Mental Health Services Act

Collaborative Statewide Early Psychosis Program Evaluation

Draft Summary Report of the Activities of the LHCN

Draft version prepared May 12, 2024

Final version prepared June 30, 2024

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This report was supported by:

Contents

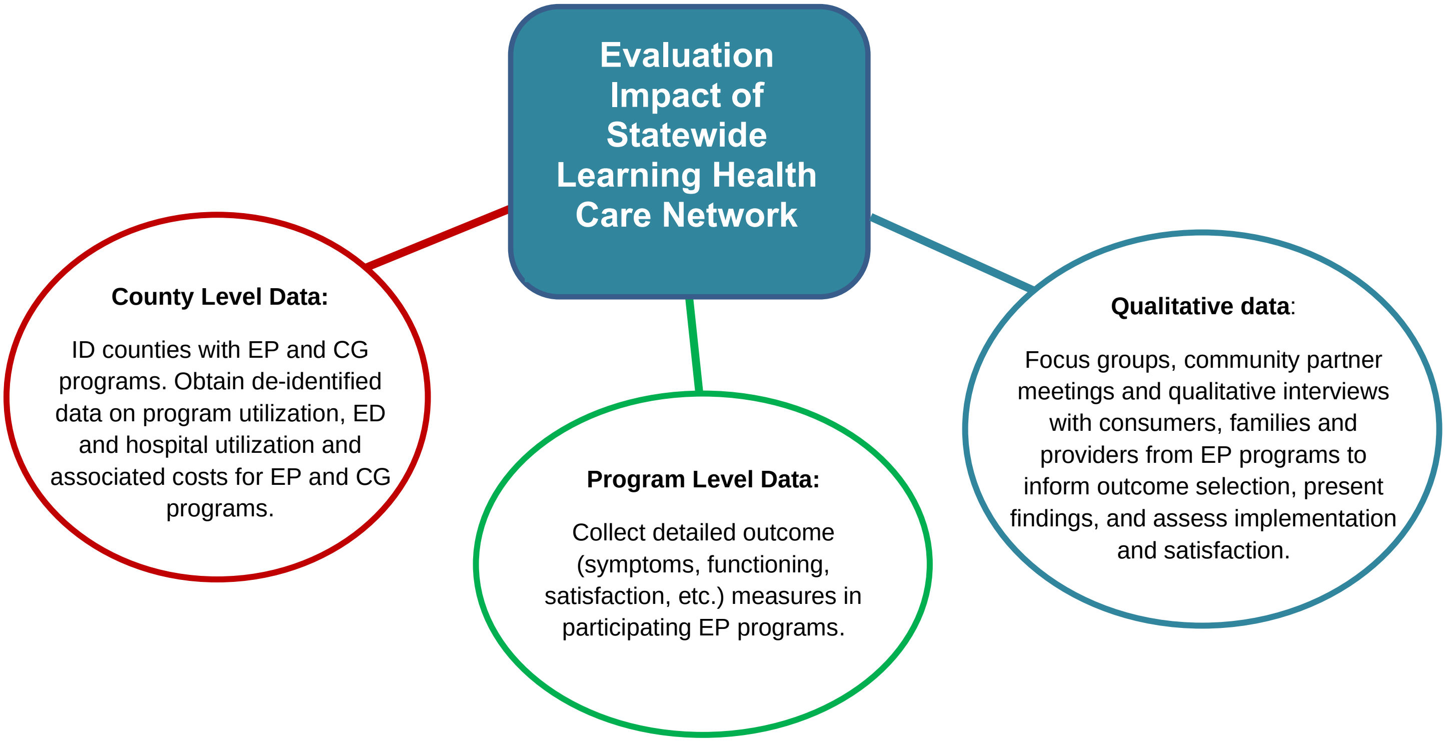
Background and Introduction

Multiple California counties in collaboration with the UC Davis Behavioral Health Center of Excellence received approval to use Innovation or other Prop 63 funds to develop infrastructure for a sustainable learning health care network (LHCN) for early psychosis (EP) programs. Original approval to use Innovation Funds by the MHSOAC was granted in December of 2018 and included Los Angeles, Solano, Orange, and San Diego counties. Since that initial approval, our current Learning Health Care Network has grown and now includes the following counties: San Diego, Solano, Sonoma, Los Angeles, Orange, Stanislaus, Napa, Lake, and the Multi-County Collaborative (MCC) which includes Nevada, Mono, and Colusa Counties. One Mind has also contributed $1.5 million in funding to support the project. This Innovation project has sought to demonstrate the utility of the network via a collaborative statewide evaluation to assess the impact of the network and these programs on the consumers and communities that they serve. The project is led by UC Davis in partnership with UC San Francisco and UC San Diego and multiple California counties. The overarching goals of the Learning Health Care Network has been to bring consumer-level data to the providers’ fingertips for real-time sharing with consumers and allow programs to learn from each other through participation in a health care network. Our goals of the LHCN are to 1) increase the quality of mental health services, including measurable outcomes, and 2) introduce a mental health practice or approach that is new to the overall mental health system.

The California Early Psychosis Learning Health Care Network (LHCN) represents a unique partnership between the University of California, multiple California counties, and One Mind to build a network of California early psychosis (EP) programs. We were able to leverage this initial investment to obtain additional funding from the National Institutes of Health (NIH) in 2019, which enabled six university and two county early psychosis programs to join and also linked the California network to a national network of EP programs, including UCSF PATH, UCSD CARE, UCLA Aftercare & CAPPS, Stanford INSPIRE, San Mateo Felton BEAM UP/(re) MIND, UC Davis EDAPT and SacEDAPT programs. The overarching name of the project, which encompasses the LHCN and the NIH-funded components, is “EPI-CAL.”

The purpose of the current report is to provide an overall summary of progress and accomplishments of the Learning Health Care Network since project activities commenced in Spring of 2019. While each participating county may be on slightly different timelines, the current report summarizes the overall progress of the EPI-CAL team and all participating counties. Since there are three components to the data collected for the LHCN: County Level, Program Level, and Qualitative data (Figure 1), the summary report has broken down progress into three sections for each component.

Figure 1. Three Components of the Evaluation Associated with the Statewide LHCN.



Evaluation Impact of Statewide Learning Health Care Network

County Level Data:

ID counties with EP and CG programs. Obtain de-identified data on program utilization, ED and hospital utilization and associated costs for EP and CG programs.

Program Level Data:

Collect detailed outcome (symptoms, functioning, satisfaction, etc.) measures in participating EP programs.

Qualitative data:

Focus groups, community partner meetings and qualitative interviews with consumers, families and providers from EP programs to inform outcome selection, present findings, and assess implementation and satisfaction.

Overall Executive Summary

The Learning Health Care Network project is a unique academic, government, and community mental health partnership that developed an innovative harmonized data collection and analysis strategy and prioritized community partner feedback. Over the course of the project, EPI-CAL's LHCN established network of California EP clinics expanded to include both community and university programs thanks to the initial investment in the LHCN infrastructure by our county partners utilizing MHSA Innovation funds. The EPI-CAL team and our community partners created a core battery of evidence-based measures for clients and family members and link them together using a unique data collection and visualization application, Beehive, a core component of the Learning Health Care Network. From its inception, the goal of the LHCN was to make a change to an existing practice in the field of mental health by introducing a collaborative LHCN to support quality improvements, consumer engagement, and provider use of measurement-based care in early psychosis (EP) programs. Since 2019, all members of the LHCN have worked incredibly hard to create a network of EP clinics in California and have contributed to quantitative and qualitative data collection that has helped inform consumer- and program-, county-, and state-level decisions and develop learning opportunities for individuals, staff, programs, and administrators, to improve consumer outcomes.

The EPI-CAL team cannot stress enough that the partnerships between counties, early psychosis programs, and our organization are absolutely essential for the successful implementation of the LHCN project, and we value our partners' commitment to success. While the LHCN has successfully been implemented to some degree across the three major components of the project, we have also experienced limitations and barriers to implementation. Since the Learning Health Care Network project began in 2019, we've learned about the difficulties in the ability of programs to implement new projects as community mental health providers have high workloads and need to prioritize client care, which does not allow for a lot of protected time to devote to other tasks. Given that providers also need sufficient motivation, training, and support to implement measurement-based care in treatment sessions and care decisions, our team has used our resources to provide as much training and direct support as we can, and have worked to define the clinical utility of using client outcomes and measurement-based care in direct treatment. We've also utilized qualitative methods to understand barriers and facilitators to implementation, and refine our approach based on the feedback we've received from providers over the course of implementation. We've learned that we need to be responsive to turnover of key positions within the county or EP program as the loss of a single key personnel can hinder the process for the entire county. Our approach of prioritizing training, support, partnership, and refinement has been essential for successful implementation of our Learning Health Care Network.

At the initiation stage of the LHCN, we had few examples of successful early psychosis networks in California and therefore limited data available to guide decision making. We continue to identify areas where more timely collection of data could be invaluable to inform early psychosis programming in the state, such as data about the general catchment area for a program and what the unmet need is (e.g., how many calls does a program get? Who is not being served?).

A major hurdle in reaching our original planned milestones for the project has been trying to operate the program in an environment that has been permanently altered by the COVID-19 pandemic. The pandemic has had lasting effects on all participating California EP programs; most programs have not recovered to their full program capacity in the wake of the lasting effects of a global pandemic on the economy, mental health workforce, and clients seeking care. Programs have been trying to meet client needs even with several staff vacancies, and the census numbers have reflected a reduced workforce. In addition to that, the entire project timeline had been shifted up due to delays introduced by the COVID-19 pandemic. EP programs have still not fully recovered from the lasting impact on program and community infrastructure.

We have also provided a detailed executive summary for each of the main components of the program below (Program Level, County Level, and Qualitative data). For the program level section, we focus on our approach to creating the infrastructure to collect harmonized outcomes, including our training and support approach, and report preliminary findings from the statewide dataset that has been generated as part of this project. In the county-level data section, we describe our progress to date in accessing linked client-level data for costs and utilization, including our findings that this process requires significant time and investment by county staff to create this dataset. In the qualitative data section, we describe how we've prioritized community partner input and feedback at each stage of development of the LHCN and review preliminary findings from barrier and facilitator interviews we've recently conducted to inform our approach. Please review each section for more details on what has been accomplished thus far over the course of the Learning Health Care Network project.

1. Learning Health Care Network Program Level Summary

1.1 Executive Summary

The LHCN focuses on a longitudinal, prospective evaluation of core data elements for early psychosis across the state. The Learning Health Care Network program works with participating EP programs for the purposes of harmonized, statewide outcomes data collection. The EPI-CAL program links these early psychosis clinical service programs into the Learning Health Care Network using a core assessment battery of valid, low burden measures and mHealth technology platform (Beehive) to collect service user-level information as part of standard care, visualize such information via clinician dashboard for treatment planning, and integrate across clinics to provide statewide summaries of outcomes data and mental health metrics from participating programs.

Beehive is a co-designed platform that was created to collect and summarize program level outcomes data across the state of California. The outcomes data collected is our EPI-CAL Core Assessment Battery (CAB) and includes various validated measures for service users, their primary support persons, and their clinical team to complete. The initial proposed CAB was reviewed and refined in focus groups conducted by our team ((Savill et al., 2024); see qualitative section below). The surveys in the CAB are administered through Beehive.

Beehive was primarily designed to: 1) collect outcomes data from service users receiving care at an EP program and their support persons (i.e., family or other close individuals who service user choose to involve in their treatment), 2) provide the data for providers on a secure web-based dashboard, a subset of which is visualized and 3) allow data to be used for program or research analysis. The use of Beehive by service users, families, and EP program staff does not require written informed consent, but rather a signed end user license agreement (EULA).Trained EP program staff introduce Beehive to participants who are either shown a video explaining the purpose of the study and how their data are used or be presented with the EULA that they are required to read to make their data sharing choices prior to participation. The EULA was designed with input from service users, family members, and providers to ensure transparent data use ((Tully et al., 2023); see qualitative section below).

The program level summary of this report focuses primarily on the data collected via Beehive, including client self-report data, data from the primary support person (PSP) for the client, and clinician-rated data. Prior to collecting outcomes data in each participating program, programs needed to engage with our team to complete training activities needed to implement Beehive in participating early psychosis (EP) programs. We summarize training progress of each EP program and the EPI-CAL team's approach. The EPI-CAL LHCN team provides initial training for implementation of Beehive in each established participating CSC EP program over a period of weeks to months, depending on availability of clinic staff. This training is most frequently offered in a virtual setting, but in-person training is also offered if requested by a program. The EPI-CAL team provides ongoing technical assistance to each participating program by supporting ongoing Beehive implementation efforts within the program, including weekly check-in meetings (if the program is available), on-demand problem-solving to resolve any technical barriers, training refreshers, and summaries of enrollment progress. Program staff have access to the Beehive resource guide, a searchable wiki, and asynchronous training videos in a learning management system for additional training and information on Beehive workflows. To date, 17 EP programs have completed the full Beehive training series, with a total of 21 completing at least some of the Beehive training series. Once Part 1 Beehive training is completed, programs can initiate enrollment of their clients in Beehive and begin data collection on the outcomes surveys. As of October 27, 2023, those 21 EPI-CAL clinics have registered 835 clients in Beehive. Of those 835 clients who have been registered, 65% (n=548) have completed their Beehive end user license agreement (EULA) and are considered to be enrolled in Beehive. Of those who have completed their EULA, 82% (n=452) have agreed to share their de-identified data with NIH and 87% percent (n=479) have agreed to share their de-identified data with UCD.

When examining current enrollment against program census data, we have found that there is quite a bit of variability across programs in the proportion of the program's census that are enrolled in Beehive (mean = 55%, range = 0-166%). There is also extensive variability in the number of PSPs enrolled in Beehive across the programs as well (mean = 31%, range = 0-100%). Four of the participating programs meet or exceed the previously defined benchmark of 50% of PSPs enrolled in Beehive.

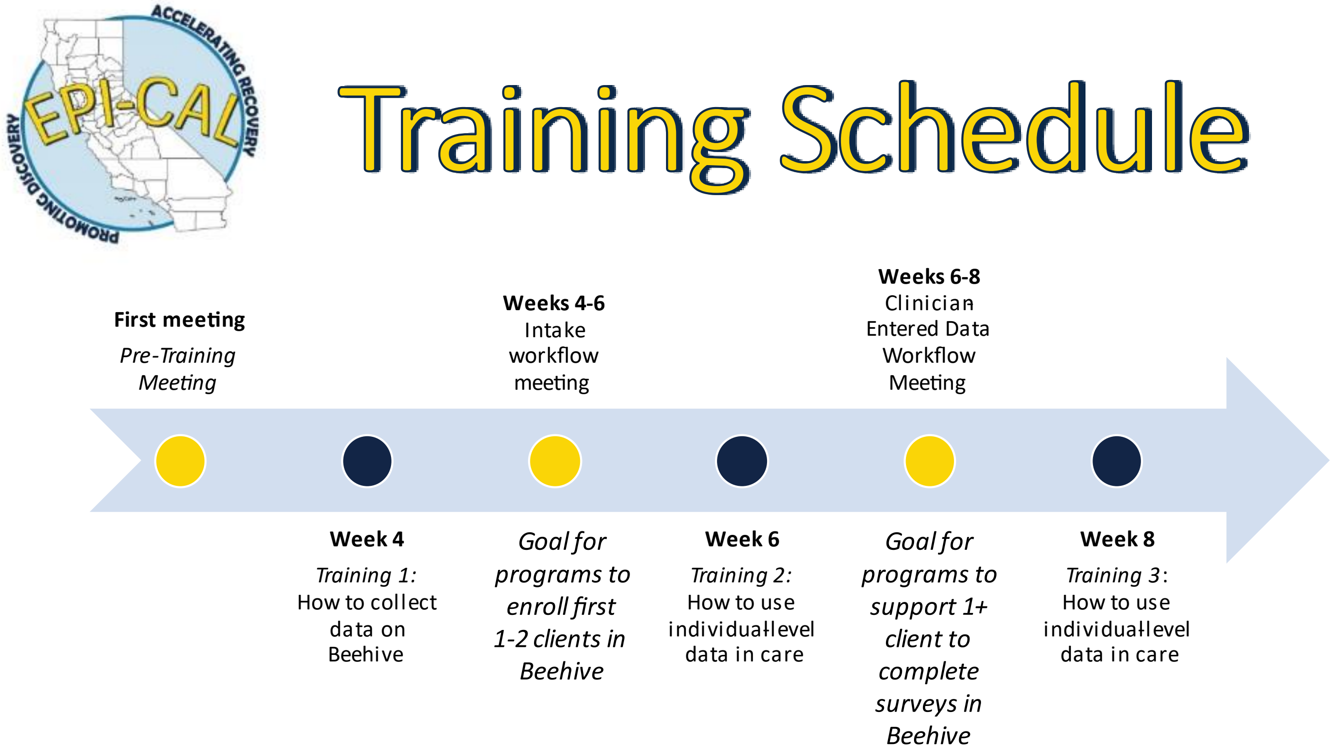
Of the 548 clients who have been enrolled in Beehive, 92% (n = 505) have completed at least one survey in Beehive. Now that there is a sufficient number of clients, staff, and primary support persons completing longitudinal surveys, we have begun preliminary analyses of Beehive outcomes data. In this report, we summarize results on client self-report symptoms, education, employment, and social activities and the relationship to quality of life, medication-taking behavior, adverse childhood experiences, substance use, family functioning, and childhood poverty.

We also summarize fidelity assessment procedures and preliminary data. As described in more detail below, EPI-CAL uses the FEPS-FS (D. Addington, 2015) and has created the CHRPS (Savill, under review), to assess EP program fidelity to the CSC model as a treatment for full psychosis and the clinical high risk for psychosis syndrome. In collaboration with the FEPS-FS author Dr. Addington, we have developed alternative assessment approaches to enable the fidelity review of new and developing programs where a standard fidelity assessment is not feasible due to a lack of data. Our team conducts a single fidelity assessment of each program as part of the LHCN, although some programs may receive a repeated assessment if they are also part of the Training and Technical Assistance (TTA) arm of the EPI-CAL program. If so, the program may receive a repeated assessment every 18 months, enabling our team to track program development longitudinally and assess if and how programs are increasing their adherence to CSC best-practices over time. Additionally, after each assessment we provide extensive feedback to each program in the form of a fidelity report, which programs can use to support quality improvement efforts and identify areas of growth. In addition to formal fidelity assessment of established programs, we have developed capacity to use these fidelity measures for programs that are in development or have recently started a new program. This allows us to give new and developing programs early feedback on their CSC components so they can resolve issues early and reach full fidelity sooner. To date, we have completed assessments in 20 programs. Thirteen provide services for both FEP and CHR clients, four serve FEP only, and three serve clinical high risk only.

1.2 Beehive Training and Implementation

The core Beehive training series is provided synchronously and remotely to all participating LHCN programs. The core trainings begin with a pre-training meeting with leadership at the program to discuss which program staff members would be designated as providers, group analysts, or group and clinic admin in Beehive (roles described below), as well as to cover topics around integrating Beehive into their current data collection system. Next, we conduct a training series consisting of three training sessions to introduce Beehive to each program (Part 1, Part 2, and Part 3) with all program staff, and an intake-workflow meeting and clinic-entered data workflow meeting with key clinic staff to understand clinic workflow and brainstorm how to best implement Beehive within their program context (Figure 2).

Figure 2: Beehive Training Schedule



The first Beehive trainings began with our pilot programs in March 2021. In June 2021, we began to onboard non-pilot programs, starting with the Los Angeles County PIER programs. See table below for all core trainings conducted through December 2023. Note that booster trainings (for entire program or for individuals at the program) have also been conducted in addition to the core trainings and are not included on the table below. We have also added all of the training modules for Beehive trainings part 1 through 3 to a learning management system, Cornerstone. Our team has enrolled all staff and providers from participating programs in Cornerstone so that they can access asynchronous training materials at any time. Individuals who are new to each program may also access Cornerstone training materials.

Table I: EPI-CAL Site Training Completion

Site	Pre-Training	Training 1	Intake Workflow	Training 2	Training 3
UCD SacEDAPT	3/10/2021	3/22/2021	3/10/2021	4/5/2021	6/14/2021
UCD EDAPT	3/10/2021	3/22/2021	3/10/2021	4/5/2021	6/14/2021
Solano SOAR	3/18/2021	3/22/2021	3/29/2021	4/12/2021	6/7/2021
Napa SOAR	7/23/2021	8/19/2021	10/21/2021	10/14/2021	12/2/2021
Sonoma SOAR	8/24/2021	9/29/2021	10/21/2021	10/14/2021	12/2/2021
Kickstart Pathways	3/24/2021	3/31/2021	6/8/2021	4/14/2021	7/28/2021
LAC- IMCES 3	5/10/2021	6/21/2021	8/11/2021	11/10/2021	12/8/2021
LAC - IMCES 4	5/10/2021	6/21/2021	8/11/2021	11/10/2021	12/8/2021
LAC - SFVCMHC	5/11/2021	6/18/2021	7/19/2021	11/18/2021	12/9/2021
LAC- The Whole Child	5/13/2021	6/17/2021	7/21/2021	11/23/2021	1/25/2022
LAC- The Help Group	5/14/2021	6/14/2021	8/10/2021	11/29/2021	1/5/2022
OC CREW	7/13/2021	8/12/2021	8/23/2021	10/13/2021	12/8/2021
San Mateo Felton	7/14/2021	10/20/2021	12/9/2021	7/13/2022	12/6/2022 & 6/13/2023
UCLA - Aftercare	7/29/21	9/1/2021	2/9/2022	5/20/2022	6/8/2023
UCLA - CAPPS	9/23/2021	11/22/2021	2/1/2022	5/3/2022	TBD
UCSF PATH	9/21/2021	5/6/2022	5/25/2022	10/28/2022	TBD
UCSD CARE	4/7/2022	5/23/2022	7/15/2022	9/30/2022	11/7/2022
Stanislaus LIFE Path	2/23/2022	4/8/2022	5/10/2022	5/31/2022	9/22/2022
Stanford INSPIRE	3/21/2023	4/26/2023	5/23/2023	TBD	TBD
MCC	2/8/2023	3/9/2023 & 3/28/2023	4/7/2023	5/1/2023	6/9/2023
Lake County	4/21/2023	6/23/2023	9/7/2023	11/20/2023	TBD
Totals	**21**	**20**	**21**	**20**	**17**

Pre-Training Meeting

The pre-training meeting is conducted between EPI-CAL staff, including the site's assigned point person, site leadership, and a site IT representative. The purpose of this meeting is to introduce the training schedule and gather information to facilitate the first Beehive training. For example, the site leadership are invited to Beehive to create their accounts and test network compatibility (e.g., ensure that invite emails are not blocked by institution, ensure that program staff can access web application). The IT representative is engaged as needed to resolve technical issues (e.g., add beehive email address to approved senders list). Site leadership complete their account registration ahead of the Part 1 training as they will be inviting all other program staff from their clinic to Beehive.

Part 1 Training

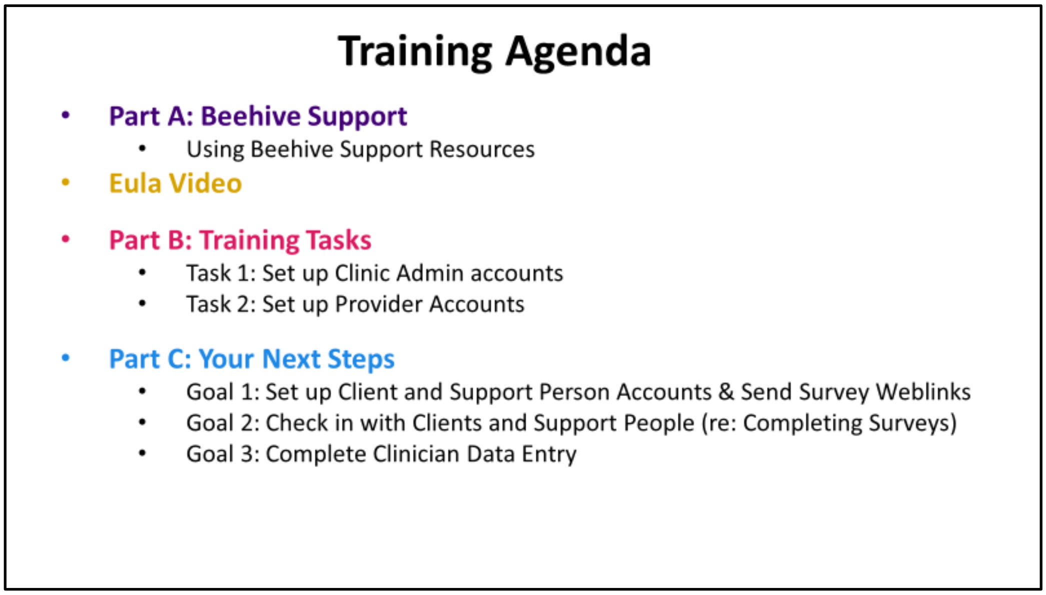
The general outline for the first training is as follows:

1. Re-introduction to the EPI-CAL project, including the overarching purpose and goals of data collection via Beehive
2. Presentation on the value of Beehive and data collection
3. Beehive Application training session (see Figure 3)

<u>Presentation- “The Value of Beehive and Data Collection”</u>

An EPI-CAL team member, Leigh Smith, Ph.D., gives a brief pre-recorded presentation that first focuses on how Beehive was developed using input from stakeholders and providers. Next, she provides a historical example of data collection that led to significant innovation in health care by giving a brief vignette of John Snow’s work with the Cholera outbreak in London in 1854. She then draws parallels between Snow’s work and how Beehive was designed, focusing on a meaningful connection between providers and stakeholders, a holistic approach to data collection, and prioritization of record keeping through automation and data consolidation. After, she speaks about Beehive’s power to facilitate dialogue between providers and consumers, and within/between clinics, through reports provided by the Beehive team or generated within Beehive. Dr. Smith covers the purpose of participating in a Learning Health Care Network (LHCN), and how valuable information collection can be in informing treatment. Finally, she emphasizes the ability of Beehive’s data collection in shaping care by illustrating how over a million points of data can be generated if each of the EPI-CAL clinics enrolled 80% of their consumers and completed the baseline and two follow-up surveys in the first year.

Figure 3: Training Agenda



Training Agenda

- **Part A: Beehive Support**
  - Using Beehive Support Resources
- **Eula Video**
- **Part B: Training Tasks**
  - Task 1: Set up Clinic Admin accounts
  - Task 2: Set up Provider Accounts
- **Part C: Your Next Steps**
  - Goal 1: Set up Client and Support Person Accounts & Send Survey Weblinks
  - Goal 2: Check in with Clients and Support People (re: Completing Surveys)
  - Goal 3: Complete Clinician Data Entry

Part A: Using Beehive Support Resources

We provide all EP program staff with the link to our detailed resource guide, accessed here: https://sites.google.com/view/beehiveguide/home

The resource guide was created so that EP program staff may reference, in detail, how to use the Beehive application and complete the tasks reviewed during the training. This includes: Creating Clinic or Group Admin Account & Inviting them to Beehive, Accepting Beehive Invite & Completing Registration, and Adding a Provider and Inviting them to Beehive. The resource guide also provides information on how to complete the "homework" that was assigned during the first training, including Adding a Consumer & Support Person and Completing Clinician Data Entry.

End User License Agreement (EULA) Video

We show the EULA video to all EP program staff for two reasons: 1) to streamline the registration process for staff during the training (as all users watch this video as part of the registration process), and 2) to orient them to what consumers and families also see when they first access the Beehive system. The EULA video can be accessed here: https://youtu.be/3E8hiEkIvSQ. (Spanish: https://youtu.be/UgY7ZUhe-Fk Vietnamese: https://youtu.be/NqdC51TqGc0). We developed the EULA video through focus groups with EPI-CAL community partners (consumers, family members and providers) to ensure that core aspects of Beehive (e.g., security, consent, and data sharing) were clear to users. The EULA video describes what Beehive is and how it is part of the EPI-CAL project, the purpose of Beehive, how data is shared and stored, and users' options for data sharing. Every new user of Beehive will be presented with the EULA video before making their data sharing choices.

Part B: Training Tasks: Setting up Clinic Admin/Provider Accounts and Registering Consumers

There are three main types of accounts in Beehive; each account is associated with the ability to complete certain actions in the Beehive system in line with that person's job duties:

- Group Admin account: For program-level staff members who provide supervision and administrative support across clinics within a particular group – for example, a Group Admin is a person whose position includes oversight of activities at more than one clinic.
- Clinic Admin account: For staff members who provide supervision and administrative support within a specific clinic in a group.
- Provider account: For staff members providing direct services to consumers in a particular clinic, for example therapists, prescribers, and peer support specialists.

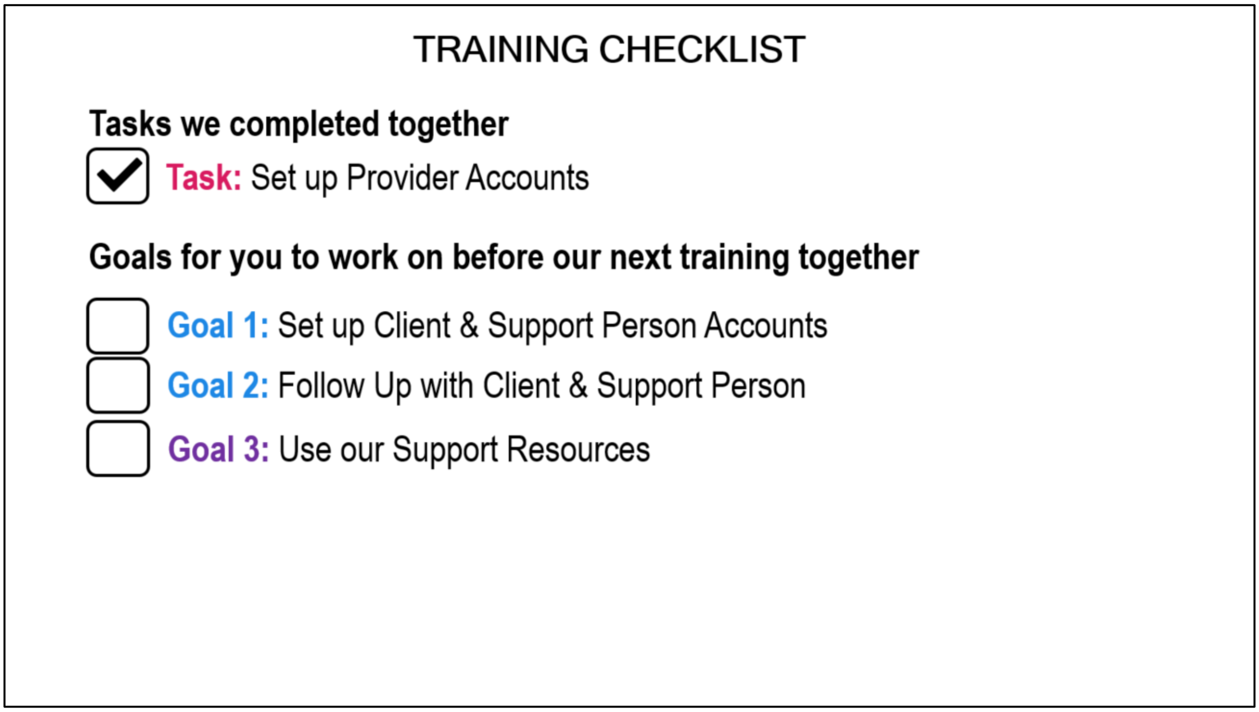
There is a general hierarchical structure to the relationship between these account types, such as who can invite new users and who can download data from Beehive.

The first training task is to set up Clinic Admin and Provider accounts in Beehive. For the initial Part 1 trainings, EPI-CAL staff created Group and Clinic Admin accounts prior to the first training meeting and sent those specific users their invitations during the live training (for trainings of non-pilot programs, EPI-CAL staff assist all admin users to register at the pre-training meeting). Once participants with Clinic Admin-level accounts accept their invitations and completed the registration process, EPI-CAL staff guide them through creating provider-level accounts for their staff and inviting those staff to complete registration in Beehive. For programs utilizing a Single Sign-On (SSO) authentication scheme, the EPI-CAL staff also walk them through the process to log in through their institution.

Part C: Next Steps

Once all providers conclude the registration process, EPI-CAL staff demonstrate the process of registering a consumer and their support persons. Next, the survey collection timeline is introduced. Baseline surveys are available for four months after the consumer’s intake date. After baseline, follow up surveys are sent, which are due every 6 months from baseline will open two months prior to the due date and close four months after the due date. Next, the process for consumers and primary support persons to complete/request help to complete surveys is shown, along with the steps to manually resend surveys. Participants are then given the goal to register two consumers and their support persons (if applicable) in Beehive, and have the consumers complete their surveys before the next training session (see Figure 4). These consumers can be at any point in treatment when they are enrolled in Beehive. A Beehive consumer introductory script is provided to support the program staff in talking about Beehive to potential participants.

Figure 4: Training Checklist



TRAINING CHECKLIST

Tasks we completed together

☑ **Task:** Set up Provider Accounts

Goals for you to work on before our next training together

☐ **Goal 1:** Set up Client & Support Person Accounts
☐ **Goal 2:** Follow Up with Client & Support Person
☐ **Goal 3:** Use our Support Resources

Intake Workflow Meeting

After the Part 1 Training, EPI-CAL staff, including the program’s point person, meet with the program’s key staff involved in intakes. The purpose of this meeting is to understand the program’s current workflow to facilitate a smooth transition to implementing Beehive. Once EPI-CAL team have a basic understanding of the program’s intake process, they ask questions to operationalize how Beehive will be integrated into this process (e.g., “Who will be responsible for registering clients in Beehive?”). They may offer suggestions or ideas based on what has worked at other programs. The goal of this meeting is to create an initial plan for the program to introduce Beehive into their current workflow.

Part 2 Training

The second Beehive training focuses on how providers can utilize individual level data in care. The Beehive team introduces the EPI-CAL Core Assessment Battery (CAB), including its domains and how these domains were selected from stakeholder input. Next, the trainer presents two surveys from the EPI-CAL CAB: the Modified Colorado Symptom Index (MCSI) and the Questionnaire about the Process of Recovery (QPR). Then, the trainer shows participants where to find consumer data in Beehive. The trainer then demonstrates how to present the data visualizations available in Beehive and asks the group what questions or concerns the sample visualizations elicit from them. Participants then participate in small group exercises focused on example data visualizations of the MCSI with the goals of 1) exercising their data comprehension skills and 2) practicing using data to explore a consumer’s story.

During small group exercises, an example consumer's MCSI scores are displayed, and participants are prompted to discuss the "story" that could be illustrated by this data set. For example, providers are presented with a graph in which MCSI scores are going up over time (indicating more frequent and/or distressing symptoms; Figure 5A) and then asked to interpret possible situations that could be leading to these data trends for this sample consumer. After providers correctly identify that the example consumer is experiencing an increase in frequency and/or number of symptoms, they are asked how they might use this information in treatment (e.g., modify the consumer's treatment plan to help reduce the frequency of these symptoms).

Figure 5: MCSI Example Graphs from Beehive

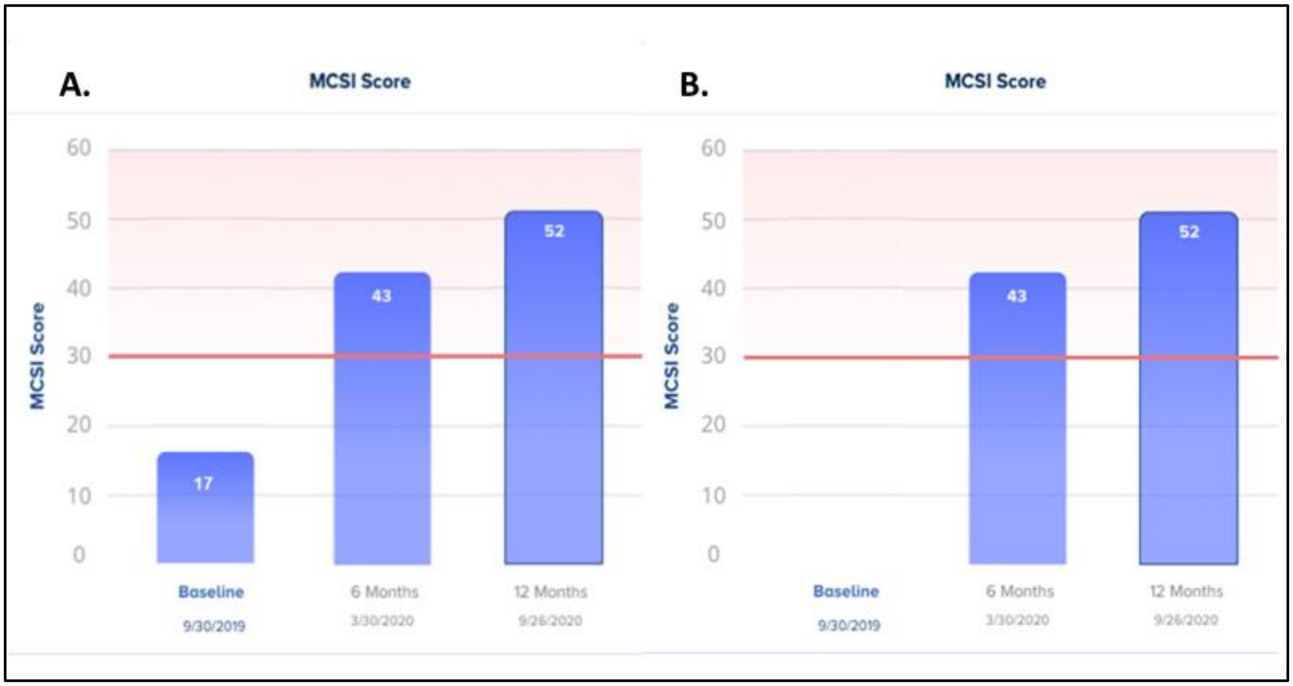


Figure legend: A. Representation of data showing increasing trend in MCSI symptom severity; B. Representation of how missing data (shown here at baseline) impacts the visualization

After these exercises conclude, small groups reconvene back into the larger group, with a member from each group presenting their group's discussion/findings to the rest of the site as a whole. As each small group has different themes and discussions that come up during the exercises, the larger group discussion is meant to help to broaden participants' understanding of data interpretation.

Next, the training details the types of urgent clinical issues that are currently tracked by Beehive, including "Risk to self", "Risk to others", "Risk of homelessness," and "Plan to stop taking medication". These issues were identified during focus groups with EP program stakeholders as critical moments for intervention during treatment. The training team also explains where each one of these alerts can be triggered within the assessment battery. Importantly, we stress that Urgent Clinical Issues in Beehive are not a replacement for each clinic's standard risk management procedures; instead, Beehive can be used as an additional tool to inform their standard risk management approaches. We also cover how to resolve urgent clinical issues using the responses programmed into Beehive (i.e., "Modified treatment plan", "Conducted risk assessment" or "Sent for emergency care") as appropriate for these alerts.

To conclude the training, the trainer introduces the "Data Use in Care" question pop up and its different response options. This pop-up appears intermittently when a user leaves a page on Beehive which displays consumer's data. It asks the user whether they reviewed the data with the consumer or family and then asks them how the data impacted treatment. These response options are the same as the response options programmed into the urgent clinical issues – the training team intentionally takes the approach of presenting these two Beehive features together to help maximize participant comprehension. These data will contribute to a data-driven understanding of Beehive's impact (e.g., whether and how staff use data as part of treatment) on the participating programs of the LHCN.

Data-Entry Workflow Meeting

After the Part 2 Training, EPI-CAL staff, including the program's point person, meet with the program leadership. The purpose of this meeting is to help the program create a reasonably sustainable plan for completing clinic-entered data about each client's clinical outcomes in Beehive. The EPI-CAL team will ask questions to understand whether there is an existing data-entry workflow already in place as well as which roles on the teams are involved in the process. Once the EPI-CAL team has an understanding of the program's existing data-entry workflow, they ask questions to operationalize how Beehive will be integrated into this process (e.g., "Who will be responsible for entering clinic-entered data for clients?"). They may offer suggestions or ideas based on what has worked at other programs. The goal of this meeting is to support the program to create an initial plan to complete clinic-entered surveys about key client outcomes. This should include a plan for which team members will monitor and track completion and which team members will enter the data.

Part 3 Training

Part 3 training revolves around applying and expanding the data interpreting skills gained in Part 2 training, with actual data from consumers that was collected after the last (Part 2) training. During Part 3 training, participants are oriented on how to input and view Clinic-entered data and how to assign additional surveys to consumers, and how to close and re-open client episodes in Beehive.

Part 3 training also familiarizes participants to two more measures included in the Core Assessment Battery: the SCORE-15 and the Burden Assessment Scale (BAS). These measures were selected because they both capture quantifiable scores on domains (family impact and family burden, respectively) that were identified as high priorities by EP community partners during EPI-CAL outcomes focus groups. These measures were chosen for this training as, like the Modified Colorado Symptom Index and Questionnaire on the Process of Recovery covered in Part 2 Training, they are scored measures which are visualized in Beehive.

Next, participants are split into small groups, and given a GUID of a consumer that receives services at their clinic and has completed surveys in Beehive. This is to ensure that each small group has real-world data to interpret. At the beginning of the small group, an EPI-CAL team member orients the group to a worksheet which includes training activities and discussion questions about finding, interpreting, and using consumer data as part of care. As these trainings require participants to examine their consumer's data (i.e., PHI), EPI-CAL training team members are only present for the beginning of the small group exercise to introduce the activity, but they leave prior to any discussion or sharing of PHI. EPI-CAL staff encourage each participant to take an active role within the small group: note taker, screen sharer, delegate to report during large group debrief, etc. Each small group uses the small group worksheet to guide their time in the small group.

After the small group exercise, participants rejoin the larger group to share their findings. After each small group has presented their findings with the rest of the groups as a whole, the EPI-CAL team facilitates a large group discussion which encourages participants to look for trends and assess what they could mean. After examining common patterns in the data, the training team encourages participants to view their consumer's data through this analytical lens and demonstrate how their treatment plans could benefit from this approach.

Implementation Support After Initial Beehive Trainings

Each program has an EPI-CAL staff point person to provide regular check-ins to provide training and implementation support. The point persons are introduced during pre-training and the Beehive training series.

Initially, we request weekly meetings or calls with key program staff (as determined by the program). At these meetings, point persons can help programs troubleshoot issues and support staff with accessing resources and learning to use Beehive.

In addition to regular check-ins with key program staff, point persons may also provide booster trainings to individuals at the program or to groups of program staff. These may be conducted remotely via web conferencing or in-person for sites that have resumed in-office operations.

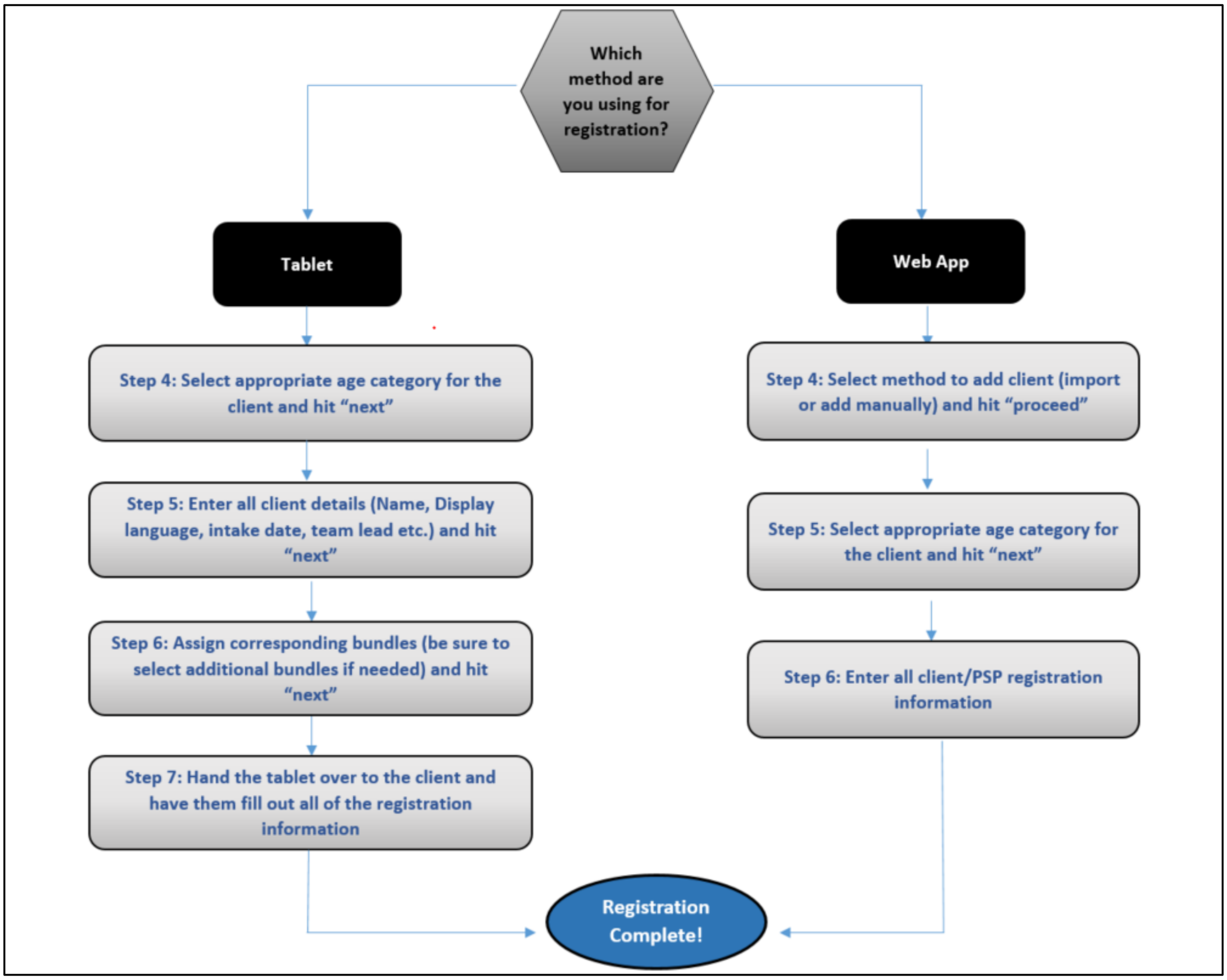
Point persons will also respond to ad hoc requests from the program for technical support and troubleshooting. For example, if a program experiences a bug or glitch while using Beehive, they are told to contact their point person who can help to troubleshoot or escalate this report.

Tablet Training

The Beehive application is available as both a web application and on tablets (i.e., iOS application). The tablet application is intended for clients who are receiving in-person services in the clinic or in the community. Due to the prevalence of telehealth and low incidence of in-person appointments, most sites did not plan to use the tablet application at the time of their initial core trainings. The EPI-CAL team developed a standalone tablet training to offer to sites on-demand whenever needed.

The tablet training covers the differences between registering clients and administering surveys on the iOS app as compared to the web application. It also covers several iOS app specific features such as the client individual check-in and group check-in features.

Figure 6: Diagram showing workflow differences in client registration based on environment



In the past year, only three programs have asked for this tablet training (OC CREW, San Mateo Felton, and Stanislaus LIFE Path). Other sites chose not to schedule a synchronous training, but rather have relied on the training materials and resource guide as they have begun to use the iOS application. We will continue to offer the live tablet training as needed, or refer staff to our asynchronous training materials.

Training Via Cornerstone
The full Beehive training series is also available to anyone in an LHCN-associated learning path on Cornerstone. While our team will continue to offer live synchronous Beehive training series to all new programs joining the LHCN, Beehive training in Cornerstone will be available for new staff at each EP program and will generally take the place of live training for individual new employees. Each employee who uses Cornerstone will be assigned a Beehive curriculum by their EPI-CAL point person. Beehive curricula are based on the users' implementation role rather than their clinical role. They include:

- **Data-User:** Intended for provider-level users whose role focuses solely on viewing data in Beehive and using in care with clients. They will not necessarily need to provide direct support to clients using Beehive, update client profiles, or enter any clinician-entered data. An example of this type of user would be prescribers (including residents).

- **Data-Enterer:** Intended for provider-level users whose role focuses on registering clients, supporting clients to use Beehive, and/or entering clinician-entered data. Examples of this type of user would be clinic coordinators or case managers who support admin implementation of Beehive but will not generally use data as part of care (and are not admin users).

- **Data-User & Data-Enterer:** This is what most users at the provider-level should are assigned. It is the most comprehensive role and will include all of the trainings outlined above and as well as any and all materials covered in our live training series. If program leadership and staff are not sure about what implementation role individuals will have, this is the training that should be assigned to them.

- **Admin:** This is intended for all users who are assigned as group admin or clinic admin users in Beehive. It covers all of the trainings above and has trainings on admin specific features such as adding new users and pulling reports.

Existing employees who have already participated in the live Beehive training series from our team are also welcome, but not required, to use Cornerstone for refresher trainings.

1.3 Beehive Outcomes Data Collection and Enrollment Progress to Date

Preliminary Feasibility Analysis
One of our primary metrics to evaluate the feasibility and acceptability of the Beehive application in EP programs it to examine is whether we achieved adequate enrollment in Beehive. We examined this using a previously defined benchmark of enrollment of at least 70% of eligible participants, who are representative of the target population based on current program demographics, and 50% of their available family members, across the network were enrolled. To approximate the number of total clients eligible for enrollment, we have asked the programs to provide us with their current total census number. This was compared to clients currently enrolled in Beehive, and not including clients who have been discharged from Beehive. Clients must have completed their EULA to be considered enrolled. For the purposes of the preliminary analysis, we are only considering individuals who have agreed to share data with UCD as "enrolled", but clients can decline this

option and still use their data within their program for clinical purposes. Data on of the number of available family members is available in Beehive and we are able to assess whether a primary support person (PSP) has completed enrollment. Just like clients, primary support persons are not considered enrolled unless they have agreed to share data with UCD. Clients and support persons can make different choices regarding their data sharing permissions, i.e., a client can decline to share their data for research purposes while a support person can opt in. For the purpose of the preliminary feasibility analysis, we are only examining what proportion of enrolled clients also have an enrolled PSP, acknowledging that there may be more enrolled PSPs whose corresponding client opted out of data sharing. Programs who had not begun enrollment are not included in this analysis (Lake County and Stanford INSPIRE), although Lake County has since begun enrollment in Beehive.

Table II: Preliminary client and PSP Beehive enrollment

Program Name	**Current Census**	**Currently Enrolled**	**% Enrolled**	**Clients with an enrolled PSP**	**% with a Primary Support Person**
UCD SacEDAPT	29	30	103%	9	30%
UCD EDAPT	61	34	56%	14	41%
Solano SOAR	11	6	54%	4	67%
Napa SOAR	12	11	92%	8	73%
Sonoma SOAR	13	13	100%	5	38%
Kickstart Pathways	89	1	1%	1	100%
LAC- IMCES 3	14	11	79%	3	27%
LAC - IMCES 4	26	16	62%	2	13%
LAC - SFVCMHC	17	3	18%	0	0%
LAC- The Whole Child	25	16	64%	3	19%
LAC- The Help Group	19	13	68%	8	62%
OC CREW	46	18	39%	3	17%
San Mateo Felton	ReMIND: 44 Beam: 25	ReMIND: 5 Beam: 10	ReMIND:11% Beam: 40%	ReMIND:2 Beam: 0	ReMIND:40% Beam: 0%
UCLA Aftercare	22	10	45%	4	40%
UCLA CAPPS	43	0	0%	0	N/A
UCSD CARE	379	27	7%	2	7%
Stanislaus LIFE PATH	11	6	54%	1	17%
MCC	Mono: 0 Nevada: 3 Colusa: 2	Mono: 0 Nevada: 5 Colusa: 1	Mono: N/A Nevada: 166% Colusa: 50%	Mono: 0 Nevada: 0 Colusa: 0	Mono: 0% Nevada: 0% Colusa: 0%

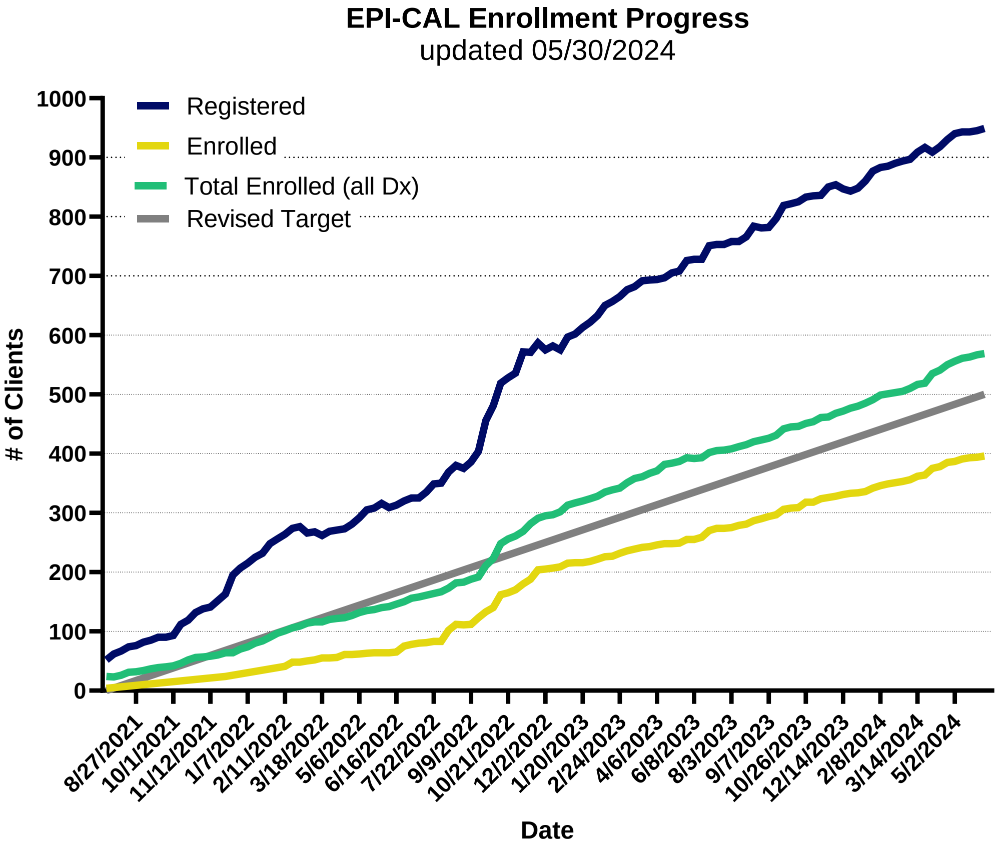
As described in Table II, there is quite a bit of variability across programs in the proportion of the program's census that are enrolled in Beehive (mean = 55%, range = 0-166%). Two programs have more clients enrolled in Beehive than currently in their program, indicating they have clients who have been discharged from the program but not Beehive. EPI-CAL point persons continue to work with the sites to make sure they discharge clients from Beehive in a timely manner moving forward. Five of the participating programs meet or exceed the previously defined benchmark of 70% of eligible clients are enrolled. There was also extensive variability in the number of PSPs enrolled in Beehive across the programs as well (mean = 31%, range = 0-100%). Four of the participating programs meet or exceed the previously defined benchmark of 50% of PSPs enrolled in Beehive.

The heterogeneity of enrollment across sites supports the need for the qualitative barriers and facilitators interviews to understand the issues that sites are facing. Future analyses will examine survey data from clients in more detail, and survey data analysis procedures for clustered data (treating early psychosis programs as clusters) will summarize characteristics of enrolled clients who complete enrollment and at least one longitudinal assessment.

