

# Mental Health Services Act

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*Evaluation of Outcomes and Associated Costs for Early Psychosis Programs:*

*UC Davis Pilot & Statewide Method Development*

*Deliverable 6:*

*Deliverable 6: Report on the Pilot Study Findings and Recommendations for Measuring Duration of Untreated Psychosis (DUP) and Duration of Untreated Mental Illness (DUMI)*

Final version submitted April 15, 2017

Revised version submitted May 1, 2017

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Interagency Agreement Number 14MHSOAC010

This report was supported by:



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## Executive Summary

**BACKGROUND:** California's Mental Health Services Act (MHSA) Prevention and Early Intervention (PEI) funds provide a unique opportunity for California counties to initiate programs that strive to intervene early in the course of mental health difficulties, thereby preventing serious mental disorders from becoming severe and disabling. Of the 58 California counties, 24 reported using MHSA funding to establish early psychosis (EP) programs to work towards PEI goals. In 2016, MHSOAC mandated that PEI programs providing access and linkage to treatment, such as EP programs, track the Duration of Untreated Mental Illness (DUMI) for individuals served. For example, in EP programs, this is measured as the duration of untreated psychosis (DUP). However, there is currently no standardized, validated method for how DUMI should be collected and recorded.

**PURPOSE OF CURRENT EVALUATION:** The goal of this deliverable is to determine how EP programs across California define, measure, collect, and record data regarding DUP, and provide a proposal for how DUP and DUMI could be measured in PEI programs at the statewide level. The current report summarizes the findings from the pilot study completed to examine and document how EP programs define, collect, and measure DUP, and provide recommendations on how such procedures may be scaled to measure DUMI across Prevention and Early Intervention (PEI) programs.

**METHODS:** A stakeholder engagement meeting was convened to provide input on the definition and measurement of DUP and the feasibility of scaling DUP measures to measure DUMI. Stakeholders included county representatives (MHSOAC), providers from multiple EP programs, and family members with lived experience who have been involved in EP programs. Active EP programs previously identified in the survey phase of the project were invited to participate in a qualitative, semi-structured phone interview to gather information regarding existing measures, collection, and recording of DUP. Transcribed interviews were evaluated using directed content analysis to identify key themes and suggested approaches for measuring DUP in EP programs and DUMI more broadly.

**RESULTS:** Of the 30 EP programs previously identified as active across the state of California, 19 programs agreed to participate in qualitative interviews, yielding a response rate of 63%. Of the 16, 15 programs ultimately completed the interview, yielding a completion rate of 50%. There were significant differences between sites in several aspects of measurement and analysis of DUP, including variability in the methods of determining psychosis onset and the start of treatment. Despite these differences, when asked if the process for measuring DUP would be an appropriate way to measure DUMI for other serious mental illnesses, almost all participants agreed that the process would be comparable. However, programs also agreed that this process would require considerable resources and expertise that may not be available to most general PEI services. As a result, a number of sites proposed more simplified solutions to determining DUMI, with the caveat that such methods may significantly impact the reliability and validity of the resulting data.

**CONCLUSIONS:** This report provides a summary of how DUP is defined, measured, and recorded in EP programs across California, and explores the ways this may be scaled to assess DUMI in other PEI services providing access to treatment and linkage to services. Despite variation in the method of determining DUP between sites, there appeared to be a consensus that the methods used to evaluate DUP in EP programs could comparably measure DUMI for other disorders. Recommendations are provided regarding definitions for psychosis onset, treatment onset and requirement for data recording related to measurement of DUP. Recommendations for measuring DUMI, including a tool for determining the timeline of symptoms, as well as 3 potential protocols for measuring DUMI in PEI programs are also provided.

## Introduction

In 2004 the California electorate passed Proposition 63, a ballot initiative that established the Mental Health Services Act (MHSa). MHSa has allowed for community-driven improvement and innovation in public mental health services. One section of the Act provides support for Prevention and Early Intervention (PEI) services, which seek to reduce specific negative outcomes that may result from untreated mental illness, including: (1) suicide, (2) incarcerations, (3) school failure or dropout, (4) unemployment, (5) prolonged suffering, (6) homelessness, and (7) removal of children from their homes [1]. Of the 58 California counties, 24 have recently been identified as using MHSa funding to establish early psychosis (EP) programs in order to work towards PEI goals (see Deliverable 5). Implementation of such programs in other countries, including Australia and the United Kingdom, have shown impacts on many of the outcomes that MHSa aims to influence, including reductions in symptom severity, reductions in substance use, and improvements in functioning over time [2, 3].

The California Mental Health Services Oversight and Accountability Commission (MHSOAC) is tasked with overseeing the implementation of MHSa. This includes the reporting and tracking of data points for MHSa programs. In 2016, MHSOAC mandated that PEI programs providing access and linkage to treatment, such as EP programs, track the Duration of Untreated Mental Illness (DUMI) for individuals served. MHSOAC has defined DUMI as “the time between self-reported and/or parent-or-family-reported onset of symptoms of mental illness and entry into treatment, defined as participating at least once in treatment to which the person was referred” [4]. The MHSOAC provided this definition to counties, but the counties were allowed discretion as to how they would develop a methodology to implement this measurement. This provides a unique challenge for PEI-funded services, as the literature has failed to identify a standardized, well-validated, and reliable assessment or clinical interview technique to measure DUMI that is feasible in front-line clinical settings. As a result, counties and services sought clarification from the MHSOAC regarding these regulations, and requested guidance on how to implement measurements for DUMI [5].

In 2016, the MSHOAC commissioned the University of California (UC), Davis, to propose a method for a statewide evaluation to examine program costs (i.e., costs expended to implement the program), outcomes (e.g., decreased hospital visits), and costs associated with those outcomes (e.g., costs associated with hospitalization) related to providing EP programs in California. In addition, the MHSOAC has requested that the UC Davis team conduct a pilot study to examine how California counties measure Duration of Untreated Psychosis (DUP), and provide suggestions as to how these approaches could be scaled to the measurement of DUMI statewide. To date, the UC Davis research team has submitted the *Summary Report of Descriptive Assessment of SacEDAPT Early Psychosis Program* (Deliverable 1); *Proposed Methodology for Analysis of Program Costs, Outcomes, and Costs Associated with those Outcomes in the SacEDAPT/Sacramento County Pilot* (Deliverable 2); *Report of Research Findings for SacEDAPT/Sacramento County Pilot: Implementation of Proposed Analysis of Program Costs, Outcomes, and Costs Associated with those Outcomes* (Deliverable 3); *Proposed Plan to Complete the Descriptive Assessment of Early Psychosis Programs Statewide* (Deliverable 4); and *Summary Report of Descriptive Assessment of Early Psychosis Program Statewide* (Deliverable 5). The current report summarizes the findings from the pilot study completed to examine and document how early psychosis programs define,

collect and measure DUP, and provide recommendations on how such procedures may be scaled to measure DUMI across for all severe mental illness.

## **Review of the Literature: Measuring the Duration of Untreated Psychosis and Mental Illness**

The first section of the literature review will outline the clinical significance of DUP/DUMI. Next, a review of how DUP has been measured in research settings, including a definition of terms, the operationalization of the concept, and the challenges inherent to the information-gathering process will be presented. Third, we describe how measures used to determine DUP have been applied to measuring DUMI for the schizophrenia prodrome. In the final section, we present a review of the published literature on methods for evaluating DUMI.

### **The clinical significance of DUP/DUMI**

There is a significant body of literature which suggests that a longer duration of untreated mental illness is associated with poorer outcomes. Much of the focus of this research has been in the field of psychosis, where a shorter duration of untreated illness has been consistently associated with positive outcomes such as better treatment response, less severe symptoms, improved neuropsychological test performance, reduction in the risk of suicide and violent behavior, better quality of life, and less functional impairment both after initial treatment and up to 15 years later[6-9]. However, there is an emerging evidence base to suggest that the duration of untreated illness may also have a significant impact in other forms of severe mental illness. In Bipolar Disorder, a longer DUMI has been found to be associated with a higher likelihood of attempting suicide and a greater frequency of suicide attempts [10, 11], in addition to more frequent hospitalizations and poorer social adjustment [10]. In major depressive disorder, a longer DUMI has predicted a greater persistence of depressive symptoms [12], and is associated with a higher number of depressive episodes [13]. In panic disorder, a longer DUMI was associated with an increased likelihood of co-morbidity with other axis I disorders [14]. Finally, in obsessive compulsive disorder (OCD), there is some evidence to suggest that a longer DUMI may be associated with a poorer treatment response [15].

One key feature of DUP and DUMI is that unlike a number of other risk factors such as familial history, the duration of untreated illness is considered to be a modifiable risk factor. In recent years, there is evidence to suggest that DUP can be reduced by early identification programs, community outreach methods to improve the understanding of psychosis, and a reduction of barriers to treatment [16, 17], which can in turn improve clinical outcomes [18]. As a result, there is increasing recognition in the importance of both measuring and reducing the length of DUMI in clinical practice.

### **Measuring the Duration of Untreated Psychosis (DUP)**

Reducing DUP is recognized as a primary goal for improving outcomes in young people with first episode psychosis, and an important outcome measure in its own right, with standards set by the World Health organization [19]. Despite the importance of DUP, there is no standard or best practice measure for DUP that can be applied across clinical EP programs [15, 20]. In studies that have reported DUP, a large

range has been reported both within studies and across research groups, which is likely to be at least partly attributable to differences in the operationalization and assessment of the construct [21].

As noted by Compton and colleagues, a number of factors require consideration when measuring DUP in either clinical or research settings. First, one must clearly define the concept (i.e. DUP) of interest. Second, it is important to consider how the onset and endpoint are operationalized in order to allow a numerical value of DUP to be calculated. Third, it is necessary to adopt a consistent assessment method to gather the information required to determine the start and end point of DUP in order to minimize variations in measurement error.

### **Definition and operationalization of DUP**

The measurement of DUP has become a focal point for Early Psychosis (EP) programs and EP research. In the literature, DUP has been consistently defined as the time between the onset of initial psychotic symptoms and the initiation of treatment [21, 22]. This is comparable with the MHSOAC definition of DUMI, stated as “the time between self-reported and/or parent-or-family-reported onset of symptoms of mental illness and entry into treatment, defined as participating at least once in treatment to which the person was referred (west law website).” These definitions will be used throughout this report.

While the definition of DUP and DUMI may be considered consistent, significant variability in the operationalization of the concept exists in the literature [21]. *Regardless of the psychiatric disorder, measuring the duration of untreated illness requires establishing two time points; the point at which the individual meets criteria for a particular mental health disorder, and the point at which treatment is initiated.* As identified in a number of reviews [21, 23, 24], DUP onset has been operationalized in the research literature in multiple ways, such as first experience of delusions or hallucinations [25]; evidence of active illness, including positive, negative and affective symptoms [26]; onset of any positive symptoms, or catatonic motor behavior [27]; and first noticeable change in behavior [28]. The frequency of the symptoms has been included as an additional qualifier in some studies, specifying that symptoms must have lasted for several days, be sustained, appear at least several times over a period of a week, and/or not be limited to brief moments [29-32]. In cases where the symptom severity ratings derived from structured clinical interviews were used to determine psychosis onset, additional features may also be incorporated into the diagnostic process. For example, in the Positive and Negative Syndrome Scale (PANSS [33]), determining the severity of a particular symptom includes an evaluation of their impact on the individual, either in terms of an impairment of functioning or the distress the symptoms cause. In clinical interviews designed to differentiate between psychosis and the clinical high risk state (CHR), such as the Structured Interview for Psychosis-Risk Syndromes (SIPS [34]), determining the degree of conviction that the interviewee may have regarding their unusual thoughts or perceptual experiences is considered key to diagnosing when individuals transition from the high-risk state to full psychosis. Other considerations when determining onset include the etiology of the symptoms (e.g. due to substance use or medical condition). This significant variation in the operationalization of psychosis onset could often result in substantial differences in the date that an individual is considered to become psychotic, and as a result may impact the reported DUP considerably. For example, less stringent symptom criteria that do not evaluate duration, frequency or impact may inflate the reported length of DUP due to more transient positive symptoms indicative of CHR being incorrectly characterized as psychosis [23].

In addition to different features of psychosis being used to determine illness onset, different measures are available to obtain information required to define illness onset. In a systematic review by Register-Brown and Hong [20], eight different assessments tools were identified that measure the onset of psychotic illness, with no one instrument identified as significantly more reliable than another. Regardless of the method employed to determine the onset of illness, careful consideration of the information sources used during the evidence-gathering process can be critical to limit the difficulties inherent to determining psychosis onset.

