

# Mental Health Services Act

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## FY 2020/21 Annual Innovation Report: Early Psychosis Learning Health Care Network

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# EPI-CAL California Early Psychosis Collaborative: Learning Healthcare Network and Statewide Evaluation

## Interested in participating in a focus group?

### What is the Learning Healthcare Network?

The project will bring together early psychosis programs across California to share information and coordinate collection of outcomes data. A tablet application will collect data from clients and families in the clinic. The clinical team will use the data to help make care choices and support clients to reach their goals.



### Why is this research being done?

The goal of the focus group is to better understand which measures to include in the tablet application. We are interested in hearing what aspects of early psychosis treatment progress are most important to clients and families.

### What does being a focus group participant entail?

We will meet as a group for 90 minutes and share with you the measures available. The goal is for you to share with us your opinion on which of the measures available are the most important and useful for psychosis treatment, and which measures are the least important.

You will be paid \$30 for your participation.

### If you are interested or would like more information, please contact:

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*\*Please do not share personal health information via email*



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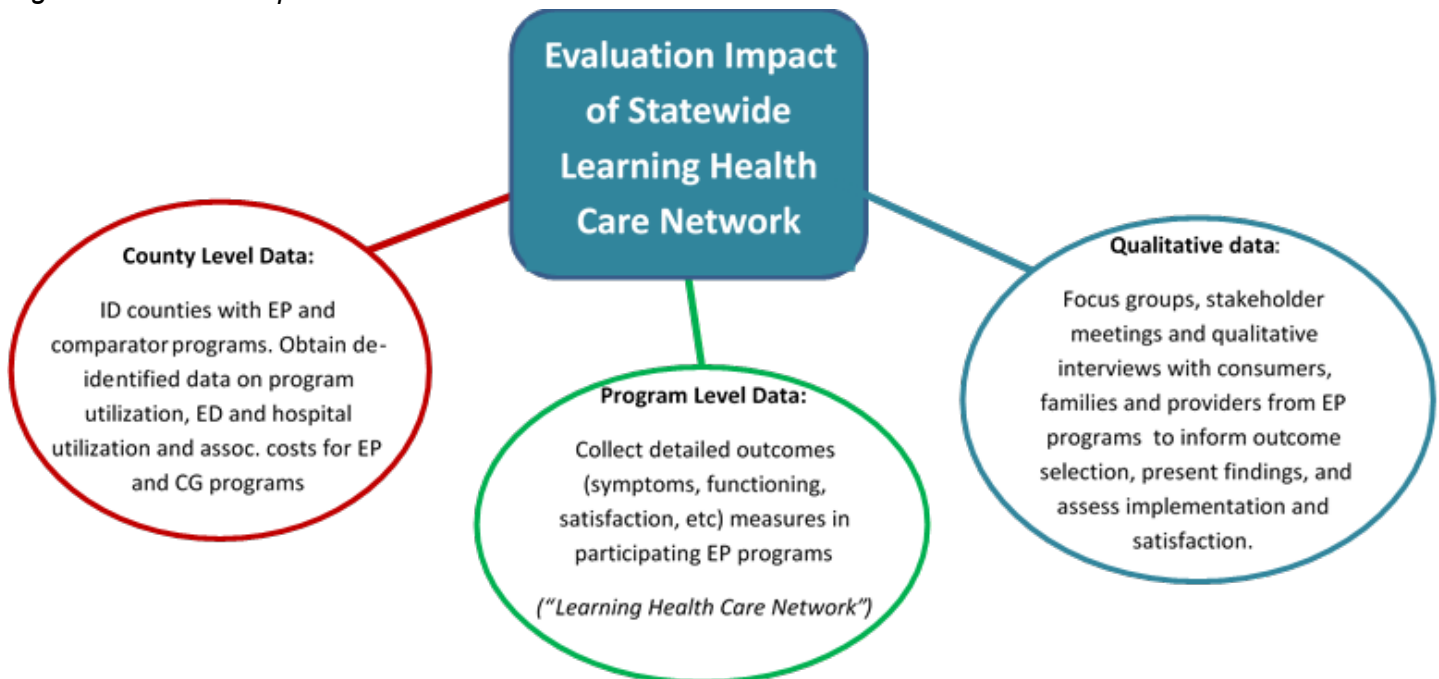
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## Background

Multiple California counties (Solano, San Diego, Los Angeles, Orange), 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. One Mind has also contributed \$1.5 million in funding to support the project. Napa and Sonoma counties have also been approved to use Innovation funds to join the LHCN and are slated to join the project in the coming months. This Innovation project seeks 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. This project, led by UC Davis in partnership with UC San Francisco, UC San Diego, University of Calgary and multiple California counties, will bring consumer-level data to the providers' fingertips for real-time sharing with consumers, and allow programs to learn from each other through a training and technical assistance collaborative. This Statewide EP Evaluation and LHCN proposed 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 project must comply with the regulatory and funding guidelines for evaluation as stipulated by the applicable Mental Health Services Act (MHSA) funding regulations, contract deliverables, and best practices.

There are three components to the data collected for the LHCN: County Level, Program Level, and Qualitative data (Figure 1). Each component of the proposal must be reviewed by an Institutional Review Board (IRB) and approved before commencement of data collection. Further, aspects of the data design will be shaped by the input of stakeholders, including mental health consumers, family members, and providers.

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



This project was approved for funding using Innovation Funds by the MHSOAC in December of 2018. 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. Our team has made significant progress towards our goals outlined in the innovation

proposal during the 19/20 fiscal year.

## Executive Summary

The purpose of this document is to provide the EP LHCN Mental Health Services Act (MHSA) Annual Innovation Report to review **EP LHCN goals accomplished during FY2019/20**. This report will include summaries and status updates on the infrastructure of the LHCN, steps taken towards implementation, and barriers that have been identified over the course of the last fiscal year. While the counties involved in the EP LHCN may be at different stages in the process, the overarching LHCN is moving forward as planned. It is important to note that we will not be reporting on MHSOAC participant demographics in the current report as we are still in the pre-implementation phase. While we have collected feedback on various components of the project from a wide range of stakeholders, this feedback is qualitative in nature and is used to better inform the design of the project and program-level intervention. Thus, we will not be reporting participant-level demographic data until data collection begins on the tablet in the LHCN programs.

- Prior to beginning activities for the LHCN, UC Davis had to have an executed contract with each of the participating counties so each party could mutually agree to a scope and terms of work. As of June 2020, UC Davis had executed contracts with Solano, San Diego, and Orange counties. In addition to existing LHCN counties, Sonoma County has received approval to join the LHCN. We are working together to execute their contract before officially beginning activities in their county program.
- All planned research activities have been reviewed and approved by the University of California (Davis, San Francisco, and San Diego) Institutional Review Boards. We have also worked closely with each county to ensure proper human subjects research review has occurred where applicable.
- A major goal of this project period was to finalize outcome domains and measures to be collected from LHCN EP clinics. During the last year, we have conducted 19 focus groups to understand what outcomes stakeholders consider to be most critical to collect in their EP clinic. Participants across sites heavily favored functioning, quality of life/well-being, recovery, and psychiatric symptoms. Functioning was the most frequently endorsed domain across all stakeholder roles. This process has significantly improved our understanding of what stakeholders consider important data to collect during EP care and how to collect it. Throughout the focus groups, stakeholders were highly engaged in the process, and readily shared their perspectives.
- Quorum and the UC Davis research team have worked collaboratively to develop the wireframe for the tablet and web-based applications. We held focus groups to obtain feedback on the application and dashboard's design, flow, and functionality. Our research team synthesized the feedback for the developers for application development; we have endeavored to balance consumer and family needs with provider and staff needs. Overall, stakeholders approved of the look and feel of the application.
- We have held an LHCN Advisory Committee meeting, which was comprised of a county representative from each participating county, a clinical provider from each participating EP program, and consumers and family members who have been or are being served by the participating programs. We will hold Advisory committee meetings on a bi-annual basis.
- In the coming year, we plan to begin testing in application in EPI-CAL/LHCN clinics, starting with alpha testing, beta testing, then full deployment across the network. We have selected two programs in the LHCN network for beta testing.
- In order to prepare for our county-level data evaluation component of the LHCN, we identified and finalized available county-level data, data transfer methods, and statistical analysis methods.
- In the LHCN proposal, we proposed to ask consumers and providers to complete self-report questionnaires. Over the last year, 100 EP program providers and staff completed our first set surveys on E-Health readiness, comfort with technology, and basic demographics.
- A key objective of establishing the LHCN was to enhance California's ability to participate and learn from EPINET, a National Institute of Mental Health funded collaborative linking regional scientific hubs of EP programs across the country. Our application outlined how the initial investment into California's LHCN by five counties and One Mind laid the groundwork for the infrastructure and resources to join EPINET as a regional scientific hub. We were awarded the EPINET R01 in late 2019 and added two



counties and five university sites to our all-encompassing California EP Learning Health Care network project (EPI-CAL).

## **LHCN Project Goals**

The current document summarizes project activities for the LHCN from the first full year of the project. This includes the following project activities as outlined in the original LHCN proposal:

- 1. Developing and executing a contract with each participating LHCN County*
- 2. Completion and approval of the Institutional Review Board (IRB) protocol covering all aspects of Learning Health Care Network and statewide evaluation data collection*
- 3. Selection of an external company to develop Learning Health Care Network (LHCN) platform application*
- 4. Recruiting for external Advisory Committee and initiation of Advisory Committee Meetings*
- 5. Identification and prioritization of outcomes of interest based on stakeholder feedback*
- 6. Development of wireframe for application submission for review by contractor and stakeholders*
- 7. Selection of and coordination with two counties for beta testing of LHCN app*
- 8. Identification of county-level available data and data transfer methods, and statistical analysis methods selected for integrated county-level data evaluation*
- 9. Finalize methods for multi-county-integrated evaluation of costs and utilization data*
- 10. Initiate LHCN pre-implementation questionnaires*

### **Selection of California's LHCN Project for Inclusion in National EPINET Project**

One of the goals of establishing the LHCN was to enhance California's ability to participate and learn from a newly established national network of EP programs and data systems, the Early Psychosis Intervention Network (EPINET). EPINET is a collaboration linking regional scientific hubs across the country that are each connected to multiple EP programs, funded by the National Institute of Mental Health (NIMH). EPINET seeks to identify and collect a standard set of measures from EP programs across the country to improve EP care, standardize outcome measures, examine contributors to variation in outcomes, and elucidate new questions for early psychosis research. Our application to the NIMH outlined how the initial investment into California's Learning Health Care Network by five counties and One Mind laid the groundwork for the infrastructure and resources to join EPINET as a regional scientific hub and network. We were awarded the EPINET R01 in late 2019 and were able to add two counties (Sacramento and San Mateo) and five university sites (UC Davis, Stanford, UCSF, UCLA, UCSD) to our all-encompassing California Early Psychosis Learning Health Care network project (EPI-CAL). There will be some procedural differences between programs that participate in both LHCN and EPINET (Los Angeles, San Diego, Orange, Solano and Napa) or just EPINET (Sacramento, San Mateo, UC Davis, Stanford, UCSF, UCLA, UCSD); for example, only counties in the initial LHCN project will be participating in the county-level data component of this project. All EPI-CAL sites will participate in the qualitative component (e.g., stakeholder input to identify core outcome domains and measures), EP program fidelity evaluations, and program-level data collection across sites.

This opportunity to join the national network of EP programs will allow our regional California network to gain insight into best practices from 58 coordinated specialty care (CSC) programs across nine states, and to influence national EP standards of care. Additional research goals of the national network are to use this information to reduce duration of untreated psychosis, mitigate suicide risk factors, improve treatment engagement using technology, improve cognition and motivation, and determine the optimal duration of CSC for those experiencing first episode psychosis.

As part of our continued participation as a hub in the EPINET project, Dr. Niendam has participated in multiple in-person and teleconference meetings to harmonize outcomes and discuss potential measures with the EPINET National Data Coordinating Center (ENDCC) and the other EPINET hubs. Dr. Niendam has presented data from our outcomes focus groups (described below) to support outcomes prioritization at the national level. Our participants in our California LHCN are not only helping us prioritize measures for California, but for the nation's EP programs as well.

