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Enriching Real-World Data Sets with Insights from Online Communities for a Robust Understanding of the Patient Experience

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Panelist Introductions

Our Panelists

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Overview of Online Health Communities

What are online health communities?

Online health communities offer patients the opportunity to:

1. Interact with others who have been diagnosed with a variety of diseases and conditions
2. Track their health information on the site
3. Become involved in research



Why does an online health community work?

To understand online health network success, look to **behavioral science**



Helping and engaging with others can trigger oxytocin in the brain, improving mood and reducing stress.



People join groups they relate to, and this bias creates a positive view of the group and allows for forgiveness.



Engagement mirrors Maslow's hierarchy of needs. User needs are met for safety, belonging, esteem and self-actualization.

Community Member Types



Reader (passive)

A member who views and engages passively.
0-5 posts/comments



Contributor

A member with needs at a particular time.
6-200 posts/comments



Super User

- A member who drives 200+ posts/comments:
- “supporters” support others (positive influence)
 - “off loaders” off load issues (negative influence)



Advocate

Representative of an advocacy group who provides support and/or moderates discussions

Users engage because of TRUST.



1. Safe space

Co-created with patient advocacy groups



2. Credible dialogue

Ensured by super users and advocates



3. Stable and safe platform

A commitment to safety of users

Audience query: What has been your exposure to or experience with online health communities?



Panel Discussion: Value of Online Communities to Members and Society

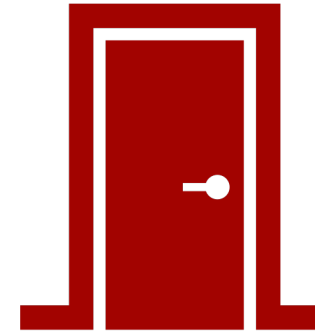


Structure of Online Communities

Open: Open to all comers



Gated: By invitation only



How do gated or “research online communities” (ROCs) operate?

Limited to participants with specific eligibility criteria

Moderated by professional researchers skilled in facilitation, behavioural modelling, and working with vulnerable participants

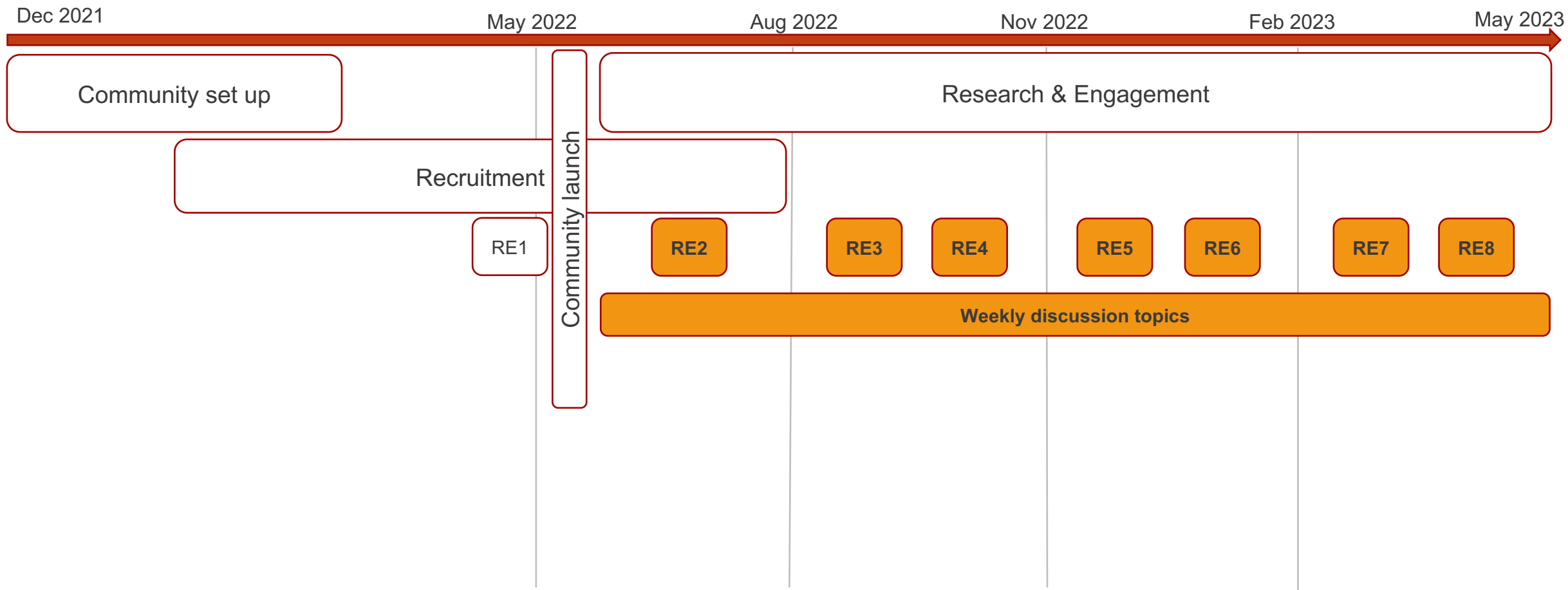
Participants are typically remunerated for their services

