



EPINET QUALITATIVE RESEARCH METHODS GROUP

March 23, 2021



Agenda

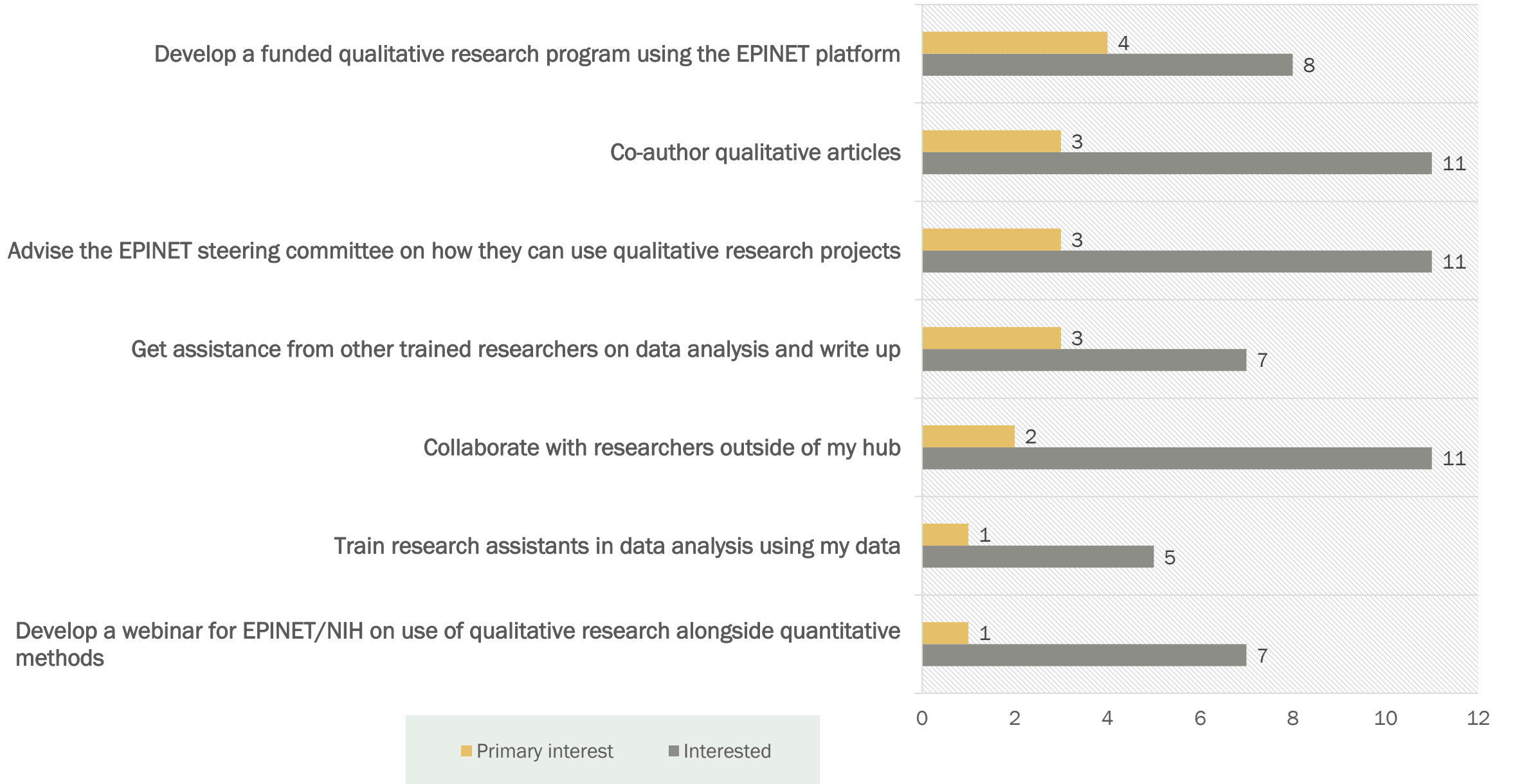
- Present survey results (15 minutes)
- How are you interested in using this group? (15 minutes)
- Structure of future meetings (15 minutes)
- Mission Statement/Longer term Goals (10 minutes)
- Homework suggestion and scheduling next meeting (5 minutes)

SURVEY SAYS....

