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Measuring the Duration of Untreated Psychosis within First Episode Psychosis Coordinated Specialty Care

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Introduction

Reducing the Duration of Untreated Psychosis, or DUP, has come to be seen as a key tenet of early intervention in psychosis. Both research and common sense tell us that the earlier one intervenes in the course of psychosis, the better the outcomes for the individual. However, despite international consensus on this, there is less agreement on how DUP should be measured and (more important) how to incorporate this measurement into routine practice. This document aims to review the literature on DUP, examine different DUP measures in existence, and consider the implications of implementing this practice in community mental health settings. Ultimately, the purpose of the document is to enable early psychosis services to be informed about the critical elements for consideration when integrating DUP measurement into routine clinical care.

ISSUE BRIEF

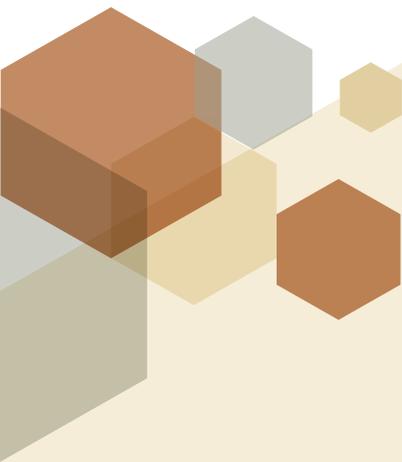
Overview of the Literature

Research on early intervention for serious mental health problems strongly suggests that improved outcomes are achieved when initial symptoms are identified early and treatment is administered as soon as possible (Mihalopoulos & Chatteron, 2015). The case for early identification and intervention is particularly compelling for individuals experiencing the onset of psychosis. Psychosis is typically characterized by sensory or cognitive experiences that are not tied to external reality, such as seeing or hearing things that are not present (hallucinations) or having false beliefs that are strongly held in the face of contradictory evidence (delusions). The symptom presentation can vary widely across individuals, which can complicate diagnosis in the early stages of the illness. Psychosis can occur in the presence of affective disorders that are characterized by mood symptoms, such as mania or depression; in isolation as part of non-affective psychotic disorders, including schizophrenia; and as a consequence of substance use disorders. While incidence rates vary across settings and studies, approximately 32 individuals per 100,000 adults and young adults experience the onset of psychosis each year (Kirkbride et al., 2012), with onset of symptoms typically occurring between the ages of 15 and 25 (Kessler et al., 2007).



Both individual and meta-analytic studies show that a prolonged period of psychotic illness without adequate treatment is the most consistent predictor of poor clinical and functional outcomes (Marshall et al., 2005). Additionally, individuals with psychotic disorders are at higher risk of poor long-term health outcomes and reduced life expectancy (Gates, Killackey, Phillips, & Álvarez-Jiménez, 2015). Remarkably, individuals with first episode psychosis have at least 24 times the mortality rate of the same age group in the general population in the 12 months after the initial psychosis diagnosis (Schoenbaum et al., 2017). Psychotic disorders also can have a major economic impact in terms of health care use. Schizophrenia alone was associated with approximately \$32.5 billion annually in health expenditures in the United States in 2005 (Penn, Waldheter, Perkins, Mueser, & Lieberman, 2005), which does not account for the human capital loss due to lifelong disability. Early identification and rapid treatment are essential, as clinical and psychosocial deterioration are expected to occur within the first five years after the onset of a psychotic illness (McGorry, Killackey, & Yung, 2008). By reducing the severity of psychosis and its impact on functioning early in the course of illness, cost savings are anticipated due to the reduced cost of long-term care necessitated by poorly controlled psychosis and significant functional deterioration (Csillag et al., 2015).

The period of time from onset of psychosis to onset of treatment is referred to as the Duration of Untreated Psychosis, or DUP. Longer DUP is associated with both poorer response to initial treatment (Kane et al., 2016) and poorer outcomes measured up to 15 years later (Bottlender et al., 2003). Across multiple studies, longer DUP is associated with increased positive symptoms (e.g., hallucinations and delusions) and negative symptoms (e.g., difficulty with motivation, expressing emotions) of psychosis. In addition, more frequent and severe global symptoms (e.g., mood and anxiety) and greater impairment in psycho-social functioning are seen, even after controlling for a variety of factors that might drive both longer DUP and poorer outcomes (Perkins, Gu, Boteva, & Lieberman, 2005). Despite the recognition that DUP is a strong predictor



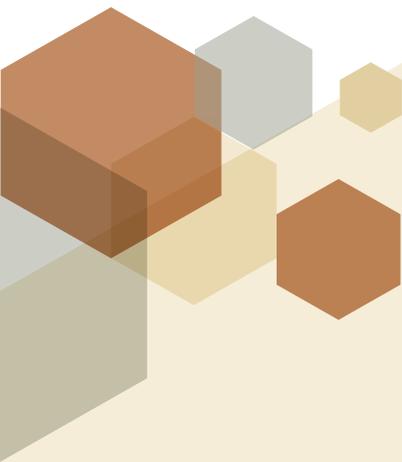
of clinical and functional outcomes, DUP in the United States remains far outside the range recommended by the World Health Organization for optimal outcomes, which is 12 weeks (Bertolote & McGorry, 2005). The U.S. average DUP is estimated at one to three years (Marshall et al., 2005; Srihari et al., 2009).

