Community Partner Perspectives on Data Collection Priorities as Part of Early Psychosis Care: A Focus Group Study to Inform the EPI-CAL Assessment Battery

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Background

EPINET has created a network of over 100 early psychosis programs committed to the systematic collection of data (see Figure I). Collecting such data in routine care can facilitate service improvement, support care delivery, and open critical new avenues for research and innovation. However, to maximize the utility of such an approach, it is critical for the data collected to reflect the priorities of everyone involved.

Methods

A mixed methods focus group study was completed with providers, clients and family members from EPI-CAL sites to explore data collection priorities.

Domains were selected from a prior county engagement process detailed in Niendam et al., (2018). Measurement tools were selected from the PhenX toolkit.

Participants identified critical domains at the start and end of each focus group. Heat maps were developed to display the proportion of votes per domain by participant role.

An inductive thematic approach was used to analyze the focus groups. Data was triangulated using Farmer's (2006) protocol.

Table 1: Focus Group Details by site

Focus Group Number	Location	Type	Language	Number of Participants N = 189	Date
1	Solano - SOAR	Provider	English	9	10/8/2019
2		Client	English	8	2/6/2020
3		Family	English	8	2/6/2020
4	Sacramento - EDAPT / Sac EDAPT	Provider	English	13	12/13/2019
5		Client	English	9	1/16/2020
6		Family	English	8	1/22/2020
7		Family*	Spanish	4	4/28/2020
8	UCSD - CARE	Provider	English	7	12/16/2019
9	San Diego - Pathways Kickstart	Provider	English	18	12/16/2019
10		Client	English	7	12/16/2019
11		Client *	Spanish	1	5/15/2020
12		Family	English	4	12/16/2019
13		Family *	Spanish	1	5/14/2020
14		Family *	Spanish	1	5/14/2020
15	UCLA - Aftercare	Provider	English	8	1/29/2020
16	UCLA - CAPPS	Provider	English	10	1/29/2020
17	Orange – OC CREW	Provider	English	15	1/20/2020
18		Client	English	4	1/30/2020
19		Family	English	3	1/30/2020
20		Family *	Spanish	2	11/3/2020
21	San Mateo - Felton	Provider	English	12	2/3/2020
22		Client	English	10	2/3/2020
23		Family	English	6	2/4/2020
24	UCSF - PATH	Provider*	English	4	6/25/2020
25	LA County - PIER	Provider*	English	12	8/26/2020
26		Client*	English	1	8/26/2020
27		Family*	English	4	8/31/2020

*Conducted via Zoom due to shelter in place order

Figure 1. The EPINET Network

EPINET National Data Coordinating Center
Westat • Rockville, MD

EPI-MINN — University of Minnesota, Minneapolis, MN
LEAP — McLean Hospital, Belmont, MA
ESPRITO — Feinstein Institute for Medical Research, Manhasset, NY
EPI-CAL — University of California, Davis, CA
OnTrackNY — New York State Psychiatric Institute, New York City, NY
AC-EPINET — Indiana University-Purdue University of Indianapolis, IN
Connection LHS — University of Maryland, Baltimore, MD
EPINET-TX — University of Texas, Austin, TX

Findings

Nature of Data Collected

Concrete Metrics: *Pros*: a) More accurate, b) track objective progress (important for Hispanic families), and c) useful for clinic promotion. *Cons*: Too narrow.

"I think for ethnic minorities, maybe particularly Latino families, that concreteness of seeing their daughter or son going back to school, it's something tangible to them that really I think makes a big difference."
Site ID: 467, Provider

Abstract Metrics: *Pros:* a) Quicker interpretation, b) conversation starters, c) clients frame own strengths and needs. *Cons:* a) Too open for interpretation, b) impersonable and c) tiresome.

"Because everyone's experiences are so different and we all have different ideas of what they should mean."
Site ID: 122, Client.

How Data Should be Collected

Accuracy:

Client Rated: *Pros:* a) More honest in writing. *Cons:* a) Fallible memory, b) mood impacting reporting, c) social desirability, d) symptoms interfering.
Clinician Rated: *Pros:* a) Explanation of terms, b) history, c) behavioral cues. *Cons:* a) Lack of consistency across clinics and clinicians, b) overestimation of adherence.
Collateral Rated: *Pros:* a) Clarify client rated. *Cons:* a) Unaware, b) lying (especially in abusive homes), c) more accurate when confidential from client.

