Utilizing Qualitative Methods to Inform the Design and Implementation of a CSC Learning Healthcare Network

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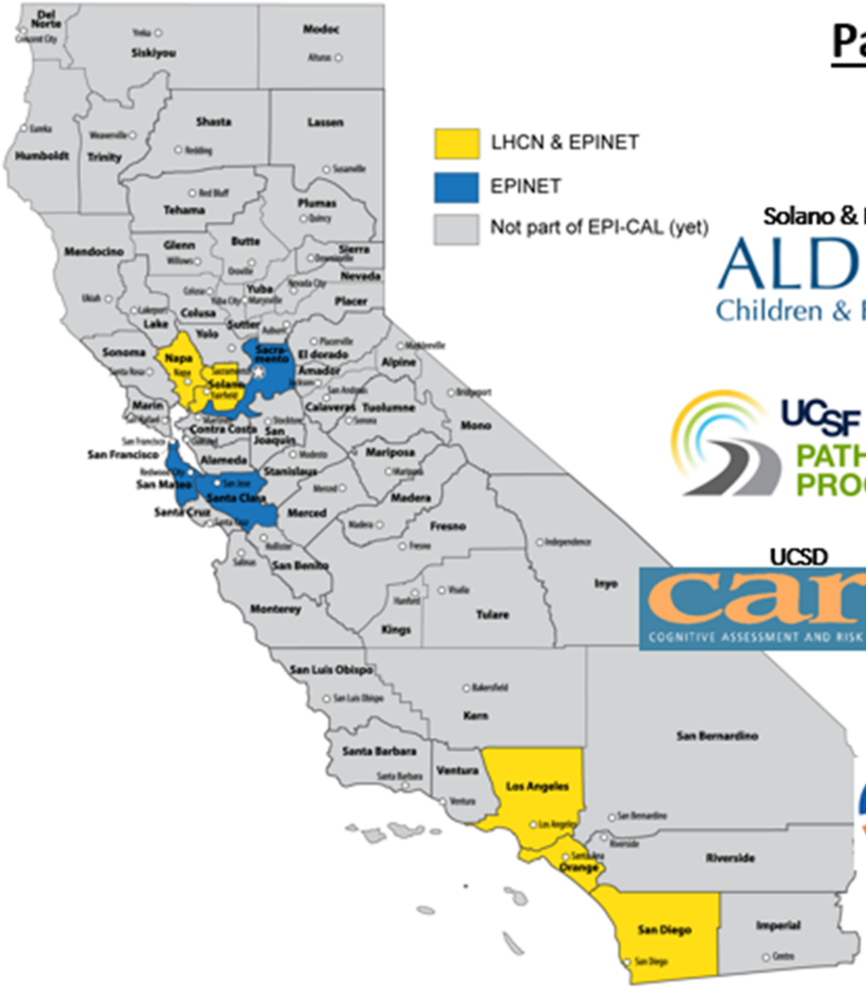
EPI-CAL

ACCELERATING RECOVERY

PROMOTING DISCOVERY

The EPI-CAL Network



🟨 LHCN & EPINET

🟦 EPINET

⬜ Not part of EPI-CAL (yet)

Participating Clinics & Counties

Solano & Napa SOAR
ALDEA
Children & Family Services

The EDAPT Clinic

SacEDAPT

UCSF
PATH PROGRAM

San Mateo
(re)MIND™
Felton BEAM UP™
Felton institute

OC health CARE AGENCY
Orange County CREW

UCSD
care
COGNITIVE ASSESSMENT AND RISK EVALUATION

San Diego
Pathways™
kickstart

Stanford
INSPIRE
CLINIC

5 PIER Programs
LOS ANGELES COUNTY
DEPARTMENT OF MENTAL HEALTH
hope. recovery. wellbeing.

SEMEL INSTITUTE UCLA
CAPPS
Center for the Assessment and Prevention of Prodromal States
Aftercare

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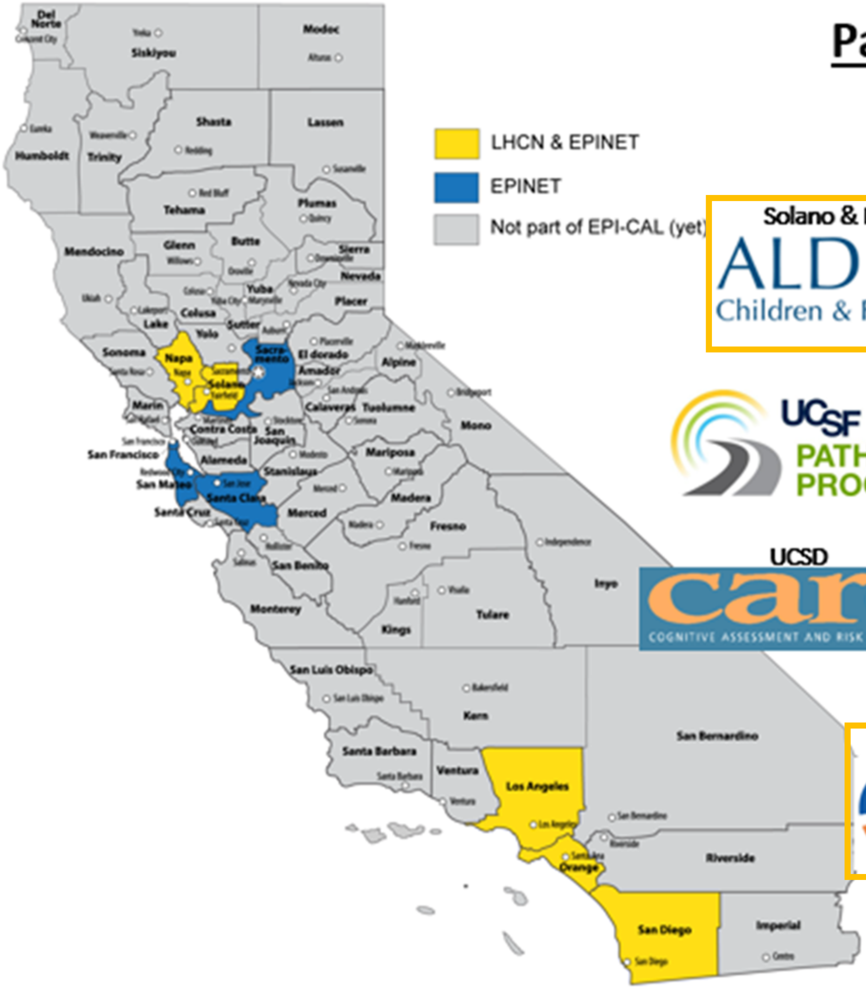

