# A Case Study Characterizing the Impacts of Engaging with Patient Advisory Councils on Long-Term **Recovery for Sepsis Survivors and their Families.**

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## Background

### SEPSIS IMPACT

- Life-threatening condition with global significance.
- Survivors face long-term disability and psychological sequelae. (Prescott, 2017)

### FAMILY IMPACT

- Caregivers and family members can experience ongoing psychological and emotional distress, including PTSD.
- Often considered patient partners in sepsis care.

### NECESSITY OF UNDERSTANDING

- Unique and persistent challenges for sepsis survivors and their families.
- Essential to comprehend factors influencing long-term recovery.

### What are the impacts of engaging with patient advisory councils on long recovery for sepsis survivors and their families?



### AIM #1

Conduct a scoping review to identify a framework for evaluating patient partner engagement in patient advisory councils.

**Explore the experiences of** patient partners engaging with patient advisory councils using a mixed-methods approach, and characterize the impact on patients' long-term recovery.



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### AIM #2

SYSTEMATIC REVIEW (UPDATE)

MIXED-METHOD STUDY

data analysis

- Quantitative survey to gather baseline data • In-depth interviews to explore experiences in depth • Sequential approach: survey informs interview
- topics



### **Expected Outcomes & Future Directions**

- Rich insights into sepsis survivors' and families' engagement experiences
- Understanding of the impact of engagement on long-term recovery
- Identification of areas for improvement in patient advisory councils
- Dissemination of findings to healthcare providers, researchers, and policymakers
- Potential refinement of patient engagement strategies

Further exploration of patient engagement's role in other medical contexts





# Methodology

- Identify tools/frameworks for evaluating patient and family partner engagement
- Inform survey questions, interview guide, and

### While sepsis can affect individuals across the spectrum, it disproportionately impacts those who face systemic barriers to healthcare access. We will aim to recruit a representative sample of participants, including equal representation of gender. Given the disproportionately distributed burden of caregiving and other family-based responsibilities, we will also conduct additional analyses, stratified by gender, to identify any potential differences in engaging with patient advisory councils across genders.



### Systematic Review

### **REVIEW BY BOIVIN ET AL. (2018)**

- Identified 27 tools for evaluating patient and public engagement in research and health decision-making.
- Most tools aimed to enhance engagement but lacked scientific rigor and patient input in their design and reporting.
- NEED FOR AN UPDATE
- Rapid growth of patient engagement in health contexts, driven by initiatives like SPOR.
- Warrants an updated systematic review.

### Integrated Knowledge Translation

- clinicians
- Ongoing patient engagement beyond the study team • Centers patient-identified research priorities
- Enhances relevance and impact of the research

- Informing patient-centered care approaches • Enhancing survivor outcomes

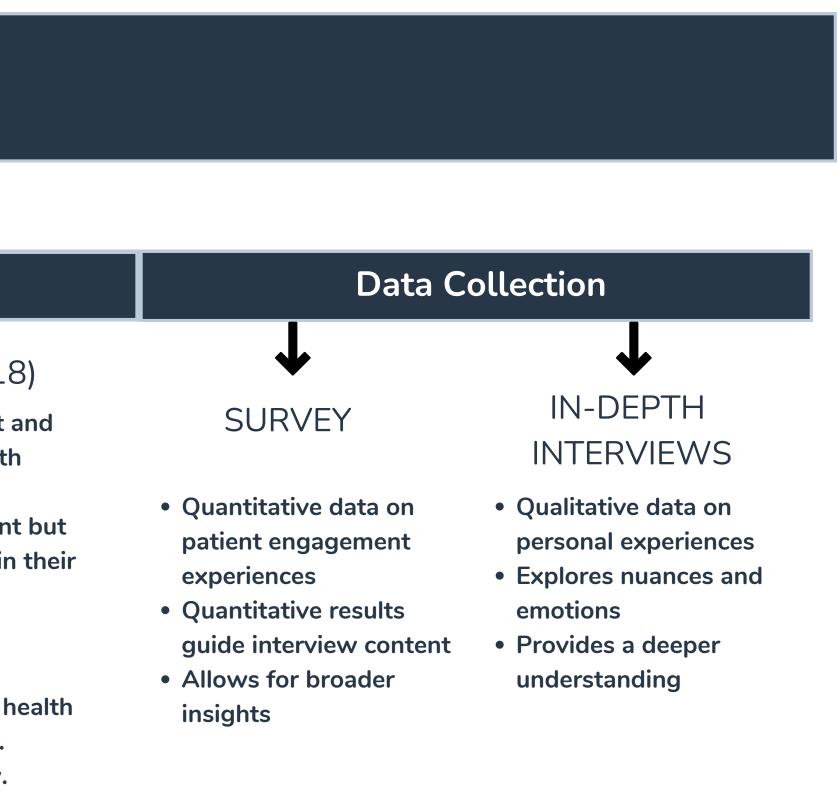
### RESEARCH

- insights
- Driving patient-centered research priorities



Strategy for Patient-Oriented Research





Collaborative approach involving patients, researchers, and

# Implications

### CLINICAL PRACTICE

- Improving research quality through patient



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