Empirically supported approaches to treating the first episode of psychosis (FEP) are based on a model called Coordinated Specialty Care (CSC) in the United States. FEP CSC programs have been shown to reduce the symptoms of psychosis and increase the individual's ability to function (Cullberg et al., 2006; Hastrup et al., 2013; Kane et al., 2016; McCrone, Craig, Power, & Garety, 2010). CSC programs have become more common in the United States in recent years and represent an important step toward improving outcomes for young people with psychosis. These team-based approaches to early psychosis treatment include psychotherapy, medication management, case management, family support and education, education and/or employment support, crisis intervention, and relapse prevention—all delivered by an integrated interdisciplinary team with a recovery orientation (Dixon et al., 2015). However, within the context of FEP specialty care, standard approaches to outreach, screening, and treatment engagement continue to be associated with unacceptably long DUP. A recent cluster randomized trial examined the impact of CSC for individuals with FEP who were enrolled in programs across the United States. Even in this well-resourced research study, the median DUP was 74 weeks. As would be expected, individuals with a shorter DUP (defined as less than 74 weeks) showed more improvement in total symptoms and quality of life in response to treatment than those who entered the program with greater than 74 weeks since psychosis onset (Kane et al., 2016).

Barriers to Seeking Care



Standard practice for most CSC programs involves education of primary referral sources (e.g., community mental health providers, schools, medical providers, community agencies) and the surrounding community, as well as advertising to “recruit” individuals with early psychosis to their clinics (Baumann et al., 2013; Lynch et al., 2016). However, findings suggest that psychosis often is underdetected in general mental health and primary care settings. In a chart review of all available medical files for adults ages 18–45 first presenting to mental health services in a catchment area of approximately 400,000 inhabitants in the Netherlands, only 33 percent of individuals reporting psychotic symptoms were diagnosed with psychotic disorders (Boonstra, Wunderink, Sytema, & Wiersma, 2008). Of most concern, 25 percent of individuals reporting two or more psychotic symptoms were given diagnoses of non-psychotic disorders or no diagnosis at all—but 53 percent of these individuals were subsequently diagnosed with a psychotic disorder over the next two years. While some people may have been accurately diagnosed as subthreshold at intake and later transitioned to a full psychotic disorder diagnosis, this is unlikely to be true of all individuals. These are individuals who reached out to the mental health care system for help and were experiencing psychotic symptoms, but their symptoms were not recognized or appropriately diagnosed, resulting in a longer DUP. Therefore, it is not surprising that studies of pathways to care for individuals with psychotic disorders have identified



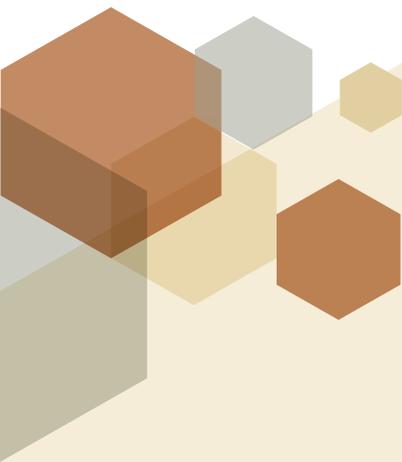
the delay between first health care contact and accurate identification to be a primary contributor to DUP (Birchwood et al., 2013; Brunet, Birchwood, Lester, & Thornhill, 2007; Norman, Malla, Verdi, Hassall, & Fazekas, 2004). Similarly, accurate and efficient case identification of FEP is challenging for both primary care and general mental health care providers, as well as schools and other “first identifiers” in the community.

In addition to these structural factors, a primary social barrier to engagement in mental health services is the social stigma attached to a mental illness diagnosis (Compton & Esterberg, 2005; McGorry, 2002). This problem was identified by the World Health Organization as one of the greatest remaining obstacles to mental illness treatment (Oral, 2007). “Stigma” refers to the negative attitudes and beliefs that cause the public to fear, avoid, and discriminate against individuals with mental illness, which leads to documented losses in educational, occupational, and social opportunities (Van Brakel, 2006). It is therefore understandable that individuals and their families often avoid mental health services to avoid stigmatizing labels (Corrigan, 2004) and often do not engage in services until the individual has become a danger to self or others and requires emergency care. This is particularly relevant for individuals with FEP and their family members, who have cited stigma as a reason they delayed seeking care (Tanskanen et al., 2011). In a series of semi-structured interviews with family members of individuals with FEP, Franz and colleagues (2010) documented these negative societal and self-beliefs and used interview results to create a “grounded theory model” for how stigma presents a barrier to seeking and engaging in FEP care, leading to increased DUP. In this model, anticipation of negative societal reactions contributes to social withdrawal and a withholding of clinical symptoms, thereby raising the threshold for engagement in treatment services and contributing to longer DUP.

Why Is It Important to Measure DUP?