The communities often have a finite lifespan of 6-12 months

Research communities rely on trained moderators to direct the conversation and insights generation using discussions, forums, and surveys to elicit unique insights

Sometimes affiliated with other real-world research methodologies, such as patient registries, or linked with electronic health records

Sample roadmap for developing a ROC



Panel Discussion: Why consider forming a gated online research community?



Sample moderated discussion thread

How have you and your healthcare provider made decisions about treatment options for your depression?

Post details

- Date posted: 27-Apr-22 Number of responses: 7 Contributors: 5

Insights

- Most community members noted treatment decisions come from their personal research and experience.
 - Many treatment choices were based on experience and what has and hasn't worked overtime, and were made in consultation with their mental health providers suggestions.
- Some dove deeper into specific areas of therapy treatments based on what they felt would be the best fit (e.g., talk therapy, CBT, trauma therapy).
 - Similarly, members carried the same approach to alternative treatments.
- Almost all members approached medications with providers by working through medication(s) options to find the right fit.
 - A couple of members noted they were not always consulted about medication options initially.

Sample online health community member verbatims

1

“I have had to LEARN how to advocate for myself. Research my own conditions, mental & physical. Ask as many questions as possible, write them down so you don't forget. I challenge my caregivers & ask about alternative treatments.”

–U.S., female

2

“My depression treatment has relied on psychiatry a lot, since I haven't been able to find a therapist or counselor than can really help me. Still, finding the right medication has been a process, and it does sometimes feel like we're just going down the list of options until we find something that really works well (which we haven't).”

–U.S., male

3

“Everything else [treatment] is been on my own steam. Learning coping skills and strategies. Listening to myself and standing up for myself advocating for myself.”

–U.K., genderqueer

4

“All mine [therapy] has been virtual since the pandemic. I like it because you can be comfy at home and relaxed.”

–Canada, female

Panel Discussion: What can we learn through discussion threads?



Your turn: Formulate an opening question for a discussion thread



1. Who would be in your online health community?
2. What is your opening question for a discussion thread?
3. Why did you choose this?
What do you hope to learn?

Research Events

What types of research can be supported in an online health community?