Determining the onset of psychosis can be highly challenging due to a number of reasons. These include, but are not limited to, the retrospective nature of the assessment, meaning the information may be prejudiced by recall bias; the impact of additional symptoms associated with psychosis such as cognitive impairment and lack of insight; and the challenge of determining at what point subthreshold psychotic symptoms transitioned to full psychosis. In order to address these limitations, a number of clinical assessment tools emphasize the need to collect data from multiple sources (i.e. SIPS [34]), with collateral information from family members considered particularly important in children and adolescents (K-SADS [35]). Different sources of information typically come via self-report; from peers, family members, and friends; and from clinical sources, such as previous treatment providers, and/or medical records. Multiple sources of information are typically required due to the inherent limitations of each source [23]. For example, difficulties in retrospective recollection of may be compounded in acutely unwell consumers with psychosis experiencing positive symptoms or cognitive impairment, and may be particularly difficult when the duration of illness is long [36]. Family members may only recognize external changes, such as a decline in functioning or behavioral changes in response to psychosis, and using this information alone may artificially reduce reported DUP as many affected individuals keep their initial psychotic experiences to themselves [23, 37]. As a result, it has been suggested that the onset of subjective symptoms are best identified by the consumer, while family members or peers may be able to provide more valid reports of behavioral changes [38]. Finally, while evidence from previous providers may be invaluable, it is important to note that the information they receive may also be compromised in the same manner. In addition, there is a body evidence to suggest that psychotic disorders are significantly under-diagnosed in non-specialty mental health care or primary care due to a lack of expertise with psychosis [39], which may result in psychotic symptoms being under-reported to prior providers.

In addition to defining the onset of psychosis, operationalizing the end point- “onset of treatment”- is also necessary. The definition of DUMI proposed by the MHSOAC defines the endpoint as “entry into treatment, defined as participating at least on session in treatment to which the person was referred.” However, significant variation in what constitutes “treatment” has been described in the DUP literature [21, 24]. In different studies, the endpoint of DUP has been defined as the first contact with a mental health professional [40]; initiation of treatment [31]; initiation of first effective treatment [29]; first treatment with antipsychotics [41]; first psychiatric hospitalization [26, 42, 43]; and study entry point [44, 45]. While the MHSOAC definition specifies singular participation in treatment as an appropriate end-point for DUP, more restrictive criteria have been adopted in research settings, such as antipsychotics given over a sufficient period of time, and at an appropriate dosage to lead to clinical response [46]; or a period of receiving antipsychotic therapy, ranging from three weeks to three months,

or clear improvement in symptoms, whichever occurs first [18, 46-50]. As a result, depending upon how the endpoint of DUP is defined, the duration of illness for the same individual could theoretically vary by at least three months. This is significant, given the current treatment recommendations for FEP is to provide treatment within three months of a psychotic episode [19]. In fact, a set of definitions has been proposed dating from psychosis onset to one of three endpoints: DUP1 ends with initiation of antipsychotic medication; DUP2 ends with enrollment into an early intervention program; DUP3 ends with antipsychotic medication taken for 4 weeks, at least 75% of the time [51]. These (and other) differing definitions of the DUP endpoint each carry significant limitations. For example, using first hospitalization can falsely lengthen the reported DUP if an individual had previously received outpatient care for psychosis, or shorten DUP if effective care was not given during the admission [52]. While most studies use either receipt of antipsychotic or first psychiatric admission, there is evidence to suggest that the initiation of intensive psychosocial treatment may be considered a more legitimate end-point for DUP, given that the delay in initiation of psychosocial treatment has been found to be a more important predictor of negative outcomes relative to a delay in starting antipsychotic treatment [47]. Due to the significant variation in operationalization and the limitations inherent to each method, at present there is insufficient consensus upon which to establish clear recommendations.

In addition to measurement-related challenges, program level differences can further complicate the availability of data needed to determine DUMI. PEI funds are utilized by a breadth of programs, some of which exist outside of a typical clinic setting. While some programs exist as comprehensive early intervention programs with full clinical capacity (i.e. EP Programs), others were established in earlier roll-outs of MHSA funding and have a range of assessment capacity. These include stigma reduction programs, peer support groups, and education and resource programs. Given the structure of such programs, they are limited in their diagnostic capacity and may not have appropriate staff with the expertise to make necessary judgments for determining DUMI. Furthermore, some PEI programs that do not primarily provide treatment (but instead offer linkage or education) may not have an electronic health record. This limits the ability to record and access DUMI information, even in cases where a program may have some assessment capacity. PEI programs that do not offer treatment would not be able to define the treatment endpoint for DUMI. PEI programs that treat an array of mental health problems may not have an index disorder to target for defining the onset of symptoms. Consequently, the diversity of PEI-funded programs will need to be considered when discussing the feasibility of implementing a protocol for measuring DUMI.

### Measuring DUMI in CHR

The typical early course of psychosis is considered to comprise of three discrete stages;<sup>1</sup> the premorbid stage, the prodromal stage, and the acute psychosis stage [46, 53, 54]. Determining DUP is calculated by measuring the length of time from the start of the acute psychosis stage, up until the initiation of treatment. However, with greater focus on the prodromal or clinical high-risk (CHR) stage, in both

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<sup>1</sup> Premorbid phase refers to the period prior to the development of any clinical or functional deterioration; the “prodrome” or clinical-high-risk phase is characterized by the onset of subthreshold symptoms of psychosis (unusual thoughts, perceptual disturbances, mood symptoms) and associated decline in functioning. Acute psychosis represents the point at which symptoms (delusions, hallucinations, disorganization) are clinically significant and impair functioning, which typically signals the need for treatment.

research and clinical practice [55], EP programs are increasingly measuring DUMI, characterized as the period from the start of the prodromal stage up until treatment initiation.

The practice of measuring DUMI in CHR and EP clients follows a similar process in a number of respects. As with measuring DUP, measuring DUMI for CHR is typically undertaken using structured clinical assessment tools, such as the SIPS [34] or the Comprehensive Assessment of At-Risk Mental States interview (CAARMS [56]) to determine the onset of attenuated positive symptoms. However, assessing the onset of DUMI can present with a number of additional challenges. For example, the attenuated positive symptoms and impairments typically experienced by individuals with CHR are typically less frequent and less severe, meaning they may be harder to accurately identify. In addition, any changes in behavior may be subtle, making it difficult for others to observe. When assessing DUMI in individuals with EP, the initiation of the prodromal period would by definition precede the onset of psychosis, meaning the impact of recall bias may be even more prominent than when determining full psychosis onset. Finally, while the SIPS and CAARMS have been consistently adopted both in research and in EP clinical programs, they are time-consuming to complete and require considerable expertise, training and supervision, meaning using such scales may not be feasible for all PEI services.

#### **DUMI for non-psychotic severe mental illness**

While there is an emerging body of evidence that highlights the negative impact of DUMI on outcomes in non-psychotic severe mental disorders [10, 13, 14], through this review we could identify no studies reviewing either the operationalization of DUMI, or identifying the challenges to accurately calculating the period. However, it is likely that many factors related to DUP would extend to the measurement of DUMI for other disorders. For example, in measuring illness onset, it may be important to consider how the presence, frequency, intensity and impact of symptoms on functioning should be measured, and what threshold symptoms need to meet with each parameter in order to qualify for disorder onset. In attempting to determine onset, similar challenges are likely to exist, such as recall bias, and difficulties in interpreting both behavioral and symptomatic changes. Other issues, such as determining the onset of symptoms which may be subtler than hallucinations, delusions or severe disorganization may present even greater challenges. Alternatively, in disorders such as post-traumatic stress disorder (PTSD), where an etiological requirement (i.e. traumatic event) is specified as part of the diagnostic criteria [57], calculating DUMI may be more straightforward given the event can be placed on a timeline as a starting point for assessment. In the review of tools appropriate to measuring DUP [20], measures like the Comprehensive Assessment of Symptoms and History (CASH [58]) and the WHO's Psychiatric History schedule (PQ [59]) are not disorder specific, and so could be used to evaluate DUMI in addition to DUP.

#### **Review of the literature: Conclusions**

While there appears to be a broad consensus on the concept of DUP [21], significant variation in the operationalization of the term exist in the literature. A number of different assessment tools are available, with little evidence to support the use of any one scale over another [20]. None have been validated in front-line clinical settings. Regarding other severe mental illnesses, a review of the literature suggests that only minimal research has been completed in the field of operationalizing and assessing DUMI to date. As a result, it appears there is an insufficient body of work to provide clear, evidence-

based recommendations in how to assess DUP and DUMI in PEI services, based on the current published literature.

In determining the onset of psychosis, Compton and colleagues [21] recommend that 1) standardized interviews should be used, 2) corroborating information in addition to consumer's report should be collected, 3) inter-reliability between raters should be consistently checked, and 4) multiple instruments and procedures should be used. While such an exhaustive approach may be feasible in research settings or perhaps some well-resourced EP clinical programs, it is unlikely to be viable in most community-based clinical settings. Incorporating detailed information regarding the presence, frequency, impact, of symptoms from various sources and across multiple instruments can be highly time-consuming, and require considerable interviewer expertise and supervision which may not be realistic for all PEI services. As a result, getting detailed feedback from clinical services about the tradeoff between feasibility and reliability may be key to successful implementation of determining psychosis onset in clinical practice.

Regarding determining the endpoint to DUP, significant variation exists in how entry into treatment has been defined, with different limitations to each approach. As a result, one way forward may be to survey which methods are currently used in clinical services to determine both what is feasible to record in such settings, and what may be considered as most clinically meaningful. Finally, there is little information in the literature concerning how DUP should be recorded in clinical services. Drawing information from EP programs on how they collect this information may be a helpful way forward in determining what may be appropriate to implement across all PEI services.

## **Deliverable 6: Report on the Pilot Study Findings and Recommendations for Measuring Duration of Untreated Psychosis (DUP) and Duration of Untreated Mental Illness (DUMI)**

### **Approach to evaluating DUP and DUMI measurement**

The goal of this deliverable is to determine how early psychosis programs across California define, measure, collect, and record data regarding DUP, and provide a proposal for how DUP and DUMI could be measured in PEI programs at the statewide level. Within this deliverable we have:

1. Conducted a stakeholder meeting to discuss issues related to defining, measuring, and collecting data on the onset of symptoms and subsequent treatment(s) as related to DUP and DUMI. Stakeholder advisers included county representatives, providers of early psychosis programs and services, evaluation experts with experience in early psychosis programs, and consumers/family members with lived experience of psychosis.
2. Analyzed the results of the stakeholder meeting, using these results to inform the development of an early psychosis program interview protocol and tool.
3. Conducted and analyzed qualitative in-person interviews with all counties that have an active early psychosis program and agreed to participate in this study to assess how DUP is defined, measured, collected, and recorded. This includes information on their ability to change onset dates in the dataset as new information becomes available; their process for review and

updates if more data becomes available; how they define DUMI; and their suggestions for how to measure DUMI.

4. Provided a proposal for the measurement of both DUP and DUMI at the statewide level (including multiple measurement options), and provided additional recommendations related to the guidance of the MHSOA to counties to assess DUMI with high reliability and validity.

### Research Questions

1. How are California County Early Psychosis programs measuring the duration of untreated psychosis (DUP)?
2. How can this process be scaled to the measurement of duration of untreated mental illness (DUMI)?

## Methods

### Design

An exploratory, qualitative, semi-structured interviewed based study was completed to assess stakeholders' perspectives evaluating DUP and DUMI. In the first stage of the process, a stakeholder meeting including county representatives, EP program managers, and family members with lived experience was convened to provide input on how to evaluate current methods used by EP programs to determine DUP, and provide guidance how this could potentially be scaled to assess DUMI across PEI services.

This feedback was used to develop an interview protocol for a series of semi-structured telephone interviews with active EP programs to gather information regarding existing measures, collection, and recording of DUP. EP Program interviews were conducted via phone to best accommodate schedule demands for interview participants, as they enabled individuals to participate regardless of location. These interviews were conducted by two PhD-level researchers, one with a background in medical sociology specializing in qualitative methods, and one with a background in psychiatry specializing in the field of early psychosis. All interviews were recorded, transcribed, and hand coded by the interviewers. The method of enquiry and the analysis of the transcribed interviews drew on directed content analysis [60]. In using this approach, the analysis drew both on the existing literature and the theories proposed during the stakeholder meeting, using this as a starting point from which the theoretical framework could be extended.

