

## Background

- Chronic pain is a leading cause of **disability** and **reduced quality of life**<sup>1</sup>
- 2S/LGBTQQA+** communities experience **higher rates of pain, negative healthcare experiences, and don't always get the care they need**<sup>2-4</sup>
- Pain research often **overlooks perspectives of 2S/LGBTQQA+ people**, focusing on experiences of cisgender, heterosexual & endosex people<sup>5</sup>
- Therefore, current pain research questions **may not reflect** the unique concerns and needs of 2S/LGBTQQA+ individuals with chronic pain
- Patient & public engagement** can help identify questions important to community, but current engagement approaches **lack diverse input**<sup>6</sup>
- Citizen science** prioritizes **active public involvement**, offering a unique opportunity for more inclusive, community-driven research<sup>7,8</sup>

## Objective

To identify important research questions related to chronic pain that reflect the needs and voices of 2S/LGBTQQA+ communities, by actively engaging 2S/LGBTQQA+ patients and the public through citizen science

## Methods

### Study Design

- We tailored our study design to **European Citizen Science Association's (ECSA) 10 Principles of Citizen Science**<sup>8,9</sup> (Fig. 1) & **characteristics**<sup>10</sup>.

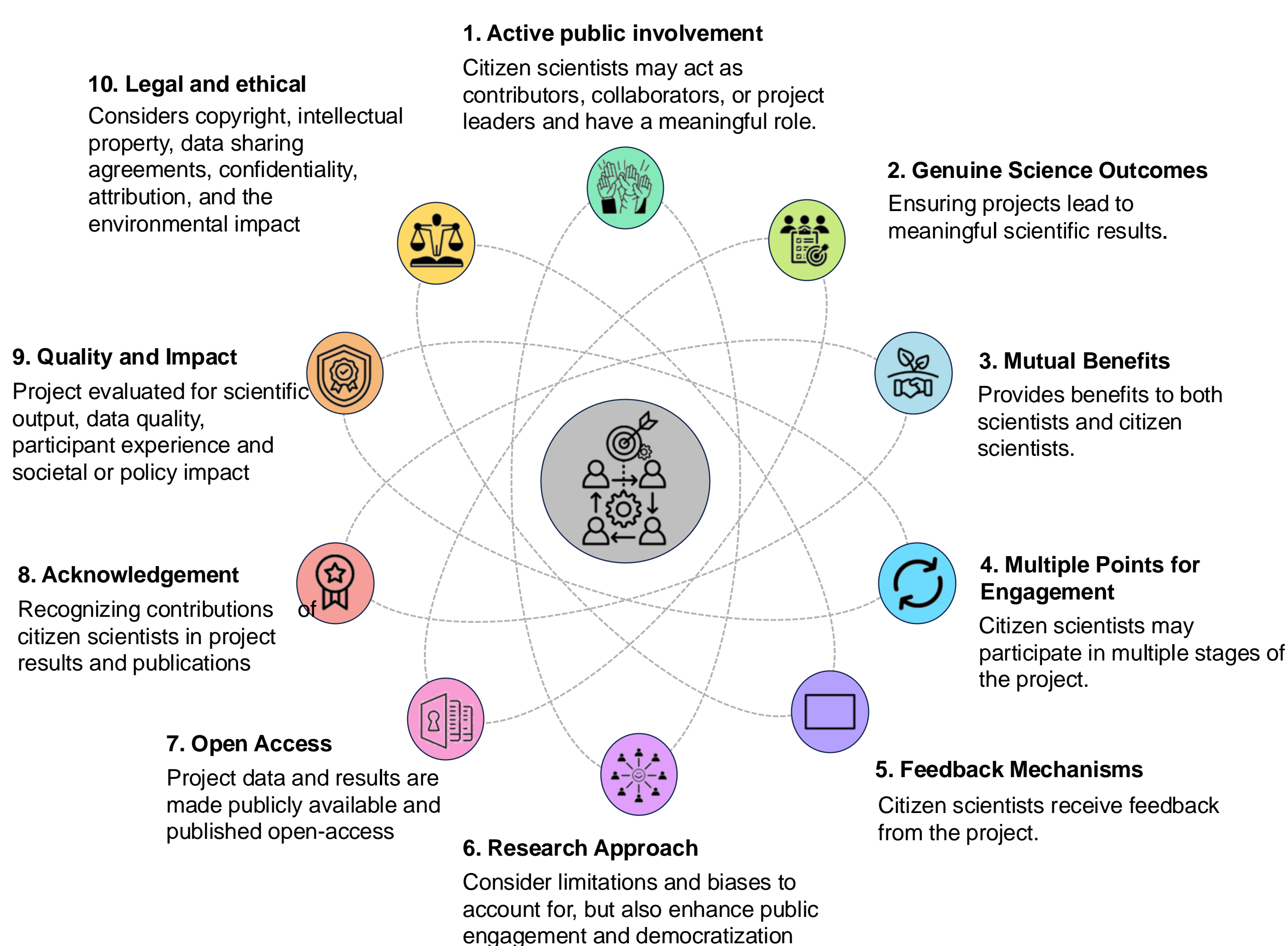


Fig 1: 10 Principles of Citizen Science defined by the European Citizen Science Association (ECSA).

### Patient and public engagement

- We assembled an **Advisory Committee of 6 members**:
  - 2S/LGBTQQA+ people with lived experience, clinicians, researchers
  - Unique, diverse lived experience and perspectives within the team
  - The group works collaboratively on **all project-related matters**
- We partnered with the **Community-Based Research Centre (CBRC)** as community partners
- The Advisory Committee and CBRC are working together to **maximize public engagement opportunities** for this study both in-person and online in various 2S/LGBTQQA+ community settings



## Methods (continued)

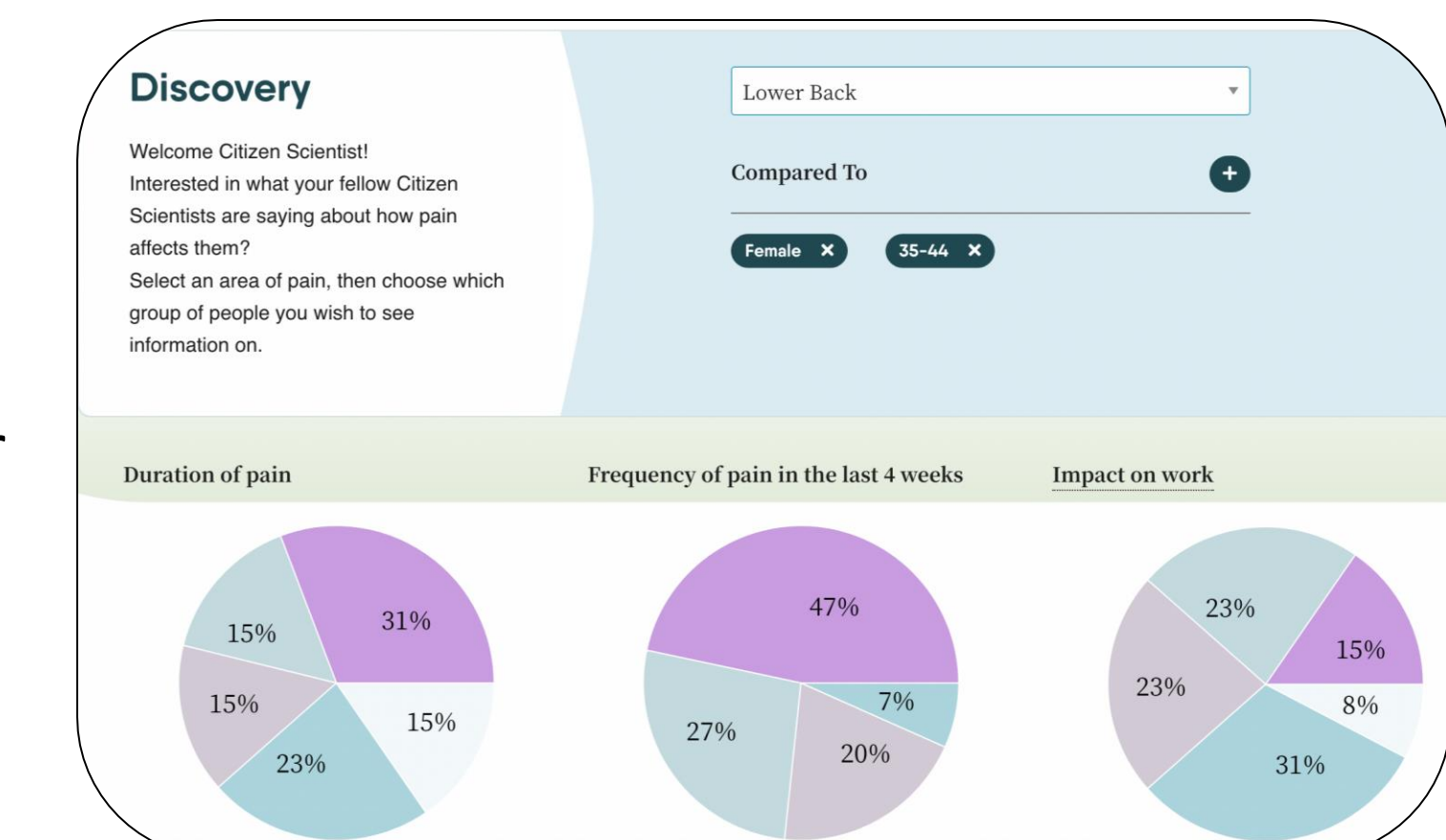
### Step 1: Gather 2S/LGBTQQA+ public input using an engagement tool