## **1. Developing and executing a contract with each participating LHCN County**

Before any work on the LHCN could begin, UC Davis had to have an executed contract with each of the participating counties so each party could mutually agree to a scope and terms of work. As of June 2020, UC Davis had executed contracts with Solano, San Diego, and Orange counties. Each county had slightly different contracting processes and therefore contracts were not all executed at the same time. The Solano County contract was executed on April 6, 2019. The San Diego County contract was executed on October 15, 2019. Orange County proceeded with the plan to contract with UC Davis through CalMHSA. The contract between UC Davis and CalMHSA was executed on January 3, 2020. While the contract with Los Angeles county was undergoing review, it was not fully executed until July 1, 2020. UC Davis is currently working with our partners in Napa and Sonoma counties to develop their contracts.

## **2. Completion and Approval of the IRB protocol covering all aspects of Learning Health Care Network and statewide evaluation data collection**

Starting in January of 2019, staff at UC Davis prepared an IRB protocol to cover all aspects of work that will be performed as part of the LHCN and statewide evaluation. This initial application was submitted for review to University of California, Davis' IRB on April 17, 2019 and UC Davis received full approval from our IRB for the LHCN project on July 17, 2019. Since then, we have made several modifications to our IRB to accommodate minor changes to the consenting process or focus group guides. We added translated materials to hold Spanish-language focus groups for the outcomes selection. We have also had all of the necessary documentation approved for UCSF and UCSD to rely on our UC Davis Single IRB.

In addition to our IRB at UC Davis, our team has worked to make sure that each county has reviewed all proposed human subjects research activities. Each county has their own process and procedures for this review, summarized below:

### *Solano County*

Prior to conducting initial site visits and focus groups in Solano County, we contacted county administrators to inquire if there is a formal review process in their county for human subjects research. Solano County informed us that there is not a formal IRB in Solano County and we sent our IRB protocol, approved by UC Davis, for their records. The county is currently in the process of inquiring if any other actions are needed at this time.

### *San Diego County*

San Diego County has an internal Behavioral Health Research Committee that reviews potential research

proposals. Their procedure includes presenting these research proposals to the committee with an IRB approval established and in place at our institution (UC Davis). However, if the research activities are covered in the scope of our contract with San Diego County, an additional review of research proposals is not required. In our case, all research activities are described in our contract, and thus, we did not have to present a proposal to the Behavioral Health Research Committee.

#### *Los Angeles County*

Los Angeles County Department of Mental Health (LACDMH) requires human subjects research projects involving LACDMH programs, staff, and data, to be reviewed by the LACDMH Human Subjects Research Committee (HSRC). In addition to completing an application, LACDMH asks for consent documents, recruitment materials, evidence of PI Qualifications, IRB of Record documents including application and approval letter, and an oath of confidentiality agreements. UC Davis staff had several clarification calls and emails with LACDMH staff during the preparation of this application. We submitted the application to LACDMH HSRC for review on November 25, 2019. The HSRC initiated calls and emails for clarification of various aspects of the application. After HSRC approval, LACDMH Data Security and Privacy Officers completed the final stage of the review process. Our Human Subjects Research Application was approved on April 23, 2020.

#### *Orange County*

Orange County staff submitted our approved UC Davis IRB protocol of record and stamped consent forms to their county IRB. The county required the application to be signed by all project PIs. After a review period, our application was approved on January 17, 2020, and we were granted the ability to conduct human subjects research in Orange County.

#### *Napa County*

Our approved UC Davis IRB protocol of record and stamped consent forms were submitted to Napa County on January 31, 2020 and are currently under review.

### **3. Identification of an external company to develop LHCN platform application**

One of the goals of the project period was to identify and select an external company to develop the LHCN platform and application. We have proposed Quorum Technologies as our developer as they have already built two applications for research purposes with UC Davis. Quorum is a Sacramento-based company that specializes in health care application development and creation of integrated specialty applications for large health systems. We have previously contracted with Quorum to build two applications - MOBI and the Duration of Untreated Psychosis (DUP) PQ-B screener application - for research purposes. Currently, UC Davis holds the rights to the MOBI application, which will serve as the foundation for the LHCN application. Due to its prior knowledge of MOBI, Quorum has participated in multiple calls with stakeholders and worked with IT teams across the state to address security needs for MOBI to work for this project. Quorum has an established team located in Sacramento that is ready to modify MOBI for the current project. Their knowledge of the healthcare landscape of California, local staff that can be deployed for project meetings, or stakeholder engagement related to the project, and intimate knowledge of the application makes them uniquely capable of executing this project. UC Davis Health approved our sole source justification for Quorum Technologies, and we signed a Purchase Agreement to establish Quorum as our vendor to build the application. Since then, our team has been working closely with Quorum to provide feedback and direction for the development of the custom LHCN application.

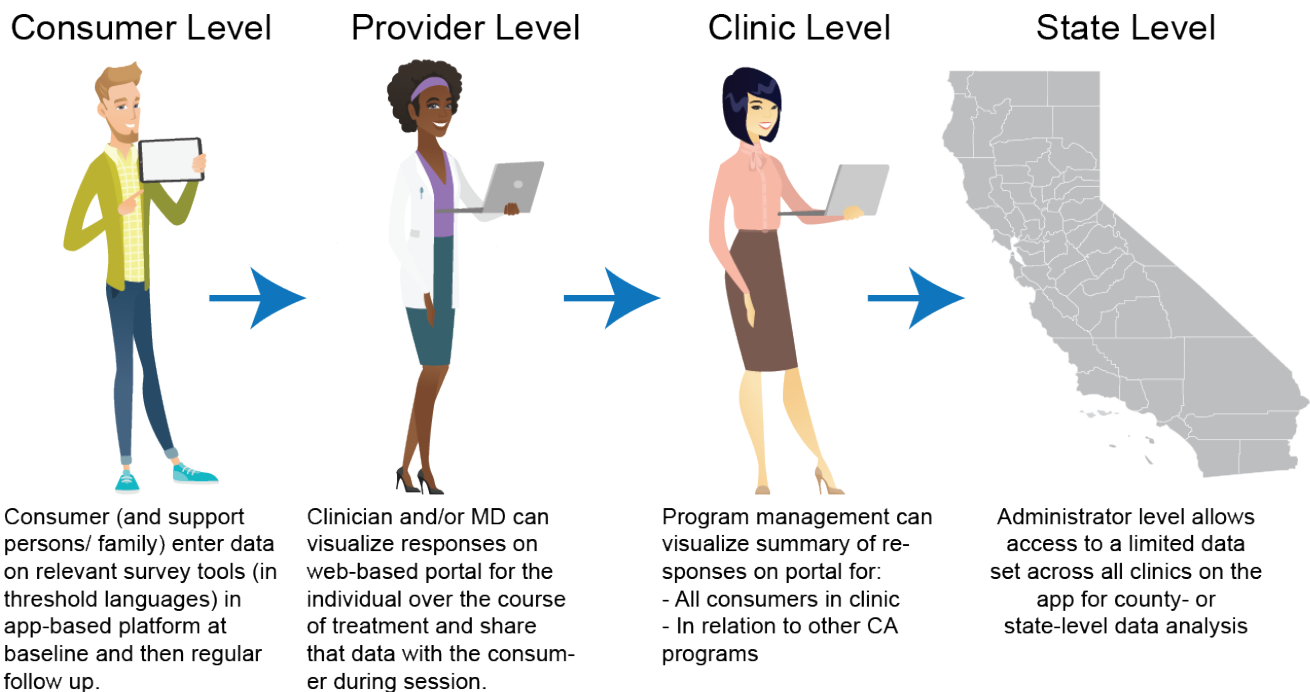
We have also worked with individual counties to ensure that the application Quorum builds will meet their individual county's IT security standards before the application is released in each program. Thus far, UC Davis has facilitated a few conversations between Orange County INN Staff, Orange County Health Care

Agency (HCA) IT, and the Quorum staff in order to discuss Orange County HCA IT security vetting process of the Quorum platform. This has included sharing the UC Davis Health System’s IT security vetting process for Quorum with OC HCA IT. In addition to the University’s security vetting procedures, OC HCA has shared their own documentation with UCD and Quorum to complete before the application is rolled out. We are in the final stages of signing a data use agreement with Orange County to cover data sharing terms, as well.

The application will serve as the basis of the program-level data component of the LHCN to collect consumer, provider, and clinic level data (Figure 2). The application will visualize consumer-entered data for use in care, and for analysis at the clinic and state level.

Figure 2. Proposed LHCN Application Workflow for CA Mental Health Programs

## Proposed Learning Healthcare Network for CA Mental Health programs



## 4. Recruitment for external Advisory Committee and focus groups

The Advisory Committee for the LHCN will be comprised of a county representative from each participating county, a representative of each participating EP program, and up to five consumers and five family members who have been, or are being served, by the participating programs. This committee will be co-led by Bonnie Hotz, family advocate from Sacramento County, and a Peer Advocate, who is yet to be determined.

Recruitment for the Advisory Committee has been ongoing, and we have confirmed membership with multiple stakeholders. These include past consumers, family members, and clinic staff and providers. We are continuing to recruit interested individuals through the participating programs as new programs join the LHCN. We held the first Advisory Committee meeting on May 8, 2020, which was held remotely. We had the call-in option because we have not been meeting in person for non-essential tasks due to the COVID-19 pandemic. During this call, we gave a brief overview of the project for the attendees who were recently recruited. We then went over the progress to date on different components of the project, starting with updates on focus groups,

surveys, and county data analysis. We were not able to get through all of the planned content and held a follow-up meeting in July 2020.

Even though we have already held our first Advisory Committee meeting, we are continuing to distribute flyers (Appendix I) to all participating clinics, as their contracts are coming through, to make sure the Advisory Committee is open to all LHCN member clinics.

## 5. Identification and prioritization of outcomes of interest based on stakeholder feedback

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, consumers and families, to inform the selection of outcomes of interest. Stakeholders joined from participating LHCN clinics, as well as from our greater EPI-CAL network (Table I). While we have continued to hold additional focus groups in recent months since the execution of the Los Angeles County contract, the data presented here is a summary through June 30, 2020 only.

### Methods

#### *Study Design*

A semi-structured qualitative focus group study was completed to explore stakeholder opinions on how and what data should be collected within the Learning Health Care Network. 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 LHCN core battery.

#### *Participants*

Eligible participants included providers, consumers, and family members of consumers 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 I. 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. In order to ensure that the sample recruited best represented the stakeholders who deliver or receive care in the participating programs, no other inclusion/exclusion criteria were adopted.

*Table I: Participating EPI-CAL Early Psychosis Program Sites*

LHCN/EPINET	County/University	Program
LHCN/EPINET	Solano	Aldea SOAR
	Orange	OCCREW
	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)MIND BEAM

In order 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 II. 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 II: 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 consumers 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 consumer services
Other CSC providers	Includes Family Advocates, Peer Support Specialists, Case Managers, Recovery Coaches, and Supportive Employment and Education Specialists

### 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: consumers/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 consumer functioning and quality of life. Areas of particular interest

highlighted by participants included homelessness and housing instability; consumers' perception of wellness; the attainment of consumer goals; justice involvement, including convictions and recidivism; suicide, suicide prevention, and self-injurious behaviors; changes in aggressive and/or violent behaviors; changes in consumer 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 III.

*Table III: 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 (e.g. 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 IV. 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 used in the Mental Health Block Grant (MHBG) evaluation.

*Table IV: Proposed Measures for each Outcome Domain*

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 <i>Computerized Neurocognitive Battery (CNB)</i> 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 consumer and family member groups. An example guide is presented in Appendix II. 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, based on the definitions outlined in Table III. 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 2019 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 two-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 consumer and family groups, EPI-CAL EP program providers invited all consumers 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, consumers 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 consumer 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 consumer 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 then 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 (Appendix III). Definitions of each domain (Appendix IV) 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 (see Appendix III). 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 consumer 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.