### Procedures

#### *Stakeholder Engagement and Interview Development*

A stakeholder engagement meeting was convened on November 17, 2016 to provide input on the definition and measurement of DUP and the feasibility of scaling DUP measures to measure DUMI. Stakeholders included county representatives (MHSOAC), providers from multiple EP programs (Sacramento, San Francisco, San Diego, Contra Costa) and family members with lived experience who have been involved in EP programs (see Appendix A).

Stakeholders were given an overview of DUMI measurement regulations for PEI programs and definitions of key terms to facilitate discussion. Discussion points included how DUP, illness onset and treatment initiation could be defined; how these different terms could be operationalized in clinical services; potential challenges of accurately identifying DUP; and data collection approaches. Stakeholders were provided with a preliminary interview guide for review. Stakeholders identified specific areas to be targeted (see Results: Stakeholder Engagement section below) which were addressed directly in the interview questions.

The final interview comprised of three sections, with a duration of approximately 90 minutes (see Appendix B). Figures were developed to aid in the discussion of key terms (See Appendix C and D) Questions pertaining to DUP and DUMI assessed for:

- If, and how, programs currently assess the onset of psychosis (including the criteria, process, staff involved, amount of time necessary, and sources used to inform a decision)
- How accurate they perceived these measures of DUP to be (e.g. availability of specific dates and times)
- Challenges of determining an accurate psychosis onset. The role of collateral information from family members and support persons of consumers in determining onset of psychosis
- How programs current define and operationalize treatment onset as an indicator of the endpoint of DUP
- How information related to DUP is recorded and whether it can be updated
- The availability of DUP information in an electronic format

Individuals were presented with potential scenarios during the interview to clarify how definitions of DUP and DUMI are applied in practice. They were also provided with the opportunity to provide additional feedback or concerns regarding measurement of DUP and DUMI.

After the preliminary interviews were completed, the interview guide was reviewed and refined, with increasing focus on the emerging themes as more interviews were completed.

### **Participants**

All active EP programs across the state of California were contacted and invited to participate in the study. To best answer the questions put forth in the interview guide, staff members with administrative, data management, and clinical roles at each site were selectively recruited for their insight and comprehensive knowledge of DUP measurement at the program level. For each interview, between 1-3 staff members elected to take part. Compensation at a rate of \$50/hour was offered to all participating individuals. Individuals were provided a copy of interview questions at the time of scheduling, along with supplementary figures (Appendix C and D). Interviews were recorded and transcribed by an external services for analysis.

### **Topic Guide**

A topic guide was developed by the research team based on the analysis of the interview data. Topics included discrepancies in definitions of DUP, issues with standardizing methods for data collection and recording, determining treatment onset, as well as barriers and facilitators to determining accurate DUMI.

## Data Analysis

Through an iterative process, the investigators conducted the interviews and analyzed the data. After conducting several interviews, the research team held a meeting to identify preliminary themes, generate hypotheses, and further develop the interview guide. This process was repeated until saturation of the main topic areas was reached. During analysis, a series of preliminary codes were developed to identify patterns in the data, and to identify manifest and latent codes. From these, a set of categories were identified, from which a set of emerging themes were established.

## Results

### Stakeholder Engagement

A stakeholder engagement meeting was convened on November 17<sup>th</sup>, 2016, and included mental health services providers and family members impacted by psychosis (see Appendix A). Stakeholders were provided with an overview of current MHSa DUMI measurement regulations for PEI programs and background regarding the development of the DUP term. Researchers outlined outstanding challenges in measuring DUP to frame discussion regarding scaling DUP measures to capture DUMI. The primary aim was to determine existing structures for measuring DUMI and feasibility of measuring DUMI to inform the development of an interview guide. Key points addressed by the group are summarized below:

1. How to define the onset of mental illness: Stakeholders identified that noticeable changes in functioning (e.g. poor school performance, disinterest in social contact) and signs of discomfort and distress were useful indicators of psychosis onset, which could be identified by both family members and individuals experiencing psychosis themselves. Stakeholders involved in providing treatment reported probing for changes in these areas during assessment. Similar metrics could be used to determine DUMI, including making use of physical symptoms (insomnia or hypersomnia, appetite changes, somatic symptoms) to track illness development in individuals that are too young or ill to verbalize emotional distress.
2. Issues with complex histories: Though some indicators of psychosis onset can be generalized to mental illness more broadly, many individuals present with complex histories. Stakeholders that identified as caregivers of individuals with psychosis reported their children had mixed histories with trauma, abuse, substance use, and developmental complications that would make it challenging to identify DUMI. Stakeholders who were clinical providers reported this is further complicated when assessing individuals who are very young, which can limit their ability to remember experiences or reflect on their own behavior.
3. How to define treatment onset: While the majority of stakeholders agreed on a definition of psychosis onset, individuals differed in their definition of treatment onset. For example, treatment onset can be considered to be first entry into a particular program, first contact with any type of mental health treatment program, first contact with psychosocial treatment, or onset of psychotropic medication. Some stakeholders believed that efficacy and adequacy of any form of treatment is a better time point to use for determining the DUP endpoint. Stakeholders agreed that these concerns are similarly present when assessing DUMI, and the definition of treatment onset would need to be standardized.

4. Treatment of substance use disorders: Stakeholders that have provided treatment consider substance use disorders to be fundamentally mental health conditions. Onset of a substance use disorder could be used to identify DUMI onset, and may need to be considered when implementing DUMI measures.
5. Availability of data: PEI programs encompass a broad spectrum of programs, including programs that do not provide typical clinical services. Stakeholders noted that they are not staffed to provide complex diagnostic assessments and may not have capacity for any type of formal evaluation. Even if they are able to provide some information regarding DUMI, stakeholders also noted that they do not have electronic health records that would allow for easy storage and access of this data.
6. Accessibility of data: Stakeholders from programs with assessment and diagnostic capacity reported that while they may collect data needed to determine DUP (and potentially DUMI), this data was not necessarily in a readily accessible format. They reported needing to manually review charts or creating a new database to house this information.
7. Engaging families: Stakeholders responded positively to example questions that could be used to determine DUMI, such as “When was your child last feeling okay, like his/her usual self?” and “When did you first notice something was wrong?” They felt confident these questions could allow families to provide some data during clinical assessment, and would start a dialogue that could provide useful information for determining DUMI.

Stakeholders were given the opportunity to review a proposed interview guide after engaging in discussion. Their input was integrated into the final interview guide.

### Qualitative Interviews with Early Psychosis Service Providers

Of the 30 EP programs previously identified as active across the state of California (see Deliverable 5), 19 programs agreed to participate in qualitative interviews, yielding a response rate of 63%. Due to scheduling constraints, 15 of these programs completed interviews prior the analysis date, yielding a completion rate of 50%. The participating programs are presented in Table 1. Of these, 11 programs are currently in receipt of public funding, (e.g., MHSA funding, Medi-Cal, or the SAMSA Mental Health Block Grant) while the remaining four are primarily funded via research grants and private donations. The 15 programs were interviewed over the course of 14 meetings, with one meeting including program managers from the San Francisco and San Mateo PREP program sites together.

Programs from Alameda, Monterey, Merced, and Los Angeles counties expressed interest in completing interviews but were unable to schedule in the provided time frame.

Table 1: EP programs that participated in the qualitative interviews

County	Program Name
El Dorado	First Episode Psychosis (FEP)
Fresno	First Onset Team
Imperial	MHSA-Transitional Engagement Supportive Services - PIER Model
Los Angeles †	UCLA Aftercare Research Program

Los Angeles †	UCLA CAPPS Program
Orange	Orange County Center for Resiliency, Education, and Wellness (OC CREW)
Sacramento	UC Davis SacEDAPT Clinic
Sacramento †	UC Davis EDAPT Clinic
San Diego	Pathways – Kickstart
San Francisco	PREP San Francisco
San Francisco †	UCSF Early Psychosis Clinic (PATH program)
San Luis Obispo	Campus Residential Crisis Program (CRCP)
San Mateo*	PREP/BEAM
Solano	Supported Outreach & Access to Resources (SOAR)
Ventura	Ventura Early Intervention Prevention

\* PREP San Mateo and PREP San Francisco were interviewed during one session

† Research site not in receipt of public funding (i.e. MHSA funding, Medi-Cal, or the SAMSA Mental Health Block Grant).

## Question 1: How are California County Early Psychosis programs measuring the duration of untreated psychosis (DUP)?

Evaluating how EP programs across California are measuring DUP requires consideration of a number of different components, including how the different programs define the terms, the methods they use to calculate the period, and finally how the information itself is recorded once the DUP is identified. As described previously, the MHSOAC defines DUP as “the time between self-reported and/or parent-or-family-reported onset of symptoms of mental illness and entry into treatment, defined as participating at least once in treatment to which the person was referred”. Using this definition, DUP will be characterized by two time points; 1) the onset of the psychotic illness marking its start, and 2) the initiation of treatment marking its end. For each of these time points, a number of different operational and conceptual challenges are likely to exist. As result, how EP programs across California define and measure these two concepts will be reported separately.

### The onset of psychosis

#### Defining psychosis onset

Following the feedback received during the stakeholder meeting, a working definition of the onset of psychosis was presented to participants as "The first point at which psychotic symptoms (such as hallucinations, delusions, and or disorganization) become recurrent or persistent AND cause significant distress, impact behavior, or are dangerous." Some participants considered this an appropriate definition, consistent with the criteria that they use in clinical practice.

*Interviewer: Are there other criteria you would use to define the onset of psychosis?*

*Interviewee: No, that pretty much covers the criteria we use.*

However, most participants thought that additional caveats may be necessary in order to improve the consistency of interpretation between programs. Some participants felt that the definition proposed was too subjective, and required either more concrete examples of functional impairment, or more clarification on what criteria should be used to determine what constitutes “recurrent and persistent”.

*I think maybe having some specific examples like inability to adhere to routine, hygiene – taking showers however many times a week is a hygiene kind of question – inability to work due to the symptoms. And I think, again, those probably need to be spelled out more specifically because I think, otherwise, it’s going to be fairly subjective like at what point do people think this impairment is significant?*

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*Interviewee: That main core point would be... was always the duration and the frequency of those presenting symptoms.*

*Interviewer: Okay. So, it sounds like sort of the recurrent and persistent need to be unpacked a bit to be a bit more detailed about what exactly that means?*

*Interviewee: Yeah.*

Other participants suggested that it was important to include exclusion criteria, such as the symptoms not being attributable to developmental disorder or temporary effects of substance use. Finally, some participants suggested that it was important to consider the degree of conviction than an individual has regarding the hallucinations and delusions, given its importance in distinguishing whether an individual may be experiencing full psychosis, or attenuated symptoms consistent with the clinical-high risk state (CHR).

*The way it’s defined right here, it is describing someone that might be under the influence of any illegal drugs, or maybe someone that might be having a stroke or having other issues. So, maybe be very specific that it’s related to mental health.*

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*Well, the other piece that we think about – which is sort of implied in this definition, but may be worth stating clearly – is the level of conviction. Particularly around unusual thoughts and delusions. It’s really something that we talk about when we’re doing our assessment. You know, “How convinced are you that this experience is real?”*

## Measuring psychosis onset

### *The process in determining psychosis onset*

Sites reported a significant degree of variability in the methods they used to determine the onset of psychosis. In some sites, an estimate of psychosis onset was made at the initial screening phase of a

multi-stage process in order to determine treatment eligibility, which was then later refined as clients went through the assessment stages. These preliminary screenings varied from using brief self-report screening tools such as PQ-B [61], to more exhaustive assessments where collateral information from previous providers was sought, in addition to more information via-self report. The level of clinical qualifications held and the length of training received by those that completed the eligibility assessments varied from non-clinical staff who received 5 hours of training, to clinical trainees who were completing hours as part of their degree requirements, to licensed clinicians who completed the phone assessment as part of their wider clinical responsibilities. In one site where a 1-hour self-report screening interview over the phone was completed by a non-clinician, the participant believed that it was possible to use this procedure to predict DUP to high accuracy in cases where there is a clear point of psychosis onset. However, in more complicated cases, they suggested it was difficult to calculate an accurate point of onset without additional collateral information such as hospital records.