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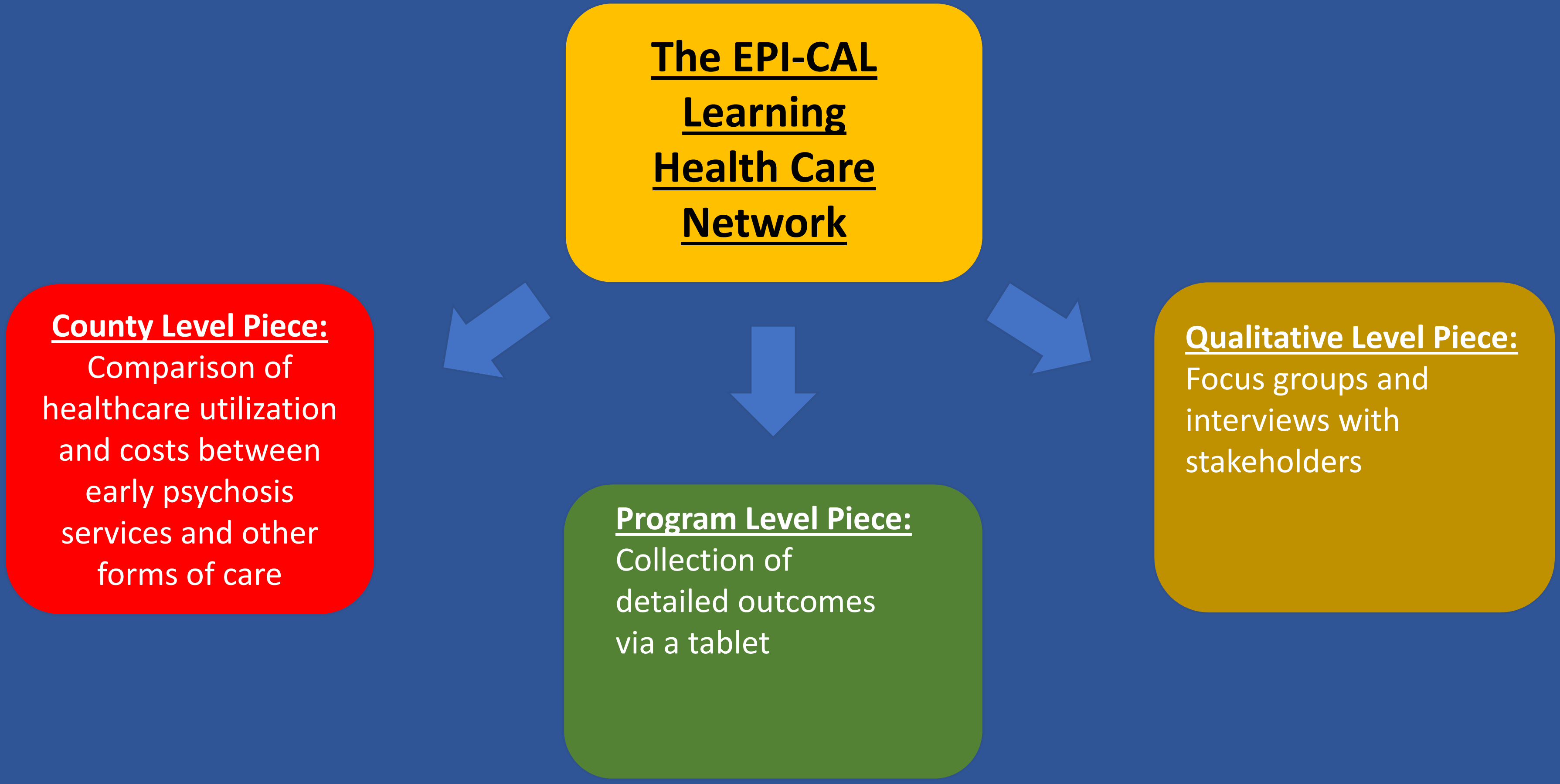
The Structure of EPI-CAL