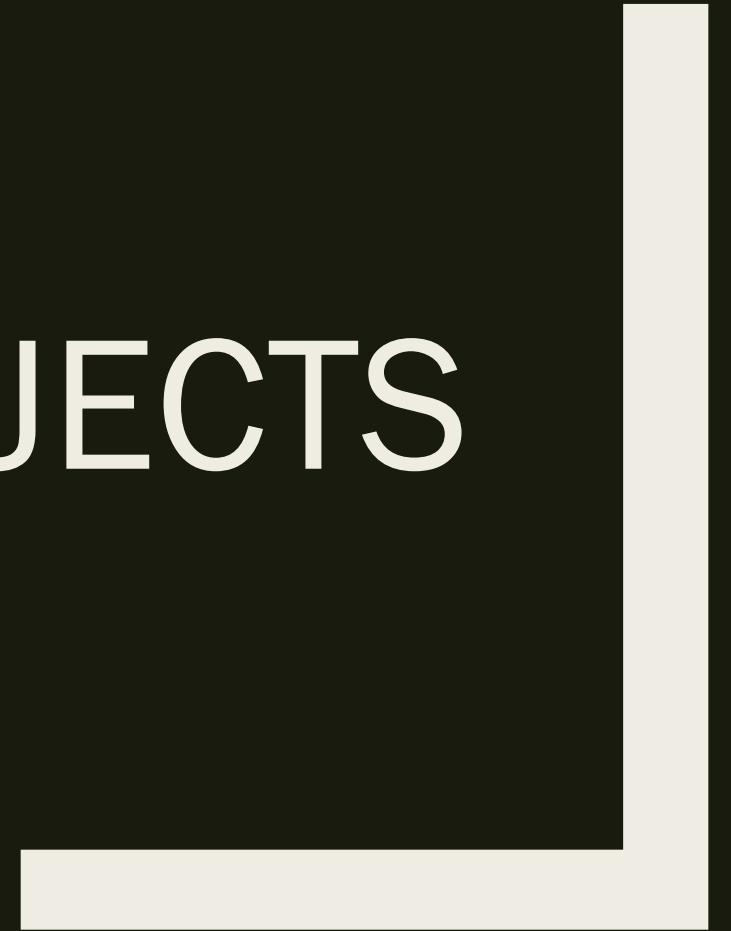
1. Please provide a description of your qualitative work that is tied to an EPINET Hub.
2. Are there other qualitative projects underway that are tied to your Hub's EPINET data collection?
3. Is there other qualitative work you are doing related to early psychosis (outside of an EPINET-HUB)?
4. Do you have any dream projects related to qualitative work and early psychosis, especially tied to EPINET? Are there particular collaborations you would like to pursue?
5. How do you want to use this group?

HOW ARE YOU INTERESTED IN
USING THIS GROUP?





POTENTIAL PROJECTS



- National prioritization of current/former service user priorities for CSC research & program development
- Improve early psychosis care for BIPOC youth and families by exploring questions related to culture and mental health equity in populations across the country
- Create a training platform to mentor qualitative researchers using these research projects and the EPINET platform
- Build a collaborative network of qualitative researchers across the country capable of pursuing large grants for more generalizable qualitative research using the EPINET platform
- Wider exploration of experiences of pathways to care, care itself, care outcomes, and the process of recovery from the perspective of stakeholders
- Qualitative studies focused on the implementation and sustainability of CSC services: what strategies, partnerships and policy level needs

- Better understand the continuous quality improvement (CQI) processes from a provider and research perspective
- Interviews of treatment participants and caregivers describing socio-emotional and life course development
- Determining the impact of systemic and structural racism and trust in institutions
- Develop a multi-channel platform for combinations of self-paced, asynchronous, and synchronous learning/intervention and peer support for CSC clients at geographic distance from each other. Could also be a useful platform for research given the challenges that small-ish client pools at each CSC program pose for most research.
- Develop and test various modes of support/intervention regarding navigating and dealing with anticipated stigma and supporting resilience, related to the intervention described above

SYNERGIES/CONNECTIONS



Methodological Creativity

- Interviews
- Focus Groups
- Coding open data –clinical notes
- Ethnography and longitudinal designs
- **Innovative methods to discuss or share?**