1.4 Enrollment Progress and Follow-Up Completion Rates of Beehive Surveys

Figure 7 shows the LHCN Progress towards EPI-CAL Enrollment targets as of May 30, 2024. Service users are considered enrolled if they have completed the Beehive EULA and agreed to share their data with UC Davis for use in research. If service users do not allow their data for use in research but agree to use Beehive as part of clinical care, their data may be used for quality management or quality assurance purposes only. The goal at this point in the project was to have 1364 individuals enrolled (solid dark gray line in figure below). In summer of 2022 we worked with sites to create a revised enrollment target (light gray line) based on observed rates of enrollment up to that point. By this point in the project, the revised goal was to have 498 individuals enrolled. The observed rate of enrollment across the LHCN is 597 service users across all diagnoses (green line in figure below), including 436 service users with a diagnosis that indicates FEP, (the yellow line in figure below). There are an additional 268 service users who are registered by the clinic in Beehive (dark blue line in figure below), but who have not engaged with Beehive by completing the EULA or starting their surveys.

Figure 7: LHCN Progress Towards EPI-CAL Enrollment Targets



Figures 8-9 show a site-by-site breakdown of the proportion of individuals who agreed to data sharing with UC Davis for research purposes as of May 30, 2023. Figure 8 shows all registered clients, regardless of EULA completion status. Hence this figure shows the room for growth if sites support clients to complete their EULA in Beehive if those clients agree to data sharing.

Figure 8: Proportion of Data Sharing with UCD for Research by Site

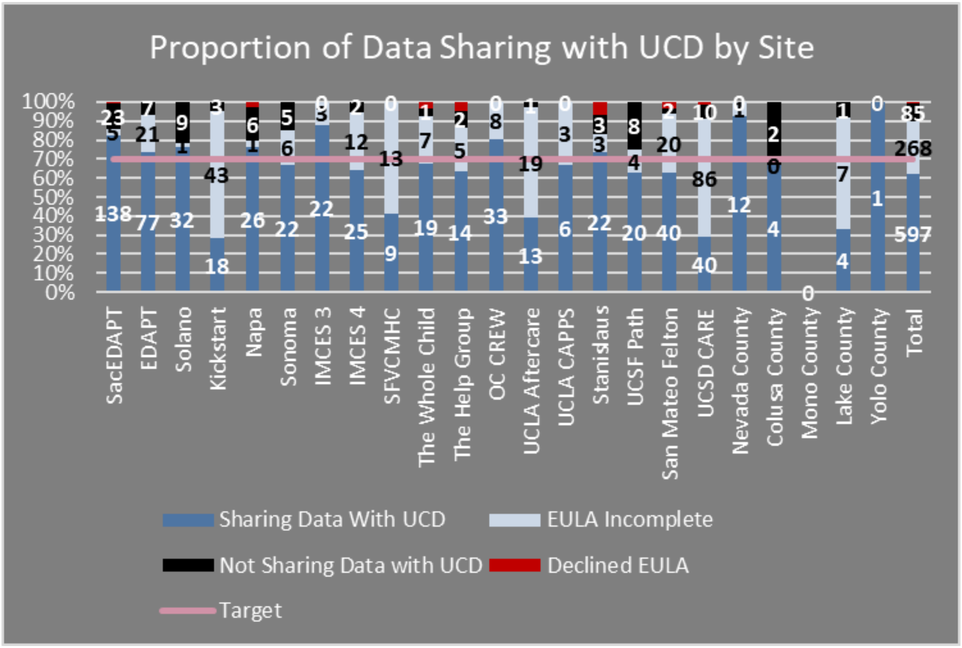
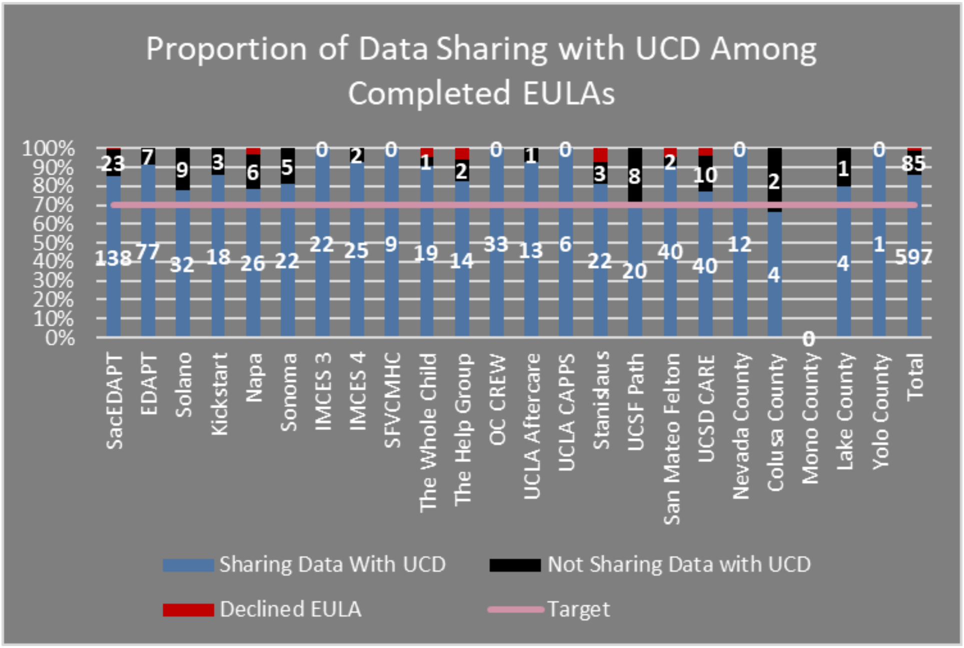


Figure 8 shows the proportion of data sharing choices made by those clients who have completed their EULA in Beehive. We can see that some sites on this graph do not have a bar at all because they do not have any clients who have been registered in Beehive.

Our goal is that 70% of active clients at each site agree to use Beehive and share their data for research purposes. When considering all clients known to EPI-CAL (i.e., all those registered in Beehive), we can see that several sites are meeting this metric. Further, among those individuals who have actually engaged with Beehive and completed the EULA, we are exceeding our target across the network, and at most sites individually as well. When considering all enrolled clients across the LHCN, 88% of clients have agreed to share their data with UC Davis and 83% of clients agreed to share their data with NIH for research purposes.

Figure 9: Proportion of Data Sharing with UCD for Research among Completed EULAs

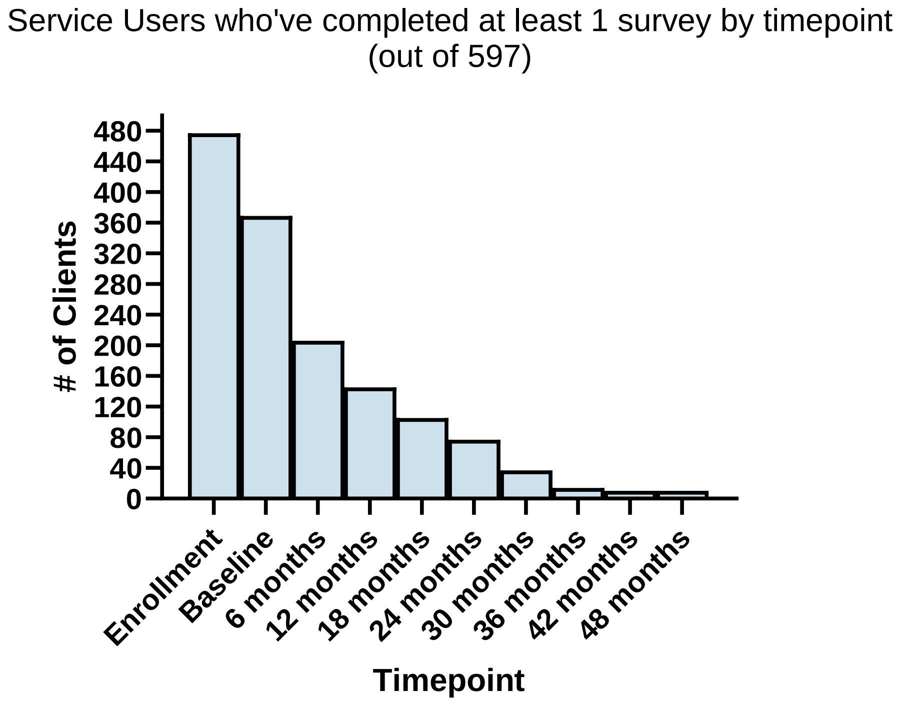


Progress of data collection in all EP programs

As of May 30, 2024, 23 EPI-CAL clinics have registered 1339 service users in Beehive. Of those 1339 service users who have been registered, 51% (n=597) have completed their Beehive EULA and are considered to be enrolled in Beehive. Of those who have completed their EULA, 83% (n=569) have agreed to share their de-identified data with NIH and 88% percent (n=597) have agreed to share their de-identified data with UCD.

Figure 10 shows network-level survey completion rates by time point as of May 30, 2024. Note that all service users are able to complete enrollment surveys regardless of when in their treatment they are enrolled. Service users are not able to complete some survey windows (e.g., baseline) if they are enrolled later in treatment. Some service users have completed surveys at more than one time point. Of the 681 service users who have been enrolled in Beehive, 97% (n=659) have completed at least one survey in Beehive. Of service users who have agreed to share their data with UCD (n = 597), 95% (N = 569) have completed at least one survey. Figure 10 shows survey completion by timepoint for individuals who have agreed to share their data with UCD

Figure 10: Survey Completion Rates Across EPI-CAL Network



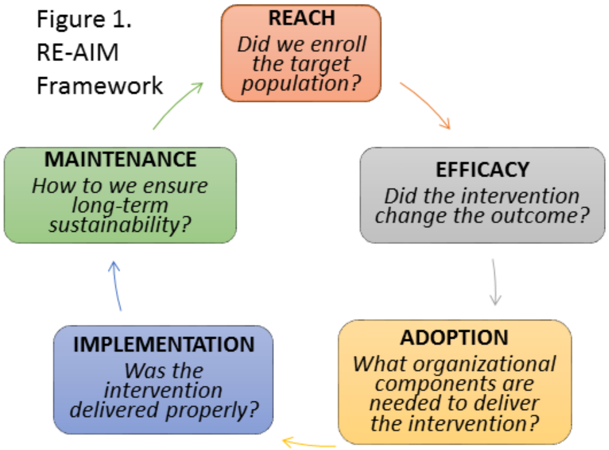
1.5 Preliminary Analysis Plan of Beehive Outcomes Data

As a reminder, this project contains data collected via three components: program-level data, county-level data, and qualitative data (Figure 1). This analysis plan will focus on program level data, i.e., client data collected via Beehive, including client self-report data, data from the primary support person for the client, and clinician rated data. The majority of the data is designed to be collected longitudinally, i.e., at baseline and then every six months of treatment thereafter. For our purposes, baseline is associated with a client's intake date, not when they are enrolled in Beehive. Therefore, any reference to "baseline" is referring to the client's intake date or start in their program regardless of their interaction with Beehive, and "enrollment" is referring to when the client was enrolled in Beehive, which occurs after intake. There are several variables that are only assessed at enrollment in Beehive, including multiple items that are assessed if they occurred over the client's lifetime. For example, clients are asked in the "EPI-CAL Baseline Only Questions" survey if they have ever, in their lifetime, experienced any legal interaction. Then, on follow-up surveys, clients are asked every 6 months thereafter if they have had legal involvement in the past 6 months. Therefore, the legal experiences variables represent variables that is assessed initially as a single lifetime variable and then longitudinally for more recent involvement. All clients are able to complete enrollment surveys regardless of when in their treatment they are enrolled. Clients are not able to complete some survey windows if they are enrolled later in their treatment (e.g., client enrolled at 6 months would complete the enrollment and 6-month bundle but would not be able to complete the baseline bundle). Please see Table III for a list of all data domains collected in Beehive. This table outlines whether a domain is rated only at enrollment or longitudinally, and also indicates who completes the survey. Who rates the data will also be included as a variable in the analysis as we want to differentiate between information that is client self-report or clinician rated.

Figure 11

RE-AIM provides a conceptual framework to facilitate the translati n to clinical practice. We will use this framework to examine the real-world impact of the proposed core battery and Beehive based on five dimensions (Figure 11): 1) Reach – the number and representativeness of the participants who use Beehive; 2) Efficacy – the impact of the intervention on specific outcomes; 3) Adoption – proportion and representativeness of people and places that adopt the intervention; 4) Implementation – quality and consistency of intervention delivery in real-world settings; and 5) Maintenance – long term outcomes of the intervention and its sustainability over time. This implementation research framework provides structure to examine initial impact of the project.

Figure 1. RE-AIM Framework



Prior to analysis, we will complete descriptive summaries for all data collected in Beehive, including client and clinician demographics, survey completion for each survey at each timepoint, and survey scores for quantitative measures. The distribution and completeness of each analysis variable will be examined to determine appropriateness of different statistical methods. Availability of within-person longitudinal data will be reviewed to determine whether longitudinal or cross-sectional approaches are most appropriate. Descriptive summaries will be generated for each clinic individually as well as network wide.

Table III: Beehive Surveys by Timepoint and Respondent Type

Respondent	**Measure**	**Timepoint**	
		Enrollment	Every 6 months (including Baseline)
Client	Registration Demographics	1*	0*
Client	EPI-CAL Baseline Only Questions	1	0
Client	Primary Caregiver background	1	0
Client	Adverse Childhood Experiences (ACES)	1	0
Client	Demographics & Background	0	1
Client	Education	0	1
Client	Employment and Related Activities	0	1
Client	Social Relationships	0	1
Client	SCORE-15	0	1
Client	Legal Involvement and Related	0	1
Client	Substance Use	0	1
Client	Medications	0	1
Client	Intent to Attend and Complete Treatment Scale	0	1
Client	Modified Colorado Symptom Index	0	1
Client	Questionnaire about the Process of Recovery (QPR)	0	1
Client	Life Outlook	0	1
Client	Hospitalizations	0	1
Client	Life Events Checklist (LEC-5) & PTSD Checklist for DSM-5 (PCL-5)	0	1
Client	Child and Adolescent Trauma Screen (CATS)	0	1
Clinician	Pathways to Care	1	0

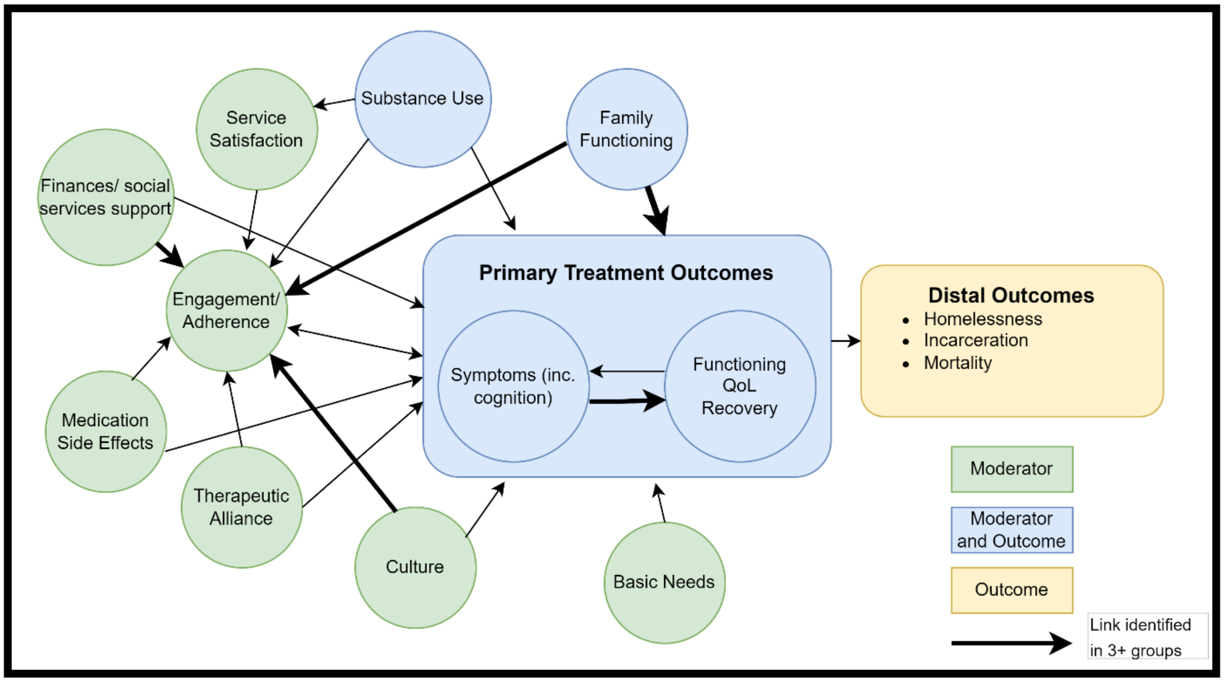
Clinician	Diagnosis and DUP	0	1
Clinician	Family Involvement	0	1
Clinician	Risk to Self/Others	0	1
Clinician	Health	0	1
Clinician	Medications	0	1
Clinician	Service Use	0	1
Clinician	Functioning	0	1
Clinician	Symptoms	0	1
PSP *	Baseline Only Questions	1	0
PSP	Demographics & Background	0	1
PSP	Legal Interactions & Related	0	1
PSP	SCORE-15	0	1
PSP	Burden Assessment Scale	0	1
PSP	Modified Colorado Symptom Index	0	1
PSP	Medications	0	1

* PSP = Primary support person; 0 = not available; 1 = available

First, we will examine is whether we achieved adequate enrollment in Beehive (*Reach)*. We will examine this using descriptive statistics to see if at least 70% of eligible participants, who are representative of the target population based on current program demographics, and 50% of their available family members, across the network were enrolled and completed at least one survey timepoint. To approximate the number of total clients eligible for enrollment, we will pull the total census number from each programs' completed fidelity assessment and program-level core assessment battery (PL-CAB). Data on of the number of available family members is available in Beehive and we are able to assess whether a primary support person (PSP) has completed enrollment and any additional surveys. Survey data analysis procedures for clustered data (treating early psychosis programs as clusters) will summarize characteristics of enrolled clients who complete enrollment and at least one longitudinal assessment. Enrollment rates (with 95% confidence interval) will be computed for 1) all eligible clients and 2) potentially available family members. For the latter, we will report, for the denominator of eligible clients with available family members, what proportion of those clients had at least one family member complete a baseline or 6-month assessment.

Through the extensive qualitative work that was completed in the first phase of this project (Figure 12), a variety of key outcomes were identified by our program, client and family workgroups. As described in the qualitative results from the Outcomes Focus groups, psychiatric symptoms, quality of life, and functioning were prioritized as key outcomes by all types of respondents and our analysis will center on these domains. Initially, as we continue to enroll and gather longitudinal data, our analyses will provide repeated cross-sectional assessment of these outcomes, with preliminary analyses of client's longitudinal trajectories when possible. As the longitudinal dataset grows, to account for the hierarchical structure of the data (nesting of measurements from clients, who are nested within clinicians within EP programs) and for continuous, binary, and count outcomes, generalized linear mixed models will be used to estimate the adjusted effects of exposures of interest on the key outcomes of interest, including quality of life, functioning, and recovery. Regression models will include independent variables (specified as fixed-effect terms) that operationalize relevant clinician metrics along with a parsimonious set of other clinician- and client-level covariates, in order to statistically adjust for confounders. Relevant clinician metrics may include clinician demographic information collected at registration, such as degree level, years working with this specific population, and other demographic variables. Random effects will be specified for sites, with additional effects specified for clinician and clients' effects if either/both improve model fit, according to Schwarz Information Criterion.

Figure 12: Moderators and Outcomes of Interest



Next, we will examine *efficacy* of measurement-based care, comparing adjusted mean differences in baseline to 12-month change in psychotic symptom severity between groups defined by clinician metrics available from Beehive. When examining group-level differences, it is important to note that there is not a "Beehive" and "not Beehive" group of clients; all clients are assigned to the Beehive group and thus any analysis cannot examine the effect of Beehive use in treatment compared to a typical control group. Instead, clients will be classified according to the timeliness of clinician assessment of the client's Beehive data; the primary clinician metric will be a binary indicator for whether clinician accessed the patient's data within two weeks of surveys being completed. Exploratory metrics will include time spent reviewing Beehive data and whether the clinician reported that Beehive data impacted treatment plan. Our primary analysis will estimate impacts on mean baseline to 12-month changes in psychotic symptom severity, with separate regression models built for each of the primary and exploratory operationalizations of the Beehive clinician-usage metrics described above.

Estimations of timepoint-specific changes (e.g. from baseline to 12-months) could either be done by computing the specific change score and using it as a dependent variable in a regression or, when data from other timepoints is also available, by analyzing the available data from each patient at each of multiple timepoints and including in the regression models terms for time, comparison group, and the interaction, to enable estimating timepoint-specific effects. When baseline data are available for a given outcome, we have opted to use regression approaches that pertain to estimating mean changes from baseline (e.g., a difference in differences type approach) instead of with baseline-adjusted mean differences at follow-up (e.g. an ANCOVA-type strategy) because our study is nonrandomized (Van Breukelen, 2006). Psychotic symptom severity data is available from both the client self-report Modified Colorado Symptom Index and a clinician-rated symptom measure, either the Brief Psychotic Rating Scale (BPRS) or the COMPASS-10. To address attrition, we will use multiple imputation to impute follow-up assessment scores and change scores based on them.

To assess the *maintenance* of measurement-based care via Beehive, we will assess timepoint-specific changes in psychotic symptom severity for each of the half-yearly assessment timepoints during the first 24 months, with the primary analysis based on a time-varying indicator for any endorsement of “impact on treatment plan” as a time-varying independent variable. We will also use data from the barriers and facilitator interviews to examine client-, provider- and program-level barriers to enrollment and completion. Separate models will be fit for each of the primary and alternative operationalization of Beehive clinician-usage metrics as the exposure variable of interest.

To examine *Adoption*, we will compare providers with respect to their reporting use of data to determine treatment choices at two timepoints, prior to Beehive implementation and after training in and using Beehive. To assess *Implementation*, we will examine if EP providers use Beehive in direct care with clients for at least 50% of completed assessments. Prior to Beehive implementation in each EP program, providers completed “pre-implementation” surveys about their demographic information (age, sex, race, ethnicity) and professional characteristics (years of education, degree type) and completed questionnaires on their 1) beliefs about the utility of data in care planning and 2) skills in discussing data with clients. Beehive training materials were implemented consistently across participating EP program, highlighting the utility of data to identify treatment goals and metrics of improvement during treatment planning, and provided guidance on client-centered ways to review data to monitor progress during treatment. For post-implementation analysis of use of data in care, we will use provider-rated “use of data in care” questions, which are intermittently presented to providers while they are reviewing a client’s data page in Beehive so that they may indicate 1) if the data was reviewed during a session with the client or family and, if yes, 2) how the data was used as part of care, such as “followed up by phone” or “scheduled follow up appointment,” or “no action taken.” These data use metrics allow analysis on rates of adoption and level of implementation of Beehive. We will use a mixed effects regression model with robust standard errors to estimate site- and provider-adjusted pre-to-post differences in the proportion of client sessions where client-level data was used. The regression model will include fixed effects for site and a binary indicator for post-implementation and random effects for providers. If convergence can be obtained, we will use a linear link with a binomial variance. Otherwise, we will use a linear-normal model, relying on the robust variance estimator to correct for heteroscedasticity. Exploratory analysis will examine clinician expertise and training needed to effectively implement clinician review of FEP participant outcome data using Beehive at 80% of available time points.

To identify barriers and facilitators to Beehive implementation, our team is in the process of completing semi-structured qualitative interviews with clients and providers. Client-, provider- and program-level implementation barriers will be identified through analyses of qualitative data. Stratified purposeful sampling was and will continue to be used to recruit participants across clinics where Beehive adoption and implementation has been both high and low, and with clients who have and have not received data-integrated care. The data will be analyzed using an inductive approach to thematic analysis to identify data-driven themes to explain aspects of a phenomenon. Multiple coding will be adopted, and where possible, service users and providers will be involved in developing the topic guide and reviewing the data analysis and interpretation. We have almost met our goal of a total of 30 interviews completed by the end of 2023.

In addition to the program-level data described here, we also collected project data via fidelity assessments, program surveys, and the PL-CAB. Each program has completed a fidelity assessment to determine the components of coordinated specialty care (CSC) provided using the First Episode Psychosis Services Fidelity Scale (FEPS-FS), a standardized measure of fidelity to EP program best practices. Similar to the fidelity assessments, program surveys and the PL-CAB assess various components offered through the CSC program, program census, and staffing. The data from these other sources may also be used to inform the analysis of the program-level data described above.

Future analyses seek to examine the other relevant outcomes and moderators identified in Figure 12. Specifically, outcomes like homelessness, incarceration, and mortality are critically important for individuals with psychosis, but were not prioritized during the qualitative work given that these outcomes are not frequently observed in during the early course of illness. Therefore, these outcomes will be described for each of the programs, but not incorporated into statistical analyses for the purposes of the current report. Instead, we may need longer-term follow up data of those that transition out of the clinic and these domains have been identified as a priority for future work.

1.6 Preliminary Beehive Outcomes Data Results

Here we report demographic information that is completed at registration, which is a subset of the demographic questions that are asked in Beehive (Table IV). Complete demographic information, including all required PEI fields, are administered via a required client-entered Beehive survey. For any cell that has an N less than 5 individuals, this data was masked and both the N and proportion cells were updated with “<5” and “<1%”, respectively. If there were 0 individuals who endorsed a response option in the demographic surveys, the category is not represented on Table 1 (e.g., Genderqueer/gender non-conforming in the gender category); we will continue to add categories to each demographic variable if there are ≥1 individuals in each respective category.

Table IV: Demographic Data from all Participating EPI-CAL Clinics

EPI-CAL Combined Demographics, n = 597 (through 05/30/2024)		
Display Language	**N**	**%**
English	583	98%
Spanish	12	2%
Missing	<5	<1%
Age	**N**	**%**
<12	<5	<1%
12-17	202	34%
18-23	279	47%
≥24	114	19%
Sex at Birth	**N**	**%**

Female	293	50%
Male	293	49%
Intersex	<5	<1%
None of these describe me	<5	<1%
Prefer not to respond	<5	<1%
Gender	**N**	**%**
Female	252	42%
Male	281	47%
Non-binary	24	4%
Transgender	9	2%
Queer	<5	<1%
Questioning or unsure of gender identity	5	1%
Other	7	1%
Prefer not to say	15	3%
Missing	<5	<1%
Pronouns	**N**	**%**
He/Him	253	42%
She/Her	213	36%
They/Them	27	5%
Other	5	1%
Missing	99	17%
Race	**N**	**%**
African/African American/Black	70	12%
Asian	61	10%
American Indian/Alaskan Native	<5	<1%
Hispanic/Latinx Only	192	32%
White/Caucasian	182	30%
More than one race	51	9%
Unsure/Don’t Know	12	2%
Missing	<5	<1%
Ethnicity	**N**	**%**
No - I do not identify as Hispanic/Latinx	215	54%
Yes - I identify as Hispanic/Latinx	321	36%
Unsure/Don’t know	57	10%
Missing	<5	<1%

Additionally, providers are asked to enter a client’s diagnosis when they register individuals in Beehive, which is reported in Table V. In the same manner as the table above, cells with less than 5 individuals were masked and both the N and proportion cells were updated with “<5” and “<1%”, respectively. Diagnoses are grouped according to two classes of early psychosis: 1) individuals who are deemed to be at clinical high risk for psychosis (CHR), and 2) individuals who have experienced psychotic level symptoms (First Episode Psychosis, FEP). There is also a section for those individuals for which their FEP or CHR status is not yet confirmed. This reflects the wide range of psychosis diagnoses that are served by the EP clinics represented in this sample.

Table V: Client Diagnoses from all Participating EPI-CAL Clinics

EPI-CAL Combined Diagnoses, n = 597 (through 05/30/2024)	**N**	**%**
Clinical High Risk (CHR)		
Attenuated Psychosis Symptoms	35	6%
Genetic Risk and Deterioration Syndrome (GRDS)	<5	<1%
Other	73	12%
First Episode Psychosis (FEP)		
Substance Induced Psychotic Disorder with onset during intoxication	7	1%
Mood disorders with psychotic features	75	13%
Schizoaffective Disorder (Bipolar or Depressive Type Combined)	39	7%
Schizophrenia	86	15%
Schizophreniform Disorder	12	2%
Delusional Disorder	<5	<1%
Brief Psychotic Disorder	<5	<1%
Other Specified Schizophrenia Spectrum Disorder	17	3%
Unspecified Psychosis	74	13%
Other FEP	90	15%
CHR or FEP Status Not Confirmed	61	10%
*Anxiety Disorders**	*17*	*3%*
*Mood Disorders**	*40*	*7%*
*Other Diagnoses**	*26*	*4%*
Not enough Information	<5	<1%
Missing	20	3%

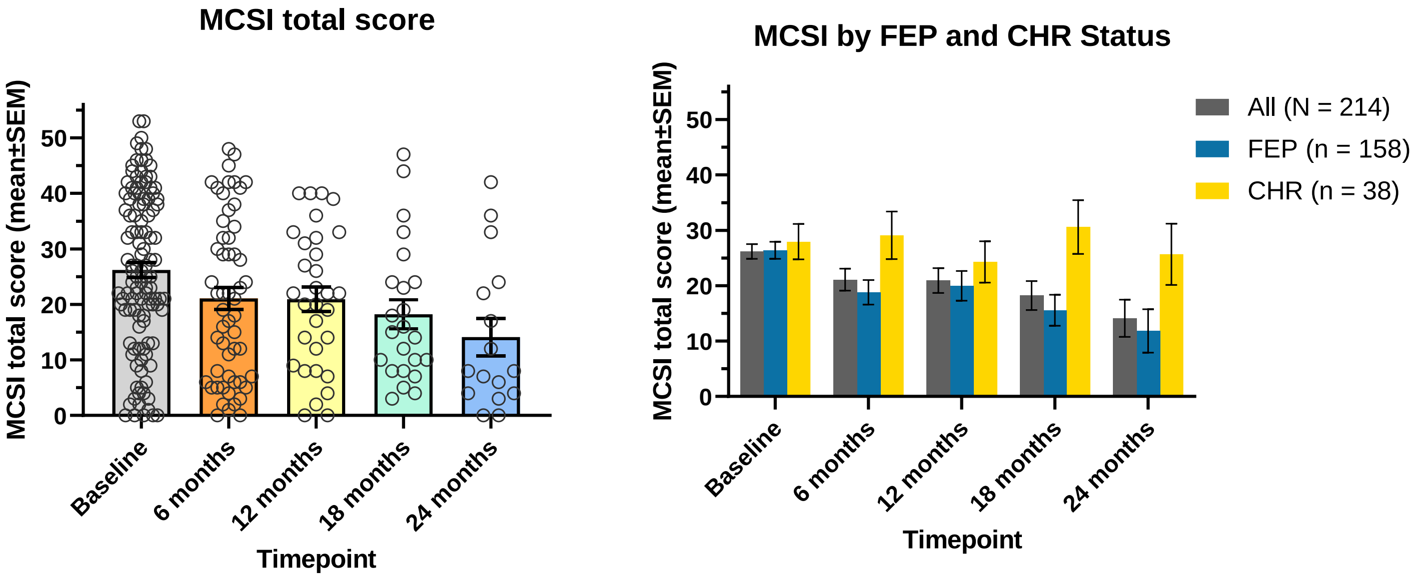
**Individuals may be counted more than once for these diagnoses*

Our team has also begun to examine descriptive summaries of specific outcomes data from all EP programs, as well as preliminary analyses examining relationships between specific outcomes. Preliminary analyses are grouped by outcome below. Data is only reported for those users who opted into data sharing for research purposes with UC Davis. Many of the preliminary data summarized in the next section below have been prepared for conference abstracts for wider dissemination.

Client Self-Report Symptoms

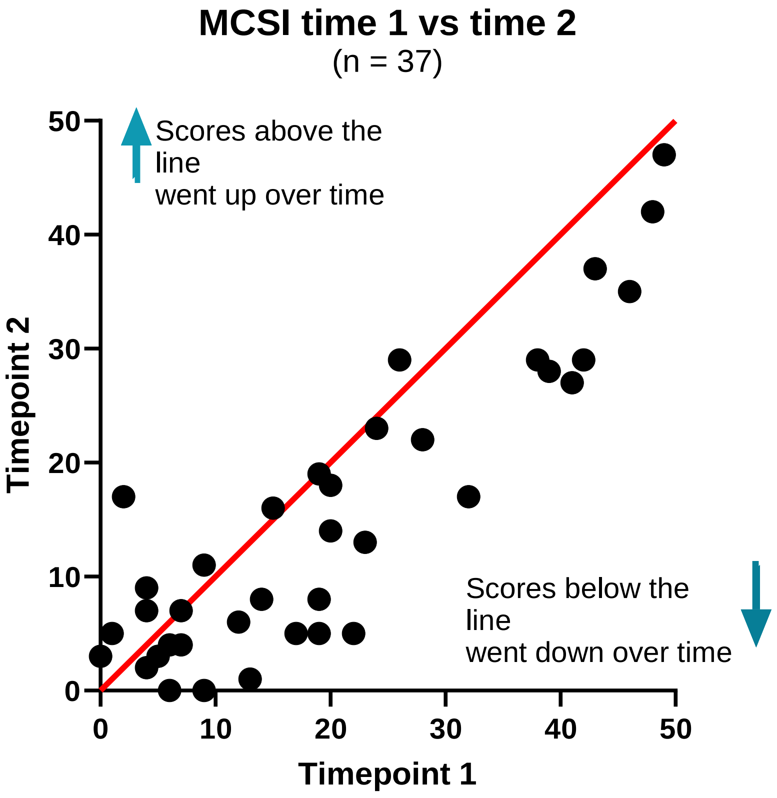
The Modified Colorado Symptom Index (MCSI) is 14 items and asks clients to rate the frequency of their symptoms over the past month. Scores range from 0-56 and scores of 16 and above meet “clinical threshold.” This survey is administered to clients in Beehive at baseline and at every 6 months thereafter. In the current sample, participants completed 326 MCSI surveys across all timepoints. When computing total scores for the MCSI, we excluded surveys that included the response “prefer not to say” (n = 58). In our initial examination, there were 319 complete MCSI surveys from 267 unique individuals across 18 clinics. In that sample, there were 261 surveys with a score for all 14 items from 214 unique individuals.

Figure 13: MCSI total Score Across Time in Program



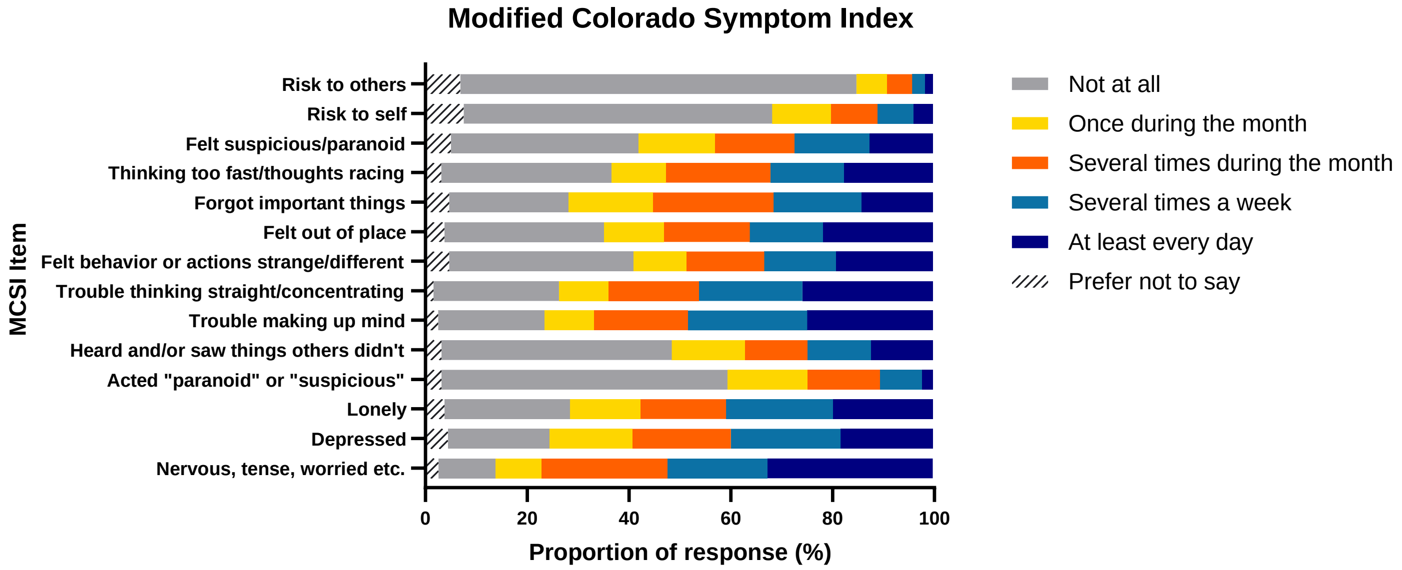
While we did not yet do any formal statistical analysis on MCSI score, we found that there is a pattern of lower scores over time. It is important to note that this is for all participants, even if they have only completed one MCSI survey. We also examined MCSI scores for those who have completed their survey at more than one timepoint. We found that clients who entered data over multiple timepoints tend to have lower scores over time.

Figure 14: MCSI Total Score Across Repeated Timepoints



We also examined responses to each individual MCSI survey question to understand which symptoms clients were endorsing most frequently. We found that clients most frequently endorsed feeling nervous, tense, worried, depressed, trouble making up their mind, and trouble thinking straight and/or concentrating (Figure 15).

Figure 15: Frequency of Symptoms Varies Item to Item



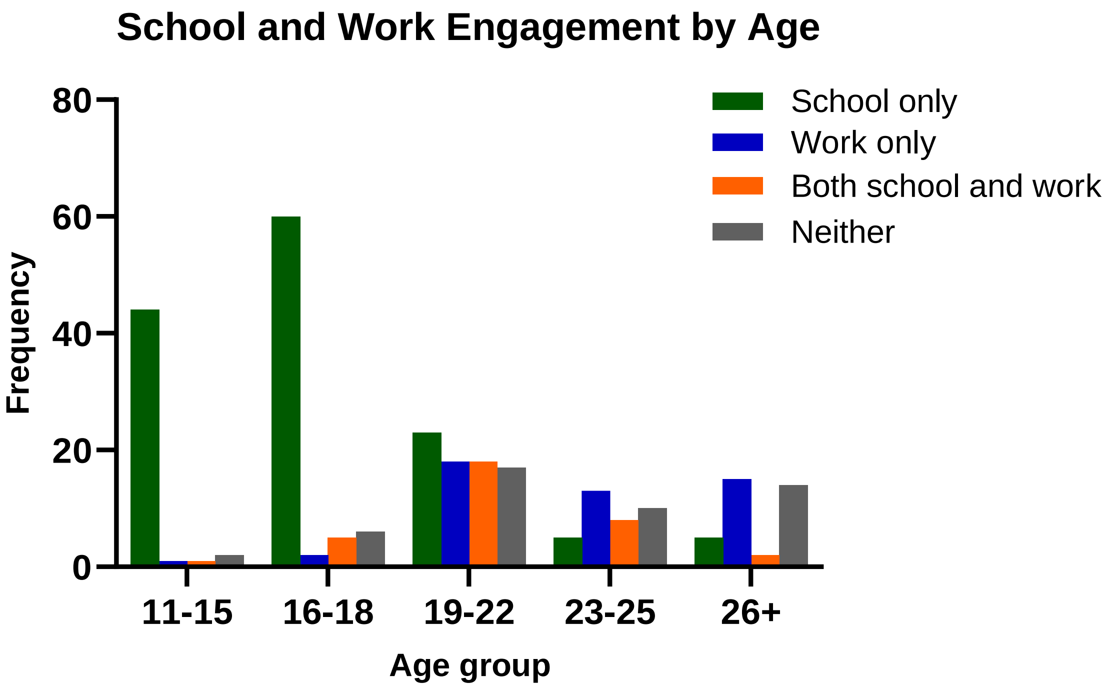
Longitudinal examination of key outcomes is important to understanding how individuals are reporting changes across outcomes of interest over the course of their EP program treatment. This data can offer clinical teams key metrics to track client progress. As data collection continues across EPI-CAL sites, results from an increased sample will be reported.

Client self-reported education, employment, and social activities

We examined outcomes data collected related to service users' self-reported functioning, including survey responses regarding life outlook, social relationships, employment, and education. At the time of the analysis, 287 service users across 20 EPI-CAL clinics have completed surveys on life outlook, education, employment and related activities, and social relationships. In that subset of participants, services users received diagnoses associated with a first episode psychosis (FEP; n = 208, 72%), clinical high risk (CHR; n = 65, 23%), or FEP/CHR status not confirmed (n = 14, 5%). Ages ranged from 11 to 36 (M = 20.01 years, SD = 4.7).

School and work attendance was examined across age groups with 137 individuals (48%) reporting school attendance only (part-time or full-time), 49 individuals (17%) in work only, 34 individuals (12%) in both school and work, and 49 individuals (17%) engaged in neither school nor work. Chi-square analysis was used to examine age group differences between education and employment activities. As expected, there was a significant effect of age on the type of activities that individuals were engaged in ($\chi 2(9)=127.75$, $p < 0.001$), with younger people proportionally participating in only school to a higher degree than other roles and older adults (26+ years) were engaged in only work or neither work nor school to a higher degree than other age groups (Figure 16).

Figure 16: School and Work Engagement by Age



When asked whether they were engaged in as much work, volunteering, or school as they wanted, 115 (40%) service users either agreed or strongly agreed and 101 (35%) disagreed or strongly disagreed. A linear regression was run to examine the effect of role satisfaction and social relationships on overall life satisfaction as measured by the Personal Wellbeing Index (PWI). Social relationships (belonging to a group of people that share attitudes and beliefs), role satisfaction (feels that current role will help them reach their long-term goals), and participation in education and/or employment activities significantly predicted overall satisfaction with life as a whole (R^2 for overall model 23.1%; F(5, 238) = 14.27, p < .001).

We found that work and school engagement vary widely across service users in EP programs as the individuals in these programs represent a diverse group that are at different developmental stages in their life. Self-reported social relationship satisfaction, role satisfaction, and work and/or school engagement were significantly related to overall life satisfaction. Therefore, EP service providers must focus on occupational, educational, and social relationship satisfaction as recovery goals for individuals receiving early intervention services.

Medication Taking Behavior

Medication side effects can impact individuals' perceptions of medication efficacy and subsequent medication taking behaviors. In early psychosis intervention (EPI), taking medications as prescribed and having a support person (e.g., family) involved in care are key factors associated with better outcomes. Facilitating communication regarding medication side effects between care providers, support persons, and individuals receiving care may assist in side effect management, shared decision making, and support healthy medication-taking behaviors. As such, it is important to identify whether individuals in care and their primary support person (PSP) report similar patterns of side effects, and whether there are areas for improved communication. The present analysis aimed to investigate whether there are differences in PSP and individual report of medication side effects, characterize any patterns in discordance, and identify areas for potential clinical intervention.

Within the first 6 months of EPI engagement, individuals and their PSPs were asked whether the individual is prescribed any medication. Those who endorsed having at least one prescription medication were administered a modified version of the Glasgow Antipsychotic Side-effect Scale (GASS). We used paired samples T-test examined GASS sum scores to determine whether individuals were systematically reporting more side effects than PSPs. Individual and PSP GASS item level endorsement concordance was evaluated utilizing Cohen's Kappa. Finally, bivariate correlations were conducted between GASS scores and measures assessing intent to remain in EPI care and taking medication as prescribed. Concordance between PSP, individual, and clinician agreement on medication status was also examined.

In a total sample of 114, agreement of medication prescription status between individuals and PSPs was high (k = .84, p>.001 at baseline, k=1.00, p>.001 at 6 months). Individuals who endorsed prescription medication and completed the GASS were examined (n=54 at baseline, n=22 at 6 months of EPI engagement). At baseline, 80% of individuals (n=41) reported taking any medication as prescribed 0-25% of the time; at 6 months, 93% of individuals (n=14) reported taking medication as prescribed 0-25% of the time. Paired sample T-test results indicated that individuals and PSPs report similar rates of side effects. However, of the 27 side effect items assessed at baseline, individuals and PSPs showed slight to moderate agreement on 16 items (ranging from k=.19 to k=.47). At 6 months, only 7 items performed above chance (ranging from k= .22 to k=.48). GASS scores did not significantly correlate with intent to continue or complete EPI services, medication-taking behaviors, or medication related beliefs. However, individuals' distress regarding side effects was significantly correlated with concerns that taking medication will do more harm than good (r=.32, p<.05).

In the present sample, most individuals reported they take medication as prescribed 25% of the time or less. These medication taking behaviors may impact the number of medication side effects individuals experience and reduce overall medication efficacy. Individual and PSP agreement on side effects was moderate to low at baseline and decreased over the course of EPI. Lack of PSP and clinician awareness and communication around individuals' medication taking behavior may contribute to poor outcomes. Therefore, increased communication between individuals, their support systems, and their care teams is crucial to address individuals' concerns regarding medication and increase shared decision making.

Adverse Childhood Experiences

Research shows individuals with psychosis often have a history of trauma that contributes to poor outcomes across multiple domains. Trauma is common (Neria et al., 2002; Varese et al., 2012): 6.8% with PTSD in general population vs 23% in first episode psychosis. Up to 80% of youth a clinical high risk for psychosis endorse a lifetime history of traumatic events and victimization during childhood. Trauma is poorly diagnosed in individuals with serious mental illness (Grubaugh et al., 2011). History of trauma exposure in psychosis can lead to more severe symptoms, poorer social relationships, increased substance use, as well as increased risk for hospitalization, homelessness, and suicide (e.g., Grattan et al., 2019).

We examined group differences between individuals who had ACEs Scores of 4+ ("High ACEs Group") as that number of experiences is associated with poorer clinical outcomes. In this preliminary analysis, 302 clients completed the ACEs survey in Beehive at enrollment. In our sample, 17% of individuals reported no history of ACEs, 47% of Individuals reported ACEs in the clinical range, and 26% of individuals reported ACEs levels expected by a 20-year life expectancy decrease (6+).

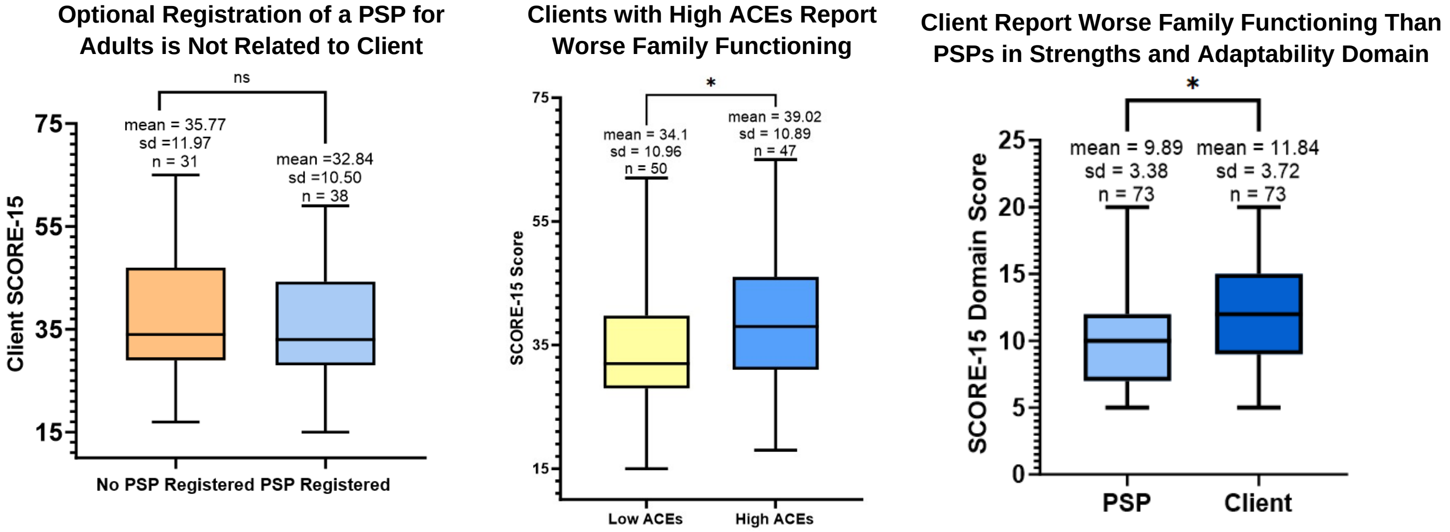
We found that experiences of several adverse childhood experiences (ACEs) in individuals with early psychosis is associated with poorer life outlook, and higher risk of suicidal and homicidal ideation in our preliminary data collected in Beehive. Additionally, individuals with higher ACEs are more likely to have experienced lifetime housing instability and individuals who identify as LGBT are more likely to report higher ACEs. ACEs and other social determinants are likely drivers of poor outcome in early psychosis and should be addressed in treatment.

Adverse Childhood Experiences and Family Functioning

Our qualitative data highlighted how adverse childhood experiences (ACEs) impact the lives of individuals experiencing psychosis. Intensity of traumatic experiences throughout childhood could represent a modulating factor of psychotic symptoms and overall functioning, including family functioning. Beyond psychosis, family functioning can have a moderating effect on the negative impact of ACEs on emotional well-being. This suggests a strong association between ACEs, mental health difficulties, and family functioning, though these relationships have been minimally examined in the context of early psychosis. The current analysis examines the relationships between client ACEs and family functioning as reported by both clients and primary support persons (PSP) in EPI-CAL.

Participants completed the Pediatric ACEs Screening and Related Life-events Screener (PEARLS) and the SCORE-15 in Beehive. In this particular analysis, 217 clients (Ages 12-32, M=19.04, SD=4.28; 71% FEP, 21% CHR, 8% Diagnosis unconfirmed), completed the PEARLS version of the ACEs-10 (M = 3.52, SD = 2.74) at enrollment. They identified as 50.5% female sex at birth; 42% female gender; 73% non-White; 41% Hispanic/Latinx; and 7% were not born in the US. All analyses utilized a subset of items reflective of the original ACEs-10. Adults were asked to rate experiences prior to age 18. ACEs scores of 4+ are considered high risk for poor outcomes. In this sample, 47% respondents had an ACEs score of 4 or higher and are considered high risk for poor outcomes. Clients' self-reported SCORE-15 total scores (n=103, M=33.68) was positively correlated to their ACEs scores ($r = 0.295$, $p=0.002$). Conversely, PSP SCORE-15 total (n=71, M=30.13) and subdomain scores were not significantly related to their associated client's ACEs score ($r = 0.19$, $p=0.11$). The same pattern was found in each of the three SCORE-15 subdomains (strengths and adaptability, overwhelmed by difficulties, and disrupted communication). Higher SCORE-15 scores indicate worse family functioning. Exploration of matched pairs between client and PSP will be examined as more data is collected.

Figure 17: ACEs and Client/PSP Reported Family Functioning (SCORE-15)



Optional Registration of a PSP for Adults is Not Related to Client

Clients with High ACEs Report Worse Family Functioning

Client Report Worse Family Functioning Than PSPs in Strengths and Adaptability Domain

ACEs are common for individuals receiving care in EP programs. These experiences are associated with worse family functioning per client report. Given the importance of family treatments as an evidence-based approach for FEP, and the negative impacts of ACEs on client outcomes, these data suggest that EP programs should identify and treat individuals who experience traumatic events and to target areas of family functioning, with the goal of improving outcomes.

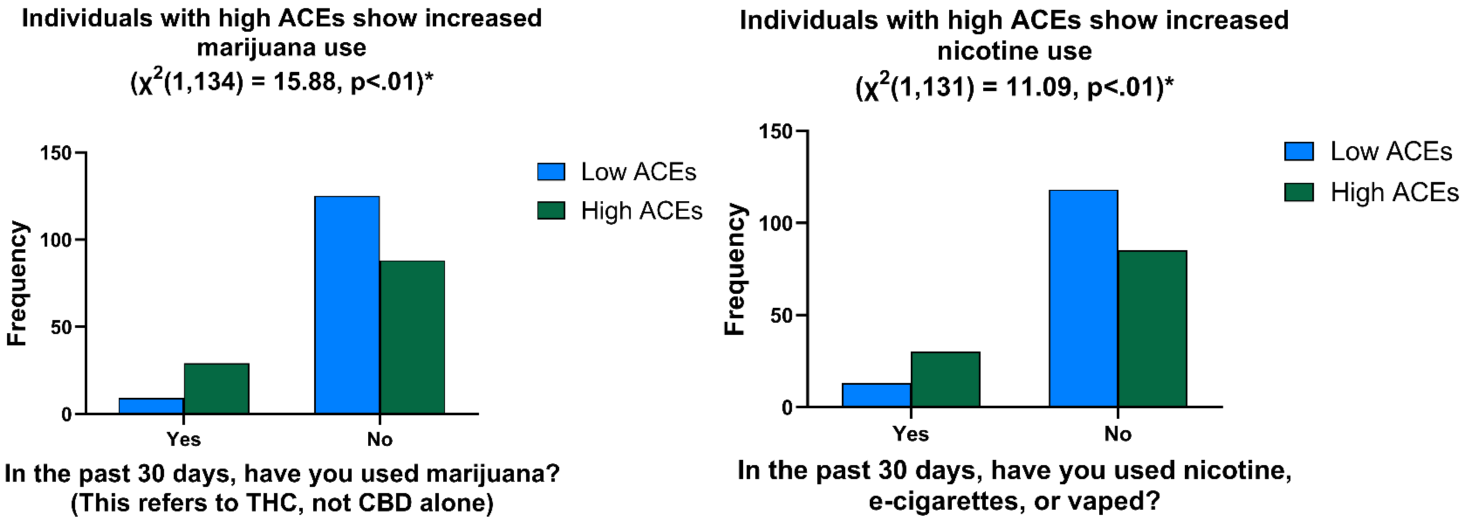
Adverse Childhood Experiences and Substance Use

Higher prevalence of adverse childhood experiences (ACEs) is related to increased rates of psychosis symptoms and substance use (SU) disorders separately. Few studies have jointly examined these factors in the early psychosis (EP) population. We investigated whether individuals in EP programs above clinical threshold for ACEs endorsed SU at higher rates.

Individuals with first episode psychosis (FEP) or at clinical high risk for psychosis (CHR) completed Pediatric ACEs Screening and Related Life-events Screener (PEARLS; adolescent version) and SU surveys. The current analysis used the ACES-10 items and the clinical threshold of ≥4 ACEs. In the SU survey, individuals reported usage of alcohol, marijuana, nicotine, opioids, and stimulants over the past 30 days. 179 clients (ages 12-32) completed the ACEs-10 and SU survey. 86 respondents (48%) had an ACEs score of 4 or higher. 30 clients (16.8%) reported nicotine use, 38 clients (21.2%) reported alcohol use, 27 clients (15.1%) reported marijuana use. Use of opioids and stimulants were minimal in this sample.

Chi-square tests were used to evaluate group differences. Individuals with high ACEs showed increased nicotine and marijuana usage (Figure 18) while there were no significant differences for alcohol usage.

Figure 18: Differences in Substance Use Between High and Low ACEs



We hypothesized individuals with a high number of ACEs would show increased substance use of nicotine, marijuana, alcohol, stimulants, and opioids compared to individuals with a low number of ACEs. There was not enough use of stimulants and opioids to perform analyses (<5). Additionally, we found that individuals who experienced a high number of ACEs showed increased use of nicotine and marijuana only when compared to individuals with low ACEs. Individuals with a high number of ACEs did not show significant differences in alcohol usage when compared to individuals with low ACEs. Highly endorsed questions can help identify specific adverse childhood experiences (ACEs) that are more prevalent among the EP population. Understanding which specific experiences result in increased substance usage can inform targeted interventions and reduce poor outcomes in this population.