As noted previously, the time shortly after the onset of psychosis represents a “critical period” in which treatment can be most successful at preserving current functioning and preventing additional clinical or psychosocial deterioration (Kane et al., 2016; Birchwood et al., 2013). During this “critical period,” individuals with psychosis may present with threshold psychotic symptoms, residual or attenuated symptoms, or complete remission and are at highest risk for relapse, disengagement from treatment, or suicide (McGorry, Killackey, & Yung, 2008). Therefore, intervention during this period represents a vital opportunity to place the individual on a trajectory toward wellness and recovery.

For an outpatient FEP program, measurement of DUP can serve many functions. First, many early psychosis programs have eligibility criteria for those they serve, which can include the duration of psychosis prior to presentation for services. In this context, determining the onset of psychosis is used to make a decision about an individual’s eligibility for participation in the FEP program. This assumes that a comprehensive clinical assessment is conducted as part of the eligibility process and that it systematically assesses the timeline of clinical symptom development.



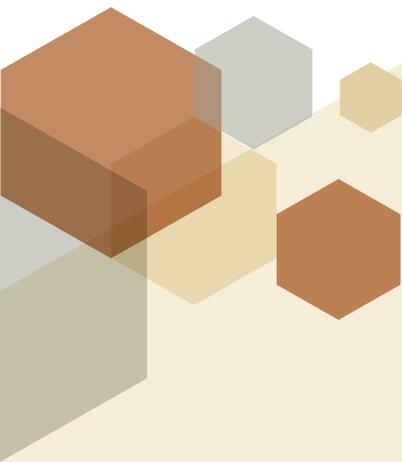
Beyond determining eligibility, measurement of DUP by clinical programs can provide useful information on the effectiveness of outreach efforts. The proactive outreach and education approach used by FEP programs (Addington, McKenzie, Norman, Wang, & Bond, 2013; McFarlane & Jaynes, 2017) typically focuses on increasing awareness about the signs of early psychosis and building collaborative relationships with community partners so they see the FEP program as a rapid and effective source of help. Outreach can engage specific community organizations (e.g., NAMI), youth-focused programs (e.g., Boys & Girls Clubs, after-school programs), school staff and personnel, primary care providers, other community mental health professionals, faith-based organizations, local TV or radio shows, online advertisements (e.g., Facebook, clinic web pages), and health and wellness fairs. Educational workshops, hands-on training, and targeted resource materials share the latest information regarding accurate identification of individuals who may be struggling with the onset of psychosis. In addition, they outline the benefits of early intervention on treatment outcomes in psychosis and describe the structure, philosophy, and treatment model of the FEP clinic. Additionally, these outreach efforts highlight procedures for expeditious referral to the FEP program. Training can focus on the subtle signs of early psychosis, including how to identify specific symptoms and changes associated with the onset of psychotic illness, and can encourage the community partners to link individuals who they have identified to the FEP program.

After such outreach activities, it is important to systematically measure DUP for each referral to determine if outreach efforts are effective. As the outreach efforts mature, average DUP should decrease. If DUP for referrals is still longer than appropriate, measurement of DUP by referral source can be used to fine-tune the outreach program by identifying what is working for shorter DUP referral sources, then modifying outreach efforts for sources whose DUP is not decreasing. This may involve joint problem-solving to develop strategies for these long DUP referral sources.

At a clinical level, a review of DUP—including onset of prodromal symptoms, fully psychotic symptoms, and help seeking attempts during this period—can help the clinician have a better appreciation of the consumer’s experience while they were developing psychosis and their pathway to care. Developing an understanding of this timeline with the consumer can provide vital information to aid in clinical formulation. This may provide clues regarding how to support a consumer around shared decision-making (i.e., if they have had multiple traumatic pathways into care, the consumer may initially struggle with trust and engagement), and it may help with engagement by demonstrating an interest in the full history of the consumer beyond an interview that primarily focuses on determining a diagnosis.



Finally, if a program seeks to evaluate the outcomes associated with program participation, inclusion of DUP as a potential variable will be important. As described earlier, DUP is one of the most significant predictors of clinical and functional outcomes (Marshall et al., 2005). In particular, it has been shown to moderate the response to FEP CSC treatment such that individuals with shorter DUP showed significant improvement in quality of life and symptoms relative to controls or to individuals with longer DUP (Kane et al., 2016). FEP programs often measure various indicators of clinical and functional outcome over the course of treatment to evaluate the impact

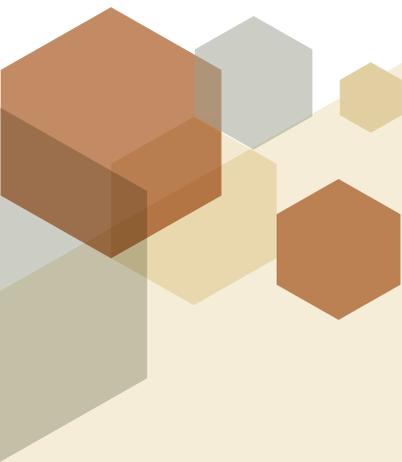


of their work. As many FEP programs serve individuals with a range of DUPs (e.g., onset within the past one to five years), it is important to use statistics to examine the impact of an individual's DUP on their outcomes in response to treatment. While some programs may serve individuals up to five years after psychosis onset in an effort to meet the needs of community members, they may find that their intervention is much more impactful for those with a shorter DUP, thereby driving differences in overall program outcomes. Collecting this information at a local level can help inform program eligibility decisions to serve those who are closer to psychosis onset, thus allowing the program to focus efforts for maximum impact. Measurement of DUP can therefore have an essential role in determining the impact of FEP program efforts, including targeting outreach and referral, examining subsequent outcomes for individuals receiving care, and planning programs.

