



Addressing Barriers to Engaging Patient and Caregivers
Experiencing Critical Illness to Build Capacity
for Patient Centered Outcomes Research

Executive Summary



2024

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Background



Collaboration / Initiatives / Overcoming Barriers / Insights



Vision

Vanderbilt University School of Nursing (VUSN), in collaboration with the Society of Critical Care Medicine (SCCM) received a two-year Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) for the project: **Addressing Barriers to Engaging Patient & Caregivers Experiencing Critical Illness to Build Capacity for Patient Centered Outcomes Research.**

Mission

The initiative aimed to identify barriers to research participation, as well as to understand how best to overcome those barriers, to involve patients and families in research who have recently experienced an ICU hospitalization. Insights were sought from stakeholders including ICU clinicians, patients, family members, and researchers.



Project Team and Engagement

Vanderbilt University School of Nursing



Ruth Kleinpell

PhD, ACNP-BC, FAAN, FAANP, MCCM (MPI)

Independence Foundation Professor of Nursing Education
Associate Dean for Clinical Scholarship, Professor | Vanderbilt University School of Nursing

Dr. Kleinpell is an advocate for patient and family centered care. She also served as PI on a PCORI funded 2-year initiative to promote patient-centered outcomes research in ICU settings, using a national collaborative with 63 hospital ICU teams to implement patient and family centered initiatives (PCOR-ICU).



Marianna LaNoue

PhD, MS (MPI)

Professor, Vanderbilt University School of Nursing

Dr. LaNoue is an experimental psychologist, research methodologist and biostatistician. Her research focuses on studying methods of patient-centered outcomes research (PCOR), particularly the development and testing of patient engagement evaluation approaches.

Society of Critical Care Medicine



Susan R. Lacey

PhD, RN, CNL FAAN

Associate Director of
Quality and Research

In Dr. Lacey's current role at SCCM, she oversees the development and publication of clinical practice guidelines and other key initiatives. She was inducted into the American Academy of Nursing in 2009 based on her development and testing of the pediatric nursing quality indicators for Magnet™, which are still used world-wide today.



Adair Andrews

RN MATD

Research Project Manager

In Ms. Andrews' most recent role at SCCM, she managed multiple clinical research studies/trials, and quality improvement (QI) projects. She also worked closely with SCCM volunteers and healthcare professionals to release practical support tools aimed to educate patients, their families, and the healthcare community about resources for how to thrive after an ICU stay.

Project Team and Engagement

Patient & Key Stakeholder Advisory Board



Julie Barroso, PhD, RN, ANP, FNAP, FAAN

[Julia Eleanor Blair Chenault Professor of Nursing](#)
[Vanderbilt University School of Nursing, Nashville, Tennessee](#)

Dr. Julie Barroso is the Julia Eleanor Blair Chenault Professor of Nursing at the Vanderbilt University School of Nursing. She is an ICU survivor.



Leanne Boehm, PhD, RN, ACNS-BC, FCCM, FAAN

[Assistant Professor | Vanderbilt University School of Nursing, Nashville, Tennessee](#)

Dr. Leanne Boehm is serving on the Advisory Board as an ICU nurse who is now conducting hospital-based research projects to improve delivery of evidence-based care within the ICU. She also enrolls patients and caregivers in studies designed to implement and test the effectiveness of interventions for identifying and managing post-intensive care syndrome (PICS).



Reverend Bruce L. Hanson, (October 2, 1948 - April 13, 2024)

Pastor Bruce Hanson served as a caregiver to his wife for many years during an ongoing illness. She had had several hospitalizations in the ICU. He provided his insights as a member of the advisory board based on his experiences in serving as a caregiver to her during and after her time in the ICU.



David Hwang, MD, FAAN, FCCM, FNCS

[Professor and Chief, Division of Neurocritical Care | Department of Neurology](#)
[Associate Faculty, Center for Bioethics | University of North Carolina School of Medicine](#)

Dave Hwang is a member of the PCORI Advisory Panel on Patient Engagement. He is the lead author of the upcoming updated Family-Centered Care Guidelines from the Society of Critical Care Medicine and previously served as a faculty member for SCCM's PCORI-funded PCOR-ICU Collaborative.