TOPICAL THEMES

- PEER SERVICES
- RACE, ETHNICITY, MENTAL HEALTH EQUITY
- TREATMENT ENGAGEMENT
- SUBSTANCE USE/ABUSE
- CSC AND COVID-19
- CLINICAL OUTCOMES
- IMPLEMENTATION OF CSC PROGRAMS

SAMPLE TRENDS

- TEAM LEADS
- CLIENTS (some looking for race/ethnicity-related issues)
- FAMILY MEMBERS
- NO CROSS-HUB SAMPLES

STRUCTURE OF FUTURE MEETINGS

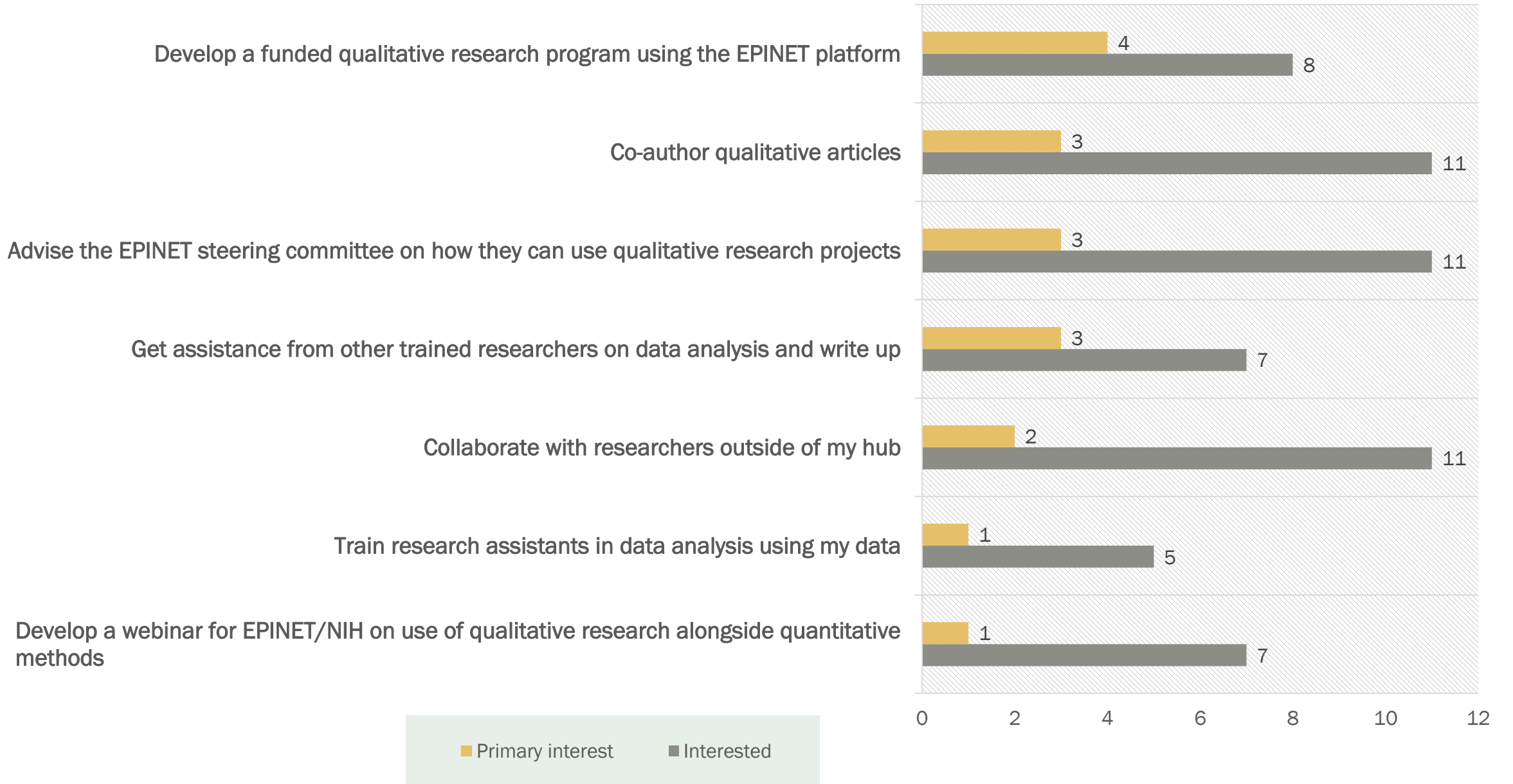


Future meetings?