Why Is Accurate and Valid Clinical Assessment Essential to Providing Early Psychosis Care?

Although this document focuses on providing guidance on the integration of DUP measurement within routine clinical care, the authors believe this is not possible without an established infrastructure supporting valid and accurate diagnostic assessment within the program. Unlike general outpatient programs that serve all individuals with mental health issues in a particular neighborhood or catchment area, CSC programs face the challenge of serving a very specific population (individuals experiencing their first episode of psychosis), which requires referring out young people with other serious mental illnesses who need and deserve care, but who are more appropriately served elsewhere. First, determining the date of psychosis symptom onset is critical to determining program eligibility to ensure that CSC programs actually serve their target population of *first episode* psychosis. In practice, many individuals who are referred to CSC programs may have been experiencing psychosis for several years and are thus beyond the “first episode” critical window. While empathetic clinicians may feel a pull to serve such individuals, the evidence suggests they will not improve as much in response to CSC treatment (Kane et al., 2016) as individuals with shorter DUP, and the programs may then have to refer longer DUP clients to other services more appropriate for their needs to save program slots.

Another common challenge is differential diagnosis of primary psychotic disorders versus other serious mental illnesses. Common presentations that require skilled assessment to differentiate them from primary psychotic disorders include trauma, substance-induced psychosis, developmental disorders, and mood and anxiety disorders. For example, perceptual experiences such as flashbacks and dissociation associated with trauma, obsessive thoughts that lack insight, or psychotic symptoms associated with methamphetamine use can all look like primary psychosis if one does not thoroughly assess for the associated symptoms and related context in which they occur. In many cases, these individuals are better served by other clinics (e.g., those that specialize in trauma, substance use, or autism-spectrum disorders). While they are well-meaning, clinicians who accept individuals with these diagnoses into CSC often are doing them a disservice. As part of the psychoeducation component of treatment, individuals are educated about their diagnosis, and providers should be

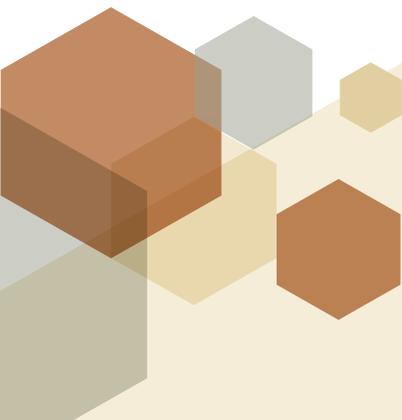


confident in the accuracy of the diagnosis they are using. Otherwise, individuals can face significant frustration as their diagnosis changes from provider to provider, which often is the case for consumers prior to entering FEP programs. Furthermore, the treatments that are purported to be part of the CSC model are designed for individuals with primary psychotic symptoms. Using these treatments with individuals who have primary trauma, obsessive compulsive disorder (OCD), or primary substance use issues would be inappropriate; evidence-based treatments exist for those other illnesses and should be used instead. Third, when individuals are served who are not intended for CSC services, appropriate FEP individuals are inadvertently excluded due to limited time and resources. Finally, if clinical samples are composed of individuals with a variety of diagnoses, all associated with different potential outcomes in response to CSC treatment, the ability to measure the effect of treatment is diluted by increasing the “noise” in the data. This potentially impacts the ability to show positive outcomes in response to CSC treatment efforts. One additional complicating issue is that many community-based CSC programs accept individuals with affective psychotic disorders, despite the current lack of evidence demonstrating that CSC is beneficial for them. However, if such programs hope to contribute evidence that individuals with affective disorders also can benefit from CSC services, accurate diagnosis is still critical.

As described above, the evaluation of DUP within a clinical program can serve many purposes; however, the measurement of DUP is predicated upon a comprehensive clinical evaluation at the onset of program entry that includes detailed assessment of the timeline of psychosis symptom onset. Such clinical evaluations often require a semi-structured interview approach to ensure that all relevant domains are assessed, including developmental and medical history, social history, work/school history, psychiatric treatment history, recent stressors, and trauma history, as well as a detailed history of mood, anxiety, substance use, and psychosis symptoms. Many research-based early psychosis programs use semi-structured interviews such as the Structured Clinical Interview for DSM (First, Williams, Karg, & Spitzer, 2015) to ensure that all relevant areas are systematically assessed. The onset of relevant symptoms is determined through routine probing for the onset, frequency, duration, distress, and effect on behavior for each potential psychosis symptom. Through this process, the evaluator can determine the timeline of symptom progression and identify the point at which symptoms reached a psychotic threshold (Miller et al., 2003). This evaluation process should be supported by extensive training as well as ongoing supervision to ensure that the procedure is followed with precision. Thus, measurement of DUP relies on comprehensive clinical evaluation at the outset of treatment, which informs the diagnosis and treatment approach. If programs are not equipped to support rigorous assessment, the measurement of DUP will be quite difficult, and the resulting data will likely be inaccurate.

