

**DEVELOPMENT AND PRELIMINARY FEASIBILITY OF THE MOBILE  
PARTICIPATION ASSESSMENT TOOL: AN ECOLOGICAL MOMENTARY  
ASSESSMENT OF PARTICIPATION IN TRAUMATIC BRAIN INJURY**

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Participation as a primary outcome of interest has gained increasing focus for disability and rehabilitation research and practice. Current means of assessing participation are limited by their static nature and reliance on an individual's accurate and unbiased recall of past events. In particular, participation is an important outcome in traumatic brain injury (TBI) research and practice, and for these individuals accurate and unbiased recall can be impacted by the functional limitations that are commonly associated with this injury. Ecological momentary assessment (EMA) is an assessment approach that employs the repeated measurement of an outcome of interests in the natural, real-world environment. EMA may reduce the limitations of current measures of participation as well as enhance reporting accuracy and reliability of individuals with a history of TBI. The main objectives of this dissertation were to 1) develop a preliminary measure of participation that can be delivered using EMA techniques and 2) examine the feasibility and usability of EMA in a TBI population that exhibits cognitive impairment.

The first aim of this study was the preliminary development of a participation assessment that could be delivered via EMA techniques. The Mobile Participation Assessment Tool (mPAT) was developed and underwent preliminary validation by the research team in conjunction with a group of experts in the field of rehabilitation and disability sciences and individuals with a history of TBI. A scoring algorithm was also developed by the group. The

second aim of examining the feasibility of using EMA techniques to assess participation in community dwelling adults with TBI and presence of cognitive impairment was completed by asking adults with TBI (n=12) to complete a four week EMA protocol to assess participation in the real-world environment in which they live.

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## **PREFACE**

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## **1.0 INTRODUCTION**

### **1.1 PROBLEM BACKGROUND**

Traumatic brain injury (TBI) is a public health concern, with approximately 5.3 million individuals in the United States living with a TBI-related disability (Faul, Xu, Wald & Coronado, 2010). As a result of the associated impairments and activity limitations, many individuals experience participation restrictions (e.g. inability to return to work, social isolation) following a TBI (Dawson & Chipman, 1995; Ponsford, Sloan, & Snow, 2012). The measurement of participation as a primary outcome has received increased focus in health, disability, and rehabilitation practice and research, as well as in TBI rehabilitation practice and research (Chung, Yun, & Khan, 2014; Cicerone, 2004; Hall, Bushnik, Lakisic-Kazasic, Wright, & Cantagallo, 2001; Sander, Maestas, Sherer, Malec, & Nakase-Richardson, 2012; Perenboom & Chorus, 2003; Noonan, Kopec, Noreau, Singer, & Dvorak, 2009; Noonan et al., 2009; Whiteneck & Dijkers, 2009; Dijkers, 2010; Eyssen, Steultjens, Dekker, & Terwee, 2011). Participation is an important outcome not just for investigators and clinicians, but for individual's with TBI and their family members (Cicerone, 2004) However, there is criticism of the conceptual clarity and measurement of participation (Jette, Haley, & Kooyoomjian, 2003; Jette, Tao & Haley, 2007; Whiteneck & Dijkers, 2009; Magasi & Post, 2010; Dijkers, 2010). While participation is a dynamic construct that occurs in the real-world environment in which the

individuals lives and functions, available measures are typically static, rely on retrospective recall, and are an indirect measure of participation (Campbell & Crews, 2001). Identifying a way to accurately and dynamically measure participation is essential.

As an alternative to traditional participation assessment approaches, ecological momentary assessment (EMA) is an approach that allows investigators and clinicians to measure a variety of biopsychosocial and health-related constructs of interests by employing repeated measurement in the real-world, natural, and multi-contextual environments of the individual (Shiffman, Stone, & Hufford, 2008). EMA eliminates the necessity to rely on retrospective recall by collecting information in real-time and on the current state, moment, behavior or trait (Shiffman et al., 2008). Thus, EMA is a unique assessment approach that may address the challenges of measuring a dynamic construct such as participation.

### **1.1.1 Statement of the Problem**

The measurement of participation is limited by the lack of consensus on an operational definition of the construct (Whiteneck & Dijkers, 2009, Eyssen et al., 2011, Dijkers, 2010). This has resulted in the development and use of a number of instruments. Available measures often differ in the ways that participation is measured (e.g. frequency, duration, impact and duration of disruption) and domains measured (e.g. self-care, employment, social relations, home integration). With such a wide variety of instruments and procedures available to investigators and practitioners, the ability to compare outcomes across studies and within populations is limited.

Participation is a dynamic construct that occurs in the real-world environment in which individuals live. Available instruments are typically static, rely on the individual's ability to

recall past experiences, and are typically administered in a clinical setting or over the phone. For instance, many of the current measures of participation rely on an individual's ability to accurately recall experiences and to average those experiences over a specified timeframe (e.g. how many hours in the last week have you spent at work). While some life situations may be more easily recalled (e.g. hours spent at work), others, such as time spent socializing with family or friends, may be more difficult to accurately recall.

EMA is a dynamic assessment approach that uses the repeated measure of a construct of interest in the real-world environment (Shiffman et al., 2008). Applying EMA techniques to the measurement of participation may address the limitations of current measures (e.g. reliance on retrospective recall, static nature). Because no current gold standard measure of participation exists, nor does one exist that could be delivered via EMA techniques, as they do not assess participation in the moment, we proposed to develop a new measure of participation. The measure was developed to be an EMA of participation that is consistent with the ICF framework. The ICF provides four options to use in distinguishing between activity and participation (World Health Organization [WHO], 2001). The fourth option allows for domains listed in the classification system to be both activities and participation (WHO, 2001). This option allows for an understanding of the dynamic relationship of activity and environmental and social factors that define participation. Employing a dynamic assessment approach in the real world may increase our understanding of participation as it happens in real-time, in the lived environment of the individual, as well as add clarity to an area of the ICF that is often criticized for its ambiguity.

## **1.2 RESEARCH PURPOSE**

The primary purpose of the current research project was to develop and examine the feasibility of a measure of participation in individuals living in the community following TBI utilizing EMA techniques. To work toward this, the current research project had three studies: (1) development, (2) preliminary beta testing, and (3) pilot feasibility. The specific research aims of each phase are detailed below.

### **1.2.1 Research Aims**

The overall aim of this project was to develop a measure of participation that could be delivered using EMA techniques in a TBI population. This aim leads to two primary questions: 1) can a measure of participation be developed that is delivered using EMA techniques, and 2) are EMA techniques feasible and usable in a TBI population with cognitive impairments. In order to address these questions we began by developing a measure of participation that could be delivered using EMA techniques.

In order to address the overarching aims of this project three studies were implemented. Study 1's first aims were to develop a participation measure that can be delivered via EMA techniques and methodologies, and to establish a set of rules that would be used to develop a scoring algorithm to quantify observations made using the tool. Following the development of the tool and scoring algorithm, aims of Study 1 were 1) to examine the content validity of the participation measure, and 2) to examine the preliminary reliability of the scoring algorithm.

Following the development phase, a second study to determine the initial feasibility of EMA of participation in a TBI population was necessary. The aim of Study 2 was to determine

the optimal sampling approach to assess participation in individuals with TBI using EMA techniques. To achieve this aim, the preliminary feasibility of a smartphone application to deliver a participation measure to individuals with TBI who demonstrate at least a mild level of cognitive impairment was examined. For this study, feasibility included compliance with EMA, usability and acceptability of technology and the measure, and ability of the measure to assess participation. Once initial support of our sampling method was established a third study was conducted. Study 3 was a pilot study that aimed: 1) to examine the construct validity of the participation measure, 2) to examine the feasibility of EMA techniques in a TBI population, and 3) to examine participation outcomes in a TBI population using EMA.

### **1.2.2 Research Questions**

Study 1 examined two research questions. First, does the mPAT have content validity? Secondly, is the developed scoring algorithm reliable? Study 2 examined the feasibility of both using EMA techniques in a TBI population, and the feasibility of using the mPAT to measure participation in order to determine the optimal sampling approach. The research questions were (1) what is the overall compliance? (2) does the compliance change over time? (3) does the measure capture momentary observations of participation? (4) does participation vary over the observation timeframe? (5) are participants satisfied with the application? (6) are participants satisfied with the assessment? and (7) was the application easy to use and learn?

Study 3 was a pilot study focused on further examination of the preliminary psychometric properties of the mPAT, feasibility of EMA in TBI, and participation as assessed by the mPAT in a community dwelling TBI population. The research questions are presented in Table 1.

**Table 1.** Research questions to be addressed by study 3

<b>Construct</b>	<b>Question</b>
Validity	Does the assessment demonstrate construct validity? Does the assessment demonstrate convergent validity? Does the assessment demonstrate discriminant validity?
Feasibility	
Compliance	What is the overall compliance? Does compliance differ by week? Does Compliance differ by time of day?
Usability & Acceptability	Are participations satisfied with smartphone application? Is the application easy to use and learn? Are participants satisfied with the assessment? Is the assessment easy to use and learn?
Participation	What does participation look like for individuals with TBI when assessed utilizing EMA techniques? How do individuals with TBI rate the importance of their participation? How satisfied with their participation are individuals with TBI?

### **1.2.3 Study Significance**

Participation is an important outcome in rehabilitation research and practice (Chung et al., 2014; Cicerone, 2004; Hall et al., 2001; Sander et al., 2012; Perenboom & Chorus, 2003; Noonan et al., 2009; Whiteneck & Dijkers, 2009; Dijkers, 2010; Eyssen et al., 2011). However, available measures may not be able to capture they dynamic nature of the outcome. An ecologically valid picture of participation may provide richer information about the experience of our participants and clients. The development of a measure of participation that utilizes EMA techniques and methodology may be the first step in working toward a better understanding of participation.

Our new measure of participation differs from existing measures in that it assesses participation in the environment in which it is occurring, and does not rely on the individual's

ability to accurately recall his or her previous experience. A previous study conducted by Seekins and colleagues (2007) utilize EMA techniques to assess participation. However, their assessment only provided frequencies of each item, no overall score. Our study proposed to build upon this earlier work. The proposed measure provides a participation score as well as a quantification of importance and satisfaction. This allows investigators and practitioners to compare between individuals, while also taking the individual's personal values into considerations. For example, identifying that an individual has a high frequency of participation but low level of satisfaction may allow us to identify the key elements and potential issues experienced by that individual. The scoring system, through further research, may also allow for the identification of change over time. Ultimately, utilizing EMA techniques to assess participation may increase the ecological validity of our measure and thus enhance our ability to look at the therapeutic outcome in a reliable and valid way.

Therefore, this project has the potential to enhance our understanding of participation. This may give us a better understanding of how often individuals with disability, and in this project specifically TBI, are engaged in participation. Also, because the measure assesses importance and satisfaction we will be able to explore how these may differ from frequency of participation. For example, for one individual participating only a few times a week may result in a high level of satisfaction, but another individual who participates daily may have low satisfaction. For investigators and clinicians, this potential difference may be key in understanding the goals of our participants and clients.

## **2.0 TRAUMATIC BRAIN INJURY, PARTICIPATION AND ECOLOGICAL MOMENTARY ASSESSMENT**

### **2.1 TRAUMATIC BRAIN INJURY**

A traumatic brain injury (TBI) occurs due to an outside force, such as a bump, blow, jolt, or penetrating injury to the head resulting in abnormal functioning of the brain (Centers of Disease Control and Prevention [CDC], 2014). The leading causes of TBI include falls, motor vehicle accidents, external forces such as being struck or the head striking against, and assaults (Langlois, Ruthland-Brown, & Thomas, 2004). The risk for TBI spans the lifetime, with the cause of TBI differing between age groups and gender. For example, falls are the leading cause of injury in young children and older adults, while motor vehicle accidents are the leading cause of injury in adolescents and young adults (Langlois et al., 2004). It is estimated that there are 1.7 million new occurrences of TBI each year, and approximately 5.3 million Americans are currently living with TBI-related disability (Faul et al., 2010; Langlois, Rutland-Brown, & Wald, 2006). While these numbers are high and cause for concern it is believed that TBIs are underestimated (Langlois et al., 2006). TBIs are believed to be underestimated because known estimates do not account for people treated in non-Emergency Department settings (e.g. physician offices), TBIs treated in military facilities are not taken into consideration in population estimates, and some TBIs are undiagnosed due to individuals not seeking care or are

overlooked during treatment for other medical conditions (Langlois et al., 2006). This underestimation may mean that the number of individuals living with a TBI-related disability may be higher than reported.

TBIs are described and categorized in a variety of ways (e.g. open versus closed injury, time of injury and severity of injury). Each of the ways in which TBIs are categorized can tell us an important piece of the puzzle to understanding the injury and the potential long-term impairments, functional limitations, activity limitations, and participation restrictions that the individual may experience in the days and years following the initial injury. However, it is important to note that the mechanism of injury alone does not necessarily indicate the severity of or functional limitations resulting from the TBI or the clinical presentation of the injury (Im, Hibbard, Grunwald, Swift, & Salimi, 2011). Impairments and functional limitations following injury are highly variable, but understanding type and location of injury can inform researchers and practitioners. Therefore, the following section will discuss the various mechanisms of injury.

### **2.1.1 TBI mechanisms of injury**

TBIs may be referred to as open or closed injuries. Closed injuries are those where the skull and lining of the brain remain intact. Open injuries refer to injuries where the intracranial vault is exposed. In regards to timing, injuries are classified as primary or secondary. Primary injuries occur at the time of the injury and are a result of the actual trauma (e.g. contusions, diffuse axonal injury (DAI), rupturing of blood vessels). Secondary injuries occur in the minutes, hours, or even days following the initial trauma, and include compression of brain structures, hypoxia, cerebral edema, and metabolic cellular damage (Im et al., 2011). TBIs can also be described by the type of injury to the brain or its associated features, such as brain contusions, DAI,

intracranial hemorrhages or hematomas, epidural hematomas, subdural hematomas, subarachnoid hematomas, or intracerebral or intraventricular hematomas. These injuries are often the result of coup or contrecoup injuries, shearing forces on the brain as a result of acceleration-deceleration and rotational forces, hemorrhages between the skull and the layers of tissue lining the brain or between the layers themselves, collections of blood within the brain or ventricles of the brain, or skull fractures (Im et al., 2011). The primary symptoms associated with acute TBI include: altered level of consciousness, loss of consciousness, headaches, visual changes, nausea, vomiting, dizziness, confusion, weakness, and difficulties with balance (CDC, 2014).