"[...]Patients are more honest on questionnaires."
Site ID: 904, Provider

"Early on in his treatment he couldn't tell you what the appropriate answer is because he's trying to figure out."
Site ID: 840, Family

Burden:

Provider Burden: Clinician rated metrics burdensome dependent on if a) standard part of care, b) additional, or c) redundant.
Client Burden: Ease of writing vs talking dependent on a) subject, b) mood, and c) therapeutic alliance.

"I don't feel like I need another tool to assess whether a participant is suicidal or not. Because we're pretty great already at kind of determining that"
Site ID: 274, Provider

"On the first test I got when I came here, I started drawing little treasure maps and stuff because I didn't want to give away that stuff. You want to talk this from me. You got to establish trust with the person."
Site ID: 122, Client

How Data can be Used / Be Impactful

Data Utility:

Program Level: a) External reporting, b) self evaluation, c) reduce redundancy.
In Care: See client changes overtime to a) share in session, and b) inform care.

"That's important for me to be able to [...] show my client that even though sometimes it can feel like you're not back to where you want to be, you've made tremendous progress, and that shouldn't be undersold."
Site ID: 467, Provider

"Right, then again, I just think – When we wanted to promote our clinic, we want to be able to say that 75% go back to college."
Site ID: 825, Provider

Figure 2: Domain Prioritization by Role
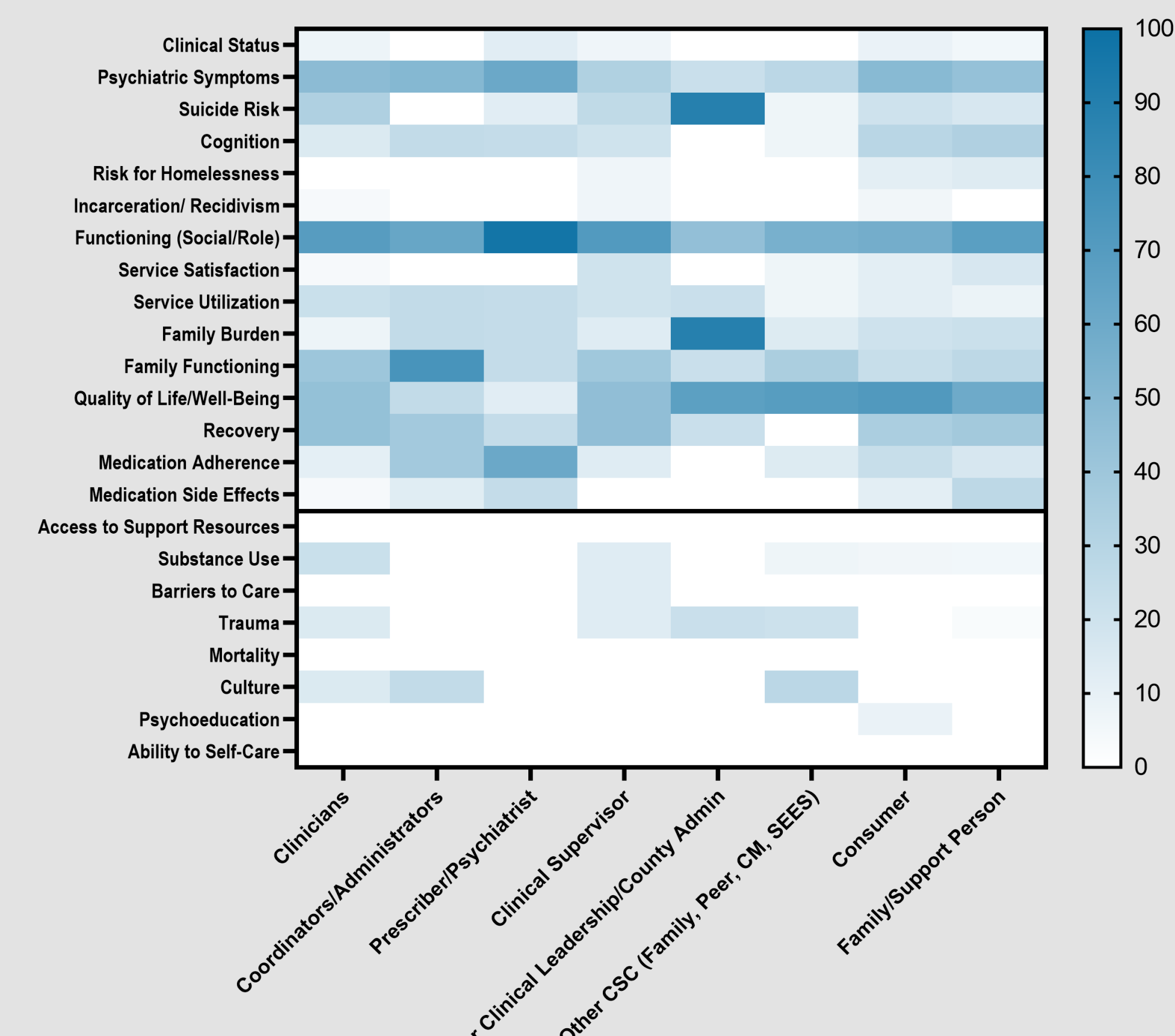
Domain importance across roles
Functioning, quality of life, psychiatric symptoms highest proportion of votes.