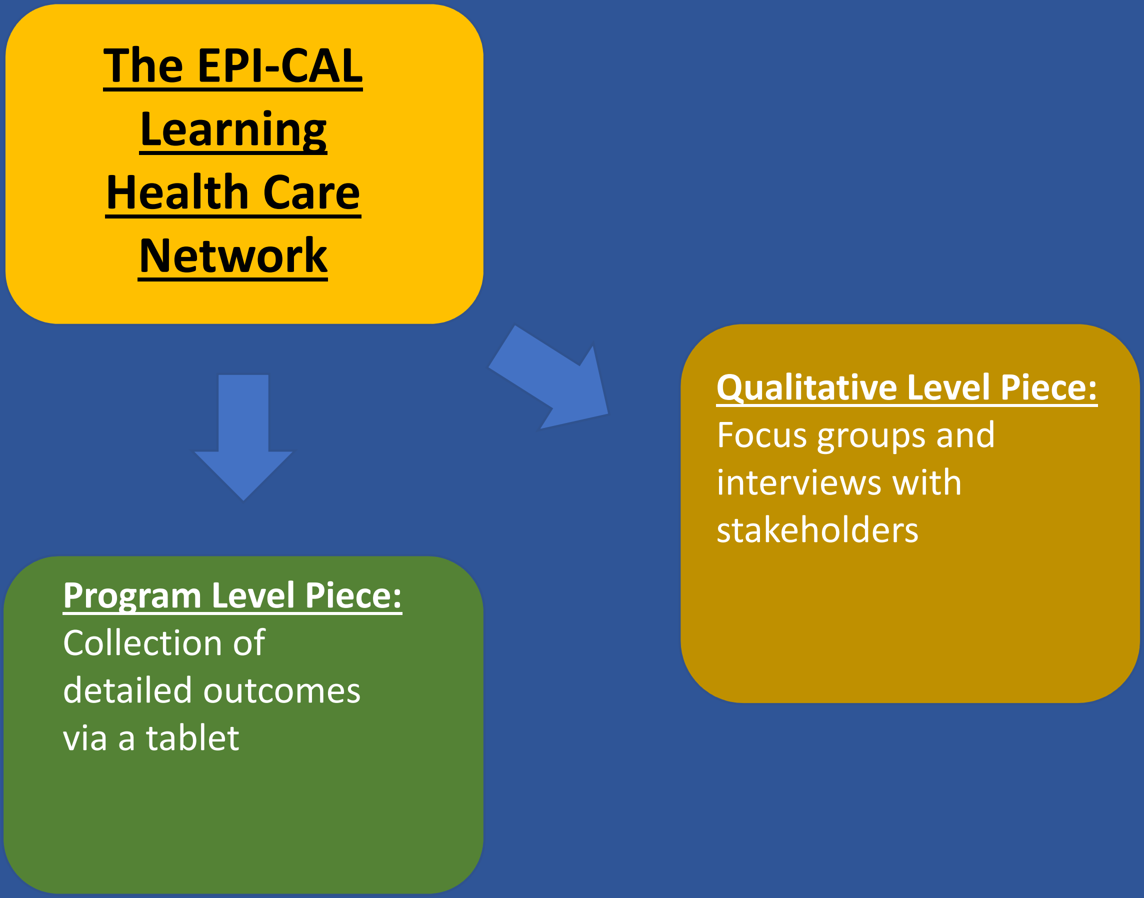
The EPI-CAL Learning Health Care Network

County Level Piece: Comparison of healthcare utilization and costs between early psychosis services and other forms of care