### Spanish Focus Group Methods

Our team sought to include Spanish-speaking consumers and families in the outcomes focus groups since Spanish is a threshold language in all participating LHCN counties. First, a team member translated all necessary forms for the focus group (e.g., consent, payment forms, outcome measures, outcome definitions, etc.), which were then reviewed by UCDHS Medical Interpretive Services and approved by our IRB. We initially had three in-person Spanish focus groups scheduled for March in the Solano, San Diego and Sacramento programs. However, these meetings were canceled due to COVID-19. Subsequently, our team recruited Spanish-speaking consumers and family members for remote focus groups. To do this, a team member (RB) was connected to interested participants by respective clinic staff to introduce the study, as this portion of the project is considered research. Interested participants were then consented over the phone; they signed and completed consent and payment forms via DocuSign. Follow-up calls were needed with each participant to assist with signing documents and submitting forms successfully. After receiving all signed forms, a team member mailed necessary documents to participants for reference during the outcomes discussion portion of the study, including a packet of the proposed measures and outcome definitions. A team member coordinated with other bi-lingual team members and participants for availability, scheduled, and carried out interviews with each participant via WebEx, Zoom, or phone calls ranging from one to two hours in duration. Four family members completed the focus group for Sacramento, and two consumers and one family member completed the individual interviews for the San Diego program. Participants from different EP programs were separated to maintain consistency between the structure of other sites' outcomes focus groups and to facilitate an honest conversation about potentially sensitive topics including family burden, family communication, suicide risk, and other outcomes under consideration.

### 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. In the primary analysis, English and Spanish-speaking groups were analyzed together. In a sub-group analysis, Spanish- and English-speaking family and consumer focus groups were reported separately, with voter preferences compared and contrasted.

### *Qualitative Data*

Conventional content analysis is typically used to describe a phenomenon, namely stakeholder 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 (LM) 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 first by the rest of the coding team, and then the wider EPI-CAL research team.

### *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

In total, 19 focus groups and three interviews with stakeholders were completed between September 10<sup>th</sup>, 2020 and June 30<sup>th</sup>, 2020. The date each occurred and the type of group conducted is presented in Table V. Data from these groups are detailed in the results below. More recently completed focus groups that are not currently included in the results—including one with the providers at the EPI-CAL UCSF PATH program—was completed on 6/25/2020. Additionally, focus groups were conducted with Los Angeles LHCN clinical sites, now that their contract has been executed. Once the data is transcribed, cleaned, and analyzed, these will be incorporated in the final results at a later date. The demographics of the participants included in the current evaluation are presented in Table VI.

Table V: Focus Group Details by Site

Focus Group Number		Location	Focus Group Details	
			Type	Date
1	LHCN/EPINET Participating Sites	Solano - SOAR	Provider	10/08/2019
2			Family	2/6/2020
3			Consumer	2/6/2020
4		Orange - OCCREW	Providers	1/30/2020
5			Family †	1/30/2020
6			Consumer	1/30/2020
7		San Diego - Kickstart	Provider	12/16/2019
8			Family	12/16/2019
9			Consumer	12/16/2019
10			Spanish Speaking Family*‡	5/14/2020
11			Spanish Speaking Consumer*‡	5/14/2020
12			Spanish Speaking Consumer*‡	5/15/2020
13	EPINET Only	Sacramento SacEDAPT/EDAPT	Provider	12/13/2019
14			Family	1/22/2020
15			Consumer	1/16/2020
16		San Mateo - Felton	Spanish-speaking Family*	4/28/2020
17			Provider	2/3/2020
18			Family	2/4/2020
19			Consumer	2/5/2020
20		UCLA – CAPPS	Provider	1/29/2020
21		UCLA - Aftercare	Provider	1/29/2020
22		UCSD – Care	Provider	12/16/2019

\* Indicates groups that were conducted remotely via Zoom due to the statewide shelter-in-place order.

† Recording error meant only quantitative data incorporated into the analysis.

‡ Conducted as one-to-one interview, as opposed to focus group.

*Table VI: Focus Group Demographics*

Variable	n	%
<b>Sites Included in Current Analysis</b> (n = 8, n %)		
University	3	37.5%
Community	4	50.0%
Both	1	12.5%
<b>Funding Source (n = 8, n %)</b>		
EPINET only	5	62.5%
LHCN + EPINET	3	37.5%
<b>Group Type (n = 22, n %)</b>		
Provider	8	36.4%
English Speaking Consumer	5	22.7%
English Speaking Family Member	5	22.7%
Spanish Speaking Consumer*	2	9.1%
Spanish Speaking Family Member**	2	9.1%
<b>Participants (n = 168, n %)</b>		
Provider	94	56.0%
English Speaking Consumer	40	23.8%
English Speaking Family Member	27	16.1%
Spanish Speaking Consumer	2	1.2%
Spanish Speaking Family Member	5	3.0%
<b>Provider Roles (n = 94, n %)</b>		
Clinicians	31	33.0%
Administrators	11	11.7%
Prescribers	10	10.6%
Clinical Supervisors / Team Lead	21	22.3%
Senior Clinic Leadership	4	4.3%
Other (SEES, Peers, Family advocates)	17	18.1%

\* Interviews via phone call

\*\* One interview and one focus group

*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 focus groups and their experience of coding the transcripts, the different

domains were re-categorized into 21 distinct areas (see Table VII). These reconfigured domains represent the basis of all the subsequent analyses detailed below.

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

<b>Amendments/ Additions to the Battery</b>	<b>Original and Proposed Titles</b>	<b>Notes</b>
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 of 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*	

Newly proposed domains integrated into the analysis		
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.

Quantitative Findings from the Voting

At the beginning and end of the focus groups, all participants voted for the four domains they considered to be most critical to measure. How participants voted by role is presented in Figures 3 and 4. In both the pre- and

post-focus group discussion voting rounds, functioning was identified as the most critical domain in which to capture data. This was consistent across consumer, family, and provider participants. Other domains with a high proportion of votes include quality of life, recovery, family functioning, and psychiatric symptoms. Similar to functioning, these domains were highly rated across participant roles. In a comparison of the pre- and post-discussion votes, these four domains appeared to receive an increase in the proportion of votes cast. Overall, the emphasis on recovery, quality of life, and functioning appears to suggest that consumers, families, and providers are particularly focused on collecting recovery-oriented outcomes.

In a review of domains that were considered less critical to measure, clinical status, risk for homelessness, law enforcement contacts, service satisfaction, and impact of medication received the fewest votes. Why these particular domains received such few votes was explored qualitatively during the discussions. Across the newly proposed domains, no areas received a high proportion of votes. However, in the post-discussion voting, substance use, trauma, and culture were most frequently identified as important.

There were a number of differences in voting priorities across participant roles. For example, prescribers appeared to be particularly focused on collecting data related to psychiatric symptoms, functioning, and medication utilization. Additionally, while the impact of medication was less important than these domains, prescribers still voted for this domain at a higher rate relative to other provider roles. Senior clinical and county leadership considered risk to self and others, and family burden, more important. Providers in the 'other' category, including peers, family advocates, and supportive employment and education specialists (SEES), consistently voted for recovery as one of the most important domains, over and above other participant roles. Broadly speaking, differences in domain priorities across provider roles appears to be attributable to their primary role in delivering care (i.e., peers, family advocates, and SEES staff work primarily on facilitating recovery, while the prescribers' role focuses primarily on alleviating psychiatric symptoms and issues around medication). This was explored in more depth during the focus group discussions.

Across the different provider roles, consumers, and family members, the areas of priority appear to be broadly consistent, suggesting a consumer-oriented approach from providers. In the post-discussion voting, both consumers and family members identified functioning, quality of life, and psychiatric symptoms as the most important areas in which to collect data. In an exploration of any contrasts between provider, family, and consumer participants, family members and consumers appeared more likely to rate cognition as one of the more important domains relative to most provider groups. In addition, family members appeared to consider the impact of medication more important than most provider groups, with the exception of a few providers.



Figure 3: Pre-Discussion Voting Priorities by Role

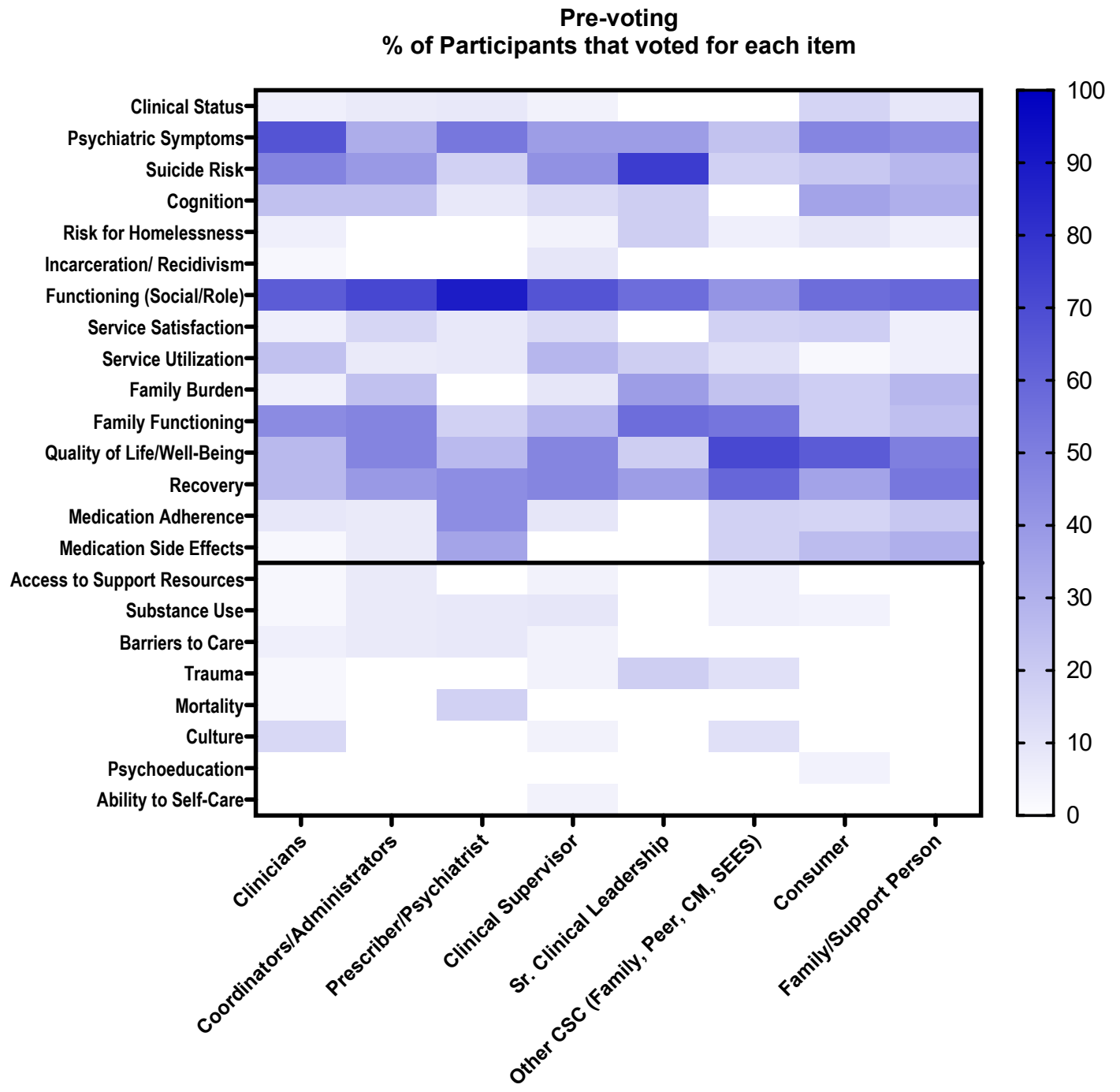
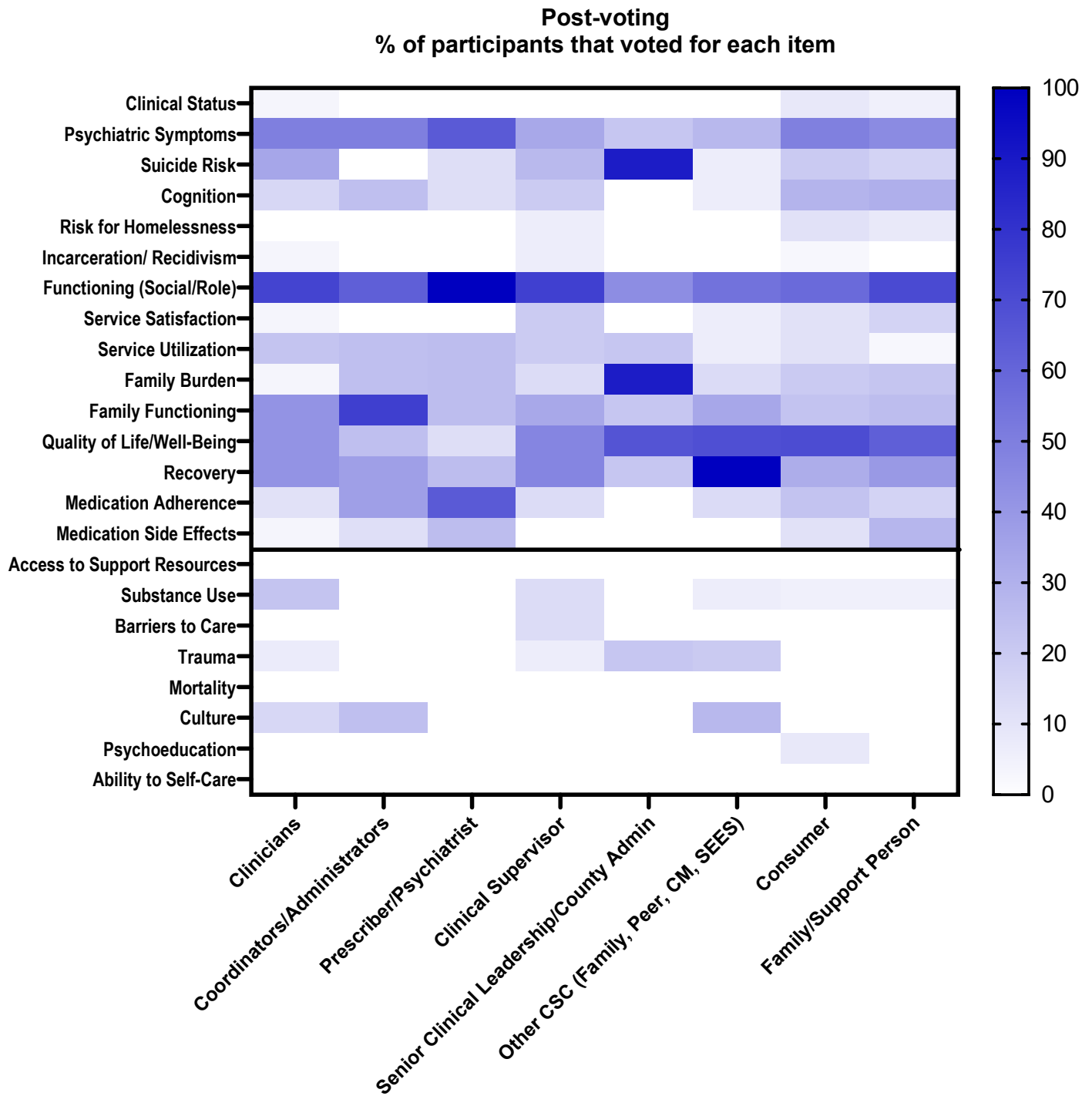