Social Dialogue Analysis

Quick Polls

Thematic Analysis

Surveys

Online Patient Panel (chat)

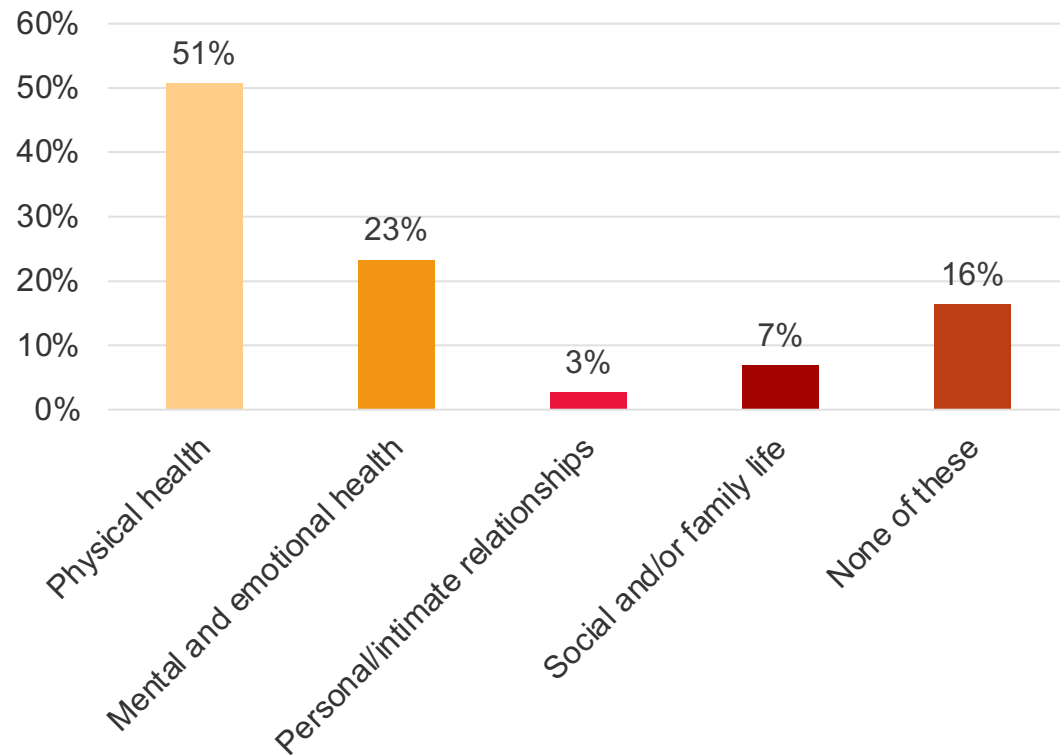
“Ask Me Anything” Events

Offline events (interviews, focus groups, etc.)

Sample quick poll results

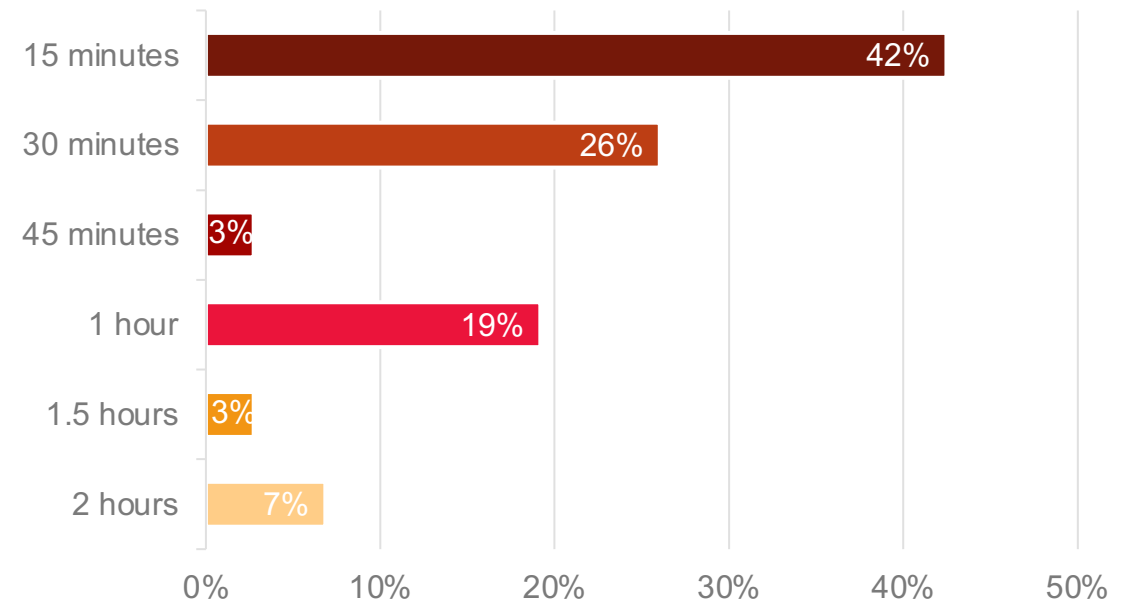
Quick Poll 1: In which of the following areas does your weight most impact your life?