Childhood Poverty

Recent studies suggest that CSC is not as effective for individuals with less economic advantage. This is critical, as approximately 37 million, or 12%, Americans, lived in poverty each year between 2020 and 2022. In 2022, 15% of American children lived in poverty, noteworthy because childhood economic disadvantage is predictive of both development of psychosis-spectrum disorders as well as other health problems. To better understand early experiences of poverty of service users in community CSC programs, this current analysis examined experiences of early childhood poverty of EPI-CAL service users and explored how these experiences are related to high-priority clinical outcomes.

CSC service users and their primary support persons (PSP) completed Beehive surveys at EPI-CAL enrollment and every 6 months throughout treatment. PSPs who lived with the service user before they turned five reported subjective poverty indicators experienced in the household during that time. Participants also reported their demographics and clinical outcomes, including symptoms (Modified Colorado Symptom Index (MCSI)), recovery (Questionnaire about the Process of Recovery (QPR)), and quality of life (Personal Wellbeing Index (PWI)). Descriptive analyses summarized demographics and poverty indicators. Independent-samples t-tests were run to determine if there were differences in specific outcomes (MCSI, QPR, and PWI) between service users with and without a history of early poverty, and family-wise error rate was adjusted to correct for multiple comparisons. Chi-square tests were used to examine group differences between specific demographic factors and those with and without childhood poverty experiences.

At enrollment, 165 PSPs (Ages 16-66, M=45.76, SD=9.17) reported on subjective experiences of poverty had by the service user (ages 12-32, M=17.78, SD=3.72; 66% FEP, 27% CHR, 11% Diagnosis Unconfirmed) prior to age five. We found 29 (18%) PSPs who endorsed that the service user had at least one subjective experience of poverty prior to age 5. When examining demographic factors, there was a significant association between race and experience of childhood poverty ($\chi^2(4) = 14.91$, $p < .01$) with African American/Black individuals reporting more childhood poverty experiences than expected. Individuals who had subjective experiences of poverty during childhood reported worse clinical outcomes on the recovery measure at baseline, with individuals without poverty experiences having higher scores on the QPR (M = 34.63, SD = 8.90) than those with poverty experiences (M = 27.94, SD = 11.00; $t\,(49) = 2.31$, $p = .01$, corrected $p = .038$).

To date, the proportion of individuals with experiences of childhood poverty is higher than the general American population. These experiences of poverty disproportionately affect Black and African American service users. Individuals with these experiences were less likely to agree with statements indicating recovery at their first recorded assessment in CSC. This continues to support that socioeconomic experiences should be considered as a factor contributing to clinical outcomes. Future analyses will examine current socioeconomic status (SES) as a moderator of clinical outcomes at baseline and explore how childhood poverty and current SES may moderate change in clinical outcomes throughout CSC treatment.

1.7 Fidelity Assessment Procedures and Preliminary Data

This section includes preliminary findings from the fidelity assessments that have been conducted with EPI-CAL EP programs, including programs that are not currently in the LHCN but have a received a fidelity assessment from our team through their participation in the EPI-CAL's training and technical assistance program. The majority of participating programs serve clients with both clinical high-risk syndrome (CHR) in addition to first episode psychosis (FEP). Therefore, most fidelity assessments were conducted using the First Episode Psychosis Services – Fidelity Scale (FEPS-FS) version 1.1 and a pilot version of the Clinical High Risk for Psychosis Services – Fidelity Scale (CHRPS-FS) (Addington, 2021). In this assessment Version FEPS-FS 1.1 was used, which includes additional items from the published 1.0 version related to discharge planning and the delivery of peer services. Additionally, given the widespread treatment of CHR clients within California CSC programs, and the inherent differences in the treatment approach between FEP and CHR, we have collaborated with the FEPS-FS 1.1 author to pilot a complimentary assessment tool that adapts some items of the FEPS-FS 1.1 to be appropriate for CHR care (i.e., the CHRPS-FS). These tools were developed to rate the degree to which the care mental health teams deliver adheres to the Coordinated Specialty Care Model (CSC; Heinssen et al., 2014) for clients with a first episode of Schizophrenia Spectrum Disorder and Clinical High Risk for Psychosis. The purpose of this fidelity assessment is to better understand the range and nature of services delivered by coordinated specialty care programs across the EPI-CAL network. Please see Table VI for a detailed summary of the components that are assessed on the FEPS-FS 1.1 Scale. This differs slightly from the currently published scale with the inclusion of two additional items (items 36 and 37); one which focuses on the peer specialist role, and the second which focuses on transitions in care. These were added due to meet our state level clinical, policy and research priorities.

It is important to note that the findings come with multiple caveats:

- The field of early psychosis is a rapidly developing one, with evidence-base practices and recommendations evolving over time.
- While there is good evidence for coordinated specialty care leading to improved outcomes in early psychosis (i.e., Guo et al., 2010; Kane et al., 2016; Secher et al., 2015), understanding what the necessary specific components of coordinated specialty care are that leads to these improved outcomes, and how they should be optimally delivered, is in many cases still a matter of debate.
- The measure selected for use across the EPI-CAL network (the FEPS-FS v1.1), is one of multiple that exist. The FEPS-FS was selected due to the fact the tool is currently one of the most extensively used and validated in the field (Addington et al., 2020; Durbin et al., 2019)
- The FEPS-FS has been developed as an international standard, and so the tool has been designed to work across different systems of care. This may make high scores on some items much harder to achieve in the US due to the current structure of behavioral health service provision across the country.
- The ratings and the feasibility of meeting high-fidelity scores may vary widely depending upon the context in which the program is delivered. The FEPS-FS may include items where a high-fidelity score may be constrained by state, local, or insurance coverage decisions outside of the control of the specific program.

Table VI: FEPS-FS 1.1 Components

	FEPS-FS 1.1		
1	Practicing team leader	20	Antipsychotic dosing within recommendations
2	Participant/provider ratio	21	Clozapine for medication-resistant symptoms
3	Services delivered by team	22	Patient psychoeducation
4	Assignment of case manager/ care coordinator	23	Family education and support
5	Psychiatrist caseload	24	Cognitive behavior therapy (CBT)
6	Psychiatrist role on team	25	Supporting Health
7	Weekly multi-disciplinary team meetings	26	Annual formal comprehensive assessment
8	Explicit diagnostic admission criteria	27	Services for patients with Substance Use Disorders
9	Population served	28	Supported employment (SE)
10	Age range served	29	Supported education (SEd)
11	Duration of FEP program	30	Active engagement and retention
12	Targeted Education to community groups	31	Patient Retention
13	Early Intervention	32	Crisis intervention services
14	Timely contact with referred individual	33	Communication between FEP and inpatient services
15	Family involvement in assessments	34	Timely contact after discharge from hospital
16	Comprehensive clinical assessment	35	Assuring Fidelity
17	Comprehensive psychosocial needs assessment	36	Peer support specialist role on team

18	Treatment / care plan after initial assessment	37	Transition in Care
19	Antipsychotic medication prescription		

The results of this assessment can be used in multiple ways. First, when combined with systematic data collection of client outcomes across multiple programs, fidelity assessments can be used to assess how variation in service delivery may impact client outcomes. Available data on which service components lead to specific outcomes could be used to advance the field of early psychosis care, and to advocate for potential changes in program funding and structure. Second, fidelity assessment can inform quality improvement efforts, highlighting individual areas of strengths and areas for improvement. Furthermore, it can enable individual clinics to review how their program compares to validated international standards and other programs in the state. Third, this information can be vital for county leadership and other key community partners to understand exactly what is being delivered by programs in a concrete, standardized format.

Assessment Summary

To date, we have completed assessments in 20 programs. Thirteen provide services for both FEP and CHR clients, four serve FEP only, and three serve clinical high risk only. Some of the assessed programs are well-established programs, but others are new and haven't even seen their first client yet. As a result, they do not have the sufficient service data to complete the health record abstraction necessary for the full fidelity assessment. To address this, in collaboration with the author of the FEPS-FS, Dr. Don Addington, we developed different levels of assessments, and operationalized rules around how to implement them. These included full assessments, formative assessments, and quality improvement (QI) assessments in cases where there were insufficient health record data to do a formal assessment. To meet criteria for a full fidelity assessment, the program must be delivering CSC services to EP clients two or more years and have five or more clients enrolled for at least one year and the time of the assessment. If those criteria are not met, the program may have a formative fidelity assessment if they have served ten or more clients ever, have at least five clients who have been enrolled for six months or more, and have supervision and defined admission criteria, assessment, and treatment approach. If the above criteria are not met, the program may have a simply quality improvement assessment in which their plan for program implementation in assessed by our team for consultation and feedback purposes.

Table VII: Fidelity Assessment Characteristics

FEPS-FS n =17			
Assessment Types			
	Full	14	82.4%
	Formative	0	0.0%
	QI	3	17.7%
Program Type			
	Community	14	82.4%
	University	3	17.7%
Mean FEPS-FS Score*		3.86	0.25

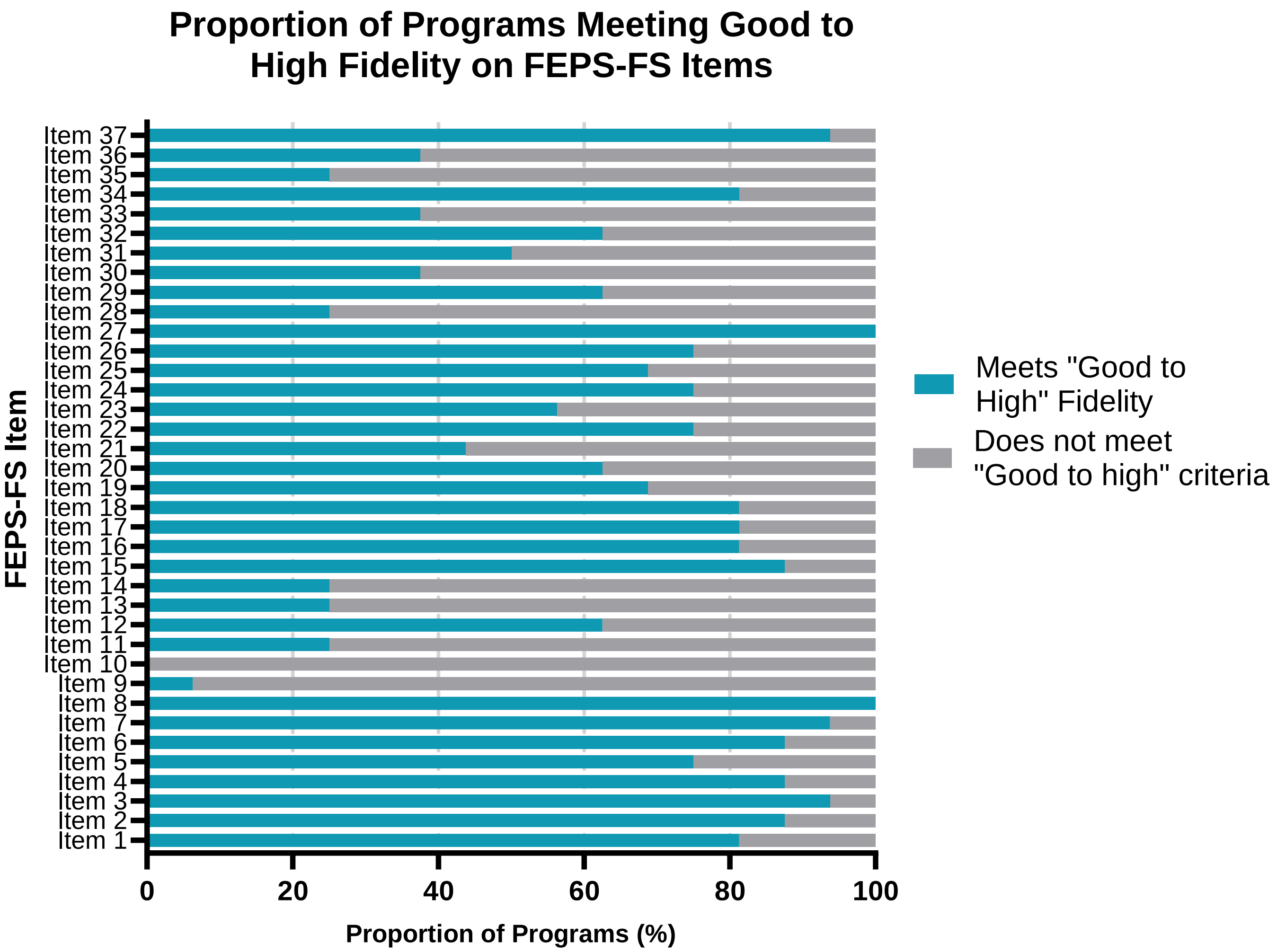
CHRPS-FS n=16			
Assessment Types			
	Full	11	68.8%
	Formative	1	6.3%
	QI	4	25.0%
Program Type			
	Community	14	87.5%
	University	2	12.5%
Mean CHRPS-FS Score*		3.96	0.32

% Items good to high fidelity*	66.6%	9.09

% Items good to high fidelity*	71.2%	8.15

For both FEPS and CHRPS, the full assessment was possible in the majority of programs. Amongst those where a full or formative assessment could be conducted, the mean FEPS-FS score was 3.86 out of 5. Figure 19 shows a breakdown of the proportion of programs meeting good to high fidelity by each FEPS-FS item. With the CHRPS, mean scores were slightly higher at 3.96 out of 5.

Figure 19: Proportion of programs meeting good to high fidelity on FEPS-FS Items



2. Learning Health Care Network County Data Analysis Level Summary

2.1 Executive Summary

The County Data evaluation of the LHCN project examines the services and costs associated with individuals treated in Early Psychosis (EP) programs across several California counties in comparison to the services and associated costs for a comparator group (CG) of similar individuals treated in other outpatient clinics. The primary goal of this component was to provide a preliminary demonstration of the proposed method for accessing data regarding EP programs and CG groups across California. The secondary goal was to analyze service utilization and costs associated with those services across counties. This is part of a larger project called EPI-CAL, Early Psychosis Intervention California, which seeks to improve the quality of services and measure the impact of treatment of early psychosis programs in California.

Specifically, in each county we identified an early psychosis (EP) group consisting of individuals served by the early psychosis program. We also identified a comparator group (CG), consisting of individuals with EP diagnoses, within the same age group, who entered standard care outpatient programs during that same time period. The counties participating in this component are Los Angeles, San Diego, Solano, Orange, Napa, Stanislaus, Lake, and Kern counties. The data evaluation has two phases: 1) the three years prior to the start of this project (e.g., January 1st, 2017 – December 31st, 2019) to harmonize data across counties and to account for potential historical trends and 2) for the 2.5-year period contemporaneous with the prospective EP program level data collection (January 1st, 2020 – June 30th, 2022).

This multicounty analysis is based on data provided by Los Angeles, Orange, and San Diego counties. These were counties that had executed contracts and were able to provide us data in time for this analysis. We used administrative data to identify youth aged 12 to 25 years who (1) were enrolled in a specialized early psychosis (EP) program from January 2017 to July 2021, and (2) received a first diagnosis of psychosis (ICD-10 codes F20, F22, F23, F25, F28, F29, F31.2, F31.5, F31.64, F32.3 F33.3) within one year prior to enrollment. We shared lists of EP youth with program staff who confirmed that these were past or current clients who received their first diagnosis of psychosis. We identified a comparison group (CG) of youth with a first diagnosis of psychosis who received at least one outpatient service during the study period, also within one year of receiving their first diagnosis of psychosis. We excluded youth with a diagnosis of psychosis in more than two years before starting outpatient services, youth with private insurance, and youth who received a diagnosis of intellectual disability (ICD-10 codes F70-F79, ICD-9 codes 317-319).

Table VIII shows standardized estimates of service use in the first and second years following the initial diagnosis of psychosis. In the first year following diagnosis, the mean annual number of outpatient visits was 22.3 greater among EP youth than CG youth: 49.7 vs 27.4 visits per year, *p*<.001. The annual probability of psychiatric inpatient admission was 6.4 percentage points lower among EP youth: 36.3% vs. 42.7% used any inpatient services, *p*=.020. However, there was no significant difference in inpatient days overall between the two groups.

Outpatient visits remained higher among EP youth during the second year following diagnosis. The probability of using outpatient services was 21.2 percentage points greater among EP youth: 76.2% vs. 55.0% used any outpatient services, *p*<.001. The mean annual number of outpatient visits was 15.1 higher among EP youth: 33.5 vs. 18.4, *p*<.001. There was no significant difference in either the probability of inpatient admission or the number of inpatient days between the two groups in the second year following diagnosis.

Table IX shows costs for outpatient and inpatient mental health services in the first and second years following the initial diagnosis of psychosis. Outpatient costs were significantly greater for EP youth compared to CG youth in both years. Outpatient costs were $6,150 greater for EP youth in the first year following diagnosis and $4,073 greater in the second year following diagnosis (*p*<.001 each). In contrast, there was no significant difference in inpatient costs in either year.

Youth enrolled in EP programs had a greater number of outpatient mental health visits and higher costs than a comparable group of youth who were receiving services in standard outpatient programs in both the first and second years following the initial diagnosis of psychosis. Youth in EP programs had a lower probability of psychiatric inpatient admission than CG youth in the year following diagnosis. However, there was no significant difference in the number of inpatient days. We did not find significant differences in psychiatric admissions or inpatient days in the second year following diagnosis, nor did we find significant differences in inpatient costs in either year. County specific results are located in this deliverable under Deliverable 7.

2.2 Identification of county-level available data and data transfer methods, and statistical analysis methods selected for integrated county-level data evaluation

One component of the LHCN project is to identify and describe the services and related costs for individuals served by the EP programs in each county. We will also examine services and costs associated with similar individuals served elsewhere in each county. We will harmonize and integrate data across all LHCN counties in order to perform these analyses.

Specifically, in each county we identified an early psychosis (EP) group consisting of individuals served by the early psychosis program. We also identified a comparator group (CG), consisting of individuals with EP diagnoses, within the same age group, who entered standard care outpatient programs during that same time period. This analysis focuses on data from Los Angeles, San Diego, Orange, Napa, Stanislaus, Lake, and Solano counties. For this component of the project, the evaluation has two phases: 1) the three years prior to the start of this project (e.g., January 1st, 2017 – December 31st, 2019) to harmonize data across counties and to account for potential historical trends and 2) for the 2.5-year period contemporaneous with the prospective EP program level data collection (January 1st, 2020 – June 30th, 2022).

For each county, our team held meetings with the EP program managers and the county data analysts. The meetings with the program managers discussed services provided by the EP program, description of clients served, staffing specifics and billing codes for each service. A follow-up meeting was held with each county to review details of funding sources, staffing levels during certain time-periods and other types of services provided for specific types of clients (i.e., foster care). Meetings were held with the county data analysts to discuss details about the data the county will be pulling for the LHCN team during the next deliverable period. The discussion included time-periods for which the LHCN team will request data, description of the clients from EP programs and how similar clients served elsewhere in the county will be identified, services provided by each program, other services provided in the county to the EP clients (i.e., hospitalization, crisis stabilization, substance use treatment), and data transfer methods. We have met with the program managers and data analysts from all LHCN counties with active contracts and have scheduled follow-up meetings with the data analysts as necessary. Each meeting has been described in detail in the call log provided in prior deliverables and is available upon request. Our research team has gathered all of the information from each program/county and summarized it in meeting notes and a multicounty data table. For the purposes of this deliverable, we have provided a sample of the data collected from each county (see Table VIII). Please note that we have yet to obtain this information from Kern County due to recent execution of their contract.

Table VIII. Multicounty Program Services and Billing Information

County	**San Diego**	**Orange**	**Solano**	**Napa**	**Stanislaus**	**Los Angeles**	**Lake**
Program Name	Kickstart	OC CREW	Aldea SOAR	Aldea SOAR	LIFE Path	CAPPS	Early Intervention Services (EIS)
Clients Served	FEP, CHR	FEP	FEP, CHR	FEP, CHR	FEP, CHR	CHR+	FEP and CHR
Census	140-160	42	26	15-Oct	Current 10-15, cap 40	60	30
Length of Services	(+/-) 2 yrs	2 - 4 yrs	(+/-) 2 yrs	(+/-) 2 yrs	2 yrs	2 yrs (case by case)	2-4 yrs

Inclusion - Ages	Ages 10-25	Ages 12-25	Ages 12-30	Ages 8-30	Ages 14 - 25	Ages 12-25	Ages 15-25
Inclusion - Diagnoses	Any type of psychoses (NOS) but not required, SIPs score of 6	FEP	CHR diagnosis or FEP within 2 yrs	All Psychotic D/Os (within 2 yrs of meeting dx criteria) & CHR diagnosis	Psychotic d/os within 1 year of meeting dx criteria including affective, & CHR diagnosis	CHR - based on SIPS, must have at least positive symptom score of 3-6.	Any type of psychoses, but not required.
Inclusion - Insurance	Medi-Cal, Uninsured	None	Medi-Cal, Uninsured	Medi-Cal, Private, Uninsured	Medi-Cal, Private, Uninsured	Medi-Cal, Uninsured	Medi-Cal, uninsured, Medicare. We are only contracted with Medi-Cal and Medicare. We bill all other insurances, but we are out-of-network.
Inclusion - Duration of Psychosis	First psychotic symptoms within 2 yrs	First psychosis within 2 yrs	First psychosis within 2 yrs	First psychotic episode within 2 yrs; Attenuated psychosis of any duration	First episode within 2 yrs;	No longer than 30 days since onset	First break within last 2 yrs.
Exclusion - Cognition	IQ < 70 - Case by case discretion	IQ < 70	IQ < 70	IQ < 70	IQ < 70, Substance induced psychosis, psychosis due to medical conditions including TBI	IQ below 70	IQ <70

Exclusion - Diagnoses	Case by case discretion: Medical diagnosis that better explains symptoms; substance use	No substance use or medical condition that better explains symptoms	Substance dependence would not allow to participate in treatment – refer to substance abuse treatment, Head injury or medical condition	Substance dependence would not allow to participate in treatment – refer to substance abuse treatment, Head injury or medical condition		Primary diagnosis of substance abuse	Primary substance use disorder
Exclusion - Other	Qualitative Judgement call: Physically aggressive, sexually inappropriate, safety issues	Not received counseling prior for psychotic disorder in the last 24 months	Qualitative Judgement call: Physically aggressive, sexually inappropriate, safety issues	Qualitative Judgement call: Physically aggressive, sexually inappropriate, safety issues	Qualitative: requires 24 hour care/higher level; staff/peer safety issues	Nothing beyond Specialty Health Services exclusions	We exclude when they are non-Specialty Mental Health Services.
Assessments - Billing Codes	10	90899-6 (H2015)	90791	10	10	90791	H2015 HE(SmartCare), 100 (Anasazi).
Assessments - Provider type	Clinicians	Clinician: master's level BHCI, BHCII, psychiatrist	Therapist; clinical supervisor	Therapist	LPHA	MD/DO, PA, PhD/PsyD (Licensed or Waivered), SW (Licensed, Registered or Waivered), MFT (Licensed, Registered or Waivered), NP or CNS (Certified), PCC (Licensed or Registered), Student professionals in these disciplines with co-signature*	Waivered Clinicians, LPHA, physician, nurse, case manager (other qualified provider).

Assessments - Notes	Behavioral Health assessment and HRA (high risk assessment)	Code 90899-6 for each of multiple sessions leading up to intake completion;Same code for psychiatrist completing conservatorship evaluation, disability assessment, or eval for med services by telephone		Initial, Annual/ Periodic	Initial, periodic	n/a	Case managers provide screenings. Anasazi is the old electronic healthcare record. SmartCare has been utilized since 3/1/2023.

2.3 Establish data collection process for obtaining county-level utilization and cost data for prior 3-year timeframe for preliminary evaluation for both EP and comparator group (CG) programs

During the last project period, we had follow-up meetings with the counties that are involved in retrospective data collection (Los Angeles, San Diego, Orange, Solano, Stanislaus, and Napa). We held a series of initial meetings with the EP program staff and county staff to address the collection of the county-level utilization and cost data for the prospective evaluation for both EP and comparator group (CG) programs (Los Angeles, San Diego, Orange, Solano, Stanislaus, Napa, and Lake). We identified EP program information, including a description of clients served, billing codes for each service, funding sources, and staffing personnel during the retrospective period. Meetings were also held with the county data analysts to discuss details about the data extraction. We reviewed all data elements that will be needed to define the EP and CG sample, including historical diagnostic and utilization data for both groups (January 1st, 2013- December 31st, 2016). We reviewed data categories, elements, and sources for utilization and cost to determine a) which services are provided in the county, and b) which data elements are available to be shared for the analysis. Any follow-up meetings with county data analysts are scheduled on an ongoing basis.

Lake and Kern counties will only be participating in the second phase of the evaluation, the prospective period, because their EP programs were not established until after the date range of the first evaluation phase concluded. In addition, Lake County will have a phase two timeframe that begins later due to the establishment of their EP program in 2022. Their prospective period will be January 1st, 2022- June 30th, 2024. This will allow for their EP program to have served more clients and collected service data for two and a half years for the prospective analysis.

Data Collection Process

The retrospective data extraction procedures have been completed for Los Angeles, Orange, and San Diego, and are in progress for Solano, Stanislaus, and Napa counties. The prospective data extraction procedures are in progress for San Diego, Los Angeles, Orange, Solano, Stanislaus, Napa, and Lake counties. The county data analysts have been asked to identify all clients served by the EP program for the retrospective period dates between January 1st, 2017 – December 31st, 2019, and the prospective period dates between January 1st, 2020 – June 30th, 2022, with an exception for Lake County. For the retrospective period, this includes individuals who started services with the EP program between January 1st, 2017 – December 31st, 2019 and excludes any individuals who received services from the EP program prior to January 1st, 2017. For prospective period this includes individuals who started services with the EP program between January 1st, 2020-June 30th, 2022 and excludes any individuals who received services from the EP program prior to January 1st, 2020. The county data analyst will send the list of clients to the EP program manager, who will then confirm the list of clients as new clients as of January 1st, 2017 – December 31st, 2019 (for retrospective period, if applicable) and January 1st, 2020-June 30th, 2022 (for prospective period) and identify whether they were: 1) clinical high risk (CHR) and enrolled in treatment; 2) first episode psychosis (FEP) and enrolled in treatment; 3) assessed and referred out during January 1st, 2017 – December 31st, 2019 (retrospective) or January 1st, 2020-June 30th, 2022 (prospective); or 4) other, with reason (e.g., incorrectly assigned to EP program in EHR or claims data). They will also add any individuals missed and repeat above 1-3 categorization, if necessary. They will also send any available data elements that are not available in the county EHR and claims data to the county data analyst, who will integrate them into the dataset. These data elements may include information on intake forms, such as regional center involvement and referral information, or other data elements. The county data analyst will integrate these data elements into the dataset and assign an ID to replace medical record numbers (MRN), names, and other identifying information, then save the key in order to create a limited dataset (dates and zip code included). The county data analyst will be sent a username and password to login to a secure UC Davis GoAnywhere portal, whereby each county can upload their county data securely and will not be able to access any other county's data.

We formally requested this information when we met with each county. A summary of what we asked for is described below for the retrospective and prospective periods, respectively.

Retrospective

We are requesting a limited dataset for all individuals served in the specified EP Program between these dates: January 1st, 2017 – December 31st, 2019. Data elements requested include: 1) all diagnoses (psychiatric, substance use, physical health) and dates of diagnoses; 2) year and month of birth (not date); 3) demographics, including: race; ethnicity; sex; gender; gender identity; sexual orientation; living arrangement (housing status); US military information/ veteran status; primary language; foster care/adoption; zip code; insurance status (i.e., insurance type); education level; marital status; and employment status; and 4) all county behavioral health services utilized, including: i) all outpatient mental health services; ii) all other mental health services including but not limited to (and as available): inpatient; crisis residential; crisis stabilization; urgent care; long-term care; forensic services and jail services; referral(s) from EP program to other services; law enforcement contacts; justice system involvement; and regional center involvement. For each service, each county will check for these data elements and include as available: service/procedure code; location code, facility code; date; EBP/supported service code; charge description; and service duration/minutes. We also requested a data dictionary from each county.

Based on our preliminary analysis of the data from Los Angeles, Orange, San Diego, and Solano counties, we determined that we also need historical diagnostic and service utilization data going back to January 1st, 2013 for both EP and CG clients. This will allow us to improve the comparability of individuals in the CG group with those in the EP group by either, a) appropriately matching individuals from the CG group to individuals in the EP group or b) weighting clients by their predicted pre-period probability of being observed in the EP program during the study period. Therefore, all counties also received this additional request:

We are now requesting to extend our service utilization data request for the EP group to the four years prior to our active period (January 1st, 2017 – December 31st, 2019), going back to January 1st, 2013.

Prospective

We are requesting a limited dataset for all individuals served in the specified EP Program between these dates: January 1st, 2020 – June 30th, 2022. Data elements requested include: 1) all diagnoses (psychiatric, substance use, physical health) and dates of diagnoses; 2) year and month of birth (not date); 3) demographics, including: race; ethnicity; sex; gender; gender identity; sexual orientation; living arrangement (housing status); US military information/ veteran status; primary language; foster care/adoption; zip code; insurance status (i.e., insurance type); education level; marital status; and employment status; and 4) all county behavioral health services utilized, including: i) all outpatient mental health services; ii) all other mental health services including but not limited to (and as available): inpatient; crisis residential; crisis stabilization; urgent care; long-term care; forensic services and jail services; referral(s) from EP program to other services; law enforcement contacts; justice system involvement; and regional center involvement. For each service, each county will check for these data elements and include as available: service/procedure code; location code, facility code; date; EBP/supported service code; charge description; and service duration/minutes. We also requested a data dictionary from each county.

Based on our preliminary analysis of the data from Los Angeles, Orange, San Diego and Solano counties, we determined that we also need historical diagnostic and service utilization data going back to January 1st, 2016 for both EP and CG clients. This will allow us to improve the comparability of individuals in the CG group with those in the EP group by either, a) appropriately matching individuals from the CG group to individuals in the EP group or b) weighting clients by their predicted pre-period probability of being observed in the EP program during the study period. Therefore, all counties also received this additional request:

We are now requesting to extend our service utilization data request for the EP group to the four years prior to our active period (January 1st, 2020 – June 30th, 2022), going back to January 1st, 2016.

2.4 Report on feasibility of obtaining cost and utilization data

Our team provided support to the county data analysts and EP program managers regarding the cost and utilization data extraction and integration process through a series of email and phone conversations. The counties submitted their retrospective datasets, which include EP utilization, CG utilization and cost, through the secure web portal on the following dates: Orange County – EP dataset: December 7, 2020, CG dataset: November 30, 2021, cost dataset: June 21, 2021; San Diego County – EP dataset: December 22, 2020, CG dataset: September 9, 2021, cost dataset: January 3, 2022; Solano County – EP dataset: February 2, 2021, CG dataset: September 14, 2021, cost dataset: April 25, 2022; Los Angeles County – EP dataset: February 18, 2021, CG dataset: October 4, 2021, cost dataset: submitted with services data; Napa County – EP dataset: November 17, 2023, they have not submitted CG or cost data yet. Stanislaus County has yet to submit any datasets during this deliverable period. Lake and Kern counties are submitting data for the prospective study period only based on overall project analysis timeline as well as the dates these programs were established.

The counties submitted their prospective datasets, which include EP utilization, CG utilization and cost, through the secure web portal on the following dates: Orange County – EP dataset: August 22, 2023, CG dataset: August 23, 2023, cost dataset: August 23, 2023; San Diego County – EP dataset: April 24, 2023, CG dataset: May, 25, 2023, cost dataset: July 25, 2023; Los Angeles County – EP, CG, and cost dataset: July 7, 2023; Napa County – partial EP dataset received: November 17, 2023. We have not yet received prospective data from Kern, Lake, Solano, or Stanislaus counties.

Additionally, we requested a data dictionary from each county in order to accurately identify each variable, and received the data dictionaries from all counties who submitted datasets. For Napa, Stanislaus, Kern, and Lake, please refer to the end of this deliverable section for specific county updates with regards to this request.

The cost data obtained thus far from each county are described in Table IX, below. Los Angeles, Orange, and Solano counties submitted cost rates (i.e., total cost of the service and the service unit). In Los Angeles County, outpatient service costs are standardized per fiscal year for all providers. For Orange, Solano, and San Diego counties, service costs vary across programs. To account for these differences, Orange and Solano counties submitted price lists for services provided by their respective EP program and other programs in the county. In the case that the county was not able to provide certain cost details, we utilized the county specific regional rates sheets to ascertain all cost information. To ensure the most accurate data were received, San Diego County provided final, reconciled costs attached to each Medi-Cal reimbursable service. We also requested that each county provide us with contracts and budgets for their EP programs as a way to account for non-billable activities and other unaccounted-for costs of running the program.

Table IX: Cost data received from each county

County	EP Program Budget	EP Program Contract with County	Outpatient Service Rates	Day/Crisis Stabilization Service Rates	24-hour: Inpatient/Residential Service Rates
Solano	Utilized regional rates sheet	N/A	Costs related to outpatient service use were based on contract service rates. Each outpatient service included a price per unit of service.	Costs related to day services/crisis stabilization were based on contract service rates. Each service included a price per unit of service.	Costs related to 24-hour services were based on regional rate sheets. Each service included a price per unit of service.
Orange	Received county dates	N/A	Costs related to outpatient service use were based on contract service rates. Each outpatient service included a service unit rate and number of service units (in minutes)	Costs related to day services/crisis stabilization were based on contract service rates which included a service unit rate and number of service units (in minutes)	Costs related to 24-hour services were day rates which varied by contract. Inpatient/hospital stays include negotiated bed day rate for each HCA contracted acute inpatient facility. These rates are different from the general regional rates set by DHCS. Skilled Nursing Facility (SNF)/IMD rates were averaged and include a bed day rate. Crisis Residential rates include a day rate and charge for the medical services by the minute
Los Angeles	Monthly expenditures for the three CAPPS program clinics from 2017-2019.	N/A	Costs rates were attached to each service and included all service types. For outpatient services, each cost rate was the total cost of the service and the service unit (recorded in minutes).	Costs related to day services included total cost of the service and the service unit (recorded in minutes)	Costs related to 24-hour services include inpatient county hospitals, Fee-for-Service hospitals and County contracted providers. These costs include total cost of the service and cost per service unit (recorded in days). This information was extracted from the regional and state rates sheet.

San Diego	Budgets calculated through annual allocation amounts	Received	County interim cost rates for outpatient services per service unit (15 minutes, bill in one-minute increments). Published reimbursable cost rates and actual reimbursable cost rates for EP community services, including case management, mental health services, medication support, and crisis intervention	County interim rates for day services/crisis stabilization per service unit (in hours)	County interim rates per service unit (in days) for inpatient/hospital stays, crisis residential, and therapeutic foster care. Contracted inpatient hospital rates for adult and adolescent services, effective February 1, 2020. Regional rate, effective July 1, 2021, for non-contracted inpatient hospitals
Stanislaus	TBD	TBD	TBD	TBD	TBD
Napa	TBD	TBD	TBD	TBD	TBD
Lake	TBD	TBD	TBD	TBD	TBD
Kern	TBD	TBD	TBD	TBD	TBD

Description of submitted data

The number of individual clients in each county's EP dataset is indicated in Table X below. All counties serve first episode psychosis (FEP) clients and some counties also serve clients at clinical high risk (CHR) for psychosis. These totals represent the number of individuals enrolled and served by the EP programs for the retrospective three-year period January 1, 2017 – December 31, 2019. We also received data on clients who were assessed for program eligibility but referred elsewhere.

Table X: Summary of clients for all counties- retrospective data pull

County	FEP served	CHR served	Total Number of Clients in EP Group
Orange	Y	N	87
San Diego	Y	Y	353
Solano	Y	Y	78
Los Angeles	Y	Y	91
Napa	Y	Y	TBD
Stanislaus	Y	Y	TBD
Lake	Y	Y	TBD
Kern	Y	N	TBD

As anticipated, there is some variation in the data elements available for each county, which are summarized here and listed in Table XI below.

Table XI. Client and utilization data elements summary for all counties retrospective data

Data Type	**Data Element**	**Source**	**County Availability**
Non-identifying ID	Identifying client ID removed and new ID assigned	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Program Name	Program Name	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Psychosis – category	1) Clinical High Risk (CHR) and enrolled in treatment 2) First Episode Psychosis (FEP) and enrolled in treatment 3) Assessed and referred out during Jan. 1, 2017 – Dec. 31, 2019 (add reason, if possible) 4) Other and reason (e.g., incorrectly assigned to EP program)	Program	Data elements # 1 and # 2 available: Orange, LA, San Diego, Solano, Stanislaus Data element # 3 available: Solano; Stanislaus N/A: Orange, LA, San Diego Data element # 4 available: Solano, San Diego; Stanislaus N/A: LA, Orange All data elements TBD: Napa
Assessed and referred out - open ended	Assessed and referred out – reason	Program	Available: Solano, LA; N/A: Orange, San Diego TBD: Napa, Stanislaus
Other and reason - open ended	Other – reason	Program	Available: Solano, LA; N/A: Orange, San Diego TBD: Napa, Stanislaus
Diagnoses associated with the episode of care	Diagnosis – Psychiatric	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Diagnosis – Substance use	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Diagnosis – Physical health	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Date of birth	Year & month of birth (not date)	County/Program	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Location (client zip code)	Zip code (as of first EP service)	County/Program	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Demographics (as of first EP service)	Race	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Ethnicity	County	Available: Orange, LA, San Diego, Solano, Stanislaus

			TBD: Napa
	Gender	County	Available: Orange, LA, San Diego, Solano TBD: Napa
	Education level	County	Available: LA, San Diego, Solano, Stanislaus; N/A: Orange TBD: Napa
	Marital status	County	Available: LA, San Diego, Solano, Stanislaus; N/A: Orange TBD: Napa
	Preferred language	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Insurance status (i.e., insurance type)	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Employment status	County	Available: LA, San Diego, Solano, Stanislaus; N/A: Orange TBD: Napa
	Living arrangement (housing status)	County	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Sex assigned at birth	Program	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Gender identity	Program	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Sexual orientation	County	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Military service / Veteran status	County	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Foster care / Adoption	County	Available: San Diego, Solano; N/A: LA, Orange TBD: Napa, Stanislaus
Outpatient mental health services in EP program between Jan. 1,	Date	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Duration	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa

2017 – Dec. 31, 2019	Service / procedure code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Funded plan (original pay sources, subunit)	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service location code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Facility code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Evidence Based Practices (EBP) / supported service code	County	Available: Solano, LA; N/A: Solano, Orange, San Diego, Stanislaus TBD: Napa
	Medi-Cal beneficiary	County	Available: Orange, Solano, Stanislaus; N/A: LA, San Diego TBD: Napa (claims person will have information on private insurance)
All other mental health services utilized by clients that started services between Jan. 1, 2017 – Dec. 31, 2019	Service / procedure code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Location code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Facility code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service Date	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Evidence Based Practices (EBP) / supported service code	County	Available: LA; N/A: Solano, Orange, San Diego, Stanislaus TBD: Napa
	Service – Inpatient	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa (Inpatient hospitals: Crestwood BH, state hospital, Bella House (12 bed psychiatric transitional program), (Crestwood may serve minors))
	Service – Crisis residential	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa (Progress Place is the name of the crisis residential service in Napa County)

	Service – Crisis stabilization	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa (Crisis stabilization unit for Napa County is operated by Crestwood and serves both youth and adults)
	Service – Urgent care	County	Available: Orange, LA, San Diego, Solano, Stanislaus May be available: Napa
	Service – Long-term care	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service – Forensic services and jail services	County/Program	N/A: San Diego, Orange, LA, Solano TBD: Napa. Stanislaus
	Service – Referrals	Program	Available: Stanislaus; N/A: Solano, Orange, LA, San Diego TBD: Napa
	Service – Law enforcement contacts	Program	Available: Stanislaus; N/A: Orange, Solano, San Diego, LA TBD: Napa
	Service – Justice system involvement	Program	Available: San Diego, Stanislaus; N/A: Orange, LA, Solano TBD: Napa
	Service – Regional center involvement (any developmental issues)	Program	Available: San Diego, Stanislaus; N/A: Orange, LA, Solano TBD: Napa
	Service – Substance use services	County	Available: Orange, Stanislaus; N/A: Solano, San Diego, LA TBD: Napa

Over the past and current deliverable periods, we have held a series of follow-up meetings with each EP program's staff and County staff to address questions and gaps in the data submitted to us. This iterative process reflects significant effort contributed by the EP programs, County staff, and our team. As a result, we are confident that we have received/will receive all relevant data that is possibly available for this analysis.

On September 7, 2023, we met with Napa County to review the retrospective data request and check in on progress in accomplishing the request. We discussed the need of Napa County to involve their IT department in order to access their old EHR to access the data being requested. They submitted their EP data for the retrospective period on November 17, 2023, but the CG and cost data are still outstanding along with the prospective dataset. Our team is currently awaiting the data dictionary and the cost data from Napa, and they are set to deliver those items during the next deliverable period.

On October 25, 2023, we met with Lake County to review the details of the prospective data request and answer any questions Lake County had about depositing the data. Lake should be able to deposit their datasets during the next deliverable period.

As for Kern County, we met with them on August 29, 2023 to review the details of the prospective data request and answer any questions Kern County had about the request. We met again to answer some follow up questions regarding logistics about the data pull on October 20, 2023 and then again on December 13, 2023 to discuss data privacy and consenting questions raised by Kern County. We are in the process of resolving those concerns and then plan to proceed with the data request which should be received in the next deliverable period.

Stanislaus County has not made progress in this current deliverable period due to vacancies at the county level. Data gathering is on pause while the staffing barrier at the county level is being worked on.

2.5 Finalize methods for multi-county-integrated evaluation of costs and utilization data

The proposed analysis is based on pilot work conducted in Sacramento County, scaled to multiple counties (Niendam et al., 2016). It focuses on consumer-level data related to program service utilization, other outpatient services utilization, crisis/ED utilization, and psychiatric hospitalization and costs associated with these utilization domains during two time periods: 1) the three years prior to implementation of project application in the Early Psychosis (EP) programs (e.g., Jan 1st, 2017 – Dec 31st, 2019), to harmonize data across counties and account for potential historical trends, and 2) for the 2.5 year period contemporaneous with the prospective EP program level data collection via the application (January 1st, 2020 - June 30th, 2022). Below, we describe the data extraction and analysis plans for the first time period.

Early Psychosis (EP) sample

First, all individuals who entered the EP programs January 1st, 2017 – December 31st, 2019 were identified using County Electronic Health Record (EHR) data. This list was cross-referenced with the County EP program(s) to identify those individuals who received treatment versus only eligibility assessment and referral to another service. We restricted the comparison to individuals diagnosed with first-episode psychosis (FEP), and did not include those at Clinical High-Risk (CHR) for psychosis, due to an inability to reliably identify individuals with CHR in the comparator group.

Comparator Group (CG) sample

We compared the utilization and costs of the FEP participants in EP programs to utilization and cost among a group of FEP individuals with similar demographic and clinical characteristics who did not receive care in the EP program during the same timeframe in the same County. FEP individuals who met the same eligibility criteria for the EP program (e.g., FEP diagnoses, within the same age group) who entered standard care outpatient programs in the County during that same time period were identified as part of the comparator group (CG). First, we identified all FEP individuals meeting these criteria receiving any outpatient services who were not served in the EP program. The Comparator Group (CG) was defined as 1) any individual seen in outpatient mental health services between January 1st, 2017 - December 31st, 2019; 2) age as of first date of service during this period: 12 years 0 days – Less than 26 years 0 days; and 3) any primary psychosis diagnosis during this period. We also requested that the counties submit a dataset of prior diagnoses and service utilization for the period of January 1st, 2013 – December 31st, 2017. This allowed us to correctly identify individuals with “first episode psychosis” (FEP) for our sample. This is defined as individuals who received a psychotic disorder diagnosis within two years of their index service date. The index service date is the first outpatient service associated with a primary psychotic disorder diagnosis in the study period.

Service Utilization

Next, data was requested from the County EHR on all services received by individuals in the EP programs and all services for members of both groups including 1) any non-EP outpatient services; 2) inpatient services and 3) crisis/Emergency Department services. As possible, we also worked with other systems identified by EP programs as having service use data not otherwise captured in the County EHR (e.g., databases of other EP program services; private inpatient hospitalizations not billed to the County; non-billable services, etc.).

Costs

Costs per unit of service were assigned to each type of service. We worked with county staff to identify the most accurate source of cost data. This may include internal financial accounting systems, contracts, cost reports, or published rates. For Los Angeles County, we were provided costs attached to the outpatient services and a daily rate sheet for the different types of 24-hour inpatient services the county offers. We then determine whether to apply a single cost across all services (by type of service) or to apply costs that are county or provider specific depending on the information we receive from a county. We include billable and non-billable services. Outcomes are calculated per month to account for varying lengths of time receiving services during the active study period. Additional details on outcomes and cost data sources are described in Table XII below.

Table XII. Outcomes, Sources of Outcome Data, and Methods to Determine Costs Associated with Outcomes

COUNTY LEVEL DATA VARIABLES			
Potential Outcomes of Interest	**Sources of Data on Relevant Outcomes**	**Levels of Analysis**	**Sources of Cost Data associated with Outcomes**
Inpatient hospitalization for mental health concerns	• County hospitalization records	• Number/proportion of individuals hospitalized per group • Number of hospitalizations per client • Duration of each hospitalization (days) • Total duration of hospitalizations (days) per client	• Daily rate paid by County • Daily rate Medi-Cal reimbursement
Emergency Department or Crisis stabilization	• County crisis stabilization unit records	• Number/proportion of individuals with crisis visits per group • Number of visits, per client • Duration of each visit (hours) • Total duration (hours) of all visits, per client	• Hourly rate paid by County
Outpatient service utilization	• Service unit records by outpatient program from County *Examples:* • Assessment • Case management • Group Rehab • Group Therapy • Individual Rehab • Individual Therapy • Family Therapy • Plan Development	• Service type • Number of service units (minutes)	• Contract service unit rates

	• Medication management • Collateral Services • Crisis Intervention		

Statistical Methods

Multi-County Analysis

The data will be harmonized on demographics, diagnoses, and service types across all participating LHCN counties, for EP and CG groups, then merged into a single dataset for our primary analyses. This combined, multi-county dataset will provide increased statistical power, allowing for a richer set of controls and error structure without compromising efficiency.

Analysis of Sample Characteristics

Student T-tests and Pearson Chi-square (or Fisher's exact) tests will be used to compare unadjusted group differences in demographic characteristics (e.g., age, sex, race, ethnicity, etc.) between the individuals in the EP and CG groups. Both unadjusted and adjusted analyses will be used to examine group differences in clinical characteristics at time of index service such as primary diagnosis, as well as the duration of enrollment.

Analysis of Outpatient Service, Day Service/Crisis Stabilization, and 24-Hour/ Inpatient Psychiatric Hospitalization Data

All service data outcomes will be analyzed with a simple empirical equation: the independent variable is regressed on a county-specific fixed effect, an epoch-specific fixed effect, an indicator taking 1 for the EP group and 0 otherwise, a set of interactions between the EP group indicator and each epoch allowing the effect of the EP program to vary over time, and a set of individual-specific controls - measured at intake - consisting of sex, ethnicity, race, and primary language. We will use all demographic variables that were available and harmonized across all counties in time for this preliminary analysis. Standard errors will be always clustered at the individual-level because repeated measures of the same outcome for the same individual are correlated, and we are interested in describing individual-level differences. Further processing of the data will allow the addition of other individual-specific controls and clinic-specific effects to the empirical equation to account for other sources of confounding variation. These will be included in future analyses.

Total outpatient service time (in minutes) of all outpatient services and total minutes of each service type (e.g., medication management, individual therapy, group therapy, rehab services), and time per month will be analyzed by estimating the empirical equation described above with negative binomial regression for count data to determine if outpatient service use differs between the EP and CG samples.

Data related to individuals' use of Day Service/Crisis Stabilization, and 24-Hour/ Inpatient Psychiatric Hospitalization Data usage will be examined using multiple measurements based on the study period: 1) a binary indicator for whether the individual had ever been hospitalized; 2) a binary indicator for whether the individual had ever utilized crisis services; 3) number of hospitalizations per month; 4) number of crisis visits per month; and 5) mean duration of hospitalizations (i.e., length of stay [LOS]) in days; 6) mean LOS for Day/Crisis services (hours); 7) total duration of hospitalizations per month; and 8) total duration of Day/crisis services per month. Data for (1) and (2) will be analyzed by estimating the empirical equation described above with multiple logistic regression. Data for (3), (4), (7), and (8) will be analyzed by estimating the empirical equation described above with negative binomial regression for count data. Data for (5) and (6) will be analyzed by estimating the empirical equation described above with linear regression. These various methods will allow us to determine whether each respective outcome differed between the EP and CG samples.

Data transfer methods

While data transferred between EP program staff and County data analysts within the same County may be identifiable, all information will be de-identified and provided with a unique numeric ID before being submitted to the UCD evaluation team. Data will be shared through an encrypted and password protected GoAnywhere MFT software, which will populate data to UCD secure servers. Counties will not have access to any identifiable data from the other counties. Counties receive instructions for uploading their data to the GoAnywhere MFT software. Each county is given a unique login and is able to securely login into the GoAnywhere portal and upload their data directly to the UCD servers. Once we receive the data, we confirm with the county that all the information was received.

2.6 Deliver a plan and timeline for working with counties to support infrastructure to access final round of county-level cost and utilization data for EP and CG programs

Overview of Deliverable

As stated above, we've received complete retrospective datasets from Los Angeles, San Diego, Orange, and Solano counties. Napa and Stanislaus are currently working on submitting complete retrospective datasets. Lake and Kern counties are working to submit their prospective only datasets in the next deliverable period.

Prospective Data Analysis

Over the last deliverable period, we held a series of meetings with each county that has already submitted data from the retrospective period (Los Angeles, Orange, San Diego, and Solano) to review the prospective data request. We also held meetings with Kern and Lake counties to review the prospective data request and introduce them to the project. In these meetings, we discussed when claims data would become available for service utilization and estimating costs, as well as time needed for data extraction. Data availability ranged from 4-11 months after the service was billed. We plan to obtain service and cost data for all remaining counties by March 2024, then finish cleaning, harmonizing and integrating data for a preliminary analysis to be completed by June 2024. The process of harmonizing and integrating data for the initial retrospective period has been incredibly useful and will allow us to do the same for the new service period much more quickly.

Further, in our meetings with program and county staff, we discussed any changes to the county EHR or billing and claims systems, changes in data elements collected during the new time period, or any other relevant changes to data availability. We met with Solano County on June 2, 2022; Los Angeles County on May 23, 2022; Orange County on May 19, 2022; San Diego County on May 23, 2022; Lake County on February 21, 2023; Kern County on August 29, 2023; and Napa County on September 7, 2023.

In addition to the preliminary analysis that we did in the December 2022 deliverable, in this project period we have an updated analysis that includes Los Angeles, San Diego, and Orange counties.

Next Steps

We plan to continue analyzing the remaining data for both retrospective and prospective periods of all outstanding counties as they provide us with their datasets. Los Angeles, San Diego, and Orange counties have provided all requested data for retrospective and prospective study periods. We await data from the remaining counties in order to properly complete a multi-county integrated analysis: Solano, Stanislaus, Napa, Lake, and Kern counties.

2.7 Provide findings on cost and utilization data from preliminary multi-county integrated evaluation, identification of problems and solutions for county-level data analysis

Please note that this deliverable was presented to the counties on December 31, 2021 and the counties that were included were Los Angeles, San Diego, Orange, and Solano counties. Changes have been made to the analysis plan since this date and these changes are reflected below.

Overview of Deliverable

The County Data evaluation of the LHCN project examines the services and costs associated with individuals treated in Early Psychosis (EP) programs across several California counties in comparison to the services and associated costs for a comparator group (CG) of similar individuals treated in other outpatient clinics representing "standard care," during a concurrent time frame in the same community. The primary goal of this component was to provide a preliminary demonstration of the proposed method for accessing data regarding EP programs and CG groups across California. The secondary goal was to analyze service utilization and costs associated with those services across counties.

For this deliverable, we were able to successfully complete our primary goal and the first part of our secondary goal (service utilization comparison). We were unable to complete the cost comparison analysis due to the complexity of the data required to be harmonized across counties and the variety of data sources. Nearly all programs and counties have been impacted by staff shortages due to unfilled positions and redeployment of staff during the COVID-19 pandemic, which has delayed project coordination and data extraction. In this deliverable, we describe the cost data we have obtained to date, the cost data still needed, and the challenges and solutions relevant to this endeavor. We are confident that the cost comparison analysis will be completed for the next deliverable, due June 2022.

Description of Early Psychosis Programs Evaluated

Los Angeles County

The Los Angeles Center for Assessment and Prevention of Prodromal States (CAPPS) program is an early psychosis program serving clients at clinical high risk for psychosis and clients who have experienced a first episode of psychosis. The majority of assessment and treatment services offered at CAPPS are free of charge to the clients. There were 6 CAPPS clinics in operation during the study period, January 1, 2017 – December 31, 2019.

Orange County

The Orange County Center for Resiliency, Education, and Wellness (OC CREW) is an early psychosis program serving clients who have experienced a first episode of psychosis in the last 2 years. OC CREW provides screening and needs assessments, clinical case management, individual counseling and family services, psychiatric care, psychoeducational groups, referrals and linkages to community resources, and community education on "The First Onset of Psychosis."

San Diego County

San Diego Kickstart is an early psychosis program serving clients who are at clinical high risk for psychosis and those who have experienced a first episode of psychosis in the last 2 years. Kickstart aims to educate the community, treat youth, and assist families in preventing psychosis.

Solano County

Solano County Aldea provides early psychosis services through the Supportive Outreach and Access to Resources (SOAR) program. They serve clients who are at clinical high risk for psychosis and those who have experienced a first episode of psychosis in the last 2 years. SOAR provides services based on the model of the UC Davis Early Diagnosis and Preventative Treatment Clinic. Components include community outreach and education, psychiatric medication management, individualized clinical case management, weekly psychoeducation and support groups, bi-monthly family and multi-family support groups, peer advocate support, and employment and education support.

Characteristics of each county program are detailed below in Table XIII.

Table XIII. EP Program Characteristics

County	Age Range Served	Duration of Services	Excluded Diagnoses
Los Angeles	Prior to March 2019: 16 – 25 March 2019 – present: 12 – 30	2 years	• medication-induced psychosis • psychosis due to a medical condition • intellectual disability
Orange	12 - 25	2 – 4 years	• delusional disorders • affective disorders • post-partum psychosis • substance-induced psychosis • substance use disorder • psychosis due to a medical condition • intellectual disability / IQ below 70
San Diego	10 - 25	1.5 years	• psychosis due to a medical condition • intellectual disability
Solano	Prior to June 2017: 12 – 25 June 2017 – present: 12 – 30	2 years	• psychosis due to a medical condition • intellectual disability • substance dependence.

Analytic Approach

This report presents: 1) descriptive analysis of the EP groups in San Diego, Los Angeles, Orange and Solano counties; 2) a preliminary comparison of the service utilization associated with individuals with first-episode psychosis (FEP) treated at the participating EP programs versus service utilization of a comparable group (CG) of individuals seen for usual outpatient care in the same counties, during the same time period; and 3) a description of cost data available to date from each county. The data were harmonized across counties for analysis, in order to obtain a larger sample size than any one county could contribute alone, allowing for more complex and robust statistical modeling with sufficient to detect even small differences bewteen EP and CG groups.

EP Sample Description

All individuals entering the EP programs January 1, 2017 – December 31, 2019 were identified using county Electronic Health Record (EHR) data. County data analysts excluded individuals who received services from the EP program prior to January 1, 2017. This list was cross-referenced with the county EP program(s) to identify 1) those individuals who enrolled in the EP program and received treatment, and 2) those who received only eligibility assessment and referral to another service.