*Interviewee: I kind of wish [the intake coordinator] was here now because she does a lot of leg work before they actually come in the door. She gets a lot of collaborative and prominent information.*

*Interviewer: Like what does she do, do you know?*

*Interviewee: She tries to get medical records from the hospital. She has to review the information with the providers; she'll speak with them before, as well. She screens pretty intensely before they get an appointment.*

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*I do think that in cases where date of onset is quite clear – like they had rather abrupt onset which precipitated a hospitalization – then I think the phone screen is very good at predicting the DUP. And that stays pretty consistent throughout the evaluation process. However, in the subset of cases where the onset is more insidious, the phone screen is not very good at that. And that is actually very, very hard to determine. And it takes a lot of discussion with the collateral source, typically. To try and pin down the time at which these symptoms became full threshold. So, that is a lot trickier. And the phone screen typically does not get at that.*

Regardless of whether the sites completed phone screens or not, all programs reported conducting face-to-face clinical assessments with the client during which a more detailed assessment of illness onset takes place. In some sites, this would include using a structured clinical assessment such as the SIPS [34] or the SCID [62], while in others this would be a typical clinical interview <sup>2</sup>. These interviews are typically completed by either a pre-licensed or fully licensed clinician, and can typically take 1-3 hours to complete.

*We don't have a scale and we don't have a questionnaire. So, it would all come out of the particular interaction of the clinical interview.*

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<sup>2</sup> A typical clinical interview may take 1-2 hours and covers a variety of topics in order to determine a diagnosis, including chief complaint, history of presenting illness and associated symptoms, impairment in functioning, risk assessment, substance use, medical and developmental history, psychosocial history, and treatment history. It also includes a mental status exam. The interview strives to cover these areas, but is not structured.

*Well, we have a staff of about 20 individuals that are certified to administer the SIPS. And we consult always with, there's always a clinician involved. So, it's a pre-licensed or a licensed clinician is involved in scoring and reaching kind of a consensus of what the score is and what the outcomes of the assessments are.*

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*We begin with a telephone screening, a referral process in which we gather as much information as we can to identify if the individual may benefit from our program services. Our intake assessment with a therapist, a clinician, is pretty thorough, consisting of hospital records, school records, past treatment, and then we conduct an unstructured clinical interview [by a psychiatrist].*

In some sites, participants highlighted the significance of the process culminating in a multidisciplinary team meeting, during which the case is presented and an agreement on the diagnosis and onset date is achieved via consensus. In one site, this collaborative team-based approach was seen as particularly important for more complex cases. Finally, in some sites external supervision with people with expertise in administering the standardized assessment interviews was considered important in addressing more complex cases.

*We basically have a friendly debate about what is the best diagnostic conceptualization of this individual based on the information that we have in front of us. And we come to a consensus as a team. And that is very helpful.*

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*Oh, I think the consensus meeting really helps us figure out everything. It's a great meeting. So, I think it could go in either direction. And then we look - I would just say that it's very rich, and it really helps us to make sure that we've dotted our I's and crossed our T's.*

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*We also discuss as a team, the whole team together, often times, if the SIPS is very difficult and consultations between two or three staff is still kind of... if there's still grey areas and a consensus can't be reached, then it's brought to the entire team and we try to get to the bottom of it via the entire team.*

*We also have, once a month, supervisions with the entire team. Telephone supervision with [expert diagnostician], who is a SIPS trainer and SIPS expert.*

### ***The nature of information sought to determine psychosis onset***

Most participants reported that it is necessary to consider a very broad array of information when attempting to both diagnose an individual, and to determine the point in which a client may have qualified for that particular diagnosis.

*Interviewer: Is it symptoms that you focus on more than functioning, perhaps – or different behavior changes – or is it the whole thing that you're really trying to get a sense of?*

*Interviewee: The whole thing.*

This information includes the presence of particular symptoms; the frequency with which they are experienced over the course of a period of time; the duration they typically last for; the degree of conviction they have regarding the reality of their experiences; the distress they may cause, any noticeable change in behaviors; and any detrimental impact of functioning relating to self-care, social functioning, or vocational functioning. This contrasts with the MHSOAC's definition of onset of DUP, which focuses specifically on the presence of symptoms of mental illness.

*Basically, positive symptoms at a psychotic level of intensity, and it has to involve frequency, duration, and urgency as well. If any symptom is seriously disorganizing or dangerous, then we would automatically count that as fully psychotic.*

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*I think the way that that the information is collected in the SIPS, I think is very thorough and it has to do with a timeline of symptoms and the frequency of the symptoms. The impairment that that symptom causes, and the distress that symptom causes.*

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*We try to get a very clear timeline of all psychiatric or emotional or psychological issues. All mental health issues. We try to get the big picture on everything and the timeline of such.*

### **Sources of information required to determine psychosis onset**

Across almost all sites, the importance of obtaining collateral information was seen as critical to determining an accurate diagnosis of illness onset. In most cases, the ideal person was identified as an immediate family member such as a parent. While it was considered important in almost all cases, it was identified as particularly important when clients have poor insight, are younger, or present as highly disorganized.

*"I think collateral contexts are very good for that, especially with teenagers, where you have family members that are saying, "Hey, you know, she's been increasingly isolated.""*

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*Interviewee: Usually, when it comes to family members, a lot of the observation for families, their main concern are the behaviors.*

*Interviewer: Okay. And do you find focusing on that is a helpful way to unpack when the psychosis first starts then?*

*Interviewee: Yeah.*

In addition, some participants highlighted the importance of collecting additional collateral information because family members and the clients typically report different types of information. Family members are often more aware of any changes in functioning which may give some indication as to when the

client transitioned to full psychosis, while clients typically focus on the internal experience and levels of distress or conviction that may be associated with reaching the full psychosis threshold. As a result, using multiple sources of information can result in a more comprehensive assessment of the individuals' mental health history.

*Family members tend to be very good at spotting the behavioral changes. And the client has to be really good at telling you about the internal experience.*

In addition to seeking information from family members, participants also reported that obtaining information from previous service providers is important. While most sites limited this to either their previous service provider, prior psychiatric hospitalization records, or the clinician who submitted the referral to the EP program, in some cases other sources such as school assessments were also incorporated. Such information was considered to be very important both in establishing onset, and determining whether somebody has received sufficient care to determine treatment onset.

*Past providers, past hospitalizations; we try to get the medical records.*  
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*If we've got somebody who's in high school or has an IEP, the most recent IEP assessment with the information; all of that is helpful. So... hospital records, previous providers, psychiatric records.*

### **Questions used to elicit required information**

Depending upon whether the participant was interviewing the client or the family member, it appeared that different methods of enquiry were adopted. When participants assessed a client for psychosis, they reported primarily using closed questions focusing on the presence or absence of experiences relating to specific positive symptomology, such as whether they feel like people can read their mind, or whether they can see things other people cannot see. Following the client endorsing a particular experience, the participant would then focus on the frequency, duration, impact and intensity of their experience of that particular symptom.

*So, we ask questions around suspiciousness and paranoia. So, "Do you feel like people might be out to get you? Do you feel like people might be watching you, trying to hurt you in some way?" If they say yes to any of those, we'll ask onset, frequency, distress. And write any notes about any explanations that individual might have. And we do the same thing for some unusual thought content. So, we ask, "Do you feel like people might read your mind? Do you feel like you might have special powers or abilities? Or that the world is affecting you in some way?"*

*We ask questions about auditory, hallucinations, and perceptual abnormalities. And visual as well. And we ask those separately. And we ask about grandiosity. "What are you good at? Have people told you that you're good at that? What's special about you?"*

Once the symptom is recognized as clinically meaningful, the participant would then attempt to identify when they started experiencing that particular phenomena. Some participants reported that using life events to anchor experiences to particular time frames helped improve the accuracy of onset dates. Others emphasized the importance of recording these experiences and events into a visual representation of a timeline, particularly in more complex cases.

*If you can help them remember the teacher that they had that year or those different pieces of life events tend to be very helpful in helping someone remember where they were. Sometimes it can be just as simple as "I know I had this teacher and it was still cold outside." Which helps you at least anchor it to not summer and whatever grade they were in at that time.*

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*The timeline is a form that basically has...you can circle, there's either years, months, or days. And then, you go backwards, and it's got all these different criteria on it. So, we would ask them, well, it would have things like when psychosis started, when prodromal started, any hospitalizations, substance, mood stuff; any physical health stuff. And, you... kind of go backwards [...]. It gives you this really clear, visual picture.*

In contrast to the interviews with clients, participants reported that when they interview family members they focus much more on behavioral and functional changes, as opposed to symptoms. In most cases, participants reported that the key question they ask family members is a variation of "When did you notice a change?"

*The question that I find most helpful, and I think I can speak for the whole team is to just ask the family member "when you did notice when something was very different?" "When did you notice when things started changing for this young person?"*

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*I think that's the one that gets to the heart of if you're determining onset. Yeah. It's, "When did you notice change?"*

In further examples, participants typically reported questions which related to either functional changes in self-care, social functioning, or vocational attainment. In addition to specific questions regarding particular aspects of functioning, a number of participants reported that they typically adopt a more open-ended form of questioning with family members, relative to when they interview the clients, in order to ensure that nothing is missed.

*And so, we get them talking about what they've noticed. We ask them about school, about friends, about family life, about work.*

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*I think just open-ended questions, what's been happening, when did it start; they tend to have a different view of behaviors, a more global view than our individuals who are living in it and*

*experiencing it. So just open-ended questions trying to find out when it started, what changed, how it impacted functioning in school or work or whatever.*

Finally, family members were identified as important in separating cultural or familial norms from psychotic psychopathology.

*If you have a family who believes in ghosts, well, "How is your experience with ghosts different than your family? And mom, "how do you feel like your son's experience is different than maybe what you or your other family members have talked about?" I think that helps us for that individual to get at what could be more psychotic versus what could be different.*

While parents may be able to notice behavioral changes, one participant reported that it is important to recognize that family member's mental health literacy made not be sufficient to identify behavioral changes as indicators of psychosis, and they may attribute it to other factors. As a result, they suggested that providing psychological education during the assessment process may be important, in addition to focusing on when parents identified behavior changes, rather than focusing on why they think those changes occurred.

*"The other thing, most families noticed something was wrong but they didn't know what was wrong. And then in retrospect, if you give them the language, they will identify oh yeah, he was saying this, or he did seem this. The first time they noticed what they were worried about is a common one. What they attribute it to is often things like drugs or relationship problems or something like that. But they usually notice what we would call psychotic symptoms."*

### **Recording onset of illness**

A significant degree of variation was reported between programs regarding the systematic recording of illness onset, the start of treatment, and DUP. Some participants reported that they are not systematically recording any of these factors due to it not being considered a priority once eligibility for the program is confirmed.

*We're not.... we're less concerned about getting the exact onset date but usually we're thinking about – we need the dates well enough to identify a diagnosis and a treatment protocol. What I don't think we would do is if we found out that it was about a year and a half ago, I don't know that we would clarify was that 19 months or 16 months. We probably wouldn't be spending our time – we'd probably prioritize other information at that point.*

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*Interviewer: You said that you do not record the onset dates in electronic format; is that correct?*

*Interviewee: That is correct.*

*Interviewer: Okay. Can you tell me why you don't? No right or wrong answer. Just curious about–*

*Interviewee: I, I don't know that. It maybe just is never thought of – as far as doing that.*

In other sites, this information is typically recorded, but included in the text of progress notes of an electronic health record rather than as a data point. As a result, this information can be difficult to find and would require someone to manually review text fields in order to pull out the required data in the event that this data was needed for analysis or reporting. In addition, this limits the programs' ability to change the data point in the event that additional information is received that suggests that the data needs to be revised.

*We don't keep that as a data point. That would require that retrospective chart review.*

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*There's not a box that would say "I'm treating, mental illness. When were the first signs of mental health issue? when did those arrive?" and then there's a box and you put how many months or how many years. We have to look in the narrative.*

The most commonly reported reason for the data being stored in this manner was that the health records the programs use do not provide a data field where this information can be added. In response to this issue, some sites store the onset date of psychosis in a separate database, along with other clinical outcome measures. In these cases, the participants reported that it would be simple to produce summaries as reports, and to amend the numbers based on new information.