Program Level Piece: Collection of detailed outcomes via a tablet

Qualitative Level Piece: Focus groups and interviews with stakeholders

The Structure of EPI-CAL

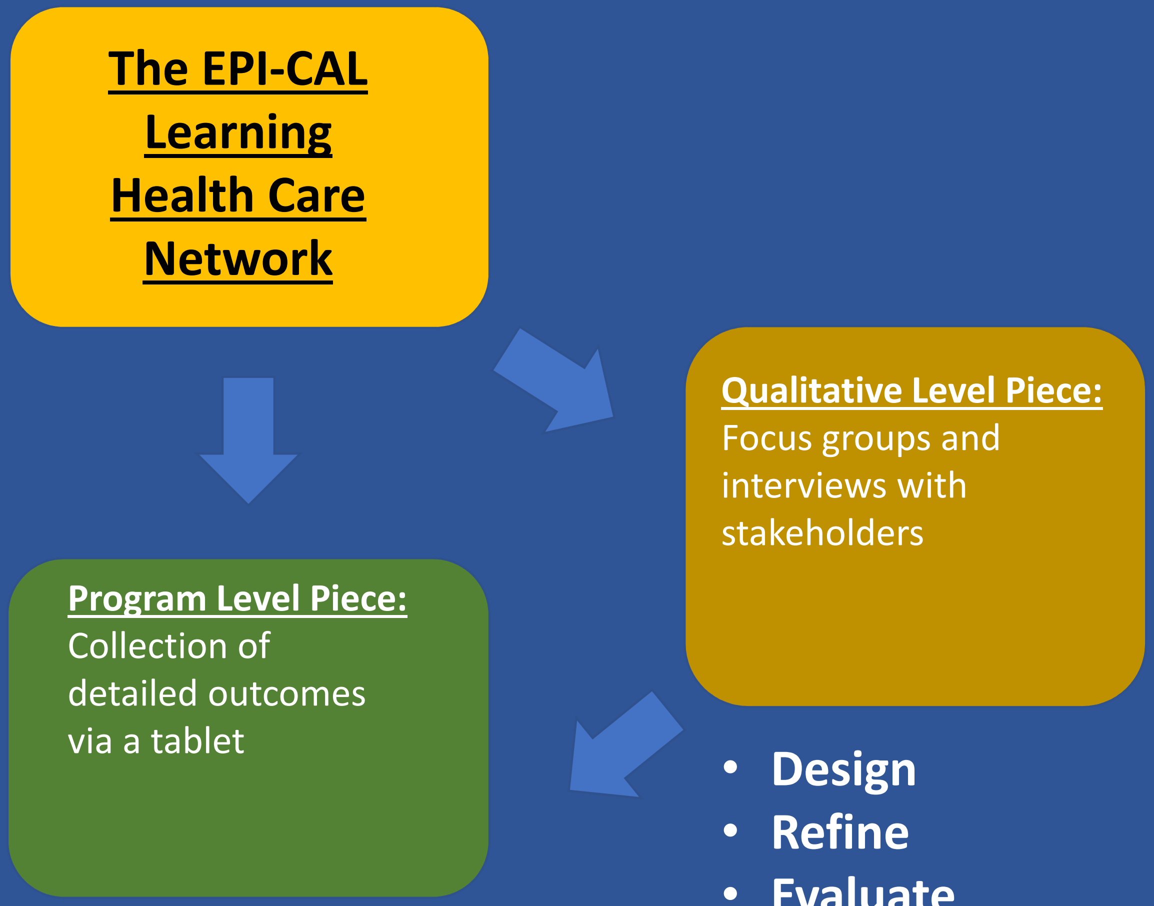


The EPI-CAL Learning Health Care Network

Program Level Piece:
Collection of detailed outcomes via a tablet

Qualitative Level Piece:
Focus groups and interviews with stakeholders

The Structure of EPI-CAL



The EPI-CAL Learning Health Care Network

Qualitative Level Piece: Focus groups and interviews with stakeholders

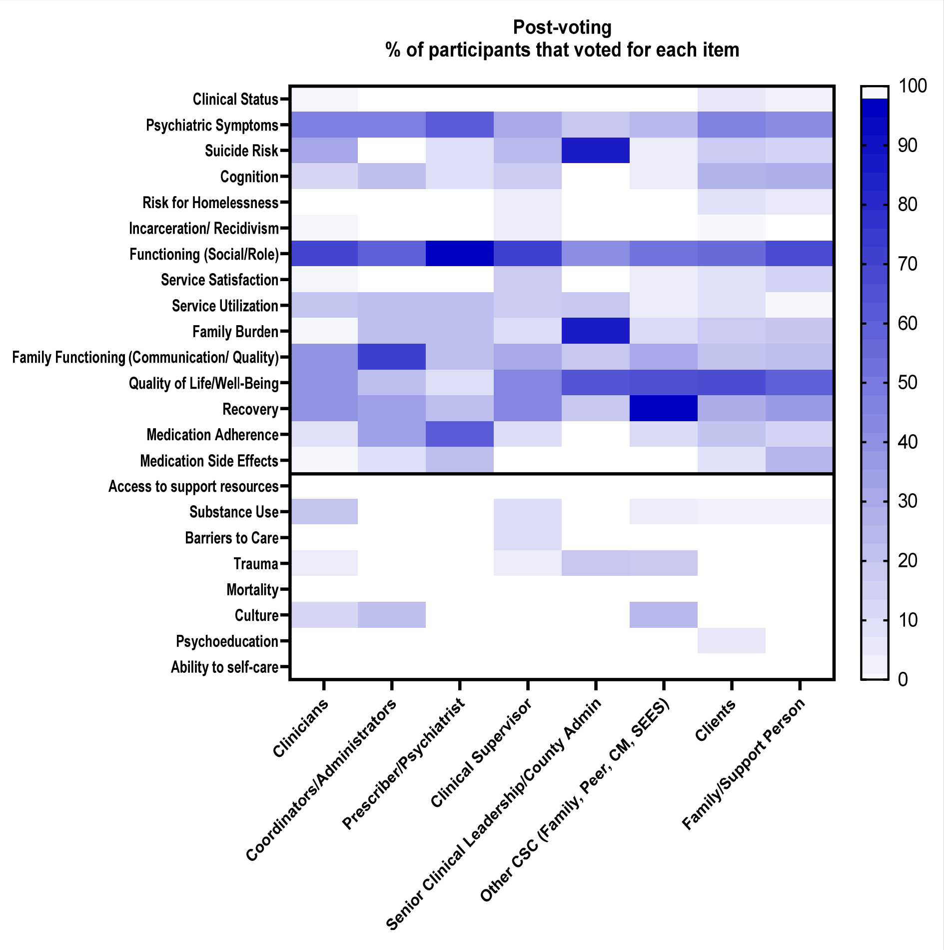
Program Level Piece: Collection of detailed outcomes via a tablet

- **Design**
- **Refine**
- **Evaluate**

Design Phase Aims

1) Document stakeholder priorities around data collection
    - 26 focus groups, 184 participants (43 clients, 107 providers, 34 family members)
2) Develop the data collection and presentation platforms
    - 14 focus groups, 74 participants (8 clients, 45 providers, 9 family members, 12 researchers)
3) Understand what information clients feel is most important to make an informed choices around data sharing (EULAs)
    - 3 focus groups x2, 24 unique participants (6 clients, 14 providers, 4 family members)

Data Domains Prioritization



- **Functioning** most frequently cited across all stakeholder roles. **Quality of Life, Psychiatric Symptoms, Recovery,** and **Family Functioning** also frequent selections.

- Reasonable heterogeneity across stakeholder roles.
  - **Prescribers** have greater focus on *Medication Adherence*
  - **Senior leadership** particular focus on *suicide risk*.
  - *Recovery* primary focus to **SEES/peer staff**.
  - *Cognition* seems more important to **clients** and **family members** than providers.

Informing Domain Selection

Appropriateness of specific terms [i.e., "Family Burden"]:

> *"…it does impact the family, but you don't ever want to let them know and make them feel like a burden. Burden is so negative. Such a downer word."*

Family Group, ID: 476

Data collection priorities:

> *"What I'm saying is that recovery, quality of life, all of that stuff: the stuff that dictates how that person will live their life from that point on. I think those are the most important things to track because those are the things that have the most significance."*

Consumer, ID: 284

Level of detail necessary to inform care:

> *"For me, it would be less about just a dichotomous "yes you have substance use disorder" or "no you don't," and more about current level of use quantity. The method of use. Type of use.* […] *Because I think that mediates outcomes, right?"*

Provider Group, ID: 476

Informing Domain Selection II

Significance of self-report

“Yeah, I think that everyone -most people- are sharing is that sense of empowerment and having this opportunity to hear the voice of the clients, and that's very important.”

Provider Group, ID: 467

Clinical Utility of longitudinal data collection

“I think it [measuring recovery] kind of encourages the clients to really self-reflect, and I think it's really hopeful. I have a lot of clients do these, and they'll express, "I'm pretty sure I marked this on the last one, so I feel like I'm improving," and I think that self-reflection's really validating for them.”