- GUEST SPEAKER (15 MINUTES)—one of us, researcher/methodologist of interest, EPINET person with a question they want us to consider?
- WORKSHOP GRANT PROPOSALS (one-pager)
- WORKSHOP PAPERS
- DISCUSSIONS (methods, synergies, article collaborations, larger projects)
- MEMORANDUM OF UNDERSTANDING

POSSIBLE THEMED DISCUSSIONS

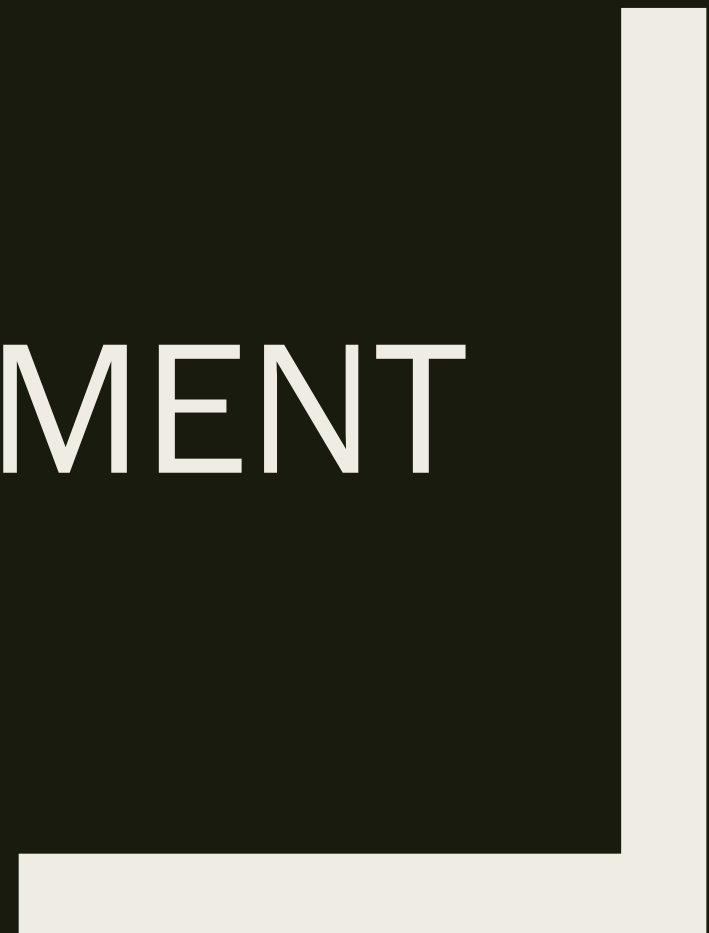
- QUALITATIVELY DRIVEN DATA HARMONIZATION ACROSS EPINET SITES—HOW DO WE HARMONIZE QUALITATIVE DATA?
- WHAT CAB DOES NOT COVER—OPEN-ENDED QUESTIONS ABOUT EXPERIENCES FOR YOUNG PEOPLE, STAFF, FAMILIES—CAN THIS BE ADDED IN A ROUTINE WAY
- HOW DO WE SAMPLE ACROSS SITES/IRB ISSUES (e.g., quality assurance exemptions)
- METHODOLOGICAL INNOVATIONS
- QUALTRICS OPEN-ENDED SURVEYS ACROSS SITES
- DEVELOPING A CROSS-HUB PLATFORM FOR QUALITATIVE RESEARCH
- DEVELOPING A TRAINING PLATFORM



LOGISTICS

- ONCE/MONTH FOR LARGER GROUP
- SET A REGULAR TIME?