*Interviewer: Okay. Do you record the onset of psychosis in electronic format?*

*Interviewee: We do.*

*Interviewer: Okay. How easy or difficult would it be for your organization to update or change existing data regarding the onset of psychosis?*

*Interviewee: Easy.*

*Interviewer: Okay. And that's something that you could do?*

*Interviewee: Yeah. Yeah. So, if we find that somebody is fully psychotic or was fully psychotic, we can just update our database.*

Overall, publicly-funded clinical programs reported focusing on diagnosis more than onset in the course of initial evaluations, with the purpose of determining eligibility for the program. They often did not require great specificity of the exact date of onset, and did not record psychosis onset as a date. If it was recorded, it was often in narrative text form, and in paper charts. Group discussions for purpose of consensus or consultation with expert supervisors were noted as particularly helpful in defining illness onset.

## Treatment onset - the endpoint of DUP

### Defining treatment onset

When attempting to calculate DUP, it is necessary to identify both the onset of the illness, and the onset of treatment. In terms of how treatment onset is defined, the participants interviewed appeared to endorse one of two very different perspectives. Some participants believed that treatment onset should be recognized as the point in which an individual engages with *appropriate* treatment. In most cases, this was considered to be the point in which they presented at their specialty EP program. With some participants that endorsed this particular definition, this was recognized to comprise of three discreet steps, including 1) contact with a service, 2) an accurate diagnosis, and then 3) the provision of treatment appropriate to the diagnosis. In situations where the three steps were not fulfilled, sites which proposed this particular definition did not generally consider DUP to have ended. Regarding these particular participants, accurate diagnosis was seen as central to correctly determining an appropriate point of treatment onset.

*Interviewee 1: I think it's the appropriate treatment for the diagnosis. So, going back to one of the examples that [interviewee 2] gave before, you have the person who's been diagnosed inaccurately with OCD and is actually psychotic. And you come in and you say, "Actually, this is psychosis. And your paranoia and need to check cameras every night is because you're afraid somebody's going to hurt you. Not because you have OCD. And we think that you need this." And the person says, "No. I'm going to continue to do exposure and response prevention." We would say they're being inaccurately treated.*

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*Often times we consider ourselves the first appropriate treatment. In most cases that's true. Though we have first steps of some clients where, no, they had psychiatrists before us [...] in those cases... we would consider, when did they start treatment with that psychiatrist? What provider first recognized that it was psychosis, and when did that treatment begin? Often times, that treatment is us.*

For psychosis, appropriate treatment was considered by some to be a broad package of care comparable to the coordinated specialty care model for psychosis, including accurate diagnosis, medication, psychosocial therapy, and family support. Contrary to much of the existing literature, none of the participants suggested that the initiation of antipsychotic treatment alone should be considered an appropriate time to define treatment onset, and in one case it was explicitly stated that this should not be the case.

*It's the broad - so it's management of symptoms, it's recognition of symptoms, it's medication, it's family support, education – everything and anything that we can throw at them to improve the trajectory of their diagnosis.*

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*Interviewee 1: Just to pick up on another point that you made a little bit earlier before we dove in. I think all three of us are agreeing that treatment is defined by engaging with the service as a whole. Not by the time that they take antipsychotic medication.*

*Interviewee 2: Yeah.*

While the majority of participants appeared to propose the importance of accurate diagnosis and appropriate treatment for that diagnosis, this was not universal. In one case, the participant suggested that they would not make such a clear distinction between different types of treatments, and that receiving at least some form of mental health services should be considered an appropriate point in which to consider the duration of untreated psychosis ended.

*I think for me I would not make such a hardline distinction between other types of treatment and early psychosis treatment. I could be convinced... that's the way that I've been thinking about it, yeah. If somebody had come from another type of treatment and had gotten at least some services, I would consider that already being beginning in treatment.*

### **How treatment onset is operationalized for recording purposes**

While the majority of participants provided an expansive definition of treatment onset for psychosis, in almost all cases this was not how treatment onset was characterized in their operationalization of the term. Instead, treatment onset was typically operationalized as the point in which clients are assessed for their EP program.

*Interviewer: Okay. So, as soon as the assessment's finished, they've been given a diagnosis – that's when you sort of see treatment as starting, in terms of how it's recorded?*

*Interviewee: That's correct, yes.*

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*I think that is actually determined in the county clinic by when we start billing. When we start having contact with the client.*

In cases where participants recognized the incongruence of their definition with their operationalization, it was suggested that it may be appropriate for treatment onset to be defined differently for data collection purposes, as opposed to clinical utility. In one site, it was proposed that it may be beneficial to record multiple endpoints in order to adhere to different reporting and clinical requirements.

*I believe when we open an episode [of care] for an individual that has been identified and agreed to treatment, then that episode would be the beginning of treatment. Just for the sake of collecting data... because I believe, once we identify – we start the work, motivating them, giving them information – but that's hard to capture when that was. But opening an episode would be the easy point.*

-----  
*I think the thing is that we could give the answer differently if we had our clinician hats on versus our data collection hats on. In terms of just hard and fast data collection, I think in this example, I would want the date of intake for those individuals that attended their welcome session and gave a thumbs-up to engaging in the clinic.*

## Recording onset of treatment

Regarding the recording of the endpoint of DUP (i.e. treatment initiation), most sites reported that this is not directly captured. Instead, the date of entry into their service is used as an equivalent, given in the vast majority of cases it is considered the same date.

*Interviewer: So, as soon as the assessment's finished, they've been given a diagnosis – that's when you sort of see treatment as starting, in terms of how it's recorded?*

*Interviewee: That's correct, yes.*

*Interviewer: Right. Okay. And is that – I guess that day would be in electronic format because that would be the day of first contact, which would be on your system anyway.*

*Interviewee: Yes.*

## Question 2: How can this process be scaled to the measurement of duration of untreated mental illness (DUMI)?

### Could the method for measuring DUP be used for DUMI?

When asked if the process for measuring DUP would be an appropriate way to measure DUMI for other serious mental illnesses, in almost all cases, the participants agreed that the process would be comparable. As with measuring DUP, the importance of both a direct interview with the client, in addition to collateral information was consistently emphasized.

*I think they're probably very similar actually. I think it requires a thorough evaluation. I believe by multiple people in different settings. I think it requires collateral information.*  
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*Interviewee 1: If you're talking about folks with PTSD, you might have to do a lot more collateral work with the family regarding measuring it, the onset of that.*

*Interviewer: Okay, do you think it would be important to include the family if it was an adult, or to ask the family to see if that corresponds with what the adult said?*

*Interviewee 2: Well, yeah, absolutely.*  
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*Interviewer: What would be the ideal way, do you think, for this group to measure the onset of illness and the onset of treatment?*

*Interviewee: Well, direct interview and collateral.*

*Interviewer: Okay. So, similar kind of method to what you're doing-*

*Interviewee: Yes.*

However, while this was recognized as being the “ideal” method, it was acknowledged that this may not be feasible for all services due to a lack of resources:

*I think our methods would do very nicely for DUMI in general. And I think it actually is the way all mental health diagnosis should be evaluated. I think the biggest challenge to that is lack of supply of mental health resources and care. But is it the ideal way? Yeah.*

### **Challenges linked to both measuring DUP and DUMI**

When asked about scaling the process of determining DUP to DUMI, almost all participants thought that the challenges of measuring duration of illness in psychotic disorders would equally apply to non-psychotic illnesses. Such challenges could be specific to eliciting the required information from an interview with the client, including a longer duration of illness, comorbid mental health conditions or developmental difficulties, disentangling culturally normative behavior from psychopathology, co-occurring substance use, mental health literacy, stigma around mental illness, younger age of clients, and cognitive impairment. As identified by one participant, all of these challenges were considered to impact the ability for the client to accurately report their internal experience in a manner consistent with mental health assessment. Of these challenges, the most commonly reported barrier to accurately determining illness onset was ongoing substance abuse. In cases where participants found it difficult to distinguish between psychotic symptoms and effects of drug use, using a timeline to identify periods when individuals were not taking substances to see if the symptoms are still present was seen as critical.

*Interviewer: Do you think there may be additional problems on top of the existing ones or do you think it's a very similar challenge and pitfalls you're having?*

*Interviewee 1: I would say similar.*

*Interviewee 2: Yeah, I would definitely say similar.*

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*I think one over-arching thing that is involved, that it's maybe it's a factor in every other thing that you listed which is just the reliability of the information given by the client. And that information may or may not be a genuine reflection of their internal experience. They might not be able to communicate their internal experience in a way where we can accurately interpret it.*  
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*I'm definitely going to echo substance use; there's no question about that. Especially marijuana; that's one that is just so frequently used and also used at such a young age. That's so common and that muddies the waters quite a bit.*

In addition to barriers in determining DUP and DUMI from the client interview, some participants identified the inability to obtain collateral information from family members as a significant barrier to

accurately identifying DUP. In these situations, other forms of collateral, such as information from previous providers, was identified as particularly important.

*I would add too, that in people who are over 18 and refuse to bring a collateral source with them. Perhaps they're too paranoid or they don't have somebody who is their primary support person. Then it's extremely difficult. Because some of these clients really struggle with memory and are just unable to come up with dates and when these symptoms became worse. Sometimes, they're so ill that we get very, very little information in the interview. And then we really have to rely on hospital records and stuff like that.*

#### **Additional challenges of measuring DUMI for other disorders**

In addition, a number of participants thought that additional challenges to measuring DUMI that may be present. For example, in depression, some participants suggested that helping clients identify the distinction between clinical depression from low mood retrospectively may represent a significant challenge, relative to psychotic experiences. Another participant suggested that Bipolar Disorder is particularly challenging given clients do not typically perceive manic or hypomanic symptoms as problematic or dysfunctional.

*With the depression, and anxiety, things like that – being able to define what makes it a clinical issue versus difficulty in life...*  
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*I think helping the individuals who are reporting understand the specific symptoms that we would be looking at could be an added challenge with that. More common symptoms like depression versus uncommon symptoms like hallucinations.*  
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*I think it's really difficult. Bipolar, now, and I've never been able to figure out when the onset happens. They don't remember. They don't experience their hypomania as dysfunctional, or very often, their mania, for that manner. So, trying to get a clear picture of when an onset is with someone with bipolar disorder would be very difficult, unless you catch them young.*

However, some participants suggested that establishing duration of illness in some non-psychotic disorders might be less complex. One participant suggested it may be much easier to identify the onset of disorders such as social phobia as they are typically less complex than psychosis, and are not associated with additional challenges such as cognitive impairment and lack of insight. In addition, due to less stigma and better mental health literacy associated with anxiety disorders, relative to psychosis, gathering the relevant information from families may be much easier. Finally, one participant suggested that disorders with a clear etiological requirement, such as Post Traumatic Stress Disorder, determining onset may be much easier as there will usually be an event from which the clinician can use as a starting point.

*They may be easier to overcome with certain populations if you don't have the cognitive impairment or the – you know. If you were assessing social phobia, social anxiety, and that's all that person is presenting with, it's unlikely that individual is going to bring with them the same*

*complexity that someone with a psychosis is going to bring.*

### **Additional challenges of measuring DUMI in other PEI settings**

As previously highlighted, the participants typically reported that their programs undergo an extensive assessment process in which both diagnosis and the onset of illness is determined. As a result, while most participants thought that their process for calculating DUP could be used to measure the DUMI for other disorders, many held significant reservations that their process could potentially be scaled across all PEI programs that provide access and linkage to treatment in their current form. The most commonly cited concern was that some sites may lack of clinical expertise to reliably diagnosis the disorder for which the client had been referred for.

*Those individuals don't have the clinical skills to really... diagnose what a mental illness is – they can't make that diagnosis so how could they then make the diagnosis or the decision that it was untreated?*

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*For example, we have a senior peer counseling program in our county. These are older adults who go visit other older adults in their homes and just do active listening. So, they're not capable of saying, "Oh, wow. I met with Jane today. Jane put forth the following symptoms. I believe her diagnosis is this. She states this, this, and this which led me to believe that she has had a mental illness since she was 14." It's just not there.*

In addition to concerns regarding non-clinicians attempting to define the onset of untreated illness, another challenge identified by participants included the additional complications of attempting to apply the concept of DUP to services which would be likely to serve different populations. For example, the eligibility criteria for the majority of the EP programs approached include the requirement that the psychotic episode occur within two years of treatment. As a result, the clients they assess are likely to have a much shorter duration of illness relative to some other services. In settings where the duration of untreated illness could be very long (for example, a depression clinic for older adults), there was concern that the chronicity of the illness may significantly impact the validity of the reported onset date.