Figure 4: Post-Discussion voting



### Comparison of Voting Patterns across English- and Spanish-Speaking Consumer and Family Groups

A subgroup analysis detailing the voting patterns of consumers and family members in English- and Spanish-speaking groups separately are presented in Figures 5 & 6. Due to the small number of participants in the Spanish-speaking cConsumer and family groups (n=2 and n=5 respectively) some caution should be exercised in making comparisons to the English-speaking groups. However, a number of notable differences were evident. For example, in both Spanish-speaking consumer and family groups, clinical status received a high proportion of votes, whereas this was not considered a priority in the English-speaking groups. Instead, in the English-speaking groups psychiatric symptoms appeared to receive a greater proportion of the votes. Concerning more recovery-oriented outcomes, it was also notable that recovery appeared to receive a much higher proportion of the votes in the Spanish-speaking groups, while in the English-speaking groups, quality of life/wellbeing received greater priority.

Interestingly, while the voting priorities across the English-speaking consumer and family groups appeared to be broadly consistent, a number of differences appeared to be evident across the Spanish-speaking consumer and family groups. For example, functioning and family functioning received a very high proportion of votes in the Spanish-speaking consumer groups, while in the English-speaking family groups medication adherence, family burden, and suicide risk received a much higher proportion of votes. Consistent with the findings across the whole sample, the voting patterns across the English- and Spanish-speaking groups appeared to be highly consistent.

Figure 5. Family and Consumers Pre-voting

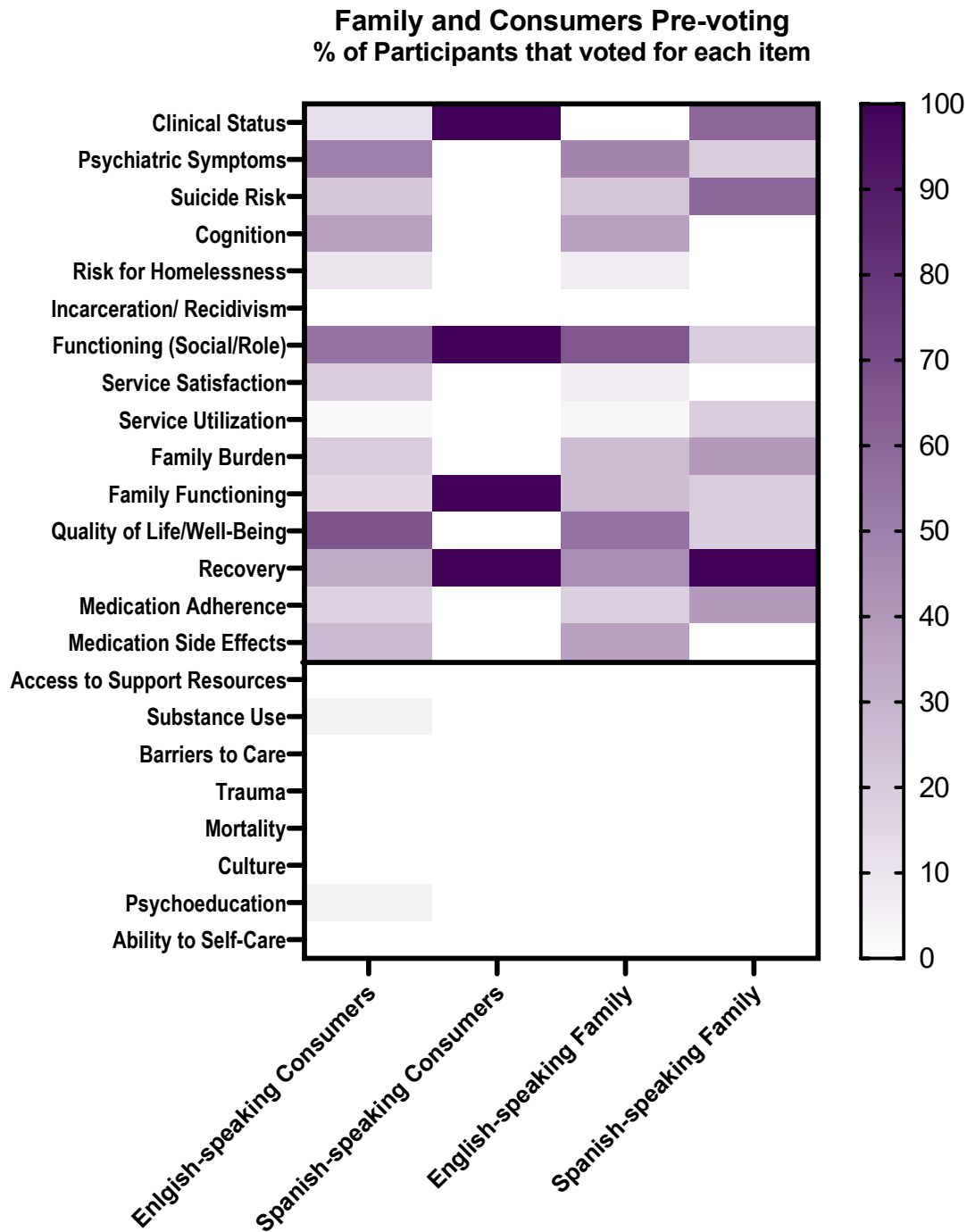
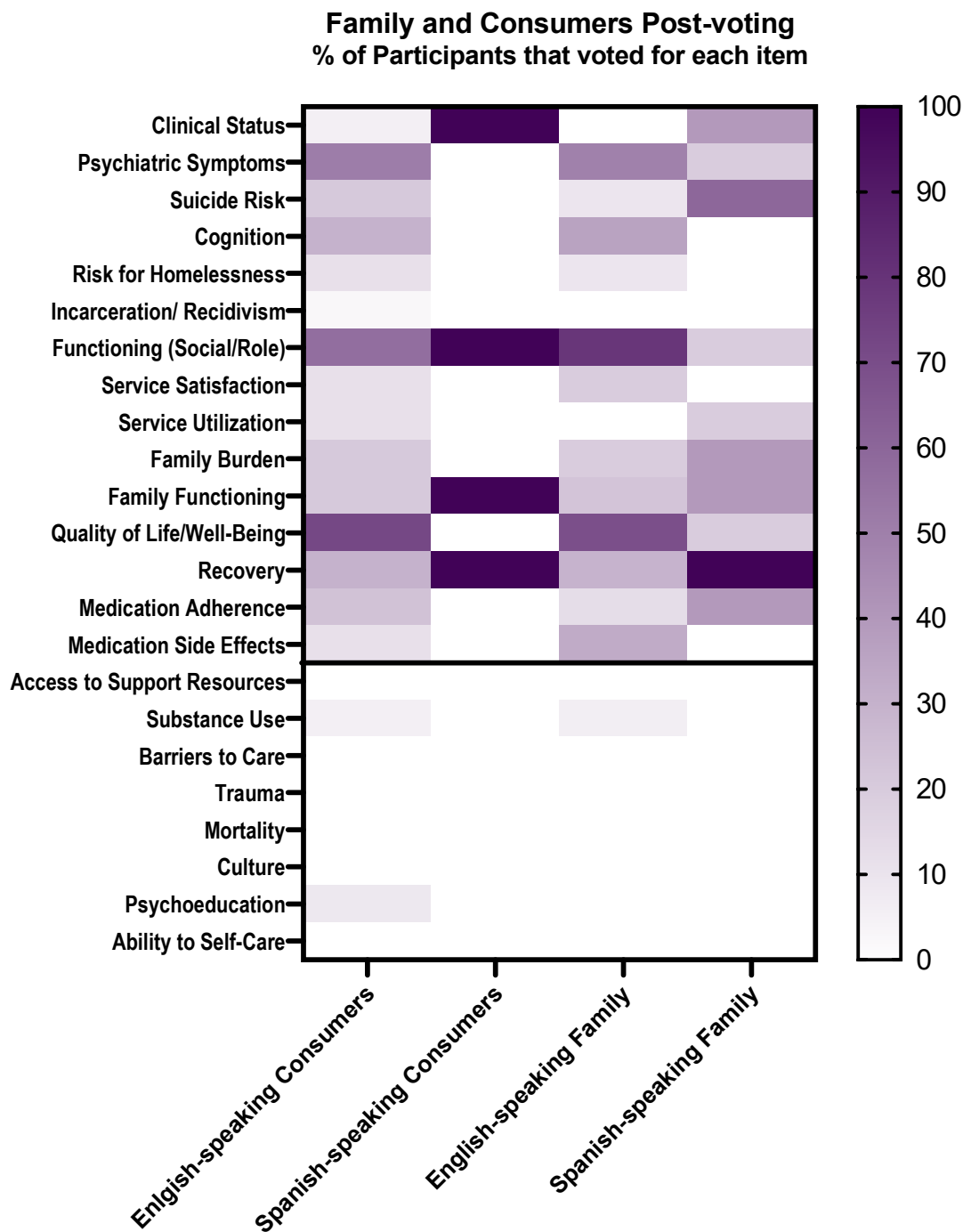


Figure 6. Family and Consumer Post-Voting



Summary of Qualitative Results

Across the 22 focus groups and qualitative interviews completed with providers, family members, and early psychosis program consumers, 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 consumer. 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 to be the least useful given that it 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 consumer 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 consumers can disclose whether they are considering stopping 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 consumers 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 consumers’ 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 individuals’ capability to live independently which could be answered by the clinician, and two questions asking if the consumer 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 country of birth across the family, consumer gender identity, sexual orientation, socioeconomic status, and level of education. Incorporate family understanding of mental health and family support of treatment into the family functioning domain.