Physical health was identified by respondents as most impacted by weight, followed by mental and emotional health.



Quick Poll 2: If you were asked to complete questionnaires related to your weight and health once every 6 months, what is the maximum amount of time you would be willing to spend completing these? (Note that participants would receive some payment for their time.)

Most respondents preferred a questionnaire they could complete in 30 minutes or less.

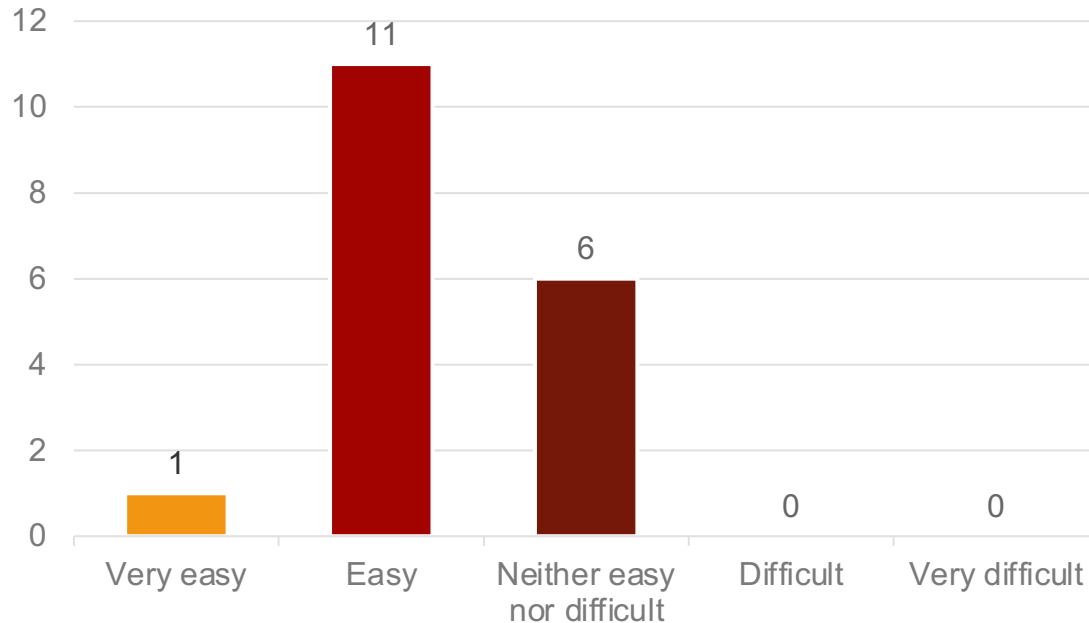


Sample survey results: quantitative (topic: onboarding to a health app)

1. How easy or difficult was it to find the app in the App Store?

67 percent of participants had an easy time finding the XYZ app in the App Store.