Domain importance by role
Prescribers: Med adherence, side effects, symptoms.
Case Managers: Functioning, quality of life, utilization, family functioning.
Family Therapy: Family functioning and family impact (i.e. burden).

Peer/Case Manager: "In my role, I don't talk about symptoms, I mean, I talk about symptoms, but not as frequent. I talk about the functioning social role, quality of life, service utilization, family function at times."
Site ID: 467, Provider

Figure 3. Moderators and Predictors
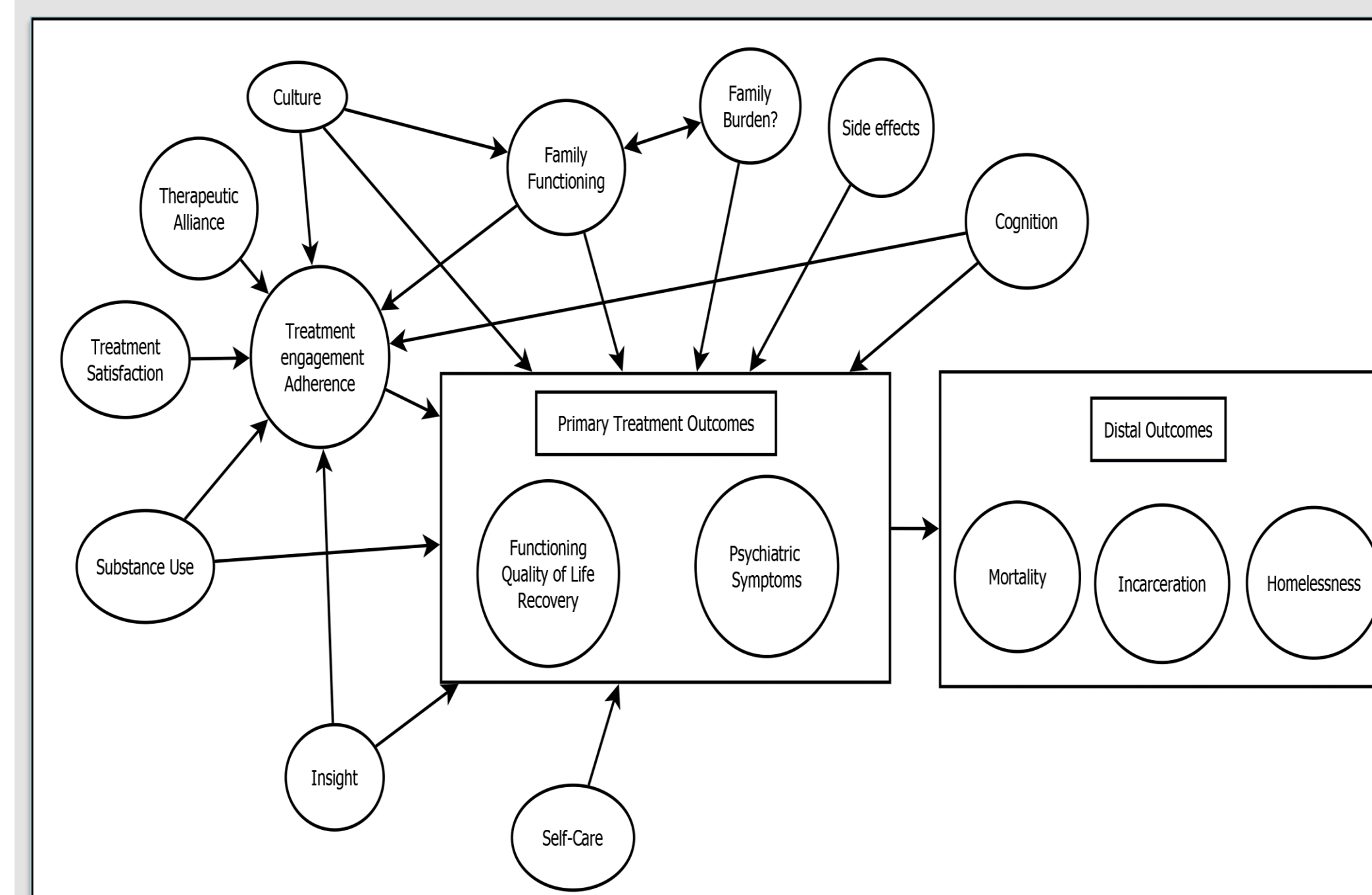
Moderators and Predictors
Quality of life, functioning, recovery, and symptoms were seen as key outcomes. Others seen as critical a predictors of outcome (see figure 3).