How to Measure DUP

A variety of measures have been used to assess DUP in the published literature, including structured interviews used in research settings. These measures differ in their definition of the two elements that constitute DUP—onset of psychosis and onset



of treatment, which determines the endpoint of DUP. Several reviews have discussed the variability across studies and measures, concluding that no one measure is preferred. A recent review and meta-analysis by Register-Brown and Hong (2014) found that both inter-rater reliability of the various measures and their association with outcome changes were roughly equivalent across measures. Another meta-analysis demonstrated no significant effect of the DUP definition on mean or median DUP scores (Large, Nielssen, Slade, & Harris, 2008). Thus, there is no clear “best” measure for assessing DUP based on the published literature. Below is a review of existing measures and the variety of DUP definitions.

DEFINING PSYCHOSIS ONSET

Onset of psychosis is typically defined by psychotic symptoms that meet a certain threshold of severity and duration through the following methods: (1) a structured interview designed to assess DUP; (2) a dimensional symptom severity measure with a specific threshold at which “psychotic level” symptoms are considered; or (3) via responses to a more general clinical interview.

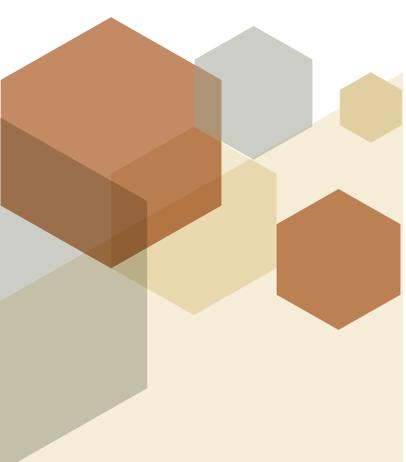


Structured interviews that are specifically designed to assess DUP include the Comprehensive Assessment of Symptoms and History (Andreasen, Flaum, & Arndt, 1992); Nottingham Onset Schedule (Singh et al., 2005); the Circumstances of Onset and Relapse Schedule (Norman & Malla, 2002); the Royal Park Multidiagnostic Instrument for Diagnosis (McGorry et al., 1990); and the Symptom Onset in Schizophrenia Inventory (Perkins et al., 2000). All of these interview protocols provide a semi-structured format with specific question and follow-up prompts to assist the interviewer in determining the onset of psychotic symptoms.

In contrast, other studies have used a severity threshold on a dimensional symptom measure, such as the Brief Psychiatric Rating Scale (BPRS; Lukoff, Nuechterlein, & Ventura, 1986) or Positive and Negative Symptoms Scale (PANSS; Kay, Fiszbein, & Opler, 1987), with a threshold that is considered to be “psychotic level.” In the TIPS project, Melle and colleagues (2004) suggest using the first week with psychotic symptoms corresponding to a score on the PANSS of 4 or more on positive subscale items 1, 3, 5, or 6 or on the general subscale item 9.

Some studies simply note that they use “first clear psychotic symptoms as rated on the Structured Clinical Interview for DSM-IV” or “onset of psychotic symptoms” based on a general clinical interview. Most studies focus on hallucinations and delusions to mark psychosis onset, while some also use symptoms of disorganization or extreme negative symptoms. Other studies are unclear about which symptom domains are included.

In addition, programs that treat the “clinical-high-risk” syndrome or “prodromal” phase of psychosis often use the Structured Interview for Psychosis Risk States (SIPS; Miller et al., 2003) to differentiate between the attenuated positive symptoms and full psychosis. In longitudinal assessments, formal psychosis onset is defined by the frequency, duration, distress, degree of conviction, and impact on behavior associated with the symptoms (Miller et al., 2003). It is unclear whether attenuated psychotic



symptoms are included in the definition of psychosis onset for many other DUP assessments.

DEFINING TREATMENT ONSET

Onset of treatment is defined variably, ranging from the date of the clinical interview at entry into the treatment program to any treatment for psychotic symptoms to the date of first hospitalization to the date of first treatment with antipsychotic medication to date of first adequate treatment. “Adequate treatment” is defined variably as well, including CSC, as well as treatment with antipsychotic medications at a threshold dosage and duration (typical definitions vary from 2–6 weeks). More recently, the National Institute of Mental Health (NIMH) defined treatment onset as entry into CSC for first episode psychosis in their guidance to investigators conducting research on DUP reduction (PAR-13-188; Chang, Steiner, & Ketter, 2000). Another approach suggests using multiple endpoints, with different acronyms to differentiate between DUP endpoint definitions, defining the DUP1 endpoint as date of initiation of antipsychotic medication; the DUP2 endpoint as date of entry into a specialized program; and the DUP3 endpoint as entry into a specialized program and adequate medication with good adherence (Polari et al., 2011). Although much of the DUP research literature focuses on initiation of antipsychotic medications, a recent qualitative investigation showed that clinicians in CSC programs in California preferred definitions that did not rely on medication use (Savill et al., 2017).