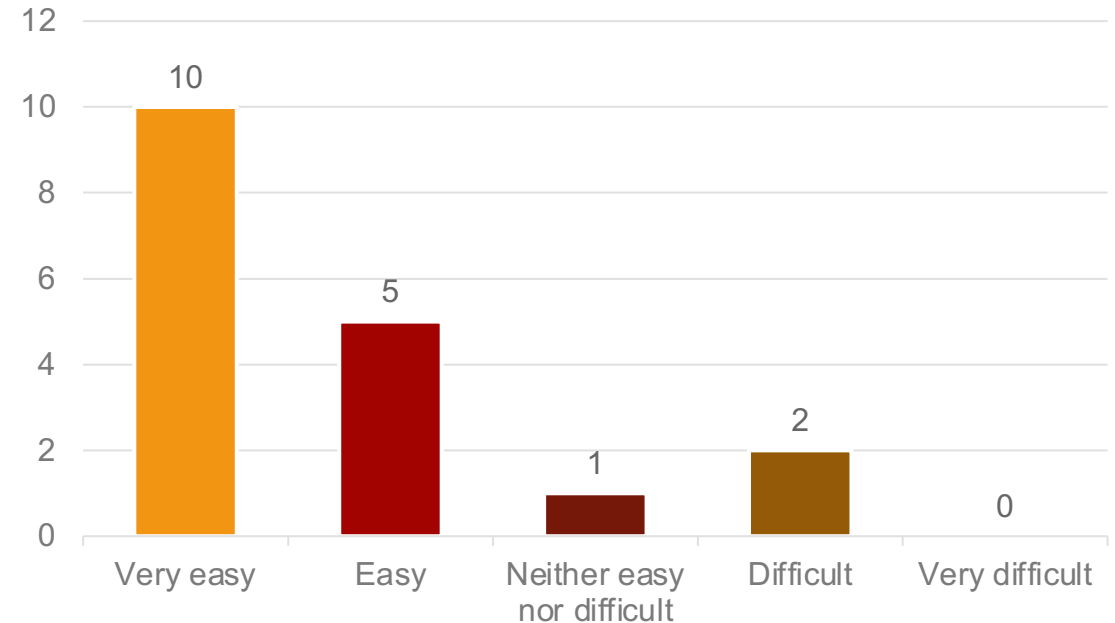
- Those who felt neutral felt that it was a similar experience to all other app downloads.



2. How easy or difficult would you rate initial set-up of your account?

83 percent of participants rated initial set-up of the app as easy.

- The 11 percent who had a difficult time:
 - Couldn't recall why they marked it as difficult and stated that "it must not have been nearly as bad in the long run as it was at that moment."
 - Explained that she just felt that setting up medications was time consuming.



Sample survey results: open-ended

5. What are three words that come to mind when you think of your onboarding experience with the XYZ app?



Sample output of online patient panel (chat)

BIPOC/H participants were deeply familiar with lack of cultural competence in their care:

- A few noted that cultural competence is one of the primary ways they select providers. Some have been able to find culturally competent providers, but often they have to travel a long distance to access that care.
- Others have been unable to locate a provider who is sensitive to these issues.
- Identified needs included:
 - Providers who are compassionate, trauma-informed, aware of implicit bias, and who can refer for appropriate support
 - Providers and staff who better reflect diversity in care settings
 - Greater awareness of the full range of patients who experience IBD
 - Increased support and guidance for culturally specific diets, and providers who do not blame patients for their disease based on their diets
 - Providers who are familiar with tests and procedures that are appropriate for different patient populations (e.g., greater difficulty inserting an IV for patients with darker skin)
 - Increased understanding of patients' typical day-to-day lives and obligations to better inform care; e.g., what are their stressors?

Sample thematic analysis report slide (Theme #3, PAIN)

Members discuss how CP impacts their quality of life and share how their pain affects them.

CP symptoms often prevent members from living a normal life.

