

# Characterizing the impacts of engaging with patient advisory councils on long-term recovery for sepsis survivors and their families

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THE UNIVERSITY OF BRITISH COLUMBIA  
Action on Sepsis  
Research Excellence Cluster



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## INTRODUCTION & BACKGROUND

Sepsis is the body's extreme response to an infection<sup>1</sup>.



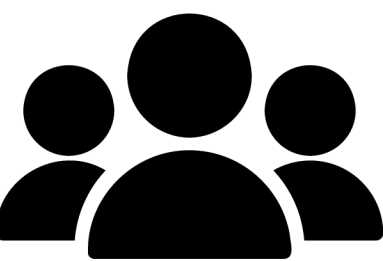
- 11M deaths and 49M cases globally<sup>2</sup>.
- Long-term health, social, and financial impacts for survivors<sup>3</sup> and their families/caregivers<sup>4</sup>.

Two sepsis research networks (**Action on Sepsis** and **Sepsis Canada**) established patient advisory councils (PACs) to guide their strategic decision-making and facilitate patient-oriented research.

**Purpose:** Explore the experiences of sepsis survivors and their families engaging in PACs and characterize the impact on this engagement on long-term recovery.

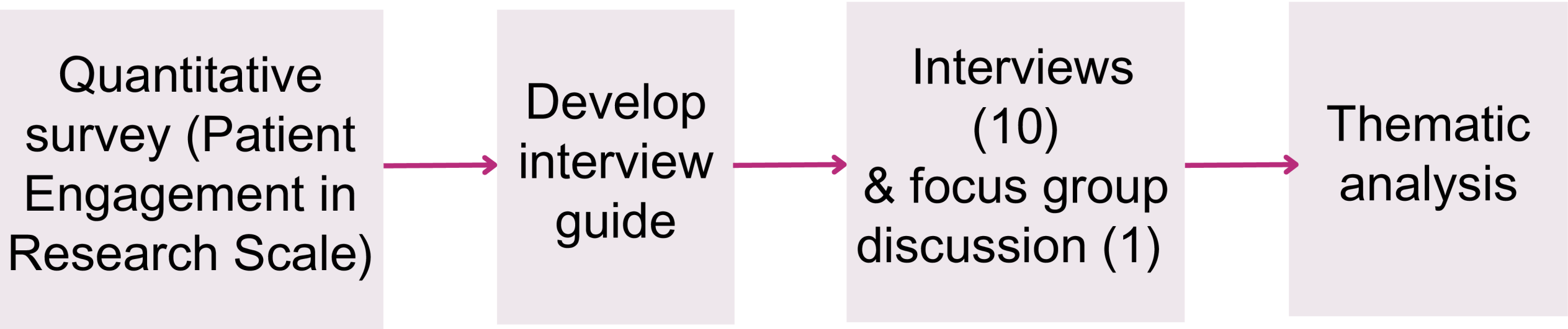
## LEARNING COMMUNITY ENGAGEMENT

### Patient Partner Engagement



- (1) Collaborate: 2 PAC members as Co-PIs
- (2) Involve: 3 additional PAC members as Co-Is
- (3) Inform: Results to be shared with all network members

### Approach



All current members of Sepsis Canada and Action on Sepsis PACs (n=29) were invited to join as study participants

- **16 members** participated
- Resided in 6 provinces
- Majority: Sepsis survivors, women, 40+ years

## KNOWLEDGE MOBILIZATION

### Sepsis experience and recovery journey

*"I didn't know I was a sepsis survivor. Those words [were] actually never used with me in the hospital. So, when I was discharged, I had no expectations [of recovery]. I didn't know what had been wrong with me."*



### Impacts of PAC involvement

*"Everyone's situation is very unique... But at the end of the day, we know what the impact of sepsis [is] and the toll it has. So, I think there still is that unity despite having very different experiences and stories to tell."*



### Characteristics of PAC participation

*"My PTSD was really bad for quite a long time. And so, it would be super triggering to go and attend and listen to other people's stories. I had to be... good enough with myself and with my... situation before I was able to really be present."*



PACs have benefits to sepsis survivors and their families that go beyond participants' sense of contributing to a specific project and can support their recovery.

Findings of this study may inform more inclusive and comprehensive practices for patient-oriented research in sepsis and use of evidence to shape patient-centred practices and policies.

## ACKNOWLEDGEMENTS & REFERENCES



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