Acutely, researchers and practitioners can also classify TBIs by severity, with injuries falling into categories of mild, moderate or severe (Saatman et al., 2008). The Glasgow Coma Scale (GCS) is the most commonly used means for classifying TBI severity (Teasdale & Jennett, 1974). The GCS is used acutely to determine the level of responsiveness of a patient (Teasdale & Jennett, 1974). GCS scores range from 3-15, with scores of 3-8 being considered severe, 9-12 moderate, and 13-15 mild (Teasdale & Jennett, 1976). While the GCS score is the most widely and commonly used indicator of TBI severity classification, presence and duration of loss of consciousness and posttraumatic amnesia has also been used (Im et al., 2011). It should be noted that severity based upon the above indices is limited to the acute phase and may not accurately reflect the severity of impairments and functional limitations following the initial injury.

### **2.1.2 Common impairments and limitations associated with TBI**

TBIs may result in of cognitive, behavioral, emotional, and physical impairments and functional limitations (Ponsford, 2013). Common impairments following injury include problems with

memory and learning, attention, communication, fatigue, aggression, impulsivity, depression, irritability and mood lability (Rao & Lykestos, 2000, Dikmen, Machamer, Fann & Temkin, 2010; Olver, Ponsford, & Curran, 1996; Rosenthal, Christensen, & Ross, 1998). These impairments and functional limitations can greatly affect treatment and rehabilitation outcomes following injury. While impairments typically correspond with the location of focal damage, this may be complicated when focal damage occurs to an area of the brain that has a wide-range of connectivity to other areas or in injuries where global damage occurs (Eisenberg, Glueckauf, & Zaretsky, 1999). Injury type and location are not the only factors to consider when examining impairments, pre-injury and unique factors of the individual (e.g. genetics, age, sex, history of depression) may contribute to post-injury manifestations of cognitive, behavioral, emotional and physical impairments (Ponsford, 2013).

The biological and mechanical underpinnings of TBI are vast, and no two injuries are exactly alike resulting in variability in outcomes (Ponsford, 2013). With a variety of cognitive, behavioral, emotional and physical changes following injury, functional deficits can range from severe impairments to milder deficits that may only manifest when the individual is under stress or fatigued (Im et al., 2011). These impairments can lead to changes and restrictions to an individual's frequency and level of participation. The next section will address the construct and outcome of participation in rehabilitation broadly and specifically for individuals following TBI.

## **2.2 PARTICIPATION**

Rehabilitation and disability research and practice has sought to validate and implement the World Health Organization's (WHO) International Classification of Functioning, Disability and

Health (ICF) since its inception in 2001. The ICF conceptual framework provides a common language for understanding, discussing and researching health and health-related states (WHO, 2001). This biopsychosocial model is organized into two parts, including: 1) functioning and disability and 2) contextual factors (WHO, 2001). Within this model, disability arises from the complex interactions of all components, as opposed to previous models where disability was seen as within the person or a product of the environment (Jette, 2006).

Investigators and clinicians are able to measure, investigate, and validate the components of the framework by providing distinct definitions of each dimension. While participation has increasingly become a key outcome in rehabilitation, the conceptual clarity and measurement of participation has been scrutinized (Jette, Haley, & Kooyoomjian, 2003; Jette, Tao & Haley, 2007; Whiteneck & Dijkers, 2009; Magasi & Post, 2010; Dijkers, 2010). The following sections will discuss participation within the ICF, the various definitions of participation, attempts to distinguishing between the ICF components of Activity and Participation, and participation after TBI.

### **2.2.1 Participation within the ICF framework**

The components of the ICF addressing functioning and disability are divided into Body Structures and Functions, Activity, and Participation. While Body Structures and Functions are generally accepted as being clearly defined, there is continued debate as to the clarity of the definition of Participation and its separation from Activity (Whiteneck & Dijkers, 2010). In the ICF, Participation is defined as “involvement in a life situation” and Activity is “the execution of a task or action by an individual” (WHO, 2001). The ICF provides a single classification system

that addresses multiple life areas for the components of Activity and Participation. The classification system is divided into nine areas that include: Learning and Applying Knowledge; General Tasks and Demands; Communication; Mobility; Self-Care; Domestic Life; Interpersonal Relationships; Major Life Areas; and Community, Social, and Civic Life. The use of a single classification system further adds to the confusion of distinguishing between Activity and Participation. The ICF acknowledges that it is difficult to distinguish between these components and offers four ways to use the single classification system (Table 2). The ICF recommends that users make their own decision as to which approach to use when distinguishing between Activity and Participation (WHO, 2001). The first option is a distinct division of the nine domains, while the second allows for partial overlap. The third option classifies broad categories as participation and more detailed categories as activities. The final option is to consider all 9 domains as both components. With such a high degree of ambiguity between the definitions of these key components of the ICF, and multiple ways in which to interpret the provided classification system, investigators and clinicians are left with little direction, which has resulted in a variety of interpretations and a multitude of assessment tools.

**Table 2.** ICF proposed ways to use the activity and participation classification system

ICF Chapters	D1	D2	D3	D4	D5	D6	D7	D8	D9
ICF Description	Learning & applying knowledge	General tasks and demands	Communication	Mobility	Self-care	Domestic life	Interpersonal interactions and relationships	Major life areas	Community, social and civic life
ICF Option 1	Activity				Participation				
ICF Option 2	Activity		Activity & Participation			Participation			
ICF Option 3	TBA	TBA	TBA	TBA	TBA	TBA	TBA	TBA	TBA
ICF Option 4	Activity & Participation								

### 2.2.2 Defining participation

Despite the implementation of the ICF, a universally accepted definition of participation does not exist (Dijkers, 2010). This has resulted in a variety of definitions and interpretations of the definition provided by the ICF. For instance, Perenboom and Chorus (2003) add the importance of autonomy to the ICF definition of participation, stating that an individual to some extent should have control over his/her own life. Whiteneck and Dijkers (2009) define participation as role performance occurring at the societal level. Similarly, Eyssen and colleagues (2011) define participation as the performance of roles requiring a social context. Some believe that participation is distinct from activity, while others believe that activities are blended with or can be added together to make up participation (Noonan et al., 2009; Jette, Tao, & Haley, 2007; Resnik, & Plow, 2009; Eyssen et al., 2011).

With no universal definition of participation and no clear distinction between participation and activity, a debate remains about whether participation and activity should be or can be separated (Resnik & Plow, 2009). Research has attempted to address the ambiguous line between activity and participation. Jette, Haley, and Kooyoomjian (2003) found that within the domain of physical functioning a distinction could be found between activity and participation. However, in a later study, Jette, Tao, and Haley (2007) were unable to replicate earlier findings and suggest that participation and activity are in fact blended and do not need to be viewed separately. Similarly, Post et al (2008) did not find a separation between activity and participation. In his review of participation and empirical work to distinguish between these concepts, Dijkers (2010) suggests that research may be unable to answer this question and perhaps the two are too closely linked. Perhaps the inability of researchers to distinguish between activity and participation not only lies within our conceptual understanding of these constructs, but also within the assessment tools utilized to measure them.

### **2.2.3 Participation in TBI**

Participation is an important outcome following TBI; however, the impairments and functional limitations following TBI can result in long-term care needs and difficulty returning to previously held life roles resulting in participation restrictions (Cicerone, 2004; Brasure, et al., 2013; Ponsford, 2013). The ICF construct of participation and its role as a key outcome of rehabilitation has become prominent in TBI research as it allows a better view into the long-term outcomes of rehabilitation (Chung et al., 2014; Cicerone, 2004; Hall et al., 2001; Sander et al., 2012). Individuals with TBI and their families value the ability to resume previous life roles and activities over the elimination of specific impairments (Cicerone, 2004). Unfortunately,

participation restrictions have been found to remain for years following injury (Sander, Krentzer, Rosenthal, Delmonico, & Young, 1996; Corrigan, Smith-Knapp, & Granger, 1998; Corrigan et al., 2014; Temkin, Corrigan, Dikmen, & Machamer, 2009).

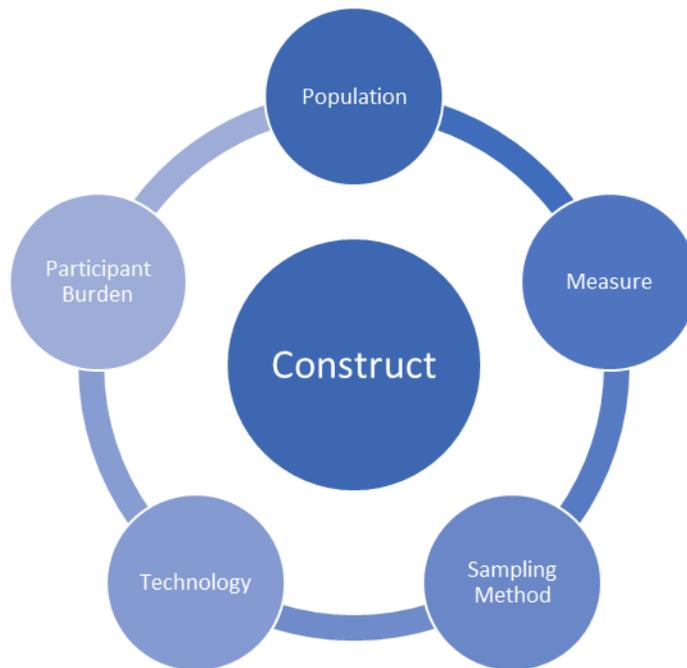
The percentage of those reporting being unemployed and experiencing social isolation is high along with an increased reliance on family for support (Dawson & Chipman, 1995; Ponsford et al., 2012). Only a small percentage of individuals living in the community following TBI report needing assistance with activities of daily living (Dawson & Chipman, 1995). Following a TBI many individuals are unable to resume pre-injury employment, as evident by reported rates of unemployment ranging from 40-50% (Hoofien, Gilboa, Vakil, & Donovan, 2001). The inability to resume, maintain, or procure employment can lead to significant changes in lifestyle, such as decreased socialization and involvement in leisure activities (Tate, Wakim, & Genders, 2014). Tate and colleagues (2014) maintain that the pursuit of leisure activities allow individuals who cannot work to develop meaningful occupation, which can indirectly improve function and mental health as well as improve participation. Also, it is not the amount or frequency of leisure activities that are solely important, but the subjective level of enjoyment and satisfaction experienced by the individual (Ragheb & Griffith, 1982).

### **2.3 ECOLOGICAL MOMENTARY ASSESSMENT**

Ecological momentary assessment (EMA) employs repeated measurement of constructs of interest in the real-world, natural, and multi-contextual environments of the individual (Shiffman et al., 2008). EMA has become an increasingly popular means of assessing a variety of biopsychosocial and health-related constructs of interest, and provides many advantages over

traditional assessments that rely on retrospective self-report and are subject to inaccurate or biased recall. Additionally, EMA techniques can provide a more complete picture of an individual's experience, behavior, or response over time and situations that allow for their generalization to the real-world environment in which the individual lives (Stone, Shiffman, Atienza, & Nebeling, 2007).

EMA techniques allow investigators and practitioners to examine frequency, intensity, duration, trajectory of symptoms, contextual factors linked to monitored events, and the interaction among factors. Ecological rich moments for assessment are typically selected based on the question of interest and the sampling method needed to best address this question (Stone et al., 2007). EMA has been conducted using a variety of sampling methods, using various technologies for assessment administration, and among various populations to measure many different symptoms, behaviors, and outcomes. As shown in Figure 1, there are multiple factors that must be considered when developing a clinical or research assessment protocol that utilizes EMA techniques. These considerations will be discussed in further detail in the following sections.



**Figure 1.** Factors influencing the use of EMA techniques on a construct of interest

### **2.3.1 Conceptual considerations**

When considering assessment of symptoms, behaviors, or outcomes in the real-world environment, one must begin by defining the constructs of interest and identifying valid and reliable approaches to measuring the construct of interest. Many considerations may influence this process. Can the construct of interest be clearly defined? Are there already valid and reliable methods for assessing this construct? What is the impact of frequent, repeated assessments obtained through EMA modalities (e.g. diaries, mobile phones)? Is the construct of interest best measured through physiological or environmental sensors or through report from the individual or caregiver? If a new assessment is designed, should it be modeled off existing valid and reliable assessments? New assessments should be studied to determine their reliability and validity when delivered using EMA techniques. This validation process can be completed by examining

content validity, criterion validity, and construct validity of the newly developed assessment in accordance with the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN; Mokkink et al. 2009). . Assuming that existing assessments remain valid and reliable when administered via an EMA approach can be a mistake, particularly when the method in which the assessment is delivered can alter established psychometric properties of the original measure. Therefore, the psychometric properties of even established assessments should be reevaluated when the assessment approach is changed from the original approach (Stone et al., 2007).

Existing research examining EMA has taken varied approaches to these conceptual considerations. For instance, Juengst and colleagues (2015) examined the use of EMA via a smartphone application to assess mood related symptoms in a TBI population utilizing existing measures. The measures were delivered via EMA techniques on a smartphone application and through traditional methods (clinician interview on a biweekly basis). Researchers found a high degree of correlation between EMA delivered and traditionally delivered measures (Juengst et al., 2015). However, some investigators have found a low degree of correlation between EMA and traditionally delivered measures (Stone et al., 1998). It is possible that because EMA addresses some of the weaknesses of traditional retrospective reports (e.g. reliance on recall ability and accuracy) that this low correlation between measures does not mean that EMA delivered measures are inadequate, but perhaps these measures are better able to assess a dynamic construct than traditionally delivered measures.