Functioning: Considered a 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 friendships 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, suggestions were 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 consumer 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 (YSS). Consider possibility of using the RSA to measure service satisfaction, as opposed to recovery.

Recovery: Use the QPR to capture consumer 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 Adverse Childhood Experiences (ACEs) 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 section of the report details an extensive process to solicit stakeholder feedback around data collection in early psychosis settings, including 168 participants across eight clinics. This engagement process has included family members, consumers, and providers across a diverse range of clinics, including county- and university-based clinics. The programs themselves deliver early psychosis care to a diverse range of consumers in terms of race/ethnicity, socioeconomic status, and current gender identity. To further support inclusion and to ensure that a diverse range of stakeholders could participate, focus groups 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 deliver 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. This led to one group being cancelled and another postponed (the Stanford Inspire program and UCSF Path program, respectively). 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, contract delays with Los Angeles County meant that the focus group could not be completed prior to June 2020. However, we have conducted focus groups with LA County stakeholders, and the responses from these groups will be integrated into the overall findings. Another limitation was the lack of video recording of the groups, which made it difficult to attribute the quotes in the audio recording to each particular consumer in some instances. 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. In order to address this, the facilitators of that particular focus group have reviewed the overall findings presented in this report 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 report has significantly informed the construction of the Learning Health Care 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 here 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 consumers 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 consumers and families.

## **6. Development of wireframe for application submission for review by contractor and stakeholders**

Quorum and the UC Davis research team worked collaboratively to develop the wireframe for the tablet and web-based applications. The process began with UC Davis providing diagrams of the flow for various aspects of the application including clinic registration, consumer registration, collection of clinical data from consumers and collateral (i.e., family members, support persons), and data visualization of both individual- and aggregate-level data. Based on these diagrams, Quorum developed an initial storyboard to illustrate various aspects of the application. The development process from that point was iterative, with weekly or bi-weekly calls to discuss and troubleshoot the more complicated aspects of the application design and flow. 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. Figures 7-10 are examples of what participants were shown to obtain feedback on various elements of the tablet application or dashboard.

Between March 26, 2020 and June 30, 2020, our team conducted 14 focus groups with various stakeholders with 82 total participants. 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), and three groups were held with consumers and families (14 participants). Due to COVID-19, all focus groups were conducted over video conferencing (Zoom). 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. The focus groups were 90 minutes long, during which time the 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 admin, 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 consumers, support persons, and staff.

Our research team discussed and synthesized the feedback for the application developers to support application development. When integrating the feedback into application development, we aimed 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 example, participants in a focus group with clinic administrators from various programs suggested that demographic information that clinic staff regularly report to their county 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. 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.

