

## Background

- Long COVID is a **chronic condition** where COVID-19 symptoms (e.g., fatigue, brain fog, short of breath) last for **>12 weeks post-infection**<sup>1</sup>
- Long COVID care requires **different types of health services**, but receiving care is described as **“complex, difficult, and exhausting”**<sup>2</sup>
- 2S/LGBTQQIA+ communities have **2-to-3 times greater rates** of Long COVID than heterosexual/cisgender folks and **greater limitations with daily activities**<sup>3</sup>
- Access** to safe healthcare can be challenging for 2S/LGBTQQIA+ people, who report **negative care experiences with care**, often resulting in **delayed or avoided care-seeking, unmet health needs, and unintentional harm**<sup>4,5</sup>
- Inclusive** Long COVID care models are needed in Canada, but there is **little guidance on how we can meet the diverse needs** of patients

## Objective

To develop an inclusive evidence-based framework for Long COVID care, co-created with 2S/LGBTQQIA+ individuals with lived experience and healthcare providers

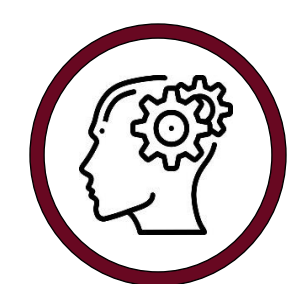