The EP programs also identified which consumers were diagnosed with a first episode of psychosis (FEP) and which were diagnosed with a clinical-high-risk for psychosis (CHR) syndrome. Programs differ in whether they serve one or both groups. If the designation was unknown, typically due to lack of program data, individuals were classified as FEP if they had documented psychotic disorder diagnoses (see Appendix II). For the comparison analysis, the LHCN research team then applied the following additional inclusion criteria to harmonize EP samples across counties: 1) age 12-25, 2) FEP, 3) enrolled in the EP program (not assessed and referred out). None of the EP clients had a diagnosed intellectual disability. We did not exclude any clients based on substance use disorders.

Comparator Group (CG) Sample Description

The CG group was defined as individuals served in outpatient behavioral health treatment in each county for a first episode of psychosis during the period January 1, 2017 – December 31, 2019. County data analysts identified individuals from the EHR based on the following inclusion criteria: 1) seen in any mental health service between January 1, 2017 – December 31, 2019; 2) age as of first date of service during the study period from January 1, 2017 – December 31, 2019: 12 yrs 0 days – 25 years 355 days; 3) psychotic disorder diagnosis documented January 1, 2017 – December 31, 2019. The eligible diagnoses were based on the psychotic disorder diagnoses accepted by the EP programs, standardized across counties (diagnosis list in Appendix II). We requested service data for an extended period of time (January 1, 2013 – December 31, 2019) in order to determine that there was no psychotic disorder diagnosis more than two years prior to their index outpatient service during the active study period. The "index service date" was defined as the first outpatient (non-FSP, when possible) service associated with an eligible diagnosis during the active study period (January 1, 2017 – December 31, 2019)

The LHCN research team then applied the following exclusion criteria to the CG group, in accordance with EP program criteria, to identify a cohort most likely experiencing FEP: 1) diagnosis of intellectual disability; 2) psychotic disorder diagnosis more than 2 years prior to the index service date during the active study period (January 1, 2017 – December 31, 2019); 3) first outpatient service during the active study period was a Full Service Partnership (FSP) OR client received FSP service in the two years prior to study period.

Data Sources Included in Analysis

Deliverable 4 described a proposed set of outcomes of interest as well as potential data sources for those outcomes and their associated costs. However, as anticipated, limitations in data availability and data quality resulted in modification of the previously described analytic approach in some areas. Table XIV represents the final set of outcomes used in this analysis. All outcomes and data sources included from the methodology proposed in prior deliverables, as well as any differences between the proposed analysis and current analysis, are described in this section. Descriptions apply to all counties, except as noted.

Table XIV. Outcomes

Finalized Outcomes of Interest	Levels of Analysis
Outpatient Services	• Service type • Number of service units (minutes)
Day Services/Crisis Stabilization	• Number/proportion of individuals with crisis visits per group • Number of visits, per client, per month • Duration of visit (hours) • Total duration (hours) of all visits, per client, per month
24-hour Services: **Psychiatric inpatient hospitalization, Residential**	• Number/proportion of individuals hospitalized per group • Number of hospitalizations per client, per month • Duration of hospitalization (days) • Total duration of hospitalizations (days) per client, per month

Description of Included Data Sources

<u>Demographic Data</u>

Client demographics were obtained from the EHR system from each county, based on the date of the first EP program or outpatient CG program service, when possible. Table XV shows dates of demographic data used, by county. Demographic data obtained for the analysis includes age, zip code, race and/or ethnicity, sex, gender identity, sexual orientation, language, education level, currently enrolled in school, employment status, marital status, living arrangement, military service/veteran status, and insurance status. In order to account for differences in how these demographics were coded across counties, we harmonized the variables before integrating them into a single dataset. For example, each county had variations in the way they collected race data for clients, with some counties having collected more detailed information than others. To accommodate for the varying levels of data collected and enable analysis across counties, a harmonized race variable was created with six main race categories: White, Black/African American, Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, and Other. Race data from each county was then re-coded to fit into one of these high-level categories (e.g. 'Korean' would be re-coded as 'Asian') to account for the counties with more limited race data. Details regarding when the demographic variables were originally entered into each county EHR system are shown in Table XV (below), and which variables were available for each county are described in Table XVI.

For this analysis, we required "baseline" demographic data, that is, demographics as of the index service date. Due to differences between counties in collection date of demographic data, as well as likelihood of that particular variable changing over time, the final demographic variables used in this analysis were age, sex, and race/ethnicity.

Table XV Demographic Data – Dates Used

County	Date used for Demographic Data	
	EP	CG
Los Angeles County	Demographics at first date of service in the program	Demographics at first service during study period (Jan 1, 2017 - Dec 31, 2019)
San Diego County	Demographics collected at first date of service in the program	Demographics at first service during study period (Jan 1, 2017 - Dec 31, 2019)
Orange County	Demographics collected at first date of service in the program	Demographics at first service during study period (Jan 1, 2017 - Dec 31, 2019)
Solano County	Demographics at first date of service in the program but can be updated at any time	Demographics at first service during study period (Jan 1, 2017 - Dec 31, 2019)

Table XVI Demographic Data – Availability by County

Data Element	**Availability by County**	**Additional Details**
Year and month of birth (not date)	SD - yes	
	OC - yes	
	Solano - yes	
	LA - yes	Year and month of birth was not available in the LA CG dataset, but rather, age at first service during the active study period.
Zip code	SD - yes	
	OC - yes	
	Solano - yes	

	LA - yes	LA provided 9-digit zip code; last 4 digits were removed to be consistent with 5-digit format of other counties.
Race	SD - yes	
	OC - yes	
	Solano - yes	
	LA - yes	LA collects race and ethnicity data as a combined variable and had to be re-coded into separate variables for harmonization across counties; endorsements of ethnicity only were re-coded as “unknown” for the harmonized race variable. "Multi" category for LA has been rolled up into "other" for harmonized race variable.
Ethnicity	SD - yes	
	OC - yes	2 items - Hispanic ethnicity and self-reported primary and secondary ethnicity
	Solano - yes	
	LA - yes	LA collects race and ethnicity data as a combined variable and had to be re-coded into separate variables for harmonization across counties.
Education level (highest level obtained)	SD - yes	
	OC - **no**	
	Solano - yes	
	LA - yes	
Education level (currently enrolled)	SD – yes	No "current education" variable across counties so variable was created using employment status variable (those who endorsed ‘student’ were coded as being currently enrolled in education)
	OC – no	
	Solano – yes	No "current education" variable across counties so variable was created using employment status variable (those who endorsed student were coded as being currently enrolled in education)
	LA – yes	No "current education" variable across counties so variable was created using employment status variable (those who endorsed student were coded as being currently enrolled in education)
Marital status	SD - yes	
	OC - **no**	
	Solano - yes	
	LA - yes	
Primary language	SD - yes	
	OC - yes	
	Solano - yes	
	LA - yes	
Insurance status (i.e., insurance type)	SD - yes	Three separate harmonized insurance variables were created: 1) Medi-Cal, 2) Medicare, 3) Private insurance.
	OC - yes	Three separate harmonized insurance variables were created: 1) Medi-Cal, 2) Medicare, 3) Private insurance.
	Solano - yes	Three separate harmonized insurance variables were created: 1) Medi-Cal, 2) Medicare, 3) Private insurance.

	LA - yes	Three separate harmonized insurance variables were created: 1) Medi-Cal, 2) Medicare, 3) Private insurance. We used the Medi-Cal claim variable from the LA EP services; this was not available for the LA CG datasets.
Employment status	SD - yes	
	OC - **no**	
	Solano - yes	
	LA - yes	
Living arrangement (housing status)	SD - yes	
	OC - yes	
	Solano - yes	
	LA - no	Data not available for EP group, included in CG data only.
Sex	SD - yes	
	OC - **no**	
	Solano - yes	
	LA - yes	
Gender identity	SD - yes	
	OC - yes	Variable for gender only, not gender identity. No trans category; only Male and Female. Therefore, some individuals in Male or Female category may be Transgender.
	Solano - yes	
	LA - **no**	
Sexual orientation	SD - yes	Intersex and transgender have been placed in the ‘unknown’ category as these are not sexual orientations. Deferred has been placed in prefer not to answer.
	OC - yes	
	Solano - yes	
	LA - **no**	
Military service / Veteran status	SD - yes	Indicates some affiliation with the military, does not necessarily indicate military status (e.g. Client self-reports that they or an immediate family member have served in the US Military).
	OC - yes	Indicates some affiliation with the military, does not necessarily indicate military status (e.g. Client self-reports that they or an immediate family member have served in the US Military).
	Solano - yes	Indicates some affiliation with the military, does not necessarily indicate military status (e.g. Client self-reports that they or an immediate family member have served in the US Military).
	LA - **no**	

Psychiatric Diagnoses

Baseline psychiatric diagnoses were obtained from the EHR systems for each county. They were selected as either the first diagnoses within the first 90 days a client was served after the index service date or the latest diagnosis before the index service date if no post-90-day diagnosis was found. Index diagnoses for FEP clients in EP groups, and all CG group clients were defined as either a primary psychotic disorder diagnosis or mood disorder with psychotic features, with other diagnoses possible for CHR clients in EP groups (e.g. PTSD, anxiety disorders, autism), using an algorithm described in Appendix II. As noted previously, classification of FEP and CHR were obtained from the EP programs. Service Dates

As described previously, we defined the index service date for individuals in the EP group as the first date of service at the EP program within the study period (January 1, 2017 – December 31, 2019). The index service date for individuals in the CG group was defined as the first date of outpatient service (non-FSP, when possible) associated with an eligible diagnosis within the study period (January 1, 2017 – December 31, 2019). The "last service date" was defined as the end of the episode of care related to the index service date. If the episode of care start or end date was outside the active study period, the first or last service within the study period was used, respectively. The "duration of enrollment" was calculated as months between index and last service dates.

A unique feature of EP programs is their limited duration: most programs offer services for a maximum period of approximately 2 years. This focus on early intervention supports transitioning clients to other services after a specific period of time and/or after treatment goals are met. It also allows new clients to enter the program as others leave. General outpatient services have no limits on duration of treatment. Therefore, our analyses focus on the first 24 months of treatment for both groups. In order to account for variation in intensity of services and attrition over time, we defined service periods as index service date to 6 months, 7-12 months, 13-18 months, 19-24 months and 25 months+ (until last service date).

Outpatient Service Data

All contacts related to outpatient mental health services are recorded as part of the reimbursement process via service billing in each county. Clinical staff input all billable and non-billable services into the EHR systems through an electronic progress note that includes the date of service, type of service provided (defined by each county), and the time spent providing the service.

Billable service types examined include: Assessment, Case Management, Collateral, Crisis Intervention, Group Therapy, Individual Therapy, Medication Management, Plan Development, Rehabilitation, Supported Education and Employment services, Therapeutic Behavioral Services, Occupational Therapy, Peer Support, Administrative, Outreach, and Forensic, Lock Out, and Travel/Transportation.

Non-billable services were also compared as work conducted and no-show rates as indicators of engagement (see descriptions of all services in Appendix IV). Availability of service categories by county are detailed in Table XVII.

Day Services/Crisis Stabilization Data

Individuals experiencing mental health exacerbation often receive treatment in mental health urgent care or crisis stabilization facilities, which are intended to resolve the mental health crisis and attempt to prevent hospitalization. All Day Services (under 24 hours) and Crisis Stabilization data utilized in the analysis includes: Crisis Stabilization, Day Treatment, and Day Rehabilitation. Data elements used in the analysis include: number of visits per individual in the sample, date of visit, and length of stay (hours).

24-Hour Services/Inpatient Psychiatric Hospitalization Data

Individuals experiencing more severe mental health exacerbation often receive treatment in inpatient psychiatric hospital settings. This includes California Welfare and Institutions Code §5150/§5585 72-hour involuntary psychiatric holds for adults and minors, respectively, and §5250 14-day involuntary psychiatric holds, the duration of which can vary depending on the severity of the individual's needs, as well as all voluntary stays. All 24-hour services used in this analysis include: Inpatient Hospitalization, Residential Other, and Crisis Residential. We were able to obtain non-comprehensive services data from some private hospitals that bill the county, with the exception of Orange County, which submitted cost data for regional inpatient hospitalization. For 24-hour service data, data elements include number of visits per individual in the sample, dates of hospitalization, and length of stay.

Details regarding which services were available by county are shown in Table XVII below.

Table XVII: Availability of services data by county

Broad Service Category	Service Subcategory	Los Angeles	San Diego	Orange	Solano
Outpatient Services (Mode 15)	Assessment	yes	yes	yes	yes
	Case Management	yes	yes	yes	yes
	Collateral	yes	yes	yes	yes
	Crisis Intervention	yes	yes	yes	yes
	Group Therapy	yes	yes	yes	yes
	Individual Therapy	yes	yes	yes	yes
	Medication Management	yes	yes	yes	yes
	Plan Development	yes	yes	**no**	yes
	Rehabilitation	yes	yes	yes	yes
	Supported Education and Employment	yes	**no**	**no**	**no**
	Therapeutic Behavioral Services	yes	**no**	yes	yes
	Occupational Therapy	**no**	**no**	**no**	**no**
	Peer Support	**no**	**no**	**no**	**no**
	Administrative	**no**	yes	yes	yes
	Outreach	**no**	yes	**no**	**no**
	Forensic Services	**no**	yes	**no**	**no**
	No Show	**no**	**no**	**no**	yes
	Lock Out Code	**no**	**no**	**no**	yes
	Transportation	**no**	yes	yes	yes
	Intensive Home-Based Services	yes	yes	yes	yes
	ECT	**no**	yes	**no**	**no**
	Outpatient – other	yes	**no**	**no**	**no**
Day Services (Mode 10)	Crisis Stabilization	**no**	yes	yes	yes
	Urgent Care	**no**	**no**	**no**	**no**
	Day Treatment	yes	yes	**no**	yes
	Day Rehabilitation	**no**	yes	**no**	**no**
	Day Services - other	yes	**no**	**no**	**no**
24-hour Services (Mode 5)	Inpatient Hospital	yes	yes	yes	**no**
	Residential Other	**no**	**no**	yes	yes
	Residential Rehabilitation	**no**	**no**	**no**	**no**
	Skilled Nursing Facility (SNF)	**no**	**no**	**no**	**no**
	Crisis Residential	**no**	yes	yes	yes

Other Mental Health Services

Other mental health services include Substance Use Services for Orange County, and any services that had insufficient information to classify into one of the other three categories. For example, some outpatient services provided by private organizations used codes indicating “Other mental health service” and a provider name.

However, there were very few of these, and their impact on the analyses would be negligible. We will explore further during the next project period to see if we can resolve and services in this category.

Description of Unavailable Data Sources

Justice system and Regional Center services were unavailable for all counties. With the exception of Orange County, substance use services could not be obtained, as these records are kept separately from mental health services for privacy protection and require additional data use permissions.

Many consumers have hospital stays in private psychiatric hospitals both within and outside of their county of residence. Some counties track this data in separate databases, but we were unable to obtain and integrate this separate data for the current analysis. Furthermore, due to lack of available psychiatric inpatient beds across California, particularly for children, many consumers are placed out of county and require transportation over extensive distances that may not be adequately captured in our data.

Although the majority of EP clients are publicly insured (e.g., Medi-Cal), San Diego Kickstart and Solano Aldea SOAR utilize MHSA, insurance contracts, and/or philanthropic funds to serve privately insured clients. Some of these services are not billed to county systems, therefore, they are not represented in our data. Furthermore, services provided to privately insured clients by other private providers (e.g., Kaiser Psychiatry) are not represented.

Table XVII summarizes individual subcategories of services that were unavailable for specific counties. This was due to either 1) lack of a specific type of service in that county; 2) service data being unable to specifically denote that service; 3) data for those services needing to be obtained separately and we could not yet do so, or 4) certain non-billed services not being tracked.

Statistical Methods

Multi-County Analysis

After harmonizing the demographics, diagnoses, and service types across all four counties, as well as EP and CG groups, the data were merged into a single dataset for our primary analyses. This combined, multi-county dataset provided increased statistical power, allowing for a richer set of controls and error structure without compromising efficiency.

Analysis of Sample Characteristics

Student T-tests and Pearson Chi-square (or Fisher's exact) tests were used to compare unadjusted group differences in demographic characteristics (e.g., age, sex, race, ethnicity, etc.) between the individuals in the EP and CG groups. Both unadjusted and adjusted analyses were used to examine group differences in clinical characteristics at time of index service such as primary diagnosis, as well as the duration of enrollment.

Analysis of Outpatient Service, Day Service/Crisis Stabilization, and 24-Hour/ Inpatient Psychiatric Hospitalization Data

All service data outcomes were analyzed with a simple empirical equation: the independent variable is regressed on a county-specific fixed effect, an epoch-specific fixed effect, an indicator taking 1 for the EP group and 0 otherwise, a set of interactions between the EP group indicator and each epoch allowing the effect of the EP program to vary over time, and a set of individual-specific controls - measured at intake - consisting of sex, ethnicity, race, and primary language. We used all demographic variables that were available and harmonized across all counties in time for this preliminary analysis. Standard errors were always clustered at the individual-level because repeated measures of the same outcome for the same individual are correlated, and we are interested in describing individual-level differences. Further processing of the data will allow the addition of other individual-specific controls and clinic-specific effects to the empirical equation to account for other sources of confounding variation. These will be included in future analyses.

Total outpatient service time (in minutes) of all outpatient services and total minutes of each service type (e.g., medication management, individual therapy, group therapy, rehab services) were analyzed by estimating the empirical equation described above with negative binomial regression for count data to determine if outpatient service use differs between the EP and CG samples.

Data related to individuals' use of Day Service/Crisis Stabilization, and 24-Hour/ Inpatient Psychiatric Hospitalization Data usage were examined using multiple measurements based on the study period: 1) a binary indicator for whether the individual had ever been hospitalized; 2) a binary indicator for whether the individual had ever utilized crisis services; 3) number of hospitalizations per month; 4) number of crisis visits per month; and 5) mean duration of hospitalizations (i.e., length of stay [LOS]) in days; 6) mean LOS for Day/Crisis services (hours); 7) total duration of hospitalizations per month; and 8) total duration of Day/crisis services per month. Data for (1) and (2) were analyzed by estimating the empirical equation described above with multiple logistic regression. Data for (3), (4), (7), and (8) were analyzed by estimating the empirical equation described above with negative binomial regression for count data. Data for (5) and (6) were analyzed by estimating the empirical equation described above with linear regression. These various methods allowed us to determine whether each respective outcome differed between the EP and CG samples.

Results

The final cohort includes a sample of 506 individuals served by EP programs and 17,092 individuals from the CG group.

Clinical and Demographic Characteristics

Table XLV (Appendix III) summarizes baseline diagnostic and demographic information for the individuals from the EP and CG cohorts.

The EP sample had an average age of 17.0 years (standard deviation [SD] = 3.1 years), 59% of whom identified as male. Of those receiving treatment in the CG group, the mean age was 20.1 (SD=3.8 years), and 61% of them identified as male. The average age of CG individuals was significantly older than the average age of EP individuals in this sample (p<.001). No statistical difference in the distribution of sex was found.

The EP group included a significantly higher number of individuals who identified as Hispanic/Latino (56%) compared to the proportion of individuals from the CG clinics (44%, p<.001). In addition, a higher percentage of EP individuals identified as Caucasian (27%) compared to CG individuals (17%). However, a majority of CG individuals reported Unknown race (54%).

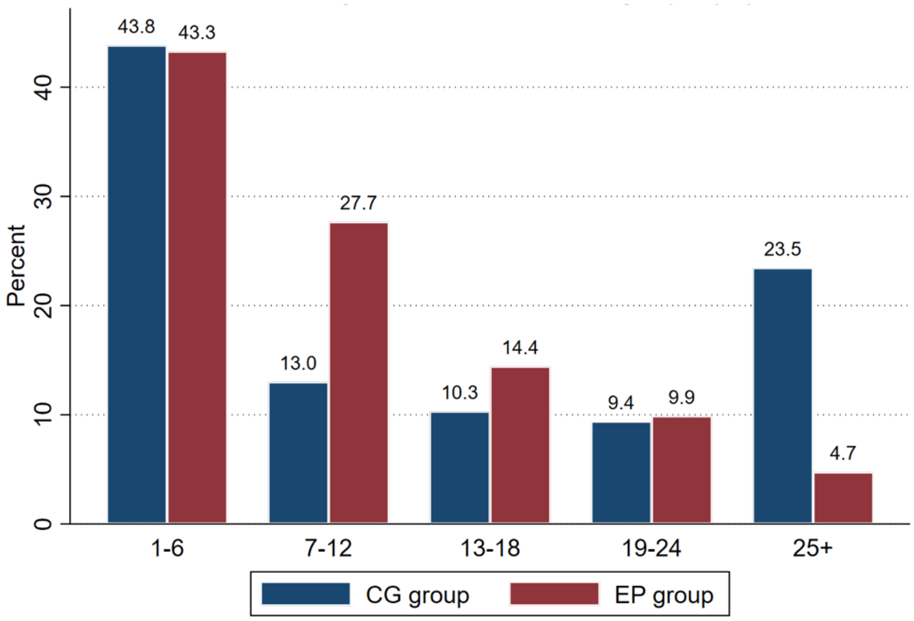
A higher proportion of individuals in the EP group had a Psychosis Spectrum disorder as the primary index diagnostic category compared to the CG group (EP Group: 80%; CG Group: 61%, p<.001). For both groups, Mood Spectrum disorders represented a smaller proportion of the primary diagnoses (EP Group: 6%; CG Group: 21%).

Service Utilization Characteristics

Duration of Enrollment

On average, individuals receiving treatment in both groups tended to remain in treatment for roughly one year (EP group: 11.1 months [SD=9.1], CG group: 12.2 months [SD=12.3]), but average duration of treatment was significantly higher for CG individuals (p<.05).

Figure 20. Percentage of clients ending treatment within each time period



As shown in Figure 20, a roughly equal proportion of EP and CG individuals ended treatment within the first 6 months (43% and 44%, respectively). A greater proportion of EP individuals ended treatment between 7 and 12 months compared to CG clients (28% vs. 13%, respectively). However, compared to EP individuals, a larger proportion of CG individuals ended treatment after they had received over 25 months of services (5% vs. 24%, respectively). For more information on differences in enrollment, see Appendix III – Table XLVII.

<u>Outpatient Service Use</u>

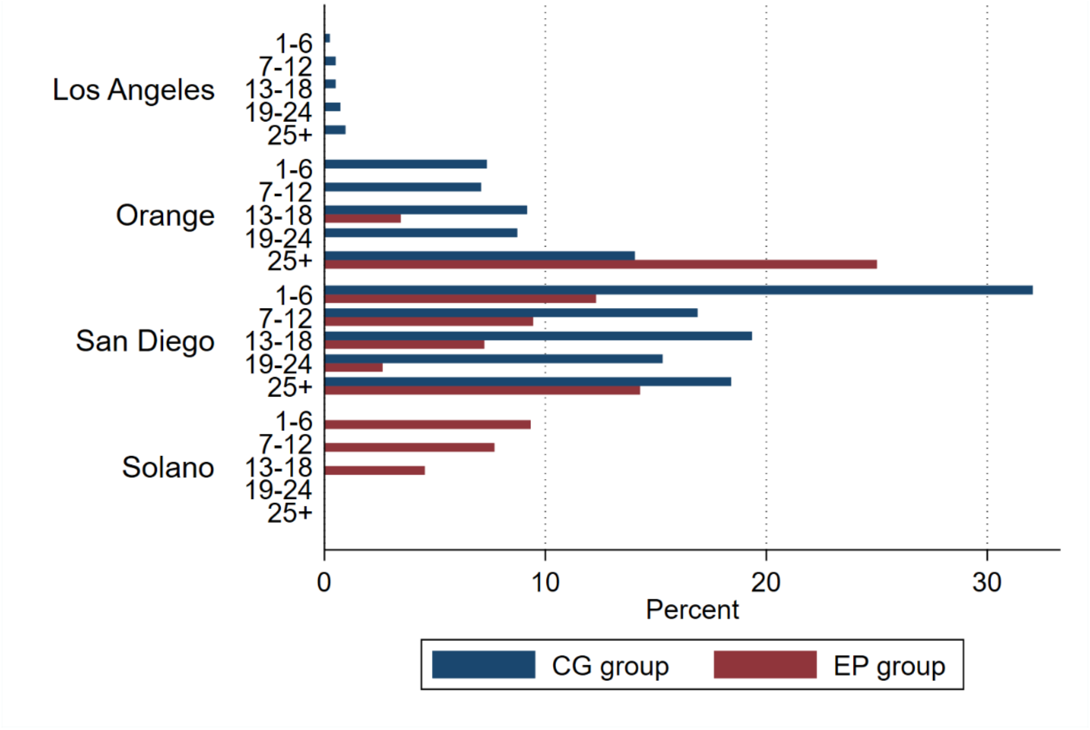
The EP and CG clinics offered similar types of outpatient services, including assessment, case management, collateral, crisis intervention, group therapy, individual therapy, medication support, plan development, and rehabilitation (see Appendix IV Service Code Definitions for descriptions of these services).

In examining the total minutes of outpatient services provided to individuals per month, those served in the EP group received significantly more minutes of service across all time points compared to the CG group (*p*<.001, see Appendix III – Tables XLVIIIA and XLVIIIB). When specific services are examined individually, the greatest difference is observed between groups in minutes of collateral, per person, per month (EP group: 140 minutes; CG group: 66 minutes) and individual therapy (EP group: 239 minutes; CG group: 188 minutes) per person.

<u>Day Services</u>

The use of day services was rare for both groups, as only 2.0% of EP and 4.7% of CG individuals received these services while enrolled in EP or general outpatient treatment (see Appendix III – Table XLIX). Calculated as the proportion of individuals with one or more visits, use of day services was greater in the CG group across all time points (*p*<.001). Further, the rate of day service visits was the highest among individuals that had been enrolled in treatment for 25 months or more (EP group: 3.3%; CG group: 5.7%, see Figure 21).

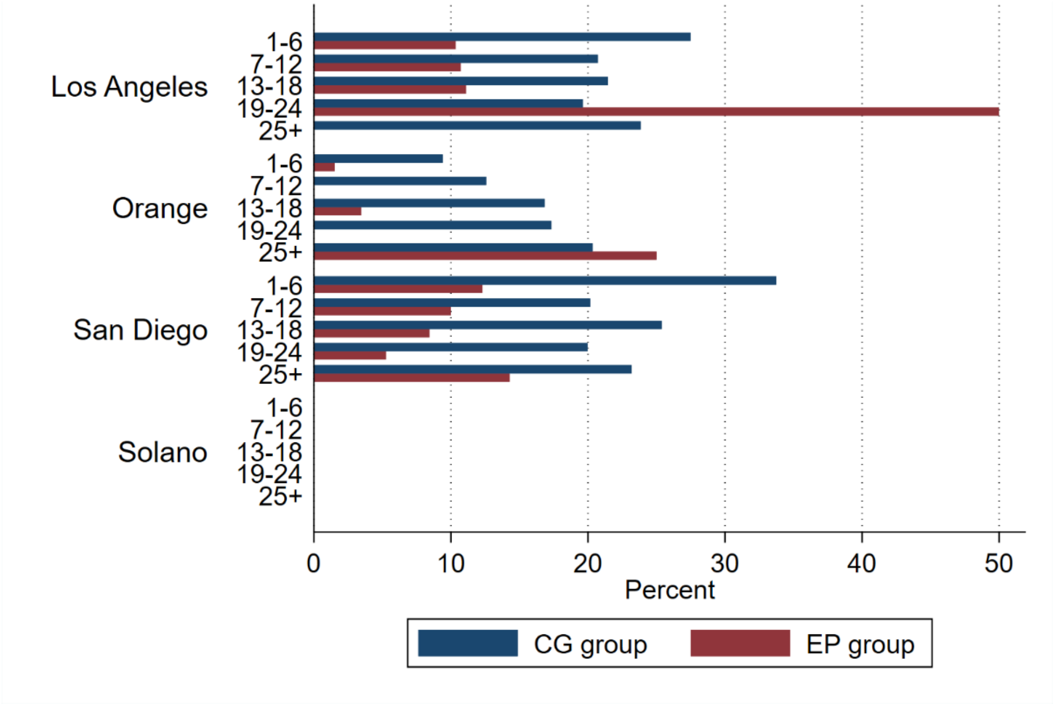
Figure 21. Proportion of clients with at least one day service visit by time period by county



24-Hour Services/Inpatient Psychiatric Hospitalization Data

A significantly greater proportion of CG individuals experienced at least one 24-hour service or inpatient hospitalization during their enrollment compared to EP individuals (22.4% vs. 8.9%, *p*<.001; see Appendix III – Table L). As shown in Figure 22, 24-hour services occurred most frequently during the first 6 months of treatment (EP group: 9.4%; CG group: 24.8%) and after 25 months of treatment (EP group: 17.0%; CG group: 23.7%), although we did not test these differences statistically. As noted previously, this data was unavailable for Solano County.

Figure 22. Proportion of clients with at least one 24-hour service by time period by county



NOTE: Data not available for Solano County

Summary

Across all time periods, the total minutes of outpatient services per month was higher among EP individuals compared to CG individuals. However, the proportion of individuals in the EP group with one or more day services and/or 24-hour services/ inpatient hospitalizations was lower compared to the CG group.

Interpretations

Regarding duration of enrollment in treatment, the EP and CG groups are generally similar, with more EP clients receiving 7-12 months of service, and the CG group having a substantial proportion of clients who received longer-term treatment (25+ months), past the standard end-point of EP treatment at 24 months. In both groups, nearly half of the clients received services for less than 6 months, which may represent challenges in engagement with this population, as well as the mobility of TAY youth, who may also have received services elsewhere.

The groups were both predominantly male, as is often typical in early psychosis clinical samples. There was a slightly older average age in the CG group, and more Hispanic/Latino clients and Caucasian clients in the EP group. This may reflect the focus of programs on outreach and staffing availability predominantly in English and Spanish. They identified as predominantly heterosexual across both groups. The results of this preliminary analysis are consistent with the intent of EP programs- to offer more intensive and evidence-based outpatient services in order to reduce the need for higher levels of care and to promote recovery. This is evident in the higher overall outpatient minutes for the EP group. Greater time spent in individual therapy likely reflects the treatment models of the EP programs, which focus on CBT for psychosis or other similar forms of therapy. EP programs make a concerted effort to involve families of these transition age youth, reflected in the results of more collateral services than the CG group.

Similarly, the significantly greater proportion of CG individuals who had inpatient hospitalizations during the study period may demonstrate the effectiveness of early intervention in reducing hospitalization rates. Day services were so rare in both groups that we only analyzed the proportion of individuals with at least one service. Overall, these group differences are quite promising, although at this time, we cannot rule out differences in severity and needs between the EP and CG groups at baseline that could partly or fully explain the service utilization differences. As noted previously, access to hospitalization data may have been limited (e.g., by treatment outside county); however, these issues should have affected the EP and CG groups in a county similarly.

Limitations and Future Analyses

The primary goal of the current deliverable was to demonstrate the availability of service utilization and cost data that can be accessed and integrated across counties. Through this process, we identified a number of issues that require additional clarification for the final analysis. We will focus on these issues during the next project period:

Defining CG clients

Identifying an equivalent comparison group relies upon identifying similar individuals to EP clients. Given the lack of the CHR syndrome as a formal DSM or ICD diagnosis, we are unable to identify CHRs for comparison. Restricting our analysis to “first episode” psychosis, we were able to exclude CG individuals with recorded psychotic disorder diagnoses for more than 2 years prior to out active service period (the most common eligibility requirement for the EP programs). However, this does not rule out individuals who had psychosis but were not accurately diagnosed as such in health records. Due to factors such as the complexity of early psychosis diagnoses, lack of information about symptoms over time, and provider hesitance related to stigma about psychosis and serious mental illness, FEP clients are often only diagnosed with a psychotic disorder in records after a substantial period of time with psychosis. Less stigmatizing disorders such as bipolar disorder, or those that represent only current symptoms, such as substance-induced psychosis are often used instead. Further, clients who recently entered the county system, but were treated for psychosis outside the county prior to the service period, may not be appropriately excluded. Finally, as we explore comparisons of baseline characteristics of EP and CG clients, we may use propensity score matching or a similar method in our final analysis.

Defining CG services

We attempted to compare services in specialized EP programs to usual outpatient care, or “treatment as usual.” These services vary greatly across counties and across child and adult systems of care, so that we may have inadvertently included other specialized programs that offer more intensive services as well. Finally, clients were not randomized to treatment, so there may be systematic biases that influence whether clients received services at the EP program or elsewhere that we cannot see in the data we obtained. We excluded CG clients who were treated in FSPs for this reason, but we were only able to accurately identify all FSP programs in our data in San Diego and Orange Counties. This will be a focus of our work during the next project period.

Inpatient services

Our preliminary analysis only includes inpatient data for county hospitals and some private hospitals that bill the counties. Some counties maintain separate databases of inpatient hospitalizations, which we expect to receive in time for the final analysis.

Private insurance services

Some EP programs serve all residents of the county, regardless of insurance. This may include individuals who have private insurance, and therefore services outside the EP program would be within a private insurance or HMO network, which cannot be included in these data. We will work with programs and counties to make sure we are accurately identifying these individuals and may need to exclude them form the final analysis.

Non-billable services

In future analyses, we plan to analyze no-show and cancellation rates as measures of treatment engagement.

Missing service categories

Although there were very few services that could not be categorized, we will follow up to obtain additional information about either subcategories for which we have no services in a county or specific services that lack sufficient detail. We will also investigate additional sources of data to determine whether more day services and 24 hour services can be integrated into our dataset. We may limit the analysis where there remain discrepancies in availability of specific service types by county or by group.

Demographic factors

Due to time constraints, we were only able to fully harmonize and analyze a subset of demographic variables. For the next deliverable, we will examine the relationship of more demographic factors to our outcomes, including: sexual orientation, language, education level, employment status, marital status, housing status, military service/veteran status, foster care status, insurance status and zip code. We will also determine which values represent true "baseline” characteristics, and which may be outcomes, recorded at later time points in treatment.

Fiscal year

In the next period we will explore fiscal year as a factor impacting outcomes, given changes over time in both service categorization and reimbursement.

Description of Sources of Cost Data

The costs associated with each service type were requested from each county. For the purposes of this deliverable, we will describe the cost data obtained thus far. Comparison of costs associated with service utilization in the EP and CG groups will be analyzed once all cost data have been received by the study team. These results will be included in the next Deliverable, June 2022. Potential sources of cost data were identified for specific service types, as described in Table XVIII, below.

Table XVIII. Sources of Cost Data by Service Type

Service Type	Included Sources of Cost Data
Outpatient	Contract service unit rates
Day/Crisis Stabilization	Hourlyrate paid by County
24-hour: Inpatient, Residential	Dailyrate paid by County Daily rate Medi-Cal reimbursement Harmonized Average Statewide Rate

Los Angeles and Orange County were able to submit their cost data to the study team prior to the completion of this deliverable report. San Diego County provided several tables of cost rates for services; however, after review of the submitted data, a revised cost data request was sent to the county seeking final costs attached to each service. Because final cost data from San Diego County are still pending, the present deliverable describes the data sources that were received. Solano County also experienced delays in obtaining and submitting their cost data. Delays included more complex data sources and lack of IT support staff available to the county data analysts to be able to pull the requested data. Final details of specific cost data sources for San Diego and Solano County will also be included in the next deliverable.

Los Angeles County

Outpatient Service Use: Los Angeles County costs rates were attached to each service and included all service types. For outpatient services each cost rate was the total cost of the service and the service unit (recorded in minutes).

Day Services/Crisis Stabilization Data: Costs related to day services included total cost of the service and the service unit (recorded in minutes).

24-Hour Services/Inpatient Psychiatric Hospitalization Data: Costs related to 24-hour services include inpatient county hospitals, Fee-for-Service hospitals and County contracted providers. These costs include total cost of the service and cost per service unit (recorded in days).

Orange County

Outpatient Service Use: Costs related to outpatient service use were based on contract service rates. Each outpatient service included a service unit rate and number of service units (in minutes).

Day Services/Crisis Stabilization Data: Costs related to day services/crisis stabilization were based on contract service rates which included a service unit rate and number of service units (in minutes).

24-Hour Services/Inpatient Psychiatric Hospitalization Data: Costs related to 24-hour services were day rates which varied by contract. Inpatient/hospital stays include negotiated bed day rate for each HCA contracted acute inpatient facility. These rates are different from the general regional rates set by DHCS. Skilled Nursing Facility (SNF)/IMD rates were averaged and include a bed day rate. Crisis Residential rates include a day rate and charge for the medical services by the minute.

San Diego County

Outpatient Service Use: County interim cost rates for outpatient services per service unit (15 minutes, bill in one-minute increments). Published reimbursable cost rates and actual reimbursable cost rates for EP community services, including case management, mental health services, medication support, and crisis intervention.

Day Services/Crisis Stabilization Data: County interim rates for day services/crisis stabilization per service unit (in hours).

24-Hour Services/Inpatient Psychiatric Hospitalization Data: County interim rates per service unit (in days) for inpatient/hospital stays, crisis residential, and therapeutic foster care. Contracted inpatient hospital rates for adult and adolescent services, effective February 1, 2020. Regional rate, effective July 1, 2021, for non-contracted inpatient hospitals.

Statewide Sources of Cost Data

Across California, psychiatric inpatient beds are often unavailable, particularly for minors. Patients are placed at both county-run and private hospitals, in or out of county. Each county negotiates different day rates with each hospital. Due to this variability, we will use multiple sources of data to develop averaged rates statewide. We will apply these cost rates to inpatient service utilization for both the EP and CG groups, across counties. Once we are able to review the day rates for residential services in each county, we may use the same harmonization method.

2.8 Present findings on cost and utilization data from preliminary multi-county integrated evaluation, identification of problems and solutions for county-level data analysis/Present preliminary results from second round of analysis for county-level cost and utilization data from all EP/CG programs

Data and Methods

This analysis is based on data provided by Los Angeles, Orange, and San Diego counties. We used administrative data to identify youth aged 12 to 25 years who (1) were enrolled in a specialized early psychosis (EP) program from January 2017 to July 2021, and (2) received a first diagnosis of psychosis (ICD-10 codes F20, F22, F23, F25, F28, F29, F31.2, F31.5, F31.64, F32.3 F33.3) within one year prior to enrollment. We shared lists of EP youth with program staff who confirmed that these were past or current clients who received their first diagnosis of psychosis. We identified a comparison group (CG) of youth with a first diagnosis of psychosis who received at least one outpatient service during the study period, also within one year of receiving their first diagnosis of psychosis. We excluded youth with a diagnosis of psychosis in more than two years before starting outpatient services, youth with private insurance, and youth who received a diagnosis of intellectual disability (ICD-10 codes F70-F79, ICD-9 codes 317-319).

We summarized service use and cost for Medi-Cal covered outpatient and inpatient services over the first and second years following the first diagnosis of psychosis. We calculated the number of outpatient mental health visits and the number of inpatient psychiatric days. Outpatient services included case management, crisis intervention, medication management, and mental health services including rehabilitation and therapy. We defined a visit as a unique day receiving services. Inpatient psychiatric days included admissions to psychiatric hospitals and admissions to psychiatric units of acute care hospitals. We also summarized the costs of outpatient and inpatient mental health services.

We estimated the number of outpatient visits and inpatient days during a year using negative binomial regression models. We estimated the probabilities of using outpatient and inpatient services with logistic regression models. We estimated costs using a generalized linear model with a gamma distribution and a log link function. In each model, we included covariates for age, gender, and race/ethnicity. We calculated standardized estimates for each outcome using the estimated coefficients to generate predicted values for each client in the sample as if they were alternately assigned to EP and CG. The standardized mean is the mean of the predicted values across the sample. We calculated standard errors using the non-parametric bootstrap, and significance values using non- parametric permutation.

Results
We identified 238 youth in EP programs (Table XIX). Mean age was 17.8 years (SD=2.9 years); 80 (33.6%) were female; 39 (16.4%) were non-Hispanic White, 28 (11.8%) were Black, 16 (6.7%) were Asian, 138 (58.0%) were Latino, 6 (2.5%) were of another race/ethnicity, and 11 (4.6%) had unknown race/ethnicity.

Table XX shows the demographics of the youth in the EP and CG groups. EP youth were significantly younger than CG youth (M=20.3 years, SD=4.0 years; $t(25124)=9.59$, $p<.001$). The groups also differ significantly in their racial/ethnic composition, $\chi^2(4, N=25126)=36.88$, $p<.001$. The EP group was comprised of a higher proportion of Asian (6.7%) and Latino (58.0%) youth compared to the CG group (3.4% and 47.0%, respectively; *p'*s<.05). Gender did not significantly differ between groups, $\chi^2(4, N=25126)=6.63$, $p=.163$).

Table XXI shows standardized estimates of service use in the first and second years following the initial diagnosis of psychosis. In the first year following diagnosis, the mean annual number of outpatient visits was 22.3 greater among EP youth than CG youth: 49.7 vs 27.4 visits per year, $p<.001$. The annual probability of psychiatric inpatient admission was 6.4 percentage points lower among EP youth: 36.3% vs. 42.7% used any inpatient services, $p=.020$. However, there was no significant difference in inpatient days overall between the two groups.

Outpatient visits remained higher among EP youth during the second year following diagnosis. The probability of using outpatient services was 21.2 percentage points greater among EP youth: 76.2% vs. 55.0% used any outpatient services, $p<.001$. The mean annual number of outpatient visits was 15.1 higher among EP youth: 33.5 vs. 18.4, $p<.001$. There was no significant difference in either the probability of inpatient admission or the number of inpatient days between the two groups in the second year following diagnosis.

Table XXII shows costs for outpatient and inpatient mental health services in the first and second years following the initial diagnosis of psychosis. Outpatient costs were significantly greater for EP youth compared to CG youth in both years. Outpatient costs were $6,150 greater for EP youth in the first year following diagnosis and $4,073 greater in the second year following diagnosis ($p<.001$ each). In contrast, there was no significant difference in inpatient costs in either year.

Summary
Youth enrolled in EP programs had a greater number of outpatient mental health visits and higher costs than a comparable group of youth who were receiving services in standard outpatient programs in both the first and second years following the initial diagnosis of psychosis. Youth in EP programs had a lower probability of psychiatric inpatient admission than CG youth in the year following diagnosis. However, there was no significant difference in the number of inpatient days. We did not find significant differences in psychiatric

admissions or inpatient days in the second year following diagnosis, nor did we find significant differences in inpatient costs in either year.

Table XIX. Demographic Characteristics of Youth in Early Psychosis Programs

	Overall	**Los Angeles**	**Orange**	**San Diego**
N	238	55	43	140
Age M (SD)	18.0 (2.9)	18.7 (2.9)	16.7 (2.8)	17.8 (2.9)
Age N (%)				
12-17 years	130 (54.6%)	23 (41.8%)	28 (65.1%)	79 (56.4%)
18-21 years	75 (31.5%)	21 (38.2%)	12 (27.9%)	42 (30.0%)
22-25 years	33 (13.9%)	11 (20.0%)	3 (7.0%)	19 (13.6%)
Gender N (%)				
Male	158 (66.4%)	33 (60.0%)	27 (62.8%)	98 (70.0%)
Female	80 (33.6%)	22 (40.0%)	16 (37.2%)	42 (30.0%)
Race/Ethnicity N (%)				
Non-Hispanic White	39 (16.4%)	8 (14.5%)	4 (9.3%)	27 (19.3%)
Black/African American	28 (11.8%)	4 (7.3%)	1 (2.3%)	23 (16.4%)
Asian	16 (6.7%)	1 (1.8%)	10 (23.3%)	5 (3.6%)
Latino	138 (58.0%)	36 (65.5%)	25 (58.1%)	77 (55.0%)
Other/ Unknown	17 (7.1%)	6 (10.9%)	3 (7.0%)	8 (5.7%)

Table XX. Demographic Characteristics of Youth in Early Psychosis Programs and a Comparison Group of Youth Receiving Usual Care

	Overall	**EP**	**CG**	**P-Value**
N	25,126	238	24,888	-
Age M (SD)	20.3 (4.0)	17.8 (2.9)	20.3 (4.0)	<.001
Age N (%)				<.001
12-17 years	6,834 (27.2%)	130 (54.6%)	6,704 (26.9%)	<.05
18-21 years	6,913 (27.5%)	75 (31.5%)	6,838 (27.5%)	*n.s.*
22-25 years	11,379 (45.3%)	33 (13.9%)	11,346 (45.6%)	<.05
Gender N (%)				0.163

Male	14,763 (58.8%)	158 (66.4%)	14,605 (58.7%)	*n.s.*
Female	10,245 (40.8%)	80 (33.6%)	10,165 (40.8%)	*n.s.*
Other/ Unknown	118 (<1%)	-	118 (<1%)	*n.s.*
Race/Ethnicity N (%)				<.001
Non-Hispanic White	3,459 (13.8%)	39 (16.4%)	3,420 (13.7%)	*n.s.*
Black/African American	4,141 (16.5%)	28 (11.8%)	4,113 (16.5%)	*n.s.*
Asian	850 (3.4%)	16 (6.7%)	834 (3.4%)	<.05
Latino	11,824 (47.1%)	138 (58.0%)	11,686 (47.0%)	<.05
Other/ Unknown	4,852 (19.3%)	17 (7.1%)	4,835 (19.4%)	<.05

Table XXI. Standardized Annual Estimates of Service Use Among Youth Early Psychosis Programs Versus Usual Care in One and Two Years Following Initial Diagnosis of Psychosis

	EP		**CG**		**Difference**		**P-Value**
Year 1	Mean	SE	Mean	SE	Mean	SE	
Outpatient Visits	49.7	2.7	27.4	.2	22.3	2.7	<.001
Probability of Inpatient Use	.363	.030	.427	.003	-.064	.031	.020
Inpatient Days	7.7	1.2	6.5	.1	1.2	1.2	.136
Year 2							
Probability of Outpatient Use	.762	.030	.550	.003	.212	.031	<.001
Outpatient Visits	33.5	2.9	18.4	.2	15.1	2.9	<.001
Probability of Inpatient Use	.197	.030	.149	.002	.048	.030	.226
Inpatient Days	3.6	1.0	3.0	.1	.6	1.1	.437

Table XXII. Standardized Annual Estimates of Costs Among Youth Early Psychosis Programs Versus Usual Care in One and Two Years Following Initial Diagnosis of Psychosis

	EP		**CG**		**Difference**		**P-Value**
Year 1	Mean	SE	Mean	SE	Mean	SE	
Outpatient Costs	$14,784	$1,012	$8,634	$81	$6,150	$1,017	<.001
Inpatient Costs	$7,457	$1,151	$6,254	$110	$1,203	$1,163	.136
Year 2							
Outpatient Costs	$9,393	$881	$5,320	$76	$4,073	$880	<.001
Inpatient Costs	$3,484	$1,010	$2,893	$100	$591	$1,014	.437

Individual County Data

Los Angeles

Table XXIII shows the demographic characteristics of youth enrolled in the Center for the Assessment and Prevention of Prodromal States (CAPPS) EP program and CG youth receiving usual care in Los Angeles County. Similar to the overall sample, EP youth (M=18.7 years, SD=2.9 years) were significantly younger than CG youth (M=20.4 years, SD=4.1 years; *t*(19404)=3.15, *p*=.002). There were also significant differences in their racial/ethnic composition, $\chi^2(4, N=19406)=12.42$, $p=.015$. The EP group was comprised of a higher proportion of Latino (65.5%) youth compared to the CG group (45.6%, $p<.05$). As in the overall sample, gender did not significantly differ between groups, $\chi^2(2, N=19406) = 0.30$, $p=.862$.

Table XXIV shows differences in outpatient service use and costs between youth receiving care from the CAPPS EP program and those receiving usual care in Los Angeles County in the first and second years following the initial diagnosis of psychosis. In the first year following diagnosis, the mean annual number outpatient visits were 17.1 greater among EP youth than CG youth: 46.8 vs 29.8 visits per year, $p<.001$. Outpatient costs were $4,623 greater for EP youth in the first year following diagnosis; however, this difference was not significant, $14,407 vs $9,784, $p=.145$. In the second year following diagnosis, the mean annual number outpatient visits were 4.1 greater among EP youth than CG youth: 24.5 vs 20.2 visits per year, $p<.001$. There was no significant difference in outpatient costs between the groups in year 2: $6,318 vs $6,119, $p=.404$.

Table XXIII. Demographic Characteristics of Youth in CAPPS Early Psychosis Program and a Comparison Group of Youth Receiving Usual Care in Los Angeles County

	Overall	EP	CG	P-Value
N	19,406	55	19,351	-
Age M (SD)	20.4 (4.1)	18.7 (2.9)	20.4 (4.1)	<.001
Age N (%)				<.001
12-17 years	5,202 (26.8%)	23 (41.8%)	5,179 (26.8%)	*n.s.*
18-21 years	5,185 (26.7%)	21 (38.2%)	5,164 (26.7%)	*n.s.*
22-25 years	9,019 (46.5%)	11 (20.0%)	9,008 (46.6%)	<.05
Gender N (%)				0.862
Male	11,301 (58.2%)	33 (60.0%)	11,268 (58.2%)	*n.s.*
Female	8,019 (41.3%)	22 (40.0%)	7,997 (41.3%)	*n.s.*
Other/ Unknown	86 (<1%)	-	86 (<1%)	*n.s.*
Race/Ethnicity N (%)				0.015
Non-Hispanic White	2,153 (11.1%)	8 (14.5%)	2,145 (11.1%)	*n.s.*
Black/African American	3,625 (18.7%)	4 (7.3%)	3,621 (18.7%)	*n.s.*
Asian	493 (2.5%)	1 (1.8%)	492 (2.5%)	*n.s.*
Latino	8,853 (45.6%)	36 (65.5%)	8,817 (45.6%)	<.05
Other/ Unknown	4,282 (22.1%)	6 (10.9%)	4,276 (22.1%)	*n.s.*

Table XXIV. Standardized Annual Estimates of Outpatient Service Use and Costs Among CAPPS Early Psychosis Program Versus Usual Care in Los Angeles County in One and Two Years Following Initial Diagnosis of Psychosis

	EP		CG		Difference		P-Value
Year 1	Mean	SE	Mean	SE	Mean	SE	
Outpatient Visits	46.8	5.1	29.8	.3	17.1	5.1	<.001
Outpatient Costs	$14,407	$1,732	$9,784	$108	$4,623	$1,732	.145
Year 2							
Outpatient Visits	24.5	4.1	20.2	.3	4.3	4.1	<.001
Outpatient Costs	$6,318	$999	$6,119	$96	$262	$1001	.404

Orange

Table XXV shows the demographic characteristics of youth enrolled in the Orange County Center for Resiliency, Education and Wellness (OC CREW) EP program and CG youth receiving usual care in Orange County. Similar to the overall sample, EP youth (M=16.7 years, SD=2.8 years) were significantly younger than CG youth (M=19.3 years, SD=4.0 years; *t*(3041)=4.20, *p*<.001). There were also significant differences in their racial/ethnic composition, χ^2(4, *N*=3043)=15.28, *p*=.004. The EP group was comprised of a higher proportion of Asian (23.3%) youth compared to the CG group (8.0%, *p*<.05). As in the overall sample, gender did not significantly differ between groups, χ^2(2, *N*=3043)=0.55, *p*=.758.

Table XXVI shows the differences in outpatient service use and costs between youth receiving care from the OC CREW EP program and those receiving usual care in Orange County in the first and second years following the initial diagnosis of psychosis. In the first year following diagnosis, the mean annual number outpatient visits were 15.2 greater among EP youth than CG youth: 36.5 vs 21.3 visits per year, *p*=.002. Outpatient costs were $3,127 greater for EP youth in the first year following diagnosis: $8,231 vs $5,104, *p*=.001. In the second year following diagnosis, the mean annual number outpatient visits were 7.9 greater among EP youth than CG youth: 21.4 vs 13.5 visits per year, *p*=.110. The difference in outpatient costs between the groups in year 2, $1,711 was marginally significant: $5,305 vs $3,407, *p*=.082.

Table XXV. Demographic Characteristics of Youth in OC CREW Early Psychosis Program and a Comparison Group of Youth Receiving Usual Care in Orange County

	Overall	EP	CG	P-Value
N	3,043	43	3,000	-
Age M (SD)	19.3 (4.0)	16.7 (2.8)	19.3 (4.0)	<.001
Age N (%)				<.001
12-17 years	1,139 (37.4%)	28 (65.1%)	1,111 (37.0%)	<.05
18-21 years	808 (26.6%)	12 (27.9%)	796 (26.5%)	*n.s.*
22-25 years	1,096 (36.0%)	3 (7.0%)	1,093 (36.4%)	<.05
Gender N (%)				0.758
Male	1,797 (59.1%)	27 (62.8%)	1,770 (59.0%)	*n.s.*
Female	1,221 (40.1%)	16 (37.2%)	1,205 (40.2%)	*n.s.*
Other/ Unknown	25 (<1%)	-	25 (<1%)	*n.s.*

Race/Ethnicity N (%)				0.004
Non-Hispanic White	595 (19.6%)	4 (9.3%)	591 (19.7%)	*n.s.*
Black/African American	143 (4.7%)	1 (2.3%)	142 (4.7%)	*n.s.*
Asian	250 (8.2%)	10 (23.3%)	240 (8.0%)	<.05
Latino	1,751 (57.5%)	25 (58.1%)	1,726 (57.5%)	*n.s.*
Other/ Unknown	304 (10.0%)	3 (7.0%)	301 (10.0%)	*n.s.*

Table XXVI. Standardized Annual Estimates of Outpatient Service Use Among OC CREW Early Psychosis Program Versus Usual Care in Orange County in One and Two Years Following Initial Diagnosis of Psychosis

	EP		**CG**		**Difference**		**P-Value**
Year 1	Mean	SE	Mean	SE	Mean	SE	
Outpatient Visits	36.5	5.6	21.3	.5	15.2	5.7	.002
Outpatient Costs	$8,231	$1,214	$5,104	$143	$3,127	$1,216	.001
Year 2							
Outpatient Visits	21.4	6.8	13.5	.6	7.9	6.8	.110
Outpatient Costs	$5,305	$1,707	$3,047	$153	$1,988	$1,711	.082

San Diego

Table XXVII shows the demographic characteristics of youth enrolled in the Kickstart EP program and CG youth receiving usual care in San Diego County. Similar to the overall sample, EP youth (M=17.8 years, SD=2.9 years) were significantly younger than CG youth (M=20.9 years, SD=2.2 years; *t*(2675)=10.68, *p*=.022). However, the racial/ethnic composition did not significantly differ between groups, χ^2(4, *N*=2677) =9.20, *p*=.056. As in the overall sample, gender did not significantly differ between groups, χ^2(2, *N*=2677) =4.07, *p*=.131.

Table XXVIII shows differences in outpatient service use and costs between youth receiving care from the Kickstart EP program and those receiving usual care in San Diego County in the first and second years following the initial diagnosis of psychosis. In the first year following diagnosis, the mean annual number outpatient visits were 22.2 visits greater among Kickstart EP youth than CG youth: 40.5 vs 18.4 visits per year, *p*<.001. Outpatient costs were $5,274 greater for EP youth in the first year following diagnosis: $9,595 vs $4,321, *p*<.001. In the second year following diagnosis, the mean annual number outpatient visits were 18.1 greater among EP youth than CG youth: 29.8 vs 11.7 visits per year, *p*<.001. Outpatient costs were $4,238 greater for EP youth in the second year following diagnosis, $6,773 vs $2,535, *p*<.001.

Table XXIX shows differences in the number of inpatient days and the probability of inpatient use between youth receiving care from the Kickstart EP program and those receiving usual care in San Diego County in the first and second years following the initial diagnosis of psychosis. In the first year following diagnosis, there was no significant difference in the probability of inpatient use (48.9% vs 47.1%, *p*=.340), but the overall number of inpatient days were 4.5 higher among EP youth than CG youth; 11.8 vs. 7.2, *p*=.011. In the second year following diagnosis, the probability of inpatient use was significantly greater among EP youth than CG youth: 25.4% vs 15.6%, *p*=.014. However, there was no significant difference in the number of inpatient days, 5.8 vs 3.4 days, *p*=.115.