*I think DUP makes sense once somebody makes it to a specialty mental health clinic. It's much harder to move DUP down into the primary care world, or the mental health into the sort of private therapist world, or counselor... It's hard to move the DUP construct down.*

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*Well, measure with what kind of validity? I mean, if you're talking about validity, that's questionable. Can we put a measure to it? Yeah. You know, I can ask my 80-year-old patient, well, when did it start? Oh, it started when I was four. How valid that is another issue.*

One participant suggested that these challenges may be compounded by other factors such as lower mental health literacy and greater stigma associated with mental illness in older adults.

*I think it's also a generational issue. We did a survey of the seniors in our county – and, certainly, it was a very limited scope survey – but we asked, “If you were depressed, why wouldn't you seek help?” and part of it was the stigma. “Oh, I didn't want to bother anyone,” or, “It was too expensive.” So, I think, if you're looking at a generation where it was not acceptable to seek treatment for a mental illness, you're going to have a lot more difficulty in having them report accurately when this all started. The younger generation is much more open to mental illness issues – they're willing to talk about it, they're willing to seek treatment. There's still that age, 65 and older, who have some serious stigma themselves about it.*

As highlighted in the previous sections, the participants interviewed reported a number of significant challenges to scaling the process of measuring DUP in EP programs to measuring DUMI across all PEI services. These challenges were considered relevant to all mental health disorders, with possible additional challenges to measuring the duration of illness in non-psychotic disorders, and service-level factors which may represent additional challenges when scaled to non-EP programs.

### **Facilitators & barriers to assessing DUP and DUMI**

To summarize, a number of concepts were identified in the interviews that could be translated from DUP to facilitate the measurement of DUMI, as well as potential barriers to valid and feasible DUMI measurement in most programs. These facilitators and barriers were described at both the level of the clinical service, as well as at the client level. A summary of these barriers and possible facilitators are presented in Table 2.

Table 2: Facilitators and Barriers to determining accurate DUP and DUMI

Service Level factors	
Barriers	Facilitators
<ul style="list-style-type: none"> <li>- Lack of diagnostic expertise for staff</li> <li>- Insufficient time for the assessment</li> </ul>	<ul style="list-style-type: none"> <li>- Strong collateral information from prior services</li> <li>- Use of a structured interview and time line</li> <li>- Comprehensive training in the assessment protocol or measure</li> <li>- Multiple assessment points (e.g. phone screen <i>plus</i> in person interview) to confirm or expand information</li> <li>- Supervision, especially if less experience staff are completing assessment</li> <li>- Consensus meetings to discuss diagnostic data and possible date of onset/offset</li> </ul>
Client/diagnosis level factors	
Barriers	Facilitators
<ul style="list-style-type: none"> <li>- Chronicity of illness</li> <li>- Lack of insight or cognitive impairment</li> <li>- Comorbid illness or developmental difficulties</li> <li>- Co-occurring substance use</li> <li>- Poor mental health literacy or stigma around mental illness</li> <li>- Clients who are either very young, or are 65 and older.</li> </ul>	<ul style="list-style-type: none"> <li>- Participation of collateral informants and support persons</li> <li>- Providing psychoeducation around subthreshold versus threshold symptoms to increase literacy</li> <li>- Anchoring time line to specific life events to improve recall</li> <li>- Assessment of specific symptom domains (e.g. depression, substance use) or functional changes (e.g. social withdrawal, school failure) separately, to clarify the timeline of each domain and their interrelatedness.</li> </ul>

### Improving DUMI measurement across PEI services

Participants provided various solutions to the barriers presented above regarding DUMI measurement. They centered on three suggestions:

***Suggestion 1. Use a simple self-report questionnaire to determine whether a client presents with symptoms indicative of a particular disorder, and then ask when they believe these symptoms occurred.***

Participants acknowledged that PEI programs may not be able to conduct a comprehensive structured interview to determine a diagnosis and its onset. As a viable alternative, participants suggested that programs could use a validated self-report survey for their target disorder (e.g. the PHQ-9 for

depression) and then ask the individual when these difficulties started. This would allow a valid yet brief assessment of specific symptoms in a manner that required less staff training.

*Interviewer: So, like short self-report questionnaires of illnesses may be an easy way to do it when the clinician isn't there to provide a more structured and formal diagnosis?*

*Interviewee: Correct. And if it's something that's kind of standardized and across the spectrum, then you get a referral and they say they answer three, seven, 13 and 14 as yes and this is what – it's a little bit more easier to understand across the continuity of care.*

***Suggestion 2. Keep the inquiry very simple and include collateral informants, recognizing that the data will not be equivalent to the assessment completed in EP programs.***

Participants presented concerns that non-clinicians will not have the capability to diagnose mental health disorders in some PEI programs, and thus it would be impossible to determine how long a disorder they might be experiencing has been left untreated. In this situation, participants suggested several solutions.

*Interviewee: I think, honestly, the best way to do it and take the data for what it is, is just to ask the individual, "Do you feel you have a mental illness and, if so, when do you feel you started?" Because you're going to get, basically, as good of information from that as anything else, in my opinion.*

*Interviewer: Okay. So, keep it very simple – one question – and go from there?*

*Interviewee: Yeah, because I don't think asking individuals to make that decision when they're not qualified or have any training to do so would provide very core data.*

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*If you're asking us for the ideal way, we'd say, "You have to dedicate the time to a thorough assessment." If you're asking us for a practical way, I think you need to ask a handful of questions. Like, "When did you notice the change? When did you ask someone for help about this? What is your treatment history?" And then you have to make an estimation.*

***Suggestion 3. If a clinical interview is conducted, programs should provide sufficient training, structure and supervision so that services can complete at least some form of a valid clinical interview.***

Most participants reported that a semi-structured interview is the best method for determining a diagnosis and its onset. However, they also acknowledge that a comprehensive interview is not feasible for most programs. Therefore, if a program uses a clinical interview to determine onset of the target diagnosis, participants felt that it was critical to ask specific follow up questions for each identified symptom, including frequency of the symptom, related distress, impact on functioning, the date of onset, and where relevant, conviction of key symptoms. A number of participants suggested that these should be included on a timeline (for an example, see Appendix E, provided by the UCLA Aftercare program), where major life events can be included to help anchor the time points. Participants stressed

the need to obtain collateral information from family members as key, particularly related to behavioral and functional changes around the onset of the diagnosis.

*So, you need to ask about frequency, distress, onset, conviction before you can come up with a conclusion about it. And so, if that's written in black and white and then provided a small amount of training on how to do that, I think people are more capable of making a fine-grained decision about that gray area. Whereas I think the traditional training in our field is a person said they hear voices. And then I stop there and I just say this person is psychotic. And I think that's the problem. We just need to extend the rules of evaluation.*

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*I actually think [the timeline sheet] could be useful for somebody that's less trained. The problem isn't the instrument itself, in terms of training. Because, it would be like anything; you get the information and you plug it in, and then you have this nice, visual picture.*

Finally, participants felt that diagnoses and onset dates should not be determined in isolation. Participants reported that they used team or consensus meetings to review the diagnostic information gathered during an assessment and agree upon a diagnosis and onset date. They felt that a similar approach could be applied to DUMI measurement, whereby information gathered during interviews could be reviewed by a team of individuals and they could reach an agreement on the onset date. When the interviewer has less training or expertise, participants felt this process was essential and should include at least one licensed clinician. Finally, participants felt that the team could give a rating for their confidence in the diagnosis and onset date that they have obtained. Given different services are likely to have very different capabilities (e.g. diagnosis by peer support versus diagnosis by a licensed clinician), a Likert scale denoting the confidence of DUMI diagnosis based upon above criteria would be clinically informative.

*So, let's pretend we're an ADHD clinic or an Autism clinic. If the individuals who are making these decisions have to sit down and present the case, review the case – either with a supervisor or with other team members who've been comparably trained. I think it's good to have at least one person with more training on that team. If they're able to sit down and say, "This is what I was told and this is what I equated it to." You'll get a better estimate of what's really going on than if you just allow one person to do it by themselves.*

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*I think you need to know how it was evaluated. And then you might add in the... something very simple that you could add in across a standard form or your local program is that reliability of information rating that we give at our assessments. We do it from zero to ten. We basically, at the end of every six-month evaluation that we do with our clients, we rate how confident we are that the information that we've collected and the conclusions that we've made from that information are accurate. Zero being not at all accurate.*

## Discussion

This report provides a summary of how DUP is defined, measured, and recorded in EP programs across California, and explores the ways this may be scaled to assess DUMI in other PEI services providing access to treatment and linkage services. Despite significant variation in the method of determining DUP between sites, almost all sites undertook an exhaustive process of assessment, involving multiple staff members collecting data from multiple sources, during which detailed information relating to a number of domains were sought. As a result, while there appeared to be a consensus that the methods used to evaluate DUP in EP programs could be used to measure DUMI for other disorders successfully, the process typically requires considerable resources and expertise which may not be available to most general PEI services. In recognition of this, a number of sites proposed more simplified solutions to determining DUMI, with the caveat that such methods may significantly impact the reliability and validity of the resulting data.

### Defining the onset of psychosis

Based on the responses from the stakeholder meeting and subsequent interviews with EP program staff and leadership, a working definition of the onset of psychosis was developed:

“The first point at which psychotic symptoms (such as hallucinations, delusions, and or disorganization) are present on average for at least once a week for an hour at a time, are experienced with full conviction, cause significant distress or are dangerous, impair the person’s ability to engage in standard daily tasks, and are not better accounted for by another cause.”

The figure denoting the frequency and duration of symptoms was derived from the SIPS definition of psychosis onset, which was the most consistently used scale used to assess CHR and psychosis across the California EP programs. The phrase “not better accounted for by another cause” uses language modified from the SCID, which is another diagnostic instrument consistently used by services. While this definition provides clarity for the onset of DUP for EP programs, it does not translate easily to a definition of onset for other disorders, which would be necessary for recording DUMI.

### Defining treatment onset

Regarding the onset of treatment, an explicit endpoint was reported in only a few cases. This was typically based on entry into the service, without considering prior treatments, or whether they successfully engaged in the service. It was felt that the date EP services were initiated was a valid and reliably coded date that could be obtained easily from medical records or county billing data across the state. This definition contrasts with the second most common conception of endpoint, where accurate diagnosis, appropriate treatment, engagement with treatment, and clinically meaningful change were all identified as important factors to consider. No participants defined treatment onset based upon use of antipsychotic medication, which has commonly been used in the research literature.

### Recording DUP

While the majority of programs reported that they identified the onset of psychosis, the majority acknowledged that they were not systematically recording DUP because a specific date of treatment onset was rarely recorded. However, the majority of programs agreed that it could be calculated using date of entry into the program as the endpoint.

## Limitations

The results of this analysis drew both on the existing literature on the measurement of DUP and DUMI, as well as the theories proposed during the stakeholder meeting and follow up EP program staff interviews. While our approach attempted to consider all possible influences on the measurement of DUP and DUMI, limitations to this analysis should be considered. First, during some stakeholder interviews, “impression management” may have been a factor guiding some of the responses. In some sites, there appeared to be some hesitation to answer for fear of providing an incorrect answer. This issue was identified early in the process, and the interview guide was amended to clarify that there were no correct answers and we were only asking for their ideas and suggestions for this process. This new approach seemed to increase the candor of the participants. Second, the ideas and opinions gathered during the stakeholder and EP program interviews were based solely upon information from individuals from California. Therefore, information from individuals outside of California may have yielded additional information. However, this analysis and the interview incorporated literature from US and international sources, which should yield comprehensive and generalizable results.

## Recommendations for measuring DUMI in PEI Programs Statewide

Based on the published literature and stakeholder input, there are several program elements required for accurate DUMI assessment and recording of data. These include:

1) Definition of an index mental health disorder/issue to determine program eligibility. Programs must be able to specify a diagnosis (e.g. Bipolar disorder, PTSD), a range of diagnoses (depression, substance use disorders) or definable mental health problem (mental health crisis) that serves as the target disorder/issue for their program and indicates eligibility.

2) Provide a minimal individual assessment as part of their services. Programs would need capacity to identify the relevant diagnosis or mental health issue and its onset date for an individual client via some method of assessment. For example, if the only services provided are group education without individual interaction, a PEI program would not be able to assess DUMI. Assessment of DUMI would be integrated into existing workflows for the initial assessment of clients.