"Family functioning is really important for how the patient functions. [...] family functioning as a step along the way. It's not an outcome in it of itself."
Site ID: 904, Provider

Outcomes with Low Prevalence in EP Care
Homelessness, incarceration, and mortality seen as key outcomes in psychosis, but more distal given current age and presentation of clients they serve and so given lower priority.

"Because of their very young age, they may have a risk for it at a later date, but not while we're seeing them so much."
Site ID: 122, Provider

Conceptualization of Constructs

Conceptual Overlap of Quality of Life, Functioning and Recovery: Participants discussed the overlap between domains, "quality of life," "functioning," and "recovery."

"Is there not a measure that combines the social and role functioning with quality of life and well-being? I mean this feels, to me it feels odd that we're separating out those things."
Site ID: 274, Provider

Recovery-Oriented Strengths Based Approach: Participants highlighted a) preference for "I" statements, b) a dislike of term "family burden," c) dislike of negative questions, and d) importance of items based on client priorities.

"I see my client looking at me, 'what do you mean I'm a burden?' I don't want to create that experience in a session."
Site ID: 122, Provider

"The problem is other measures that are confounded by some of our objective paternalistic sense of what we think someone's quality of life should look like."
Site ID: 467, Provider

Broadening of Conceptualization: Broadening a) background to include culture, b) cognition to social cognition, c) justice involvement to police contacts, d) family impact (formerly burden) to financial, social, vocational, health, e) family functioning to communication dynamic, views and support of treatment, f) medication adherence to satisfaction with meds.

"Medication satisfaction, [...] So, while there may be presence of side-effects, is what is happening for you worth it?"
Site ID: 122, Provider

Suitability to Audience: Participants discussed suitability by age, language choice, and desiring more sensitive scales.

"But you don't see that reflected, because they're not able to go to school or work for whatever reason because their illness is so severe, but they've still made tremendous gains."
Site ID: 467, Provider

Conclusion

1. While there was consistency across participants in the importance of primary outcomes (functioning, quality of life, recovery, psychiatric symptoms), there were notably different prioritizations between roles for the remaining domains, highlighting the importance of engaging all partners involved in care.
2. Recording predictors of outcomes was seen as critically important, particularly modifiable ones, differing from our original goal of determining key outcomes. This highlights the differences in research and clinical priorities around data collection.
3. Outcomes around homelessness, incarceration, and mortality, while viewed as important in psychosis, were not selected as critical for EP data tracking due to their low prevalence in this stage of care.
4. The engagement process led to critical insights around the language used, what data to collect, and how to collect it.
5. These findings significantly informed the data collection battery utilized both within EPI-CAL and EPINET more broadly.