- The **online Citizen Science platform** is where people with chronic pain can share their experiences with pain, including details about health needs, symptoms, quality of life & personal pain stories
- The Advisory Committee & CBRC are working together to **maximize 2S/LGBTQQA+ public engagement** with the online platform
- People using the platform can see how their experiences compare to other people with pain through **data visualizations** (Fig. 2)
- The Advisory Committee will co-analyze the shared data, and findings will be **used in group discussions to develop research questions** (Step 2)

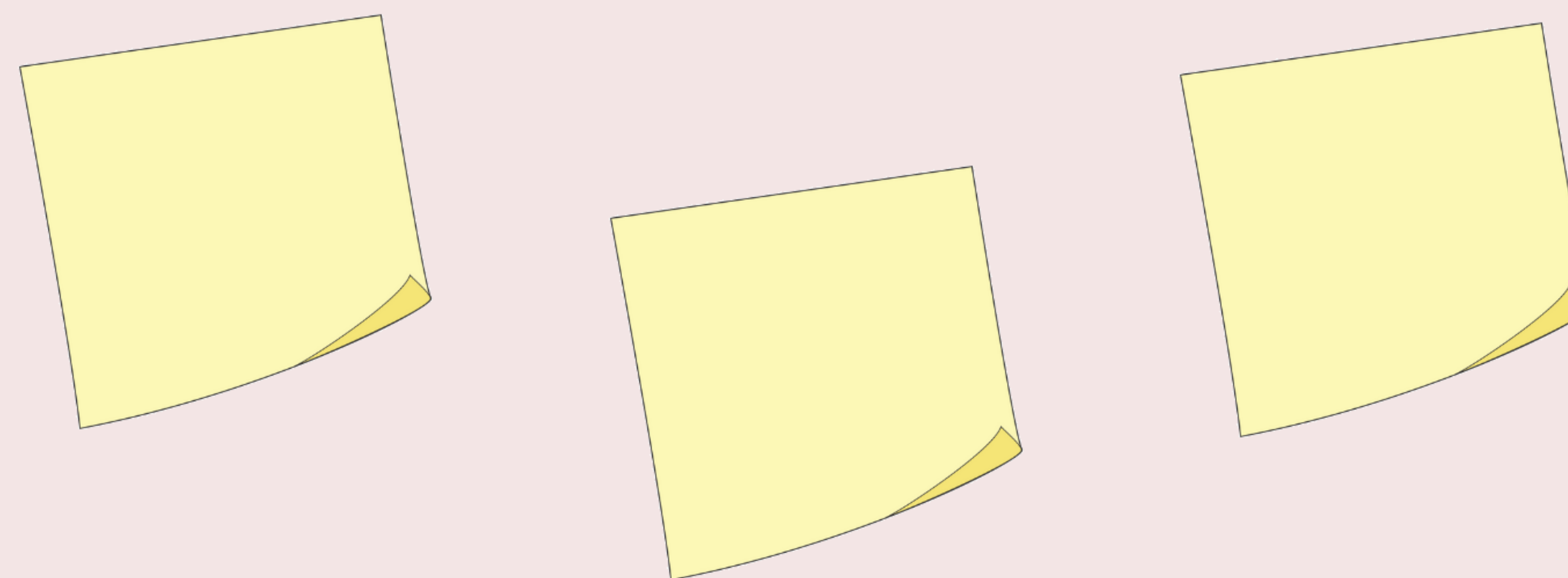


Learn about the online Citizen Science platform via the QR code or visit [www.patientscientist.ca](http://www.patientscientist.ca)

Fig. 2: Data visualizations are available through the online platform to make it easier for users to share and compare symptoms and experiences with others.