Table XXVII. Demographic Characteristics of Youth in Kickstart Early Psychosis Program and a Comparison Group of Youth Receiving Usual Care in San Diego County

	Overall	EP	CG	P-Value
N	2,677	140	2,537	-
Age M (SD)	20.7 (3.4)	17.8 (2.9)	20.9 (2.2)	.022
Age N (%)				<.001
12-17 years	493 (18.4%)	79 (56.4%)	414 (16.3%)	*n.s.*
18-21 years	920 (34.4%)	42 (30.0%)	878 (34.6%)	*n.s.*
22-25 years	1,264 (47.2%)	19 (13.6%)	1,245 (49.1%)	*n.s.*
Gender N (%)				0.131
Male	1,665 (62.2%)	98 (70.0%)	1,567 (61.8%)	*n.s.*
Female	1,005 (37.5%)	42 (30.0%)	963 (38.0%)	*n.s.*
Other/ Unknown	7 (<1%)	-	7 (<1%)	*n.s.*
Race/Ethnicity N (%)				0.056
Non-Hispanic White	711 (26.6%)	27 (19.3%)	684 (27.0%)	*n.s.*
Black/African American	373 (13.9%)	23 (16.4%)	350 (13.8%)	*n.s.*
Asian	107 (4.0%)	5 (3.6%)	102 (4.0%)	*n.s.*
Latino	1,220 (45.6%)	77 (55.0%)	1,143 (45.1%)	*n.s.*
Other/ Unknown	266 (9.9%)	8 (5.7%)	258 (10.2%)	*n.s.*

Table XXVIII. Standardized Annual Estimates of Outpatient Service Use and Costs Among Kickstart Early Psychosis Program Versus Usual Care in San Diego County One and Two Years Following Initial Diagnosis of Psychosis

	EP		CG		Difference		P-Value
Year 1	Mean	SE	Mean	SE	Mean	SE	
Outpatient Visits	40.5	2.5	18.4	.5	22.2	2.6	<.001
Outpatient Costs	$9,595	$771	$4,321	$124	$5,274	$777	<.001
Year 2							
Outpatient Visits	29.8	2.8	11.7	.5	18.1	2.8	<.001
Outpatient Costs	$6,773	$698	$2,535	$113	$4,238	$712	<.001

Table XXIX. Standardized Annual Estimates of Inpatient Service Use and Costs Among Kickstart Early Psychosis Program Versus Usual Care in San Diego County in One and Two Years Following Initial Diagnosis of Psychosis

	EP	CG	Difference	P-Value

Year 1	Mean	SE	Mean	SE	Mean	SE	
Probability of Inpatient Use	.489	.045	.471	.010	.018	.046	.340
Inpatient Days	11.8	2.1	7.2	.39	4.5	2.2	.011
Year 2							
Probability of Inpatient Use	.254	.046	.156	.008	.098	.047	.014
Inpatient Days	5.8	1.9	3.4	.4	2.4	2.0	.115

3. Summary of the Qualitative Projects Conducted as Part of EPI-CAL to Solicit and Integrate Community Partner Feedback

3.1 Executive Summary

Implementing new approaches in routine healthcare delivery can be a challenging process. A key feature of successful implementation is rooted in the perception of the innovation amongst relevant community partners, including its perceived benefit, complexity, and compatibility with existing values and needs (Berwick, 2003). Additionally, the National Academy of Sciences recognizes that actively incorporating the perspectives of service users and family members is an integral feature of the learning health care paradigm (McGinnis, Stuckhardt, Saunders, & Smith, 2013). In recognition of this, alongside oversight from our Advisory Committee and extensive outreach with community partners, the project's qualitative efforts have represented a central feature to support the implementation and evaluation of EPI-CAL. In this report, we summarize the qualitative activities that have been completed to date in support of this aim.

The qualitative component of EPI-CAL comprised of two distinct phases: the first focused on soliciting input from service users, family members, providers, and county leadership to support the co-design of the EPI-CAL approach, and the second focused on engaging with community partners to understand provider and service user experiences of integrating EPI-CAL and the measurement-based care approach into early psychosis services. The primary aims of the interviews were to identify effective facilitators and solutions to barriers to improve project implementation, and evaluate the feasibility, acceptability, and impact of delivering early psychosis care within a learning health care environment.

During the design phase, focus groups held in English and Spanish were conducted to support a co-design approach to the development of the assessment battery, data sharing procedures, and the creation of the data collection and presentation application (Beehive). During the implementation and evaluation phase, provider and service user interviews were conducted to identify barriers and facilitators to effective implementation, with findings iteratively fed back to the implementation team to inform program delivery.

To date, 34 interviews and 40 focus groups including 284 providers, service users, and family members have been completed across 15 EP programs. In the outcomes focus groups functioning, quality of life, recovery, and symptoms of psychosis were identified as key domains to assess in EP care. Participants emphasized the clinical utility of predictors of outcomes, and the importance of concrete, client reported measures. In the focus groups concerning data sharing priorities, participants reported being receptive to data sharing, but exhibited concerns regarding third-party sharing, risk of breaches, and hidden motives in user legal agreements. Increased user-level control for data, and an understandable, transparent EULA was considered key to mitigating concerns. In focus groups supporting Beehive development, participants suggested adding program demographic visualizations, modifications to the registration process to reduce service user burden, and aesthetic changes to make the tool look less "clinical".

In the refining and evaluation stages of the project, interviews with EP program providers and service users identified numerous benefits to Beehive and the adoption of measurement-based care in early psychosis settings. However, substantial variability in both in the feasibility of implementation, and the perception of the benefits and drawbacks of adopting such an approach was found. These findings highlight the importance of exploring the barriers and facilitators to effective implementation to identify and potentially address some of the causes of this variability.

3.2 Introduction

During the design phase of EPI-CAL two distinct qualitative projects were conducted. The first included focus groups to explore community partner data collection priorities in early psychosis care with the intention of informing the development of the California EPI-CAL assessment battery. The second included focus groups with community partners to support the development of the application designed to collect and present the data collected as part of EPI-CAL participation, in addition to focus groups that to inform the development of an accessible end user licensing agreement (EULA) designed to support informed decision making around data sharing. In the implementation and evaluation phase of the project, qualitative interviews were conducted with EP program providers and service users to explore the acceptability, feasibility, and utility of the adopting measurement-based care practices in an EP program setting, in addition to exploring the barriers and facilitators to effective implementation. A summary of each three is presented below.

3.3 Exploring data collection priorities of early psychosis community partners in view to informing the development of the EPI-CAL assessment battery.

A major goal of this project period was to finalize outcomes to be collected for the duration of the project. While we identified candidate measures during the proposal phase of the project, we did not want to be prescriptive when it came to the data to be collected in the program evaluation component within the clinics. Instead, we wanted our stakeholders, including providers, staff, clients and families, to inform the selection of outcomes of interest.

Methods

Study Design

A focus group study was completed to explore stakeholder options on what data should be collected within the learning health care network, and how. The data collected was analyzed utilizing a mixed-methods design, incorporating both qualitative and quantitative methods. The findings of this investigation were used to inform the construction of the learning health care network core battery.

Participants

Eligible participants included providers, clients, and family members of clients who either deliver or receive care at one of the 13 EPI-CAL early psychosis care sites. The list of eligible programs is presented in Table XXX. For the Spanish speaking groups, participants were eligible to take part if they identified Spanish as their primary language and were sufficiently competent in written and conversational Spanish to participate in the focus groups. to ensure that the sample recruited best represents the stakeholders who deliver or receive care in the participating programs, no other inclusion/exclusion criteria were adopted. All procedures were approved by the UC Davis IRB (Protocol 1403828) and individual county boards, as necessary. Prior to each group, participants provided consent, or assent with parental consent.

Table XXX: Participating EPI-CAL Early Psychosis Program Sites

LHCN/EPINET	County/University	Program
LHCN/EPINET	Solano	Aldea SOAR
	Orange	OCREW
	Los Angeles	PIER-LA
	San Diego	KickStart
	Napa	Aldea SOAR
EPINET only	UCLA	Aftercare
	UCLA	CAPPS program
	UCSF	Path Program
	UCSD	CARE clinic
	Stanford	Inspire Clinic
	UC Davis	EDAPT
	Sacramento	SacEDAPT
	San Mateo	RE(AIM)/BEAM

to explore possible differences in data collection preferences and priorities by provider role, each provider participant was categorized by their role, determined via self-report. The list of possible categories providers could identify as are specified in Table XXXI. In cases where providers could meet criteria for multiple roles (i.e., a team lead who may also work as a clinician for the program), the providers were advised to select the role that best represents their primary function to the program.

Table XXXI: Provider Categories in the Focus Groups

Provider Role	Description
Clinicians	Licensed behavioral health clinicians that are directly involved in the delivery of clinical care.
Coordinators/Administrators	Provider that has non-clinical direct contact with clients and families
Medical Personnel	Includes prescribers, psychiatrists, and nurses – Individuals whose primary responsibility relates to the review and delivery of medication
Clinical Supervisor/Team Lead	Includes program directors, team leaders, and licensed clinicians whose primary role involves the supervision of other clinicians
Senior Leadership	Include senior clinic leadership, and county administrators – No direct delivery of client services
Other CSC providers	Includes Family Advocates, Peer Support Specialists, Case Managers, Recovery Coaches, and Supportive Employment and Education Specialists

Spanish Focus Group Methods

Our team sought to include Spanish speaking clients and families in the outcomes focus groups. Spanish is a threshold language in all participating LHCN counties. For the Spanish-speaking groups, all study documents were translated by a bilingual research team member, reviewed, back translated by UC Davis medical interpretive services, and approved by our IRB.

Procedures

The process for conducting the groups was completed across three discrete steps: the domain and scale selection process, the development of the focus group guides, and then the recruitment and delivery of the focus groups. The details for each step are specified below.

Domain and Scale Selection Process

The preliminary domains of interest were selected based on findings detailed in the summary report of the prior county engagement process undertaken to develop the statewide process (Niendam et al., 2018). As part of this process, six California Counties who had expressed an interest in participating in the statewide evaluation, along with their corresponding EP programs, were sent a consultation packet and interviewed by a member of the evaluation team. Each meeting was recorded using software embedded in the teleconference software (Zoom). As part of this interview, participants were asked the following question:

> “What are the questions you want answered from this evaluation? What are the key outcomes or impacts that you would like to show from your program to: clients/families, county/state, program staff, and community stakeholders? “

In the stakeholder meetings, county and program staff consistently emphasized the adoption of outcome measures designed to capture changes in client functioning and quality of life. Areas of particular interest highlighted by participants included homelessness and housing instability; clients' perception of wellness; the attainment of client goals; justice involvement, including convictions and recidivism; suicide, suicide prevention, and self-injurious behaviors; changes in aggressive and/or violent behaviors; changes in client distress; and changes in general functioning. These areas of priority were broadly consistent with the domains identified as being potentially associated with, or impacted by, participation in EP programming as part of the review process conducted in the MHSOAC Proposed Statewide Evaluation of EP programs report (Niendam et al., 2017). In this review, a preliminary list of eight outcome variables were identified: (1) healthcare utilization, (2) justice involvement, (3) homelessness, (4) education, (5) income and employment, (6) social and family relationships, (7) clinical disability, and (8) suicide. These lists were combined into the preliminary domain list for inclusion in the core battery, presented in Table XXXII.

Table XXXII: List of the Proposed Domains to Include in the Learning Health Care Network Data Collection Battery

Domains	Definitions Proposed
Clinical Status	Diagnosis, medication, date of onset, and remission status.
Psychiatric Symptoms	The presence of clinical symptoms (anxiety, depression, mania, hallucinations, paranoia, etc.).
Suicide Risk	The presence of thoughts, wish, plan, or behavior aiming to end one's life.
Service Satisfaction	How satisfied an individual is with the mental health services they receive.
Service Utilization	How often health services are used or received.
Quality of Life / Well-being	How satisfied an individual is with how they live their life (past, present, future).
Recovery	The individual's belief they can live a meaningful life, meet goals they consider important, and develop support to maintain wellness outside treatment.
Risk for Homelessness	History of homelessness or insecure/unstable housing (i.e., couch surfing) and things that increase the risk of homelessness (e.g., foster care, unsteady income).
Incarceration / Recidivism	Experience of arrest, probation, or parole.
Functioning (Social / Role)	An individual's ability, interest, and engagement in employment, volunteering, homemaking, and/or school; and their quantity, quality, and engagement in social relationships with friends.
Cognition	The individual's ability to solve problems, pay attention, process and remember information, or do things quickly.
Family Burden	The impact of a loved one's mental illness on the support person's life.
Family Functioning	How well a family communicates/functions how accepted members feel within the family, and reactions to family problems or successes.
Medication Side Effects	The presence, duration, and severity of medication side effects.

Medication Adherence	Taking medication the way the doctor prescribes (i.e., every day, time of day).

With a preliminary list of domains selected, the next stage was to identify a list of all possible measurement tools to collect data pertaining to each domain. The tools identified were primarily sourced from the PhenX Toolkit (https://www.phenxtoolkit.org/index.php). The PhenX toolkit is a list of non-proprietary data collection measures and protocols identified as being appropriate for biomedical research. The toolkit is divided by disease area, and measures for each area are selected by working groups chaired by domain experts. As part of this project, measures identified as appropriate for use with an early psychosis population by the Early Psychosis Working Group (Dixon et al., 2019) were considered as appropriate for inclusion. The list of scales considered appropriate are detailed in Table XXXIII. The PhenX Workgroup was not able to identify sufficiently low-burden, validated, and reliable measures assessing for outcomes related to risk for homelessness, and so items to measure this construct will be developed by the UC Davis evaluation team. Regarding other proposed domains not represented in the PhenX toolkit, it was proposed that data related to clinical status (i.e. diagnosis, remission status, etc.) could be collected by an adapted form survey used in the Mental Health Block Grant (MHBG) evaluation.

<u>Table XXXIII: Proposed Measures for each Outcome Domain</u>

Domain	Proposed Measure
Suicide Risk	Suicidal Behaviors Screening Questionnaire-Revised (SBQ-R) Columbia-Suicide Severity Rating Scale (C-SSRS)
Service Satisfaction	MHSIP Youth Services Survey (YSS)
Recovery	Recovery Self-Assessment (RSA) Questionnaire about the Process of Recovery (QPR)
Quality of Life/Well-Being	Lehman Quality of Life Scale Personal Well-being Index (PWI)
Incarceration/ Recidivism	The National Survey on Drug Use and Health (NSDUH)
Functioning	Global Functioning: Social and Role scales (GF-S and GF-R) UCD derived self-report option of social and role domains
Cognition	Penn *Computerized Neurocognitive Battery (CNB)* Matrix Reasoning Test (PMAT), Word Memory Test (PWMT), Digit Symbol Substitution Test (DSST)
Family Burden	Burden Assessment Scale (BAS)
Family Functioning	Systematic Clinical Outcome Routine Evaluation (SCORE-15) Expressed Emotion Scale: Family Communication (EES)
Clinical Status	MHBG Minimum Data Set version 7.3 – diagnosis, past/present psychosocial treatment, medications
Medication Side Effects	Glasgow Antipsychotic Side-effect Scale (GASS) Extrapyramidal Symptom Rating Scale (ESRS)
Medication Adherence	Brief Adherence Scale (BARS)
Psychiatric Symptoms	Modified Colorado Symptom Index (MCSI) Brief Psychiatric Rating Scale (BPRS)

Service Utilization: Psychiatric hospitalization	County hospitalization records Self-report of hospitalization
Service Utilization: Emergency or Crisis stabilization	County ED/crisis stabilization unit records Self-report of ED or crisis utilization
Service Utilization: Outpatient	Service unit records by outpatient program
Risk for Homelessness	Items to be developed by the UC Davis evaluation team.

Focus Group Guide Development

Following the completion of the preliminary list of domains and their corresponding measures, interview guides were developed by the qualitative evaluation team, and then reviewed by the broader evaluation team. To account for the different degree of background knowledge different stakeholders are likely to have regarding the project and its aims, different guides were developed for the provider, and for client and family member groups. To ensure consistency in the starting point for the discussions in regard to the terms used, a definition of terms sheet was developed for all focus group participants. For the Spanish-speaking groups, these documents were translated by a Spanish-Speaking member of the evaluation team (RB).

The interview guide was piloted in October at our first site visit in Solano County, and was updated incrementally based on the feedback and participant responses during each focus group.

Focus Group Recruitment and Delivery

Following the execution of the relevant county contracts and IRB approval by UC Davis and County review boards (where appropriate), the Project Manager (VT) contacted the EP program lead to arrange the project introductory meeting. Prior to the start of the project introductory meeting, all clinic providers were invited to take part in the focus group and survey portions of the research study. The meeting started with research staff going through the consent process. Following the completion of the consent process, all providers completed a series of surveys, and then participated in a 2-hour introductory session into the overall EPI-CAL project. At the end of the introductory session, providers were offered refreshments and a break, and then participated in the focus group. Each focus group took approximately 90 minutes. All focus groups only included participants from that respective EP program/county.

For the client and family groups, EPI-CAL EP program providers invited all clients currently receiving services at their program, and their families, to take part in the site focus group. All interested potential participants attended a brief presentation of the focus group study held by members of the evaluation team, hosted at their EP program clinical site. Following the presentation of the study, clients and family members were then invited to take part in the focus group, and following their agreement, were consented to take part. In most cases, the client and family groups were hosted outside of work hours to maximize attendance. During the groups, an EP provider from that clinic remained on site to provide support in case any possible risk issues emerged. For the client and family groups, the introduction, consent procedure and focus group all together took approximately 90 minutes.

Following the “shelter in place” state mandate for the COVID-19 pandemic, the onsite focus groups were switched to take place via remote, secure teleconference (Zoom).

After the purpose of the focus group was explained, participants were invited to review the 15 outcome domains under consideration, which were presented on a large poster. Definitions of each domain and copies of the PhenX measures under consideration were provided. Participants were asked to identify other domains for consideration (outside of the 15) and ask questions as needed. Additional domains were then added to the poster for focus group consideration. Next, participants were asked to select four outcome domains they felt were most important for demonstrating the impact of EP care, out of the list of 15 and any additions provided by participants, by placing stickers in their assigned color on a large poster. This activity sought to: 1) engage participants in the topic; 2) orient the subsequent qualitative discussion to four domains that the group as a whole considered to be most critical; and 3) provide quantitative data that could be examined in the context of the qualitative data. The group facilitator then identified the two to four domains with the highest number of participant votes for discussion. The facilitator and co-facilitator then solicited participants' opinions on these domains, their importance to EP care and client outcomes, as well as whether the proposed measures captured information that was relevant to the constructs of interest. Facilitators sought to obtain input from all group members, including contradictory opinions, and input on potential barriers and facilitators to measure implementation. Once all of the top four domains were discussed, the facilitators shifted to domains with lower ratings to solicit opinions on why some participants had voted for these domains, or why no votes were made for certain domains. At the end, all participants were asked to vote again for their top four domains with their colored stickers. Participants were then asked to report whether their votes changed and, if so, why.

Data Analysis

Analysis of the focus group data involves two components: 1) descriptive data for pre- and post-discussion rankings of relevant domains based on participant sticker voting and 2) a conventional content analysis of the de-identified recorded group discussions.

Quantitative data:

For the pre- and post-discussion ratings, participants' votes for the top four outcome domains were tallied within stakeholder groups and reported as a proportion of votes per domain. Heat maps were developed across all roles at the pre- and post- voting stage.

Qualitative data

Conventional content analysis is typically used to describe a phenomenon, namely community partner preferences for data collection in the LHCN battery (Hsieh & Shannon, 2005). The analysis followed an inductive approach. Five coders were involved in the preliminary coding of the transcripts. First, the coders reviewed the transcripts and developed a preliminary coding framework. This coding framework was developed by multiple researchers in a process of multiple coding (Barbour, 2001). All coders coded the same two transcripts separately using the coding framework, and then came together to review coding fidelity. After two transcripts, the team was deemed sufficiently concordant to code transcripts separately. All transcripts were coded either directly into Nvivo 12 (QSR International, 1999), or else was coded in Microsoft Word before being transferred into Nvivo.

After completing each transcript, the coder met with another member of the team to review responses to ensure consistency. For each transcript, the coder and reviewer dyad involved different researchers to minimize the risk of siloing amongst coders. In addition to these meetings, the coding team met on a weekly basis to resolve discrepancies and update the coding framework as necessary. Once all the transcripts were coded, one member of the research team collated the different coding files across the coding team and combined the analysis into a single Nvivo document. This preliminary coding framework was then analyzed primarily by one member of the coding team (MS) and reviewed both by the rest of the coding team, and the wider EPI-CAL research team.

In the quotes detailed in this deliverable, some were amended by the authors to anonymize responses, remove crosstalk, and to elucidate pronouns. In these instances, the edits were denoted though the use of square brackets ("[ ]").

Data Triangulation Process

Areas of agreement and convergence between the qualitative and quantitative data were then explored, drawing from the triangulation protocol proposed by (Farmer, Robinson, Elliott, & Eyles, 2006). Of particular interest were areas of agreement, partial agreement, silence, and dissonance that may exist across the different data forms.

Results

Focus Group and Participant Demographics

Twenty-two focus groups (20 in English, two in Spanish) were completed between 10/08/2019 and 8/31/2020, including 178 participants. Group and participant-level demographics are presented in Table XXXIV. Group sizes ranged from two to 18 participants.

Table XXXIV: Focus Group and Participant Demographics

Variable	n	%
Sites Included in Current Analysis (n = 10, n %)		
University	4	40.0%
Community	5	50.0%
Both	1	10.0%
Group Type (n = 22, n %)		
Provider	10	45.5%
Service-user	5	22.7%
Family member	7	31.8%
Group Format (n = 22, n%)		
In-person group	17	77.3%
Remote teleconference	5	22.7%
Participants (N = 178, n %)		
Provider	108	60.7%
Service-user	34	19.1%
Family member	36	20.2%
Provider Roles (n = 108, n %)		
Clinicians	37	34.3%
Administrators	13	12.0%
Prescribers	11	10.2%
Clinical supervisors / Team lead	25	23.1%
Senior leadership	4	3.7%
Other (SEES, Peers, Family advocates)	17	15.7%
Missing	1	0.9%

Proposed Additions and Amendments to the Domain List

Within the focus groups, participants proposed an additional 38 different domains to be considered for inclusion into the battery. Following a review of these different domains and their descriptions, many appeared to show considerable conceptual overlap, either with other new domains or existing ones. Therefore, in order to simplify the analysis and ensure that domains were not underrepresented in the data due to parsing, commonalities across all the new and original domains were explored by the five members of the coding team. Drawing from their involvement in the groups and their experience of coding the transcripts, the different domains were re-categorized into 21 distinct areas (see Table XXXV). These reconfigured domains represent the basis of all the subsequent analyses detailed below.

Table XXXV: Proposed Additions to the Battery, and how these were Incorporated into the Final List for Review.

Amendments/ Additions to the Battery	**Original and Proposed Titles**	**Notes**
About You	Demographics	
	Family History*	
	Legal System*	
	Clinical status	
Cognition	Cognition	
	Social Cognition*	
Family Functioning	Family Functioning	
	Family Satisfaction*	
Functioning	Functioning	
	Premorbid functioning*	
	Work Engagement*	
Impact of medication	Medication side effects (changes in health).	Previously medication side effects. Includes weight gain/impact on physical health as a consequence on medications
	Beliefs about medication*	
	Medication Satisfaction*	
Medication utilization	Medication Adherence	Previously medication adherence
	Access to Medication*	
Psychiatric Symptoms	Impulsivity*	
	Insight*	
	Distress associated with symptoms*	
	Questioning reality*	
	Motivation/confidence*	
	Optimism*	
	Mood*	
	Psychiatric Symptoms	

Quality of Life/ Wellbeing	Quality of Life-Wellbeing	
	Wellness	
Risk to self/others	Suicide Risk	Previously suicide risk
	Non-suicidal self-injury*	
	Homicidal ideation*	
Service Utilization	Service Utilization	
	Adherence to treatment components*	
Service Satisfaction	Service Satisfaction	
	Therapeutic Alliance*	
Access to Support Resources	Access to Social Resources*	
	Access/receipt of wider social supports/resources*	
	Accessing Social Service Supports (i.e. SSI, SSDI, Subsidized housing, etc.)*	
	Social communication*	
	Community integration/resources*	
	Access to Social Support*	
	Access to resources*	
Basic Needs	Activities of daily living*	Section includes sleep, nutrition, hygiene, basic functioning.
	Sleep*	
Independent Living Skills	Future Planning Skills*	
	Transition to independence*	
	Independent Living*	
	Transition Plan*	
Psychoeducation	Psychoeducation*	While they are different, in the qualitative data the concepts appear to overlap
	Acceptance*	
Trauma	Trauma*	If the distress discussed relates predominantly to symptoms, as opposed to trauma or experiences, then this will be included within the psychiatric symptoms section.
	Distress associated with experiences*	
Barriers to Care	Newly proposed domains to be kept as separate*	
Culture		
Mortality		
Stigma		

Substance Use	

Key: *New domains proposed (i.e., still under consideration), either during the voting stage or during the focus group discussion.

Domain Titles/Areas

In addition to a number of domains either being added or expanded, focus group participants suggested amendments to the original titles proposed. These include suggestions to amend Family Burden, Clinical Status, Medication Adherence, and Medication Side Effects.

Family Burden

While some participants felt that the term ‘burden’ was appropriate, in most cases participants expressed a strong dislike of the term. This displeasure was evident across family, client, and provider groups. Some participants did not like it due to concerns that clients and family members may not understand the term, but the main reason cited for it to be changed was that it was considered to be pejorative, and in some cases offensive.

Participant: *“…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.

However, in a few cases participants felt the term was appropriate because it was the most accurate assessment of the situation.

Supervisor: *“But if the measurement is only burden, I would not advocate for just putting lipstick on a pig, so to speak. If what we're talking about is burden then I would be real.”*

Provider Group, ID: 122

Family impact, family stress, and family experiences were all proposed as alternatives to family burden. While all were considered an improvement on ‘burden’, some participants did not like ‘stress’ due to it also having negative connotations. In most cases, the term ‘family impact’ was preferred, with a number of participants stating a preference on the basis of it being a neutral term. Additionally, in one case there were concerns that the term ‘stress’ may lead to additional challenges in how it may be interpreted across cultures. Consequently, the domain ‘Family Burden’ has been redefined as ‘Family Impact’ both in the current deliverable, and for use in the Learning Health Care Network.

Clinician: *“I think stress is more neutral, where burden has more of a negative impact.*

Supervisor 1: *So, what about just impact? Because stress also makes that assumption that it’s stressful, and I mean, I would imagine it is, but nevertheless just something more neutral.”*

Supervisor 2: *I also like impact, because I just feel like with a lot of families, they might not be as willing to acknowledge, like "Oh it's not that stressful, but I did have to rearrange my job." So impact is a more non-judgmental way to capture how their lives have changed about it, versus how they're perceiving.*

Interviewer 1: *I'm going to write that on here.*

Supervisor 3: *Plus, I think there will be a language consideration for the translation of that terminology, and also cultural piece, that I think we want to be really sensitive to."*

Provider Group, ID: 710.

Medication Adherence

In three focus groups (two provider, one client) some concerns were raised with the domain title 'Medication Adherence'. In the client group, there was some confusion with regards to what the term meant, while in the two provider groups, one was concerned that the focus was too much on medication as opposed to treatment as a whole, while in the other there were concerns that the term was loaded and not sufficiently recovery-oriented. In the latter group, the terms 'utilization' and 'engagement' were offered as more neutral alternatives, with the group eventually coming to a consensus around the term 'utilization'. In response to this, the term 'medication utilization' has been adopted both in this deliverable, and in the overall project going forwards.

Prescriber: ***"****And lastly, just the word adherence can be loaded and not recovery oriented and since we went through kind of changing names and thinking about other names, I just want to throw that out there*.

Interviewer 1: *What word would you prefer?*

Prescriber: *I mean, I would just strike it, altogether. I'm not sure, because I understand what it's meant to capture, but it's something that we as providers have used for so long, but it suggests that, is the person following my directions. You know?*

Other: *We're supposed to embrace that.*

Sr. Leadership: *So could utilization or engagement…?*

Prescriber: *Yeah, utilization could be good, engagement. Either way."*

Provider Group, ID: 122

Medication Side-Effects

In one provider group, there was some concern that using the term 'medication side-effects' may actively mislead some clients in reporting their experiences due to the challenge of attributing cause. In particular, one provider highlighted that they typically obtained more pertinent client information when they asked about changes in health, where the potential source of the experience isn't included in the definition. Additionally, both providers and family members expressed a preference for a wider discussion around side effects, including information regarding medication satisfaction, costs versus benefits of medication, and an assessment of beliefs around medication. In response to these comments, the term medication side effects was changed to "Impact of Medication" in order to incorporate the broader area of interest. Furthermore, in the client-facing measures incorporated into the battery, the medication side effects subheading has been changed to 'changes in health'.

Clinician 1: *"Often times at least what I've seen with patients is that, a lot of times what they'll bring up like as medication side effects or when they'll mention medication side effects. They'll report it more as like either symptoms or just [inaudible 00:20:39] things like that. And so it's not necessarily something that's reported as a medication side effect. So I think that's something might be better captured under* *just changes in health or things like that.*

Clinician 2: *That's a good point, you. Yeah, that is true. People don't always talk about it the way we think about it*."

Provider Group, ID: 904

Interviewer: **"***What are you looking for?*

Prescriber: *Medication satisfaction. Something that I look for is, do you feel like yourself and are the side-effects worth the results that you're seeing? So while there may be presence of side-effects, is what is happening for you worth it? So again, benefits versus risks or benefits versus side-effects and just the satisfaction of the entire experience of taking medications."*

Provider Group, ID: 122

Suicide Risk

While no group identified an issue with the term 'suicide risk' during a review of the domains, some providers and family members emphasized the importance of other, related constructs such as non-suicidal self-injury (NSSI), risk to others, and mortality. While there was some discussion regarding where it may be most appropriate to house these different constructs (i.e. psychiatric symptoms, suicide risk), more participants appeared to discuss it within the context of risk, and risk of suicide. As a result, these were combined into one domain along with suicide risk, and was defined as 'risk to self and others'. The exception to this was mortality, where this was categorized as a distinct domain given it would not be possible to collect via self-report, and so would need to be sourced via a different method to the others.

Speaker 4: *"Do you see a question about self-harm? Yeah, right there. It's 13.*

Interviewer: *13? Okay, good.*

Speaker 4: *I'm like it's got to be there. It's got to be there somewhere."*

Family Group, ID: 303.

Clinician: *"A quick thought about the prior one, is homicide risk encompassed on psychiatric symptoms, or is that? For safety concerns.*

Interviewer 1: *I don't think so. Is that another important one that you?*

Clinician: *Yeah.*

Interviewer 1: *Okay, so let's create it.*

Supervisor: *Or even like just aggressive intent.*

Clinician: *Yeah.*

Supervisor: *Maybe not homicidal but…*

Clinician: *Yeah, more broadly, as safety.*

Supervisor: *That's a good point, yeah."*

Provider Group, ID: 710

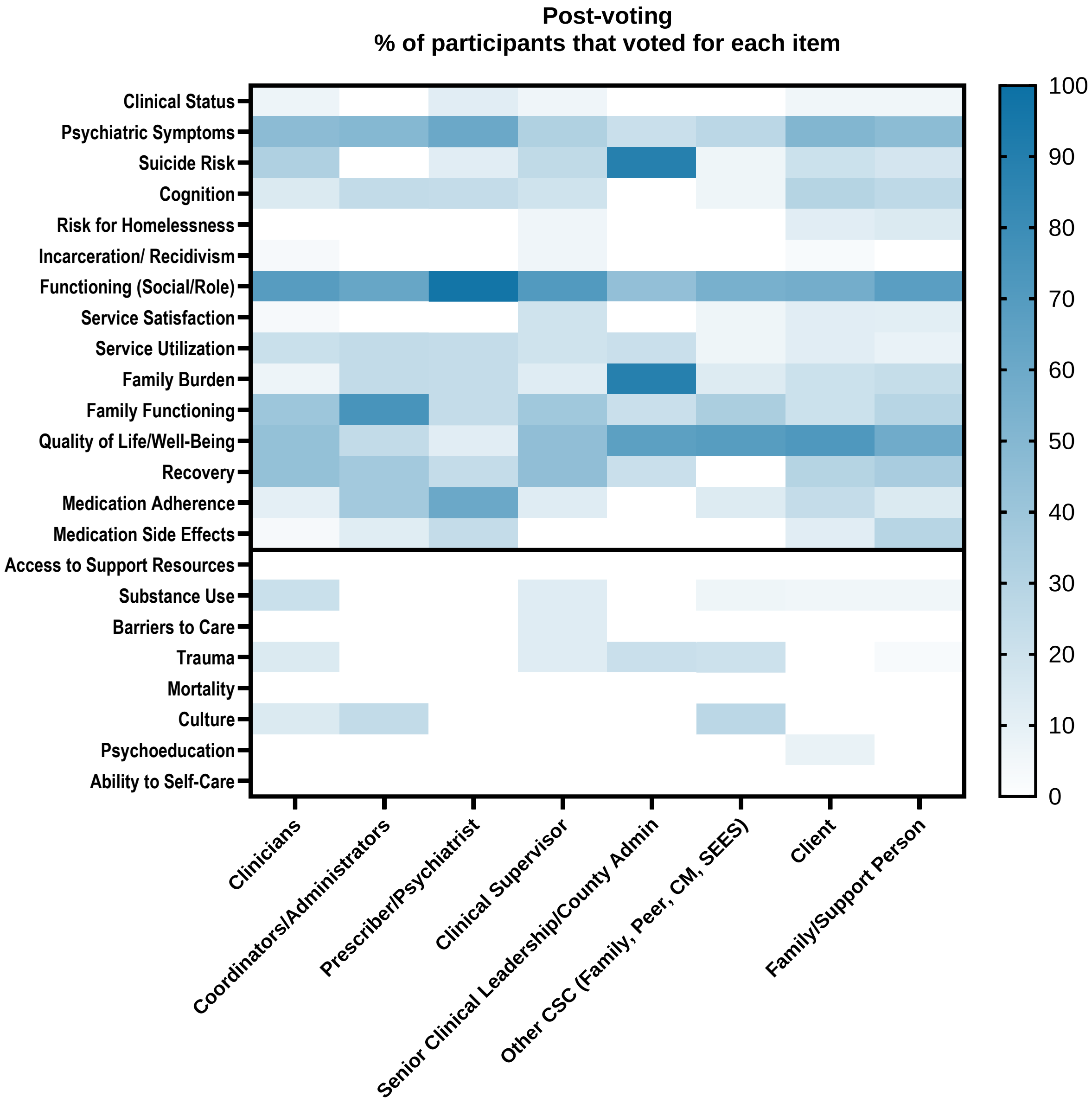
Incarceration/Recidivism
During the reviews of the domain titles, no changes to ‘incarceration/recidivism’ were proposed. However, during the discussions, some participants suggested that this domain is too narrow, given incarceration in this particular client group is relatively rare, and proposed expanding this domain to include contact with law enforcement. However, while this was considered to be useful, there were some concerns that this may be complicated by police involvement in emergency mental health admissions. To mitigate this, the proposal is to still expand and redefine it as ‘law enforcement contacts’ but add the caveat that police involvement during a mental health crisis assessment not be included in data.

> Interviewer 2: *“So, do you think we should expand incarceration residents to law enforcement contacts? Would that be more useful?*
>
> Clinician: *Perhaps.*
>
> Prescriber: *No, because then you don't know what is actually illegal versus a 5150 because they are actively psychotic. I think that muddies the waters a lot.*
>
> Interviewer 2: *Right. So, you think it needs to be more detailed.*
>
> Clinician: *I think it's helpful to find out if they're having contact with the police, though*.”

Provider Group, ID: 825

Quantitative Findings from the Voting
Participant voting patterns post-discussion are presented in Figure 23. Functioning was identified as the most important domain. Other domains with a high proportion of votes included quality of life, recovery, family functioning, and psychiatric symptoms. Clinical status, homelessness risk, incarceration/recidivism, service satisfaction, and impact of medication received the fewest votes. Trauma, substance use, and details regarding culture were proposed for inclusion. Some variability by role was evident. Prescribers prioritized psychiatric symptoms, functioning, and medication utilization. Senior leadership considered risk to self and others and family impact as most important. Peers, family advocates, and supported employment and education specialists prioritized recovery. Family members and service-users were more likely to prioritize homelessness risk and the impact of medication, relative to most provider groups.:

Figure 23: Post-discussion Voting Priorities by Role



Note: Darker squares indicate a higher proportion of time each domain was selected as one of the four most important by participants. The bottom eight rows in the figure represent domains not originally included in the proposed battery, but suggested by participants

Qualitative Findings

Reflections on the proposed battery

Most participants liked the original list of domains. However, some were concerned with conceptual overlap, particularly around recovery, quality of life, and functioning. Some suggested additions to the battery include ability for self-care, barriers to care, trauma, and substance use. Thoughts regarding these specific domains are detailed below.

> Interviewer: *“Are there any areas that you guys think are particularly important that aren't up here? Something you think is important to you? Again, that sort of shows how you are doing, good or bad or-*
>
> Speaker 10: *That, for me, pretty much covers it. I just wanna like tell the story of those things.*
>
> Interviewer 1: *You want to tell the story of it? So when you look up here, you see the things that you think represent you getting better?*
>
> Speaker 10: *Yeah.”*
>
> Client Group, ID:303

> Interviewer: *“Do you think there's anything that's really important that we've missed or do you think that really covers the stuff that's important to you?*
>
> Speaker 1: *I don't think anything was missed, in my opinion.*
>
> Interviewer: *You're good? Okay. You're good as well?*
>
> Speaker 7: *Yeah.*
>
> Interviewer: *You're thinking anything?*
>
> Speaker 4: *I'm just kind of going over it and it looks like it’s pretty good.”*
>
> Family Group, ID:303

> Sr. Leadership: *“And I think that's why I did not actually choose that particular one, because I couldn't really see quality of life and functioning being completely fully independent of one another.”*
>
> Provider Group, ID:840

Non-Domain Specific Reflections

While most reflections on data collection pertained to specific domains, some comments represented broader reflections that related to the data collection process more generally. These different reflections were represented across three distinct themes: 1) how the data should be collected, 2) the challenge of data collection and interpretation in an early psychosis clinic setting, and 3) the importance of the data in clinical practice. A brief summary of these three themes are presented below.

How the data should be collected

One frequent topic of discussion across most groups was the challenges and opportunities of utilizing predominantly client-rated measures, as opposed to clinician administered scales. In a number of groups, participants were concerned about the accuracy of data collected via self-report. Some of the concerns shared included: 1) a believe that clients would answer questionnaires in the manner to which they think they should respond, 2) that clients may want to minimize the symptoms they are experiencing, 3) that clients may forget or may struggle to remember all events and experiences, and 4) that clients may experience a lack of insight to their symptoms, all of which may skew their responses. In most cases, it was thought that self-report would lead to significant under-reporting, and this concern was particularly acute in cases where clients are experiencing more severe symptoms. However, some participants thought that utilizing client-report could be more recovery-oriented and empowering for the client, and that – in some cases – families and providers suggested that the client might respond more honestly via self-report, as opposed to verbal report in a session (particularly in regards to medication adherence, and risk of suicide). Overall, there was a recognition that self-report scales may be the only feasible option in this context.

To mitigate some of the inherent issues of utilizing self-report with an early psychosis population, participants suggested that having providers review client responses and indicate if the responses are consistent with their clinical interactions with the client would be helpful, particularly in regard to medication adherence and psychiatric symptoms. In addition, some participants emphasized the importance of collateral information, particularly around domains that relate to behaviors as opposed to client experiences. Finally, some clinics reported that they already systematically collect clinician-administered data, and they suggested that there should be an option to include it into the data collection system.

Speaker 23: *“I have the same problem, but my daughter is more like “everything's fine.” It's just even if she had symptoms last night, she'll wake up “everything's fine.” She just wants everything to be fine so that would be skewed on a self-report because she'd just be like I just want to get out of here. So it becomes kind of flawed in that way, so yeah. Definitely taking inventory of what the parent is saying, or the caregiver, and what the therapist is seeing as well.”*

Family Group, ID: 840.

Speaker 19: “*I would say that when my daughter's symptoms are bad she can't remember.*

Interviewer 2: *Okay.*

Speaker 19: *She'll tell me something, and then I'll bring it up and she's like “that never happened.” But it did happen*.

Interviewer 2: *Interesting.*

Speaker 19: *So if she was going to self-report, she may not report accurately.*

Interviewer 2: *So do you think in that case talking with her clinician that she has care with would be easier to prompt her to remember?*

Speaker 19: *Yeah.”*

Family Group, ID: 840

Supervisor 2: “*…the data are clear that both psychiatrist over-estimate how much their patients are taking their meds, and some patients are willing to say something on self-reports that they won’t tell their psychiatrist.*

Clinician 1: *Yeah.*

Supervisor 1: *Right, yeah, that’s right.”*

Provider Group, ID: 904

In addition to discussions around who should provide the data for each domain, focus group participants discussed at length the nature of the data that should be collected. In particular, discussions centered on whether it was preferable for the questions posed to responders to be concrete and objective (i.e. yes/no questions regarding current employment, or if they had met a friend in the past week) or if more subjective Likert-style questions (i.e. graded satisfaction with friendships) would be preferable. These discussions then went on to explore whether responses to these items should be available singularly, or if they should be combined into summary scores (i.e. global functioning scores, or the answers to the questions that led to the determination of the functioning rating). While these questions focused predominantly on functioning, these issues were also discussed with respect to other domains such as medication utilization and substance use.

Generally, participants appeared to support the use of concrete, objective items, where possible. The main reasons cited included greater clinical utility, greater challenges in interpreting subjective rating scales, and in some cases client participants reported finding Likert-style questions tiresome. However, in a minority of cases, there was some concern that objective questions could be more impacted by memory recall issues, particularly around frequency of experiences.

Clinician 1: “*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.*

Interviewer 1: *Okay, but it sounds more about the “use” than the “impact,” when there's various scales that talk about how impactful the substance use can be. It sounds like for you guys, it's more about the quantity and what it is, and how often it is, and when it is.*

Clinician 2: *Because I think that mediates outcomes, right?*”

Provider Group, ID: 476

Speaker 5: *“I know that when I was filling out… questions like these, it was really hard for me to remember or pinpoint exactly how much it happens, so maybe instead of* *saying, "Exactly once during the month," maybe like, "About one to two times a month," or maybe about something to something, like a range. Because it's very hard to remember exactly when you're experiencing what when you have all this stuff going on in your head.”*

Client Group, ID: 840

With regards to whether the singular item responses of summary scores should be available, there appeared to be a preference for concrete granular information, but a number of participants also appeared to appreciate summary scores of particular domains. Some participants thought summary scores were considered to be more easily digestible, while others suggested they had clinical utility (particularly when reviewed over time). However, others thought that more granular, concrete measures had greater clinical utility, and more impactful when reviewing progress on a clinic level. In addition, in one group providers suggested that concrete metrics may be a particularly important for the Latinx families they work with. In order to accommodate these different perspectives, some participants suggested that collecting and presenting both types of data would be a positive step forwards.

Speaker 6: “*I feel like the scale is really good for getting a general idea, but in order to personalize care you need to ask-- I can’t think of the right word, but like targeted questions to the person. You know, like, "Are you in school?” How's work?" kind of thing.*

Interviewer 1: *You feel like those are much more specific to-*

Speaker 6: *Yeah, specific is what I want.”*

Client Group, ID: 122

Clinician: “*I was going to say, I think he just said it. That word concrete. 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 in treatment recovery if that makes sense.”*

Provider Group, ID: 476

Interviewer: “*Have you used the global functioning scale clinically? Is it useful when you use it clinically, or is it really more detail like that that's actually useful?*

Clinician: “*I think it's useful. It's useful on a patient basis, but as an overall clinic-wide, if you want to say, "Okay, there are so many who were –" I don't know. Four-year University, and then now they're going to a community college. I think –*

Prescriber: *They used to live independently and now they live at home.*

Clinician: *Yeah. I think that that's where the other granular one would be more useful.”*

Provider Group, ID: 825

Client 10: "*I think you should do a scale and questions. You can easily write, 'On a scale of one through 10, how functioning are you throughout? Well, I feel like an eight point five or something like that.' Then you can say questions, 'Are you attending school, are you working, blah, blah, blah, other questions.' I think both.*"

Client Group, ID: 122

The challenge of data collection and interpretation in an early psychosis clinic setting

Participants identified a number of challenges to systematically collecting data across early psychosis program settings. For example, a number of participants suggested that clients would either find the language or the concepts challenging to comprehend, particularly in cases where the clients were young or had comorbid developmental disorders such as autism. This is despite all the scales being validated for use in this population as part of the PhenX review (Dixon et al., 2019). Another concern identified by clients and providers was the potential burden of the scales, particularly in the context of what is typically a very extensive intake assessment process. Furthermore, concerns surrounding how one's culture can impact one's interpretation and response to a scale were also identified as important issues to consider. Some clients talked about how asking detailed personal questions in the early stages may impact the accuracy of the responses either due to guardedness, or severe negative symptoms. Linked to this, others thought that the issue of impaired insight may be particularly acute in the baseline assessment. Finally, provider participants based primarily in University programs expressed concern about the consistency of clinician-administered ratings across clinics, and the challenges of maintaining a consistent inter-rater reliability in a clinical context.

Supervisor: "*Things like wellbeing, and quality of life, and even recovery. With our younger clients, a lot of teens have no idea what you're talking about when you ask about their wellbeing.*"

Provider Group, ID: 710

Clinician: "*When we're doing the SIPS, we've already done a phone screen, which takes about 30 minutes. Then, by the time we meet them, that's two hours. So, we've already done a two hour interview. That's just to get them screened into our program. Then we're supposed to kind of do this. To me it just seems, if we're talking about feasibility, it doesn't seem very feasible from a clinical standpoint.*"

Provider Group, ID: 303

Supervisor: "*Depending on your ethnicity, background, race, whatever, that can definitely impact and adjust your perception of what's going on, can impact whether you want to come into the office or not, whether you want to take a vacation or not, all that stuff.*"

Provider Group, ID: 303

Speaker 10: *“I recall 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, that they can help you and to hear your argument.”*

Client Group, ID: 122

Clinical utility of the data

When client, family, and provider participants discussed the clinical utility of the data collected, two themes were consistently raised across domains and scales. The first related to the importance of collecting data that serves as moderators and predictors of outcomes, in addition to the primary outcomes of interest themselves. This concept was consistently reported across almost all the groups, and despite the initial framing of the focus groups centering on what outcomes were most important to collect. In particular, some providers identified the clinical of collecting *modifiable* predictors of outcomes, identifying this information as helpful to improving client outcomes. This emphasis on moderators and predictors resulting a shift from asking what “outcomes” participants are most important, to what “domains” are critical, which lead to a further emphasis on moderators and predictors of outcome. The second important feature of the data related to the ability to be able to track changes in the data collected over time. Clients, family members, and providers considered this a useful tool to highlight any areas of progress that clients may have experienced during the course of treatment.

Clinician 3: “*I do think, from the consumer's perspective, how they feel like their symptoms are improving is a different and important measure.*

Clinician 1: *Right. Imagine thinking, and then they're like "Oh, how do symptoms change with this treatment run?” “We don't know. We actually didn’t measure it.”*

Provider Group, ID: 476

Clinician 1: ***“****You know how I prioritize things is when I looked at this list? I thought to myself, okay, why do patients keep coming to our clinic? Because they feel satisfied with what we're giving them. If they feel satisfied with what we're giving them, they're more likely to listen to us and take our recommendations. If they do that, they're more likely to do all the things that are going to lead to better functioning and then they're more likely to have better service utilization. And if they do that, then their functioning and their social role is going to improve and be better. And then family ties in there. So that's how I picked my four.”*

Provider Group, ID: 904

Reflections specific to Each Domain – Originally Proposed Domains

Psychiatric Symptoms

The definition of psychiatric symptoms presented to the group for the purposes of starting the discussion was as follows: “The presence of clinical symptoms (anxiety, depression, mania, hallucinations, paranoia, etc.).” The measurement tools presented to the group included the Modified Colorado Symptom Index (MCSI), and the Brief Psychiatric Rating Scale (BPRS).

In review of what symptoms participants wanted to be collected, most emphasized the importance of collecting a broad array of symptoms, as opposed to focusing on the core symptoms of psychosis, such as hallucinations and delusions. In particular, participants identified the importance of measuring impulsivity, insight, mood, motivation, and social anxiety, recognizing these as having a major impact on the early psychosis population.

Interviewer 1: *“Are these the kind of things that you're thinking about symptoms, or are you thinking mostly about symptoms of psychosis? So hallucinations and delusions. When you say symptoms, what are you thinking of? Everything?*

Speaker 3: *Yeah, everything.”*

Client Group, ID: 274

Supervisor: “*I mean, there's so many things: hit by loneliness, which is a huge issue in our population, as well as things like the last questions about aggressive intent, and suicide homicide and plus the symptoms and anxiety. And you know, just a broad swoop.”*

Provider Group, ID: 710

Psychiatric symptoms were considered to be important to measure for a number of reasons. For example, a number of participants identified the clinical utility of measuring psychiatric symptoms, suggesting that doing so could facilitate therapeutic conversations in the session. On a broader level, some clinicians and senior management thought measuring psychiatric symptoms was important from the perspective of evaluating the effectiveness of the clinic, and of early psychosis care statewide.

Interviewer: *“So, things like depression, anxiety, delusions, hallucinations, that kind of stuff. So why did people choose this one as an important one for us to look at?*

Speaker 7: *Because it's like a part on giving a glimpse on what their psychiatric disorder may be. “Have you often felt depressed, and then lonely?” You start pairing these together and it can show you just, "Okay, this person is in depression, let's look at this and talk to them about this."*

Family Group, ID: 303

Clinician: *“And I guess I looked at it as leadership overall. The clinic, how is the clinic working? Are the patients satisfied? What is the re-hospitalization rate? The symptoms and then the functioning as being part of the recovery of the patient overall, you know?”*

Provider Group, ID: 825

Prescriber: “*If I know, in California, psychiatric symptoms tend to improve in a coordinated specially care clinic, and correspond to these particular… that would be actually useful to me.”*

Provider Group, ID: 476

Measuring psychiatric symptoms was considered to be particularly important to some prescribers, given the focus on symptoms during their consultations with clients. Prescribers suggested that this additional information could aid their clinical activities. However, some prescribers did report some concerns regarding the accuracy of the reports, and consequently the utility of the data from a clinical perspective, with difficulties around insight being of particular concern.

Interviewer 1: *“So, as a prescriber, why the psychiatric symptoms will be particularly useful for you to measure?*

Prescriber: *That's mostly what I'm talking about with the session is what I'm working around. I think that will help in all of the other goals as well.”*

Provider Group, ID: 476

Interviewer: *“As the prescribers, would this be helpful to inform that decision, or are you so worried about insight you don't think it'll be that useful?*

Prescriber 1: *I think it's not going to be accurate. At least the one specifically related to the psychotic symptoms.*

Clinician: *I think it's just we see a spectrum of patients. I mean, some patients, it might be accurate. I don't know, I mean-*

Prescriber 1: *Who are not actively psychotic?*

Prescriber 2: *I mean, let’s pretend like we’re not getting… What would be helpful to us?”*

Provider Group, ID: 825

Aside from concerns around the accuracy of the data attributable to insight, only a minority of participants did not psychiatric symptoms to be important. In both cases, this was because providers considered other domains such as functioning and recovery as a higher priority. One provider reported that measuring symptoms was less of a priority to them given it is information they can easily get from the client during the session, and at a later point during the same focus group other providers were concerned that an over-emphasis on symptoms may invalidate client experiences.

Clinician 1: “*I can ask about psychiatric symptoms any time I want to in a session, but I like being able to see the trajectory of someone's family functioning, general social and role functioning for— I was the one person who put incarceration and in cognition. Seeing that tracked over time with them just filling out a tablet is more impactful to me, because I can get at everything else I need to whenever I decide I want to.”*

Provider Group, ID: 476

Clinician 2: *“See, I worry sometimes that we're too symptom- the impact of being too* *symptom heavy in our questions on assessments that people may feel invalidated as being just have-ers of symptoms.*

Interviewer 1: *So that's the other side, because I guess this leads to these areas, and if the focus is on this, then it's less about the actual impact of them. Is that your concern, or—*

Other: *Yup, because 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."*

Provider Group, ID: 476

With regards to psychiatric symptom measurement, the majority of participants considered the MCSI to be the most appropriate tool to use. When asked, clients suggested that the questions posed in the tool were representative of their psychotic experiences and responses to the MCSI questions would be able to reflect the improvements they experienced during the course of treatment. Additionally, many family members, clients, and providers liked the fact that the tool was self-report. In some cases, participants thoughts that utilizing self-report would lead to additional and more accurate information than a clinical interview, where particular experiences may be less likely to be disclosed. Others thought that utilizing self-report tools would be more empowering for their clients.

Speaker 20: *"My child rarely talks with their clinician, ever. But would be more apt to fill out the checklist.*

Interviewer 2: *So in that way do you think the Colorado would be better?*

Speaker 20: *I would think so, for my child, yes."*

Family Group, ID: 840

While participants were generally favorable towards the MSCI, approval for the tool was not universal. The most common issue stated was a concern surrounding the accuracy of self-reporting symptoms, particularly in clients where lack of insight was an issue. These concerns led the providers of one clinic to suggest that the tool would have limited clinical utility. In order to mitigate these issues, some participants suggested having providers review the scores after being completed, and then indicating whether the symptoms reported are broadly consistent with the presentation exhibited during treatment. Regarding other issues, one clinic was critical of the wording of some items, suggesting that they conflated different constructs impacting the tools clinical use. Furthermore, in one client group, one participant expressed difficulty in accurately reporting the frequency of experiences, particularly when symptoms were more severe. In groups where the MSCI was not favored, it was proposed that existing tools clinics already use to determine symptom severity (i.e. the Structured Interview for Prodromal Syndromes, SIPS) be added as an optional template on a by-clinic basis.

Clinician: *"I think just having a clinician be able to say "Yeah, I think this is mostly accurate." Or "This seems like they're under reporting" whatever the case may be, I liked that check on whether or not someone was being as forthcoming, or had the insight to accurately rate this, so that you know how accurate the data is.*

Interviewer 1: *Right. I guess that requires you as a clinician as to then review the responses. Is that realistic? Or is that- I guess if you're using the data, you need to be reviewing it anyway.*

Clinician: *We already do. Yeah*.

Interviewer 1: *Okay.*

Clinician: *So that's why I didn't think it would add burden, at least to us. We already use this, and already review it, and say yay or nay."*

Provider Group, ID: 476

Clinician: "*I think the questions are kind of loaded with verbiage that isn't specific to the rating. Like number seven, there's several reasons that you could have difficulty concentrating, and they give examples, but those are two totally different examples. So, I think it would just be very hard to get a real sense of what's going on with this, so I echo what [clinician] said*."

Provider Group, ID: 303

Family Functioning

The definition of family functioning presented to the group for the purposes of starting the discussion was: "How well a family communicates/functions, how accepted members feel within the family, and reactions to family problems or successes". The measurement tools presented to the group included the Systematic Clinical Outcome Routine Evaluation (SCORE-15), and the Expressed Emotion Scale: Family Communication (EES).

