Toward meaningful data interpretation: results of a co-developed patient engagement process to inform evaluation of the ENCOMPASS Community Health Navigator program

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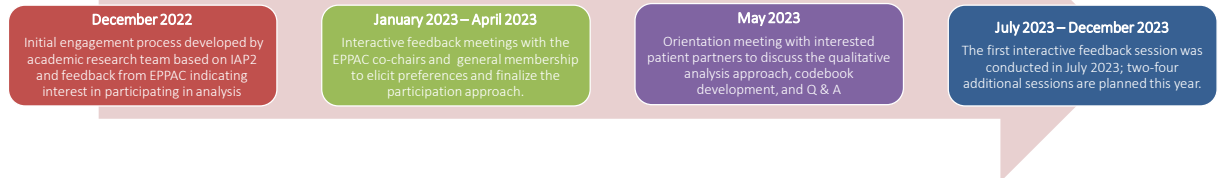
BACKGROUND

- ENhancing COMmunity health through Patient navigation, Advocacy, and Social Support (ENCOMPASS) is a study investigating the impact of a Community Health Navigator (CHN) intervention in Alberta.
- Since 2020, the ENCOMPASS Patient Partner Advisory Committee (EPPAC) has worked alongside the academic research team to provide advice on research materials and procedures.
- The study involves collection of interview data from approximately 100 respondents; the volume of data poses a challenge to including patient partners in the analysis process.
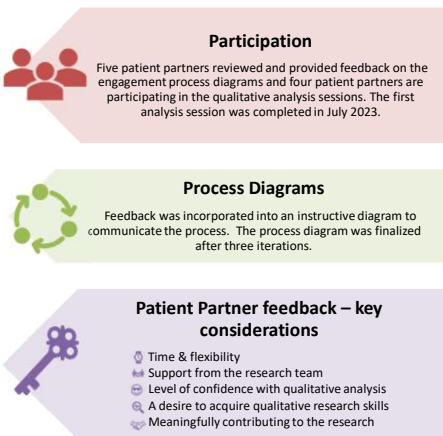
Objectives:

1. **Co-develop a meaningful, pragmatic approach to engage patient research partners in the analysis** and interpretation of high-volume qualitative data.

2. **Explore the experience of patient partners and academic researchers** participating in the qualitative analysis and refine the engagement process, as needed.
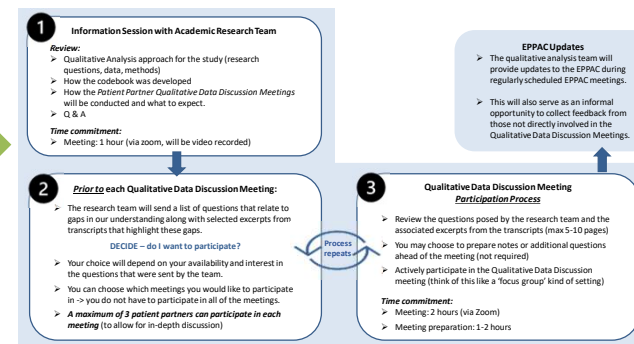
METHODS

- This engagement initiative is part of a multi-phase, mixed methods evaluation of the CHN program. We used process diagrams and feedback meetings to elicit and confirm patient preferences for engagement in the qualitative research process.
- The International Association of Public Participation (IAP2) framework was used to structure the development and co-design of the patient engagement approach.
- Detailed notes from the qualitative analysis sessions will be collected and incorporated into the overall interpretation of study results and the Public and Patient Engagement Evaluation Tool (PPEET) will be used to assess patient partner and academic research team experience (the analysis work is underway, and results will be available later this year).

December 2022	January 2023 – April 2023	May 2023	July 2023 – December 2023
Initial engagement process developed by academic research team based on IAP2 and feedback from EPPAC indicating interest in participating in analysis	Interactive feedback meetings with the EPPAC co-chairs and general membership to elicit preferences and finalize the participation approach.	Orientation meeting with interested patient partners to discuss the qualitative analysis approach, codebook development, and Q & A	The first interactive feedback session was conducted in July 2023; two-four additional sessions are planned this year.