MISSION STATEMENT

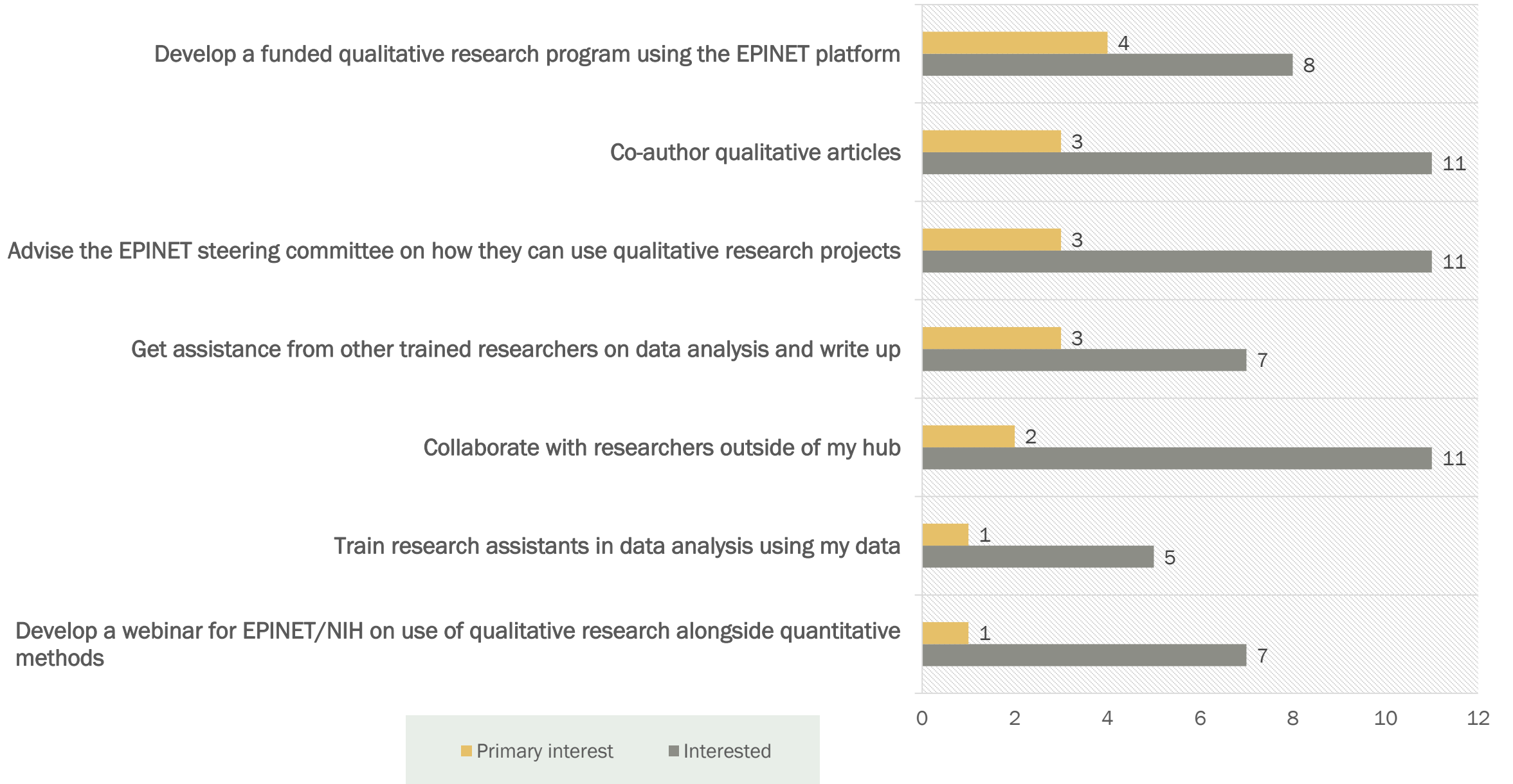


Possible Statements

- To generate qualitative research designed to improve services/supports for young persons with early psychosis and their families

LONGER-TERM GOALS





- EPINET Qualitative Research Training Platform
- Cross-hub qualitative research
- More participatory projects employing users with lived experience, family members
- Longitudinal studies
- Barriers and facilitators to meeting these goals and how can we address them?