During the focus group, family functioning appeared to be conceptualized in a broader fashion than how it was provisionally defined, incorporating three distinct, but interconnected components. These included: 1) the importance of the family dynamic, 2) the mental health literacy of the family, and 3) the level of support that family members provide the client in their engagement and progression through treatment. All three were considered to play an important part in the ongoing wellbeing of the client, their engagement in the clinic and its different treatment components, and in the clients' path to recovery. For some clients, the lack of mental health literacy was identified as being a particular issue in Latinx families, leading to an increase in isolation and exacerbation of symptoms.

Speaker 6: *"I'm really close to my family. They kind of help me think logically through certain things when I'm personally not being very logical when I'm making decisions. They help me kind of take a second look at what I'm doing, and kind of give me perspective. They're support means a lot to me so if I'm on bad terms with any of my family members, it affects my wellbeing and my quality of life because I really value my relationship with them and how they perceive me."*

Client Group, ID: 122

Interviewer: "*When you guys were voting for family impact, what sort of things were you thinking of? Like for how you guys impact your family and how your family impacts you, what does it mean to you?*

Speaker 3: *To me it, it made me think about the cultural part of it. Because in my Mexican culture, they don't really talk about mental health. So that was a really big impact on my symptoms.*

Interviewer 1: *Can you say more about that? What made that impactful to you?*

Speaker 3: *Well just cause like they never really understood a lot of psychiatric or mental health, just because they don't know how to talk about it. Because to them, they just thought that you were able to control it yourself. They didn't really understand more of the chemistry behind it. Yeah.*

Interviewer 1: *And so when that came up in your family, what sort of impact did that have on you as a person when you were having experiences that they didn't understand?*

Speaker 3: *Well for me it made me feel more alone just because no one in my family really understood where I was coming from because they just kept telling me, just change your mind process. But I literally couldn't."*

Client Group, ID: 303

Administrator: *"I would say 90% of the time the people that call to start their treatment is a family member. So that's the first person that is reaching out for help. So that's why I think the most important is to have that foundation of somebody like, "Okay, this does it. Let's go. Come on." So, I think that's why that's another important thing because it's rare when I get a call that is for a potential patient [crosstalk 00:36:29]*

Supervisor: *That's what I'd say. How the family contributes to the treatment is absolutely critical."*

Provider Group, ID: 904

Participants identified two main reasons as to why they thought it important to measure family functioning. Providers talked about how the data could materially impact the quality of care that they would be able to deliver to clients and their families, while clients, families, and providers all identified good family functioning as crucial to supporting recovery. While most participants considered collecting this data to be important due to its impact on other outcomes, in some cases measuring family functioning was considered to be important as an outcome in and of itself.

Clinician: *"Part of what we often offer here, is brief sessions with families. So whenever we feel like that would be helpful, we try to offer that for participants. So I think a measure like this would help us know what we can touch on, what we can help them with, in those brief sessions, and also as she was saying, inform later care, so inform other treatment or if family therapy can be helpful, this can really help us know that."*

Provider Group, ID: 710

Speaker 12: *"Family functioning is a very important thing because of the fact that if you don't have a functioning family, then it's going to be very difficult to have a functioning life sometimes."*

Client Group, ID: 840

Clinician: *"I just think in terms of the first one [the EES], it would be really interesting to see six months down the road after psycho-education and MFG and family therapy, if any of those have moved at all. I think that would be fascinating."*

Provider Group, ID: 840

With regards to the two proposed measures, participant feedback was mixed. Neither the EES nor the SCORE-15 appeared to receive consistent strong support. However, of the two, participants appeared to be less critical of the SCORE-15, and in direct comparison of the measures, most participants expressed a clear preference for the SCORE-15. Regarding the EES, one client thought that the wording of the questions might be particularly problematic to some cultures, suggesting that some of the terms used may be considered offensive. Both measures focus on the family dynamic component of family functioning, and so to address all areas considered important by participants, such as mental health literacy and family support of treatment, additional questions may be necessary.

Sister: "*Yes. The main thing, it's like offending if you're from a different culture. So, asking a mother this kind of question [the EES] is really offended. That's why. Or like, you're basically cornering her, that's how they take it and that's why we don't agree with some of this questions. I understand yours. But ours from a different culture.*

Mother: *Right."*

Family Group, ID: 476

Speaker 4: "*For the scales, I like the one on page 36 [the SCORE-15] better than the one on page 35 [the SEES].*

Interviewer 1: *Okay. Is there any reason why?*

Speaker 4: *Yeah, the one on page 35 just used a lot of negative words, like neglect, irritates, criticize, but the one on page 36 was kind of like a mix, half, half."*

Client Group, ID: 122

Family Impact (previously Family Burden)

The definition of family burden presented to the group for the purposes of starting the discussion was: "The impact of a loved one's mental illness on the support person's life." The measurement tool presented to the group was the Burden Assessment Scale (BAS, Reinhard et al., 1994). As previously described, many participants expressed a dislike for the term "family burden," and so during the groups and thereafter was replaced with "family impact."

In defining family impact, one issue highlighted by participants – family members and family advocates in particular – was whether the domain should focus primarily on the emotional impact of the mental illness, or if this should be conceptualized more broadly to incorporate financial, vocational, and social impact. While many family members highlighted the emotional impact of dealing with a loved-ones mental illness, vocational and social impact was also considered important, and there were concerns that by not incorporating these features then this would provide an incomplete picture of the challenges that families face. One family advocate suggested that the importance of financial impact was a particular concern for lower socioeconomic status (SES) families.

Speaker 7: *“I didn't realize with helping her with mental health, mine was going to... the more I helped her, the worst mine was going to get.”*

Family Group, ID: 303

Speaker 4: *“I mean I literally quit my job to stay home. I couldn't do it forever, but I literally had to choose between go to work or quit my job so I could take care of my kid.”*

Family Group, ID: 303

Interviewer: “*In terms of what we're thinking of and what we're wanting to measure, is it more the emotional impact or burden that the family experiences, or is it the financial, the time impact? What is most important? Are they both important? What would you want this domain to capture?*

Other: *I think actually it really depends on the family. We have some families that are very, very poor and so the financial impact surfaces very quickly and other families who are quite well off too so it's not really a financial burden as an emotional burden. So, it kind of depends on their own socioeconomic status.”*

Provider Group, ID: 122

Participants identified a number of reasons why it was important to include an assessment of family impact. In some family member groups, it was emphasized that family impact was distinct from family functioning, and therefore in order to get the full picture of the family situation it was necessary to collect both pieces of information. In these groups, participants described that, while their family appeared to function at a high level, the impact of the illness on the family was a significant and important issue that might otherwise be missed. Additionally, some provider and family groups suggested that measuring family functioning had clinical utility in terms of identifying areas of need, predicting clients’ recovery trajectories, and in evaluating the impact of interventions designed to reduce family stress. Linked to this, some family members and providers suggested that measuring family impact was important to facilitate help for at-need family members, leading to additional help either being provided within the program, or via a referral to outside services. Finally, in one group family impact was considered important to measure in order to quantify the degree of need that their families may have, which in turn could support the argument that a family therapist should be recruited into the program.

Speaker 8: *“That's just what I was getting at some of these things just how difficult it is. I mean we have, family functioning is totally fine, at least for us, we really know, there's no fighting, there's no, just everyone gets along pretty well. But there's* *some features of the illness that just add this additional burden. It takes more work than you might imagine to get through the day sometimes.*

Interviewer 1: *So family burden, family functioning are very different concepts. They can occur in good family functioning they can occur in families where there is a lot of that feeling of that burden, the tanks are running dry.*

Speaker 8: *Yeah, that's kind of where I feel like I land sometimes.*

Interviewer 1: *Yeah we had some acknowledgement. From a lot of the folks who really agreed with you.*

Speaker 7: *Absolutely."*

Family Group, ID: 122

Clinician: *"I will say that our programs doesn't offer family therapy as one of its compliments and so when there's an identified need we usually have to refer to an outside therapist, because a lot of our families are working, they don't sense that they have time for more therapy in addition to our program. So, if I were to have this as part of our overall assessment, I'd be constantly going back to them saying, well it says here that you're very burdened or stressed, have you followed up on the referral that I sent you? Well, why not? Well, not covered by insurance, too far, I have no time. So, I can see why we'd find use in this. Second time, what would we do with it, unless we could make a case saying, families have a lot of stress, see? And we need more money to hire a family therapist for our team."*

Provider Group, ID: 122

While the BAS was presented as the primary measure of family impact, in a number of groups the Expressed Emotion Scale: Family Communication (EES) was also considered an appropriate measure of emotional impact, and so was included in the discussion at the discretion of the participants. Broadly speaking, family member participants appeared to relate to a lot of the content of both scales. However, there was some concern that both scales, and the EES in particular, was too focused on the negative aspects of the relationship. For participants, questions such as item 4 "he/she irritates me", and item 12 "he/she sometimes gets on my nerves" evoked a strong negative reaction. In addition, there was a suggestion that these questions may be considered even more problematic in some cultures, with one participant stating that this would be viewed as offensive to their Latinx parents. Finally, to ensure candid responses, one family member participant highlighted the importance of being given the space to complete the scale away from the client.

Mother 4: *"I do like these questions [the EES]. I do feel like they were very helpful."*

Family Group, ID: 467

Interviewer: *"What we really want to do is when we hear those stories, we want to make sure we understand how that's impacting you. So we need to use the right scales to make sure that we're getting it.*

Speaker 1: *This one's [the BAS] covered it pretty well, I think."*

Family Group, ID: 303

Mother 1: “*This would be a form that if you want my true answers, I have to be alone to fill this out because, you know, she's sitting right next to me, there's no way that I'm going to say that "I often think of what's going to become of her." You know? I'm always going to be like, “nope, never because I have 100% faith in you”. But if I'm alone, it's "very often." So these - because these are very strongly weighted, you know this is if you want the true answers for someone like me, you need to let us fill this out without them there.”*

Family Group, ID: 467

Law Enforcement Contacts (previously Incarceration/Recidivism)

The definition of incarceration/recidivism presented to the group for the purposes of starting the discussion was: “Experience of arrest, probation, or parole”. The measurement tool presented to the group to for this domain was The National Survey on Drug Use and Health (NSDUH) 2014 Questionnaire (*National Survey on Drug Use and Health, 2014* 2016)

During both the pre- and post-discussion voting exercises, incarceration/recidivism received very few votes from participants, regardless of their role. However, when it was discussed, it was consistently identified as an important, even “scary” possible outcome. When this was highlighted, most participants acknowledged that while incarceration and recidivism is a significant issue in serious mental illness, providers reported that only a small proportion of their early psychosis clients have been incarcerated. This led to suggestions that the metric may not be as relevant to a population comprising primarily of transition-aged youths experiencing a first-episode of psychosis, relative to older individuals experiencing chronic psychosis.

To make it more relevant to this population, some participants suggested that questions related to risk for incarceration may be more appropriate. In particular this may relate to contact with the justice system. However, some providers and client did identify that this is complicated by police officers being frequently involved in their transition to inpatient care, and so it was suggested that for this data to be meaningful these contacts may need to be removed or separated in the data.

Speaker 11: “*I see incarceration on there, so that's scary. So, I feel like to counter that thought of incarceration that we'll instill skills that will avoid incarceration.”*

Family Group, ID: 840

Interviewer 4: *“How about incarceration and recidivism?*

Clinician: *Also because we have young adults to teens -*

Supervisor 1: *We have very few teens who have been in the juvenile justice system, and whose case workers or family members will contact us to consult. But it's a really small number*.

Supervisor 2: *I think it's another issue, so not to say - that's not a big issue just in terms of who we're working with.”*

Provider Group, ID: 710

Clinician 1: “*We don't tend to have too many homeless people because they usually don't come to us or stay in the program. They kind of disappear or stop, they just disappear. But we do have some kids and young adults that are at the risk of homelessness or more specifically more probably pertinently at risk of instability.*

Prescriber: *So, hospitalization or incarceration - that would be more of a risk.”*

Provider Group, ID: 274

Interviewer 2: “*So, do you think we should expand incarceration/recidivism to law enforcement contacts? Would that be more useful?*

Clinician: *Perhaps.*

Prescriber: *No, because then you don't know what is actually illegal versus a 5150 because they are actively psychotic. I think that muddies the waters a lot.*

Interviewer 2**:** *Right. So, you think it needs to be more detailed?*

Clinician: *I think it's helpful to find out if they're having contact with the police, though”.*

Provider Group, ID: 825

Cognition

The definition of cognition presented to the group for the purposes of starting the discussion was: “The individual’s ability to solve problems, pay attention, process and remember information, or do things quickly”. The proposal to measure cognition included the Matrix Reasoning Test (PMAT), the Word Memory Test (PWMT), and the Digit Symbol Substitution Test (DSST) from the PENN Computerized Neurocognitive Battery (CBI).

Participants from client, family, and provider groups all identified cognition as an important domain to be included in the battery. When asked why, in almost every case, participants identified the significant impact cognition has on social and role functioning. In particular, provider participants highlighted the importance of capturing data related to social cognition, identifying it as an area where their clients frequently exhibit deficits. Other providers highlighted the clinical utility of being able to track changes in cognition over time.

Speaker 3: *“Cognition is a value highly emphasized by society, that people expect you to be able to solve problems and think quickly. It's necessary for almost every job that you need to have and then also necessary for school as well.”*

Client Group, ID: 467

Supervisor: *“I would say it's because first of all, it's a domain that's separate from the symptoms. So I'd want to measure it separately, it’s not as commonly measured, but it's so related to everything other than cognitive symptoms. And if you can* *change cognition, we know it generalizes into functional changes and it's just, I mean, we could get into this key- is it mediating variable intervening variable or is it an ultimate outcome? I would say it might be an intervening variable in that way because functioning would be the ultimate outcome."*

Provider Group, ID: 904

Supervisor: *"In the Penn battery is there a social cognition measure?*

Interviewer 1: *From what I understand, no-*

Supervisor: *I didn't think so.*

Interviewer 1: *-So it would have to be then aside something else put in, and that's come up at other-*

Clinician: *Yeah because, if you think about functioning right and overall doing well, a lot of times our folks really struggle with that piece. I mean, we do, there's not one day that I'm not doing social skills training."*

Provider Group, ID: 904

Of the original three cognitive tests proposed, all three received support from providers who had experience using them. One provider suggested that the DSST is most critical because it is the best correlate of other neurocognitive measures. However, other providers identified the lack of any measures for social cognition as problematic. The main reasons cited included the fact that social cognition is typically less correlated to other neurocognitive domains, meaning the test can provide additional information. Additionally, social cognition is a critical component for social functioning, which was the most commonly cited reason for cognition being considered an important data point to capture. In both provider groups where the lack of a social cognition was identified as a concern, it was suggested that an emotional recognition task would be the most appropriate addition to the battery. One such example proposed was the Emotional Recognition – 40 (ER 40), which was expected to add 5-10 minutes to the battery. If this was too long, one participant suggested that this replace measure of IQ, the matrix reasoning test, due to the fact that the measure would not be able to capture premorbid IQ.

Supervisor 2: *"digit-processing speed is the single best correlate of all other neurocognitive measures. So I – definitely - if you only could do one, neurocognition, I'd do processing speed."*

Provider Group, ID: 904

Clinician 1: *"I'm trying to think of any that are computer or tablet friendly to make us be able to all be on a tablet. The ER 40 would add five to 10 minutes to the battery*

Interviewer 1: *Okay.*

Clinician 2: *It's a little bit of social cognition.*

Clinician 1: *Yeah, just to get it— I'm thinking of being able to then marry that with social and role functioning scales, as well as QoL, family burden, all those things."*

Provider Group, ID: 467

Medication Utilization (previously Medication Adherence)

The main reason that medication utilization was considered an important data point to capture related to the fact that it is one of the strongest predictors of relapse. Consequently, this data is useful both in terms of its clinical utility, and in terms of predicting future outcomes. Across provider roles, data regarding medication utilization was considered to be particularly useful for program prescribers, given the focus on medication in daily clinical work.

Supervisor: *"Well, when it comes to medication adherence, it's the single best predictor of relapse. Patients that stay on their medication don't tend to relapse. Those that go off tend to relapse."*

Provider Group, ID: 904

Prescriber: *"As a prescriber, I still worry about side effects and adherence, and that's what I focus on during my visits but I don't consider those the big picture things we're worried about with the patient."*

Provider Group, ID: 825

The most appropriate method in which to assess medication utilization was explored in depth during one provider focus group. In this group, there was a consensus amongst the participants that in the absence of a pill-count or monthly plasma tests, the BARS would be an appropriate tool to use. While the scale was originally developed as a clinician-administered tool, the participants thought that the scale could be completed via self-report with minimal adaptations. The modifications suggested included removing the note that describe "poor" vs. "good" adherence, and for question 3, rather than presenting a 4-point Likert scale indicating percentage adherence, have a drop-down list with days listed from 1-31. It was thought that indicating adherence by percentage only would lead to client over-estimation. Furthermore, the group suggested that the scale have an additional item where providers could review the response, and confirm/deny if the degree of utilization reported by the client is consistent with their clinical opinion. Finally, it was suggested that the scale have an additional question that asks the client if they are considering stopping taking their medication, which was considered to be an important piece of information that could be used to inform their clients' care.

Supervisor 2: *"It [the BARS] wouldn't take that long. I think you could adapt this.*

Interviewer 1: *Which of these questions might you ask the client? Maybe if you prioritize, maybe one or two of the questions.*

Supervisor 1: *Oh, number two.*

Clinician: *Either two or three.*

Supervisor 1: *Either two or three.*

Clinician: *Three is good too.*

Supervisor 1: *Yeah. No, this seems simple enough.”*

Provider Group, ID: 904

Clinician 1: *“Then what we do is, it says, how much do you agree with what your client's saying? So, then there's that added- I think that's a cool thing to do, to add but obviously not on the self-report, but have that as a separate. Because that guy is right that psychiatrists tend to overestimate. We often figure out before they do that somebody is not compliant.”*

Provider Group, ID: 904

Interviewer: *“…you think medication adherence would be a good one to do, perhaps, […] just a very quick condition check “yeah this is consistent with my experiences”, or not?*

Clinician 1: *Yeah*.

Supervisor 2: *Yeah.*

Clinician 2: *Also, the question like, “Are you thinking to stop medication? Yes or no?”*

Supervisor 1: *Are you thinking about stopping your medication?*

Clinician 2: *Are you thinking to stop-*

Supervisor 1: *Yeah that’s a good.*

Clinician 1: *Are you speaking from some experience?*

Interviewer 1: *Is that a question you would want flagged on the system even?*

Clinician 2: *Yes.”*

Provider Group, ID: 904

Medication Impact (previously Medication Side Effects)

The definition of medication side effects presented to the group for the purposes of starting the discussion was: “The presence, duration, and severity of medication side effects”. The measurement tools presented to the group included the Glasgow Antipsychotic Side-Effect Scale (GASS; Waddell & Taylor, 2008), and the Extrapyramidal Symptom Rating Scale (ESRS, Chouinard & Margolsese, 2005).

During one family member group in particular, multiple participants talked powerfully about the highly detrimental impact that antipsychotic medication has had on the lives on their loved one. However, others in the group talked about the importance of viewing these side effects alongside any positive changes that may have occurred, emphasizing the importance of talking about both sides with the aim to utilize this data to optimize client care. These thoughts were consistent with the reflections of a prescriber from one of the provider groups, who suggested that medication satisfaction and reviewing both the positive and negative aspects of taking antipsychotic medication together was a more useful construct to guide care decision-making.

> Mother: *"Yes. Medication or not the medication is the big question. Even coming into the clinic, I myself was on the team of "I don't want you on the pharmaceuticals, we don't need to you be on the pharmaceuticals. There's so many negative…", again, like you say, side effects that, you know, they increase. That sometimes even the side effects - and what the pills for increases what it's for.*"
>
> Family Group, ID: 467

> Sister: "*More of a fear for us is the side effects, because they take a great toll on - not just them physically, but mentally, and not just them but their surroundings. So, that's what's been a huge worry from our side of the fence, is will it help, or will it just dig a bigger hole?"*
>
> Family Group, ID: 467

> Father: "*Medication side effect we know already, but what about the positive side? Because I see in my son, for example, when we came here was really bad; after he takes the medication […] the positive side is I see a lot. […] Without that medication, it's very hard to see anybody with that mental suffering. Because any kind of sickness, any kind of medication, they are side effects.*"
>
> Family Group, ID: 467

A review of the side-effect scales was completed in one client focus group. When asked, the clients stated a preference for the self-report GASS scale over the clinician administered ESRS. There was a consensus that the items in the GASS detailed side-effects that were consistent with their experiences, and that when they stopped their medication the stated side-effects diminished, suggesting that, based on their experiences, the scale may be sensitive to change.

> Interviewer 1: *Did you experience side effects then when you were on medication?*
>
> Speaker 2: *I experienced side effects*.
>
> Interviewer 1: *Okay. And were these [items in the GASS] the kind of symptoms that you were having?*
>
> Speaker 2: *The sleepiness during the day, the zombie part. Tense muscles. And restless legs.*
>
> Interviewer 1: *So it sounds like lots of side effects.*
>
> Speaker 2: *And vision, blurry vision as well.*
>
> Interviewer 1: *Okay. So it sounds like it's tapping into a lot of the stuff that you were*

experiencing.

Speaker 2: *A lot of the side effects from when I was on medication, yeah.”*

Client Group, ID: 274

Interviewer: *“Okay. So this [the GASS] applied more when you were feeling very ill. And as you-*

Speaker 6: *It applied to me when I was on the medication, because I feel like it gave me those side effects-*

Interviewer 1: *Right.*

Speaker 6: *But now that I'm not on them, I feel okay.*

Interviewer 1: *Okay.*

Speaker 6: *Like, the side effects, ‘Cause before I was on them I didn't feel like that.*

Client Group, ID: 274

Risk for Homelessness (Housing Instability/Insecurity)

The definition of risk for homelessness presented to the group for the purposes of starting the discussion was: “History of homelessness or insecure/unstable housing (i.e., couch surfing) and things that increase the risk of homelessness (e.g., foster care, unsteady income)”. PhenX does not recommend a tool to measure this particular domain, and no appropriate tool was found following a search of the literature. Therefore, items for measuring this construct are currently in development by the evaluation team, in consultation with homelessness experts.

When risk for homelessness was highlighted during provider focus groups, most participants suggested that this was not highly prevalent in either their clinics, or in this particular population due to their young age. However, it was noted that homelessness may become a significant concern later on in the clients’ lives.

Interviewer 1: *“So, is homelessness something that is particularly important to this clinic, do you think? Is that something that you're often tracking for risk factors of or do you have any clients that are homeless?*

Other: *Actually no, not really. In particular because of their very young age. So, they may have a risk for it at a later date, but not while we're seeing them so much. Most of them live at home with their parents.”*

Provider Group, ID: 122

Speaker: “*A lot of people didn't vote for that, but those of us that have older children - my daughter has left this - it becomes more of an issue is what happens to them after we're not on the planet. How are they going to function afterward? So that looms large in the minds of a lot of parents I've talked to.”*

Family Group, ID: 122

Interestingly, it was notable that in some clinics the initial reaction to the question was that this was not a significant issue, however, later clarifications identified multiple existing clients that are either homeless, or at risk of homelessness. This suggests that the issue of homelessness or risk of homelessness may be more prevalent than initially considered by providers. One possible explanation for this dissonance was articulated by one provider participant, noting that the presentation of homelessness for TAY youths in an early psychosis clinic may look very different than the homelessness that people typically encounter on the streets, and so as a result the issue is either hidden, or not seen as relevant.

> Prescriber 1: *"Seems like we worry about risk for homelessness with a few people, but not that many.*
>
> Clinician: *Most of our patients, our patients are insured. So, some means they're -- so typically, unless it's a patient who's just refusing all treatment and family saying "you're out unless you –"*
>
> Prescriber 2: *We've had some students who live in cars.*
>
> Clinician: *That's true. In vans. We have had that."*
>
> Provider Group, ID: 825

> Sr. Leadership: *"What it looks like for chronic severely mentally ill adult, it may look like being on the street, being completely outdoors. For TAY, it may be couch surfing. So, like one day at somebody else's house, right? So it's exactly the same thing, just with two different faces."*
>
> Provider Group, ID: 122

When participants were asked why they considered homelessness and risk for homelessness to be an important domain to measure, some client participants considered it an outcome that has the potential to be hugely impactful on their ability to recover and have a positive quality of life. Provider participants talked about the impact of seeing homelessness in their neighborhood, and in particular the high degree of homeless individuals that appear to exhibit symptoms of psychosis. One senior leadership participant stated that this was an important metric for the county, and so additional data related to this domain would help with reporting requirements.

> Speaker 2: "Because obviously if you're homeless, you won't be able to recover, right?"
>
> Client Group, ID: 274

> Supervisor 1: *So again, for me, it was more of another element that we're asked to report on. And so that just felt like "obviously I want to look at suicide risk and homelessness"."*
>
> Provider Group, ID: 274

In considering what factors may be important to measure in this domain, participants proposed two main areas for consideration. These included the importance of a steady income, including the ability to navigate the system during periods of employment, and the degree of stability in the home. Both were considered to be important factors that could potentially lead to homelessness in the early psychosis clinic population.

Mother: *“But as far their risk for homelessness, just the steady income, on that behalf - during relapses and things like that. When somebody has employment - but of course loses it too - but doesn't quite qualify for disability. I guess, how to navigate maybe around that and get them - I don't know -geared at that and how to problem solve that. That's the big issue.”*

Family Group, ID: 467

Clinician: *“I guess what I look for - well not a lot, but every so often - is that instability with family members, that leads to the potential of being kicked out or running away or absconding. So that part is pertinent to [our clinic].*

Interviewer 2: *Anyone able to expand?*

Clinician: *Yeah, or just maybe the participant was causing too much stress in the home: acting out, throwing things, parents not having the skills to be able to redirect or and that resulting in leaving, starts to leave. Just a state of instability which, you know: symptoms up, stress up, sleep down, not taking medications.”*

Provider Group, ID: 274

Risk to Self and Others (previously Suicide Risk)

The definition of suicide risk presented to the group for the purposes of starting the discussion was: “The presence of thoughts, wish, plan, or behavior aiming to end one’s life”. The measurement tools presented to the group included the Suicidal Behaviors Screening Questionnaire-Revised (SBQ-R, Osman et al., 2001), and the Columbia-Suicide Severity Rating Scale (C-SSRS, Posner et al., 2011). During the discussion, participants expressed a preference for this particular domain to be extended to include non-serious self-injury (NSSI), and homicidal ideation. Consequently, this was re-defined as “risk to self and others”.

Amongst client participants, the presence or absence of suicidal ideation was considered to be a good indicator of how well or badly they were doing in that present moment. Providers suggested that measuring suicidal ideation is an important metric due to the seriousness of the outcome, and the prevalence of suicidal ideation in the population. In addition, some providers suggested that being able to track these experiences over time would have strong clinical utility. From the perspective of senior providers, participants identified suicide risk as an important reporting metric, and so for this data to be more systematically collected would be highly beneficial. In one clinic that had previously experienced multiple client deaths by suicide in the past year, providers talked passionately about the importance of this information to guide clinical care and potentially minimize the risk of further suicide events in the future.

> Interviewer 1: “*So it sounds like you, you were saying that during those times that you were feeling badly, or if things were hard, that was when you started to have those thoughts and consider those behaviors.*
>
> Speaker 2: *Mm-hmm [affirmative], yeah. I would just go mentally insane. I wouldn't be myself for a moment.”*
>
> Client Group, ID: 303

> Clinician: “*Safety concerns are always something we always pay very close attention to and then do a great in depth assessing and do the safety plan if we need to. Unfortunately, we do see it quite a bit in our population, so I would always sort of welcome any measure.”*
>
> Provider Group, ID: 710

> Supervisor: *“So, I thought it was important, because from my end when I have to report certain numbers, this is a big topic. There’s huge initiatives that are always asking “how are your programs treating this? How are you capturing it?” And we don't, because we usually rely on clinician feedback. We don't have a really good way to say, “Well, they came at this level, and this is how the program is affecting them positively to reduce suicide risk”.”*
>
> Provider Group, ID: 274

> Clinician: *“Even if that loss of hope is there for 1% of the time, I want to know about that 1% of the time. “How dark is that for you, and where do you go that 1% of the time in the middle of the night?” Because that's when I'm worried, and I want to make sure at those moments you can channel what you're looking forward to, and who you care about in your family in those relationships.”*
>
> Provider Group, ID: 825

In a review of the proposed measures, most participants suggested that while the Columbia is a comprehensive and useful clinical tool, the measure was not feasible for this context due to its length and complexity. In addition, some participants suggested that having the suicide risk measure be self-report, as opposed to a clinician administered measure, may lead to a greater likelihood that clients would disclose suicidal ideation. However, this was not universal, with some providers reporting concern that some clients may be wary of writing down suicidal thoughts, in fear of providers’ obligation to respond to risk factors of suicidal ideation. Moreover, clinicians were worried about missing non-verbal cues from clients that aren’t reported in self-report assessments. Overall, there appeared to be a trend towards incorporating the SBQ-R into the measurement battery, with the idea that clinicians would be able to follow this up in more depth in the event of any positive endorsements. Some suggested that in these situations, incorporating the Columbia into the assessment as the second step in a two-step procedure may be appropriate.

Clinician 5: *“Specifically I find that people are more likely to disclose that when they're completing it themselves, and then you have that concrete information already to follow up with.*

Interviewer 1: *Okay, so from your perspective, it sounds like it's a lot less information, but there's almost an additional clinical utility to having it as a self-report as opposed to a more in depth one.*

Clinician 5: *Absolutely. Mm-hmm (affirmative).*

Clinician 2: *I agree with that. All of that.”*

Provider Group, ID: 467

Supervisor: *“A lot of our teams and young adults know very well if they get their questions and inform consent, we talk about how we may need to disclose and so, I feel a little bit more comfortable, and we can navigate those issues a little bit better by interview. You can see them, you can read their body language.”*

Provider Group, ID: 710

Clinician 3: *“I love the Columbia too, but I feel that for this specific purpose, this [the SBQ-R] is more direct and simple. It might be more effective, but Columbia is something that we can do one on one in our office with them instead of a whole bunch of questions.*

Clinician 1: *I wouldn't even be opposed to a hybrid, like something like this, like the brief questionnaire and maybe the first two questions to the Columbia where if they answer yes, then we just do the Columbia separately.”*

Provider Group, ID: 840

Functioning

The definition of functioning presented to the group for the purposes of starting the discussion was: “An individual’s ability, interest, and engagement in employment, volunteering, homemaking, and/or school; and their quantity, quality, and engagement in social relationships with friends.” The measurement tools presented to the group included the Global Functioning: Social and Role scales (Cornblatt et al., 2007), and an unpublished UCD derived self-report option of social and role domains.

Functioning was the most frequently voted-for domain both at pre- and post-discussion phases, and represented a significant proportion of discussion in a number of the focus groups. Consistent with the literature, almost all participants emphasized the importance of measuring role and social functioning as separate constructs.

Regarding social functioning, multiple participants from client and family groups emphasized the importance of the quality of the social contacts they may have, as opposed to the frequency. Some clients talked about having more friends and social contacts prior to treatment, but described these friendships as poorer in quality, and being an impediment to their recovery. This issue was considered to be particularly important in clients who reported having a substance use disorder history. In defining quality, participants emphasized the ability to trust and confide in that person, their ability to add value to your life through things such as shared interests and hobbies, and their ability to facilitate and not impede recovery. Additionally, some participants thought that both close and casual acquaintances should be recorded, but separately, as both were considered to add value to one's life and be indicative of social functioning. Finally, while the responses from family member and provider participants were somewhat mixed, most clients considered online friendships an important component of the social group which should be incorporated into the assessment.

Speaker: *"I think you should change the question of how many friends do you have? Because I don't think that really matters how many.*

Interviewer 1: *Tell me why.*

Speaker: *It's like quality over quantity.*

Interviewer 1: *Okay. How might you capture that quality?*

Speaker: *Like how many close friends sounds good."*

Client Group, ID: 467

Speaker: *"Because I didn't really have my family support, I kind of went to go find a different type of support, like in a bad way. So that's when I started using drugs as well because those people really accepted me and were like, we're going to help you. This stuff is going to help you. So because I didn't have my family, I felt like these other people were my family because they were giving me things that I thought were making me feel better, but in reality they were really not making me feel better."*

Client Group, ID: 303

Interviewer 1: *"So when we think about social functioning, what bits should we really be thinking about? Is it the number of friends? Or is the quality of friends? Or both?*

Speaker: *Yeah. Like, how, well, it used to matter the number of friends I have. But I think it matters more if they're like trustworthy, and like they're worth being in your life."*

Client Group, ID: 274

Speaker 4: "*I would say close friend, and then you'd be looking for indications of recency and frequency and in-person, or even talking on the phone.*

Speaker 7: *Mm-hmm (affirmative).*

Speaker 4: *And then, acquaintances would be less frequent, texting. You can feel a sense of community with people that- I mean, I have a friend who decided she was going to quit drinking at the age of 40-something, and she found an online community that helped her immensely. So I don't want to discount -although it's not my experience- having really close relationships that you just develop virtually. I wouldn't discount that, but then you get in to the trust thing. Have you confided in them? I think it's a really important question about friends."*

Family Group, ID: 122

Regarding role functioning, some providers suggested that it is important to capture the degree to which they engage in work or school separately from how they are able to function in these particular roles. In addition, other providers emphasized the importance of asking about both volunteering and homemaking tasks separately from work and school, as this can otherwise go unrecorded, which is an issue given these activities can be relatively common in the age range and presentation of the clients served.

Other: ***“****I think there's enough research showing that participants name work and school engagement as important goals for themselves. That work and school is often listed as their top recovery goal, especially for our age range. So I think work and school should be its own category.”*

Provider Group, ID 122

Clinician: ***“‘****Cause you know, we'll say things like, “okay, so you know, just going to check in with you about work or school”. And then I explain what we mean by work at home and then volunteering and things. And so then we find out like, we didn't know this -that’s my favorite- “well, we can't afford a babysitter. So my parents pay me to pick up my sister from school and babysit for four hours until they get home for dinner. And then my job is, you know, like stuff.” We wouldn't know if, we didn't- Yeah.”*

Provider Group, ID: 904

Many participants articulated the clinical utility of measuring functioning. Improvements in functioning was frequently identified as the primary goal of both families and clients that receive early psychosis care. In the context of clinical care delivery, some providers suggested that being able to present changes in functioning over time to clients would be very useful. Additionally, some providers suggested that being able to report changes in functioning on a clinic level could be very useful both to meet external reporting requirements, and to be used as a justification to continue funding for the programs.

Speaker 8: “*Ultimately, one could say that the goal is to function in the world again. A lot of times you lose functioning -just kind of add to what you're saying- and you lose functioning and it's kind of a test. If you can function in the world then you have successfully recovered, or you have successfully treated your illness.”*

Client Group, ID: 467

Clinician 2: *“When we talk with the clients and the families about the clients functioning, it's really focused on like that progress, right? And it's- it does create a strength-based approach for the family as well, because our families have a difficult time, kind of like seeing progress when they lost their child. And so being able to look at their child who is currently sick, and seeing progress overall is very hard for them because they keep comparing back to before they were sick. They were* *doing all of this and now they're not. And so that gives not only the client but the family as well kind of an idea of what the progress is, for that specific client.*

Clinician 1: *It's also a tangible thing.*

Clinician 1: *When we look back at our participants and we talk to parents, if they've been here 6 months or a year, and we talk about where they've come in their recovery, it's very you know, in the air. But if we had something tangible [to] show, "you went from here to here, and that might not be where you want to be, but it's not where we were". And it's a very visual thing that families can help you understand better than us being like remember when it wasn't as good, 6 months ago? Yeah, so that would be helpful."*

Provider Group, ID: 274

Clinician: *"I think it would also speak in part of using this data then to justify services. I mean, you're working specifically on social and role functioning, right? That is an outcome that's important to you. I think that might… I can see that having more weight than the more hope, or teaching beliefs."*

Provider Group, ID: 467

While assessing functioning was seen as critical to most participants, some articulated concerns about perceiving functioning as the most important outcome. Other domains, such as quality of life and recovery were thought to be more subjective, and therefore a bigger priority. Some participants went on to articulate concerns that functional changes may represent societal expectations, as opposed to the treatment goals and experiences of the client themselves. Linked to this, a number of participants queried the idea that functioning, quality of life and recovery really represented distinct constructs. In addition, other provider participants suggested that improved functioning may not be a realistic treatment goal for a significant proportion of their population, indicating that much of the clinical work focuses on improving belief and hope around recovery, which they considered to be the antecedents to improved functioning.

Other: *"I have a fear that if we focus primarily on behavioral measures that we will really miss what's going on with these young people, when they come to us. Say for example, somebody could be fully enrolled at Berkeley and everything's rolling along just fine. Everything seems to just be perfect, but it's not, because they're not being existentially authentic with themselves, or conforming to a role that was put on them as opposed to one that they've adopted for themselves. Many things could happen and we see this. Yeah, I'm weary that the behaviors really translate into the underlying existential problem."*

Provider Group, ID: 122

Senior Director: *"And I think that's why I did not actually choose that particular one [functioning] because I couldn't really see quality of life and functioning being completely fully independent of one another, and quality of life to me, it's, like it's important that* *it's client-driven.*

Provider Group, ID: 840

Other: *"I was surprised by the functioning, because I see quality of life as the belief that you can get there, and functioning is the action that you are doing it, so I see a lot more of our clients and their families in the belief stage than the functioning stage, so I thought it was interesting that there were so many dots on functioning, because we're always in the process of trying to get somebody there."*

Provider Group, ID 467

When exploring how participants would like functioning to be measured, both the GFS-S/R and the UCD-developed tool received support. The questions posed across both scales were considered to be appropriate for the TAY youth typically seen in these programs. Participants appeared to particularly appreciate the specific questions around role functioning. However, while some preferred the summary score values obtained from the GFS-S/R, most preferred the more concrete, granular information that could be collected from the UCD-developed self-report measure. Many participants suggested that the data collected from the specific questions would have more clinical utility, although there were some concerns that this could lead to reporting inaccuracies, particularly regarding social functioning, due to deficits in insight. To remedy this, some participants suggested that for the self-report to be viable, the questions need to focus primarily on concrete metrics (i.e. seen friend in past week yes/no, number of friend contacts over past month, etc.). In addition, there were concerns that the more concrete questions asked may not be sufficiently sensitive to detect change in very low-functioning clients, while the summary scale anchors of the GFS-S/R provided a clearer distinction. Overall, most participants appeared to suggest that there may be benefits to collecting data utilizing both the GFS-S/R and the UCD-developed tools, with the different data being useful in different contexts.

Clinician: "*The role questions are really good.*

Prescriber: *This is one thing that we've talked about with our clinic. I'd like to know how many are in school, mainstream school, how many are back at college."*

Provider Group, ID: 825

Prescriber: *"I just don't know how reliable the client self-report is.*

Interviewer 1: *What do you think might get in the way?*

Clinician: *Insight. Social especially. Like, "Oh yeah, I have lots of friends."*

Prescriber 2: *But here they actually prompt you. I think this is actually – They could respond like that in a more superficial question, but then actually here, it specifically asks you number of people, and do you ever initiate contact? Have you had recent contact?"*

Provider Group, ID: 825

Speaker 10: *“I like both. I think you should do a scale and questions. You can easily write, "On a scale of one through 10, how functioning are you throughout? Well, I feel like an eight point five or something like that." Then you can say questions, "Are you attending school, are you working, blah, blah, blah, other questions." I think both.”*

Client Group, ID: 122

Interviewer 2: *“The provider one is just a single kind of scale item that you rate as from the past month. And there are some versions that rate highest in the past year and lowest in the past year. Versus self-report data. Some of it is yes or no data, some of it's quantifiable like “how many friends you have?”. How might that, just like the way the data’s presented, impact how you might use it?*

Prescriber: *I mean, I have a preference, but I also think the clinicians need to provide it.*

Interviewer 1: *Well, what is your preference though?*

Prescriber: *My personal preference is I think that both add to information. I'm fine with both and I do like the global function scales because they’re pretty efficient.”*

Provider Group, ID: 274

Recovery

The definition of recovery presented to the group for the purposes of starting the discussion was: “The individual’s belief they can live a meaningful life, meet goals they consider important, and develop support to maintain wellness outside treatment”. The measurement tools presented to the group included the Recovery Self-Assessment tool (RSA, O’Connell et al., 2005), and the Questionnaire about the Process of Recovery tool (QPR, Neil et al., 2009).

While some saw recovery more within the context of clinical remission, most considered the term consistent with the recovery model as presented in the definition list. In this more central-oriented conception of the term, recovery was described as consisting of two distinct components. The first related to the clients’ hopes and belief in their ability to live a meaningful life. This component of recovery appeared to be particularly important to family and family advocates, who at times passionately described the impact and importance of hope in the wellbeing of their loved one. These participants identified the absence of hope a significant source of distress to both the client and the family, and its presence as an important part of being able to experience a positive quality of life. The second component of recovery focused on the individuals’ ability to take control in one’s recovery, and included things such as having and knowing a clear relapse prevention plan.

Throughout the discussion participants highlighted the overlap between quality of life, recovery, and functioning. At times, this led to the terms being used interchangeably, complicating the interpretation of the analysis.

Clinician 3: “*Yeah, like this definition is very subjective, whereas I see recovery as* *completely objective.”*

Provider Group, ID: 825

Other: *“I think from the family perspective, what touches my heart is I just want her to know that she is capable.*

Clinician 3: *I wonder if what you're thinking about them is more recovery than quality of life*.

Other: *Oh it is. It's definitely recovery. It's the belief that you can be. It has to be important to me, because functioning doesn't always happen, so I have to constantly keep the belief, and so do the people I work with, that our loved one's can be.”*

Provider Group, ID: 467

Mother 4: *“They're adolescents, and they're at an age, like you say, they want to go knock it out of the park. They're, they're game to go, and they want to be able to be employed, to uphold school, to drive, to do everything that they should be able to do at their age. And I think they feel stifled with this, with what's going on in their life and they're at a time when they're already so self-conscious about self just in general. And then to be, kind of knocked down and know “I'm going to have to deal with this”, and I can't imagine what it would be like not to have control of my mind at times, or feel like I don't have control of my mind. I would- I don't know what I would do. That's one of the things with my [son’s name] and I feel so strongly about, and why I'll never stop supporting him.”*

Family Group, ID: 467.

Interviewer 1: *“So, something about developing resiliency and support constructs to enable the recovery? Is that-*

Clinician 3: *Yeah, “I know what I need to do know if I need help, if I have a relapse” or, “I have, I know who I can go to. I know my support. I know how to be more..” - It implied this resourceful active taking control of my recovery.*

Interviewer 1: *So we didn't actually mention relapse on here, so would you think relapse would be an area that we should be- plans for relapse and that kind of thing. I know there's been- well you- do you think it really is assumed under recovery?*

Clinician 3: *Under recovery.*

Clinician 2: *Yeah.*

Clinician 1: *I think so too.”*

Provider Group, ID: 467

Prescriber 1: *“A lot of the recovery models are more focused on functioning, how they're doing in life, because a lot of these patients –*

Prescriber 2: *That’s why, yeah, they need to go hand in hand. Yeah. Yeah.*

Prescriber 2: *They don't deliver symptoms, but you're really wondering “how are they doing in life?”*

Provider Group, ID: 825

During the groups clients, providers and family members all highlighted the importance of including recovery as part of the data collection battery. Some participants appreciated the subjective nature of the domain, relative to other, more objective measures such as functioning. In addition, measuring recovery was considered to have significant clinical utility, particularly when this could be measured over time and shared with the client as an indication of their progress.

Clinician: *“I just think that recovery of piece is so important. I actually like how it's defined here because it's the individual's belief that they can live a meaningful life. So, like why are we doing all of this if we don't have that? And this is so, being more – this is about how a person views what's important, how a person sees their life, how they, if they have hope or not, how they can cope with symptoms, but it's from their point of view is what I think is really important.”*

Provider Group, ID: 825

Clinician: *“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

Clinician: *“I think it [measuring recovery] kind of encourages the client 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

In the groups, the RSA and the QPR were reviewed as measures of recovery. Regarding the RSA, there was a consensus amongst all the provider groups that the RSA appears to measure service satisfaction, as opposed to recovery, and so as a result should not be considered as appropriate as a measure for use. In addition, some providers expressed concern regarding its length, suggesting it could be burdensome and overwhelming to their clients.

Clinician 1: *“I didn't expect it [the RSA] to be so much about what the staff is doing.*

Interviewer 1: *Okay, so it sounds like the first one then is not really what we want to look at when we're thinking about recovery. That's not-*

Clinician 4: *It's more like does the program have a recovery orientation versus-*

Clinician 1: *I would've concurred with that. This feels like the service satisfaction, “I feel like I'm getting what I need” kind of thing versus “I feel like this is where I am in my life”.*

Provider Group, ID: 467

Prescriber: *“And again, as some people have already touched on, actually a lot of recovery questions seemed like service satisfaction questions. Either way, they were long and seemed burdensome.”*

Provider Group, ID: 274

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In contrast, there appeared to be qualified support for the QPR. Many participants suggested that the questions tap into the concept of recovery previously outlined that they considered to be important. In multiple groups, providers highlighted and approved the frequent use of declarative “I” statements in the items, suggesting that these would be well received by their clients. Additionally, the scale was considered to have clinical utility, and could be effectively used as an outcome measure when tracked over time. However, while participants appeared to suggest that the tool adequately captures the client hopes and beliefs around recovery, some were concerned that the tool did not adequately tap into the whole construct of recovery. In one provider group, participants suggested that an additional item related to how the client feels they are progressing towards their goals should be added, and in another, providers thought a question covering relapse prevention would be important.

Clinician 2: “*These questions are amazing and this [the QPR] is great. Like, this would be so helpful in outcomes, but also in clinical value. And for quality of life it gives a really good overview of how they are thinking directly about themselves, or ‘I’ statements for most of them. Like 99%.*

Clinician 3: *I like that you noticed that. ‘I’ feel great.*

Clinician 2: *Yeah. Well, if we're talking about satisfaction it’s from an ‘i’s perspective, which is helpful in directing them in that already it's orienting them to, ‘Oh, I, it's me,’ not just in general life, right? I can do this, I can feel this.*

Interviewer 1: *So you feel this has clinical utility as well as being something that we can use as an outcome measure?*

Clinician 2: *Yes.”*

Provider Group, ID: 840

Other: *“It's asking for their opinion. How do I feel as a person, and not just as a questions or database. Just adding the “I” statement is like "Oh, they want to know about me." And it makes it more personal.*

Interviewer 1: *So you think that clients will respond positively to that?*

Other: *Mm-hmm (affirmative).*

Interviewer 1: *Okay, and what do you think about the actual measure itself? Do you like it? Do you think it's not quite hitting where we want it to? Or what are peoples’ thoughts about that one?*

Clinician 1: *I like it.*

Group: Yeah. It's good. Mm-hmm (affirmative).”

Provider Group, ID: 467

Clinician: *“I think there should be a separate category for progress towards treatment goals, or progress in treatment, however that's measured, whether it's their goals or the OQs or other measurements that we use. If we don't see an increase, because some clients do absolutely love coming here, and they don't make any progress. Not any, that's very black and white. But they don't make a lot of progress.”*

Provider Group, ID: 303

Clinician 3: *“In a perfect world that we don't have, it would be nice to see something like "I feel like I can get help now when I need it." Like a relapse recovery type of question.*

Clinician 1: *Right, like, I feel like I have a good support system.*

Clinician 2: *Support system, and family is so important. It's just a piece of their recovery that I wish there was an item that could capture that.”*

Provider Group, ID: 467

Quality of Life/Well-Being

The definition of quality of life/wellbeing presented to the group for the purposes of starting the discussion was: “How satisfied an individual is with how they live their life (past, present, future)”. The measurement tools presented to the group included the Lehman Quality of Life Scale (Lehman, 1988), and the Personal Well-being Index (PWI, Cummins et al., 2013).

Overall, client participants proposed a broad conception of quality of life, suggesting that the domain is a representation of many of the other constructs that have been discussed. Some client participants emphasized the importance of incorporating elements such as satisfaction around personal safety, spirituality, work, the family, and friendships due to their importance in determining a good quality of life. In contrast to other domains such as recovery, all participants who discussed the topic recognized the importance of the subjective element of quality of life.

Interviewer 1: *“Anyone else want to share why they chose quality of life or wellbeing?*

Speaker 3: *For me it seems the holistic thing. It’s an overarching view of everything, not just the particular detail, like family functioning, which is in relation only with your family, but quality of life is over everything. It just sounds like a very positive trait to have, well-being. I guess it's the final deciding factor in deciding whether your treatment has been effective.”*

Client Group, ID: 467

Speaker 3: *“I would like to recommend a sense of spirituality or philosophical views. I was apprehensive to say it because it's not measurable, but I don't feel like plenty of these other things are very measurable either.*

Interviewer 1: *Okay, in what way is that important for us to measure in terms of clinically? Is it-*

Speaker 3: *That's where I run into a wall there. Yeah. I think it's important to a person's health and quality of life.”*

Client Group, ID: 122

Speaker 8: *I feel like safety is a really big part of people's lives because if you don't feel safe doing something, then you're not going to feel good, ever. For me at least.*

Interviewer 1: *You could feel very strongly about this question, yeah. I can hear that. You want to add?*

Speaker 6: *Yeah, safety gives you this sense of comfort. Because you could even be uncomfortable, but if you feel safe, at some point you're going to start to feel comfortable. It's just if you know you're safe.”*

Client Group, ID: 840

Prescriber: *“Quality of life is subjective, and it should be.*

Clinician: *Yeah, I think that we need-*

Prescriber: *Not everybody wants-*

Clinician: *Yeah, my idea of what good quality of life is or positive quality of life may be different, so I think that's good that it's a client measure.”*

Provider Group, ID: 825

Quality of life was identified as an important domain for a number of reasons. Some provider participants indicated that working to improve the clients’ quality of life represented a significant proportion of their ongoing clinical activities with their clients. Consequently, collecting such data could potentially support such activities. Some provider participants also suggested quality of life could be considered to be a good outcome measure of program effectiveness, relative to other areas such as functioning where it may be harder to detect change over time. This issue was considered to be particularly important for more severely ill clients, where significant changes in quality of life might not be represented in major changes in role or social functioning. One provider suggested that measuring changes in quality of life would be helpful for reporting requirements, and to help justify the ongoing funding of services to insurers, lawmakers, and other stakeholders. However, support for quality of life as an important domain to collect was not universal. Some providers were concerned that quality of life may be too impacted by factors outside their illness and treatment, meaning the measure may not be a strong outcome measure to evaluate treatment effectiveness, while others stated a preference for related constructs such as functioning and recovery.

Clinician 4: *“So, going back to quality of life, I chose that as a clinician because when a client comes to my office, I always ask them, "What can I do?" Or, "What can we work on and to make help you have a better quality of life?" And so then I can get from their own perspective what they would like to work on and how I can assist them in getting there.”*

Provider Group, ID: 840

Prescriber 1: *“There might be somebody who we never—who does amazing with our treatment, and really does so much better, 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.”*

Interviewer 1: *Okay, so you feel like quality of life may be a better metric for your more severe clients where significant improvement is the main object you’re achieving when you're working with them. Is that-*

Prescriber 2: *Yeah.”*

Provider Group, ID: 467

Prescriber: *“I think if engagement in our program moves people on average two points on the quality of life scale, that's a simple thing that you can say to an insurer, to a stakeholder, to a lawmaker. That's a valuable outcome.”*

Provider Group, ID: 467

Clinician 1: *“Because QOL also depends on where they are in life, and where their family might be. They may have lower quality of life ratings purely because of some family discord they're having, which isn't necessarily associated with even their illness. That would be an outside factor, so there are just things that make it a little more murky for me.”*

Provider Group, ID: 467

In the participant review of the Lehman’s Quality of Life Scale and the PWI, the feedback received was highly mixed. Regarding the Lehman’s scale, some participants reported appreciating the simplicity and efficiency of measuring quality of life as a single item. Additionally, while some questioned the clinical utility of the data, some thought that it might be useful as an outcome to track over time. However, most appeared to view the tool unfavorably, particularly if used as a standalone tool. One client expressed discomfort with the idea of such an important construct being represented by one item, while other participants expressed concern about the validity of the tool, suggesting it may be highly affected by mood, and interpreted very differently across different participants. Finally, multiple providers suggested that such limited information gathered would serve little purpose clinically.

Speaker 6: *“I feel like the single question is pretty straight forward.”*

Client Group, ID: 122

Interviewer 1: “*Do you think that tracking that [Lehman’s QoL] over time would be really effective for us?*

Clinician: *I think it would be, because it's easy and it kind of gives a good snapshot of how they're feeling in that time. It's straight to the point and it's not asking why. You're just trying to figure out how they feel about their quality of life, and that answers that.”*

Provider Group, ID: 303

Prescriber: *“It may not be terribly useful clinically, but as an outcome measure it's really easy to just track over time. If they feel like their quality of life is improving or not.*

Provider Group, ID: 840

Speaker 2: *“I don't think you should quantify your entire life by a single number. I think your life is separated by many different aspects and multiple questions gives you specific areas that you want to work toward. It's very hard to summarize, "I want my life to be better. My life is a six. I want to be an eight." You don't have any steps to get there unless you have these other areas.”*

Client Group, ID: 122

Speaker 10: *“I mean, I mainly ... when I'm in a good mood, I feel more inclined to put pleased, but if I were in a more neutral mood, I would be more inclined to put mixed.*

Interviewer 1: *Okay. I think, I'm understanding what you're saying. So, your mood really impacts how you even fill out this measure?*

Speaker 10: *Yeah.”*

Client Group, ID: 467

Mother 1: *“Yeah, so some people, like if somebody puts terrible for one person, they may be thinking, oh, my mom passed away, Terrible. But for another person, especially with these kind of mental illnesses for my daughter, if she got an A minus, that would be a "terrible." She would be crushing herself. So that's why it's definitely just a good starter.*

Interviewer 1: *Those being that it can be interpreted differently person to person, maybe it's a little bit of an issue?*

Mother 1: *Yeah.”*

Family Group, ID: 467

Other: *“[Lehmann’s QOL] is way too broad. I don't know how you would actually use that.”*

Provider Group, ID: 303

In the review of the PWI, some client and provider participants appeared to like the scale, suggesting the questions asked related to areas they considered important. However, while most participants appeared to favor the PWI over the Lehman’s QoL, many of the participants also raised concerns around adding this measure to the battery. One client participant stated that the 0-10 rating scale would feel overwhelming to use if they were not feeling well. Some participants were concerned that the tool includes language and concepts that may not be appropriate for a transitional age youth (TAY) population, and that some may struggle to complete the measure as a self-report. Additionally, some provider participants suggested that based on previous use of the scale, most client rated their satisfaction in the middle, meaning the tool served relatively little purpose from a clinical perspective.

Interviewer 1: *“Does this capture when, if you think about what it means, a good quality of life?*

[Unknown]: *I know I'm going to have a good future because I've got a lot of things going for me.*

Interviewer 1: *Does that questionnaire capture all of the good things that are going for you?*

[Unknown]: *Yeah. It's pretty good.*

Interviewer 1: *Look on that other page, too. There's two pages to it. Take a look, see if you think that this communicates.*

Interviewer 4: *Yeah, it looks pretty good.”*

Client Group, ID: 303

Speaker 2: *“I think with the standard of living with your health and what you’re achieving, I think those are good questions to ask someone. Even the personal relationships one too, those are good.*

Interviewer 1: *How do you like the word satisfied, that's included in this question?*

Speaker 8: *I think that works.*

Interviewer 1: *Yeah*.