RESULTS

Participation

Five patient partners reviewed and provided feedback on the engagement process diagrams and four patient partners are participating in the qualitative analysis sessions. The first analysis session was completed in July 2023.

Process Diagrams

Feedback was incorporated into an instructive diagram to communicate the process. The process diagram was finalized after three iterations.

Patient Partner feedback – key considerations

- Time & flexibility
- Support from the research team
- Level of confidence with qualitative analysis
- A desire to acquire qualitative research skills
- Meaningfully contributing to the research

ENCOMPASS Patient partner involvement in qualitative data interpretation (Process Diagram, version 3)

1. Information Session with Academic Research Team

Review:
- Qualitative Analysis approach for the study (research questions, data, methods)
- How the codebook was developed
- How the *Patient Partner Qualitative Data Discussion Meetings* will be conducted and what to expect.
- Q & A

Time commitment:
- Meeting: 1 hour (via zoom, will be video recorded)

EPPAC Updates
- The qualitative analysis team will provide updates to the EPPAC during regularly scheduled EPPAC meetings.
- This will also serve as an informal opportunity to collect feedback from those not directly involved in the Qualitative Data Discussion Meetings.

2. *Prior to* each Qualitative Data Discussion Meeting:
- The research team will send a list of questions that relate to gaps in our understanding along with selected excerpts from transcripts that highlight these gaps.

DECIDE – do I want to participate?
- Your choice will depend on your availability and interest in the questions that were sent by the team.
- You can choose which meetings you would like to participate in -> you do not have to participate in all of the meetings.
- *A maximum of 3 patient partners can participate in each meeting* (to allow for in-depth discussion)

Process repeats

3. Qualitative Data Discussion Meeting
Participation Process
- Review the questions posed by the research team and the associated excerpts from the transcripts (max 5-10 pages)
- You may choose to prepare notes or additional questions ahead of the meeting (not required)
- Actively participate in the Qualitative Data Discussion meeting (think of this like a 'focus group' kind of setting)

Time commitment:
- Meeting: 2 hours (via Zoom)
- Meeting preparation: 1-2 hours

Feedback after first analysis session:
- ● Patient Researchers   ▲ Academic Researchers

Strengths:
- ●▲ Small group size
- ●▲ Knowledgeable patient partners (PACER grads)
- ● Discussion was focused
- ` Adequate compensation (meeting & prep time)
- ● Appreciate being involved in designing the process & having research team's support
- ● Had information prior to meeting and knew what to expect
- ▲ New & different perspectives brought into analysis
- ▲ Patients' lived experience highlighted important factors related to CHN program delivery

Recommendations:
- ● Include a "mini" meeting prior to discussion meeting to ensure partners understand the materials and can ask questions prior to discussion meeting
- ● Consider providing more of the transcript(s) and/or provide access to audio files; this may help partners better immerse themselves in the data
- ●▲ Include some break time
- ● Fewer questions, consider broader topics, or overarching themes, rather than specific questions.

CONCLUSIONS

Sequential meetings and iterative revisions to the process diagram provided useful information about the needs and preferences of patient partners when participating in qualitative research. This co-developed approach may help to inform similar studies where the volume of qualitative data poses a challenge to meaningful patient engagement in analysis and interpretation.

Next Steps:

The qualitative analysis sessions are underway, with an anticipated completion of December 2023. **Future results will include:**

1. Additional feedback and modifications to the participation approach
2. Patient partner and academic research team experience (PPEET)
3. Any unique insights made to the ENCOMPASS study interpretation resulting from patient partner engagement

Equity, Diversity and Inclusion (EDI) & Sex- and Gender-Based Analysis+ (SGBA+) Considerations: The ENCOMPASS team strives to integrate principles of EDI by thoughtfully collaborating with diverse voices, including patient partners, PCN team members, CHNs and researchers in the study's design, conduct, and analysis. We have co-developed our engagement approach to promote equitable opportunities for participation and foster inclusivity. SGBA+ considerations are incorporated in our data analysis sessions (for example considering participant sex/gender, and health conditions/experiences that may be influenced/affected by sex and/or gender).