Figure 7. Tablet Survey List

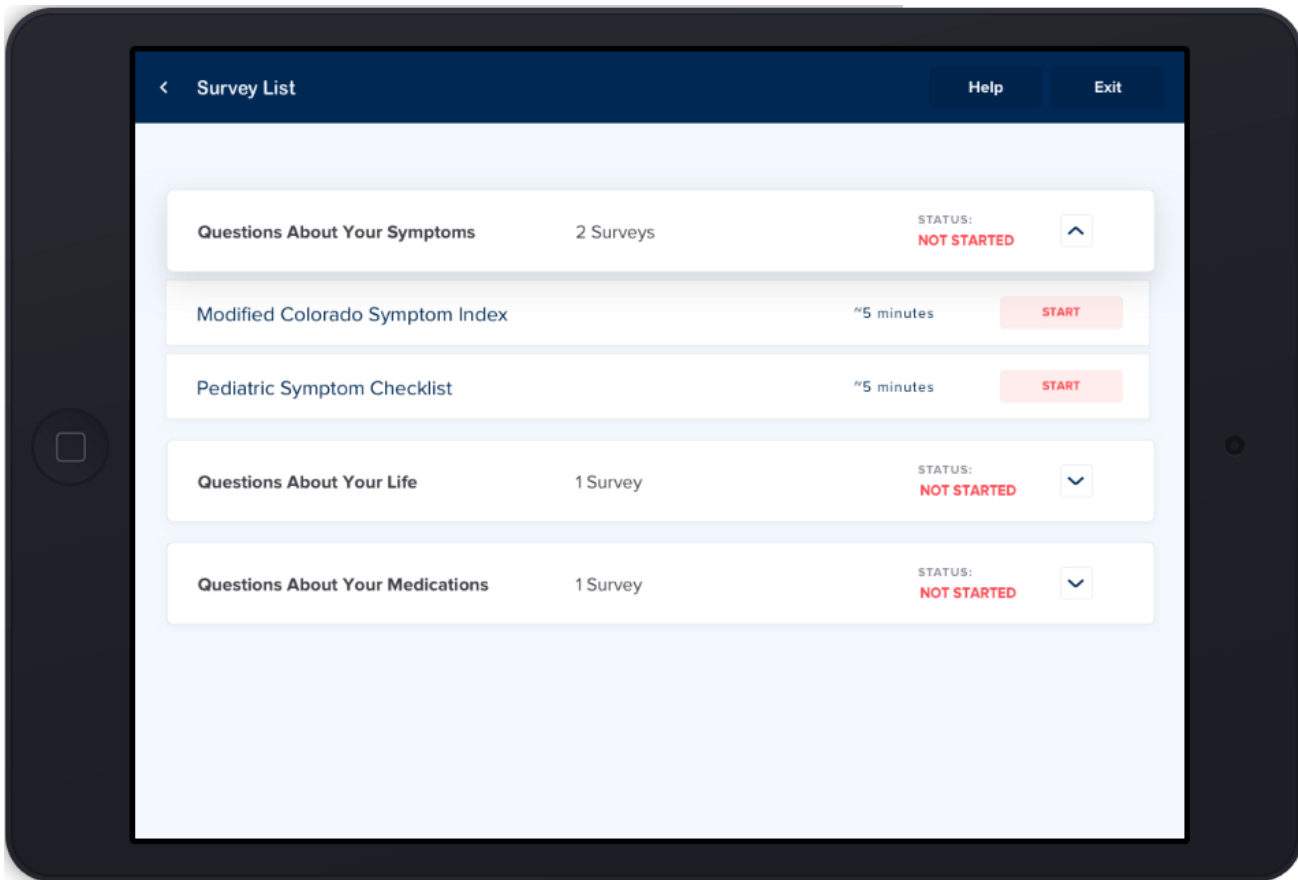


Figure 8. Tablet Survey Item

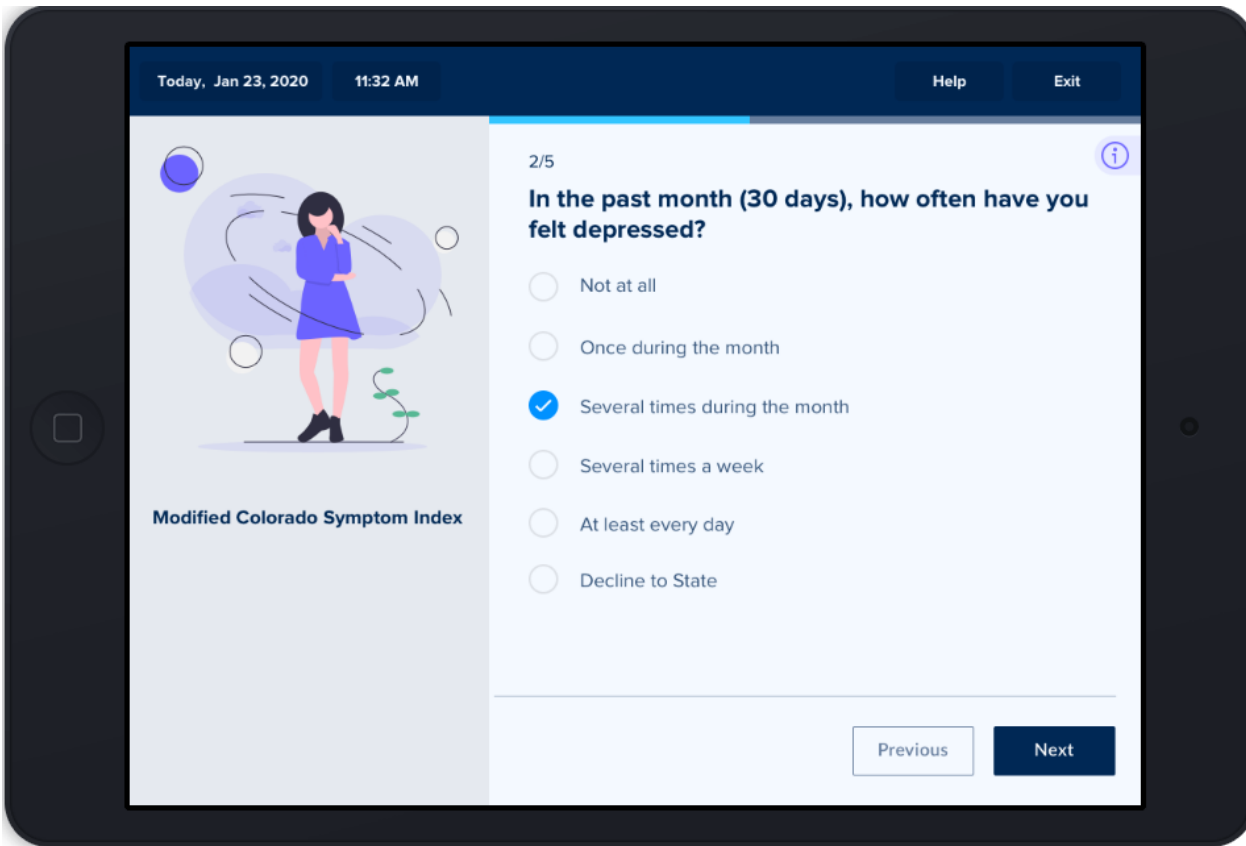


Figure 9. Individual-Level Test Consumer Survey Visualization

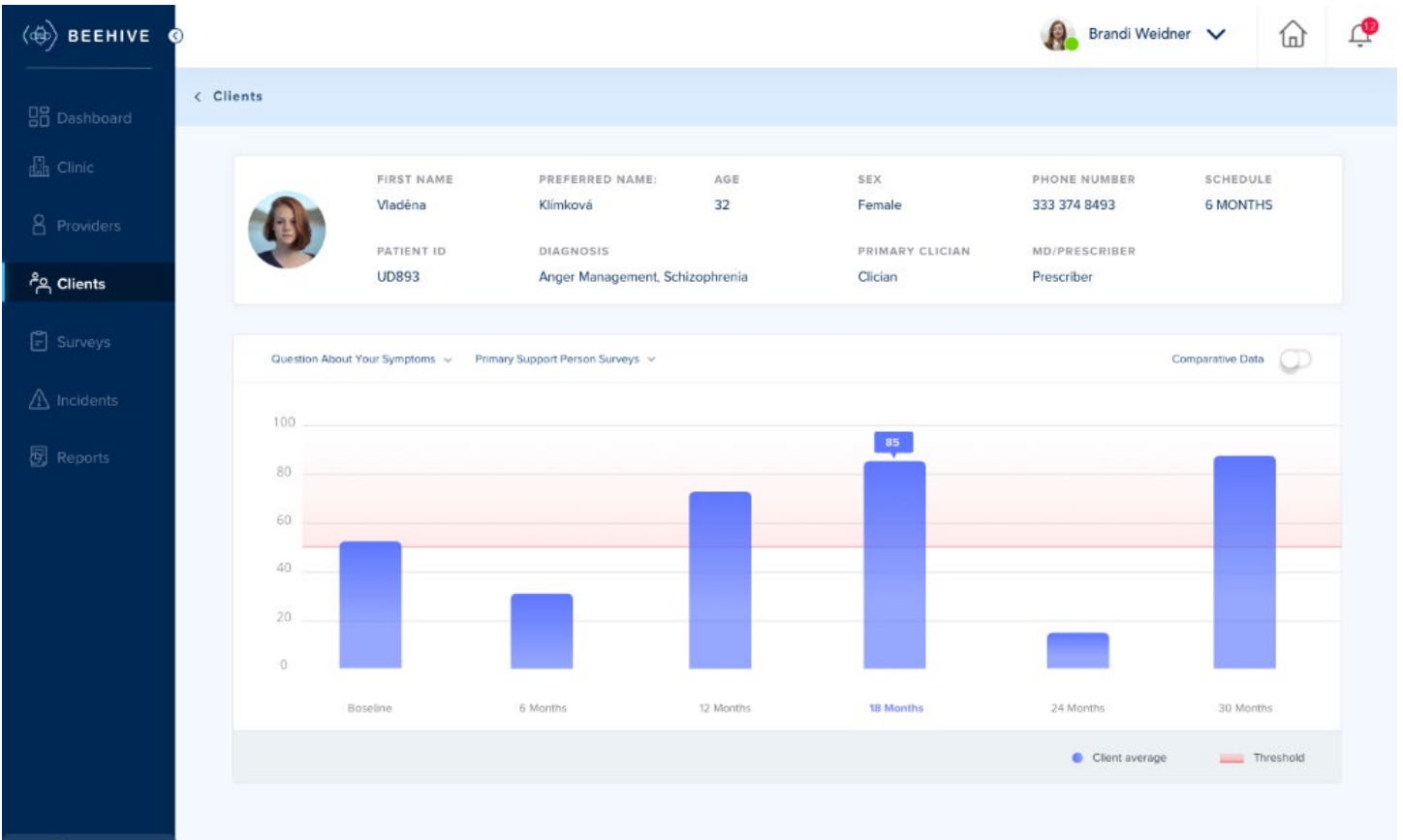
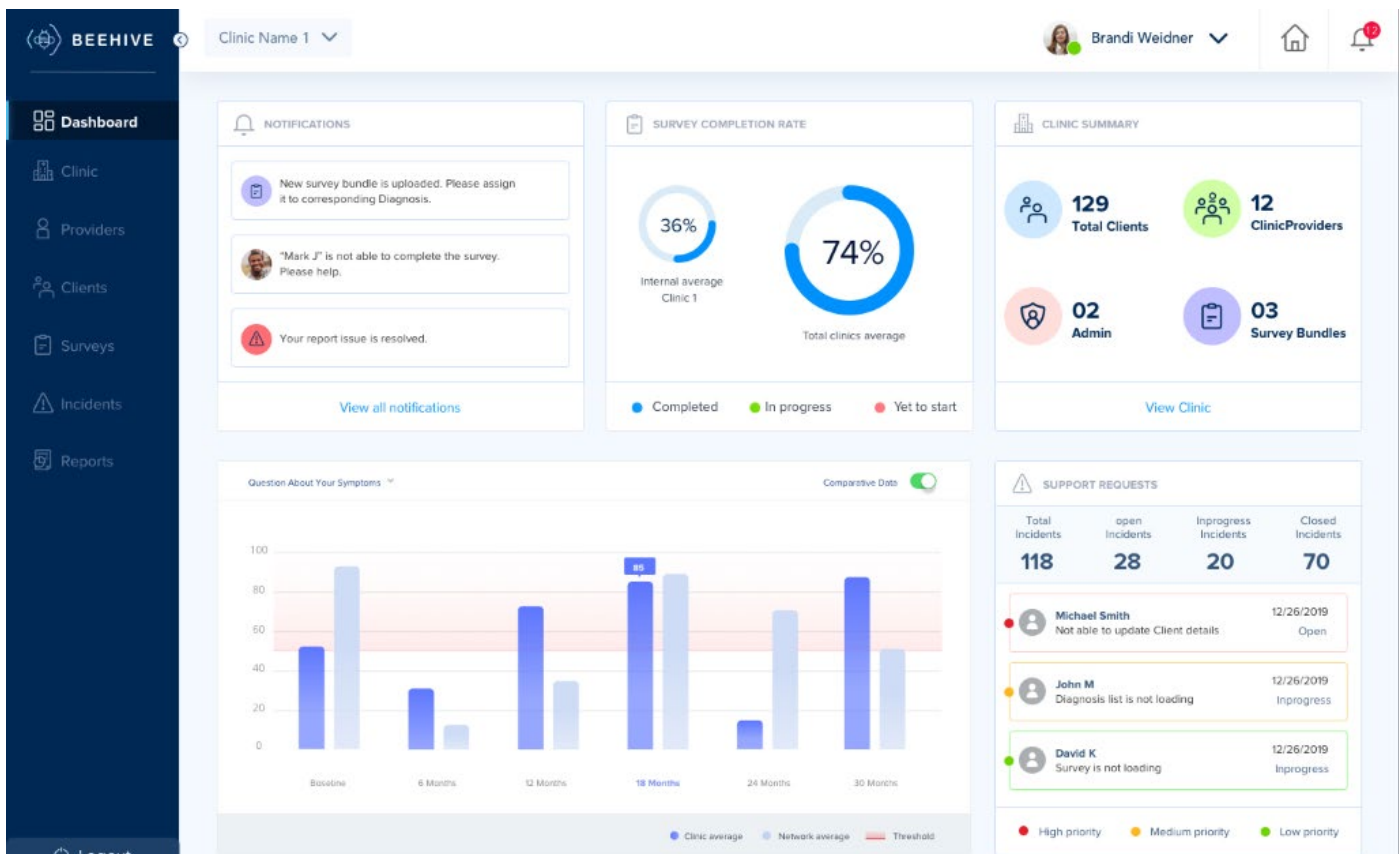


Figure 10. Clinical Administrator Dashboard Homepage



## 7. Selection of and coordination with two counties for beta testing of LHCN app

At this time, we plan to beta test the application in Kickstart San Diego program and Aldea SOAR Solano. We wanted to have representation from one Southern and one Northern California program for the beta testing of the application. Both of these programs are willing to serve in this capacity. While we originally planned to begin beta testing at these sites in Fall 2020, we have notified them that beta testing will be delayed until January or February 2021.

## 8. 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, describe, and analyze the costs incurred by providing early psychosis clinical services, the outcomes associated with such a program, and the costs associated with those outcomes for individuals served by each program in each county. We will also examine services and costs associated with similar individuals served elsewhere in the county. This project component will only include data from those counties who are participating in the LHCN (Los Angeles, Orange, San Diego, Solano, and Napa); it will not include the two counties (San Mateo, Sacramento) or university sites that are included via EPINET support in the overall EPI-CAL project.

For each county, our team held meetings with the EP program managers and the county data analysts. The meeting with the program managers discussed services provided by the EP program, description of consumers served, staffing specifics and billings 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 consumers (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 period. The

discussion included time-periods for which the LHCN team will request data, description of the consumers from EP programs and how similar consumers served elsewhere in the county will be identified, services provided by each program, and other services provided in the county to the EP consumers (i.e., hospitalization, crisis stabilization and substance use). We have also determined data transfer methods with each county, whereby each county will de-identify consumer level data and upload their data to a secure server housed at UC Davis. Counties will not have access to data from other counties. We are actively discussing data identification with each county and the next steps will be to have each county pull the first set of data, de-identify, and upload it to the UC Davis secure server. We have met with all of the program managers and data analysts from all LHCN counties with active contracts. 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 report we have provided a sample of the data collected from each county (see Table VIII).

**Table VIII. Multicounty Program Services and Billing Information**

<b>County</b>	<b>San Diego</b>	<b>Orange</b>	<b>Solano</b>	<b>Napa</b>
<b>Program Name</b>	Kickstart	OC CREW	Aldea SOAR	Aldea SOAR
<b>Consumers Served</b>	FEP, CHR	FEP	FEP, CHR	FEP, CHR
<b>Census</b>	140-160	42	26	10-15
<b>Length of Services</b>	(+/-) 2 yrs	2 - 4 yrs	(+/-) 2 yrs	(+/-) 2 yrs
<b>Inclusion - Ages</b>	Ages 10-25	Ages 12-25	Ages 12-30	Ages 8-30
<b>Inclusion - Diagnoses</b>	Any type of psychosis (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
<b>Inclusion - Insurance</b>	Medi-Cal, Uninsured	None	Medi-Cal, Uninsured	Medi-Cal, Private, Uninsured
<b>Inclusion - Duration of Psychosis</b>	First psychotic symptoms within 2 years	First psychosis within 2 yrs	First psychosis within 2 yrs	First psychotic episode within 2 years; Attenuated psychosis of any duration
<b>Exclusion - Cognition</b>	IQ under 70 - Case by case discretion	IQ below 70	IQ below 70	IQ below 70

<b>Exclusion - Diagnoses</b>	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
<b>Exclusion - Other</b>	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
<b>Assessments - Billing Codes</b>	10	90899-6 (H2015)	90791	10
<b>Assessments - Provider type</b>	Clinicians	Clinician: master's level BHCI, BHCII, psychiatrist	Therapist; clinical supervisor	Therapist
<b>Assessments - Notes</b>	Behavioral Health assessment and HRA (high risk assessment)	If a clinician takes multiple sessions to complete the Initial Assessment, the code 90899-6 should be used for each of the sessions leading up to the completion of the intake process. This code can also be used by a psychiatrist when completing a conservatorship evaluation, a disability assessment, or if an evaluation for medication services is being provided via the telephone		Initial, Annual/Periodic
<b>Targeted case management - Billing Codes</b>	50	90899-1 (T1017)	T1017	50

<b>Targeted Case Management - Provider Type</b>	All direct service staff: clinical team, OT, Peer Support or EES. As well as medical team (NP, Psychiatrist, or LVN)	BHCI, BHCII, psychiatrist, Mental Health Specialist, Psychiatrist, Behavioral Health Nurse, Mental Health Worker	Therapist, family partner; Medical director or PNP	Therapist, Family Partner/SEE
<b>Targeted Case Management - Notes</b>	Monitoring progress toward goals -information gathered from schools and parents	A variety of services can be billed under case management as long as they referred to coordination of care, monitor service delivery and linkage access to community services.	Examples: Therapist discusses consumer with PNP or Family Partner; Therapist or Family Partner discusses consumer need for housing with Caminar; Therapist facilitates consumer's transition to a new service upon completion of program	Linkage to Resources; SEE support
<b>Group Psychotherapy (Multifamily) - Billing Codes</b>	35	90849 (H2015)	H2017	35
<b>Group Psychotherapy (Multifamily) - Provider Type</b>	Clinician, Peer Support Specialist, Education Employment Specialist, OT	BHCI, BHCII, Mental Health Specialist, Behavioral Health Nurse	Therapist, Family Partner	Therapist, Family Partner/SEE
<b>Group Psychotherapy (Multifamily) - Notes</b>	10 different groups offered. Collateral services billed 8-15 to capture other support specialist for any group with multiple facilitators	Group Psych-multifamily	Group rehab	Multi-Family, Peer Group for Adolescents & Adults

## 9. Finalize methods for multi-county-integrated evaluation of costs and utilization data

The cost and utilization 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,

crisis/ED utilization, and psychiatric hospitalization, with costs associated with these utilization domains during two time periods: 1) the three years prior to implementation of project tablet in the EP programs (Jan 2017 – Dec 2019) to harmonize data across counties and 2) for the 3 year period contemporaneous with the prospective EP program level data collection via the tablet (Jan 2021 - Dec 2024), to account for potential historical trends during the evaluation period.

