable patient engagement practices within the CAIRIBU Community and potentially expand this model to other programs and disciplines.

Systematic Approach and Organizational Structure

- Kris suggests a systematic approach to ensure the process is writable as a manuscript and presentable at meetings.
- Ajinkya agrees that organization is crucial for understanding what has been done and what is planned.
- Mariana outlines the outputs, including the number of patients and researchers trained, regular meetings of the community advisory board, and published summaries.
- Short-term outcomes include increased awareness among researchers and improved patient confidence, while long-term outcomes focus on enhanced research quality and impact.

Next Steps and Action Plan

- Kris proposes creating a plan of action and a timeline for the next steps, including engaging other people and identifying tasks. Suggests a Gantt chart to identify specific tasks and deadlines.
- Ajinkya suggests reviewing the logic model and coming up with attainable goals, including materials and clinicians to involve in finding patients.

Logic Model and Tool Discussion

- Kris suggests breaking down each activity in the logic model and deciding what needs to be done to make it happen.
- Ajinkya agrees and suggests reviewing the logic model and coming up with ideas for attainable goals.
- Kris proposes using tools like Gantt charts and process flows to move from the logic model to action.
- Mariana and Ajinkya discuss the challenges of creating and implementing a logic model, with Ajinkya suggesting revisiting tools used in medical school.

Website and Document Sharing

- Kris suggests creating a page on the CAIRIBU Connect website for sharing materials related to the project.

- Mariana agrees and plans to give Ajinkya admin access to the website.
- Kris proposes using the website to upload tools and materials for the project.
- Mariana suggests updating the website with the most recent version of the logic model and proposal for feedback.