Provider Group, ID: 303

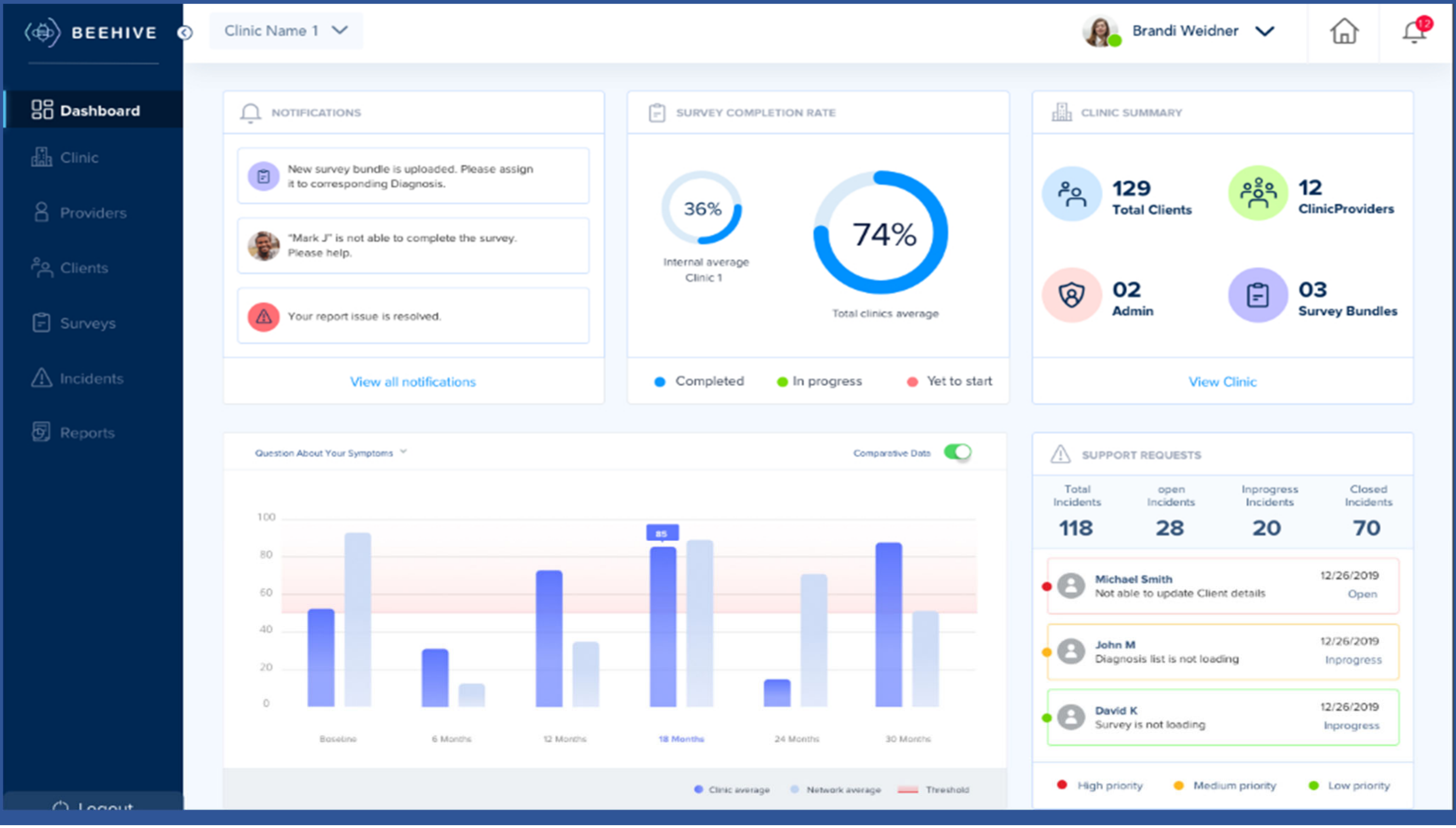
Importance of modifiers/predictors of outcome

“I think some level of a measure regarding therapeutic alliance will be helpful. […] I think it helps to be able to understand how well there is a relationship established between you and the clients, and how that affects the outcomes and their engagement within treatment.

Provider Group, ID: 467

Wireframe Focus Groups

Developing the Beehive Platform



New survey bundle is uploaded. Please assign it to corresponding Diagnosis.

"Mark J" is not able to complete the survey. Please help.

Your report issue is resolved.

129 Total Clients

12 ClinicProviders

02 Admin

03 Survey Bundles

Total Incidents	open Incidents	Inprogress Incidents	Closed Incidents
118	28	20	70

Michael Smith 12/26/2019
Not able to update Client details Open

John M 12/26/2019
Diagnosis list is not loading Inprogress

David K 12/26/2019
Survey is not loading Inprogress

Designing the Platform

"My thought it is with the progress bar, if it were a different color it would be easier to see."

Provider Group, ID: 501

"Yeah therapy is for individuals, and individuals should not be compared to others. It makes sense for the clinic to need to look at the data, but the parent or client doesn't want to know about that data."