What ideas do you have to reach 2S/LGBTQQA+ people with chronic pain? This project is dedicated to community co-design. Share your input by posting a Post-It or the QR code:



[cprimeau@arthritisresearch.ca](mailto:cprimeau@arthritisresearch.ca)  
[@codieprimeau@bsky.social](https://twitter.com/codieprimeau)

### Step 2: Co-develop pain research questions through group discussion workshops

- Gather a working group of 2S/LGBTQQA+ patients, clinicians, & researchers from across the country
- Leverage **shared public input** from the online platform to support **co-developing research questions** for pain during **group discussions**
- Analyze group discussion data with **Group Concept Mapping** to create **question map clusters** (Fig. 3)

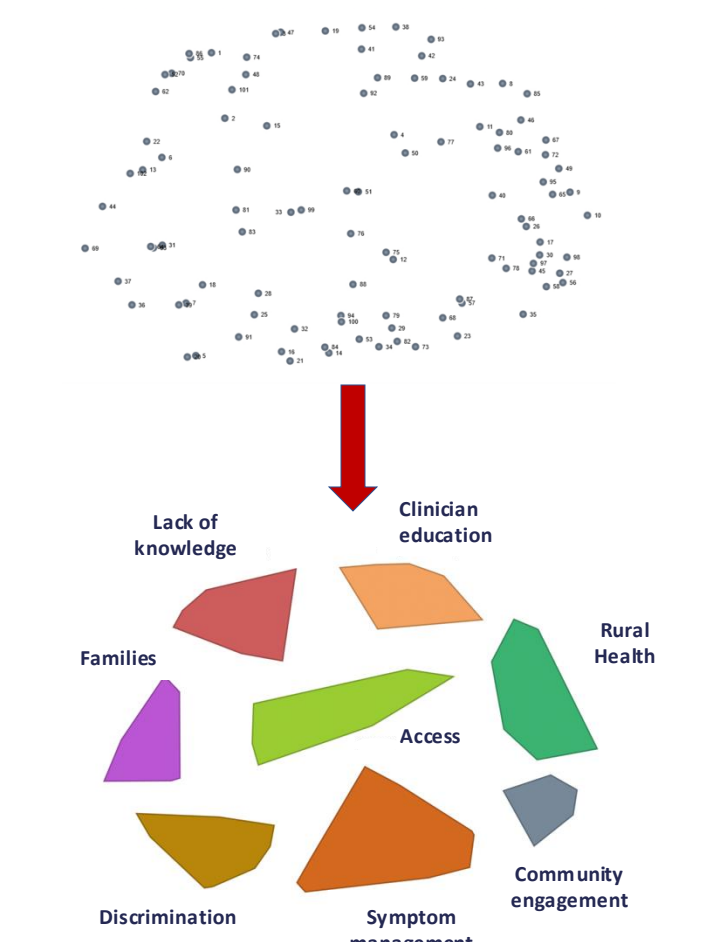


Fig 3. Visual example of cluster maps created by grouping related research questions together

### Step 3: Co-prioritize the questions via nationwide input

Delphi – Iterative (back-and-forth) consensus process

- Share questions identified in Step 2 **back with the 2S/LGBTQQA+ public** via an online survey
- Public **rates questions** over repeated survey rounds
- Between rounds, the Advisory Committee meets to **discuss results** and **refine** questions until consensus
- Combine results to summarize **final priority rankings** for the questions

- The **outcome** is a list of research questions reflecting **2S/LGBTQQA+ community input, co-developed by community.**
- Lays the foundation for future research and encourages ongoing collaboration with 2S/LGBTQQA+ partners in this work.**

## Significance

- Our approach prioritizes **building relationships & trust within 2S/LGBTQQA+ communities, knowledge sharing with community, and engaging underrepresented individuals** who are typically excluded or do not have the opportunity to participate in research.
- This project, led **by and with 2S/LGBTQQA+ communities**, shapes **research questions** that truly reflect **community needs**, ensuring future policies are grounded in the authentic experiences of 2S/LGBTQQA+ individuals.

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