Challenges of Measurement in Routine Clinical Programming

To date, DUP has been measured primarily in research studies that utilize highly trained staff with ongoing supervision and checks on reliability (similar measurement across raters). Staff have dedicated time for formal DUP assessment, and individuals with FEP are compensated for their time completing study measures. These resources are not typically available to community-based clinical programs, in which staff often have many competing priorities for their time, less training, and supervision available for assessment activities. DUP is usually measured at program entry or evaluation for program eligibility—a time when clinicians are simultaneously trying to establish rapport, engage consumers and their families, gather copious amounts of information, develop initial treatment goals, and complete opening paperwork, all in a timely fashion. Furthermore, most of the established DUP instruments focus exclusively on psychopathology and impairment, and some use language that is inconsistent with the recovery orientation of most FEP services.

In 2015, the NIMH sponsored two working groups to identify well-validated measures that could be feasibly implemented across sponsored research in early psychosis, through the PhenX (consensus measures for Phenotypes and eXposures) Toolkit. The PhenX Toolkit was originally developed to identify standard measures in genomics research and includes several mental health domains. PhenX measures are selected by working groups of domain experts using a consensus process established by a steering committee (Maiese et al., 2013). Working groups select potential measures based on the following criteria:

1. Measures are valid and reliable and have demonstrated utility.
2. They are not burdensome to participants and investigators.
3. The measures are broadly applicable and generally accepted in the field.

Feedback from the clinical and scientific community informs final deliberations and selection of assessment protocols. Measures selected by PhenX working groups are made freely available to biomedical research and clinical practice communities through a web-based resource (<https://www.phenxtoolkit.org>).

In the early psychosis domain, a Clinical Services Working Group was tasked with one additional selection criterion: that the measures be relevant and feasible for community-based CSC programs in addition to research studies or university-based CSC programs. Although the working group reviewed a number of measures that assess DUP, none were found that met all selection criteria. Therefore, despite the importance of this domain for early psychosis clinical services and research, no measure was proposed. Instead, the working group suggested that a brief DUP measure needed to be developed and validated in community-based CSC settings.

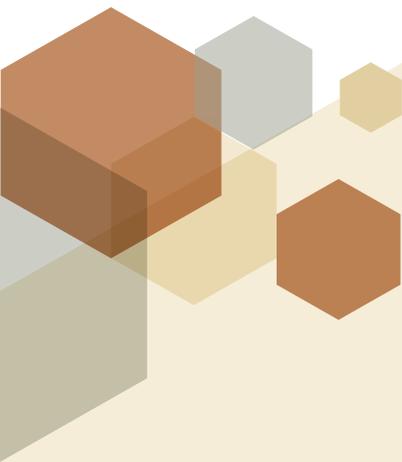
Thus, although the routine measurement of DUP within clinical settings is recommended, there is limited consensus on the definition(s) and methods for measuring DUP, as noted in several review papers and by the PhenX Clinical Services Working Group. In addition to the challenges described above, a number of barriers exist that are specific to community-based CSC programs, and we list them below, along with potential solutions.

Staffing Considerations and Training Needs

The measures described earlier—although differing in their definition of DUP—all assume that the individual administering the interview is trained in comprehensive diagnostic assessment. This is one of the largest barriers to the implementation of existing DUP measures in a community setting. Community agencies are typically staffed by clinicians, often with excellent clinical and case management skills, who have limited experience in diagnostic assessment. As described earlier, consideration of offering specialty services may require a complete paradigm shift for many clinicians who previously have been used to offering services to any consumer presenting for treatment. Instead, CSC programs are developed specifically for an early psychosis population, so it is important to ensure that those receiving services are appropriate to the model. Therefore, staff will require initial orientation to this model to support buy-in and address potential concerns about not providing services to all who present for assessment.

Following initial orientation, clinicians will require further training and supervision in diagnostic assessment, including interview techniques, differential diagnosis, and how to provide psychoeducational feedback to the consumer and their family. Hiring clinicians with some exposure to diagnostic assessment and training in the DSM will aid this process. Throughout the process, it is imperative that training and supervision are conducted by a clinician experienced in these elements. Ongoing





case consultation, where individual assessments are reviewed in a group or individual setting, can support ongoing supervision and learning.

Established DUP measures assume that staff are sufficiently trained in structured assessments and have ongoing supervision to establish reliability across assessors. Committing to measuring DUP means committing to training and ongoing consultation for staff engaged in collecting DUP data. This includes an intensive assessment process, supervision and review, and review of intake data after six months or more of treatment to verify accuracy of information collected. Where it is found that the consumer is not appropriate for the service, either at intake or at a later review point, clinical staff need to be trained in identifying local resources and brokering the transfer of the consumer to the new service through a warm hand-off.