Speaker 8: *It sums up what you want. You want to be satisfied in your life.*

Interviewer 1: *Head nods, okay.*

Speaker 7: *Yeah. Instead of happy, I think satisfied is more of a, I think it's a little bit deeper. It has more meaning to it, like satisfied, I don't know.”*

Client Group, ID: 467

Sr. Leadership: ***“****I particularly like the PWI. The satisfaction with life as a whole, the next page, because it's the one that includes spirituality and it includes how the person sees in their future in terms of their security. It hints at this transition to independence, personal relationships, how safe you are, things like that.”*

Provider Group, ID: 122

Speaker 4: *“I feel like, if I were to do this like before going into a session or something, and if I saw a dropdown of one to 10s, if I was already not feeling very well, I would just be pretty exhausted going through it.*

Interviewer 1: *Right. So, this doesn't feel very accessible, it feels a bit too dense if you're not feeling very well.*

Speaker 4: *It would almost feel like a chore.”*

Client Group, ID: 122

Supervisor: “*I think clinically some of this would be useful. I just don't think that the clients will be able to really access and process and report on it without it being too much of an interactive process for them to understand it.*

Interviewer 1: *And this has been defined as a self-report, so this will be something where you're not providing commentary and what this means. So it sounds like, I'm seeing eyebrows raise. So do you think they'll struggle to understand what this is, the construct?*

Clinician 3: *Absolutely*.

Clinician 2: *Yeah.”*

Provider Group, ID: 840

Sr. Leadership: *“I worry about the language of some of the questions because I'm not convinced that, I mean, even I'm sitting here kind of like perseverating in my brain about like, how would I answer this question? Am I a nine? Am I am an eight? Are they really going to understand the difference between that kind of a scale, right? I mean, generally in our system we try to do like the five-point scale. It's very clear and defined, but some of this like standard of living, it's like, well, I can think about that I'm not sure if some of our clients can. And like number three, like with how satisfied am I with achieving with what I'm achieving in life? Like, what does that really mean? I can sit here and think like, I don't even know how I’d answer that question, let alone some of our clients. So the language of this measure I'm not convinced would be good for our population.”*

Provider Group, ID: 274

Clinician 1: “*But I also hate the PWI with the fire of a thousand suns, but that's a personal.*

Interviewer 1: *Right, and why?*

Clinician 1: *I think it also isn't operationalizing quality of life in a way that is objectively measurable, and then can affect change for me on the backend as a clinician. How satisfied are you is such a vague term, and most people are in the three to seven range, and so being solidly in that middle for most of these questions does not help my cause, because it's hard to know where to then impact anything, whereas the ILS [Independent Living Scale] is more helpful.”*

Provider Group, ID: 467

Service Satisfaction

The definition of service satisfaction presented to the group for the purposes of starting the discussion was: “How satisfied an individual is with the mental health services they receive.” The measurement tool presented to the group to measure this domain was the MHSIP Youth Services Survey (YSS, Brunk, Koch, & McCall, 2000).

When exploring how service satisfaction should be conceptualized, one program focus group suggested to expand the definition to include therapeutic alliance. It was considered that this may be able to add additional information that could potentially moderate treatment engagement and outcomes.

Clinician: *“I think some level of a measure regarding therapeutic alliance will be helpful.*

Interviewer 1: *[…] is there anything in particular are you thinking how that- is a predictor of outcome, or-*

Clinician: *Yeah, I think just that my work with a few clients, I think it helps to be able to understand how well there is a relationship established between you and the client, and how that affects the outcomes and their engagement within treatment.*

Interviewer 1: *And is that something you measure at the beginning, or would that be something you'd want longitudinally as well?*

Clinician: *Yeah, definitely something throughout treatment.*

Interviewer 1: *Okay. Anyone else have thoughts about that? I'm seeing some nodding.*

Prescriber: *I'm just wondering, because I do think that's important, and I also think it's related to service satisfaction, so I'm just wondering how to tease those two things apart.”*

Provider Group, ID: 467

Two distinct themes were discussed in regard to why service satisfaction was considered to be important to measure. Across three provider groups, service satisfaction was seen – similarly to therapeutic alliance – as a strong predictor of dropout in services. One participant suggested that this data could be used to identify those potentially at risk of disengagement. Such data is useful, as providers could then attempt to intervene earlier to minimize treatment dropout. The second theme across provider groups was the use of service satisfaction data in reviewing the performance of the clinic.

Prescriber: *“I did because service satisfaction often is an indirect measure of adherence and sticking with us. So, I think sometimes you can pick up on subtle cues before someone explicitly expresses their discontent with ratings.*

Clinician: *I guess I looked at it as leadership overall. The clinic, how is the clinic working? Are the patients satisfied? What is the re-hospitalization rate?”*

Provider Group, ID: 825

Exploring how best to capture service satisfaction was not extensively discussed across the focus group. However, when it was addressed there appeared to be little support for using the YSS. One provider expressed concern about adding an additional satisfaction questionnaire alongside satisfaction measures already mandated at the county- and state- level.

Prescriber: “When I looked at the service satisfaction scales, I can't say I was blown away by them.”

Provider Group, ID: 274

Sr. Leadership: “This program, and our other PEI programs, do the internal satisfaction survey every March and September. And then we do the state one every May and November. So it would seem excessive to me to add another one on.

Clinician 1: And that's already a lot for our kids.”

Provider Group, ID: 274

Clinical Status

The definition of clinical status presented to the group for the purposes of starting the discussion was: “Diagnosis, medication, date of onset, and remission status”. The measurement tool presented to the group derived from the Mental Health Block Grant (MHBG) Minimum Data Set version 7.3.

In one provider group, there was some concerns that clinical status was an inappropriate term for the construct, given the definition described constructs that were primarily fixed (i.e. date of onset). However, the group did recognize the importance of collecting such information. Overall, the clinical status domain was not a domain extensively discussed during the various focus groups. However, some family participants did highlight the importance of collecting data on comorbid disorders such as autism spectrum disorder that could either mimic some psychosis symptoms, or impact recovery trajectories. Additionally, some providers expressed concern around the accuracy of any diagnoses that clients may have received prior to starting services. To minimize issues related to misdiagnosis, one possible solution may be that all diagnoses entered into the data collection system should be those made or reviewed by the early psychosis clinical team. Finally, in one group it was importance to detail prior diagnoses and treatments as this could help inform future treatment directions and could potentially impact outcomes.

> Interviewer 1: *“Anyone else about anything, any other definitions, or just the outcomes in general that's here? Anything that's not on here, something that we're not considering?*
>
> Speaker: *ASD.*
>
> Interviewer 1: *So is that, can you tell me a little bit more about what you mean by that?*
>
> Speaker: *Well, Autism Spectrum Disorder. So, that can mimic psychosis in some ways if it's very extreme.”*
>
> Family Group, ID: 122

> Speaker: *“Well it's [the functioning scale] not very useful for my son because he's autistic, so he kind of has to—*
>
> Interviewer 1: *Both aren't useful, or which one?*
>
> Speaker: *Well, I mean just the social functioning questions. Like obviously his social functioning is going to be much lower. But he could be at a very great place for him, but I don't know if that will tell you his level of psychosis that he is experiencing at a particular time because he has a social deficit.”*
>
> Family Group, ID: 840

> Prescriber: “Clinical status helps. It's hard for me to trust as much in an outsider's diagnosis, because I may not know what has gone into that.”
>
> Provider Group, ID: 467

Service Utilization

The definition of service utilization presented to the group for the purposes of starting the discussion was: “How often health services are used or received”. The proposal to collect this data was to source the information directly from county/service electronic health records. In one provider group in particular, topics around the importance of service utilization and methods to collect this data was explored in depth.

Overall, clients and provider participants identified a number of different ways that collecting systematic data around the types of services clients receive could be useful. Some participants considered reducing the number of hospitalizations and emergency room visits as some of the main outcomes related to the services they provide, and so considered it critical to collect such data. These data were considered important to evaluate patient recovery on a client level, to review the effectiveness of the service clinic-wide, and to help determine the cost-effectiveness of the services which could be important to help justify the ongoing funding of programs.

Prescriber: *“I want to know whether our services are preventing hospitalization, ER visits*.

Clinician: *Yeah. That's one of the main outcomes.”*

Provider Group, ID: 825

Prescriber: *“We get frustrated with the hospital who doesn't care for preventing hospitalization because they make money on that, but I think the insurance companies would care about that information if supporting the services that we provide will prevent future cost.*

Clinician: *Remember we had that [service contract], and that was a big aspect of it.*

Prescriber: *We were forced – Yeah, we had to close our [intensive outpatient clinic] because our census hadn't been high enough, but our argument was "but you don't know how many hospitalizations and ER visits we're preventing." But to the hospital system, they're not aware.*

[*Murmurs of agreement.*]

Provider Group, ID: 825

In addition to tracking hospitalization rates and emergency room visits, focus group participants also emphasized the importance of collecting data around the different outpatient services they receive, both within the early psychosis program and with other services. This was considered important for three reasons. First, to be able to model how engagement in the early psychosis program generally, and then in each particular component of early psychosis may be associated with changes in particular outcomes. Second, some providers suggested that having an ongoing record of outpatient services that clients may receive outside of their program would both be clinically useful to have, and important to interpret changes in other outcomes. Third, in one provider group, one participant suggested that such information would be critical to explore under-utilization of services amongst historically underserved groups, which would be important information to help improve access to underserved individuals.

Speaker 7: *“Yeah. I like going to groups too because I think it made me braver as a person, socially brave. I don't know if that makes sense, but my communication has improved. I can actually speak what I'm thinking instead of just holding on the information to myself, kind of let it out there.”*

Client Group, ID: 467

Supervisor: *“I think that would be really helpful for us and quality- I mean, I'm guessing other clinics as well, because as [other participant name] was saying, we're sort of one of many things they may be participating in.”*

Provider Group, ID: 710

[Unidentified] *“I chose service utilization because I was thinking about underserved populations, because I think they have access, or they have no access. At [clinic name] we don't see enough underserved population groups, it's just the nature of lots of different factors: language, transportation issues, where to go. I think that's not in [clinic name] itself, but it would be good to see more underserved populations.”*

Provider Groups, ID: 710

With regards to measuring service utilization, the originally proposed plan was for this data to be collected via a mixture of self-report, and from county- and program-held records. While this was not discussed in great depth in most of the programs, in one provider program suggested that both methods may viable.

Interviewer 1: *“Do you think that clients could reliably report this information [hospitalizations]?*

Clinician 1: *I think usually, yeah.*

Interviewer 1: *But do we need to verify with the county level? I think these were some things that –*

Clinician 2: *We usually find out either from the client or from the medical record or from the hospital where they were admitted.*

Clinician 1: *They were being discharged to us usually afterwards so I don't think we have- yeah.*

Prescriber: *I mean we would know.*

Clinician 2: *Yeah, we would find out.*

Clinician 3: *I think it’s easy. We’re the first one they serve.”*

Provider Group, ID: 904

Reflections specific to Each Domain – Newly Proposed Domains

Ability for Self-Care

In over half of the groups, the clients’ ability to maintain self-care was considered an important domain in which to track within the battery, and some expressed concern that at present this was not being considered. Ability for self-care included tracking basic needs such as the ability to maintain basic hygiene, get adequate sleep, and to take care of any nutritional needs. Participants considered the ability to maintain self-care as important to support quality of life and functioning, and could significantly impact psychiatric symptoms. The domain was considered to have clinical utility as the questions can indicate a significant client need, while any changes in these capabilities can serve as a useful indicator of how the client is doing over time.

Interviewer: “*What do you mean by adaptive living skills?*

Speaker 2: *Well just basic living: being able to obtain your own food from the house, showering, brushing your teeth.*

Interviewer 1: *Yeah*.

Speaker 2: *Changing your clothing. Just taking care of yourself.*

Interviewer 1: *Yeah. Why is that important? What would that demonstrate if you were able to kind of track that over time?*

Speaker 2: *Well where - it would be concerning is that if the patient was able to do it at one time and then they lose those skills and why. Why did they lose those skills?”*

Family Group, ID: 122

Other: “*I don't know if that could be captured in here, like sleep, food, nutrition, because all those things can also impact the person's mental health.”*

Provider Group, ID: 274

Substance use

Participants across client, family, and provider groups all suggested that collecting data around substance use may be merited for inclusion in the battery. Many participants recognized that substance use is highly prevalent in this population and is a frequent topic for discussion during early psychosis care. While in most cases measuring substance use was considered important given its impact on other domains such as treatment engagement, medication, psychiatric symptoms, and functioning, in some cases participants also considered measuring substances important to evaluate as an outcome of treatment itself.

Interviewer: *“Are you seeing improving [substance abuse] that as an outcome goal? Or, are you thinking how they may change the ability to engage in treatment? Or everything?*

Speaker Unknown: *Both.*

Clinician: *I was specifically thinking as an outcome measure. A significant portion of the clients that we work with have co-occurring disorders, and oftentimes it's not uncommon for them to even come to therapy intoxicated, and so we use a harm reduction approach. So, figuring out a way to talk about how to address symptoms and not specifically talking about addressing substance use would leave people to question, well why are they not doing better? Why are they disengaged? But if we're capturing it in the beginning, that would be really useful.”*

Provider Group, ID: 122

Clinician 1: *“I think it would be a moderating factor throughout. So, medication adherence,* *treatment engagements, service satisfaction can all be impacted by substance use.”*

Provider Group, ID: 467

Clinician 4: *“I guess the one question is, you were asking: should it also include something about how much it's impairing them? I would probably say yes, because if we just go by quantity, and certain quantity could affect someone differently, so I imagine that that wouldn't give us quite as much information as how much they're impacted by their-*

Clinician 1: *I feel you, but if this is a subjective questionnaire, how much insight do they have to know how much they're impacted by the substance use?*

Clinician 4: *Oh right. It's a self-report. Yeah.”*

Provider Group, ID: 467

Independent Living

Across multiple groups, data relating to the clients’ capability of living alone was considered important. This relates to the ability of the client to develop a plan during treatment, and summary data on the proportion of clients who either do or used to live alone. This data was considered an important metric to capture as it was frequently recognized as a client goal, representing an important part of the treatment they receive. In addition, metrics around independent living status was considered to be an important metric to have on a clinic-wide level for reporting purposes.

Prescriber 1: *“Many of our clients want independent living, not to be under their parents, and I don't know where that fits.”*

Provider Group, ID: 825

Clinician: *I think it's useful. It's useful on a patient basis, but as an overall clinic-wide, if you want to say, "Okay, there are so many who were – I don't know. “Four-year University, and then now they're going to a community college.” I think –*

Prescriber 2: *“They used to live independently and now they live at home.”*

Clinician: *Yeah. I think that that's where the other granular one would be more useful.*

Provider Group, ID: 825

Mortality

In one provider group there was consensus across the participants that mortality is an extremely important outcome to collect as part of the battery. In this particular clinic, they had reported that a number of their clients had died by suicide in the past year, and so identified this as highly relevant to the population they serve. During the discussion it was suggested that sourcing mortality data from county records would be preferable to enable this outcome to be tracked in clients that leave the program. However, if this was not possible, then it was suggested that this could be something that could be reported by the clinic providers themselves.

> Prescriber: "*That [mortality] an extremely important outcome*.
>
> Interviewer 2: *Absolutely*.
>
> Clinician 3: *That might be an important one to add, because that's an outcome.*
>
> Interviewer 2: *Yeah.*
>
> Prescriber: *The real deal."*
>
> Provider Group, ID: 825

Culture

Collecting data regarding culture was considered very important in multiple focus groups. However, many participants struggled to consistently conceptualize what the necessary features would be to collect, and how to collect it. Some participants suggested collecting the data qualitatively. However, that could have limited utility from a data-analysis perspective, and some participants suggested that in most cases clients would just leave open text boxes unanswered.

> Supervisor: *"*sigh* It's difficult for me to answer, because culture is, I mean, it's just constantly expanding. There's no boundary to it. Right? So even a lot of us may come from similar backgrounds, but everyone's household is different. Right?"*
>
> Provider Group, ID: 303

Broadly speaking, the notion of culture in this context appeared to be represented across four distinct domains: 1) detailed demographic information of both the client and the family, 2) how the client identifies themselves from a cultural perspective, 3) an understanding of how mental health is understood within their cultural context (primarily the immediate family), and 4) the degree of support for treatment that they receive from their family.

> Interviewer 2: *"We do have some questions that we are hoping to add to what we're going to call an "about you" section. It's kind of demographics, but also expanded information and some things that we've kind of floated around as being important to collect. Information about racial and ethnic identity, obviously, but other things like acculturation that they were brought up, issues with immigration or, Instead of asking them directly, if they have any family member who has any issues with kind of status in the country, tests say, "Do you know anyone that has issues like that."*
>
> Interviewer 4: *Where you were born.*
>
> Interviewer 2: *Where you were born, where your family, where your parents were born-*

Interviewer 4: *Parents both were born.*

Interviewer 2: *To talk about generational issues.*

Other: *How about gender identity?*

Interviewer 2: *Yep, definitely.*

Interviewer 5: *Socio economic status, education.*

Interviewer 1: *Since that was your idea, do those sound like the appropriate things to look at to measure culture?*

Supervisor: *Those sound like a good start."*

Provider Group, ID: 303

Other: *"I can fill in a bubble that says "Hispanic", no problem. But do I identify that way? Probably not, because you also have to think about - I think you would need to have a little square in here that says type , Maybe 50 words or something, get a different answer. Because I can tell you, I can easily fill that bubble, but I don't identify in that area, because I can't. I don't know what some of the Mexican cultures are, such as I'm not into the music."*

Provider Group, ID: 303

Speaker 6: *For me, I don't know about anybody else, but for me it was more of my culture type thing, my race. With my family it was more of a "we don't go to therapy" type thing, "therapy isn't us, we just suck it up and deal with it". Or my dad or something, "Oh, suck it up," always telling me, "Oh, since you're a man, you don't show emotion, suck it up, deal with it, don't cry. Men don't cry,"*

Client Group, ID: 840

Access to Support and Resources

Areas of interest reported by participants appeared to focus on two issues. The first related to whether they were receiving financial support such as supplemental security income (SSI), and the second concerned the access and links to wider social support. This may come in the form of outside therapy, or support from the religious institutions or other community services. In some cases, this support was seen to be an important component of their treatment and recovery.

Supervisor: *"I don't know if this would be a separate outcome, or if it could be added to the definition of one of these and I'm having some trouble thinking out which one it might be added to, but one of the things I'm thinking about is the rate at which participants are taking social service support. Whether it's SSI, SSDI, subsidized housing, you know all of these factors that one, are going to contribute to potential homelessness or quality of life, poverty rate, but also it's going to impact things like service utilization if there on things like Medi-Cal that's going to limit* *the services. So, sort of that public benefits utilization."*

Provider Group, ID: 122

Clinician: *"Access to resources or social, either meaning their own therapy or, I don't know, church support or community support.*

Interviewer 1: *Yeah, what does everyone else think about that? Do you think this is a really important thing to measure as well? Access to other supports?*

Other: *Maybe if you framed it under community integration?*

Interviewer 1**:** *Community integration? Do you think, is that capturing the same thing?*

Other: *Yeah."*

Provider Group, ID: 303

Trauma

Multiple provider participants discussed the possible clinical utility of measuring trauma as part of the battery, while some client participants talked about how traumatic experiences impacted both their engagement with treatment and ongoing recovery. Participants suggested that trauma would be important to measure both as a moderator of outcomes, and as an outcome itself, identifying that processing their trauma was a treatment goal for many of their clients.

In one provider group, participants discussed in depth what data related to trauma would be most useful. Some participants suggested that focusing on the impact of trauma would have the greater clinical utility, while others suggested that collecting data focusing on the number and range of childhood adverse events would be both less stigmatizing and feasible to implement.

Other: *"One of the things I've found sometimes with participants, they have an underlying trauma that resulted in symptoms that we call psychosis or bipolar and because of the defenses they've created to try to survive that, inappropriate defenses, they're not forthcoming with their clinician until the therapeutic alliance has been built and that can take a couple years."*

Provider Group, ID: 122

Speaker 12: *"My dad is a very alcoholic induced person. He loves vodka, he loves the heavy drinking stuff, and he loves to just yell a lot, and I was living with him for three months and I had to just leave. I almost broke half my crap because I was just done with getting yelled at constantly, get told what to do constantly, and not having my own freedom, having my own safety, my own space. But now that I'm with my mom, I've been getting better and takings my meds now, I'm starting to realize I'm not as bad off as I thought I was with her, and I've even gotten to the point where I've been helping her around the house."*

Client Group, ID: 840

Prescriber: *"I mean we may assess that as part of the session, but are we looking that as like an outcome of their treatment?*

Clinician: *I think in psychotherapy, it comes up a lot, so it's one of the treatment goals to get over their trauma, to process their trauma."*

Provider Group, ID: 825

Interviewer 1: *"So, in terms of what you would want to know, is it sort of the quality of the trauma, like the number of events the type of the event, duration, frequency, that kind of thing? Is it the impact of the trauma? Is it both? What's more important for those of you that voted on trauma, or for those of you that have dealt with trauma in your providing services?*

Supervisor: *Impact. I would say impact.*

Other: *Impact, because depending on how resilient the person is, some can resolve it for themselves*.

Interviewer 2: *So impact, I heard impact. I saw a lot of nods for impact."*

Provider Group, ID: 122

Sr. Leadership: *Yes, as I was thinking about trauma, depending on whether it is self-report and the way that we are going to be collecting some of these, it could be as simple as sticking to something that is less stigmatizing today like adverse childhood experiences that people can often describe, or check a box and kind of in a less intimidating way versus if we are talking about the details of frequency, duration, how many events, types of events then that would be in the context of therapy and perhaps a provider would-*

Clinician: *So, we can include the ACE, we can do the ACE markers which are very simple-*

Sr. Leadership*: And the person can do it too.*

Clinician: *Yeah, the person can do it. The ACE- [they] can do it themselves."*

Provider Group, ID: 122

Barriers to Care

In two different provider groups, participants articulated the importance of capturing data related to barriers to care. This focused on two different issues: possible barriers to taking medication, and structural and logistical barriers to care. In terms of medication, there were concerns that in privately insured clinics some clients may experience barriers in accessing antipsychotic medication. In terms of other barriers to care, this included features such as transportation, distance to the clinic, support to engage in treatment, socioeconomic status, and possible cultural barriers. In both cases, these barriers were seen to moderators to both engagement in treatment, and other treatment outcomes.

Clinician 1: *“Here, our clients are all in Medical and they all have access in terms of getting medication. They don't have to pay out of pocket. But, in terms of looking, when I'm looking at medication adherence and medication side effects, I'd almost wonder on putting access to medication for other, maybe, counties that they have to pay out of pocket? Whether or not they can kind of-*

Clinician 2: *Would that fall under community resources?*

Supervisor: *Access to all services?*

Clinician 1: *Yeah, I would think it’s, But, just making sure, I mean-*

Clinician 3: *That's it's own subset.*

Clinician 1: *Yeah, putting that. Because, we're assuming that they have access or the means or the resources.”*

Provider Group, ID: 303

Clinician 2: *“I think barriers to care, which is a big topic, is not on there really.*

Interviewer 1: *So by barriers of care, what do you mean exactly?*

Clinician 2: *I think that there are a lot of ways to think about it, but some are maybe structural, or pragmatic like lack of transportation or a distance to clinic. I mean, I think that-*

Other: *Hours of operation from the clinic.*

Clinician 2: *Mm-hmm (affirmative). Right, like do parents work schedules allow them to come?*

Other: *Socioeconomic status.*

Clinician 4: *Systemic barriers.*

Clinician 2: *I think there's a large literature on some of the barriers to care. There certain subcultural factors, or stigma.”*

Provider Group, ID:467

Stigma

Across some client, family, and provider groups stigma was considered an important and prevalent issue that many clients experience. The types of stigmas experienced by the clients appeared to fall into one of two categories, self-stigma, and stigma they may encounter from others. In both cases, these were considered experiences that could potentially impact the clients’ path to recovery.

Clinician: *“There's a lot of stigma and it'd be interesting to track that. Also, by generation, religion, how all of that impacts their treatment.”*

Provider Group, ID: 303

Speaker 15: *“I think my daughter came home and understood what was happening in her brain and so that was really important to her. And also it does kind of decrease the fear a little bit. It normalizes it. Like this is normal, not for everyone, but it's normal for you, it's normal for a lot of people. And she was able to I guess, I don't want to say intellectualize it, but when symptoms did come up they weren't in the context of a nightmare or something. It was in the context of okay something is happening and I need to tell someone. And not not talking about it.”*

Family Group, ID: 840

Speaker 10*:* *“For me, functioning is harder now thanks to the large amount of time where I was just, excuse my language, acting bad shit crazy.*

Interviewer 1: *So you mean it's been harder to get back to school?*

Speaker 10: *No, it's been harder to talk to the people that I used to talk to you back then after the way I acted and because they don't understand that this a mental illness. It was obvious there was a mental illness, but they didn't think I would recover from it.”*

Client Group, ID: 303

Discussion

Across the 22 focus groups completed with providers, family members, and early psychosis program clients, an extensive array of suggestions and recommendations were given around what data is important to collect, how to define the domains of interest, and how to collect the data itself. These data have been compiled into a summary of recommendations for each of the identified domains detailed below:

Recommendations for Data Collection Based on Participant Feedback

Psychiatric Symptoms: Use MCSI, but add provider review field to indicate their perspective from their knowledge of the client. Consider adding additional optional template for PANSS/SIPS/BPRS for clinics that use these scales.

Family Functioning: Adopt a broader conception of family functioning than that originally proposed, evaluating the family dynamic, the mental health literacy of the family, and the level of support in care provided by family members. Utilize the SCORE-15 to evaluate family dynamic, add additional questions to tap into other constructs.

Law enforcement contacts: Broaden the domain of interest from incarceration/recidivism to include any contact with justice services. However, important to differentiate contacts related to criminal behavior, as opposed to emergency behavioral health contact.

Cognition: Use proposed battery but add the ER-40 in order to capture social functioning. If any scale needs to be removed to accommodate this, then the matrix reasoning task was considered the least useful, given the measure cannot measure pre-morbid cognition.

Family impact: Replace the term “family burden” with “family impact”. Use the BAS as opposed to the EES as it covers a broader conception of family impact and is less negative than the EES. Of note, it is important to give family members space to complete their responses away from the client to ensure that they feel comfortable giving honest answers.

Medication Utilization: Replace the term “medication adherence” with “medication utilization”. Use the BARS, modifying the questions slightly to make it more appropriate for self-report. Additionally, adding an item where providers then review and confirm the response, and an item where clients can disclose whether they are considering stopping taking medication would improve the accuracy of data and improve clinical utility.

Impact of medication: Replace the term “medication side effects” with “impact of medication”. Use the GASS to measure side effects, but to minimize attribution errors introduce the scale as a measure of “changes in health” since taking medication, as opposed to a measure of side effects. In addition to this scale, consider adding two questions to the battery, one that explores any possible positive impact of the medication they are taking, and a second asking clients in light of the positive and negative aspects of taking their medication, if they are satisfied with their current regimen.

Risk for Homelessness: Few concrete proposals were provided by participants. However, in developing the scale to assess risk for homelessness it was suggested that the clients’ income stability, their receipt of SSI, and the degree of stress in the home should be considered important factors to include.

Risk to self/others: Expand the original domain of “suicide risk” to incorporate NSSI and homicidal thoughts, and change the domain name to “risk to self and others” to incorporate these amendments. Use the SBQ-R to measure suicidal ideation, add questions for NSSI and homicidal ideation, and consider adding the first two questions of the Columbia, which in the event of an endorsement, the clinician can follow up and complete the full assessment.

Substance use: Suggestion for this to be incorporated into the battery. Data collected should detail the substance(s) used, the frequency, and the method of use.

Independent Living: Consider adding questions relating to the individual’s capability to live independently which could be answered by the clinician, and two questions asking if the client currently lives alone, and if they have ever lived alone.

Mortality: Collect mortality data, either via county records or from the programs themselves.

Culture: Ensure demographics/about you section incorporates detailed information regarding race/ethnicity and county of birth across the family, client gender identity, socioeconomic status, and level of education. Incorporate family understanding of mental health, and family support of treatment into the family functioning domain.

Functioning: Considered critical domain to capture by most, but should not be adopted to the exclusion of more subjective measure (i.e., quality of life, recovery). Important to measure role and social functioning separately. Role should include work, school, volunteer, and homemaking tasks. Social functioning should focus on the quality of friendships, as opposed to quantity. Close and casual friendship should be recorded separately, including online friendships. Reporting granular, concrete metrics of functioning was considered most useful, but summary scores also considered to have merit. Given importance, suggestion made to incorporate both forms of data.

Clinical Status: No comprehensive recommendations came from the focus groups. Suggestion that comorbid diagnoses may impact treatment trajectory or complicate etiology and should be added as data. However, care needs to be taken around reviewing diagnoses made prior to starting treatment at the early psychosis program.

Service Utilization: Important to collect full description of outpatient services (both within and outside the early psychosis services) in addition to hospitalization and emergency room visits. Mixture of client self-report and a review of program and county medical records considered an appropriate source of this data.

Service Satisfaction: Little support for the measure presented to the group (the YSS). Consider possibility of using the RSA to measure service satisfaction, as opposed to recovery.

Recovery: Use the QPR to capture client hope and beliefs around the ability to recovery and live a meaningful life. Consider adding two additional items to capture relapse prevention, and progress towards goals.

Quality of Life: Feedback regarding both scales was very mixed, however there appeared to be a general preference for a multiple-itemed scale such as the PWI over the Lehman QoL. Given the importance of the construct to stakeholders, consider a review of alternative scales.

Access to Support and Resources: Ensure detailed information related to social security income and their links to wider social support is included in the “about you” section.

Trauma: Add a trauma measure to the battery. While a scale recording the impact of trauma may have greater utility, the ACE was considered to be more feasible to implement, particularly if the focus is on self-report.

Barriers to Care: Ensure the “about you” section has sufficient information regarding possible barriers to care, including access to transportation, distance from clinic, access to medication, and other cultural factors.

Stigma: Consider adding two sets of questions to the battery: one relating to the self-stigma of experiencing a mental illness, and the other detailing stigma they may experience from others.

Strengths and Limitations

This deliverable details an extensive process to solicit stakeholder feedback around data collection in early psychosis settings, including 178 participants across 10 clinics. This engagement process has included family members, clients, and providers across a diverse range of clinics, including county- and University-based clinics, in urban and rural locations. The programs themselves deliver early psychosis care to a diverse range of clients in terms of race/ethnicity, socioeconomic status, and gender identity. To further support inclusion and to ensure that a diverse range of stakeholders could participate, focus group were held both in Spanish and English. Consequently, one major strength of this study is that it provides strong representation of the various stakeholders that either utilize or delivery early psychosis care in California.

Regarding limitations, one important consideration is the challenges of implementing this portion of the project against the backdrop of the COVID-19 pandemic, and the subsequent “shelter in place” order. In addition, it was necessary to scale back some of the original plans that were intended to further increase engagement. For example, plans were being developed to conduct focus groups in languages besides English and Spanish, such as Mandarin, potentially utilizing a blogging format provided by services such as FocusGroupIt.com. In addition, there was an intention to conduct a focus group with individuals with chronic schizophrenia, and potentially other providers such as education workers, law enforcement partners, and emergency service workers. Linked to this, the first round of Spanish-speaking groups had to be cancelled due to the shelter in place order. This resulted in the groups being shifted to a remote platform (either via telephone or Zoom/WebEx). While successful, it was recognized that internet connectivity was required to participate in the Zoom/WebEx enabled focus groups, which represented a barrier to engagement to some lower SES families.

Overall, while this project has exhibited a strong commitment to listening to a diverse range of voices, these issues led to a reduced degree of engagement than what would have otherwise been the case.

Regarding other limitations, due to the lack of video recording of the groups, in some instances it was not possible to attribute the quotes in the audio recording to each particular client. Additionally, the provider roles assigned to each participant were self-defined, and so it was possible that some provider participants selected their role incorrectly. This issue may be particularly significant with more senior providers, who typically cover multiple roles within a clinic (i.e. clinician, supervisor, and leader). Finally, in one focus group (OCREW family group), a recording error led to their qualitative data not being integrated into the overall dataset. To address this, the facilitators of that particular focus group have reviewed the overall findings presented in this deliverable to ensure that the results are consistent with the experiences of the stakeholder who participated in that group. No major discrepancies were detected.

Conclusion

The extensive outreach process detailed in this deliverable has significantly informed the construction of the Learning Healthcare Network battery, ensuring that the data to be collected during the project is feasible to collect and as clinically meaningful as possible. This process has significantly improved our understanding of what stakeholders consider important data to collect during early psychosis care and how to collect it. In addition, it has reinforced the collaborative ethos of the project that has underpinned it since its inception.

The preliminary findings of the results detailed in this deliverable were presented to the national EPINET Executive Committee meeting on February 6-7, 2020, which included the five EPINET hub Principal Investigators, NIH program officers, and the Westat National Data Coordinating Center. These findings significantly contributed to the standardization of outcomes for the national network. Consequently, this work has not only impacted how data will be collected across the California EPI-CAL programs, but it has also informed the national conversation around what data should be considered to be important and meaningful to stakeholders. This work has therefore ensured that the voices of California early psychosis program stakeholders have been heard on the national level.

Throughout the implementation of the focus groups, providers, family members, and clients were all highly engaged in the process, and very keen to share their perspectives on how this project should move forward. This collaborative approach appears to have further supported stakeholder buy-in, laying the foundation for an improved product that can better serve the needs of California early psychosis program clients and families.

Next Steps

The recommendations detailed in the deliverable above will be incorporated into the final Early Psychosis Network data collection battery, and once the final list is compiled and approved by the executive committee, the data collection system will be piloted in two EPI-CAL early psychosis programs.

Acknowledgements

The authors would like to acknowledge the support of a number of individuals that supported the implementation of this project. Dr. Mark Savill, Dr. Sabrina Ereshefsky, Kathleen Nye, Dr. Karina Muro, Lindsay Matthews, Renata Botello, Dr. Valerie Tryon, and Dr. Tara Niendam facilitated the focus groups. Lindsay Matthews, Kathleen Nye, Renata Botello, Gabi Gonzales, Julianna Kirkpatrick, Romi Yount, Adrienne Maguire, Vivienne Alcantar, Christopher Blay, San Sadler, and Janet Mendoza were involved in the cleaning of the focus group transcripts. Dr. Sabrina Ereshefsky, Lindsay Matthews, Kathleen Nye, Dr. Mark Savill, and Dr. Valerie Tryon were involved in the coding of the transcripts. Finally, the authors would like to thank all the participants who agreed to take part in the qualitative focus groups and interviews, and all the program staff

who assisted in the logistics and participant recruitment that made these groups possible.

3.4 Development of the Beehive Application and the End User Licensing Agreement

During the design phase of the project, the EPI-CAL team conducted extensive qualitative research in order to engage various stakeholders and utilize their valuable feedback to shape the development of the Beehive application and its implementation in diverse clinical settings. We received qualitative feedback throughout the development of this custom application in three different types of qualitative focus groups: wireframe focus groups, alpha testing groups, and data-sharing/end user license agreement (EULA) focus groups. We have conducted a total of 23 focus groups spanning these three focus group types in order to get detailed feedback and suggestions for the application and dashboard from EP program staff, EP program consumers, and their family members.

Wireframe focus groups

Quorum and the EPI-CAL research team have worked collaboratively to develop the wireframe for the tablet and web-based applications. The UC Davis team used these storyboards as materials for focus groups to obtain feedback on the application and dashboard's design, flow, and functionality.

Methods

We conducted a total of 16 wireframe focus groups. Each group was 90 minutes long and categorized by the types of participants, including research staff, clinic providers, clinic administration, consumers, and their family members. Two groups were held with research staff and data experts (12 participants), six groups were held with providers at EP programs (36 participants), three groups were held with clinic administrators (20 participants), one group was held with both EP providers and clinic administrators (nine participants from Los Angeles County programs), and four groups were held with consumers and families (17 participants; see Tables 1 & 2). We did not meet separately with consumers and families for these groups, but instead held combined groups for consumers and families to attend together. Due to COVID-19, all focus groups were conducted over video conferencing (Zoom or WebEx). To maximize convenience and availability for staff during this time of transition, multiple groups were scheduled and open to participation from staff at any EPI-CAL clinic. Many of the groups had representation from multiple clinics in the network, which allowed for the study team to better understand the differing needs and environments of programs in the network. During each group, EPI-CAL research staff presented various aspects of the application storyboard, which allows for visualization of the look, feel, and functionality of the application prior to development. Each presentation was tailored to demonstrate scenarios pertinent to how specific users (i.e., providers, clinic administration, consumers, and families) will interact with the tablet and web applications. We asked for feedback on the look and feel of the application, the functionality of the application as it relates to the current EP program workflow, and ease of use and acceptability for both consumers, support persons, and staff.

Table XXXVI

Total Wireframe Focus Groups	**16**
Research Focus Groups	2
Provider Focus Groups	6
Clinic Admin Focus Groups	3
Provider & Clinic Admin Focus Groups	1
Consumer & Family Focus Groups	4

Table XXXVII

Total Participants*	**94**
Research	12
Providers	36
Clinic Admin	20
Providers & Clinic Admin	9
Consumer & Family	17

**Participants could attend more than one group*

Results

Our research team discussed and synthesized the feedback for the application developers to support application development. When integrating the feedback into application development, we endeavored to balance consumer and family needs with provider and staff needs. Overall, stakeholders approved of the look and feel of the application. Some stakeholders (both consumers and providers) noted that the color scheme and layout seemed overly clinical. They suggested, specifically when presenting surveys, to bring in more color, engaging imagery, and visual information. Occasionally, stakeholders disagreed on whether certain visual aspects of the application were acceptable or not. For example, several providers and family members raised the concern that the current images (drawings of individuals who do not have facial details drawn in) would be disconcerting or upsetting for consumers. However, when we asked consumers about this, they said they felt either neutrally or positively about these images. Often, stakeholders unanimously agreed on an aspect of the user interface that should change, such as changing the color of the survey progress bar in the tablet application to be more prominent.

Stakeholders provided several suggestions to improve integration of the application into their EP clinic workflow and procedures. After demonstrating the process of registering a new consumer in the tablet, clinic staff, consumers, and families alike emphasized the importance of having an option for clinic staff to pre-register consumers if they gather registration information over the phone prior to the consumer's first visit in the clinic. Stakeholders agreed this would reduce burden on the consumer and demonstrate that the clinic was well organized and listening to the information consumers and family members had already provided.

Some stakeholders provided feedback specific to their role in the clinic. For instance, participants in a focus group with clinic administrators from various programs suggested that demographic information that clinic staff regularly report to their county, for example, be visualized on the clinic administrator dashboard. We subsequently built in data visualizations for race, ethnicity, sex, gender identity, and other metrics which clinics are commonly asked to report. On the other hand, consumers and their family members, from their unique perspective as consumers, nearly unanimously agreed that when viewing data visualizations on the web application with their provider, they would not like to see the results of the symptom survey as the default display. They instead preferred to see a more recovery-oriented measure, such as the Questionnaire about the Process of Recovery (QPR), when first looking at their survey responses. Based on this feedback, we will set the QPR to be the default data visualization presented when a provider is clicking into a consumer's data on the web application.

During focus groups with Los Angeles County stakeholders in August 2020, our team also asked for feedback about how to adapt both the data collection and data visualization components of the application for use with telehealth. Multiple EP staff participants agreed that a remote data collection option, which would allow consumers to complete surveys from home, would be ideal. Consumer and family stakeholders agreed with providers for the remote option, but and were split between their preference for a mobile application or a personalized link that could be emailed or texted from their provider. Consumer and family stakeholders said they would prefer to look at their data with their provider and would not necessarily want individual access to look at their results from home.

Alpha Version Focus Group

We held a focus group for stakeholders to review the alpha version of the Beehive application to elicit valuable feedback from our stakeholders on the development of the Beehive application. This feedback was valuable as it was the first opportunity for stakeholders to review the application in a production environment, rather than wireframes or plans.

Methods

On October 22, 2020 the EPI-CAL team conducted a focus group with four staff members from an EPI-CAL clinic (SacEDAPT) including a clinician, two peer case-managers, and a clinical supervisor. The focus group began with a demonstration of survey-completion on the tablet application and a demonstration of navigation around the web application, including registering a new consumer and viewing consumer survey data visualizations. Focus group attendees were asked for their comments and questions on the application. They were asked to think about the feasibility of the integration of the application within their current clinic workflow and ease of use. After the demonstration, the focus group attendees logged into the alpha version of the application and were able to test out functions such as consumer registration and data visualization.

Feedback

Focus group participants made suggestions to improve the application, including changes to language, look and feel, features, and information presented to consumers (Table XXXVIII). The UCD team discussed these suggestions and the action taken is described in Table 3.

Table XXXVIII: Examples of Alpha Focus Group Feedback

Suggestion /Question Content Area	**Example**	**Outcome**
Language Used in Application	It is unclear that “primary language” during tablet registration refers to the tablet display language.	UCD team discussed and decided to rename this field to “Display language” to make this more clear.
Information Presented to Consumers	During consumer follow-up visits, a reminder should be added about confidentiality and how data will be used. This information is covered in detail at the first visit but consumers may forget after 6 months.	UCD team will plan to draft a message to returning consumers at follow-up visits that will remind them of confidentiality and how data will be used.
Application Feature	Will consumers have the option to visualize any service that they deem important as part of their treatment, for example, case management, or just the four options listed (medication management, individual therapy, group	UCD team to discuss this feature with developers. It is not part of alpha and is not yet functional, but there will be variation at the program-level and consumer-level services offered and received, so

	therapy, education/employment support)?	flexibility in this visualization will be needed.
Look and Feel of Application	The image that appears during survey completion does not represent people of color.	While there is diversity of sex/race/ethnicity in the images throughout the survey modules in the application, it is currently showing the same image repeatedly for each survey question. UCD team to ask developers whether different images can appear during each survey to avoid over-representation of one sex/race.

Data-sharing & EULA focus groups

To develop the End User License Agreement (EULA) and presentation of data-sharing options for Beehive, the EPI-CAL team conducted a series of six focus groups to gather stakeholder feedback (n=24). Two different phases of groups were conducted: (1) Data-Sharing Preferences Focus Groups, and (2) EULA Focus Groups. Each type of group was conducted three times with a different group of stakeholders in EPI-CAL EP clinics: (1) providers and clinic staff (n=14), (2) consumers (n= 6), and (3) family members and support persons of consumers (n=4). Some stakeholders attended both phase 1 and phase 2 groups.

Focus groups were conducted remotely via web conferencing (Zoom for the provider group, WebEx for the consumer and family groups), each lasting approximately 90 minutes. Informed consent was collected before the groups.

Phase 1 focus groups

These three groups were conducted in August 2020 to understand stakeholders' views on how their personal health information is and should be used. The introduction to the discussion topics began with a brief description of the EPI-CAL study and a review of definitions of key terms (e.g., privacy, confidentiality). The first part of the discussion focused on stakeholders' understanding of and perspective on data sharing. The second part focused on stakeholder's understanding of and perspective of changing sharing options (i.e., "living informed consent" and "the right to be deleted"). The third part of the discussion focused on stakeholders' understanding of and perspective on sharing different types of data (i.e., identifiable vs. de-identified) at different levels (i.e., individual- and group-levels).

Using notes and preliminary analysis of the transcripts from these focus groups as guidance, the EPI-CAL team developed the materials for the EULA focus group, described below. In general, stakeholders expressed that they were willing to share their de-identified data in order to "help others" (i.e., increase funding to their EP program or other EP programs, contribute to EP research that will improve treatment options for others, promote policy changes that increase accessibility to EP programs). They indicated that transparency of what data is collected, who has access to the data, and how it will be used is imperative for them to make informed decisions about data sharing. They also highlighted the importance of describing the data protections that are in place (i.e., laws and regulations) as well as knowing how the entity to which they are entrusting their data actually follows those laws and regulations. They expressed that giving them more control over their data (i.e., ability to access their own data, change their data sharing permissions, delete their data) would make them more comfortable sharing data.

Table XXXIX

Total Data-Sharing Focus Groups	**3**
Provider Focus Group	1
Consumer Focus Group	1
Family Focus Group	1

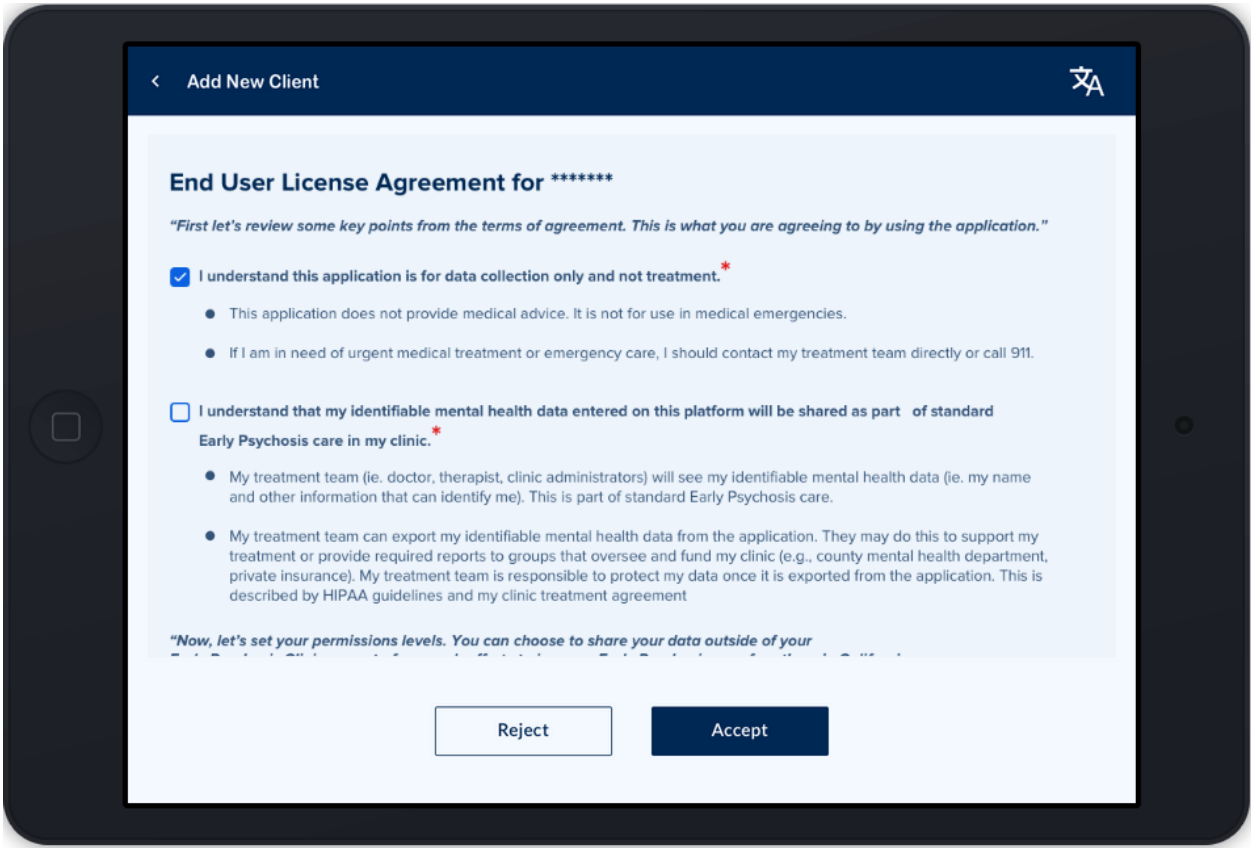
Table XL

Total Participants	**19**
Providers	9
Consumers	6
Family	4

Phase 2 Focus Groups

The three EULA focus groups were conducted in January 2021 to understand stakeholders' response to how the End User License Agreement (EULA) in Beehive is presented. First, participants were shown an informational video (YouTube link: https://www.youtube.com/watch?v=jzrVmToiGmo&ab_channel=EPI-CAL) created by the research team presenting the key points of the Beehive EULA. After watching the video, participants were asked their opinions about how the information was presented, what questions they still had after watching the video, and how they felt about this method of presenting a EULA. Participants were then shown a demonstration of how the EULA would be presented in the application (Figure 24), with a specific emphasis on the screen on which users may opt-in to data-sharing outside of their clinic for research purposes. Participants were asked for their perspective on how the information was written and presented.

Figure 24: EULA Demonstration



End User License Agreement for ***

"First let's review some key points from the terms of agreement. This is what you are agreeing to by using the application."

☑ **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 team 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

"Now, let's set your permissions levels. You can choose to share your data outside of your

In general, stakeholders thought that using a video to present the EULA was a creative approach that may help users to understand this information better than if they were simply presented this information in a written format alone. All stakeholder groups commented on how to further clarify the information provided.

Provider stakeholders made suggestions about slowing the pace of the video, simplifying visuals, and even culling information from the video to make it simpler. Consumers similarly commented that they would want the ability to pause the video and ask questions of a clinic staff member while watching the video.

In contrast to provider suggestions to remove information from the video to simplify it, consumers approved of the level of detail provided in the video. Consumers said the video helped them to understand the concepts presented. For example, one consumer indicated he had a very clear understanding of how data becomes de-identified by watching the video. Consumers even stated areas where they thought additional detail could be beneficial. For example, consumers thought the video should provide a bit more information about how Beehive would directly benefit them if they chose to use it as part of their care.

Family stakeholders likewise approved of the level of detail provided in the video. For example, they agreed it was important to include the level of detail currently present in the video to describe the relationship between National Institutes of Health (NIH) and EPI-CAL. All participants said the video helped them to have an understanding of the research scope of EPI-CAL and how the data may be used at the national-level as part of the NIH funded study.

When presented with the Beehive EULA screens, stakeholders thought that the written information on data sharing was consistent with the information presented in the video. Stakeholders provided suggestions to change text and formatting. All stakeholder groups agreed that it needed to be made clearer what was optional (e.g., sharing de-identified data with UC Davis researchers) and what was required (e.g., acknowledging that that the application is for data collection, not treatment). A suggestion on how to do this simply would be to add "(optional)" to the text on those statements, rather than relying on a lack of asterisk to indicate that it is optional. One provider stakeholder suggested requiring a response of yes or no for the options to share data with research, rather than a checked box meaning "yes" and a blank box meaning "no."

The research team used feedback from these groups to update the EULA video and EULA screens in Beehive. Some changes were implemented for Beta testing (e.g., providing more information about how Beehive may directly benefit users) and others will be considered for future versions of the application (e.g., re-formatting Beehive EULA screen). User feedback from Beta testing will help the team to prioritize what changes to implement moving forward.

Table XLI

Total EULA Focus Groups	**3**
Provider Focus Group	1
Consumer Focus Group	1
Family Focus Group	1

Table XLII

Total Participants	**14**
Providers	8
Consumers	3
Family	3

Summary

The extensive, iterative, feedback-process detailed in the qualitative section of this report has significantly informed the construction of the Beehive application. We find community partner feedback extremely valuable as it ensures that aspects of the application are designed and built with the end-user in mind, increasing the likelihood that other users will find the product useful and valuable. This process has significantly improved our understanding of what different groups of stakeholders consider important in a data-collection application to be used in early psychosis care. In addition, it has reinforced that a collaborative approach is foundational to the success of this project.

3.5 Gather feedback from interviews with EP community partners about their experiences of integrating Beehive and the measurement-based approach care in EP service delivery.

Background

Implementing measurement-based care in behavioral health settings can come with numerous benefits(Lewis et al., 2019). These can include improvements in service user-provider communication, help in identifying previously undetected needs, and support for service improvement efforts(Jenkins, 1996; Priebe et al., 2015). Furthermore, when data is actively incorporated into care, it can lead to positive treatment outcomes for service users such as improved quality of life.

However, implementing measurement-based care can be challenging, both in terms of data collection and utilization(Lewis et al., 2019). Barriers that have been identified can include finding the service-user time to complete data collection(de Beurs et al., 2011; Lewis et al., 2019), the impact of service-user symptoms(Lavallee et al., 2016), practitioner attitudes, administrative burden(Jensen-Doss & Hawley, 2011), high staff turnover, and a lack of incentives(Boswell, Kraus, Miller, & Lambert, 2015). Some of these challenges may be particularly acute in the early psychosis setting. For example, the intake assessment process for EP programs can be extensive, with significant emphasis given to rapid referral and intake procedures (MacDonald et al., 2018). As a result, including additional data collection efforts during the intake process may be in direct conflict with these goals. In addition, it is common for service users to experience symptoms such as cognitive impairment, intrusive delusions and hallucinations, and amotivation(American Psychiatric Association & Association, 2013), all of which may make completing multiple service-user-reported outcomes difficult.

To understand the acceptability of utilizing the Beehive platform in early psychosis, and the barriers and facilitators to implementation, the EPI-CAL team conducted a series of interviews with providers across the network. The work to interview service users to explore their experiences of utilizing Beehive in care is ongoing.

The interviews focus on each stage of the Beehive process, from registering new clients, to client enrollment and indicating data sharing preferences, inputting data into the system, and then utilizing the collected data as part of program delivery. Barriers, solutions, and potential facilitators to effective Beehive implementation were explored at each of these stages. Service users are currently being interviewed to understand their experiences of interacting with Beehive, and its impact on the nature of the care they received.

Overall, the primary aims of this investigation are 1) to identify methods by which to improve the implementation and impact of Beehive both in individual clinics and across the network of EPI-CAL, and 2) to develop generalizable knowledge of utilizing applications such as Beehive as a method to integrate measurement-based care principles into early psychosis care settings.

Methods

Design

A qualitative interview project was conducted to explore provider experiences of utilizing the Beehive platform and attempting to adopt measure-based care in an early psychosis setting. Efforts to interview service users to understand their experiences of care are currently ongoing.

Participants

Early psychosis service users and clinic staff across all EPI-CAL programs were eligible to participate. The only additional inclusion criterion was the requirement for the participants to have activity engaged in utilizing

Beehive. For providers, this could include registering clients into Beehive, supporting clients with the EULA process, assisting clients/support persons with data collection either at baseline or at follow-up, integrating Beehive data into the provision of care, and/or supervising those charged with conducting these activities. For service users, this could include navigating the EULA process, entering data into Beehive, and/or knowingly receiving care informed either by the Beehive app, or the data provided.

For the provider interviews, stratified purposive sampling has been employed. This means that efforts have been made to recruit participants across all programs to explore potential differences in how programs have implemented Beehive. At the provider level, we actively recruited those who had engaged with Beehive to various degrees to fully explore the barriers and facilitators experienced in its adoption. Based on program feedback throughout the project, it has been evident that University programs that primarily utilize private insurance, and community clinics that utilize Medi-Cal and block grant funding have faced unique challenges integrating Beehive. Consequently, there has been an attempt to interview a substantial number from both settings. Finally, intake-coordinators, licensed clinicians, and senior management were actively recruited to ensure that all aspects of the implementation of the Beehive application were considered.

Procedures and Data Analysis

Before conducting the interviews, the qualitative team developed topic guides for provider and service user participants. Questions focused on overall impressions of the Beehive platform, in addition to their experiences of each step in the Beehive process (training, enrollment, registration, data collection, and use of data in care). Open-ended questions were used to provide an opportunity for providers to describe a wide range of impressions and experiences as they adapted to new challenges and opportunities. Once a first draft of the guides was completed, they were reviewed and edited by the wider EPI-CAL team, including point persons, program coordinators, and senior leadership both in clinical and non-clinical roles.

Approximately one year into Beehive implementation, providers were contacted to participate in the interviews. Prior to the study initiation, UC Davis IRB approved all procedures. All interviews were conducted via video conference, at a time most convenient to the participant. Prior to the interview starting, all participants signed a consent form. Participants were compensated $30 for their time, as permitted by county policy. Prior to recruitment, all study procedures were reviewed and approved by the UCD IRB, in addition to county offices as required.

Up to two investigators from the qualitative research team have been involved in each interview. After each interview was completed, two qualitative research team members met briefly to discuss possible preliminary themes and refine the interview guides, as appropriate. All interviews were audio recorded and transcribed, with any identifying information removed prior to analysis.