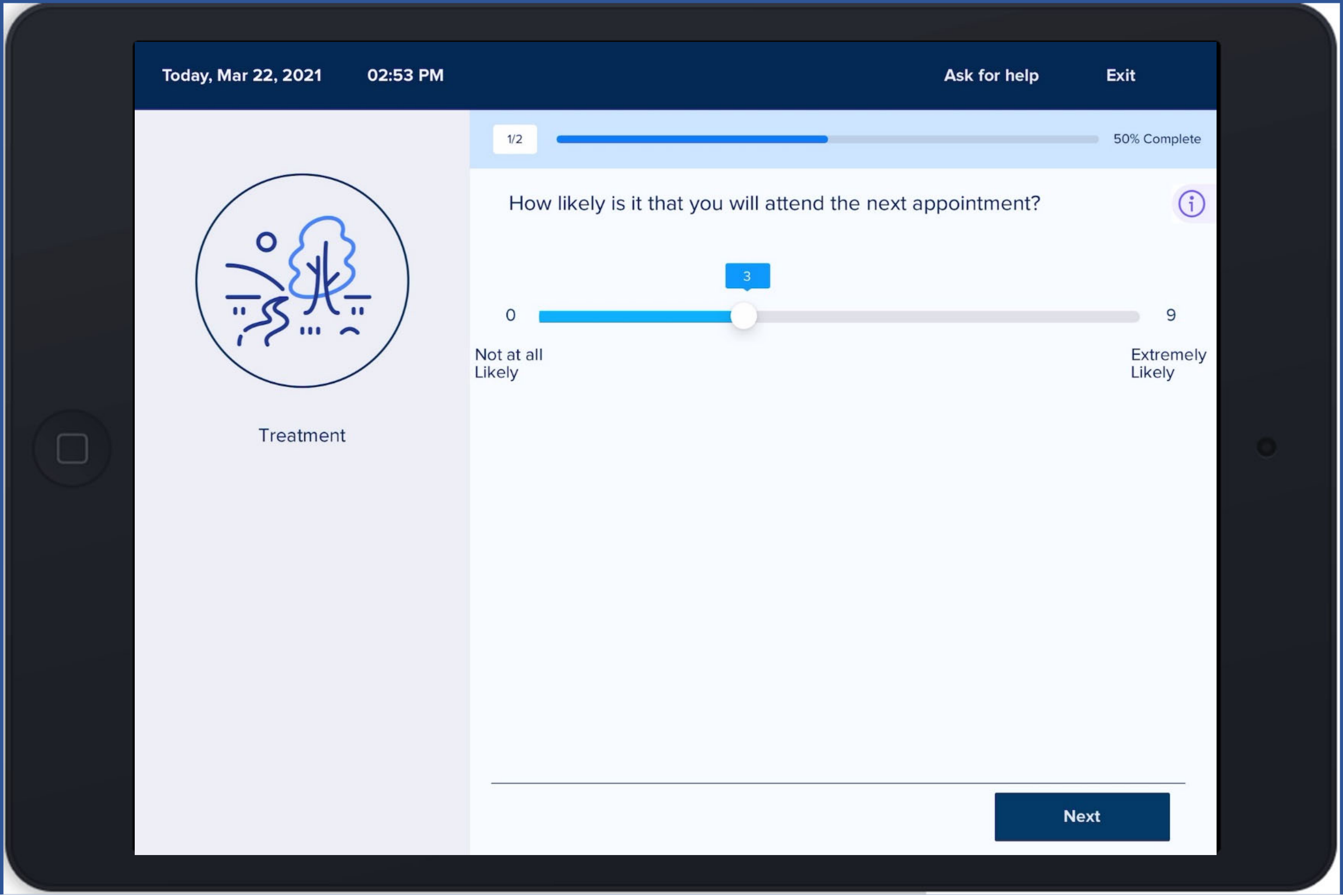
Client and Family Group, ID: 422

"From an administrator perspective, they'll want demographics and diagnosis. A pie chart that shows race, ethnicity, gender. When I think of a dashboard, I want graphic displays of data."

Clinic Admin Group, ID: 415

“My thought it is with the progress bar, if it were a different color it would be easier to see.”

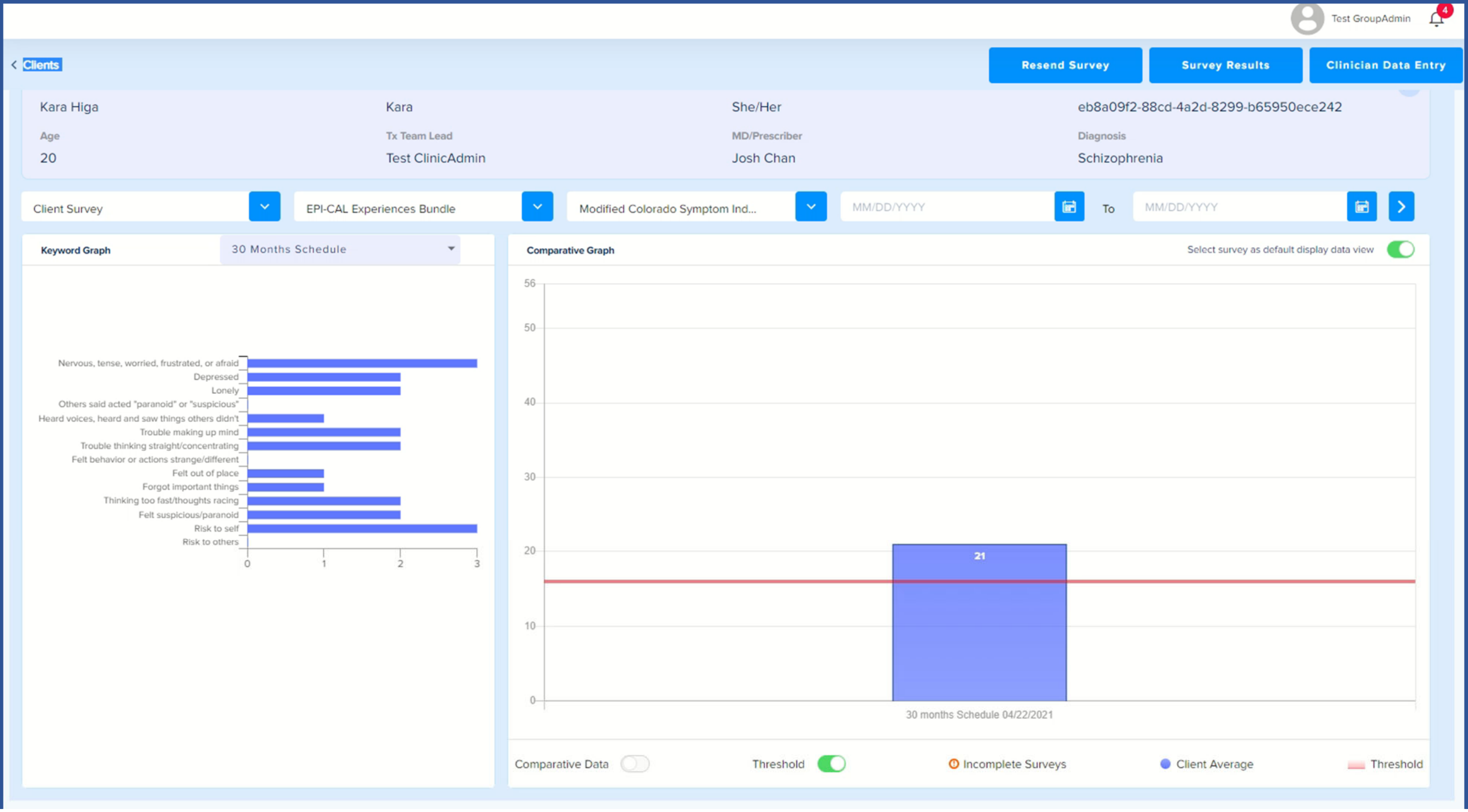
(Provider Group, ID: 501)



Today, Mar 22, 2021 02:53 PM

How likely is it that you will attend the next appointment?