3) A place to record date of disorder/issue onset for clients, preferably in electronic format. An estimated date of onset, including month and year, for the index disorder or mental health issue would be determined as part of the assessment process. In cases where only the year can be estimated, a default date of mid-year (e.g. July) would be recorded. A space for onset date would be clearly indicated on screening or intake paperwork, not embedded in narrative text.

4) The DUMI endpoint, onset of treatment, is defined as the first service date with the PEI program (DUMI1). This is the simplest, most feasible and standardized way to measure treatment onset, and does not confound access to care with treatment engagement. It also provides an end date for programs that do not provide treatment and would be unable to gather information on other programs accessed by clients. In this case (e.g. linkage programs), the date of interaction with the client suffices as

the service date and onset of “treatment,” which would be provision of information about resources. Programs would be welcome to measure additional endpoints for date of first treatment session (versus assessment, DUMI2) or a measure of adequate treatment (e.g. one month of services, DUMI3) but this would not be required.

## Potential protocols for measuring DUMI

In addition to these basic elements, three options are provided for consideration to support PEI programs in the requirement to measure DUMI, as stipulated by the regulations [4]:

### Option 1: Self-report questionnaire.

This option is the least rigorous, but most feasible. Programs that address a particular condition (e.g. depression, PTSD) would ask clients to complete a brief self-report questionnaire (e.g. PHQ-9, CATS) and indicate when these symptoms began (month and year). Other programs would provide a basic questionnaire to the client asking, “What do you want help with?” and “When did this problem or issue begin (month and year)?” Program staff might prompt the client to complete the questionnaire, or administer it verbally if the client cannot read, but they would not probe or ask additional questions. One limitation of this approach is that valid self-report questionnaires do not exist for all mental health issues and screening instruments may not be sufficient for determining reliably that an index condition (e.g. psychosis) currently exist. In this situation, programs would be limited to asking the basic questions (“What do you want help with?” and “When did this problem or issue begin (month and year?)”), which would have potentially more limited reliability and validity.

### Option 2: Basic unstructured assessment.

This option is moderately rigorous and moderately feasible. Programs would identify the index disorder or issue that the client is seeking help for (e.g. depression) and ask: “When did these difficulties first begin? When did you first notice a change?” Follow up questions would focus on frequency, severity, distress, and functional impairment related to symptoms and (when relevant for psychosis) degree of conviction in experiences. This would require some knowledge of symptoms and diagnostic criteria related to the index diagnosis to facilitate appropriate follow up. The interview would utilize a basic visual timeline as a tool to track symptom and reference important life events to anchor responses (An example timeline tool is provided in Appendix E). Program staff would obtain collateral information from family members, peers, health records or referring providers when at all possible, but it is recognized that these sources may not be available. If such assessments are administered by para-professionals, assessments results would be reviewed with the team and/or supervisor to confirm findings. Holding such regular review/consensus meetings with team members can help to establish and maintain reliability across staff and resolve difficult estimations. While this approach would likely yield results with increased validity and reliability, the burden placed upon PEI programs to complete such assessments may outweigh the information gained.

### Option 3: Structured interview.

This option is the most rigorous, but least feasible for most programs. It requires a complete clinical interview with client and collateral informant using standardized measures (e.g. SCID, SIPS, CASH, WHO-PQ), a review of records, as well as case review with the team to determine consensus on onset and

diagnosis. Although this is achievable by many EP programs, it is not likely to be achievable by most other PEI programs due to the requirement for extensive training and supervision, as well as the time burden to complete such assessments.

## Conclusions

Results of this project have developed definitions of the onset of psychosis, onset of treatment and approaches to the measurement of DUP for early psychosis programs. In addition, based on the feedback of stakeholders and EP program staff and leadership, we have provided suggestions for how these approaches could be scaled to the measurement of DUMI, which is required by state regulations for all PEI programs. These recommendations include program elements that are essential to support DUMI measurement, as well as 3 possible protocols for DUMI measurement by PEI programs. Each of these elements and protocols attempts to balance the validity of information gathered with the feasibility of data collection in a diverse array of PEI programs.

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## Appendix A. Stakeholder List

Stakeholder Name/ Affiliated County	Stakeholder Group(s)	Relevant Status
Nancy Ebbert, M.D. <i>Contra Costa</i>	Early psychosis program provider	Lead Psychiatrist <i>First Hope Contra Costa</i>
Julie Godzikovskaya, M.A. <i>San Francisco</i>	Early psychosis program provider	Research & Evaluation Analyst <i>PREP Early Psychosis Program</i>
Bonita Hotz <i>Sacramento</i>	Family Advocate	Parent of EP service consumer Family Advocate <i>UC Davis SacEDAPT Clinic</i>
Adriana Furuzawa <i>San Francisco</i>	Early psychosis program provider	Division Director <i>Felton Institute</i> <i>PREP Early Psychosis Program- San Francisco</i>
Jane Ann LeBlanc <i>Sacramento</i>	County Representative	MHSA Program Manager <i>Sacramento County Behavioral Health Services</i>
Dawn Williams <i>Sacramento</i>	County Representative	Research, Evaluation and Performance <i>Sacramento County Department of Health and Human Services</i>
Joseph Edwards <i>San Diego</i>	Early psychosis program provider	Assistant Program Director <i>San Diego Pathways- Kickstart</i>
Maria Dimas <i>Sacramento</i>	Family Member	Parent of EP service consumer <i>UC Davis SacEDAPT Clinic</i>
Shannon and Jeff Solomon <i>Sacramento</i>	Family Member	Parents of EP service consumer <i>UC Davis SacEDAPT Clinic</i>
Brandon Staglin <i>Napa</i>	Consumer Advocate	Communications Director <i>International Mental Health Research Organization (IMHRO)/One Mind Institute</i>

## Appendix B. Interview Guide

### Early Psychosis Evaluation & DUP/DUMI Pilot Project Semi-Structured Interview Guide

#### Verbal consent for in-depth interview with program directors and related staff of active early psychosis programs

*We are conducting an interview today to talk about how your organization defines, measures and collects data regarding both early psychosis specialty care and the duration of untreated mental illness. Some of the questions will follow up on information you provided in the online survey in November. My name is \_\_\_\_\_ and I am part of the early psychosis research team led by Dr. Tara Niendam at UC Davis.*

*As part of the study, we are interviewing program directors and other appropriate clinical and support staff of early psychosis programs throughout California. One purpose of this study is to develop a methodology for the measurement of costs and outcomes associated with early psychosis programs. A second goal is to clarify how early psychosis programs are measuring the duration of untreated psychosis in order to propose a method for how this could be scaled to the measurement of untreated mental illness by early intervention programs in California.*

*The interview will last approximately 1.5 hours. If there are any questions you do not want to answer, you are free to skip them. You are also free to end the interview at any time.*

*The **interview will be recorded and transcribed** so we can review the conversation after the interview. Only the evaluation team will review the transcripts. Your responses are **confidential**. You will not be identified in any description or summary of the results.*

*The interview will be conducted as a guided conversation. I have a list of topics and general questions that I will go through, but your responses will guide the interview.*

*We appreciate your participation. We expect that the results of this study will be of interest to your organization and help to inform a statewide system for evaluating early psychosis programs throughout California. At the end of the study, we anticipate that de-identified information from these interviews will be used in reports and publications.*

*Do you have any questions before we begin? Do you agree to participate? [Wait for verbal confirmation]*

Agrees to participate:  YES  NO

**Early Psychosis Evaluation & DUP/DUMI Pilot Project  
Semi-Structured Interview**

<b>Site Name:</b>	<b>County:</b>
<b>Interviewer:</b>	<b>Date:</b>
<b>Conducted:</b> <input type="checkbox"/> In Person <input type="checkbox"/> By Phone <input type="checkbox"/> Internet	
<b>Interview Participants:</b>	<b>Roles of Participants in the Organization:</b>

**Program serves:**  FEP only     FEP and CHR

**Part 1: Determining Feasibility of Statewide Evaluation of Early Psychosis Programs**

[READ ITEMS IN ITALICS. FOLLOW UP WITH QUESTIONS] *As mentioned previously, one purpose of this study is to develop a methodology for the measurement of costs and outcomes associated with early psychosis programs in California. We would like to follow up on your survey responses to ask a few more questions about the data you have available and what might be needed to support a statewide evaluation of California’s early psychosis programs.*

**DOES THE PROGRAM SERVE BOTH FEP AND CHR?**     YES     NO

IF YES: Are you able to identify individuals who were diagnosed as FEP versus individuals at clinical high risk in your data? Is this data recorded in your EMR? (e.g. if FEP and CHR are both recorded as Psychosis NOS in the medical record, would they be able to clarify this in the data set).

**1. DID PROGRAM INDICATE THAT THEY COULD GENERATE REPORTS ON THE DATA THEY HAVE COLLECTED TO DATE?**     YES     NO

IF YES: Tell me a little bit about the data you have available on the clients who have been served by your program. [try to get a sense of the file format – excel, access; completeness, how to access, etc.]

**2. DID PROGRAM INDICATE WHO CAN GENERATE SUMMARY DATA REPORTS (e.g. in excel or another quantitative format)? If not, please clarify.**

Clinic Staff                       County Staff                       Clinic and County Staff

**3. DOES PROGRAM KEEP PAPER OR ELECTRONIC RECORDS – OR BOTH?**

- Paper Only                       Electronic only                       Both electronic and paper
- a. **FOR OPTION 1 (PROGRAM ONLY HAS PAPER CHARTS), DID THEY REPORT HAVING ELECTRONIC DATA (E.G. A SPREADSHEET OR DATABASE) AVAILABLE FOR ANALYSIS?**  
 YES     NO – ask iii below
- i. IF YES: You reported on the survey that you have primarily paper charts, but you collect outcomes data in a separate dataset. Is that correct?  YES             NO
  - ii. IF YES: What file format (excel, access, etc) is your data in? Are there any additional outcomes data elements that are NOT currently included in your data set? What are they?
  - iii. FOR ALL: How long would you estimate it would take per chart to identify the relevant data components and put them in a data set (estimate hours per chart)?
- b. **FOR OPTIONS 2 AND 3:** For paper records or client charts that existed PRIOR to the implementation of your EMR, have those older documents been transcribed/uploaded into your EMR?
- i. IF NO: Would it be possible to integrate these documents into your EMR so they could be downloaded as data? OR is this not possible (e.g. paper documents uploaded as PDFs)?
  - ii. How long would you estimate it would take per chart to identify the relevant data components and put them in a data set (estimate hours per chart)?
- c. **FOR OPTION 3 (PAPER AND ELECTRONIC):**
- i. What percentage the outcomes-related data elements are in paper format ONLY?
  - ii. How long would you estimate it would take per chart to identify relevant data components (described previously) and put them in a data set (estimate hours per chart)?

*We are considering two options for the proposed statewide evaluation. For both options, we would use the survey responses to identify currently active EP programs that are funded through public funds and provide a comparable package of early psychosis services that align as closely as possible to evidence based practices. These programs would then be asked to participate in either a RETROSPECTIVE or PROSPECTIVE evaluation.*

- *In the RETROSPECTIVE evaluation, the selected EP programs would be asked to provide the research team a de-identified dataset with particular data elements that you have already gathered with your various assessment tools. The dataset would include data from each program participant (client) from the initial evaluation and any subsequent follow up evaluations that were collected up to a specific date (e.g. June 30, 2016). This option has the benefit of capitalizing on data that has already been collected, BUT would require organize of the data from all of the sites into a format that could be analyzed.*
- *Alternatively, in a PROSPECTIVE evaluation, the selected EP programs would agree to collect data on specific outcome data elements for a period of time (e.g. starting in July 2017 and going forward until June 2019) on all individuals served by your program. This option has the benefit of having all sites collect the same data in the same format from the beginning, but requires a commitment to the project over time.*

4. If your program was selected as a site for a RETROSPECTIVE statewide evaluation of EP programs, what support would you need to make the data you already have available for a statewide evaluation? (e.g. training or technical assistance, staff support/\$, county support, etc.)
5. What support would you need to participate in a PROSPECTIVE statewide evaluation?
6. For either option, what additional steps would need to happen to facilitate data sharing with the research team? (e.g. MOU, county approval, university or county IRB approval)
7. Do you think your county would support you in participating in this statewide evaluation? Would they help to provide data or other information if asked?