Over the first year of this project, we held a series of meetings with EP program staff and county staff to address the project goals. With EP program staff, we reviewed the project goals and planned timeline, and verified the following information for the retrospective data period 1/1/2017 – 12/31/2019: program eligibility criteria, services and staffing, duration of services, collaborative relationships and subcontracting, documentation of pre-enrollment assessment activities and referrals, any changes to these categories over the time period. We also verified current information in these areas and plans for future changes. With county leadership and data analysts we reviewed project goals and timelines, and verified: EHR in use during the retrospective period, billing codes used, availability of different county mental health service types (e.g. outpatient, inpatient, crisis, etc.), other sources required for services, such as private hospital billing databases, and availability of specific variables. With both groups, we discussed the most efficient way for them to extract the relevant data, methods for de-identification, and plans for uploading data files securely. As we gathered information from different counties and their EP programs, we circled back to other counties/programs to discuss similar issues. As of June 30, 2020, we had begun the process of these meetings with three counties. The results of these meetings have been integrated into our plans below.

#### Early Psychosis (EP) Sample

First, all individuals entering the EP programs January 1, 2017 – December 31, 2019 will be identified using County Electronic Health Record (EHR) data. This list will be cross-referenced with the County EP program(s) to identify those individuals who received treatment versus only eligibility assessment and referral to another service. The programs will also identify which consumers were diagnosed with a first episode of psychosis, and which were diagnosed with a clinical-high-risk (CHR) for psychosis syndrome. Programs differ in whether they serve one or both groups.

#### Comparator Group (CG) Sample

We will compare the utilization and costs of the EP program participants to utilization and cost among a group of individuals with similar demographic and clinical characteristics who do not receive care in the EP program during the same timeframe in the same County. Individuals meeting similar eligibility criteria for the EP program (e.g., EP diagnoses, within the same age group) who enter standard care outpatient programs in the County during that same time period will be identified as part of the comparator group (CG). First, we will identify all individuals meeting these criteria receiving any outpatient services who are not served in the EP program. An exact definition for the CG sample will depend upon which EP program eligibility criteria can be reliably identified in the County EHR data (e.g., no psychotic disorder diagnosis more than two years prior to index outpatient service). The CG criteria will be finalized later in 2020 and described in the next annual report.

If a sufficient number of these individuals are clustered in specific clinics to match the EP group sample size, we will restrict our analyses to those clinics. Otherwise, we will select all individuals, regardless of primary behavioral health clinic. If there are more CG consumers than EP individuals, we may attempt to statistically match the groups on demographic variables at the group level, although we will summarize demographic characteristics of the entire CG sample.

#### Service Utilization

Next, data will be 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/ED services. If possible, we will also work 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 peer services, etc.). We have identified these potential additional sources of data in expert interviews with program directors and senior program staff.

Costs

Costs per unit of service will be assigned to each type of service. We will work 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. We will determine whether to apply a single cost across all services (by type of service) or to apply costs that are county- or provider-specific. We will include billable and non-billable services. Additional details on outcomes and cost data sources are described in Table IX below.

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

Potential Outcomes of Interest	Sources of Data on Relevant Outcomes	Levels of Analysis	Sources of Cost Data associated with Outcomes
<b>COUNTY LEVEL DATA VARIABLES</b>			
<b>Inpatient hospitalization for mental health concerns</b>	<ul style="list-style-type: none"> <li>County hospitalization records</li> </ul>	<ul style="list-style-type: none"> <li>Number/proportion of individuals hospitalized per group</li> <li>Number of hospitalizations per group</li> <li>Number of hospitalizations per individual</li> <li>Duration of each hospitalization (days)</li> <li>Total duration of hospitalizations (days) per individual</li> </ul>	<ul style="list-style-type: none"> <li>Daily rate paid by County</li> <li>Daily rate Medi-Cal reimbursement</li> </ul>
<b>Emergency Department or Crisis stabilization</b>	<ul style="list-style-type: none"> <li>County crisis stabilization unit records</li> </ul>	<ul style="list-style-type: none"> <li>Number/proportion of individuals with crisis visits per group</li> <li>Number of visits per group</li> <li>Duration of each visit (hours)</li> </ul>	<ul style="list-style-type: none"> <li>Hourly rate paid by County</li> </ul>
<b>Outpatient service utilization</b>	<ul style="list-style-type: none"> <li>Service unit records by outpatient program from County</li> </ul>	<ul style="list-style-type: none"> <li>Service type</li> <li>Number of service units (minutes)</li> </ul>	<ul style="list-style-type: none"> <li>Contract service unit rates</li> </ul>

Potential Outcomes of Interest	Sources of Data on Relevant Outcomes	Levels of Analysis	Sources of Cost Data associated with Outcomes
	<p><i>Examples:</i></p> <ul style="list-style-type: none"> <li>• Assessment</li> <li>• Case management</li> <li>• Group Rehab</li> <li>• Group Therapy</li> <li>• Individual Rehab</li> <li>• Individual Therapy</li> <li>• Family Therapy</li> <li>• Plan Development</li> <li>• Medication management</li> <li>• Collateral Services</li> <li>• Crisis Intervention</li> </ul>		

Statistical Methods

*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, current gender, race, ethnicity, etc.) between the individuals in the EP and comparator groups. Analyses adjusting for county and/or clinic effects will be performed using methods for stratified data, primarily multiple linear or logistic regression analyses. The same methods will be used to examine group differences in clinical characteristics at time of index intake such as primary diagnosis, substance use diagnosis, Global Assessment of Functioning (GAF), as well as the duration of time that clinical services were provided (i.e., duration of follow-up period = elapsed time from initiating clinical services to discharge from services or maximum period EP program allows, whichever is greater).

*Analysis of Outpatient Service, Crisis Stabilization, and Psychiatric Hospitalization Data*

Data related to outpatient services over the follow up period will be analyzed using generalized linear mixed models to determine if outpatient service use differs between the EP clinic (EP) and comparator group (CG) samples, by total outpatient service time (by minute) and time for each service type (e.g., medication management, individual therapy, group therapy, rehab services), adjusting for a parsimonious set of demographic confounders.

Data related to individuals’ experiences of psychiatric hospitalization and crisis/ER usage (see Table IX) over the follow-up period will be examined across multiple levels of analysis: (1) has the individual ever been hospitalized or utilized crisis services; (2) total number of hospitalizations/crisis visits; and (3) total duration of hospitalizations (i.e., length of stay [LOS]) in days. These data will also be analyzed using generalized linear mixed models to determine if hospitalization/crisis outcomes differ between the EP and CG samples.

If sample sizes are large enough, based on power analysis, we will examine the effect of potential moderating variables, including demographic, clinical, treatment participation and program fidelity variables, on service utilization.

*Analysis of Costs Associated with Outcomes of Interest*

Potential sources of cost data have been identified for specific outcomes of interest: outpatient utilization, ED/crisis utilization, and hospitalization. The distributions of costs will be examined statistically. If costs are highly skewed, a nonparametric bootstrap method may be used in the analyses. Means and confidence intervals of costs will be calculated and compared between groups. Alternatively, we may exclude extreme outliers and use non-parametric methods or mixed-effects models in the analyses. If cost rates differ for children and adults, we will stratify by these groups in the analysis. We will also examine the impact of time (fiscal year) on costs and utilization of these services.

#### *Multi-County Analysis*

Data from individual counties participating in this project will be cleaned and standardized in order to integrate samples across counties. Baseline demographic and clinical characteristics will be compared across counties and can be used as covariates in the generalized linear mixed models, which will also include county as a fixed factor to account for unobserved county-level variation correlated with individual outcomes. The larger combined sample size is expected to provide increased statistical power, allowing for a richer set of controls and error structure, for better statistical inference in estimating the effect of the intervention on the EP treatment group. The increased sample size will also permit moderation analyses, such as examining the impact of program fidelity on the relationship between service utilization and clinical outcomes.

#### *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 encrypted and password-protected methods. Files will be uploaded to a secure study-specific web portal, housed on secure servers at UC Davis. These files will be accessible to study staff via Secure File Transfer Protocol (SFTP). Counties will be able to upload their own data but will not have access to data on the UCD servers, including any identifiable data from the other counties.

## **10. Initiate Pre-LHCN Implementation Questionnaires**

In the LHCN proposal, we proposed to ask consumers and providers to complete self-report questionnaires in the pre-implementation period of the project. Consumers will be asked to complete self-report questionnaires about insight into illness, perceived utility of the tablet, satisfaction with treatment, treatment alliance, and comfort with technology. We also planned to have providers at each clinic complete questionnaires on treatment alliance, use of data in care planning, perceived effect of use for the LHCN, and Comfort with Technology. In addition to the originally planned pre-implementation surveys, we have also added provider surveys that assess demographics, eHealth Readiness, Organizational Readiness for Changes, Attitudes Towards Evidence Based Practice, Clinician Attitudes of Recovery and Stigma, Modified Practice Pattern Questionnaire, and Professional Quality Scale. This battery of questionnaires has been designed to assess potential factors that could influence outcomes for EP consumers that are measured in the project. Therefore, the study team felt it was important to assess these factors for inclusion in the future analysis of outcomes data.

At this time, we have not had any consumers complete pre-implementation questionnaires. All our planned in-person visits have been put on hold due to COVID-19. We are currently working with programs to devise strategies to be able to contact consumers and families for remote research participation prior to full roll-out of the tablets in each program.

We were able to have providers from some clinics finish a subset of surveys after completing consent during the site visits described above. As of June 2020, we had providers at the following sites complete some of their

questionnaires: San Diego Kickstart, OC CREW, Aldea SOAR Solano, Stanford Inspire, UCLA CAPPs, UCLA Aftercare, UCSD CARE, UC Davis EDAPT, SacEDAPT, UCSF PATH, and San Mateo Felton BEAM (re) MIND. Questionnaires completed thus far include demographics, comfort with technology, and eHealth readiness. To date, 100 EP program providers and staff completed our first set surveys of eHealth readiness, comfort with technology, and basic demographics. We have had 85 EP program providers and staff complete the second set of surveys on organizational readiness for change, burnout and satisfaction, attitudes on evidence-based practices, clinician attitudes on recovery and stigma, and practice style. The results of the findings from the surveys will be summarized in the next report, and summaries with potential action items will be provided to each clinical site as a first step in using data to enhance care delivery in EP programs.

## **Discussion and Next Steps**

Over FY2019/20, the team has worked hard to address each of the initial goals laid out in the LHCN proposal. It should be noted that the LHCN represents one of the first partnerships between the University of California, Davis, San Diego and San Francisco with multiple California counties, building a foundation to implement and expand a collaborative and 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. While the project has experienced some delays in contracting and many barriers due to the global COVID-19 pandemic, the team feels confident that we are making excellent progress.

The extensive outreach process detailed in this deliverable has significantly informed the construction of the Learning Health Care 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 different groups of 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 report 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 consumers 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 consumers and families. This further supports the importance of meaningful community engagement when implementing such programs.

We have also made significant progress in the county-level data component of this project in preparation for the first county data pull for the retrospective period.

### **Barriers to Implementation and Changes from Initial Study Design**

One of the initial barriers to completing planned project activities was the delays that counties have faced in executing their contracts. This was initially problematic because we couldn't finish some activities without

getting feedback from all participating counties, which was challenging for counties who had executed their contract early, like Solano County, as we couldn't move on the next set of objectives in their contract. In addition, it made it difficult to align all contract objectives to the same timeline with such varied start dates. Even so, all parties have worked together and been flexible to make significant progress on our planned LHCN goals. We are mostly on track with our initial proposed timeline with a few exceptions. For example, delays in contracting with the counties led to delays with establishing an agreement with Quorum technologies. Due to this, and other factors outlined below, the original application development timeline has been delayed.

#### *Impact of COVID-19 on EP LHCN Activities*

Many of our planned activities have been affected by COVID-19 and our team and participating programs had to shift some aspects of the initial study design to successfully accommodate constraints put in place by COVID-19. Of note, we have continued to conduct several focus groups with all LHCN county programs that have an executed contract. Even though we had to cancel scheduled in-person visits due to COVID-19, our team rapidly adapted to these new remote research parameters in order to continue to meet project goals. This included updating our IRB to reflect the procedural changes needed to accommodate remote research activities. Our participants have also had to adjust; they sign all documents and payment forms remotely via DocuSign. In addition to transitioning outcome focus groups to a remote format, we rapidly transitioned our plans to be able to conduct wire frame groups in a remote format from the beginning. The wire frame focus groups have been extremely valuable in providing data on the application and dashboard design, flow, and functionality from a diverse group of stakeholders. This feedback ensures that we build an application with the users in mind, which will increase adoption and utility.