### **2.3.2 Sampling methods**

EMA techniques allow investigators and practitioners to employ many approaches to data sampling. These include event-based, time-based, or a combination sampling method. The sampling method one uses should be driven by the nature of the construct of interest and the purpose of the assessment. Event-based sampling is when an event (e.g. headache) triggers the completion of an assessment or logging of the event. Event-based sampling therefore lends itself toward efficaciously assessing discrete events (Stone et al. 2007). There are advantages to event-based sampling compared to traditional retrospective assessments that typically ask participants to report an average number of times the event has occurred. Using an event-based sampling strategy allows measurement of discrete events in relatively close proximity to the time the event occurs. Event-based sampling strategies can be employed to track the frequency and duration of complex secondary conditions like post-traumatic headaches as well as what strategies were used to stop the headache (e.g. medication, sleep, meditation). Participants can report the onset of a headache and what they are doing to cope with the headache as well as report when the symptoms terminated. Event-based sampling methods are limited, specifically in TBI, as the investigator or practitioner relies on the participant to initiate completion of assessments, which may leave assessment findings vulnerable to bias with either under or over reporting of events. Furthermore, if the event occurs frequently, requiring multiple entries throughout a single day, this could become burdensome to participants, which may result in low compliance rates.

Time-based sampling allows investigators and practitioners to predetermine the moments of assessment and manipulate assessment time and frequency to address the nature of the construct of interest. Time-based sampling methods typically occur at fixed or random times, and as such lend themselves towards use in assessing continuous constructs that may vary in intensity

(Stone et al., 2007). Also, investigators and practitioners can employ a coverage or sampling strategy when assessing via time-based sampling. Coverage strategies ask participants to average or report on symptoms or behaviors over the entire day or from the last assessment time point (Stone et al., 2007). Sampling strategies are typically randomly scheduled and the assessment is aimed at assessing that particular moment (Stone et al., 2007). By scheduling or predetermining moments for assessments, investigators and practitioners may learn a variety of information about the symptom or behavior being assessed (e.g. does emotion vary by time of day, are individuals more likely to experience an onset of a headache while at work). However, time-based sampling may miss symptoms or behaviors that do not occur relatively close to the time of assessment.

Combination sampling methods include: 1) event-based or time-based sampling combined with an end of day assessment; 2) event-based sampling combined with time-based random sampling; and 3) time-based sampling that follows an event (Stone et al., 2007). Definitions and examples of each combination sampling method are provided in Table 3. A combination sampling approach allows the investigator or practitioner to address complex questions, and in some instances reduce participant burden. Thus, by combining event-based sampling with time-based random sampling, participants are not asked to complete an assessment at each log of an event. For example, if the question of interest is evaluating coping strategies used when stress is experienced, we would ask participants to log each time they experience stress, but instead of assessing coping at every event we would randomly select reports to complete further assessment.

**Table 3.** Combination sampling methods and examples

Sampling Method	Example
Event or time-based with end of day	Recording headache (event) at onset and assessing overall impact of pain on individuals ability to perform daily activities (end of day)
Event-based with random time-based	Recording alcohol consumption (event) with random assessment of emotion
Time-based following event	Track onset of headache (event) as they occur and assess feelings of stress (time-based) every day, three times per day

End of day assessments allow us to ask participants to average experiences (e.g. how much time did you spend working today), which could be used to determine if end of day reports are similar to those assessments given throughout the day. An example of event-based sampling combined with time-based sampling that reduces participant burden might involve participants in a study examining stress and coping strategies being asked to respond to randomly scheduled assessments of stressful events, and if a stressful event was reported, coping could also be assessed (Stone et al., 1998). If coping was assessed using only time-based sampling, use of coping strategies may be missed if they did not occur relatively close in time to the assessment.

### **2.3.3 Technology**

EMA studies have reported using many different types of technologies (e.g. paper and pencil journals, telephone calls, personal digital assistants [PDAs]). More recently, studies have taken advantage of readily available commercial technologies. For instance, in some studies, participants were loaned PDAs that were programmed to prompt participants to complete daily

assessments; in other studies, participants were loaned answer-only cell phones on which investigators contacted participants via phone calls (Silk et al, 2011; Husky et al., 2014; Anestis et al., 2010). Some studies have used PDA technologies as “reminder” and “motivator” tools and as a memory aid to increase activity participation and independent behaviors among those with TBI (Depompei et al, 2008; Dowds et al., 2011; Stapleton, Adams, & Atterton, 2007).

Advances in technology, such as cell phones and smartphones, have allowed researchers, in populations other than TBI, to employ more complex and technologically driven methods of employing EMA techniques. In one study, participants with autism were loaned cell phones with a specially designed program to administer modules of questions (Khor, Gray, Reid, & Melvin, 2014). Participants were prompted to complete assessments in the program through text messaging (Khor et al., 2014). Another study reported on the development of a smartphone application that participants were able to download on to their personal cell phones (Runyan et al., 2013). Researchers were then able to send notifications to participants through the application to alert them to complete daily assessments. By utilizing commonly available technology, such as an individual’s own smartphone, researchers can reduce the amount of training necessary when compared to providing participants with a novel device. Additionally, participant burden may be reduced when participants are able to utilize personal technology and are not required to carry an additional device.

There are multiple issues that one must consider when selecting a device for EMA administration: 1) how the assessments will be presented on the device; 2) how suitable the device is to deliver the assessment in a valid manner; 3) data transport and security; 4) the ability to complete time-based tracking of longitudinal data; 5) the sampling schedule planned for the assessments selected; and 6) the ability to set reminders and other features that enhance

compliance with EMA data collection (Stone et al., 2007). Additional technology considerations are particularly relevant with regard to how these variables may be influenced by cognitive or behavioral impairments associated with TBI. For instance, instructions on how to complete assessment questions should be clearly presented with the questions, allowing participants to review before completing the assessment. Likewise, navigation to the assessment questions should be simple, and participants should be able to quickly access assessment questions without navigating through multiple steps. There should be no additional wording, design, or functionality that may be distracting for participants. How assessments are presented on the device may influence the veracity of the data to be collected and user perceptions about the assessment which may influence data collected. For those with TBI, having devices with the ability to provide reminders to complete assessments may be crucial to ensure compliance, due to a high rate of memory and planning limitations associated with TBI.

#### **2.3.4 Methodological considerations**

EMA allows for the collection of real-time data in the participant's natural environments; however, in doing so, the burden of assessment completion is more firmly placed on the participant. As such, methodological considerations of participant burden and compliance must be addressed. As discussed previously, the technology used to deliver EMA may contribute to or reduce participant burden. When appropriate, investigators and practitioners should use the participant's own device or a device that is easily carried and requires minimal training. The interface that exists between the device and EMA delivery method (e.g. smartphone application) should be easily navigated and operated. Participant burden may also be influenced by how long the sampling will last (e.g. one week, one month), frequency of assessment (e.g. once per day,

four times per day), and duration of assessment. Competing with participant burden is the construct of interest and the purpose of the assessment. Accurately assessing the construct of interest through valid measures is important, but investigators and practitioners should find a balance between accurately assessing the construct of interest and minimizing participant burden.

The type of questions being asked can heavily influence methodological consideration decision process. For example, asking participants to complete an assessment composed of 20 open-ended questions five times a day for one week may be too burdensome for many populations, while asking them to complete an assessment of 20 Likert scale questions at the same frequency and time-frame maybe more manageable. Time-frame length, in combination with frequency and duration, should also be considered. As previously stated, the construct and purpose of the assessment must still be considered. For instance, to accurately capture a construct like mood, which typically does not fluctuate from day to day, a longer sampling time-frame may be necessary. Fatigue, on the other hand, may be more susceptible to variation in a shorter time-frame, and this construct may be more easily captured using brief assessment tools. When selecting a tool, the time-frame for which it has been validated should be considered when deciding if it can be employed via EMA techniques and may require additional validation. For instance, a tool such as the Patient Health Questionnaire 9 (PHQ-9) is a validated measure of depression symptoms that ask the individual to report the frequency of symptoms over the past two weeks (Kroenke, Spitzer, & Williams, 2001). If the tool is given more frequently via EMA techniques, revalidation may be necessary.

The methodological considerations of participant burden directly relate to compliance rate, or the participant's accurate and timely completion of assessments. Compliance could be affected if the technology used is too complicated or a burden to carry. Similarly, length of

sampling and frequency and duration of assessments may impact compliance. High frequency and duration of assessments over a long sampling time-frame may result in a low or fluctuating compliance rate over time. Therefore, while again it is important for investigators and practitioners to consider the construct of interest and the purpose of the assessment, the population of interests and any associated characteristics that may impact compliance should also be considered. For individuals living in the community following TBI, a complex sampling schedule or testing construct, as well as carrying a new or additional device, may impact compliance for those with cognitive or behavioral dysfunction. Likewise, a high frequency and duration of assessments may interfere with participation in daily activities, such as school and work, resulting in lower compliance.

Similar to the methodological considerations of participant burden and compliance are considerations of the population being assessed. Investigators and clinicians should consider if there are unique characteristics of the population that may influence the measure to be used, technology, sampling method, or degree of acceptable participant burden?

### **2.3.5 EMA in TBI**

Long-term outcomes following TBI are highly heterogeneous, with no two individuals experiencing the same impairments, functional limitations, or recovery patterns. EMA techniques, paired with current standards of assessment and care, may enhance our understanding of TBI-related disability and the impairments and functional limitations associated with it, as well as help to guide our approaches to treatment, rehabilitation, and supportive services, by providing a more ecologically-based picture of individuals with TBI. However,

there are very few studies addressing the use and feasibility of employing EMA techniques in TBI.

Current research has focused on symptom and behavior tracking following mild TBI (m-TBI) and concussion, leaving questions about the applicability of EMA techniques in more severely injured and chronic populations (Lewandowski, Rieger, Smyth, Perry, & Gathje, 2009; Suffoletto et al., 2013; Smith et al., 2012). Furthermore, much of the research has employed the assessment of participants at multiple time points each day for only a short-time frame (Lewandowski et al., 2009; Suffoletto et al., 2013). For example, Lewandowski et al. (2009) examined the feasibility of EMA, administered via PDA devices, to collect symptom data in adolescents following concussion five times per day for five days. They found that it was easy to teach adolescents to use the new technology; the system was manageable in the school setting, and the compliance rate was high with participants completing 93.3% of assessments (Lewandowski et al., 2009). However, despite positive findings, it is questionable as to whether this approach would be sustainable over a longer time period, as many of the outcomes important for follow-up after TBI may require longer tracking in order to gain a true picture. One study examined the feasibility of using mobile technology to collect data in both active and follow-up phases of treatment for veterans receiving care for post-traumatic stress disorder and m-TBI. This study tracked participants for a longer time frame (up to 60 days), but the study was conducted in a controlled treatment environment, as opposed to the community and participants were only assessed once per day (Smith et al, 2012). Researchers found that when assessments were randomly assigned, the compliance rate was 23%, but when assessments were done as part of a treatment group, the compliance rate increased to 89% (Smith et al., 2012). Similar to the length of tracking, some constructs may need to be assessed multiple times a day.

In order to address the unique needs of individuals with TBI, future research should address feasibility of EMA techniques among individuals with moderate to severe injuries, particularly those with more severe cognitive impairments. For example, deficits in accurate self-awareness in persons with TBI might confound the validity of self-report, regardless of the assessment method. Alternatively, for those with memory impairment, delayed recall impairments would be expected to be improved using an EMA approach. Preliminary data suggest that conducting EMA to evaluate emotional symptoms after complicated mild to severe TBI via a smartphone application is feasible (Juengst et al., 2015). In this study, participants were able to complete 73.4 percent of prompted daily mood assessments using a smartphone based EMA over an eight week period. Furthermore, because much of the current research to date has utilized short time frames for active tracking, participant burden with number of assessments per day and length of active tracking should also be examined.

## **2.4 SUMMARY**

There has been an increasing focus on the measurement of participation as a health, disability and rehabilitation outcome (Perenboom & Chorus, 2003; Noonan, Kopec, Noreau, Singer, & Dvorak, 2009; Noonan et al., 2009; Whiteneck & Dijkers, 2009; Dijkers, 2010; Eyssen et al., 2011). Current measures of participation remain relatively static despite the dynamic nature of participation (Crews & Campbell, 2001). Individuals are typically asked to average their rates of participation over extended periods of time rendering these reports subject to recall and reporting error. The static nature of current measures and report of average rate of participation

may not provide investigators and clinicians with a true picture of participation in individuals living in the community with disability.

Ecological momentary assessment (EMA) has been identified as a means of assessing a variety of biopsychosocial and health-related constructs of interest (e.g., smoking cessation, mood, anorexia). EMA employs the repeated measurement of a construct of interest in the real-world, natural, and multi-contextual environments of the individual (Shiffman et al., 2008). EMA has many advantages over traditional assessments that rely on retrospective self-report and are subject to inaccurate or biased recall. Individuals may inaccurately recall experiences over extended time intervals about previous weeks or months, often resulting in reporting error. However, because EMA focuses on assessing the current state, moment, or trait in the real-world, these techniques can minimize reliance on retrospective self-report, while enhancing ecological validity (Shiffman et al., 2008). EMA techniques allow investigators and clinicians the ability to obtain a more complete picture of an individual's experience, behavior, or response over time and situations that allow for their generalization to the real-world environment (Stone et al., 2007). Application of EMA techniques to the assessment of participation may allow investigators and clinicians to reduce the limitations of traditional assessments and provide a more accurate and complete picture of participation in individuals living in the community with disability.

One population that may benefit from the use of EMA techniques to examine participation is individuals with traumatic brain injury (TBI). There are approximately 5.3 million individuals living with TBI-related disability (Faul et al., 2010; Langolis et al., 2006). The trauma associated with TBI is only the beginning of an ongoing process that impacts multiple domains of an individual's health and well-being (Masel & DeWitt, 2010). TBI is often

viewed as an event that has transient effects or is readily treatable, requiring only time-limited services. However, for many, TBI is a chronic disease requiring long-term care and treatment (Masel & DeWitt, 2010). Many experience limitations with work and daily activities as a result of TBI-related disabilities, as well as biological and cognitive issues that often require continued medical care, rehabilitation services and supports (Zaloshnja, Miller, Langlois, & Selassie, 2008). These long-term impairments and limitations associated with TBI may significantly impact an individual's ability to participate in life-roles.