- National prioritization of current/former service user priorities for CSC research & program development
- Improve early psychosis care for BIPOC youth and families by exploring questions related to culture and mental health equity in populations across the country
- Create a training platform to mentor qualitative researchers using these research projects and the EPINET platform
- Build a collaborative network of qualitative researchers across the country capable of pursuing large grants for more generalizable qualitative research using the EPINET platform
- Wider exploration of experiences of pathways to care, care itself, care outcomes, and the process of recovery from the perspective of stakeholders
- Qualitative studies focused on the implementation and sustainability of CSC services: what strategies, partnerships and policy level needs

- Better understand the continuous quality improvement (CQI) processes from a provider and research perspective
- Interviews of treatment participants and caregivers describing socio-emotional and life course development
- Determining the impact of systemic and structural racism and trust in institutions
- Develop a multi-channel platform for combinations of self-paced, asynchronous, and synchronous learning/intervention and peer support for CSC clients at geographic distance from each other. Could also be a useful platform for research given the challenges that small-ish client pools at each CSC program pose for most research.
- Develop and test various modes of support/intervention regarding navigating and dealing with anticipated stigma and supporting resilience, related to the intervention described above

HOMEWORK?

Review the following to look for collaborators



EPINET HUB RELATED WORK (BY GROUP MEMBERS)



EPI-CAL (Mark, Kathleen, Sabrina)

- Focus groups with stakeholders (clients, providers, families) (N=26 groups, 180 respondents)
 - To explore priorities around data collection; what domains areas should be included in the California CAB, why, and how this data should be collected (survey selection, review)
 - To review app development for data collection system and online dashboard where data can be presented and utilized in the clinical consultation
- Semi-structured qualitative interviews with stakeholders
 - To review barriers and facilitators to implementation of the data collection and presentation system. Focus on logistical, structural, and attitudinal, and software components. Particular attention given to areas that may disproportionately impact historically underserved groups.
 - To explore delivering or receiving care within a learning healthcare network that utilizes data-driven care. Aim to combine this with quantitative data collected in a mixed-methods approach.
- Methods
 - Clients, families, CSC staff, clinic and county leadership
 - Took place between October 2019 – August 2020
 - NVivo coding and content analysis

EPI-CAL (Khalima)

- Assessing the role of perceived discrimination on treatment engagement and perception of clinician rapport
 - Subjective questionnaires for perceived discrimination
 - An open ended interview regarding client's perception of clinician relationship development

OnTrackNY (Nev, Sapano)

- Client perspectives on data, data collection & measurement based care and a data dashboard
 - Focus groups/interviews; primary focus on client self-report data
- Coding administrative/clinical open text data re the nature & purpose of meetings between peer specialists & clients
- Exploring the impact of racism and discrimination on OnTrackNY participants and families

OnTrackNY (Leo, Sapanana)

- Adapting Coordinated Specialty Care Services in the Post-COVID-19 Era
- Examining stakeholders' views of OnTrack Services and how to make them better
 - Interviews and focus groups

EPINET-TX (Vanessa)

- Peer support delivery across Texas CSC sites and how peer providers discuss and support client substance use related struggles
- Methods
 - Population of focus: Peer Support Providers (N= 16-20)
 - Interviews will be conducted by individuals who have lived experience & who have served in peer provider roles
 - In-depth interviews & thematic coding
- Relates to EPINET
 - Inform a manualized peer-delivered substance use treatment approach for CSC programs to be tested as part of the EPINET-TX project

EPINET-TX (Neely)

- Substance use and early psychosis for young people with early psychosis
- Methods
 - Initial screening survey
 - Person-centered, semi-structured interviews with 30 young people about substance use and abuse and what kinds of supports they are interested or not interested in receiving
- Relates to EPINET
 - Helping design and test interventions for substance use and abuse with young people with early psychosis

EPI-MINN (Jamie)

- Focus on psychosocial functioning
 - Mixed-methods (interviews, chart reviews, project-related quantitative measures)
 - Descriptions of quality of life, social success and barriers experienced in context of ongoing clinical care

Connection LHS (Alicia)

- Better understand experiences of talking about substance use during CSC treatment (clients), trying to be supportive of a loved one with persistent cannabis use (family member), and experience of providing CSC services with a client whose cannabis use is negatively impacting health and functioning (clinicians)
 - Qualitative interviews and focus groups to be conducted through sites
 - Results will be used to adapt an existing intervention, designed for cannabis users un-interested in treatment and shown to reduce their cannabis use, to CSC clients and programs to yield reductions in cannabis use over three months, to emphasize maintaining engagement in CSC and focusing on risk reduction in the context of continued use

