

EACB-26623

Open Access Executive Summary For The Project Website -
<https://nursing.vanderbilt.edu/projects/pcori/index.php>

Involving patients, families and caregivers in patient-centered research during and after a critical illness is essential to ensure that research questions that matter are being asked, and that outcomes that matter are being measured. It's also important to engage clinicians and staff to provide a real-world perspective tailored to the critical-care setting.

Our project, titled “Addressing Barriers to Engaging Patient & Caregivers Experiencing Critical Illness to Build Capacity for Patient Centered Outcomes Research”, aimed to understand how to involve patients and families who have recently experienced intensive care unit (ICU) stays in research. We gathered insights from various stakeholders including ICU clinicians, patients, family members, and researchers.

Our main goals were:

- 1) Use group concept mapping (GCM) to identify barriers to research participation as well as strategies that can be used for overcoming those barriers to research in the ICU and post-ICU settings. GCM involves group brainstorming of ideas and organization of those ideas into visual ‘concept maps’.
- 2) Use the results from GCM to develop an open-access website toolkit to share facilitation tools, engagement techniques and other resources for healthcare clinicians and researchers as well as patients and families.

The project has an eight-member *Patient and Key Stakeholder Advisory Board* that includes two former ICU patients, three family members, three ICU clinician/researchers, two physicians and one nurse. Advisory board meetings are held quarterly to review progress and to obtain feedback. Our advisory board were instrumental in helping to interpret the data and will consult on the toolkit to ensure its usefulness.

We held four group concept mapping sessions with 34 participants including 14 former ICU patients and/or their family members and 20 ICU clinicians and researchers. From these sessions, we identified ninety themes, which were analyzed and refined through further participant input, including how feasible and impactful participants felt it would be to address each identified barrier. This process helped us create a visual ‘concept map’ outlining barriers to engaging patients and families in research during and after ICU stays, along with feasibility and impact of strategies for addressing them.

- We are designing the toolkit with the goal of providing clinicians and researchers who want to engage patients and families in ICU-related research with education and skills to do so. The toolkit will be organized according to the themes that emerged from group concept mapping and will also include:

- The visual concept map detailing the identified domains of barriers to engaging patients and family members in research during and after the ICU stay
- The concept map visualized by average ratings of feasibility to address and impact of addressing the barrier to research participation
- Strategies for engaging patients and family members experiencing an acute or critical illness in research at the domain level, identified in our literature review.

We intend the results of our project and our toolkit to contribute to the evidence base for strategies to conduct stakeholder engaged and patient centered outcomes research in the intensive care unit (ICU) and post-ICU environments.

The toolkit will be publicized using the Society of Critical Care Medicine's (SCCM's) robust communication structures including announcements distributed via email blasts; SCCM's newsletter (which is distributed to the 16,000 members); via the National ICU Recovery Network, a social media dissemination campaign including use of 'X' (Twitter), Facebook and LinkedIn, and a podcast.

Results of the project as a whole will be presented at a planned educational session for the 2025 SCCM Congress, and a manuscript will be submitted to the critical care focused research journal *Critical Care Medicine*.