Rehabilitation of chronic disease and disability, including TBI, spans a continuum of care from acute inpatient care to services such as vocational rehabilitation that can be provided years following injury or diagnosis. The goal of rehabilitation, regardless of when and for whom it is happening, is to improve the individual's participation in his or her environment (WHO, 2001). However, investigators and clinicians often struggle with assessing this outcome in an ecologically valid manner. Many of the traditional assessments used in the rehabilitation field are performed in clinical or simulated environments as opposed to the environments in which the individual lives and functions. EMA is a unique assessment approach for ensuring ecologically relevant assessments that may address the limitations of current participation measures. Because EMA focuses on the current state, moment, or trait, thus reducing the individual's need to recall or average an experience over an extended period of time, it may be especially useful in the assessment of individuals living in the community following TBI.

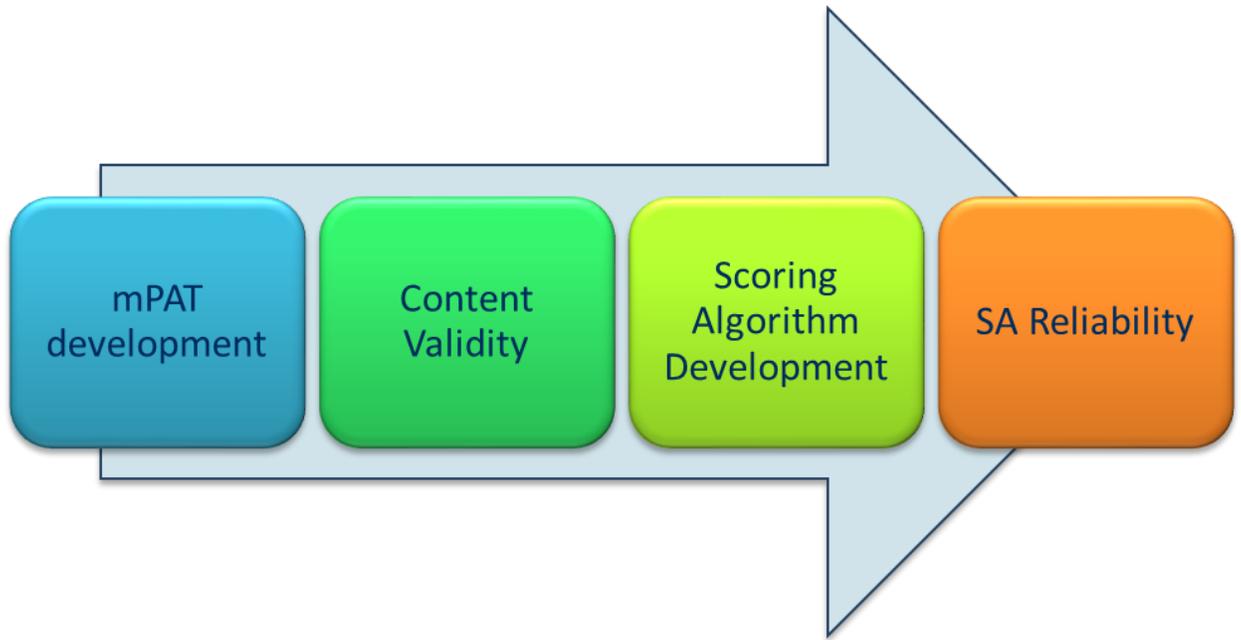
### **3.0 STUDY 1 DEVELOPMENT, VALIDITY AND RELIABILITY OF THE MOBILE PARTICIPATION ASSESSMENT TOOL AND SCORING ALGORITHM**

Many individuals experience participation restrictions following a TBI, due to the impairments and functional limitations associated with the injury (Cicerone, 2004; Brausre, et al., 2013; Ponsford, 2013). As a result participation has become an important long-term TBI outcome for investigators, clinicians, and individuals with TBI and their families (Chung et al., 2014; Cicerone, 2004; Hall et al., 2001; Sander et al., 2012). Reviews of available measures of participation, including those commonly used in TBI research, have found that current measures have a variety of issues, such as variations between operational definitions of participation, assessment of different domains of participation, and many rely on retrospective self-report (Noonan et al., 2009; Magasi & Post, 2010; Chung et al., 2014). The reliance on an individual's ability to accurately, retrospectively self-report may be a concern for individuals following TBI, for whom cognitive impairment is common (Ponsford, 2013). EMA, which employs the repeated and real-time measurement of constructs of interest, may be a means of improving the assessment of participation after TBI (Shiffman et al., 2008).

The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist was developed to provide taxonomy, terminology and definitions of measurement properties for health related patient-reported outcomes (HR-PROs; Mokkink et al., 2010b). The COSMIN checklist can be used to evaluate the methodological quality of studies, as

well as be used by researchers in the design of studies developing new instruments (Mokkink et al., 2010a). The checklist consists of twelve boxes, nine of which contain the following standards for measurement properties: internal consistency, reliability, measurement error, content validity, structural validity, hypothesis testing, and cross-cultural validity (Mokkink et al., 2010a). The overarching objective of this study was to develop and validate a new tool aimed at assessing participation utilizing EMA techniques in individuals with TBI. As such, we aimed to follow the COSMIN recommendations on terminology and research design to the extent it was appropriate for the scope of this project (Mokkink et al., 2009).

The development of a measure of participation to be delivered using EMA techniques requires many phases of examination to ensure that it is a reliable, valid and feasible assessment of participation. The first study, which will be discussed in this chapter, includes four phases, as seen in Figure 2. Phase 1 was the development of the measure, the Mobile Participation Assessment Tool (mPAT). Phase 2, was the examination of the measure's content validity. The development of a means of quantifying the assessed construct constituted phase 3. Finally, phase 4 was the examination of the reliability of developed quantification mechanism. Therefore, the specific aims of this study were (1) to develop a measure of participation to be delivered via EMA, (2) to examine the content validity of the measure, (3) to develop a scoring algorithm to quantify participation, and (4) to examine the preliminary reliability of the developed scoring algorithm.



**Figure 2.** Progression of phases for study 1

### **3.1 DEVELOPMENT OF THE MOBILE PARTICIPATION ASSESSMENT TOOL**

The Mobile Participation Assessment Tool (mPAT) was developed to assess participation via EMA techniques in individuals with TBI. The methodological framework for developing the mPAT included the following steps: (1) review of participation literature and existing measures, (2) defining participation, (3) item development, (4) item response generation, and (5) developing instructions for completing the tool. To meet the study aim of developing a new measure the methodology employed by the research team is detailed below.

### **3.1.1 Methodology**

#### **3.1.1.1 Literature review**

As a first step, a review of participation literature, participation measures, and specifically those measures commonly used in TBI research was performed. Participation was first reviewed in the context of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF; 2001). The ICF defines participation in regards to an individual's "involvement in a life situation" (WHO, 2001). This definition, and the conceptual clarity and assessment of participation has been criticized, specifically for the difficulty in distinguishing participation from the ICF component of activity (Jette, Haley, & Kooyoomjian, 2003; Jette, Tao, & Haley, 2007; Whiteneck & Dijkers, 2009; Magasi & Post, 2010; Dijkers, 2010).

Despite the implementation of the ICF, which provides a common language for understanding and research health and health-related states, there is no universally accepted definition of participation (WHO, 2001; Dijkers, 2010). As a result, there are numerous interpretations of the ICF's definition of participation (Perenboom & Chorus, 2003; Whiteneck & Dijkers, 2009; Eyssen, et al., 2011). Furthermore, with no universally accepted definition, a large number of instruments to assess participation have been developed (Whiteneck & Dijkers, 2009). Therefore, the next step in development of the mPAT was a review of available measures of participation, and specifically those commonly used in TBI.

Several reviews of participation measures have been conducted (Perenboom & Chorus, 2003; Resnik & Plow, 2009; Noonan et al., 2009; Magasi & Post, 2010; Eyssen et al., 2011; Seekins et al., 2012; Chung et al., 2014). However, these reviews differ in how participation is defined, and as such the number of measures identified, how they were evaluated and their conclusions differ. A summary of the reviews of participation that were evaluated is provided in

Table 4, including (1) the definition of participation used to identify and evaluate measures, (2) the number of measures identified and evaluated, and (3) the overall conclusions of the review.

**Table 4.** Summary of reviews of participation measures

Citation	Definition of Participation	Measures Identified	Measures Evaluated	Conclusion
Perenboom & Chorus, 2003	ICF – “participation is the involvement in life situations, which includes being autonomous to some extent or being able to control your own life, even if one is not actually doing something themselves” (pg. 578)	11	9	Evaluated measures assess one or more domains of participation and activity, but none assess all domains.
Resnik & Plow, 2009	ICF – Chapters 1-9	40	34	Five measures contained items relating to all 9 domains of activity and participation in the ICF. Comprehensive measures did not only assess participation, but also activities, impairments, personal, and environmental factors.
Noonan et al., 2009	ICF – Chapters 3-9	8	8	Measures differ in how participation is operationalized.
Magasi & Post, 2010	ICF	8	8	Measures have strong conceptual foundations and psychometric properties but are not equivalent because each represents different domains of participation.

**Table 4. (continued)**

Eyssen et al., 2011	“Performing roles in the domains of social functioning, family, home, financial, work/education, or in a general domain” (pg. 984)	112	103	Few measures assess only participation and do so to a limited extent. The majority of measures assess participation as well as other constructs such as activity or impairment.
Seekins et al., 2012	“Involving a person fulfilling social roles; programs to promote such participation; or judgments, measures, or assessments of the quality or quantity of the form, duration, intensity, richness, or variety of activates involved in fulfilling social roles” (pg. 225)	67	67	Of the 67 measures identified, only 23 cited the ICF as the foundation for development. Participation requires a dynamic assessment approach.
Chung, Yun, & Khan, 2014	ICF – Chapters 7-9 and ‘assisting others’ from Chapter 6	101	9	Defining participation continues to be a challenge and thus instruments developed to assess this construct differ.

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One review of participation measures, using the ICF as a guide, found that even the most comprehensive measures of participation did not exclusively measure this construct, but also measured aspects of activities, impairments and contextual factors (Resnik & Plow, 2009). Likewise, Noonan et al (2009) found in a review of participation measures that while the ICF attempts to provide an objective means of evaluating measures, there is a great discrepancy in the operationalization and measurement of participation. Another review found that most measures are limited in the extent to which they measure participation (Eyssen et al., 2011). After

completing a review of existing measures of participation, Magasi and Post (2010) recommend the following as guidance for investigators and clinicians in identifying an appropriate measure: (1) individuals should determine how they define participation, (2) what aspect they are most interested in measuring, and (3) what level of specificity do they need to measure participation.

In general, these reviews state that participation is an important rehabilitation outcome, and the lack of agreement upon an operational definition of participation has resulted in a number of developed measures. In addition to utilizing differing definitions of participation, many of the reviews found that the identified measures also differ by what domains of participation are being assessed (e.g. work, social involvement, leisure). Furthermore, many of the identified measures of participation do not solely assess participation, but other constructs such as activity and impairment. The differences in how participation is defined and what domains are being assessed results in the inability of investigators and practitioners to compare outcomes between measures. A consensus on the definition is needed in order to develop a measure that solely assesses participation; however, this may not be possible until we reach a better understanding of the difference and interaction between activity and participation. Perhaps knowing what someone is doing (activity) and the environmental and social context in which they are doing it will lead to a better conceptualization of participation.

One of the identified reviews of participation specifically compared participation measures frequently utilized in TBI research using the ICF TBI core set (Chung et al., 2014). The following nine instruments were identified as being utilized in at least two TBI studies: Community Integration Questionnaire (CIQ), Craig Handicap Assessment and Reporting Technique (CHART), Mayo-Portland Adaptability Inventory – 4 Participation Index (M2PI), Sydney Psychosocial Reintegration Scale Version – 2 (SPRS-2), Participation Assessment with

Recombined Tools – Objective (PART-O), Community Integration Measure (CIM), Participation Objective Participation Subjective (POPS), Community Integration Questionnaire-2 (CIQ-2), and Quality of Community Integration Questionnaire (QCIQ) (Chung et al., 2014). Characteristics of these instruments are provided in Table 4. Chung and colleagues (2014) concluded that although the instruments are intended to measure participation, over one-third of the categories that were linked to the ICF core set were considered activities rather than participation. This may be a result of the lack of consensus regarding the definition of participation, as even when instruments are developed utilizing the ICF’s definition of participation the interpretation can vary.