“Yeah therapy is for individuals, and individuals should not be compared to others. It makes sense for the clinic to need to look at the data, but the parent or client doesn’t want to know about that data.”
(Client and Family Group, ID: 422)

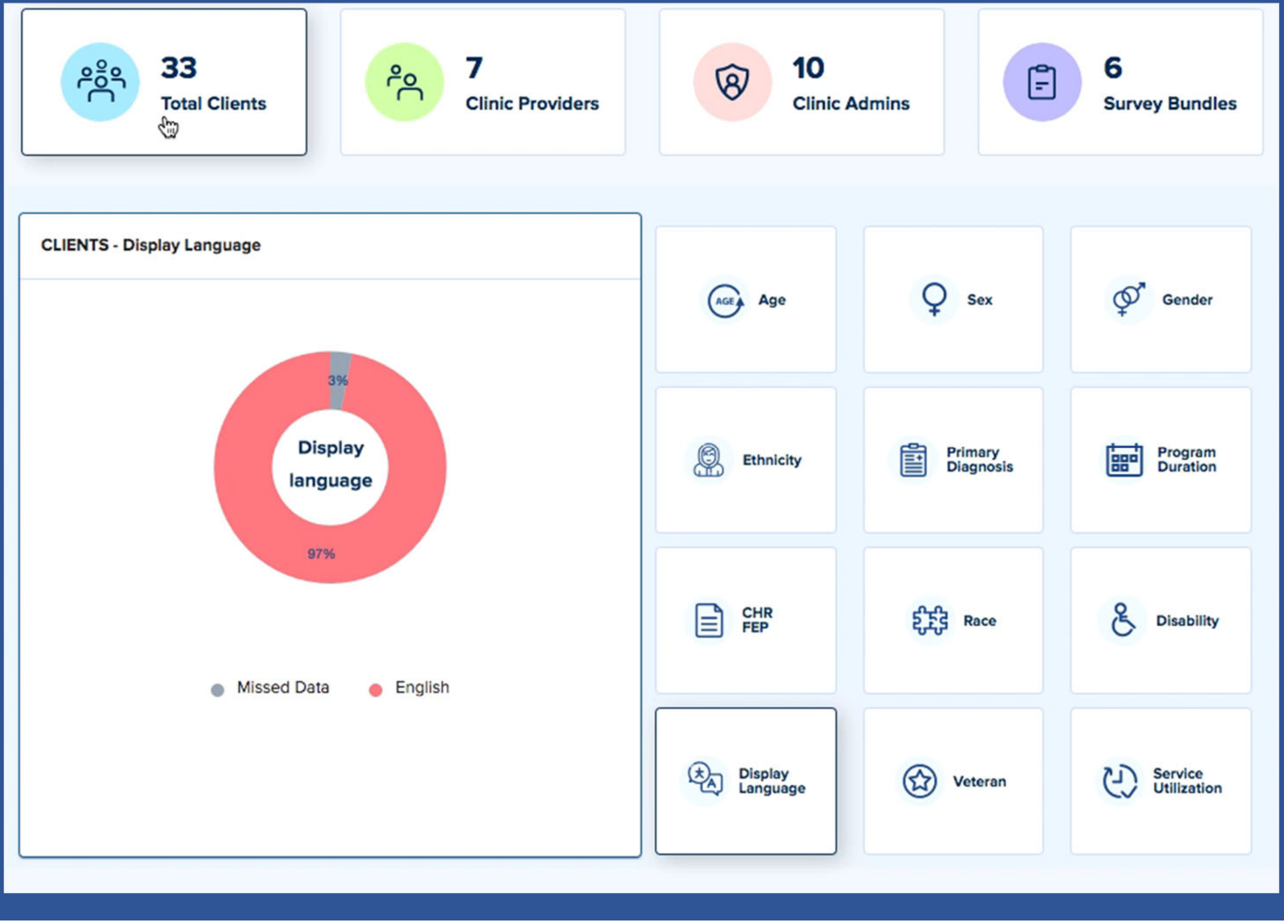


Kara Higa
Kara
She/Her
eb8a09f2-88cd-4a2d-8299-b65950ece242
Age: 20
Tx Team Lead: Test ClinicAdmin
MD/Prescriber: Josh Chan
Diagnosis: Schizophrenia

Client Survey
EPI-CAL Experiences Bundle
Modified Colorado Symptom Ind...

“From an administrator perspective, they’ll want demographics and diagnosis. A pie chart that shows race, ethnicity, gender. When I think of a dashboard, I want graphic displays of data.”

(Clinic Admin Group, ID: 415)



33 Total Clients

7 Clinic Providers

10 Clinic Admins

6 Survey Bundles

CLIENTS - Display Language

Understanding Data Sharing
and
End-User License Agreement (EULA)
Focus Groups

A Few Core Themes

- Transparency

"… I feel like our clients would ask, "What is going to be shared and why?…why do we want to do this? I think [the benefits] is what could maybe sway somebody one way or another, and then understanding exactly…which de-identified information is going to be shared and how that will be beneficial." Provider Group, ID: 811

- Communication

"I teach all our trainees to…know how to talk about it [consent] in layman's terms, so that people really understand and make sure they understand what they're saying… I've had patients that are extremely symptomatic, but they'll say, "[Psychologist/Case Manager], I wasn't going to fill it out, but the way you explained it, I actually think I feel comfortable now."" Provider Group, ID: 811

- Agency

There's so many protections on my information that even I can't access it, which I find really ridiculous. … That doesn't make sense to me. Why would I want you to share that information to other people if you won't even share it to me? Client Group, ID: 819

- Protection of data

"I think [the ability to delete your data] provides you with a level of security. You feel secure if you have the ability to do that. And if you feel secure you put more information…out there." Parent Group, ID: 827