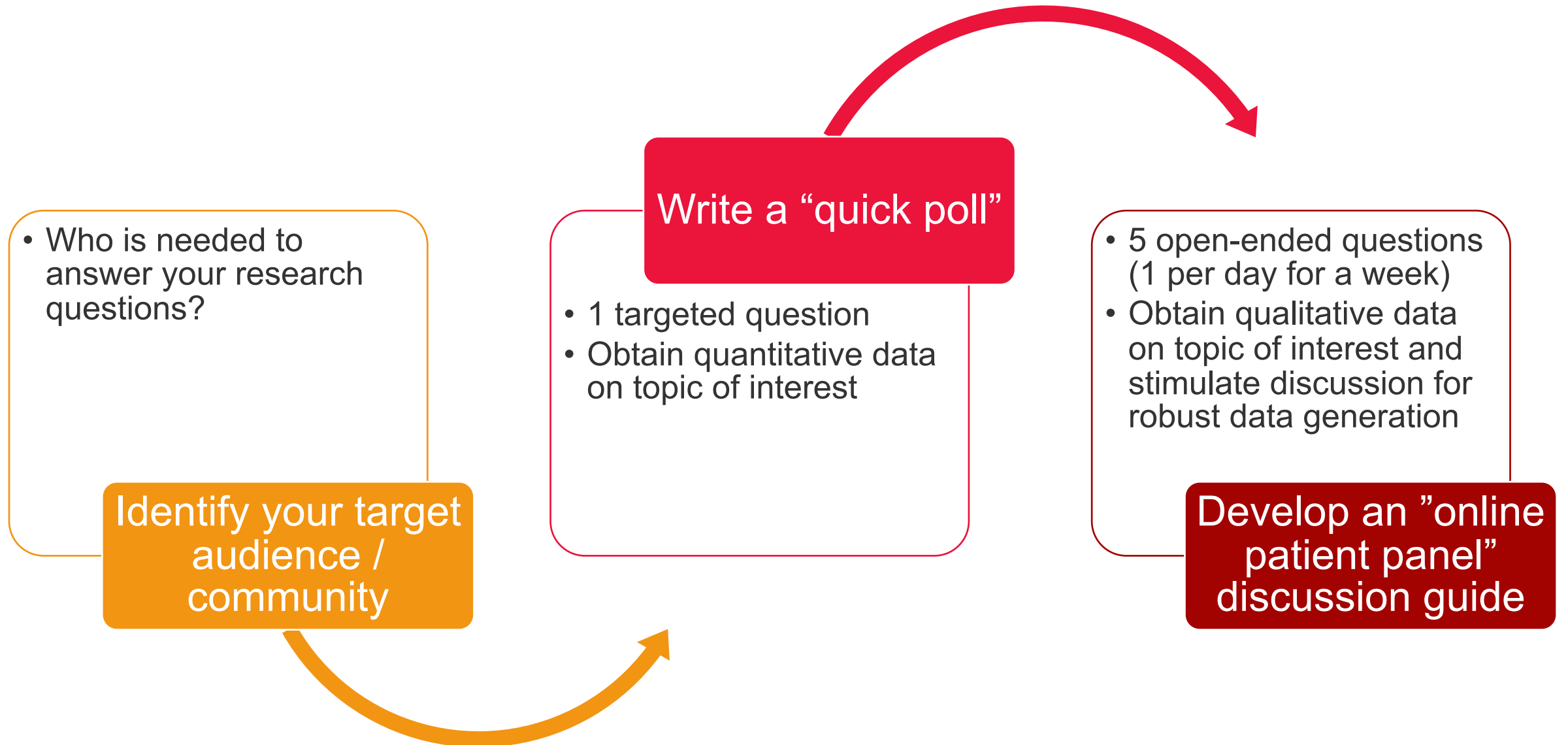
Members note that finding the source of their pain and proper treatment options can be difficult, and often prolongs their pain.

Members mention that a “silver lining” to necrotizing pancreatitis is the almost non-existent pain.

Panel Discussion: What can we learn through research events?



Practice



Your turn: Formulate a quick poll and follow-up online patient panel



1. Target audience
2. 1 quick poll question
3. Patient panel questions (5 open-ended)

Your turn: Debate and Discussion

Debate with 2 – 4 people sitting near you:

1. How useful is online health community data?
 - Social dialogue analysis?
 - Research event data?
2. What is the optimal use of this data?



Discussion and Q&A

Thank You