In the analysis, an inductive approach to thematic analysis has been used to analyze the interview transcripts (Braun and Clarke, 2006). The analysis of the provider interviews is still ongoing, using the software package NVivo 12. The analysis of the service user interviews will take place once the recruitment has been completed.

Each preliminary theme is presented with supporting quotes from the transcripts. In the quotes presented, some were amended by the authors to anonymize responses, remove crosstalk, and to elucidate pronouns. In these instances, the edits were indicated though the use of square brackets (“[ ]”).

Findings

As of 12/13/2023, 32 providers across 16 programs participated in an interview. In addition, two interviews with service user participants have been completed, with another one scheduled. In total, 40 service user interviews will be conducted, with recruitment taking place over the next three months.

Provider participant details are summarized in Table XLIII. Of these, 12 interviews have been completed with providers that work in university programs that utilize a range of funding sources including private insurance, research grant funding, and in one case Medi-Cal billing, while 21 providers were based in community programs that are funded primarily through Medi-Cal billing and MHBG funding. A broad range of provider roles are represented, including clinicians (n=12), program managers and senior leadership (n=9), intake and program coordinators (n=5), supported education and employment specialists (N=2), and peers, research assistants, case managers, and administrative leads (n=4). In total, 78% of the sample identified as female.

Table XLIII: Provider Participant Demographics

Provider Participant Demographics	**N=32**	**%**
Programs		
UCD SacEDAPT	2	6
UCD EDAPT	1	3
UCD SacEDAPT & EDAPT	4	13
UCD EDAPT & MCC	1	3
Aldea SOAR Solano	3	10
Aldea SOAR Sonoma	1	3
Aldea SOAR Napa & Sonoma	3	10
Kickstart Pathways	1	3
IMCES 3 & 4	3	10
SFVCMHC	1	3
The Whole Child	1	3
The Help Group	1	3
OC CREW	2	6
San Mateo Felton re(MIND)	1	3
UCLA – Aftercare	1	3
UCSF PATH	1	3
UCSD CARE	2	6
Stanislaus LIFE PATH	3	10
Program Type		
University	4	13
Community	20	63
Both	8	25
Gender		
Male	7	22
Female	25	78
Other	0	0
Role		
Clinician Providers	12	38
Managers/ Supervisors	9	28
Coordinators	5	16
SEE Specialists	2	6
Other	4	13

Key: SEE, Supported Employment and Education, SFVCMHC = San Fernando Valley Community Mental Health Center, IMCES = Institute for Multicultural Counseling & Education Services, MCC = Multi-County collaborative, UCD = University of California, Davis, UCLA = University of California, Los Angeles, UCSD = University of California San Diego.

The provider interviews were broadly structured around the acceptability and feasibility of utilizing measurement-based care and the Beehive application in an early psychosis setting, and the barriers and facilitators to implementing such a model. A summary of the key themes is presented below.

Acceptability of Using Beehive to Support Measurement Based Care in an Early Psychosis Service Setting

Usability and Feasibility of using Beehive in EPI-CAL Early Psychosis Programs

Overall, the provider experiences of implementing measurement-based care and the Beehive application into their clinics was mixed. Regarding the application itself, some providers reported that the system is very easy to use, while others reported that they found it somewhat complicated, particularly setting up the graphs to track trajectories over time. These differences appeared to be attributable to two factors; one was the providers self-reported proficiency with tech, with some reporting a general unfamiliarity with apple products. The second appeared to be a feature of the degree of integration into their clinic procedures and the frequency in which they used it. Amongst most providers that reported frequently using the tool, many participants reported that it was easy to use and got easier to navigate over time. Amongst providers that did not frequently interact with the tool, either due to the lack of Beehive integration into their daily activities, or the small size of the clinic meaning they did not have frequent opportunities to use it, providers suggested that not only did they find the system difficult to navigate, but what they had learned from the training at the beginning of the project faded over non-use, resulting in it getting harder to use over time, as opposed to easier.

> *"I mean, it's pretty much easy to follow. It's, you go in, and you push the button, and they tell you which button to push, and you push it, and by golly, it works."*

Provider ID BF1000.

> *"It's fairly easy I would say. I've used Beehive a little bit longer now, so I think for me it's easier to navigate because I am familiar with it. I will say though, at the beginning it was a bit confusing just because it looks so, I know this sounds counteractive, but it just looks so clean and nice. I'm like, "where do I click? Where do I go?" I'm used to seeing links here, links there, but it was just so nice."*

Participant ID BF1024.

> *Because I don't do the Beehive every day, then the skills just diminish over time. So, that training just seems like it was so far away, I don't even remember.*

Provider ID BF1012.

Amongst providers that do frequently interact with the Beehive system, numerous benefits to utilizing measurement-based care in early psychosis were reported. On a program level, the data was seen to be useful to support supervision activities and external reporting. Providers also suggested the data collected can be effectively used in care in multiple ways. The self-report nature of much of the data collected was considered important, with multiple providers indicating that that this had led to new clinically relevant information about the service user that was not previously disclosed verbally, particularly during the assessment process. Additionally, for some providers the self-report format was considered helpful to supporting service user autonomy and adopting a service-users focused approach, where care decision making and evaluation can be rooted in their own responses, rather than clinician judgement.

Other areas that were identified as clinically useful include Beehive survey questions prompting clinically meaningful conversations; supporting the psychological education of service users, supporting clinical decision making, assessments, and care planning; and encouraging client reflection. For some providers, being able to present responses and their trajectories visually was considered important to aid communication and reflection.

> *"I'm supporting some of our trainees in their caseloads, whether that be therapeutic or assessment, I like that I can easily go in under a provider username or a client username and see all of their data as someone that's providing training and supervision. It's really helpful for me.[…] I think from a training perspective is really helpful for me to be able to support and monitor others' caseloads."*
>
> Participant ID BF1001.

> Interviewer:
>
> *"You mentioned risk information. I was wondering if there's anywhere else as well where the baseline data is helpful as part of your intake process?*
>
> Participant:
>
> *Yeah, I think there is also some trauma questions, those are super helpful. And then I find specifically for younger adults, if their collateral is coming in to complete Beehive with them, to see each of their understanding of trauma or of early life experiences and how that comes into play. So, I think that in itself is helpful. We get an understanding of the family dynamic also from looking at that data."*
>
> Participant ID BF1024.

> *"With time, as we work with them, they start to see how this tool, Beehive, helps them realize the progress that they're making. So, I know, for example, the early clients that have been part of filling out Beehive the longest, when they fill it out like, "Oh, I remember I wasn't answering the questions this way." And they get to see... Sometimes they don't realize the progress that they've made."*
>
> Participant ID BF1021

One feature of the Beehive system that was a frequent topic of conversation was the alert system, where if service users reported thoughts or plans of harm to self or others, the clinical team would be immediately notified via email. Overall, most providers suggested this notification was helpful, with some suggesting that it had improved risk assessment and response. Given its utility, some suggested that this could be extended to include other key indicators, such as changes in housing status or other basic needs. However, for some there was a concern that the alert system was over-sensitive, leading to unnecessary program action, and confusing the service user. To mitigate this, some suggested that modifying the threshold at which point a positive endorsement triggers an email alert would be helpful.

> *"Well, I'll tell you the most helpful is the clinical risk factors. The alerts that I get are really, really helpful, and really important. So, I get alerts, "Steven" does as well, I believe he's on those emails. We're able to see what clients have reported what, and then that informs... I mean we take immediate action whenever we get those, it informs our supervision with the clinician, we have to do immediate safety assessments and plannings."*
>
> Participant ID BF1010

> Participant:
>
> *"I thought of one thing that I would change, it just popped in my head, the danger to self-question is always, I think it's, since the last reporting period, have you experienced danger to self? Or something like that. Or thought of death or anything like that. When they say yes, it triggers everybody. But all*

> *these warnings go out, but when we get the person, they're like, "Well, remember that was five months ago when I had such and such?" So, it's like, if it can be fixed, so a follow-up question, has this occurred in the last blank time? To make it more relevant.*
>
> Interviewer:
>
> *So, I guess the threshold for a trigger is too low?*
>
> Participant:
>
> *Yes."*

Participant ID BF1018.

While some provider participants indicated that they did not see any drawbacks to utilizing the Beehive platform, some were concerned that the tool can take up valuable clinical time, and can impact establishing client report, particularly surveys that could be distressing.

> *"I haven't personally had any clients give any negative feedback or state any challenges."*

Participant ID BF1001.

> *"One more thing I want to say is that, it does impact rapport with the client. When they have to decide, "I'm going to lose his client, because I'm already having trouble engaging him, and now I'm supposed to try to get him to fill these forms out and he just doesn't want to do it." It is in the way of my treatment with the client. That can be a problem."*

Participant ID BF1000.

Summary of Acceptability of Beehive from the Perspective of Early Psychosis Program Providers

Overall, providers reported mixed experiences of integrating the Beehive system into their early psychosis program. Some providers reported that Beehive was easy to use and brought a multitude of benefits as a clinical tool, a supervision aid, and as a method to quantify clinic-level data. However, for other provider providers they suggested the tool was difficult to navigate and created a barrier to the effective delivery of early psychosis care. Given the variability of perceptions and experiences of using the tool, it is critical to explore barriers and facilitators to effective utilization to attempt to understand some of the root causes of this variability. Such work may provide important insights to support the improvement of implementation and effectiveness network wide.

<u>Barriers Implementation of Beehive and Measurement Based Care in and Early Psychosis Setting</u>

Regarding barriers to the implementation of Beehive and measurement-based care in an early psychosis setting more broadly, three main themes emerged. These include service user and family member challenges regarding data collection, provider level challenges, and barriers caused by technological challenges of the Beehive system.

Provider- Level Challenges

The most frequently reported provider-level challenge was lack of provider time. Many providers reported feeling burned out and overburdened, both by the demanding nature of clinical care that requires prioritization, and the extensive program, county, and state reporting requirements in addition to Beehive data collection needs. Multiple providers described a wish for the data systems to be more integrated, although amongst many there was a recognition of how challenging that might be.

Where lack of time for Beehive was particularly acute was in programs that reported being understaffed of trained clinical providers, or not having enough administrative staff support to implement Beehive procedures. The lack of administrative staff support was seen to be a particular issue in clinics funded by private insurance, as opposed to Medi-Cal billing, which included most university-based programs.

The impact insufficient provider time was considered problematic both in terms of finding the time to time to support data collection, and the time to learn the nuances of the system or integrate it into care. One solution proposed by some participants was for service users to complete more of the surveys at home, rather than during clinical time. However, while this appeared to be an effective solution for higher-functioning clients, for most this appeared to lead to Beehive surveys not being completed. Other proposed solutions included shifting more of the data collection responsibility from licensed clinicians to the administrative staff and shifting Beehive data collection to later in the intake process. While collecting the data later in the process meant that survey data could not be integrated into the intake assessment, which was considered a drawback, completing it later meant the service user and provider had gone through much of the exhaustive other administrative requirements, and had much more information on the client, which meant the provider reported sections could be completed quicker. Notably, amongst clinics where the Beehive integration has been particularly effective, one has incorporated Beehive very early in the process, while the other initiates Beehive approximately 4-6 after the first appointment. This suggests that rather than there being a one-size fits all solution, tailoring the approach to best fit individual clinic procedures may be necessary.

> *“I think that adds to the staff feeling a little bit burned out. Now I've got to, like, do the phone call, or schedule the in-person, or do all of this, just so I can get that data. And then, I've got to put that data four different places, and now three hours are gone kind of a thing.”*
>
> Participant ID BF1001.

> *I have *this much time* to dedicate to stuff like that. So, if it's going to be more complicated than that, then it gets pushed to the bottom of list because there's more pressing things that are important. The clinical aspect of things, and the Medi-Cal paperwork and all that stuff, those take precedent over everything else. So, if that's going to be super complicated, and it's going to need me to take time, it almost pushes it off the list.*
>
> Participant ID BF1012.

> Interviewer:
> *“Having that four-to-six-week delay before Beehive is brought in, do you think that's helpful, or do you think they're moved on and just want therapy […]?*
>
> Participant:
> *I think it's quite helpful because by the time the clinician enters the data, we've basically done all of our screenings, and so we just go in and punch in all the answers.”*
>
> Participant ID BF1018.

Challenges Experienced by Service Users in Data Collection

Provider participants reported different experiences of the Beehive data collection procedures. For some, they reported that the service users they worked with did not experience substantial barriers to completing the Beehive survey packets, and in most cases, these were completed successfully. However, for others they reported that the service users they worked with experienced multiple significant challenges. Factors associated with challenges included the exhaustive nature of the intake process into their programs, the service user and support persons wanting to prioritize urgent clinical and psychosocial needs over data collection, symptoms associated with psychosis such as paranoia and negative symptoms, resistance being reflective of wider ambivalence around early psychosis care, and service user concern about how data would be used, particularly for those with undocumented family members.

> Interviewer:
> *Are they fairly receptive to coming back and doing that [Beehive data surveys], or is it, "oh god, I'm doing this yet again?" What's their feedback you get from that?*
>
> Speaker 2:
> *I haven't hit any resistance with them doing it with me.*
>
> Participant ID BF1012.

> *"I think it's been really difficult for the clients, from what I've heard. Because here people who just want help and they're not thinking clearly, and they're already burdened, and we already make them sign a bazillion forms and now they have to come in and fill out a bunch more forms.*
>
> Participant ID BF1000.

> *"I know one of the clients, for example, very highly paranoid. For example, her parents are undocumented, so that paranoia is there. "We don't want to give out more information than is needed.""*
>
> Participant ID BF1021.

For many of the challenges, doing the Beehive surveys later in the process, prioritizing key survey batteries first, and breaking up the data collection process over multiple sessions was seen as an effective solution to mitigate some of the identified barriers. Going forwards, some providers suggested that revising and reducing the length of the battery may be helpful to support future implementation. Another solution adopted by some clinics involved the greater provision of provider support, be it from intake coordinators, supported education and employment specialists, or licensed clinicians. This additional support was considered important to explain benefits of data collection to an individuals' care, provide reassurance and transparency around data protection, and to develop greater rapport, which was recognized as an important facilitator to Beehive engagement. However, while additional provider time was identified as an effective solution, it is important to note that providing this was considered very challenging for some programs where clinicians reported feeling burned out or programs understaffed.

> *"It's a little bit easier getting them in the second or third session. Just because having an interview with us for two hours is pretty exhausting for the participants in the first place and asking lots and lots of sensitive questions."*
>
> Participant ID BF1012.

> *"I let them know, "This is a tool to help you find more information about yourself and other specialists. It's how we tie it in that we communicate with specialists to help you on your treatment." So, focusing it back on them, and the benefits of that. Because they usually worry about who's going to take my Social Security number or who's going to use this information, and sort of, bringing it back to them."*
>
> Participant ID BF1021.

Technology Related Challenges of the Beehive System

The third barrier identified by multiple providers concerned bugs and other technological issues with the Beehive application. The issues identified included challenges logging on to the system or view the end user licensing agreement (EULA) video, not being able to proceed through the survey packets, pages being very slow to load, and the software not being optimized for cellphones, which is frequently how service users accessed Beehive when not in the clinic. These technical issues were considered source of frustration to providers, service users, and support persons, and were seen as important factor in participants refusing to use the system. In situations where service users and support persons experienced tech issue and persevered, this could lead to less time available to focus on clinical care. However, while this was identified as problematic, it is notable that these were much more of a feature of the interviews earlier in the project, and in more recent interviews participants indicated that either the bug issue has substantially improved over time after multiple software updates, or that as new staff members they hadn't particularly noted bugs as an issue. Another effective solution identified by some participants included the distribution of the hotspots, which helped address connection issues particularly when working with service users in the field.

> *"I can't get it to upload. I'm trying to get it to upload. I can't watch it. Sometimes we just have to forego it because people can get surprisingly frustrated to where they're like, "Forget it. I don't want to do this anymore." Just because they're tired of trying to act with it. So, we'll just have to forego it."*
>
> Participant ID BF1001.

> *"Well, how I feel is my honest opinion is when I'm doing the Beehive in my session is I've wasted my time with my kiddo. I should be doing psychosis related stuff. And I've spent a half or three quarters of it just trying to log in with the Beehive app with them."*
>
> Participant ID BF1012.

> Interviewer:
>
> *"How is the tablet working would you say?*
>
> Interviewee:
>
> *We've had issues for sure. It seems like recently things have been better. A lot of the bugs seem to have been okay. It seems like when I first started, there was a lot of, "they can't get the tablet to work, they can't log in on the tablet. We don't know why." It was a lot of trial and error as far as that goes, but now it seems like every time we're using it with them, it's going a little more smoothly."*
>
> Participant ID BF1025.

Facilitators to Beehive Implementation and Measurement Based Care in and Early Psychosis Setting

Regarding facilitators to the effective implementation of Beehive, two main themes emerged. These included EPI-CAL research team related facilitators, and program-related facilitators. A summary of each is provided below.

Program Related Facilitators

Multiple provider participants emphasized the importance of support from administrators that worked in the early psychosis clinics. Depending upon the clinic, this support took on different forms, from actively supporting enrollment and service user data collection, to replacing service user anonymized ID codes with identifiers in secure clinic correspondences and adding data collection calendar reminders to make the process easier for clinics to keep on top of Beehive related tasks. In clinics that serve privately insured individuals less administrative support was available due to billing restrictions, and this was considered a major barrier to effective Beehive implementation. Another critical program-level facilitator identified by multiple participants was the importance of leadership support and prioritization of the project. Across the clinics, it was notable that data collection Beehive utilization in care was much more consistent and effective in programs where program leadership were active and vocal in their support of the project.

> *“Your staff will not understand the importance of it until the supervisor actually gets them on board by letting them understand the importance. And our agency understands the importance. We've had a lot of support from our nonprofit agency.”*
>
> Participant ID BF1018.

> *“All the training was really helpful, but I think really just doing it, getting the clients in, figuring out where in our intake process we can also start introducing Beehive, who really has the capacity to do extra tasks along the way to get this integrated, that was really helpful. And I think that's why the program coordinators have taken on so much, because the clinicians just couldn't. And I think when it was first rolled out, it was like, "Okay, the clinicians and the client will start this together." And it wasn't happening. We were just juggling too much, so I think it was the insight of the supervisors to really pull back and see who could actually implement Beehive in a successful way, and then what could the clinicians do with the data after.”*
>
> Participant ID BF1015.

> Participant:
> *Because she [the admin manager] goes through all that, deciphers it so we don't have to look up numbers, and then she adds it to all the calendars to make sure it's being kept up. And we have spreadsheets that has a lot of different information about clients, and she also keeps that going so that it's updated.*
>
> Interviewer:
> *Great, so it sounds like the admin support that you have in your team has been a big facilitator to getting this ongoing stuff done. […]*
>
> Participant:
> *Yeah, it's made it a lot easier.*
>
> Participant ID BF1018.

EPI-CAL Research Team Related Facilitators

Two important facilitators regarding EPI-CAL involvement, first is importance and utility of training. After that, consistent responsive follow-up helpful. Necessary to address the tech related barriers that were reported earlier in the deliverable, in addition to other implementation issues. Point people in particular very helpful. Noted that when the regular check-ins were implemented, this was particularly effective.

> *“But there have been lots of little things, but UCD or whoever it is that comes on every week at UCD is very helpful, very responsive, fixes the glitches, comes back.”*
>
> Participant ID BF1000.

> *“We have a short 10-minute check-in. We allow a half hour, but it's usually five, 10 minutes on a weekly basis if there's any issues. And when staff have run into issues, they just email her directly and we figure it out. We haven't had a whole lot of problems with it. She's been very receptive.*
>
> Participant ID BF1018.

The second major facilitator identified related to training. Most participants interviewed indicated that they found the training helpful, and address their primary need and questions to use Beehive in care. However, it was notable that in many programs, most of the staff since the training had left, highlighting the need for frequent refreshers. Additionally, some providers indicated that there was a long time between receiving the training, and then actually having service users enrolled in the system, which meant they had forgotten how to certain features of the application by the time it came round to using it in care.

> Interviewer:
>
> *"So, what has your experience been of Beehive training?*
>
> Participant:
>
> *Fantastic. The people from UCD are very, very clear. It's a very clear process. So, the training has been wonderful."*
>
> Participant ID BF1000.

> *"Because turnover's happening all the time. I just wish in a perfect world where I could see the future and know, hey, in a couple of months it's going to be stable and I'm going to be fully staffed, and those staff are going to stick around for a while. That would be a great time to come and do a refresher training, because those people are going to stick around and they're going to... But you don't know, I don't know."*
>
> Participant ID BF1010.

> Interviewer:
>
> *"I guess part of the challenge of the training is all of that happens before you start, but you can't really look at over time until you've been doing it at least six months, probably longer from start to finish. So, the very first time you're trying to remember something you probably did seven or eight months ago.*
>
> Participant:
>
> *Exactly. And by then we also have so much more information and training that's been downloaded into us that trying to pull that out of my memory feels impossible."*
>
> Participant ID BF1025.

Service User Experiences of the Beehive Application

To date, two service user participants have been interviewed about their experiences of using the Beehive platform as part of early psychosis care. The recruitment and interview of service user participants is still ongoing. At this stage, there is insufficient data to draw meaningful conclusions. That said, it is notable that in both interviews the participants indicated that the data collection process was feasible, appropriate, and did not negatively impact their experience of the program intake progress. At the time of the interview, neither participant had actively used the Beehive application in their care, so their experiences of using the data in care was not explored.

Conclusion

In total, 32 providers across 18 EPI-CAL programs were interviewed about their experiences of utilizing Beehive in early psychosis care. The data collected through this process highlight many notable benefits to Beehive and the adoption of measurement-based care in early psychosis settings. These include the collection and presentation of data that can support external reporting, service user assessment, risk management, care planning, and tracking and communicating progress with service users. However, substantial variability in both in the feasibility of implementation, and the perception of the benefits and drawbacks of adopting such an approach was found. Consequently, exploring potential barriers and facilitators to effective implementation is critical to identifying and potentially addressing some of the causes of this variability.

To support the implementation of Beehive, strong program leadership support, effective training with refreshers to support new staff, effective links with the EPI-CAL research team, the availability of clinical and administrative staff time dedicated to Beehive, strong tech support, and a plan for Beehive data collection tailored specifically to accommodate ongoing clinical and administrative requirements were all considered key facilitators to effective implementation.

Going forwards, we will continue the recruitment and interviewing of service user participants. Notably, amongst the two service user participants that were interviewed, neither considered the data collection process they navigated during their intake assessment problematic. If this is later found to be a consistent theme across the majority of our interviews with service user participants, this may be considered an important finding in support of the acceptability of the adopting Beehive in early psychosis care settings.

3.6 Summary

Integrating qualitative approaches to better understand community partner needs and experiences during healthcare innovation initiatives can serve multiple aims. These include supporting a co-design process that can improve community partner buy-in, feasibility, and utility, and supporting the implementation and evaluation of health care innovations. In EPI-CAL, ongoing and systematic feedback from partners has been critical to developing an outcomes battery that meets the needs and values of users, a usable data collection and presentation system that focuses on the clinical priorities of those delivering and receiving care, and process whereby barriers to successful implementation can be identified and addressed as they emerge. While the integration of the Beehive has been variable, these data collected throughout the process has led to substantive changes in the development and implementation of the process, re-orienting the project direction towards community partner needs. This approach has supported the successful implementation of EPI-CAL and may serve as a template to support the implementation of other innovations in healthcare delivery and the results have been disseminated in peer-reviewed publications (e.g., (Savill et al., 2024; Tully et al., 2023))..

Summary and Discussion

The EPI-CAL team has continued to meet each of the goals that were set to out for the original the multi-county Innovation project, which has grown to include other funding streams and additional counties over the years. The LHCN represents one of the first collaborative university-county partnerships between the University of California, Davis, San Diego and San Francisco with multiple California counties to implement and expand an integrated Innovation project. Through this endeavor, all parties hope to have a larger impact on mental health services than any one county can create on their own. The team feels confident that we have made excellent progress at implementation of an innovative mental health strategy.

Lessons Learned and Ongoing Development

As noted above in the qualitative and Beehive implementation sections of this report, there is quite a bit of heterogeneity in the ability of programs to implement the LHCN. This can be due to several factors, including but not limited to lack of perceived benefit, high staff turnover, and contracting delays. We’ve also experienced significant challenges due to the COVID-19 pandemic, which began one year into implementing the LHCN in California. The pandemic has had lasting effects on all participating California EP programs; most programs have not recovered to their full program capacity in the wake of the lasting effects of a global pandemic on the economy, mental health workforce, and clients seeking care. Programs have been trying to meet client needs even with several staff vacancies, and the lower client census numbers have reflected a reduced workforce. Even so, the EP programs have been great partners with our team in implementing the LHCN and actively contribute to problem-solving. For example, they continue to participate in qualitative interviews, as summarized above, to help provide insight on what is working well, and meet regularly with our team to address any active issues or challenges in real-time. Our team has learned that we cannot take a one-size-fits-all approach to implementation, and we must prioritize the input from programs in order to resolve issues rather than a standalone, top-down approach. While this approach has been effective, we've also learned that it takes quite a bit of time to implement in this manner. Additionally, this partnered approach and the structure of the LHCN doesn't allow our team to enforce consequences if objectives aren't met in a timely manner.

Over the course of implementing the LHCN in California, we've also identified the need to center Lived Experience/Peer Integration as well as Diversity, Equity, Inclusion and Accessibility (DEIA) because these two areas have been historically marginalized in early psychosis research and treatment work. We believe it is essential to center these two factors in our work to achieve equitable access and better access for all individuals with early psychosis and inform outcomes data collection and analysis. While early intervention approaches for First Episode Psychosis (FEP), such as coordinated specialty care (CSC), are generally associated with better outcomes than treatment as usual (Correll et al., 2018; Kane et al., 2016). Recent studies show that access to (de Pablo et al., 2024; Oluwoye et al., 2018) and outcomes from such services(Bennett & Rosenheck, 2021; Huxley et al., 2021) are lower for diverse and marginalized populations. This has prompted questions about how to ensure that individuals with FEP can quickly reach CSC care and which CSC components – and the quality of those components– produce positive outcomes and/or are most important for specific populations. Studies examining pathways to FEP care elucidate multiple barriers to access for most individuals (Cabassa et al., 2018). Based on census and estimated incidence data (Radigan et al., 2019; Simon et al., 2017), California would need over 350 CSC programs serving 75 individuals each – and current program availability can only meet 10% of that need. These numbers highlight the critical need to address access to and engagement in CSC services, and track the outcomes and effectiveness for those who do access care. The lack of service user and diverse community engagement in the development and execution of these programs have been cited (Breitborde & Moe, 2017; Pope, Jordan, Venkataraman, Malla, & Iyer, 2019; Read & Kohrt, 2022) as core contributing factors for understanding whether current CSC components provide equitable access to services and impact outcomes that are relevant to service users' view of recovery. Therefore, we are working hard to integrate the LEI and DEIA teams across all areas of our EPI-CAL program. This requires significant time and effort for the LEI and DEIA teams as well as a fundamental restructuring of the EPI-CAL team and its approach to its work across both the training and technical assistance (TTA) and LHCN components of the EPI-CAL program.

Continued Expansion of LHCN

At the time of this summary report, the Learning Health Care Network is an actively expanding network that continues to allow new programs to join the existing infrastructure. While at this stage programs will not be able to have input on the battery of outcomes to be collected or the initial design of the application, there are benefits to joining the project at this later stage. For example, counties joining at this later stage are joining at a time where the application for data collection, Beehive, has already been developed and data collection is active and ongoing. Therefore, new LHCN programs are able to hit the ground running with data collection and do not have to wait for the development stage of the project to transpire. In addition, our training approach to implementing Beehive in EP programs in well-established. We have refined our training approach over the years from continuous feedback on what works and what doesn't, and now administer both synchronous and asynchronous training materials to programs so that all staff members have an opportunity to participate in the LHCN data collection. Our team is starting detailed analysis on outcomes and what components of care influence client outcomes, and new programs joining the LHCN will be able to benefit from that information from the large statewide dataset to inform clinical practice in their own clinics. In summary, counties and their EP programs joining at a later stage of the project are benefitting from an established infrastructure.

In addition to the benefits to the program to joining an established Learning Health Care Network, the LHCN itself benefits from additional programs joining. There are more programs contributing data to the harmonized dataset, and the clients in each of the programs are unique to their region of California.

Conclusions

In summary, the Learning Health Care Network program was successfully implemented over the past five years and represents an innovative and unique academic, government, and community mental health partnership. Our team and our partners developed an innovative harmonized data collection and analysis strategy and prioritized community partner feedback. The partnership we've collectively created successfully met our goal to make a change to an existing practice in the field of mental health by introducing a collaborative LHCN to support quality improvements, consumer engagement, and provider use of measurement-based care in early psychosis (EP) programs. While the program has experiences setbacks and unique challenges, the EPI-CAL LHCN, in conjunction with our county and EP program partners, created a network of EP clinics in California and have contributed to quantitative and qualitative data collection that has helped inform consumer- and program-, county-, and state-level decisions and develop learning opportunities for individuals, staff, programs, and administrators, to improve consumer outcomes.

Appendix I: Data Elements Summary for all Counties Retrospective Data Pull

Table XLIV. Client and utilization data elements summary for all counties retrospective data

Data Type	**Data Element**	**Source**	**County Availability**
Non-identifying ID	Identifying client ID removed and new ID assigned	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Program Name	Program Name	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Psychosis – category	1) Clinical High Risk (CHR) and enrolled in treatment 2) First Episode Psychosis (FEP) and enrolled in treatment 3) Assessed and referred out during Jan. 1, 2017 – Dec. 31, 2019 (add reason, if possible) 4) Other and reason (e.g., incorrectly assigned to EP program)	Program	Data elements # 1 and # 2 available: Orange, LA, San Diego, Solano, Stanislaus Data element # 3 available: Solano; Stanislaus N/A: Orange, LA, San Diego Data element # 4 available: Solano, San Diego; Stanislaus N/A: LA, Orange All data elements TBD: Napa
Assessed and referred out - open ended	Assessed and referred out – reason	Program	Available: Solano, LA; N/A: Orange, San Diego TBD: Napa, Stanislaus
Other and reason - open ended	Other – reason	Program	Available: Solano, LA; N/A: Orange, San Diego TBD: Napa, Stanislaus
Diagnoses associated with the episode of care	Diagnosis – Psychiatric	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Diagnosis – Substance use	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Diagnosis – Physical health	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Date of birth	Year & month of birth (not date)	County/Program	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Location (client zip code)	Zip code (as of first EP service)	County/Program	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
Demographics	Race	County	Available: Orange, LA, San Diego, Solano, Stanislaus

(as of first EP service)			TBD: Napa
	Ethnicity	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Gender	County	Available: Orange, LA, San Diego, Solano TBD: Napa
	Education level	County	Available: LA, San Diego, Solano, Stanislaus; N/A: Orange TBD: Napa
	Marital status	County	Available: LA, San Diego, Solano, Stanislaus; N/A: Orange TBD: Napa
	Preferred language	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Insurance status (i.e., insurance type)	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Employment status	County	Available: LA, San Diego, Solano, Stanislaus; N/A: Orange TBD: Napa
	Living arrangement (housing status)	County	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Sex assigned at birth	Program	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Gender identity	Program	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Sexual orientation	County	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Military service / Veteran status	County	Available: Orange, San Diego, Solano, Stanislaus; N/A: LA TBD: Napa
	Foster care / Adoption	County	Available: San Diego, Solano; N/A: LA, Orange TBD: Napa, Stanislaus

Outpatient mental health services in EP program between Jan. 1, 2017 – Dec. 31, 2019	Date	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Duration	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service / procedure code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Funded plan (original pay sources, subunit)	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service location code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Facility code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Evidence Based Practices (EBP) / supported service code	County	Available: Solano, LA; N/A: Solano, Orange, San Diego, Stanislaus TBD: Napa
	Medi-Cal beneficiary	County	Available: Orange, Solano, Stanislaus; N/A: LA, San Diego TBD: Napa (claims person will have information on private insurance)
All other mental health services utilized by clients that started services between Jan. 1, 2017 – Dec. 31, 2019	Service / procedure code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Location code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Facility code	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service Date	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Evidence Based Practices (EBP) / supported service code	County	Available: LA; N/A: Solano, Orange, San Diego, Stanislaus TBD: Napa
	Service – Inpatient	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa (Inpatient hospitals: Crestwood BH, state hospital, Bella House (12 bed psychiatric

			transitional program), (Crestwood may serve minors))
	Service – Crisis residential	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa (Progress Place is the name of the crisis residential service in Napa County)
	Service – Crisis stabilization	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa (Crisis stabilization unit for Napa County is operated by Crestwood and serves both youth and adults)
	Service – Urgent care	County	Available: Orange, LA, San Diego, Solano, Stanislaus May be available: Napa
	Service – Long-term care	County	Available: Orange, LA, San Diego, Solano, Stanislaus TBD: Napa
	Service – Forensic services and jail services	County/Program	N/A: San Diego, Orange, LA, Solano TBD: Napa. Stanislaus
	Service – Referrals	Program	Available: Stanislaus; N/A: Solano, Orange, LA, San Diego TBD: Napa
	Service – Law enforcement contacts	Program	Available: Stanislaus; N/A: Orange, Solano, San Diego, LA TBD: Napa
	Service – Justice system involvement	Program	Available: San Diego, Stanislaus; N/A: Orange, LA, Solano TBD: Napa
	Service – Regional center involvement (any developmental issues)	Program	Available: San Diego, Stanislaus; N/A: Orange, LA, Solano TBD: Napa
	Service – Substance use services	County	Available: Orange, Stanislaus; N/A: Solano, San Diego, LA TBD: Napa

*Note: The availability of these data elements is still being finalized.

Appendix II. Algorithm Used to Determine Index FEP Diagnoses

1. If present, the psychotic disorders listed below will always be the index diagnosis:

    - F20.0 Paranoid schizophrenia (ICD 9: 295.12)
    - F20.3 Undifferentiated schizophrenia (ICD 9: 295.15)
    - F20.81 Schizophreniform disorder (ICD 9: 295.21)
    - F20.9 Schizophrenia (ICD 9: 295.23)
    - F22 Delusional disorders (ICD 9: 295.25)
    - F23 Brief psychotic disorder (ICD 9: 295.30)
    - F25.0 Schizoaffective disorder, bipolar type (ICD 9: 295.32)
    - F25.1 Schizoaffective disorder (ICD 9: 295.33)
    - F25.9 Schizoaffective disorder, unspecified (ICD 9: 295.35)
    - F28 Other psychotic disorder not due to a substance or known physiological condition (ICD 9: 295.40)
    - F29 Unspecified psychosis not due to a substance or known physiological condition (ICD 9: 295.41)

2. If no psychotic disorder is present, these mood disorders with psychotic features will be the index diagnosis

    - F31.64 Bipolar disorder, current episode mixed, severe, with psychotic features (ICD 9: 295.82)
    - F31.5 Bipolar disorder, current episode depressed, severe, with psychotic features (ICD 9: 295.73)
    - F31.2 Bipolar disorder, current episode manic severe with psychotic features (ICD 9: 295.64)
    - F33.3 Major depression with psychotic features (ICD 9: 296.20)
    - F32.3 Major depressive disorder, single episode, severe with psychotic features (ICD 9: 296.06)

Appendix III.

Demographic Characteristics

Table XLV. Demographics of Individuals included in Analysis

	Early Psychosis (N=506)		**Comparator Group (N=17,092)**			
	n	**%**	**n**	**%**	**X^2**	p-value
Sex						
Male	300	59%	10,345	61%	2.04	0.564
Female	206	41%	6,672	39%		
Other	-	0%	46	<1%		
Unknown	-	0%	7	<1%		
Gender Identity						
Male	288	57%	9,783	60%	407.99	<.001
Female	185	37%	6,391	39%		
Transgender	3	<1%	61	<1%		
Other	10	2%	33	<1%		
Prefer not to Answer	2	<1%	11	<1%		
Unknown	15	3%	6	<1%		
Sexual Orientation						
Heterosexual	232	69%	2,624	68%	51.40	<.001
Gay/ Lesbian	9	3%	86	2%		
Bisexual	31	9%	109	3%		
Other	16	5%	116	3%		
Prefer not to Answer	17	5%	324	8%		
Unknown	32	9%	577	15%		
Ethnicity						
No - Not Hispanic/Latino	205	41%	9,426	55%	62.57	<.001
Yes - Hispanic/Latino	285	56%	7,507	44%		
Unknown	16	3%	153	1%		
Race						
White	137	27%	2,894	17%	356.83	<.001
Black/African American	67	13%	2,791	16%		
Asian	32	6%	627	4%		
American Indian/Native Alaskan	4	1%	114	1%		
Native Hawaiian/Other Pacific Islander	4	1%	114	1%		
Other	140	28%	1,328	8%		
Unknown	122	24%	9,208	54%		
Language						
English	448	89%	14,361	89%	1.42	.702
Spanish	47	9%	1,463	9%		

Other	8	2%	292	2%		
Unknown	1	<1%	93	1%		
Education level						
Grade K-4	-	0%	739	9%	92.67	<.001
Grade 5 (completed elementary school)	41	12%	982	12%		
Grade 8 (completed middle school)	209	58%	3,027	38%		
Grade 12 (completed high school)	48	13%	856	11%		
Some college	32	9%	1,196	15%		
Completed college	2	1%	67	1%		
Graduate degree	2	1%	51	1%		
Prefer not to Answer	-	0%	14	<1%		
Unknown	24	7%	1,039	13%		
Employment Status						
Employed full time	8	2%	163	2%	51.83	<.001
Employed part time	30	7%	234	3%		
Student	280	65%	4,776	57%		
Unemployed, seeking employment	17	4%	311	4%		
Unemployed, not seeking employment	40	9%	1,551	18%		
Other	32	7%	596	7%		
Unknown	27	6%	782	9%		
Marital Status						
Single/ never married	396	97%	7,663	90%	22.39	<.001
Married	-	0%	95	1%		
Other	-	0%	46	1%		
Unknown	12	3%	698	8%		
Living Arrangement						
House/ apartment (No support required)	289	78%	3,634	63%	125.37	<.001
House/ apartment (Support required)	56	15%	346	6%		
Foster care	2	1%	91	2%		
Residential treatment	4	1%	271	5%		
Inpatient psychiatric hospital	-	0%	7	<1%		
Homeless	8	2%	785	14%		
Jail/ prison/ correctional facility/ juvenile hall	-	0%	198	3%		
Other	3	1%	134	2%		
Unknown	11	3%	325	6%		
Military Service/Veteran Status						
No	403	99%	4,612	99%	2.02	.155
Yes	5	1%	29	1%		
Diagnosis Category						
Psychosis Spectrum	405	80%	10,346	61%	84.47	<.001

Mood Spectrum	30	6%	3,618	21%		
Other	69	14%	2,646	16%		
Unknown	2	<1%	482	3%		

Table XLVI. Age of Individuals included in Analysis

	Early Psychosis		**Comparator Group**				
	Mean	**SD**	**Mean**	**SD**	***t***	***df***	**p-value**
Age	17.0	3.1	20.1	3.8	18.41	17596	<.001

Table XLVII. Proportion of Individuals Ending Treatment within each Time Period

	Early Psychosis		**Comparator Group**			
	n	**%**	**n**	**%**	**X^2**	**p-value**
≤6 months	219	43%	7,493	44%	162.14	<.001
7 to 12 months	140	28%	2,221	13%		
13 to 18 months	73	14%	1,762	10%		
19 to 24 months	50	10%	1,606	9%		
>25 months	24	5%	4,010	24%		
Total	506	100%	17,092	100%		

Service Utilization Characteristics

Outpatient Service Use

Table XLVIIIA. Total Minutes of Outpatient Services per Individual per Month

	Early Psychosis		**Comparator Group**			
	Mean	**95% CI**	**Mean**	**95% CI**	***z***	***p*-value**
Total minutes of outpatient services (per month)	452	417 - 488	296	290 - 302	8.63	<.001

Table XLVIIIB. Total Minutes of Outpatient Services per Individual per Month by Time Period

	Early Psychosis		Comparator Group			
	Mean	**95% CI**	**Mean**	**95% CI**	***z***	***p*-value**
≤6 months	537	493 - 582	287	281 - 292	11.11	<.001
7 to 12 months	455	403 - 508	305	297 - 314	5.58	<.001
13 to 18 months	433	375 - 491	313	302 - 323	4.02	<.001
19 to 24 months	321	261 - 380	299	288 - 309	0.71	.48
>25 months	297	218 - 377	285	274 - 297	0.29	.77

Table XLVIIIC. Total Minutes of Outpatient Services per Individual per Month by Service Type and Time Period

		Early Psychosis		Comparator Group			
		Total Minutes of Service per Individual per Month		**Total Minutes of Service per Individual per Month**			
		Mean	**95% CI**	**Mean**	**95% CI**	***z***	***p*-value**
Service date from enrollment	**Service Type**						
<6 months	**Assessment**	90	82 - 97	69	68 - 70	5.51	<.01
	Case Management	89	72 - 106	81	77 - 84	0.93	.35
	Collateral	139	121 - 157	62	60 - 65	8.44	<.01
	Crisis Intervention	66	49 - 83	125	121 - 128	-6.79	<.01
	Group Therapy	75	60 - 89	95	84 - 106	-2.37	.02
	Individual Therapy	238	215 - 260	171	165 - 176	6.00	<.01
	Medication Support	73	67 - 79	64	62 - 65	3.08	<.01
	Plan Development	47	42 - 52	48	46 - 50	-0.30	.76
	Rehabilitation	98	84 - 113	66	59 - 73	4.14	<.01
	Assessment	44	36 - 53	59	56 - 63	-3.55	<.01

7-12 months	**Case Management**	93	68 - 119	100	95 - 106	-0.52	.61
	Collateral	157	132 - 182	72	68 - 75	6.64	<.01
	Crisis Intervention	64	35 - 93	92	86 - 98	-1.86	.06
	Group Therapy	64	51 - 78	110	96 - 124	-4.94	<.01
	Individual Therapy	258	225 - 291	201	193 - 209	3.39	<.01
	Medication Support	64	57 - 71	55	54 - 57	2.34	.02
	Plan Development	39	31 - 46	53	50 - 56	-3.56	<.01
	Rehabilitation	106	89 - 122	79	68 - 89	2.59	.01
13-18 months	**Assessment**	50	37 - 64	60	57 - 63	-1.40	.16
	Case Management	69	50 - 88	105	99 - 111	-3.60	<.01
	Collateral	137	110 - 164	70	66 - 74	4.82	<.01
	Crisis Intervention	89	34 - 144	92	86 - 98	-0.10	.92
	Group Therapy	63	40 - 86	129	106 - 152	-4.12	<.01
	Individual Therapy	232	199 - 264	202	193 - 211	1.79	.07
	Medication Support	63	52 - 74	59	57 - 61	0.67	.50
	Plan Development	50	32 - 68	54	51 - 57	-0.43	.67
	Rehabilitation	108	84 - 132	80	69 - 92	1.94	.05
>19-24 months	**Assessment**	52	33 - 70	58	55 - 61	-0.66	.51
	Case Management	40	29 - 52	105	98 - 111	-9.59	<.01
	Collateral	132	92 - 172	67	63 - 72	3.15	<.01
	Crisis Intervention	58	50 - 66	81	74 - 87	-4.53	<.01
	Group Therapy	85	33 - 137	141	114 - 168	-1.88	.06
	Individual Therapy	222	181 - 264	198	189 - 208	1.13	.26

	Medication Support	68	53 - 83	59	57 - 61	1.18	.24
	Plan Development	44	22 - 66	49	46 - 52	-0.46	.65
	Rehabilitation	68	46 - 91	68	58 - 78	0.02	.98
25+ months	**Assessment**	57	30 - 84	46	43 - 48	0.82	.41
	Case Management	62	37 - 87	91	85 - 97	-2.21	.03
	Collateral	118	70 - 166	59	55 - 64	2.42	.02
	Crisis Intervention	66	-9 - 140	65	59 - 71	0.01	.00
	Group Therapy	97	85 - 109	124	100 - 147	-1.87	.06
	Individual Therapy	232	177 - 288	184	174 - 193	1.70	.09
	Medication Support	64	40 - 87	57	54 - 60	0.57	.57
	Plan Development	95	14 - 177	43	40 - 46	1.26	.21
	Rehabilitation	47	13 - 80	52	44 - 60	-0.29	.77

Day Service Use

Table XLIX. Day Services – Proportion of Individuals with One or More Visits

	Early Psychosis		**Comparator Group**			
Visit date from enrollment	**%**	**95% CI**	**%**	**95% CI**	***z***	***p*-value**
≤6 months	2.4%	0.017 - 0.032	5.0%	0.047 - 0.054	-6.24	<.001
7 to 12 months	1.8%	0.010 - 0.026	4.0%	0.036 - 0.044	-4.67	<.001
13 to 18 months	1.5%	0.004 - 0.025	4.7%	0.041 - 0.052	-5.43	<.001
19 to 24 months	0.4%	-0.003 - 0.011	4.2%	0.037 - 0.048	-8.33	<.001
>25 months	3.3%	-0.006 - 0.071	5.7%	0.050 - 0.064	-1.22	.222

Across All Time Periods	2.0%	0.014 - 0.026	4.7%	0.044 - 0.050	-7.93	<.001

24-Hour Service/Inpatient Hospitalization

Table L. 24-Hour/ Inpatient Hospitalization Services – Proportion of Individuals with One or More Visits

	Early Psychosis		**Comparator Group**			
Visit date from enrollment	**%**	**95% CI**	**%**	**95% CI**	***z***	***p*-value**
≤6 months	9.4%	0.067 - 0.121	24.8%	0.242 - 0.255	-10.83	<.001
7 to 12 months	7.7%	0.044 - 0.109	19.5%	0.186 - 0.204	-7.00	<.001
13 to 18 months	7.1%	0.026 - 0.116	21.4%	0.204 - 0.225	-6.10	<.001
19 to 24 months	5.4%	-0.005 - 0.114	19.5%	0.184 - 0.207	-4.57	<.001
>25 months	17.0%	-0.014 - 0.353	23.7%	0.191 - 0.216	-0.72	.472
Across All Time Periods	8.9%	0.061 - 0.118	22.4%	0.224 - 0.250	-9.03	<.001

Appendix IV. Service Code Definitions

These definitions are based upon the Medi-Cal Billing Manual published in September 2019 by the State of California—Health and Human Services Agency Department of Health Care Services, Mental Health Services Division.

Medication Support
Psychiatric medication-related services provided by nurse or physician including obtaining informed consent linked to providing Medication Support Services activities; instructions in the use, risks and benefits of and alternatives for medication; and plan development related to Medication Support Services. This may include services to client, family and caregivers.

Assessment
A service activity designed to evaluate the current status of a client's mental, emotional, or behavioral health. Assessment includes but is not limited to the following: mental status determination, analysis of client's clinical history; analysis of relevant cultural issues and history and diagnosis. The Server may be gathering information from a variety of sources. Interactive complexity includes the need to manage high reactivity, emotions or behavior of participants that interferes/complicates implementation or delivery of treatment services. It also may include mandated reporting such as in situations involving abuse or neglect. May include the use of play equipment, other physical devices, and interpreter or translator services.

Collateral
A service activity to a significant support person in the client's life for the purpose of meeting the needs of the client in achieving the goals of the client plan. May include but is not limited to consultation and training of the significant support person(s) to assist in better understanding of mental illness. The client may or may not be present for this service activity.

Plan Development
A service activity that consists of development of client plans, approval of client plans, and/or monitoring of a client’s progress. Includes team meetings for these purposes. Whenever possible, client should be present for these activities.

Rehabilitation
Individual: A service activity provided to a client and may include the following: counseling, assistance in improving, maintaining, or restoring an individual's functional skills, daily living skills, social and leisure skills, grooming and personal hygiene skills, meal preparation skills, and support resources; and/or medication education. If family or others are present, the focus of the session shall be on the client’s individual goals.

Group
A service activity provided to a group of individuals and may include the following: counseling, assistance in improving, maintaining, or restoring an individual's functional skills, daily living skills, social and leisure skills, grooming and personal hygiene skills, meal preparation skills, and support resources; and/or medication education. This may include clients with family (can be foster family) for example multi-family groups, clients with clients, or clients with others.

Individual Therapy
Psychotherapy conducted with a client: includes insight-oriented, behavior modifying and/or supportive psychotherapy. If family or others are present, the focus of the session shall be on the client’s individual goals.

Group Session/Group Therapy
Psychotherapy conducted with a group of individuals. Interactions among members are considered to be insight-oriented, behavior modifying and/or supportive. This may include clients with family (can be foster family) for example multi-family groups, clients with clients, or clients with others.

Case Management/Brokerage (CMB)
Case management services provided to assist the client to access needed housing, medical, educational, social, prevocational, vocational, rehabilitative, alcohol or drug treatment, or other needed community services. Includes targeted case management services of monitoring the beneficiary's progress toward client plan goals and placement services.

Crisis Intervention
Response to an unplanned event enabling client to cope with a crisis while maintaining his/her status as a functioning community member to the greatest extent possible. Includes related components such as assessment, evaluation, collateral contacts and therapy. Crisis Intervention is only provided to the client or the client with family present.

Non-Billable Codes

No-Show (Missed Visit)

Cancelled by Client

Cancelled by Program

References

American Psychiatric Association, D., & Association, A. P. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Vol. 5): American psychiatric association Washington, DC.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ, 322*(7294), 1115-1117.

Bennett, D., & Rosenheck, R. (2021). Socioeconomic status and the effectiveness of treatment for first-episode psychosis. *Health services research, 56*(3), 409-417.

Berwick, D. M. (2003). Disseminating innovations in health care. *Jama, 289*(15), 1969-1975.

Boswell, J. F., Kraus, D. R., Miller, S. D., & Lambert, M. J. (2015). Fostering collaboration between researchers and clinicians through building practice-oriented research: An introduction. *Psychotherapy Research, 25*(1), 6-19.

Breitborde, N. J., & Moe, A. M. (2017). Early intervention in psychosis in the United States: from science to policy reform. *Policy Insights from the Behavioral and Brain Sciences, 4*(1), 79-87.

Cabassa, L. J., Piscitelli, S., Haselden, M., Lee, R. J., Essock, S. M., & Dixon, L. B. (2018). Understanding pathways to care of individuals entering a specialized early intervention service for first-episode psychosis. *Psychiatric Services, 69*(6), 648-656.

Correll, C. U., Galling, B., Pawar, A., Krivko, A., Bonetto, C., Ruggeri, M., . . . Guloksuz, S. (2018). Comparison of early intervention services vs treatment as usual for early-phase psychosis: a systematic review, meta-analysis, and meta-regression. *JAMA psychiatry, 75*(6), 555-565.

de Beurs, E., den Hollander-Gijsman, M. E., van Rood, Y. R., Van der Wee, N. J., Giltay, E. J., van Noorden, M. S., . . . Zitman, F. G. (2011). Routine outcome monitoring in the Netherlands: practical experiences with a web-based strategy for the assessment of treatment outcome in clinical practice. *Clinical psychology & psychotherapy, 18*(1), 1-12.

de Pablo, G. S., Aymerich, C., Guinart, D., Catalan, A., Alameda, L., Trotta, G., . . . Rubio, J. M. (2024). What is the duration of untreated psychosis worldwide?–A meta-analysis of pooled mean and median time and regional trends and other correlates across 369 studies. *Psychological medicine, 54*(4), 652-662.

Farmer, T., Robinson, K., Elliott, S. J., & Eyles, J. (2006). Developing and implementing a triangulation protocol for qualitative health research. *Qualitative health research, 16*(3), 377-394.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research, 15*(9), 1277-1288.

Huxley, P., Krayer, A., Poole, R., Prendergast, L., Aryal, S., & Warner, R. (2021). Schizophrenia outcomes in the 21st century: a systematic review. *Brain and behavior, 11*(6), e02172.

Jenkins, R. (1996). Measuring outcomes in mental health: implications for policy. In *Mental health outcome measures* (pp. 227-228): Springer.

Jensen-Doss, A., & Hawley, K. M. (2011). Understanding clinicians' diagnostic practices: Attitudes toward the utility of diagnosis and standardized diagnostic tools. *Administration and Policy in Mental Health and Mental Health Services Research, 38*, 476-485.

Kane, J. M., Robinson, D. G., Schooler, N. R., Mueser, K. T., Penn, D. L., Rosenheck, R. A., . . . Estroff, S. E. (2016). Comprehensive versus usual community care for first-episode psychosis: 2-year outcomes from the NIMH RAISE early treatment program. *American Journal of Psychiatry, 173*(4), 362-372.

Lavallee, D. C., Chenok, K. E., Love, R. M., Petersen, C., Holve, E., Segal, C. D., & Franklin, P. D. (2016). Incorporating patient-reported outcomes into health care to engage patients and enhance care. *Health Affairs, 35*(4), 575-582.

Lewis, C. C., Boyd, M., Puspitasari, A., Navarro, E., Howard, J., Kassab, H., . . . Douglas, S. (2019). Implementing measurement-based care in behavioral health: a review. *JAMA psychiatry, 76*(3), 324-335.

MacDonald, K., Malla, A., Joober, R., Shah, J. L., Goldberg, K., Abadi, S., . . . Iyer, S. N. (2018). Description, evaluation and scale-up potential of a model for rapid access to early intervention for psychosis. *Early intervention in psychiatry, 12*(6), 1222-1228.

McGinnis, J. M., Stuckhardt, L., Saunders, R., & Smith, M. (2013). Best care at lower cost: the path to continuously learning health care in America.

Oluwoye, O., Stiles, B., Monroe-DeVita, M., Chwastiak, L., McClellan, J. M., Dyck, D., . . . McDonell, M. G. (2018). Racial-ethnic disparities in first-episode psychosis treatment outcomes from the RAISE-ETP study. *Psychiatric Services, 69*(11), 1138-1145.

Pope, M. A., Jordan, G., Venkataraman, S., Malla, A. K., & Iyer, S. N. (2019). “Everyone has a role”: perspectives of service users with first-episode psychosis, family caregivers, treatment providers, and policymakers on responsibility for supporting individuals with mental health problems. *Qualitative health research, 29*(9), 1299-1312.

Priebe, S., Kelley, L., Omer, S., Golden, E., Walsh, S., Khanom, H., . . . McCabe, R. (2015). The effectiveness of a patient-centred assessment with a solution-focused approach (DIALOG+) for patients with psychosis: a pragmatic cluster-randomised controlled trial in community care. *Psychotherapy and psychosomatics, 84*(5), 304-313.

Radigan, M., Gu, G., Frimpong, E. Y., Wang, R., Huz, S., Li, M., . . . Dixon, L. (2019). A new method for estimating incidence of first psychotic diagnosis in a Medicaid population. *Psychiatric Services, 70*(8), 665-673.

Read, H., & Kohrt, B. A. (2022). The history of coordinated specialty care for early intervention in psychosis in the United States: A review of effectiveness, implementation, and fidelity. *Community Mental Health Journal*, 1-12.

Savill, M., Banks, L. M., Tryon, V. L., Ereshefsky, S., Nye, K. E., Botello, R. M., . . . Niendam, T. A. (2024). Exploring Data Collection Priorities of Community Partners in Early Psychosis Care. *Psychiatric Services*, appi. ps. 20230455.

Simon, G. E., Coleman, K. J., Yarborough, B. J. H., Operskalski, B., Stewart, C., Hunkeler, E. M., . . . Beck, A. (2017). First presentation with psychotic symptoms in a population-based sample. *Psychiatric Services, 68*(5), 456-461.

Tully, L. M., Nye, K. E., Ereshefsky, S., Tryon, V. L., Hakusui, C. K., Savill, M., & Niendam, T. A. (2023). Incorporating Community Partner Perspectives on eHealth Technology Data Sharing Practices for the California Early Psychosis Intervention Network: Qualitative Focus Group Study With a User-Centered Design Approach. *JMIR Human Factors, 10*, e44194.