End-User License Agreement (EULA) Focus Groups

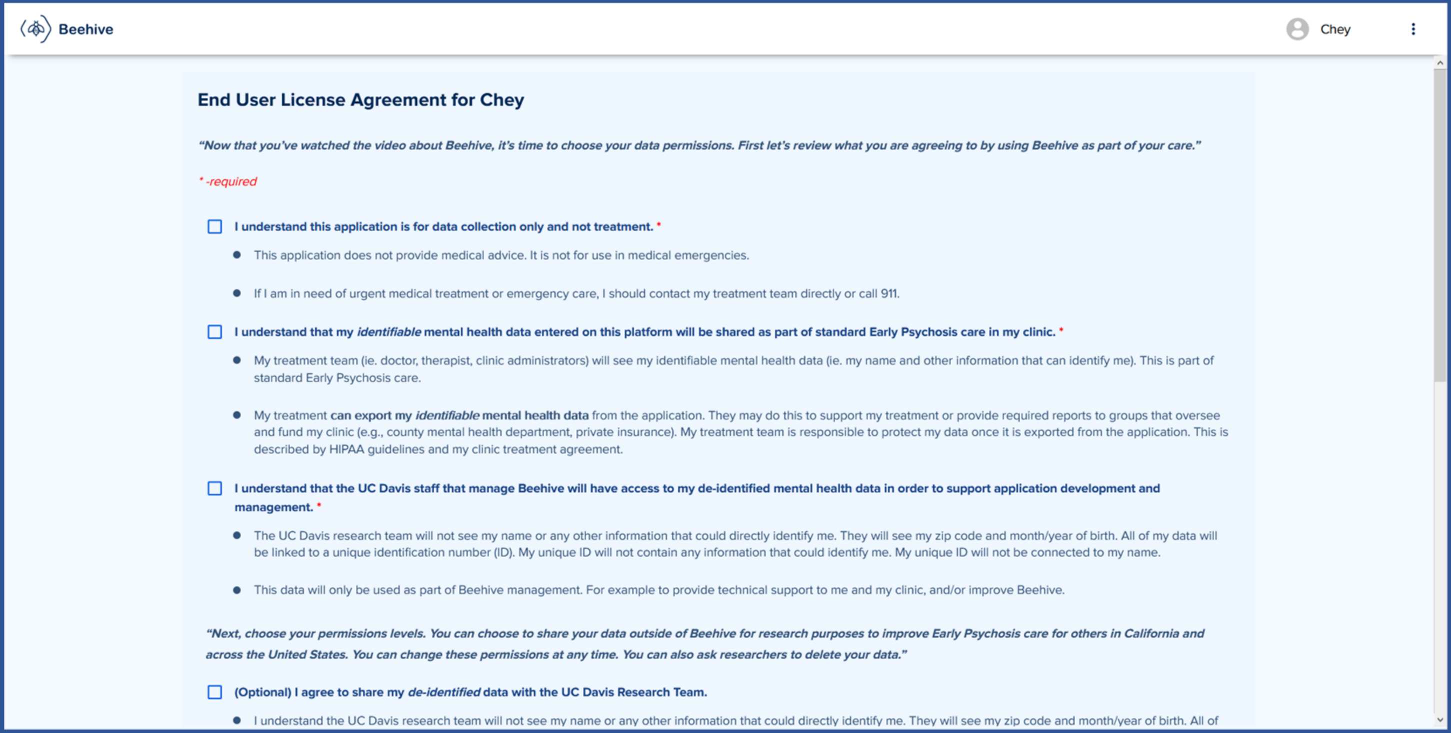
Part 1: 7 min video presentation
Part 2: Text and checkboxes

Part 1: Developing the End User License Agreement (EULA) Video

“The pace was the overwhelming thing. I loved the video I thought was great. I love the cartoons, super entertaining. But I think the pace was way too fast.”

Provider Group, ID: 113

Part 2: Developing the End User License Agreement (EULA) Data-Permissions Screen



End User License Agreement for Chey

"Now that you've watched the video about Beehive, it's time to choose your data permissions. First let's review what you are agreeing to by using Beehive as part of your care."

** -required*

☐ **I understand this application is for data collection only and not treatment. ***
- This application does not provide medical advice. It is not for use in medical emergencies.
- If I am in need of urgent medical treatment or emergency care, I should contact my treatment team directly or call 911.

☐ **I understand that my *identifiable* mental health data entered on this platform will be shared as part of standard Early Psychosis care in my clinic. ***
- My treatment team (ie. doctor, therapist, clinic administrators) will see my identifiable mental health data (ie. my name and other information that can identify me). This is part of standard Early Psychosis care.
- My treatment **can export my *identifiable* mental health data** from the application. They may do this to support my treatment or provide required reports to groups that oversee and fund my clinic (e.g., county mental health department, private insurance). My treatment team is responsible to protect my data once it is exported from the application. This is described by HIPAA guidelines and my clinic treatment agreement.

☐ **I understand that the UC Davis staff that manage Beehive will have access to my de-identified mental health data in order to support application development and management. ***
- The UC Davis research team will not see my name or any other information that could directly identify me. They will see my zip code and month/year of birth. All of my data will be linked to a unique identification number (ID). My unique ID will not contain any information that could identify me. My unique ID will not be connected to my name.
- This data will only be used as part of Beehive management. For example to provide technical support to me and my clinic, and/or improve Beehive.

"Next, choose your permissions levels. You can choose to share your data outside of Beehive for research purposes to improve Early Psychosis care for others in California and across the United States. You can change these permissions at any time. You can also ask researchers to delete your data."

☐ **(Optional) I agree to share my *de-identified* data with the UC Davis Research Team.**
- I understand the UC Davis research team will not see my name or any other information that could directly identify me. They will see my zip code and month/year of birth. All of

"I guess in the past with EULAs it's like they're already pre-typed into the form. If I did want to have it sent to somewhere, I would physically have to cross it out. But since you guys have checkboxes that's much more convenient."
Client Group, ID:120

Summary

- Qualitative work critical to informing implementation
- Key component of maximizing the utility of the network for stakeholders
- Major facilitator to stakeholder buy-in
- Driver for the success of EPI-CAL overall