Project Team and Engagement

Patient & Key Stakeholder Advisory Board



Mariann R. Piano, PhD, RN, FAAN, FAHA

[Nancy and Hilliard Travis Professor of Nursing, Senior Associate Dean for Research, Postdoctoral Fellowship Director | Vanderbilt University School of Nursing, Nashville Tennessee](#)

Dr. Mariann Piano is serving on this Advisory Board as a family member of a ICU patient. She also has a unique perspective and lens, because she was an ICU nurse and is currently a professor in an academic/university setting. The ICU patient was her husband who experienced a prolonged (7 week) ICU stay and experienced multiple procedures (e.g. intubation, extracorporeal membrane oxygenation) and who ultimately passed away in the ICU.



Carla M. Sevin, MD, FCCM

[Associate Professor of Medicine, Division of Allergy, Pulmonary and Critical Care Medicine Director, Pulmonary Patient Care Center](#)

Carla Sevin, MD, is the Director of the Pulmonary Patient Care Center and an Associate Professor of Medicine in the Division of Allergy, Pulmonary, and Critical Care Medicine, Department of Medicine, at Vanderbilt University Medical Center. Her clinical interests include the care of patients with occupational lung diseases and long-term outcomes after critical illness. She is board certified in Internal Medicine, Pulmonary Medicine, and Critical Care Medicine. Her research interests include the study of inflammatory lung diseases and improving critical illness recovery through ICU aftercare and peer support.



Victoria (Tory) Short & Tim Short

Victoria Short spent more than 2 months in various levels of care at Johns Hopkins. She and her husband, Timothy, stayed in the ICU and cardiac ICU before, during and after heart transplant. She survived the procedure and today she lives in North Carolina and is active in raising awareness for the American Heart Association and Donate Life.





Our Approach and Findings

In order to identify barriers to research participation as well as strategies for overcoming the barriers in the ICU and post-ICU settings, we used a method called group concept mapping (GCM), a research-supported approach designed to elicit, synthesize and make actionable information from diverse stakeholders.

Fourteen patients/family members and 21 ICU clinicians and researchers were invited to one of four virtual (zoom) brainstorming sessions. They generated 98 ideas in response to the prompt:

What are some barriers, challenges or difficulties, that patients and family members might experience that impacts whether they participate in research studies?

Our results identified seven clusters of barriers shown in Table 1 on page 7, with example statements from each one.

Participants also responded to questions about the feasibility and impact of addressing each barrier:

How feasible/possible would it be to address this barrier to research participation?

How impactful would it be to address this barrier in terms of increasing research participation?

We identified the barriers that stakeholders from both groups felt were both feasible and impactful to address (indicated in bold in Table 1 on page 8). The majority of these came from the cluster 'Difficult Research Logistics.'

Table 1 – Our Approach & Findings: Identified Barriers

Domain	Example Statements
Difficult Research Logistics	Researchers don't know the best time of day to contact
	The person recruiting or enrolling for the research is unskilled or unenthusiastic
	Patient taking certain medications not allowed in the study
Negative Experiences Surrounding ICU Stay	A bad outcome causes lack of trust
	Received poor care in the ICU
	Trust was not built during ICU stay
Patient & Family Characteristics	Lack of transportation
	Cannot follow-up because of housing insecurity or homelessness
	Belong to a racial/political/cultural group with systemic mistrust of medical system
ICU Setting Limitations	Don't remember what happened in the ICU
	The ICU is too overwhelming to make informed decisions
	Family member/surrogate is not comfortable making the decision for the patient
Post-Critical Illness Issues	Physical and/or cognitive impairments reduce stamina
	Don't have the mental energy
	Post-ICU adjustment (grief, social & physical changes) too difficult
Research Fears	The research involves procedures that the patient is not comfortable with
	Fear looking like they don't understand research in front of their clinical providers
	Fear being harmed by research
(Mis) Perceptions About Research	Worry that being in research will impact their care
	Think they will be unable to meet the requirements/demands of the study
	Feel that research participation is dehumanizing



Next Steps



The last stage of the project is currently ongoing to design an open-access toolkit to share facilitation tools, engagement techniques and other resources for healthcare clinicians and researchers as well as patients and families.

- This toolkit will be located open access on the project website and SCCM website upon project completion.
- An educational session has been accepted for the 2025 Annual SCCM Congress, to be held in Orlando, Florida.
- A manuscript describing the project and its findings is being finalized for submission to The Patient - Patient-Centered Outcomes Research.
- Widescale dissemination of the project results are planned via social media and Vanderbilt University School of Nursing and SCCM's communication channels including the newsletter Critical Connections, which is received by the 17,000 members of the organization.