*This statewide evaluation also seeks to determine COSTS associated with providing an early psychosis program in your community. These costs can be associated with program start up and daily activities. Costs can also be associated with outcomes for the clients, such as the cost of psychiatric hospitalization.*

8. Would your program be willing to share information on the costs associated with providing your early psychosis program, such as staffing numbers and salaries, training costs, as well as fixed costs such as rent, utilities, etc.?
9. Do you have data on the costs of psychiatric hospitalization, crisis treatment or emergency room visits in your community? Is there someone at the county level who might be able to help identify such cost data? Is cost data available for previous fiscal years (e.g. Fiscal year 2013-14), as this would be needed for a retrospective analysis?
10. Is there someone at the county level who could provide data on costs?

*As part of a statewide evaluation, we would attempt to identify a clinic in your county that provides standard outpatient mental health services to a similar population (ages, diagnoses) to serve as a comparator to your service in the analysis.*

11. Are you aware of an appropriate clinic to contact? How might we identify such a comparator program? Is there somebody we should discuss this with at either a county or local leadership level?

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## **Part 2: Duration of Untreated Psychosis & Duration of Untreated Mental Illness**

*For this part of the interview, we are going to ask you some questions to clarify how early psychosis programs are measuring the duration of untreated psychosis for the clients they serve. This information will be used to propose a method for how this could be scaled to the measurement of duration of untreated mental illness by other programs in California that receive Prevention and Early Intervention funding through MHSA.*

### **Assessment/data collection**

How does your organization currently assess the onset of psychosis?

*Probe:* Please explain the criteria, process, who is involved, amount of time spent, etc.

*Probe:* Do you use a particular instrument? Unstructured interview?

*Probe:* What sources do you consult (client, informant, chart review, etc.)?

*Probe:* *If not assessed, why not?*

How exact/detailed would you say these measurements are? Able to get month and year?

One suggested definition of the onset of psychosis is the first point at which psychotic symptoms (such as hallucinations, delusions and/or disorganization) become recurrent or persistent AND cause significant distress, impact behavior, or are dangerous. Are there other criteria you would use to define the onset of psychosis?

Would you agree that this is a reasonable definition?

What factors pose challenges to measuring the onset of psychosis? We have previously identified these complicating issues: Comorbidity, substance abuse, discrepancies between the information provided by patients and family members, age of the informant, cognitive capacity, and duration of illness. Can you think of any other factors?

Do you record the onset of psychosis in an electronic format (e.g. electronic medical record, data base)? How easy or difficult would it be for your organization to update/change existing data regarding the onset of psychosis?

*Probe:* How often is data on specific clients updated when you receive new information? How often is data reported out?

When you are speaking with the family members or significant support persons of your clients, what questions have proven to be the most helpful/informative in defining the onset of psychosis?

How does your organization define the onset of early psychosis treatment?

*Probe:* Do you record these onset dates in an electronic format?

**NOTE:** If program does not define the onset of treatment for early psychosis ask why.

**[If program serves both FEP & CHR]** In addition to measuring the duration of untreated psychosis in patients diagnosed with a psychotic disorder, do you also measure the duration of untreated illness in those diagnosed with CHR? For CHR individuals, this would typically mean collecting information on the start of the prodrome.

*Probe:* Is this process different to measuring DUP? If so, in what way?

*Probe:* Are there any additional challenges in measuring onset of prodrome/at-risk syndrome for CHR patients, relative to those with full psychosis?

### Scenarios

The same state regulations for measuring duration of untreated psychosis apply to other early intervention programs, who are required to measure the duration of untreated mental illness [show additional DUMI figure].

Do you think the methods you have outlined previously related to measuring DUP could be extended to measure the duration of untreated mental illness for other severe mental illnesses, such as major depressive and bipolar disorders?

*Probe: Do any additional challenges to measuring DUMI exist?*

---

Please consider the following three examples and explain how the methods you described for your program could be extended to these programs to support the measurement of the duration of untreated mental illness.

Example #1: Program for seniors age 60 and older with depression or dysthymia. The program provides screenings, home visits, depression management training, problem solving treatment and social and physical activity planning.

*Probe: What is the ideal way to measure the onset of illness in this program? How about the onset of treatment?*

*Probe: What are the challenges to this ideal approach to measuring the duration of untreated mental illness exist?*

*Probe: Given these potential challenges, is there a more feasible/inclusive way to measure the onset of illness in this program for as many people as possible? How about the onset of treatment?*

Example #2: A program for active and former military personnel with PTSD and other anxiety disorders assists veterans in transitioning back into community life following service abroad while also providing support for their families.

*Probe: What is the ideal way to measure the onset of illness in this program? How about the onset of treatment?*

*Probe: What are the challenges to this ideal approach to measuring the duration of untreated mental illness exist?*

*Probe: Given these potential challenges, is there a more feasible/inclusive way to measure the onset of illness in this program for as many people as possible? How about the onset of treatment?*

Example #3: A “warm line” which is available to anyone in the community who has questions about mental health, needs linkage to mental health and related services, or needs a friendly, supportive

person to speak to. The line is staffed by trained peers (people with lived experience) who also serve as Coaches and Case Managers.

*Probe: What is the ideal way to measure the onset of illness in this program? How about the onset of treatment?*

*Probe: What are the challenges to this ideal approach to measuring the duration of untreated mental illness exist?*

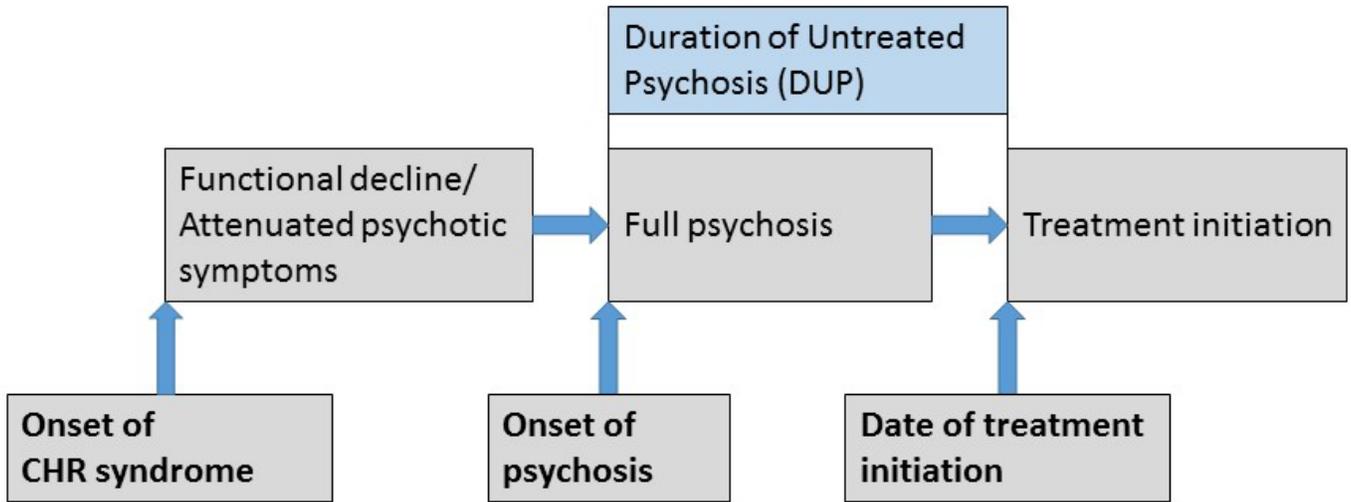
*Probe: Given these potential challenges, is there a more feasible/inclusive way to measure the onset of illness in this program for as many people as possible? How about the onset of treatment?*

### Closing questions

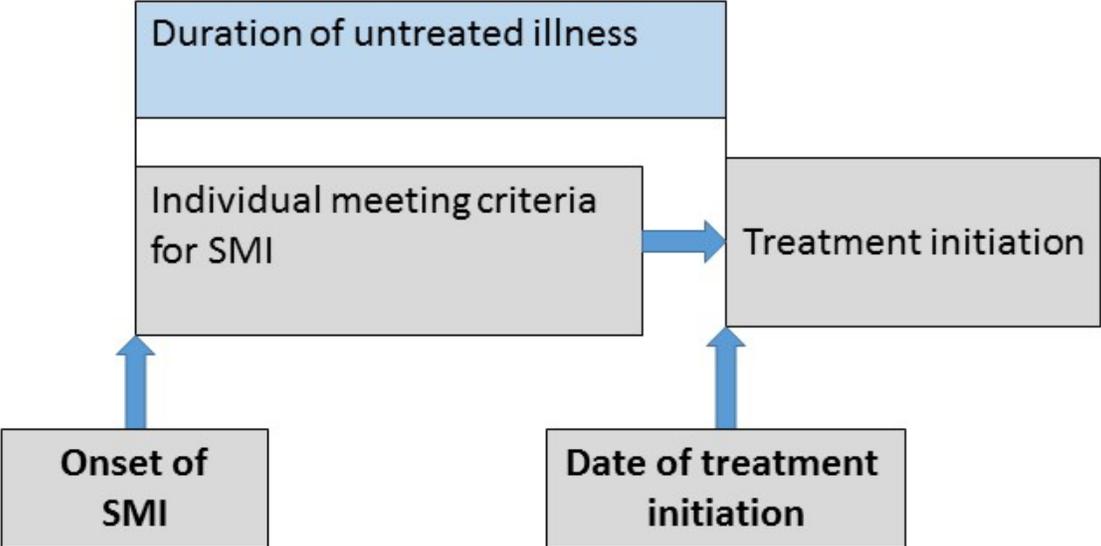
Can you think of anything that I have not asked that may be helpful concerning the definition, measurement, or data collection of duration of untreated psychosis and/or severe mental illness?

Do you have any additional concerns about tracking and/or reporting data on the duration of untreated psychosis and/or duration of untreated mental illness?

**Appendix C. Figure 1- Assessing the duration of untreated psychosis**



Appendix D. Figure 2- Assessing the duration of untreated mental illness



Appendix E. Timeline Tool for Assessing DUP/DUMI

Name \_\_\_\_\_

Pt. ID \_\_\_\_\_

Rater \_\_\_\_\_

Date of Interview

## Diagnostic Timeline

### Time Frame

Symptoms/ Functioning	1 day mo. yr. ago	2 day mo. yr. ago	3 day mo. yr. ago	4 day mo. yr. ago	5 day mo. yr. ago	6 day mo. yr. ago	7 day mo. yr. ago	8 day mo. yr. ago	9 day mo. yr. ago	10 day mo. yr. ago	11 day mo. yr. ago	12 day mo. yr. ago	13 day mo. yr. ago	14 day mo. yr. ago	15 day mo. yr. ago	16 day mo. yr. ago	17 day mo. yr. ago	18 day mo. yr. ago	19 day mo. yr. ago	20 day mo. yr. ago	21 day mo. yr. ago	22 day mo. yr. ago	23 day mo. yr. ago	24 day mo. yr. ago	25 day mo. yr. ago	26 day mo. yr. ago	27 day mo. yr. ago	28 day mo. yr. ago	29 day mo. yr. ago	30 day mo. yr. ago
Psychotic Symptoms																														
Prodromal Symptoms																														
Medication Use																														
Depressive Symptoms																														
Manic Symptoms																														
Hospitalizations																														
Residual Symptoms																														
Substance Use																														
Alcohol Use																														

**TIMELINE INSTRUCTIONS:** *Establish a temporal relationship between medication use, hospitalization(s), residual, prodromal, and psychotic symptoms. Use life milestones, e.g., graduation from HS, birthdays, holidays. If there is more than one episode, add them all to the right. If a Manic or Depressive Episode has been present, establish the temporal relationship between mood and psychotic symptoms. Use If substance use has been associated with the development of psychotic symptoms, establish the temporal relationship between substance ingestion and the psychotic symptoms. Be sure to write-in the date of the first onset of psychotic vs prodromal symptoms on the timeline. Regarding medication use, establish dates when anti-psychotic medication was started, the length of time the medication was taken, and when the patient stopped taking medication. Please note if the patient started taking medication again and when he or she stopped.*

Notes: \_\_\_\_\_

**PLEASE NOTE:** \_\_\_\_\_ = *Periods of definite psychosis such as delusions or hallucinations, or depression and/or mania that meet the full DSM-5 criteria for an episode. Also, periods that meet criteria for moderate or severe substance use disorder.*

----- = *Periods in which psychotic, depressive or manic symptoms were present, but without full delusional conviction, or hallucinations such as prodromal or residual symptoms, or did not fulfill the full criteria for depressive or manic*

Developed by UCLA Aftercare Research

This figure was graciously provided by the UCLA Aftercare Program.