While completion of the current activities covered in this document have not been delayed with the exception of questionnaire completion, future objectives have been impacted by the global COVID-19 pandemic. The most notable effect is a delay on the beta testing and full roll-out of tablets in the LHCN. In our original timeline, we planned to have the tablets with our custom-built application to collect outcomes data in all programs by early 2021. However, due to unforeseen circumstances such as the global COVID-19 pandemic and delays in securing a sole-source contract with our application developer, this timeline has been delayed. While we do not have an exact date for expected rollout, we believe we will be able to have the application in all of the programs by early Summer of 2021. We have notified all participating program and county leadership of this change.

While selection of sites for beta testing was not affected, actual beta testing has been delayed by about three to four months. We have notified beta test sites to expect beta testing to begin in January or February of 2021.

#### *EP LHCN Goals and Activities for FY 20/21*

We have several major objectives we plan to work towards and accomplish in the 20/21 fiscal year. For the program-level component of the EP LHCN project, we plan to initiate and complete alpha and beta testing of the tablet application in the current fiscal year. Any outcome data collected from the beta sites will be summarized, including information from qualitative interviews that help us understand barriers and facilitators to app implementation. Feedback from alpha and beta testing will be communicated to the development team in order to address issues in application design and workflow. In addition to testing, we will get preliminary feedback from focus groups on the alpha and/or beta versions of the application and dashboard. If the application is ready for full role out in all EP LHCN sites during this fiscal year, we will conduct initial site visits to train EP program staff in application implementation and data collection.

We will also establish and finalize the data collection process for obtaining county-level utilization and cost data for the retrospective data pull. This county-level data will cover a prior three-year timeframe for preliminary evaluation for both EP and comparator group (CG) programs. After this data pull, we will prepare a report on

the feasibility of obtaining cost and utilization data from multiple counties.

A final goal of the 20/2021 fiscal year will be to schedule for EP Program Fidelity assessments, in preparation for fidelity assessments that will occur in the next year.

## Appendix I: Advisory Committee Recruitment Flyer

# EPI-CAL California Early Psychosis Collaborative: Learning Healthcare Network and Statewide Evaluation

## Interested in participating in a focus group?

### What is the Learning Healthcare Network?

The project will bring together early psychosis programs across California to share information and coordinate collection of outcomes data. A tablet application will collect data from clients and families in the clinic. The clinical team will use the data to help make care choices and support clients to reach their goals.



### Why is this research being done?

The goal of the focus group is to better understand which measures to include in the tablet application. We are interested in hearing what aspects of early psychosis treatment progress are most important to clients and families.

### What does being a focus group participant entail?

We will meet as a group for 90 minutes and share with you the measures available. The goal is for you to share with us your opinion on which of the measures available are the most important and useful for psychosis treatment, and which measures are the least important.

You will be paid \$30 for your participation.

### If you are interested or would like more information, please contact:

Valerie Tryon, PhD  
Clinical Research Coordinator  
University of California, Davis  
Work: 916-734-3247  
Email: [vltryon@ucdavis.edu](mailto:vltryon@ucdavis.edu)\*

*\*Please do not share personal health information via email*



UC San Diego



## Appendix II: Example Focus Group Guide

*FACILITATOR: PASS OUT COLOR STICKERS (one color for pre vote, one for post vote)*

### **Consent Process AND compensation (15mins)—Together in 1 room for simultaneous FGs**

Brief staff introductions

Brief intro to project by lead facilitator

Use consent/assent script

Compensation forms and pass out gift cards

Describe feedback form

### **BEFORE START AUDIO RECORDER:**

INTRODUCE SELF AS A RESEARCHER:

“I am coming to you today as a researcher, so you all are the EXPERTs in your own experiences and perspectives. We are here to learn from you.”

PROCESS FOR AUDIO:

We are using an audio recording because we want to capture all of the rich information you will be sharing with us today.

“Again as a reminder, please try your best not to say your name or others’ names or other identifying information about yourself or others. Please try to speak loudly and clearly and try to only have one person talk at a time. If possible, please refrain from side conversations. We ask this of you so that we can get a really clear audio recording but also as a sign of respect for your fellow person.”

Before we start the recording, does anyone have any questions?

FOR FAMILY FGs: Please go around the room and state your relationship to the EP consumer.

### **Introduction (3mins)**

“In December 2018, your clinic joined the Early Psychosis Learning Healthcare Network. As part of this network, additional data will be collected and then be available to individuals in this clinic to be used to actively support treatment. This will provide consumers and family members, with an additional way to help identify and address treatment priorities, and to follow progress over time.

However, for this to work and be useful, it is essential for us to collect data that is meaningful to **you**.

Therefore, the purpose of today is to understand what data you think will be most useful to track as part of ongoing treatment. In addition, we also want to know what you think will be feasible for us to collect in this setting.

### **Part 1: Outcome prioritization (10mins)**

First off, I think it is important for us to show you what kind of outcomes we are currently thinking might be important to collect (Fig 1).



“Take out the outcomes definition handout in your folder and start reading through them.”

[FACILITATOR – MAY NEED TO GO THROUGH ALL OF THESE WITH THIS POPULATION]

- 1) Does anyone have any questions about what these different domains mean?
- 2) Can you think of other important outcome domains for us to consider that are not on this list?  
(FACILITATOR: ADD THESE TO THE “OTHER” SPOTS ON THE POSTER)
- 3) What do you think of “Family Burden”?
  - a. FACILITATOR: Go to POSTER AND CROSS OUT BURDEN (under family burden) CHANGE TO IMPACT/STRESS?
- 4) “Including all of the new and original domains, I’d like everyone to select the 4 outcome domains you consider to be the most important for us to measure by using the \_\_\_\_ color stickers you have in front of you. Before you get up and put these on the poster, take a moment to really think about which 4 you will choose then commit to those. Once you decide, you can all get up. More than 1 person can go up to the poster at a time 😊”

**[REMINDER: “PLACE STICKERS IN THE DESIGNATED AREA AT THE TOP OF THE BOX OR use SPECIFIED COLOR]**

*TALLY UP THE STICKERS FOR EACH DOMAIN TO HELP WITH PRIORITIZING REMAINING DISCUSSION.*

## **Part 2: Participant Prioritized Outcomes (35mins –9 mins per top 4)**

### **1. Review selected domains**

*FACILITATOR: DISTRIBUTE OUTCOME MEASURES RELATED TO THE DOMAINS THEY CONSIDER MOST IMPORTANT ONE DOMAIN AT A TIME. ORIENT THEM TO THE TABLE OF CONTENTS.*

*“Please do not write on the measures packets or the tables of contents as we will be reusing these for each group we visit”*

**GO THROUGH WHOLE OF PART 2 FOR EACH SELECTED DOMAIN**

FACILITATOR: EXPLORE/ENCOURAGE CONTRADICTIONS. HOWEVER, AIM TO DRAW SOME DEGREE OF CONSENSUS ABOUT WHICH ONES ARE CONSIDERED MOST IMPORTANT/USEFUL. FINISH WITH CIRCLING WHAT THE GROUP CONSIDERS TO BE THE MOST IMPORTANT 4-6 DOMAINS.

Sample questions: Why did you choose this domain? Why did you not choose this domain?

Why is this domain so important to collect over another?

***IF THERE IS ONLY 1 MEASURE RELATED TO THIS DOMAIN:***

- i) This is currently our only measure that attempts to capture information in this domain. Do you think it adequately captures what you think is most important to measure here?

ii) What makes it good/bad? Is it missing anything? What are the areas that are necessary?

*IF MORE THAN 1 MEASURE RELATED TO THIS DOMAIN:*

- i) You have said that measuring outcomes related to this domain would be useful. Here are some of the validated measures that have been identified as appropriate for use. Of these, which ones do you think might be best? Why?
- ii) Which ones would you consider definitely not usable (if any)? Why?

## **2. How much detail is absolutely necessary for each domain?**

[FACILITATOR: If necessary, FLESH THIS OUT BY GIVING EXAMPLES:]

If *quality of life* was selected, would just one global score be useful, or would it be more helpful to go into specific sub-domains (satisfaction with housing, social, work/school, treatment, family, etc.)?

- i. What information would be helpful, if not absolutely necessary?
- ii. Is there any information related to this domain that would not be useful?

## **3. Final review of measure**

- 1) Do you think there will be any difficulties with using this measure?
- 2) What might we be able to do to lessen these challenges?
- 3) Are there any aspects in particular that you think will work well?

**Part 3: Other Outcomes (at least 30 mins; but also may be helpful to focus on topics that they are uniquely able to comment on, such as the family fx/burden measure). SPEND REMAINDER TIME HERE TO DISCUSS DOMAINS PAST GROUPS HAVE NOT BROUGHT UP, AIM FOR 5MINS MAX PER DOMAIN, UNLESS CONVERSATION REALLY FRUITFUL).**

“Here are some of the measures we are currently considering for the domains that you did not prioritize as a group”

- 1) Of these, which ones do you think might be the most appropriate (if any)? Why?
- 2) Which ones would you consider to be definitely not appropriate (if any)? Why?

*IF THERE IS 1 MEASURE FOR THE DOMAIN:*

- i) What do you think of this measure?
- ii) Does this measure cover the areas you would like it to measure?
- iii) Are there any key pieces, or are all the components important?

*IF THERE ARE MULTIPLE MEASURES FOR THE DOMAIN:*

- i) Of these, which do this think is better? Why?
- ii) Are there any you think that are unusable? Why?
- iii) Does this measure cover the areas you would like it to measure?
- iv) Are there any key pieces to the selected measure, or are all the components important?

## **Part 4: Re-scoring the outcomes (2mins)**

FACILITATOR: PASS OUT COLOR STICKERS 1 MORE TIME.

“Now that we have had the chance to go through many of the different outcomes, I’d like for you to select the 4

you *now* consider to be most important. Using the second set of stickers, please rate your final 4 prioritized measures. Again take some time to think about which 4 you will place and then commit.”

*FACILITATOR NOTE: Remind participants to PLACE STICKERS IN THE DESIGNATED AREA AT THE **BOTTOM** OF THE BOX OR using \_\_\_\_\_ color).*

*Thank everyone for their participation and valuable input!!*

# Appendix III: Outcome Domains Focus Group Poster

1<sup>st</sup> Vote = *Above* dotted line  
2<sup>nd</sup> Vote = *Below* dotted line

## PROPOSED OUTCOME DOMAINS San Mateo Felton Providers

**KEY**

Client self-report measures

Family/Collateral self-report measures

Provider/Prescriber-completed measures

Client OR Family/Collateral measures

Client OR Provider/Prescriber measures

		<b>Clinical Status</b>	<b>Psychiatric Symptoms</b>	<b>Suicide Risk</b>
Other: _____	<b>Cognition</b>	<b>Risk for Homelessness</b>	<b>Incarceration/ Recidivism</b>	<b>Functioning (Social/Role)</b>
Other: _____	<b>Service Satisfaction</b>	<b>Service Utilization (Inpatient, Outpatient, Emergency)</b>	<b>Family Burden</b>	<b>Medication Adherence</b>
Other: _____	<b>Quality of Life/ Well-Being</b>	<b>Recovery</b>	<b>Family Functioning (Communication/ Quality)</b>	<b>Medication Side Effects</b>

## Appendix IV: Proposed Outcome Domains and Definitions

### Outcome Areas Under Consideration

Here are some simple definitions of the outcomes we will be discussing today in the focus group. It is important that these should just be seen as a starting point. For some there is no “right” definition. If you understand one of these outcomes to mean something different, then it would be very helpful to bring it up in the discussion. We are here to understand what areas are important to you, so if you think we should be using it in a different way we really want to know about it.

**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 (Stress/Impact):** The impact of a loved one’s mental illness on the support person’s life.

**Family Functioning (Communication / Quality):** 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).

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