**Table 5.** Characteristics of frequently used participation instruments for TBI research

<b>Instrument</b>	<b>Abbreviation</b>	<b>Citation</b>	<b>Approach to assessment</b>	<b>Domains</b>
Community Integration Questionnaire	CIQ	Willer et al., 1993	Frequency Type of assistance	Integration to productive activities Social integration
Craig Handicap Assessment and Reporting Technique	CHART	Whiteneck et al, 1992	Frequency	Cognitive independence Physical independence Mobility Occupation Social integration Economic self-sufficiency
Mayo-Portland Adaptability Inventory – 4 Participation Index	M2PI	Malec, 2004	Difficulty Impact/extent of disruption	Initiation Self-care Social contact Recreation Employment Transportation Household management Financial management

**Table 5. (continued)**

Sydney Psychosocial Reintegration Scale Version – 2	SPRS-2	Tate et al, 2011	Impact/extent of disruption Difficulty	Occupation activities Interpersonal relationships Independent living skills
Participation Assessment with Recombined Tools – Objective	PART-O	Whiteneck et al., 2011	Frequency	Productivity Social relations Out and about
Community Integration Measure	CIM	McColl et al., 2001	Perceived limitations Satisfaction	General assimilation Social support Occupation Independent living
Participation Objective Participation Subjective	POPS	Brown et al., 2004	Duration Frequency	Domestic life Interpersonal interactions & relationships Major life areas Transportation Community, recreational & civic life
Community Integration Questionnaire-2	CIQ-2	Johnston, 2005	Frequency	Home integration Social integration Productive activity
Quality of Community Integration Questionnaire	QCIQ	Cicerone et al., 2004	Satisfaction	Home integration Social integration Productive activity

The domains assessed in these commonly used instruments (e.g. home and social integration, productive activity, cognition, mobility, self-care, occupation, level of support, civic life) vary across instruments. This means that participation outcomes across instruments are difficult to compare. For example, the CIQ domains include home integration, social integration,

and integration into productive activity, while the PART-O domains include productivity, social relations, and “out and about” (Willer et al, 1993; Whiteneck et al, 2011). While some overlap exists between domains measured, it would be difficult for investigators and practitioners to compare outcomes on these instruments as both measure different aspects of participation. Similarly, how participation is being measured (e.g. frequency of participation, change in participation since injury) and by whom (e.g. individual self-report, caregiver report, medical or rehabilitation staff report) differs between instruments. Finally, the time frame and setting of assessments differ between instruments. For instance, the PART-O asks individuals to average their rate of participation over various time frames (e.g. typical week, typical month, last 3 months), while the SPRS-2 does not provide a time frame but asks individuals to rate their level of participation. Both of these approaches, like many used in participation measures, rely on the individual’s ability to recall and/or average their participation from past experience. Additionally, the measures are often given in clinical or research environments and do not take into account the contextual information that may influence participation or the reporting of participation. The utilization of EMA techniques and methodologies may allow researchers and practitioners to minimize some of the current limitations associated with available instruments.

A review was conducted to identify previous research that had examined the EMA of participation. One study was identified. Seekins and colleagues (2007) utilized EMA to measure participation as an outcome of a larger project. They assessed location, activity, social contact, environmental barriers and facilitators, secondary conditions, and ratings of community connectedness and fulfillment (Seekins, Ispen, & Arnold, 2007). The sample consisted of five individuals with differing disabilities or health conditions (Seekins et al., 2007). Participants were prompted six times per day for a one week period, over seven different weeks during a nine

month period. Participants responded to 92.7% of prompts; however, participants were only considered to have full compliance, defined as completion of the participation survey within 30 minutes of the prompt, for 77% of the prompts (Seekins et al., 2007). Results of the survey of participation, found participants spent a majority of their time at home, engaged in social or leisure activities, and spent a large part of their time alone. The study reported that it supported the feasibility of EMA to measure participation (Seekins et al., 2007). This research was a first step in understanding participation within the context of EMA; however, the research did not focus on one population of interest and did not attempt to produce a meaningful score of participation. We aimed to build upon this work in our project by combining the information gleaned from the above literature review and our understanding of EMA techniques and methodologies.

### **3.1.1.2 Defining participation**

Defining participation for the purpose of the mPAT was the next step in the developmental process. Based on the review of literature and available definitions of participation, we determined that despite the criticism of the ICF definition of participation that as rehabilitation science investigators and clinicians it is important to support the ICF as a conceptual framework. Therefore, the proposed definition of participation for the mPAT builds upon the ICF's definition, and states that participation is defined by the dynamic relationship between an individual's involvement in an activity and the environmental and social context in which it occurs. This definition is in line with those proposed by Whiteneck and Dijkers (2009) and Eyssen and colleagues (2011) that maintain that participation occurs at the societal level (environmental context) and within a social context. Additionally, for the purpose of this study, activity is defined as engagement in an act, or what the individual is doing in the moment of

assessment. Environmental context is defined as where the individual is during the activity, and social context is defined as who the individual is engaging with during the activity.

### **3.1.1.3 Sampling method**

The next step in developing a measure to be delivered using EMA techniques and methodologies is determining the most effective sampling methods. Choosing a sampling method should be driven by the construct and the intended population. While participation may seem to consist of discrete events, which are typically best assessed using event-based sampling, it can also be continuous and may vary in frequency (Stone et al., 2007). For example, working could be considered both a discrete event, happening once in a day, and also continuous, occurring for many hours in a day. Additionally, other forms of participation (e.g. socializing and working) may occur at the same time. While event-based sampling could be used to assess participation, this approach relies on the individual to initiate completion of assessments, which may leave assessment findings vulnerable to under or over reporting of events. Likewise, participant burden could be increased if frequency of participation is high. Additionally, event-based sampling requires the individual to have a clear understanding of the construct being measured in order to accurately and reliability report.

Time-based sampling, which has been shown to be feasible in TBI, allows investigators to control assessment frequency and duration in order to capture observations of the construct of interest (Juengst, et al., 2015; Stone et al., 2007). Sampling strategies that utilize randomly scheduled assessments aimed at assessing that particular moment can also be used in time-based sampling (Stone et al., 2007). Anchoring the individual's response to the moment of assessment may reduce the likelihood of recall bias and inaccurate reporting. Additionally, this approach may allow us gain insight into the frequency and variability of participation over time and

throughout the day. Therefore, the mPAT was designed to use a time-based sampling approach that incorporates sampling strategies of scheduled and time-anchored assessments of participation.

#### **3.1.1.4 Item development**

The next phase in mPAT development was the generation of an item pool. Because the mPAT would be delivered via a time-based sampling approach that incorporates a sampling strategy the pool of items should be small and provide a list of responses to reduce participant burden. Providing a list of responses would also allow us to have consistency across observations made using the mPAT, and allow for the development of a standard scoring method. Additionally, predetermined responses may be best for the intended population, as it would reduce the cognitive load placed on the individual. Finally, the item pool should be reflective of the definition of the construct. Additionally, the research team determined that individuals could be engaged in more than one activity or person, and that their location may be best described with more than one response. Therefore, the mPAT items allowed for selection of more than one response.

Items were developed to be reflective of the definition of participation discussed in section **3.1.1.2 Defining participation**. The initial version of the mPAT consisted of four items: *activity*, *location*, *surrounding people*, and *satisfaction* with participation. Item wording is presented in Table 6. Each item is time anchored to the moment of assessment. This means that respondents should answer for the moment they are responding to the measure.

**Table 6.** Item wording for mPAT version 1

<b>Item</b>	<b>Question</b>
Activity	What are you doing at this moment? (select all that apply)
Location	Where are you at this moment? (select all that apply)
Surrounding people	Who are you with at this moment? (select all that apply)
Satisfaction	How satisfied are you with what you are doing right now?

### **3.1.1.5 Item Responses**

As discussed above, the mPAT was developed to have a response list for each item that would allow individuals to select the appropriate response or responses for each question. Possible responses for the items of *Activity*, *Location*, and *Surrounding People* were primarily developed based upon the nine ICF chapters provided for the classification of activity and participation: Learning and Applying Knowledge; General Tasks and Demands; Communication; Mobility; Self-Care; Domestic Life; Interpersonal Relationships; Major Life Areas; and Community, Social, and Civic Life (WHO, 2001). Item responses were generated using the ICF classification system so that the mPAT will be consistent with the ICF framework. Additionally, the Participation Assessment with Recombined Tools – Objective/Subjective (PART-O/S) was also used to format language of responses for items as it is a measure of participation validated in our intended population (Whiteneck et al., 2011). The satisfaction item asks the individual to rate their level of satisfaction with their participation in the moment. A list of potential responses for each item was developed using both the ICF and PART-OS as a reference. The pool of potential responses was reviewed and approved by each member of the research team. The mPAT version 1 is located in Appendix A.

### **3.1.1.6 mPAT instruction development**

To ensure that responders would understand how to complete the mPAT the research team developed instructions for responding. Instructions were developed to inform responders (1) how the tool would be delivered, (2) when to complete the tool, and (3) how to respond to questions. The initial instructions developed for the mPAT are available in Appendix A.

### **3.1.2 Summary**

The mPAT version 1 (Appendix A) is the primary outcome of this stage of development. It was developed to measure participation following TBI using EMA techniques and methods. The mPAT version 1 consisted of four time anchored items, developed to assess participation as defined by the ICF and the result of our review of participation literature. Time anchoring of questions allows for the repeated assessment of the construct and supports the sampling approach the researchers determined would be most effective for assessing participation and reducing the burden on responders. Additionally, the possible responses for each item were developed using ICF language and that used in an existing measure of participation used in the intended population. The next step is examining the preliminary psychometric properties of the tool, specifically content validity.

## **3.2 CONTENT VALIDATION OF THE MOBILE PARTICIPATION ASSESSMENT TOOL**

A critical factor in selecting and developing an instrument is its validity (Mokkink et al., 2010a). An instrument is valid when it measures what it is intended to measure (Lynn, 1986). Specifically, content validity is the degree to which the instrument is an acceptable reflection of the construct of interest (Mokkink et al., 2009). The concept of content validity holds that all elements of the construct to be measured must be represented in the instrument and that irrelevant factors should have no influence on the instrument (Portney & Watkins, 2009). Therefore, the second aim of this study was to assess the content validity of the mPAT. The relevance of items and comprehensiveness of item responses were examined by a group of experts, which included experts in the field of rehabilitation science and disability and our target population (Mokkink et al., 2010a). The following sections will detail the examination of the content validity of the mPAT and the results of this examination.

### **3.2.1 Methods**

#### **3.2.1.1 Participants**

Seven experts in the field of rehabilitation science and disability, and rehabilitation practitioners were recruited to participate in this study. Additionally, two individuals with a history of TBI were invited to participate, for a total of nine participants. Participants were recruited through established relationships with our research team and were referred to as the expert review panel for the purpose of this research.

### **3.2.1.2 Procedure**

Members of the expert review panel were provided with a PDF version of the mPAT version 1 (Appendix A). The document included a definition of participation, instructions on completing the measure, items and item responses. Participants were asked to review the measure and complete a questionnaire via the Qualtrics survey system. The Qualtrics survey system is an online application that allows researchers to develop and distribute questionnaires and collect data. The Qualtrics questionnaire contained: (1) instructions for evaluation; (2) a brief rationale for developing the assessment (Figure 3); (3) questions for rating the assessment instructions and rating the relevancy of the items and response options; and (4) space for rewording suggestions or general comments was provided in all of the evaluation sections as well as space for suggestions for missing responses or items (Figure 4). Participants were asked to (1) rate the clarity of instructions of the mPAT using a 4 point Likert scale (1 = strongly disagree; 2 = Disagree; 3 = agree and ; 4 = strongly agree); (2) rate the relevancy of the items to participation using a 4 point Likert scale (1 = not relevant; 2 = unable to assess relevancy without item revision or item is in need of such revision that it would no longer be relevant; 3 = relevant but needs minor alteration and ; 4 = very relevant; Figure 5); and (3) rate the relevancy of the item responses to participation using a 4 point Likert scale (1 = not relevant; 2 = unable to assess relevancy without item revision or item is in need of such revision that it would no longer be relevant; 3 = relevant but needs minor alteration and ; 4 = very relevant; Figure 6). Additionally, participants were asked to provide additional feedback on items, item responses, and the mPAT as a whole. All research efforts were approved by the University of Pittsburgh Institutional Review Board (IRB) prior to conducting any research activities (#PRO15120106)



The Mobile Participation Assessment Tool (mPAT) was developed to be a measure of participation that can be delivered using ecological momentary assessment (EMA) methodology. Participation is a dynamic construct that may not be accurately captured using traditional static measures that rely on retrospective recall and are typically delivered in clinical settings. EMA methodology employs the repeated measure of a construct of interest in the real-world environment. This assessment approach is dynamic and may decrease reporting errors that can occur in measures that rely on retrospective recall as the assessment of the construct is happening at the moment in which it is occurring and in the natural environment of the individual.

The mPAT was developed using the World Health Organizations International Classification of Functioning, Disability, and Health (ICF) classification system of participation as a framework for measuring participation. **Participation is defined by the dynamic relationship between an individual's involvement in an activity within an environmental and social context.** Therefore, the mPAT's items and item responses were developed to be reflective of this definition of participation.

**Figure 3.** Qualtrics survey rationale for development of the mPAT

What alterations would you recommend to any of the item responses **Activity**?

Are there any item responses that you would add? If so, what are they?

**Figure 4.** Example of space for additional feedback provided in the Qualtrics survey

Rate the relevancy of the items of the mPAT based on the rationale and definition of participation provided above.

**Item 2**

*Location – Where are you at this moment*

not relevant

unable to assess relevance without item revision or item is in need of such revision that it would no longer be relevant

relevant but needs minor alteration

very relevant

For **Item 2 - Location**, what, if any, alterations would you recommend?

**Figure 5.** Qualtrics survey example of item relevancy question

Rate the relevancy of the item responses of the mPAT based on the rationale and definition of participation provided above.

**Activity**

Use the scale below to rate the relevancy of each item response to the item "Activity"

1 = not relevant

2 = unable to assess relevance without item revision or item is in need of such revision that it would no longer be relevant

3 = relevant by needs minor alteration

4 = very relevant

Click to write the question text

	1	2	3	4
Learning/studying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating/conversation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercising	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Figure 6.** Qualtrics survey example of item response relevancy question

### 3.2.2 Analysis

Descriptive statistics, including means and standard deviations, were used to examine participants' responses to clarity of instructions. To quantify the content validity for the mPAT, the content validity ratio (CVR) and content validity index (CVI) were used. The CVR is utilized to determine if an item is essential and is computed for each item of an instrument (Lawshe, 1975). CVR values fall between zero and 1.00, with a score of 1.00 indicating that the item is essential (Lawshe, 1975). For nine participants the minimum value to retain an item was 0.78. Items that reach the minimum CVR value (0.78) were retained in the second version of the mPAT. The CVI was computed after determining what items would be retained in the second

version of the mPAT. The CVI is the mean of all of the CVR values of retained items (Lawshe, 1975). The CVI has been found to have advantages over alternative indexes, specifically the focus on agreement of relevance of the items to the construct, which is in line with COSMIN guidance (Polit, Beck & Owen, 2007, Mokkink et al., 2010a). Finally, percent agreement was calculated to determine the relevancy of item responses to each item. This allowed us to examine the comprehensiveness of our tool (Mokkink et al., 2010a). Item responses where a majority (>50%) of participants rated an item as relevant (rated as 3 or 4) were retained for the second version of the mPAT. Feedback provided by participants was reviewed by the research team to determine if suggested changes should be included in the second version of the mPAT. All statistical analyses were conducted using the Statistical Package for the Social Sciences Software (SPSS, v 23).