2. ADDITIONAL HUB PROJECTS UNDERWAY



- **EPINET-TX:** Team leader interviews about implementing new early psychosis programs using On-Track NY training in Texas: barriers and facilitators to startup and success; some COVID-related data
- **EPI-CAL:** Develop a community based assessment measure to assess Duration of Untreated Psychosis
- **EPI-CAL:** CSC provider burnout in the context of e-health readiness during the transition to telehealth in Covid using quantitative as well as open-ended questions about strengths and challenges in their organization pre-covid and post-covid, and what is contributing to burnout and wellness
- **OnTrackNY:** COVID-19 related studies and how OnTrack has adapted to the pandemic; also others

3. NON-EPINET WORK



■ Danni

- Black individuals and their family members on pathways to care and CSC services
- Exit interviews with CSC providers to understand reasons for leaving and program improvements
- Interviews with family members as part of a mixed methods study focused on family engagement
- Focus groups with CSC providers about barriers and facilitators addressing substance use

■ Mark

- Focus groups exploring stakeholder experiences concerning end user licensing agreements (EULA's) for software used in a mental health setting. Aim to develop guidelines to enable a much more approachable/focused EULA based on stakeholder priorities relative to industry standard.

■ Nev

- CSC client experiences of peer support
- Former client/family experiences during & following discharge from CSC
- Provider perspectives on trauma, disadvantage & cultural difference in CSC
- Systematic review of the global qualitative literature on psychosis – focus on under-represented cultural groups & regions; systematic review as an integrated component of the Lancet Commission on Psychosis

■ Neely

- Young people's (primarily African American and Latinx) treatment decision-making during the first six months after an initial hospitalization for psychosis
 - Used longitudinal, team-based, ethnographic research with young people and their families; 2 interviews with key supporters and 4 interviews with young person and ethnographic home visits
 - 5,000 pages of interview data and fieldnotes; currently writing articles and a book from the data

■ Alicia

- Working to secure resources to do a clinical demonstration project of an intervention I created with colleagues to assist CSC clients in navigating stigma and its identity / self concept impacts from a resilience and empowerment framework. Hope is to use the clinical demo to refine the intervention and as preliminary data for a later funded study. Collaborators welcome.

■ Leo

- Developing a multi-level health promotion program that can be integrated into OnTrack. Sequential mixed method intervention development process using a collaborative intervention development approach. To develop this intervention, we are using a systematic literature review, secondary analyses of existing OnTrack health and healthcare use data and interviews and focus groups with providers, clients and their family members
- On Track Chile For First Episode Psychosis (R01MH115502: MPI; Alvarado, Dixon, Susser and Cabassa) Clustered randomized effectiveness/implementation hybrid type 1 trial examining the adaptation, implementation, effectiveness and costs of an adapted ONTrack program in Santiago, Chile. We are using a mixed-method longitudinal design to capture the dynamic adaptation and implementation of Ontrack Chile and examining its implementation via semi-structured qualitative interviews with providers, administrators and policy makers, focus groups with clients and their family members, participant observations of clinical supervision meetings and site visits, as well as two waves of surveys with clinicians and clients.

■ Leo

- Leading the Qualitative Research Methods Core for the Optimizing and Personalizing Interventions for Schizophrenia Across the Lifespan (OPAL) (P50MH115843; PI Stroup), an NIMH ALACRITY Center. The goal of OPAL is to accelerate the adaptation, development and implementation of effective, personalized treatments in real-world settings by creating an infrastructure that supports research that tests innovative ways to optimize treatments for people with schizophrenia throughout the lifespan and that accelerates the translation of clinical research on schizophrenia to routine practice settings, conducting exploratory and pilot projects that develop, adapt, and test innovative methods to personalize treatments for schizophrenia and to make them effective and readily deployable, and training scientists who will conduct translational research on services and treatments for persons with schizophrenia
- Book project under contract with Oxford University Press on the physical health inequities of people with serious mental illness. The book manuscript has been submitted to published and is currently under review and production. The book focuses on examining why people with SMI die at a much earlier age than the rest of the population and what is being done to address these persistent and growing health inequities. It draws from the existing literature, multiple mixed-methods studies that our team has conducted, including two intervention studies, and a series interviews with experts in the field. The book is intended for a informed general audience. The working title of the book: Our Failure to Act: Understanding and Ending Health Inequities in People with Serious Mental Illness