## Methods

### Patient Advisory Committee

- Integral to supporting all steps of the project, including active involvement in the framework development process

### 1) Identify attributes of health services for people with Long COVID

#### Design:



- Scoping review – Joanna Briggs Institute methodology<sup>6</sup>, guided by the 6-stage Arksey & O’Malley’s framework<sup>7</sup>

#### Search and Selection:



- Databases – Embase, MEDLINE, CINAHL, Web of Science, PsycINFO, Google Scholar, JBI EBP Database, etc.
- Search developed with SPOR Evidence Alliance librarian
- 8 raters reviewed abstracts/titles and full-texts in pairs

#### Inclusion Criteria:



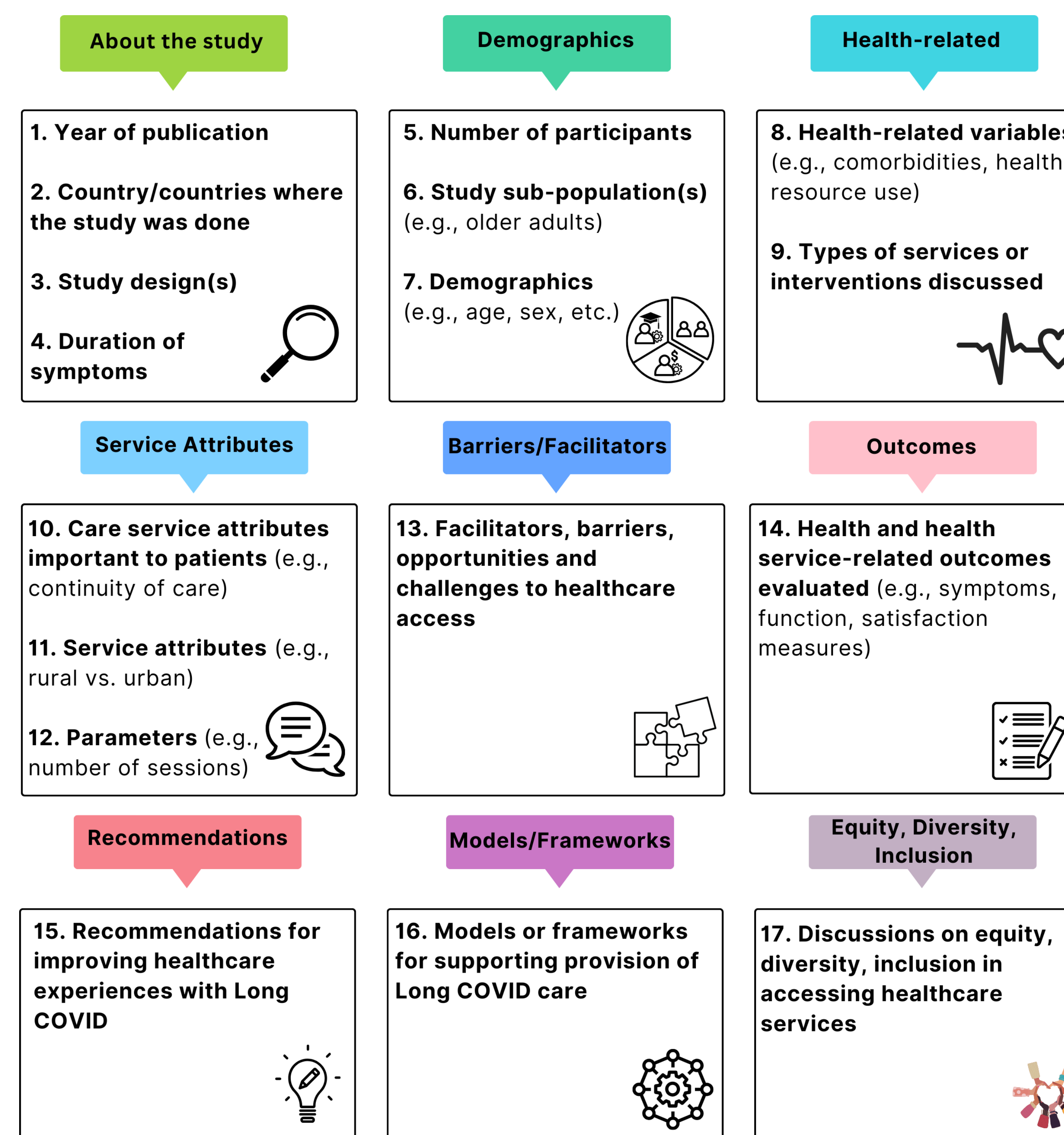
- People** – people with Long COVID or support networks (e.g., family, friends, caregivers, etc.) of people with long COVID
- Concept** – experiences with long COVID seeking, access, or receiving care, treatment, and/or self-management resources
- Context** – community & primary care settings where clinical encounters are delivered in-person or remotely