### **3.2.3 Results**

#### **3.2.3.1 Participants**

Members of the expert review panel represented the fields of rehabilitation counseling, occupational therapy, neuropsychology, and rehabilitation psychology in a clinical or academic role. On average members had been involved in the field of rehabilitation for 14.33 years (SD = 9.72) and had 9.44 years (SD = 8.72) of experience working with individuals with TBI.

#### **3.2.3.2 Instructions**

Of the members of the expert review panel (n=9), 77.8% agreed that the instructions for the mPAT were clear. Participants' feedback was reviewed to identify potential improvements to the instructions. Feedback included the identification of a grammatical error, and suggested

wording changes. Examples of participants' feedback on the instructions included that they were "extremely straight forward and concise" and "the instructions are clear to me," "the only thing I would suggest adding is the first time you say you will be prompted, to specify what you mean," and "the instructions are clear to me, but are likely too long and complex for some individuals with TBI." Participants' feedback was used to improve the instructions for the mPAT. The revised instructions can be found in Appendix B, mPAT version 2.

### **3.2.3.3 Items**

The CVRs for the *Activity*, *Location*, and *Surrounding People* items were found to be 1.00, indicating that they were essential to the construct of participation. The CVR for the *Satisfaction* item was 0.78, which met the minimum CVR value to retain an item. For the Satisfaction item, only one participant felt that it was not essential to the construct of participation, with all other participants rating it as essential. Because all four items met the minimum CVR value for retention, all item values were used to compute the CVI. The final CVI of 0.94 is indicative of good content validity.

### **3.2.3.4 Item responses**

The percent agreement of participant's ratings that an item response is relevant to the item is presented in Table 7 (*Activity*), Table 8 (*Location*) and Table 9 (*Surrounding People*). All item responses were found to be relevant by a majority (>50%) of the participants and were retained for the second version of the mPAT. However, feedback from participants suggested rewording (i.e. change "Sports – playing" to "Playing sports/recreation"), separating double worded item responses (i.e. separating "Leaning/Studying" to be separate responses), and giving examples of

select item responses (i.e. change “Play” to “Playing (i.e. board game, video game, cards, etc.”).

Participants also suggested the addition of several item responses for each item.

**Table 7.** Activity item response percent agreement of relevancy to participation

<b>Item Response</b>	<b>%</b>
Working	100
Learning/studying	100
Communicating/conversation	100
Exercising	100
Using transportation	100
Self-care	100
Eating	100
Shopping	100
Housework	100
Assisting others	100
Socializing	100
Travel – riding in or driving vehicle	100
Resting/sleeping	100
Preparing a meal	88.9
Play	88.9
Arts and culture	88.9
Crafts	88.9
Hobby	88.9
Attending religious/spiritual event or service	88.9
Internet communication	88.9
Volunteering	88.9
Watching television	88.9
Listening to music	88.9
Other	88.9
In class	77.8
Sports – playing	77.8
No activity	66.7

**Table 8.** Location item response percent agreement of relevancy to participation

<b>Item Response</b>	<b>%</b>
Home	100
Work	100
Restaurant	100
School	100
Transportation vehicle	100
Friend's home	88.9
Relative's home	88.9
Medical institution	88.9
Shop/store	88.9
Block/neighborhood	88.9
Religious facility	88.9
Bar	88.9
Sporting event venue	88.9
Movie theater	88.9
Museum	88.9
Art gallery	88.9
Theater	88.9
Other	88.9
Gym	77.8

**Table 9.** Surrounding People item response percent agreement of relevancy to participation

<b>Item Response</b>	<b>%</b>
Alone	100
Family	100
Unknown people	100
Spouse/partner	100
Significant other	100
Peers	88.9
Professionals	88.9
Other	88.9
Coworkers	77.8
Friends	77.8

### 3.2.4 Discussion

Our expert review panel found the mPAT version 1 to have content validity. Items were found to be relevant to participation, and item responses were comprehensive. No items or item responses were removed from the mPAT. However, based upon panel feedback, alterations to item responses, such as rewording or providing examples, and item responses were added to the mPAT version 2. The most significant alteration to the mPAT was the addition of an item to assess importance. A member of the expert review panel provided feedback that assessing how important what the individual is doing as well as how satisfied they are could be clinically meaningful. The research team agreed with this feedback and added an item to assess importance of participation. Therefore, the mPAT version 2 contains five items: *Activity*, *Location*, *Surrounding People*, *Importance*, and *Satisfaction*. With the addition of an item to the mPAT the content validity should be re-evaluated in future studies.

Additionally, the wording of the *Satisfaction* item was edited to ensure clarity of the question in regards to the definition of participation used in the development of the mPAT. In the first version, the item states “how satisfied are you with what you are doing right now?” The research team edited the item to be reflective of the mPAT definition of participation that includes environmental and social context. Thus the item was reworded to ask “considering what you are doing, where you are, and who you are with, how **satisfied** are you with what you are doing right now?” Table 10 shows the wording of each item for the mPAT version 2 and the complete mPAT version 2 can be found in the Appendix B.

**Table 10.** Item wording for mPAT version 2

<b>Item</b>	<b>Question</b>
Activity	What are you doing at this moment?
Location	Where are you at this moment?
Surrounding people	Who are you with at this moment?
Importance	Considering what you are doing, where you are, and who you are with, how important to you is what you are doing right now?
Satisfaction	Considering what you are doing, where you are, and who you are with, how satisfied are you with what you are doing right now?

#### **3.2.4.1 Limitations**

It is important to note that while the members of the expert review panel are representative of the field of rehabilitation science and disability and our population of TBI, the group was selected based on their relationship to the research team. Further examination of the content validity of version 2 and future versions of the mPAT should be made to determine if it is a universally agreed upon measure of participation.

### **3.3 DEVELOPMENT OF THE mPAT SCORING ALGORITHM**

A means of producing a score based on the data collected using the mPAT is necessary to examine the tool's feasibility and usability, as well as further examine the measurement properties of the tool. A score allowed us to examine the mPAT's ability to detect observations of participation using EMA techniques in subsequent studies. Additionally, by producing a score we were able to examine the construct validity of the mPAT, and will be able to examine other

measurement properties identified by the COSMIN checklist in future studies (Mokkink et al., 2009).

Because the mPAT is intended to be administered multiple times over a period of time, resulting in intensive longitudinal data, a set of rules that can be used to develop a scoring algorithm that can interpret each observation as being either representative of participation or not representative of participation is necessary. A scoring algorithm would be used to produce a score that in turn would allow users to determine frequency or an average rate of participation over time.

### **3.3.1 Methods**

#### **3.3.1.1 Participants**

Participants from the original expert review panel of the content validity of the mPAT were asked to take part in the development of the mPAT scoring algorithm. One member declined to participate due to a schedule conflict, leaving eight participants.

#### **3.3.1.2 Procedure**

Using the Qualtrics survey system, members of the expert review panel were asked to rate each possible response of the mPAT version 2 items of *Activity*, *Location*, and *Surrounding People* as 1) always participation, 2) never participation, or 3) contextual information is needed. Participants were then invited to participate in an in-person meeting, with other members of the group and the research team, to reach consensus on rating item responses and develop the preliminary rules that would be used to develop the scoring algorithm. Participants who could not attend in person were given the option to attend via teleconference.

At the time of the meeting the members of the expert review panel were given a copy of their responses to the Qualtrics survey. Members of the research team were provided with a copy of the mPAT for reference. The primary investigator (KG) led the discussion for the meeting. The ratings for each of possible response were presented individually to the group. The group discussed how each item response should be rated. The group discussed whether or not the response alone was always or never representative of participation, or if additional contextual information (e.g. where the activity occurred) was needed to determine if it were representative of participation. The group discussed each item response until unanimous agreement was reached as to which of the three ratings the item response would be assigned. A full list of possible responses to each item can be found in Appendix B.

Following the in person meeting, members of the research team met to develop rules for the scoring algorithm based upon the discussion from the meeting of the larger group. All research efforts were approved by the University of Pittsburgh Institutional Review Board (IRB) prior to conducting any research activities (#PRO15120106)

### **3.3.2 Results**

As a result of the in person meeting, each item response was assigned to one of the following categories: Always Participation, Never Participation, or Contextual Information Needed. A full list of the categorization of the item responses that were placed in these categories are provided in Table 11 (Always Participation), Table 12 (Never Participation), and Table 13 (Contextual Information Needed). If an item response was categorized as Always Participation, this means that this response is always representative of participation. For the category of Always Participation, 10 *Activity* item responses and nine *Location* item responses were placed in this

category (Table 11). If an item response was categorized as Never Participation this means that this response is not representative of participation. Four *Activity* item responses were categorized as Never Participation (Table 12). If an item response was categorized as Contextual Information Needed this means that additional information, such as where the individual is or who they are engaged with, is needed to determine if the response is representative of participation or not. Nineteen *Activity* item responses, 14 *Location* item responses and all *Surrounding People* item responses were categorized as contextual information needed. Meaning that if any of these responses were selected further information is needed to determine the presence or absence of participation.

**Table 11.** Item responses categorized as always participation

Item	Response
Activity	Working
	Volunteering
	Communicating/conversation
	Socializing
	Assisting others
	Caring for children
	Playing sports/recreation
	Attending religious/spiritual service
	Attending religious/spiritual event
	Physical intimacy
	Location
School	
Religious Facility	
Sporting event venue	
Gym	
Movie theater	
Museum	
Art gallery	
Theater	

**Table 12.** Item responses categorized as never participation

<b>Item</b>	<b>Response</b>
Activity	Medical/dental appointment Rehabilitation/therapy appointment Self-care Paying bills

**Table 13.** Item responses categorized as contextual information needed

<b>Item</b>	<b>Response</b>
Activity	Learning Studying Doing homework Travel – riding in or driving a vehicle Eating Preparing a meal Doing housework Engaging with pets Exercising Shopping Playing (i.e. board game, video game, cards, etc.) Watching sports Doing a craft Doing a hobby Using the internet Watching television Listening to music Resting/sleeping No activity
Location	Home Friend’s home Relative’s home Distant relative’s home Hospital/medical facility Rehabilitation facility Shop/store Library Coffee shop Restaurant Bar Block/neighborhood Outside Transportation vehicle

**Table 13. (continued)**

Surrounding People	Alone
	Spouse/partner
	Significant other
	Family
	Distant relative
	Friend(s)
	Peer(s)
	Acquaintance(s)
	Classmate(s)
	Coworker(s)
	Professional(s)
	Medical professional(s)
	Caregiver (paid)
	Unknown people

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In holding with the definition of participation used to develop the mPAT, the environmental (*Location*) and social (*Surrounding People*) context can have a mediating effect on if what an individual is doing (*Activity*) is participation. Throughout the course of the in-person meeting, the group decided in order for *activity* item responses categorized as contextual information needed, to be rated as participation that were categorized as contextual information the *Location* response should be in the community or the individual needed to be engaged with someone while performing the activity. For instance, watching sports (*Activity*) at home (*Location*), and alone (*Surrounding People*) would not be representative of participation, but watching sports (*Activity*) at a sporting event venue (*Location*), and alone (*Surrounding People*) would be representative of participation. This is because the activity took place in the community.

Using these ratings and rules a preliminary scoring algorithm was developed by the research team. The scoring algorithm produced two levels of participation and two levels of not participation. The instances that produce these levels are outlined below:

- If an *Activity* Always Participation item response is selected = Participation Level 1
- If a *Location* Always participation item response is selected = Participation Level 1
- If an *Activity* Contextual Information item response is selected and either a *Location* Contextual Information Needed item response or *Surrounding People* Contextual Information item responses is selected = Participation Level 2
  - Cases when this is true are outlined in the **Appendix C** “Participation Level 2 cases”
- If an *Activity* Never Participation item response is selected = Not Participation Level 1
- If an *Activity* Contextual Information Needed item response is selected and *Surrounding People* “Alone” is selected = Not Participation Level 2

Because more than one response can be selected for each item it is possible that an observation could be coded as more than one of the levels of participation or not participation detailed above. For instance, if a responder selects “caring for children” and “self-care” for the *Activity item*, the observation would be coded as both Participation Level 1 and Not Participation Level 1. As a result, the following rule was added to the scoring algorithm: Participation Level 1 and Participation Level 2 always outweigh a coding of Not Participation Level 1 or Not Participation Level 2.

Once each observation is coded they are combined into Participation Combined (Participation Level 1 + Participation Level 2) and Not Participation Combined (Not

Participation Level 1 + Not Participation Level 2). Then another coding is completed that includes the rule above, in regards to a participation level outweighing a not participation level, that creates Not Participation Combined Conditional. For Not Participation Combined Conditional, an observation cannot be coded as not participation if it is also coded as either of the two participation levels. This methodology allows a final Participation Score to be coded. Each observation is coded as Not Participation (0) or Participation (1). The final Participation Score is calculated by dividing the total number of observations coded as Participation by the total number of observations

$(\textit{Participation Score} = \left( \frac{\textit{Total Participation}}{\textit{Total Observations}} \right) \times 100)$ . For instance, if an individual completes

the mPAT 100 times for a total of 100 observations, and 75 of those observations are coded as Participation, 75 would be divided by 100 to equal a Participation Score of 75%.