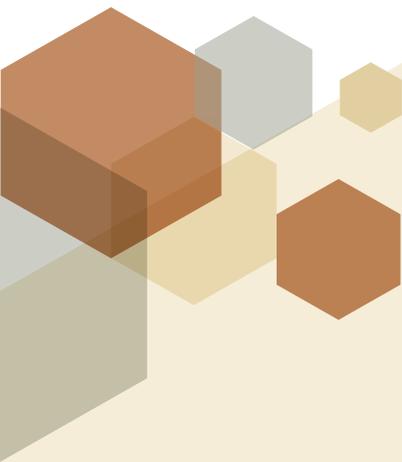
The routine measurement of DUP requires staff to be trained in assessment of the onset of psychosis. This includes an understanding of the onset of prodromal symptoms, conversion to full psychosis, and differentiation between the two. In addition, the clinician needs to be skilled in clinical interviewing while establishing rapport, timeline review, and incorporation of information from collateral informants and medical records. As discussed earlier, several DUP interview measures exist that can aid in this process. Whatever interview technique or measure is chosen, it is important that there is consistency between interviewers. Regular consensus meetings may help ensure consistency between raters, although this may not be feasible within all community clinical settings.

TIME AND FUNDING CONSTRAINTS

Community clinicians may not have availability in their schedules to conduct lengthy interviews to determine DUP. As such, the authors recommend that the DUP interview is incorporated into the initial intake evaluation (particularly if it is being used to determine eligibility for the program) and linked to care planning. As stated previously, this information can then be used to help with shared decision-making and clinical formulation. Without a clear link to care planning, staff will find the assessment burdensome and irrelevant and will be less likely to complete it, especially when there are competing urgent clinical demands.

Common Pitfalls and Mistakes in DUP Measurement

Measurement of DUP is complex. We have noted several common pitfalls in measuring DUP that can be avoided with awareness and planning. Clinicians may be tempted to use the date of first hospitalization or date of first diagnosis recorded in hospital records as the onset of psychosis. In our experience, this rarely accurately captures the onset of psychosis, as the actual onset often occurs weeks or months before this date. It also is essential to collect information from multiple collateral informants rather than rely on a single source of information. DUP should be established through integrating several sources of information. Retrospective recall of the onset of psychosis is challenging for consumers and their families, as it requires recall of a stressful and often chaotic period. Gathering information from the consumer, family members, and medical records can aid in this process.



As mentioned before, there is still disagreement in the field as to the definition of “psychosis onset” and “treatment onset.” The organization needs to have an accepted definition of these two dates and a standardized practice by which they are measured and recorded. This will ensure that the data collected are reliable.

It is important to note that determination of the date of onset of psychotic symptoms is only one piece of the initial diagnosis process that occurs at intake in most CSC clinics. A diagnostic determination requires the clinician to gather other important pieces of information related to the psychosis and other associated symptoms (e.g., Have the psychosis symptoms been present for six months? Are they only present in the context of mood symptoms? Did they only occur in the context of substance use?). However, a diagnosis does not require you to specify the onset date, only to determine that the symptoms have been present for a specified period of time. Therefore, determination of DUP requires clinicians to go one step further and clarify the date of psychosis onset as part of the initial evaluation.

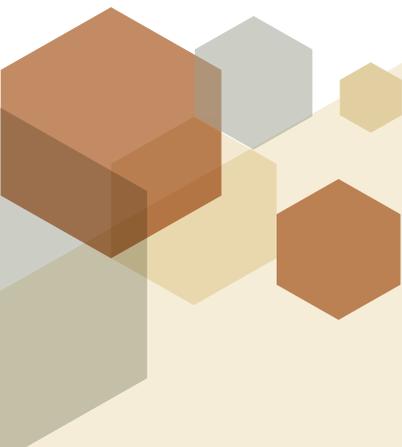
While no existing structured interview has been recommended in reviews of DUP measures, the UCLA Aftercare Research Group (2017) has developed a visual timeline tool to be used when assessing DUP. The timeline tool (see Appendix A) prompts the assessor to identify key events in a person’s life relevant to the onset of psychosis and to map different symptom domains to identify the onset of full psychosis. Although the timeline tool was developed to be used with the DUP definition provided by Melle and colleagues (2004), it can be used with any definition, thus providing flexibility for different programs. It is important to note that the timeline tool still requires that clinicians are trained in assessment of psychotic symptoms.

Case Examples

The following case examples outline different potential methods that could be used to integrate DUP measurement into a community early psychosis program.

Case study 1: Partnering with local expertise

A community-based early intervention service in a large urban area is interested in measuring DUP. The manager of this service approaches the local university or professional psychology graduate school to determine available resources around training and consultation for routine DUP assessment. Through this process, a collaboration is formed whereby pre- and post-doctoral students are offered the opportunity to accrue clinical hours by conducting DUP assessments using an established DUP instrument and initial diagnostic assessments. A licensed psychologist who has training and experience in assessment of DUP and differential diagnosis of psychosis supervises these students at the early-intervention program. Annual training in diagnostic assessment and DUP measurement is developed, and a weekly consensus meeting is implemented. The students are integrated into the CSC program weekly team meetings, where they contribute to clinical case presentations and treatment planning, drawing upon information gathered through the assessment process.



Case study 2: Integrated remote collaboration

The director of a statewide behavioral health organization wants to implement DUP data collection across multiple sites. However, staff within these sites are not routinely trained in diagnostic assessment and do not have the bandwidth to take on additional responsibilities. The director approaches an academic medical center with a reputation for early psychosis research and DUP measurement. They are able to establish a contract through which research assistants or other staff trained in DUP measurement will conduct remote DUP assessment of consumers and their families, with local program administrative staff aiding in chart review and gathering medical records. The assessors remotely join clinical team meetings to provide information from the assessment.