#### Screening and Data Extraction:

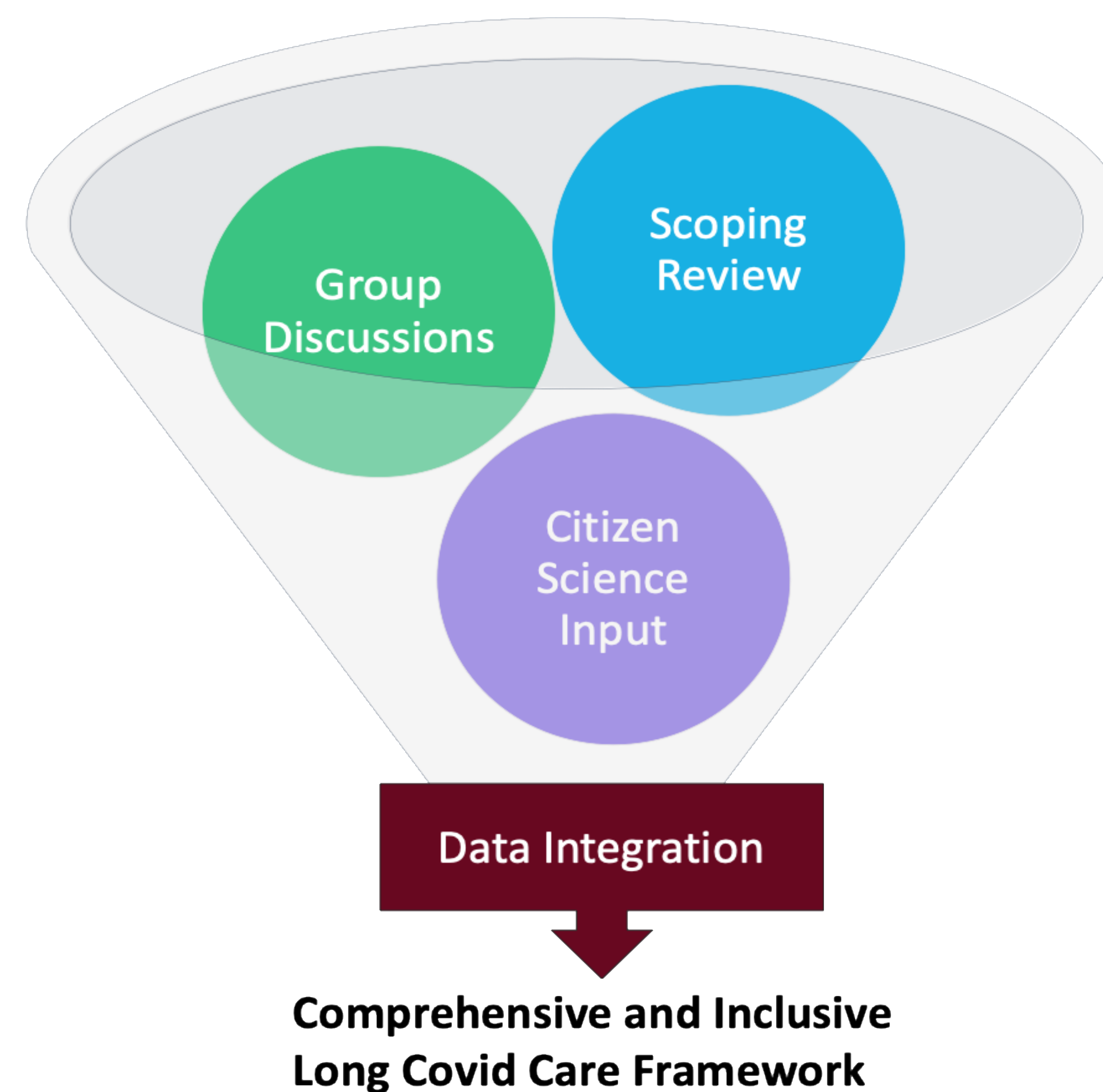


- 8,526 titles and abstracts were screened, 78 articles were assessed for eligibility, and **62 are included**
- We are currently at the stage of data extraction. An overview of the key focus areas for extraction are presented in Fig. 1

## Methods (continued)



**Fig 1.** Key topics being explored for the data extraction phase of the Long COVID Scoping Review. We are currently in this phase, gathering information about health services to inform the development of an inclusive model of care.



**Fig 2.** Developing a comprehensive Long COVID care framework by integrating data from a scoping review, focus group consultations, and public input through an online Citizen Science platform.

### 2a) Identify attributes for a framework to support developing inclusive Long COVID care models

- Arksey & O’Malley’s framework<sup>7</sup> Stage 6 – **community consultation**
  - Group discussions with **people with lived experience of Long COVID** to uncover important, silent aspects of seeking care
  - Group discussions with **health providers who work with Long COVID** to provide insight about health service delivery
- Data will be analyzed through **directed content analysis**

**We are looking to connect with people interested in joining these discussions**

Are you or someone you know living with Long COVID, or are you a healthcare provider in Long COVID care?

Scan the QR code to connect with us:



### 2b) Gather input from 2S/LGBTQQIA+ people about seeking care

- We co-created the **online Citizen Science platform** (<https://patientscientist.ca/>) with community, researchers, clinicians & digital health experts to promote public engagement and sharing of information on the **burden of Long COVID**
- To date, over **400 public participants** have shared information on their experiences with Long COVID, including personal stories
- Personal stories** with Long COVID will be analyzed via **directed content analysis** to explore care-seeking experiences from diverse nationwide perspectives
- These data will help **validate results** from the scoping review & community consultations

## Significance

- Our approach to developing this framework for inclusive Long COVID care models incorporates multiple engagement methods, including a scoping review, group discussions (people with lived experience & providers) & public input via citizen science (Fig. 2)
- It is a crucial step towards improving care experiences and outcomes for 2S/LGBTQQIA+ individuals with Long COVID, who continue to face barriers accessing care, safety challenges, and gaslighting in healthcare settings
- Active engagement of diverse 2S/LGBTQQIA+ voices throughout supports design of a more community-centered model

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## References

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