### 3.3.3 Discussion

The scoring algorithm developed by the expert review panel and the research team allows each observation made using the mPAT to be rated as either participation or not participation. This allows a Participation Score to be calculated based on the total number of observations collected using the mPAT and the total number of observations coded as participation. Additionally, the ability to code observations as participation allows us to examine the tools ability to detect our construct of interests. This was an important step in further examining the feasibility and usability of the tool, our sampling approach, and construct validity, which will be discussed in sections **4.0 Study 2 Beta testing: determination of optimal sampling approach to assess participation in a TBI population using EMA techniques** and **5.0 Study 3 Pilot study:**

**preliminary examination of the validity, feasibility, and usability of the mPAT delivered via EMA techniques.**

The scoring algorithm is limited in that it does not take importance or satisfaction into account when providing a final Participation Score. However, because the mPAT is designed to collect ratings of importance and satisfaction, it is possible to also calculate a mean Importance Score and Satisfaction Score. We would recommend that these scores only be calculated for those observations collected that are rated as participation. By calculating means for *Importance* and *Satisfaction* ratings of only participation observations the scores are representative of importance of participation and satisfaction with participation.

Another significant limitation of developing a scoring algorithm that reduces each observation into participation or not participation is the loss off the rich and unique information that is collected by the mPAT. The frequency of *Activity*, *Location*, and *Surrounding People* responses could be of interest to investigators and clinicians; however, by coding each observation as participation or not this information is lost. Future research should examine how this information could be used and interpreted.

Likewise, future research is needed to determine how the three scores that the mPAT produces (Participation Score, Importance Score, and Satisfaction Score) can be used and interpreted. However, the next step in this project is to determine the preliminary inter-rater reliability of the developed scoring algorithm. This is discussed in the following sections.

### **3.4 PRELIMINARY RELIABILITY OF THE mPAT SCORING ALGORITHM**

The aim of the final phase of this study was to examine the preliminary inter-rater reliability of the developed scoring algorithm. In order to examine the reliability of the scoring algorithm the research team agreed that real-world observations using the mPAT would need to be collected. This data was called ecological momentary observations (EMO). The following sections will discuss the methods used to collect the ecological momentary observations data as well as the methods used to examine the reliability of the scoring algorithm.

#### **3.4.1 Methods**

##### **3.4.1.1 Participants**

###### *Expert review panel*

The participants of the expert review panel (n=8) were asked to take part in this portion of the study. One declined to participate for an n = 7.

###### *Ecological momentary observations*

Ten individuals with a history of TBI and currently living in the community were recruited to participate in this study for the collection of ecological momentary observations using the mPAT. Individuals were recruited through the University of Pittsburgh Medical Center's TBI Research Registry. To be included individuals must identify as having sustained a TBI and be currently living in the community. Ecological momentary observations collected from these individuals were used to examine the reliability of the developed scoring algorithm.

### **3.4.1.2 Protocol**

#### ***EMO protocol***

TBI participants (n = 10) were called on the telephone to administer the mPAT over a two-week period. Phone calls were made during a 12-hour time frame (8:00am to 8:00pm). This time frame was divided into morning (8:00am to 12:00pm), afternoon (12:00pm to 4:00pm), and evening (4:00pm to 8:00pm). Participants were called daily to obtain EMOs using the mPAT version 2. No more than two phone call attempts were made each day. A research team member (KG) made the phone calls. The team member varied phone calls throughout the three time periods listed above in order to attempt to sample a variety of activities. A total of 98 observations were collected.

#### ***Inter-rater reliability protocol***

A research team member reviewed all collected observations for duplicates. Duplicates were removed, and of the 98 observations collected, 68 remained. These 68 observations were presented to members of the expert review panel (n = 7) via a Qualtrics survey. To determine the inter-rater reliability of the preliminary scoring algorithm members were originally asked to rate each observation, considering our definition of participation, as participation, not participation, or unable to determine. However, because the developed scoring algorithm does not allow for an “unable to determine” coding of the mPAT, members were asked to re-rate those observations they originally rated as “unable to determine” as either participation or not participation. The analysis of both ratings will be presented in the results section. All research efforts were approved by the University of Pittsburgh Institutional Review Board (IRB) prior to conducting any research activities (#PRO15120106)

### 3.4.2 Analysis

The intraclass correlation coefficient (ICC) is a inter-rater reliability coefficient that is illustrative of rater agreement, and appropriate for use in examining ordinal data and with two or more rates (Barkto, 1966; Hallgren, 2012). Additionally, unlike other inter-rater reliability coefficients, ICCs account for the magnitude of disagreement between raters and provides information on variability between and within raters (Hallgren, 2012). Therefore, the ICC was used to assess the inter-rater reliability of the experts' ratings of the EMOs. ICC model 2 was used to determine the inter-rater reliability, as each observation was rated by all raters, and the group was expected to be representative of experts in the field of rehabilitation science and individuals with TBI (Shrout & Fleiss, 1979). Specifically, ICC (2,7) reliability coefficient was used. The following criteria for interpreting the ICC reliability coefficient values were utilized:  $< 0.40$  = poor;  $0.40 - 0.59$  = fair;  $0.60 - 0.74$  = good; and  $> 0.75$  = excellent (Hallgren, 2012).

Following calculation of the ICC, as suggested by Portney and Watkins (2009), members of the research team met to subjectively examine the data to determine if and where major discrepancies lie. To identify discrepancies, percent agreement was calculated for each unique observation to determine where differences between the experts and the scoring algorithm existed. A priori, members of the research team determined that observations with percent agreement lower than 60% would be reviewed by members of the research team. Necessary changes and adjustments to the scoring algorithm were made at this time. Instances where percent agreement was lower than 60% were reviewed by two members of the research team, to determine if and how the scoring algorithm should be altered. If the two researchers could not reach agreement, a third researcher was available to be consulted. All statistical analyses were conducted using the Statistical Package for the Social Sciences Software (SPSS, v 23).

### 3.4.3 Results

#### 3.4.3.1 Reliability

##### *Inter-rater reliability*

Good inter-rater reliability (ICC = 0.72) was found between raters when rating observations as participation, not participation or unable to determine ( $F(67, 402) = 3.579, p < .001, 95\% \text{ CI } [0.61, 0.81]$ ). However, when raters were asked to re-rate observations previously rated as unable to determine, excellent inter-rater reliability (ICC = 0.87) was observed between raters ( $F(67, 402) = 7.802, p < .001, 95\% \text{ CI } [0.82, 0.91]$ ), indicating that raters had a high degree of agreement. This suggests that participation and not participation was rated similarly across raters.

##### *Percent agreement*

Of the 68 observations rated by the experts, 15 were identified as having low agreement (57% or below) with the scoring algorithm. Table 14 presents the distribution of percent agreement of the raters with the scoring algorithm. Two researchers reviewed the 15 identified observations for consistency with the scoring algorithm rules established during the in person meeting and subsequent building of the scoring algorithm. Observations in which the raters differed from the preliminary scoring algorithm rules were reviewed by the researchers. Of the 15, one adjustment to a scoring algorithm rule was changed following review. The researchers reached 100% agreement on the changes or retention of the preliminary scoring algorithm rules established. A third reviewer of the rules was available but not necessary due to the agreement of the initial researcher review.

**Table 14.** Percent agreement distribution

<b>Agreement (%)</b>	<b># of observations</b>
100	27
86	13
71	13
57	10
43	2
29	2
0	1

#### **3.4.4 Discussion**

Excellent inter-rater reliability was found when members of the expert review panel were asked to rate observations collected using the mPAT as either participation or not participation. Because our raters were found to have excellent agreement, we were able to compare their ratings to the ratings of the developed scoring algorithm in order to determine where discrepancies lie. The identification of discrepancies allowed us to examine the scoring algorithm's constancy with our definition of participation for the mPAT. While there were 15 observations that showed a deviation between the expert review panel and the preliminary scoring algorithm, researchers felt that the established rules of the scoring algorithm were consistent with the in person meeting, in which the scoring algorithm was initially developed. For instance, while in person members of the group agreed that the activity of "working" was always representative of participation. However, when presented with EMOs where individuals selected "working" but a location of "home" or surrounding people of "alone" some members rated these EMOs as not participation. When reviewed by the two researchers, they agreed with the initial rule that the activity of "working" was always representative of participation regardless of location or surrounding people. It is important to note that "working" was only selected if the individual was working for money or employed.

#### **3.4.4.1 Changes to the scoring algorithm**

The rule that was changed in the scoring algorithm as a result of the reliability analysis was that the activity of traveling was only representative of participation if engaged with someone at the time. The previous version of the rule held that traveling while alone was also representative of participation.

### **3.5 SUMMARY**

A review of available participation measures revealed that there is little consistency between measures in regards to operationally defining participation, as well as how and what aspects of participation are assessed. Additionally, no tool was identified that could be delivered using EMA techniques. As a result, the research team began the development of the Mobile Participation Assessment Tool (mPAT). The mPAT was developed specifically to measure participation using EMA techniques and methodology in a TBI population. EMA conceptual considerations (as discussed in Section **2.3 Ecological Momentary Assessment**) and COSMIN checklist guidance were used in the development of the mPAT, including format, items and potential responses (Mokkink et al., 2009; Mokkink et al., 2010a, Mokkink et al., 2010b). The mPAT version 1 was found to have content validity. Feedback provided by the expert review panel resulted in several improvements to the tool, including the addition of an item assessing importance of participation. The mPAT version 2 (Appendix B) was developed as a result of this analysis and feedback.

In order to quantifying participation, the research team and expert review panel developed a set of rules that were used to create a scoring algorithm to quantify observations

made using the mPAT. The scoring algorithm is a unique product of this study as it allows for the quantification of observations made using the mPAT and allows us to rate each as either being representative of participation or not. Additionally, quantifying observations made using the mPAT as either participation or not participation allows for the examination of the tools ability to capture moments of participation using EMA techniques and methodologies. The ability to produce a score allowed us to further examine the feasibility, usability and measurement properties of the mPAT (Mokkink et al., 2010a).

When members of the expert review panel were presented with observations made using the mPAT, excellent inter-rater reliability was found. Also, by calculating percent agreements between raters and the preliminary scoring algorithm, we were able to examine the scoring algorithm for inconsistencies with the expert review panel and determine if alterations were necessary. As a result, one alteration was made to the scoring algorithm: for the *activity* of traveling, the individual must be engaged with someone for the observation to be coded as participation.

The results of this study are the preliminary steps in developing a measure of participation after TBI that utilizes EMA techniques and methodology. The next study was a beta testing study that examined the preliminary feasibility of delivering the mPAT via a smartphone application in individuals with TBI to determine an appropriate sampling approach. This study and the results will be discussed in the following chapter.

#### **4.0 STUDY 2 BETA TESTING: DETERMINATION OF OPTIMAL SAMPLING APPROACH TO ASSESS PARTICIPATION IN A TBI POPULATION USING EMA TECHNIQUES**

Previous research has addressed the feasibility of utilizing EMA techniques in individuals with TBI; however, the majority of these studies have focused on mTBI and those individuals with minimal cognitive impairment (Lewandowski et al., 2009; Suffoletto et al., 2013; Smith et al., 2012; Juengst et al., 2015). These studies suggest that the utilization of EMA techniques to assess various outcomes and behaviors in individuals with brain injury is promising. However, further investigation that includes individuals who demonstrate more severe cognitive impairment is necessary. Additionally, determining the appropriate sampling approach, including duration and frequency of sampling, to both accurately capture the construct of participation as well as minimize participant burden is necessary.

Prior research has typically utilized novel technology to deliver EMA, which requires the individual to learn to use the new technology and remember to carry the technology. In order to reduce participant burden, we used a smartphone application that is part of a larger system, ilumivu, developed to employ EMA techniques. Further description of the ilumivu system is provided in section 4.1 Ilumivu. By utilizing a smartphone application available for both Apple and Android devices, participants were able to use their personal smartphones to participate in the study.

Because little is known about the utilization of EMA techniques in a more cognitively impaired population, nor in the assessment of participation, this study aimed to determine the optimal EMA sampling approach to assess participation in individuals with TBI. To achieve this aim the preliminary feasibility and usability of a smartphone application to deliver the mPAT to individuals with TBI who demonstrate at least a mild level of cognitive impairment was examined. For the purpose of this study feasibility was defined as (1) participants' compliance with completion of prompted assessments, (2) participants' feedback in regards to the usability and acceptability of the smartphone application and mPAT, and (3) the ability to assess participation using the mPAT.

Earlier research found a compliance rate of at least 70% was acceptable and supported feasibility of EMA (Dunbar, Scharf, Kirchner, & Shiffman, 2010; Kirk et al., 2013; Garcia et al., 2014; Juengst et al., 2015). In the current study, compliance was reviewed over the entire sampling time frame, as well as by week and by time period to determine if compliance rate supported the sampling approach. Additionally, participants' feedback on the usability and acceptability of the smartphone application as a delivery method and the mPAT as an assessment of participation was reviewed to determine the ease of use and learnability of the smartphone application and mPAT. Satisfaction with both the smartphone application and mPAT was also reviewed. Participants' feedback was taken into consideration in determining the optimal sampling approach. Finally, we reviewed the frequency with which the mPAT was able to identify observations of participation as a means of determining the optimal sampling approach. The mPAT Participation Score was reviewed over the entire sampling time frame as well as by week and by time period to support the sampling approach. Findings were used to in part

determine the optimal EMA sampling approach for delivery of the mPAT, with the goal of reducing participant burden while still capturing the construct of participation.

#### **4.1 ILUMIVU**

The mPAT was delivered via the ilumivu system (<https://ilumivu.com/>). The ilumivu system is a software platform with a mobile application (mEMA) and web-based portal designed to capture data through user interaction. The system allows researchers to customize for project need. Ilumivu can be used by investigators and practitioners to deliver online and mobile EMA. The mobile application is available for devices with both iOS and Android operating systems. Investigators and practitioners can create assessments to be delivered through the mobile application on the web-based survey module. This system also allows investigators and practitioners to view and download data being collected through the mobile application. Data is stored locally on the mobile device if not in cellular or WiFi range. When in cellular or WiFi range data is automatically pushed to an online secure server when users push the upload button on the mEMA application. Participants can be assigned anonymous identifiers so that no identifiable information is collected with the intended data.