Case study 3: Assessing needs and resources

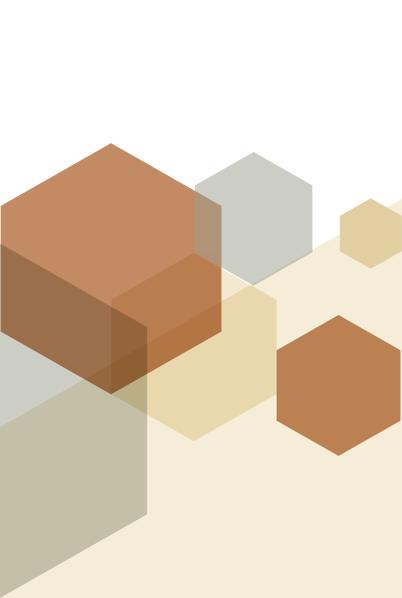
The program manager of a suburban early-intervention program is interested in DUP measurement. Program officials review the literature on this topic and conduct a needs analysis within their program, taking into account current resources, staffing, and training needs. Through this process, they determine that the workforce will require additional training in clinical assessment of psychosis before implementing DUP measurement. In addition, they note that the current staffing of the program would not allow for this additional programmatic element. As such, they decide to focus on staff training around psychosis assessment and pursue staffing changes (including hiring a person dedicated to supporting the intake process who also will be able to train and supervise staff on assessment), with a long-term plan to implement DUP measurement once these changes have taken effect.

Next Steps in DUP Measurement

DUP is an important outcome marker for early-intervention services at multiple levels. There is a need for accessible, well-validated measures that can be used in community settings to ensure that DUP is routinely measured in a standardized fashion. In addition to encouraging the early psychosis field to invest in developing and validating a DUP measure for routine clinical practice, there are several recommendations for community-based programs provided below.

Recommendations

- Reduction of DUP should be included as a key performance metric for all early psychosis programs.
- Clinicians should be trained and appropriately supervised in assessment of psychosis and differential diagnosis.
- DUP should be embedded in the intake and assessment process for all consumers entering early psychosis programs. Assessment and diagnosis are critical to the ability to reliably measure DUP and eligibility for the service.
- Information gathered in the DUP assessment should be integrated into clinical formulation and treatment planning.
- Information on DUP and pathways into care should be regularly reviewed to inform future targeted education efforts.
- Programs should coordinate and standardize DUP measurement across the program if possible.



RESOURCES

Prodrome and Early Psychosis Program Network (PEPPNET)

This is a frequently updated training directory highlighting nationally available training opportunities, including training on clinical diagnostic assessment.

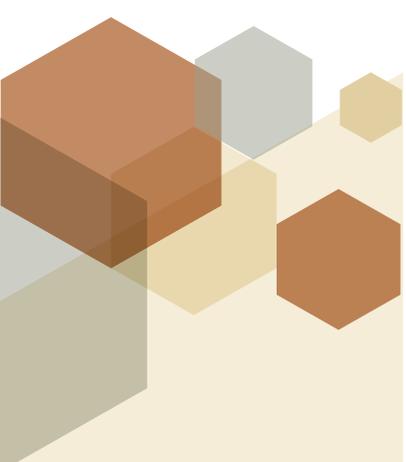
<https://med.stanford.edu/peppnet.html>

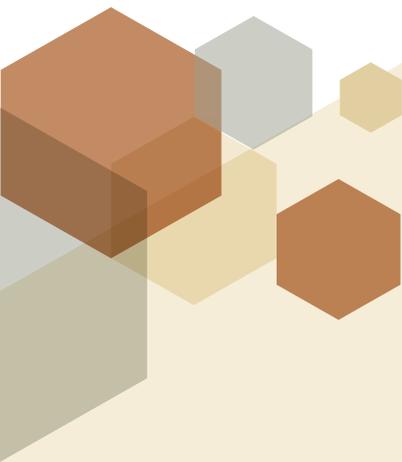
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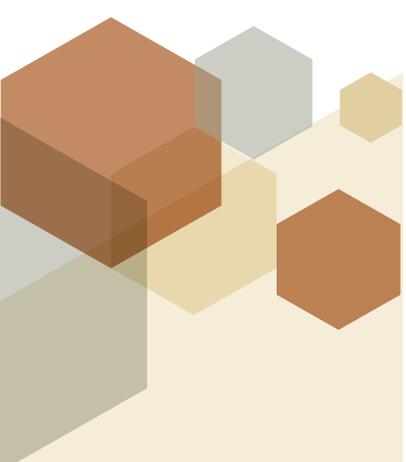
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APPENDIX A. TIMELINE TOOL FROM UCLA AFTERCARE RESEARCH GROUP

Date of Interview

Diagnostic Timeline

Name _____

Pt. ID _____

Rater _____

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																															
Antipsychotic 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. 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.

Initial DUP in weeks: _____

Cumulative DUP in weeks: _____

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 episode, or periods of mild substance use disorder.