Interactions Core
Collaborating for the Advancement of Interdisciplinary Research in Benign Urology

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Attendance: Ajinkya Limkar (MD-PhD student, UW-Madison U54), Mariana Coughlin (Research Program Coordinator, CAIRIBU Interactions Core), and Kristina Penniston (PI, CAIRIBU Interactions Core)

Transcript

https://otter.ai/u/p1_eIKhNyp-FWKR4I0Sol2wib_M?view=transcript

The team discussed refining a logic model for patient engagement in research. Key points included defining diversity metrics for the Community Advisory Board (CAB), incorporating patient input in training materials, and ensuring feedback transparency. We proposed adding qualitative measures like pre-post surveys and Patient-Centered Outcome Measures (PCOMs) to assess effectiveness. The idea of an annual patient-prioritized research agenda was supported, along with accountability measures to prevent tokenization. We plan to revise the patient engagement proposal and timeline, involving key advisors like Allison Huang and Kat Phelps. The meeting concluded with a plan to review and edit the logic model and proposal in a collaborative manner.

Action Items

[ ] Incorporate the feedback provided and revise the logic model.

[ ] Schedule another meeting in the next couple of weeks to review the updated logic model.

[ ] Send out a Google Doc or editable PDF version of the logic model for Kris and Ajinkya to provide further input.

[ ] Engage with CAIRIBU leadership, such as Allison Wong, to get feedback on the revised logic model and patient engagement proposal.

Outline

Feedback on Logic Model Structure

- Mariana initiates the meeting by outlining the agenda to provide feedback on the logic model discussed previously.

- Ajinkya shares their annotated copy of the logic model and plans to discuss questions raised while reviewing it.

- Ajinkya emphasizes the importance of identifying barriers for patient participation and suggests considering patient compensation and other potential barriers.

- Discussion on defining diversity within the Community Advisory Board (CAB) and the need for specific measures to ensure adequate representation.

Training and Capacity Building Feedback

- Ajinkya suggests involving patients in the design of training materials to ensure relevance and avoid redundancy.

- Ajinkya raises concerns about how patients can know if their feedback is used in research and proposes a structured impact reporting mechanism.

- Kris agrees with the idea and mentions feedback from Kat Phelps on ensuring patients know the final product.
- Ajinkya proposes adding a structured impact reporting mechanism or an annual CAB impact report to address this issue.

Specifying Training and Engagement Goals

- Ajinkya recommends specifying the number of patients to be trained and the number of research proposals to be reviewed annually.
- Ajinkya suggests adding qualitative measures to assess the effectiveness of training and engagement.
- Kris supports the idea of using pre and post surveys to collect data on training effectiveness.
- Ajinkya highlights the need for accountability measures to prevent tokenization of patient input and suggests setting guidelines for researchers.

Creating a Patient-Prioritized Research Agenda

- Ajinkya proposes creating an annual patient-prioritized research agenda based on CAB feedback.
- Kris suggests pointing patients to existing initiatives and prompting leaders to create patient-centered research agendas.
- Ajinkya introduces the concept of Patient-Centered Outcome Measures (PCOMs) to track the impact of CAB-reviewed proposals.
- Kris and Ajinkya discuss the potential of measuring PCOMs and the importance of direct patient influence in research.

Next Steps and Collaboration

- Mariana plans to incorporate feedback into a second draft of the logic model and suggests a follow-up meeting.
- Kris and Mariana discuss involving CAIRIBU leadership, including Allison Huang, in the process.
- Mariana proposes creating an advisory board to provide feedback on a polished version of the logic model.
- Ajinkya and Kris discuss the timeline for the project and the need to revise the patient engagement proposal.

Final Remarks and Scheduling

- Kris and Mariana discuss the importance of involving key stakeholders and setting clear timelines for the project.
- Ajinkya shares their availability and plans to continue contributing to the project.
- Mariana outlines the next steps, including sharing a revised proposal and the logic model and scheduling the next meeting.
- The meeting concludes with a plan to review the logic model and patient engagement proposal and involve additional advisors as needed.