The ilumivu system allows for a range of EMA techniques to be employed. Data can be collected actively (participants prompted to complete assessment), passively (data collected automatically, such as through the use of sensors to detect light or motion), or a combination of active and passive techniques. Question order can be pre-specified or random. The system also allows for event-based and time-based sampling. Time-based sampling strategies include pre-specified times or intervals, random sampling during predetermined time frames or within

certain hours of the day. Additionally, researchers can allow mEMA application users to view upcoming scheduled assessments. Previous research found that the ability to view scheduled assessments was helpful for our population (Juengst et al., 2015). Additionally, as reported helpful for individuals with TBI, the mEMA application requires minimal navigation to access assessments and can prompt and send follow-up prompts to individuals alerting them to complete assessments (Juengst et al., 2015).

The ilumivu system was chosen as the delivery method of the mPAT as it (1) allows customization of assessment delivery, (2) the mEMA application is available for both iOS and Android devices, (3) the system allows the research team to prompt users to complete assessments, (4) the interface requires minimal navigation, and (5) users can view times and dates for scheduled assessments. The research team purchased a subscription to the ilumivu system in order to complete this study and the following pilot study. There was no customization of the off-the-shelf produce, save our development of the mPAT survey using the web-based portal and scheduling of assessments. All of which is customizable in the off-the-shelf product.

Before using the system to collect data, the research team pilot tested the mEMA application with the mPAT. By doing so the research team was able to ensure that (1) assessment scheduling prompted users to complete the mPAT, (2) reminders were sent for missed or ignored notifications, (3) formatting of the assessment on the application was suitable, and (4) data collection (including item responses and time-stamping of prompts) was recorded and accessible to the research team.

## 4.2 METHODS

### 4.2.1 Overview of study

This study used a multimethod approach to assess the feasibility and usability of EMA techniques to deliver the mPAT. The data collection modalities included an in-person interview, self-report questionnaires, a brief neuropsychological assessment, telephone interviews, and a four week long time-based EMA sampling via the ilumivu mEMA application on participants' personal smartphones. A prospective repeated measures design was used

### 4.2.2 Sample

Three individuals with TBI who demonstrated at least mild cognitive impairment participated in this study. To be eligible to participate in this study individuals had to be (1) at least 18 years of age, (2) of working age (18-66 years old), (3) English speaking, (4) be capable of providing informed consent, (5) have an eligible smartphone with a data plan and be capable of using the device independently, (6) have a history of sustaining a TBI, and (7) demonstrate, at minimum, mild cognitive impairment, as assessed by a brief neuropsychological assessment. Individuals who (1) do not have a smartphone with a data plan, (2) history of TBI is undeterminable, (3) are involved in active litigation, (4) diagnosis limited to concussion only, or (5) had been hospitalized due to psychiatric issues or had suicidal ideations within the last six months were excluded from participation. To determine preliminary eligibility participants were screened over the phone by a member of the research team (KG).

### 4.2.3 Procedure

The study consisted of four phases: screening, baseline, active tracking, and follow up (Figure 7). The screening and baseline phases were conducted in-person in a private clinical setting. During the screening phase participants completed the Cognistat assessment to determine presence and level of cognitive impairment. MCI index of 2 or higher are suggestive of mild cognitive impairment. The Cognistat is further discussed in section **4.2.5 Measures**. Demographic information (i.e. age, gender, time since injury) was also collected as part of the screening phase. If at least mild cognitive impairment was present as determined by administering the Cognistat, the baseline phase began immediately following the screening.



**Figure 7.** Timeline of study listing the assessments that will be conducted during each of the four phases.

Data collected during the baseline phase included: mobile device experience, affect (Patient Health Questionnaire-9 and Generalized Anxiety Disorder-7), a traditional measure of participation (Participation Assessment with Recombined Tools – Objective/Satisfaction), and a measure of activities of daily living (Barthel Index). A full description of all measures used is provided in section **4.2.5 Measures**. Also, during the in-person baseline phase, training and instructions on the mEMA application and the mPAT were provided. A full description of the training is provided in section **4.2.4 Training**.

During the active tracking phase of this study EMA data collection occurred via participants' personal smartphones. The ilumivu application, mEMA, was downloaded onto participants' personal smartphones at the completion of the baseline in-person interview. Delivery of the mPAT was scheduled utilizing the ilumivu web-based portal. Data collection occurred for four consecutive weeks of monitoring. Random time-based assessments were initiated by the web-based application and synced to the participant's personal smartphone during baseline and training. Time-based assessments were delivered four times per day, during a 14-hour timeframe that included one prompt in the morning (8a-12p), afternoon (12p-4p), evening (4p-8p), and late evening (8p-10p). Using the web-based application researchers programed the mEMA application to randomly prompt participants once during each of the four time-frames. At these times the mEMA application prompted the participant to begin the mPAT (screen shot of alert). Each scheduled assessment was date and time-stamped and was recorded as completed or missed. Participants were given a 15-minute window to complete scheduled assessments. During that time two additional prompts were sent to remind participants to complete the mPAT. For instance, if an assessment was scheduled for 2:00pm, the initial prompt would be sent at 2:00pm. If the participant missed or ignored this prompt, a follow up prompt would be sent at 2:05pm. If this prompt was missed or ignored a final prompt would be sent at 2:10pm. The participant would have from 2:00pm to 2:15pm to begin the assessment. Missed prompts are those that are not completed during the 15-minute window. No identifiable information (i.e. name, cell phone number) was stored or sent during this time.

The decision to monitor for four consecutive weeks and four times per day was made to determine the optimal sampling duration and frequency that would not be a high burden on the participant but also capture the construct of participation. The duration of sampling allows us to

examine if participation varies from week to week or is consistent. The sampling frequency and 14-hour time frame allows us to examine how someone's participation varies by time of day.

Participants were called on a weekly basis to check in for any issues and remind participants to sync the mEMA application to the online server. Syncing of the mEMA application occurred when the participant pressed the "Upload" button on the mEMA application. This sent stored mPAT responses to the online portal. Detailed notes of phone conversations were kept to track questions and issues that arose. Following completion of the active tracking phase, the follow up phase began. During this phase, participants were called within 3 days of the final Active Tracking day to collect usability and satisfaction measures of the mPAT and assessment delivery method (mEMA application), as well as complete the PART-OS. All research efforts were approved by the University of Pittsburgh Institutional Review Board (IRB) prior to conducting any research activities (#PRO15110547).

#### **4.2.4 Training**

At the conclusion of the baseline interview a researcher (KG) assisted the participant in downloading the mEMA application on to his/her personal smartphone. Each participant completed training on the use of the mEMA application on his/her personal smartphone. Training lasted for 30 minutes to one hour depending on the participant's individual needs. Participants were provided with a pamphlet developed by the research team the provided step by step instructions for downloading the mEMA application and completing the mPAT assessment. Participants were able to take the training pamphlet with them to reference if needed. The training pamphlet is provided in Appendix D. During the training, the following information was covered 1) download and installation of the mEMA application, 2) navigating the application

(accessing assessments, manual synchronization of device, alerts), 3) how to respond to prompts, and 4) how to complete assessments. The mPAT was also reviewed during training. The purpose of the assessment and instructions for answering questions was reviewed with participants. Each item and item response for the mPAT was also reviewed with each participant. For the *Surrounding People* item, participants were instructed to only select people with whom they were engaged. For example, if they were at home and their spouse was at home also, but in another room and they were not engaged they would not select “spouse/partner” for the *Surrounding People* item. However, if they were engaged with them, such as having a conversation, they were directed to select “spouse/partner” for this item. At the conclusion of the training period participants were asked to complete the mPAT using the mEMA application to ensure that they could independently navigate the application and assessment as well as successfully upload a completed assessment.

## **4.2.5 Measures**

### **4.2.5.1 Screening**

Two measures were used during the screening phase to determine study eligibility. The Cognistat was used to determine presence and level of cognitive impairment. The Cognistat is a cognitive screening assessment that measures orientation, attention, language, spatial skills, memory, constructions and reasoning (Kiernan, Mueller, Langston, & Van Dyke, 1987). The assessment provides a mild cognitive impairment (MCI) index. The MCI index is derived from the subtests of memory and constructions and is adjusted for the patient’s age and education level to provide an index level. There are seven index levels: 0 = no indication of cognitive impairment, 1 = raises the question of MCI, 2 = suggests MCI, 3 = strongly suggests MCI, 4 = raises the question

of a dementia syndrome, 5 = suggests a dementia syndrome, 6 = strongly suggests a dementia syndrome. The Cognistat has been shown to be a reliable assessment of level of cognitive status in community dwelling individuals with TBI (Doninger et al., 2006). Participants who's MCI index was 2 or higher were eligible for this study. Demographic information was also collected. Information collected included: date of birth, age, gender, race/ethnicity, marital status, education level, employment status, nature of injury, time since injury, current psychiatric diagnosis and current treatment if applicable.

#### **4.2.5.2 Baseline**

During the baseline phase, several interview based and self-report measures were utilized to describe the sample. Participant's affect was assessed using the Patient Health Questionnaire – 9 (PHQ-9) and Generalized Anxiety Disorder – 7 (GAD-7). The PHQ-9 assesses frequency of nine symptoms of a major depressive episode over the previous two weeks. Total scores range from 0-27, with interpretation cut-off scores of 0-4 (none), 5-9 (mild), 10-14 (moderate), 15-19 (moderately severe) and >20 (severe) (Kroenke et al., 2001). The PHQ-9 has been validated to measure depressive symptoms in individuals with TBI (Fann et al., 2005). The GAD-7 assesses frequency of seven symptoms of generalized anxiety disorder over the previous two weeks (Spitzer, Kroenke, Williams, & Lowe, 2006). Total scores range from 0-21, with interpretation cut-off scores of 0-4 (none), 5-9 (mild), 10-14 (moderate) and >15 (severe) (Spitzer et al., 2006).

Additionally, participants were asked questions in regards to experience with mobile devices. This included questions regarding type of smartphone used, experience with their current smartphone and previous experience, as well as comfort using the device.

Participants' frequency and satisfaction with participation was assessed using the Participation Assessment with Recombined Tools – Objective/Satisfaction (PART-OS). The

PART-OS is divided into two sections with the first, “O,” being an objective measure of participation and the second, “S,” measuring the subjective experience and satisfaction with participation for individuals with TBI (Whiteneck et al., 2011). The “O” section contains 24 questions that can be calculated into a total score that indicates an individual’s level of participation, with higher scores indicating a higher level of participation. The “S” section contains eleven domains of participation, but individuals can add additional areas that they find important. Satisfaction is rated on a scale of 0-10 and a mean satisfaction score is calculated to produce a participation satisfaction score. Higher satisfaction scores indicate higher levels of satisfaction. The PART-OS was developed to incorporate the strengths of previously utilized measures of participation. These include the Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF), Community Integration Questionnaire version 2 (CIQ-2), and Participation Objective, Participation Subject (POPS) objective scale, all of which the PART-OS is highly correlated with (Whiteneck et al., 2011). The PART-O was found to have construct and concurrent validity (Whiteneck et al., 2011).

The Barthel Index assesses an individual’s performance on 10 ADLs and measures functional ability (Mahoney & Barthel, 1965). It has been found to have inter-rater reliability, test-retest reliability and validity (Mahoney & Barthel, 1965). Each item of the Barthel Index is rated based on how much physical assistance the individual requires to complete or perform a task, and items are summed to produce a score that ranges from 0-100. Lower scores indicate higher levels of assistance are needed.

#### **4.2.5.3 Active Tracking**

During the Active tracking phase the mPAT version 2 (Appendix B) was utilized to assess participation, importance of participation and satisfaction with participation. The mPAT was

delivered via the mEMA application. The mPAT consists of five items: *Activity*, *Location*, *Surrounding People*, *Importance*, and *Satisfaction*. The mPAT provides a Participation Score that is the percent of participation (total number of participation observations divided by the total number of observations collected over the sampling time frame), and Importance Score (average importance of participation observations) and Satisfaction Score (average satisfaction of participation observations). Higher scores are indicative of higher frequency of participation, and higher levels of importance of participation and satisfaction with participation. Scores can be computed for overall (total sampling period), by week and by time period. It should be noted that the interpretability of the scores produced by the mPAT is unknown at this time, and was used to examine the preliminary feasibility of the tool and sampling approach used in this study. Further research is needed to examine the interpretability of the scores produced by the mPAT.

#### **4.2.5.4 Follow-up**

During the follow up phase of the study participants' participation was reassessed using the PART-OS. Additionally, a Usability and Satisfaction Questionnaire was utilized to assess the usability and acceptability of the mEMA application and mPAT. The questionnaires were developed by the research team utilizing an existing measure (the Telehealth Usability Questionnaire (TUQ); Parmanto, Lewis, Graham, & Bertolet, 2016) and modifying wording to address usability and satisfaction of the mEMA application and mPAT. The questionnaire consisted of items addressing the following: satisfaction, ease of use, learnability, and interface quality. Responses were on a Likert scale, and participants were able to provide additional comments. Higher ratings indicate better ratings of usability and acceptability.

#### **4.2.6 Data Collection**

Confidentiality was maintained due to all data collected being assigned a study specific identification number. In regards to EMA data collection, this identification number was used when creating individual profiles on the mEMA web-based portal. Once a profile was created and schedule of assessments created by a research team member (KG) participants were provided with a unique mobile code to be entered into the mEMA application. The mobile code allowed participants to download the assigned schedule of assessments. When an assessment was completed and the participant pressed “upload” on the mEMA application, the data was sent to the mEMA web-based portal. No identifiable information, such as phone number or name, was transmitted at this time. Instead the mEMA web-based portal assigned a unique identification number to all assessment data linked to the mobile code. In order to distinguish between completed and missed assessments, the mEMA web-based portal coded each scheduled assessment as “true” for completed or “false” for missed.

#### **4.2.7 EMA Data Management**

The management of the EMA data involved extraction and cleaning. Extraction of data was completed for each participant individually as he/she completed the active tracking phase of the study. A research team member (KG) extracted data by logging on to the mEMA web-based portal and selecting the appropriate participant. Data were downloaded in a long file form as a Microsoft Excel file. Cleaning of data included coding of scheduled assessments by week and time period. Additionally, when a participants data were extracted from the mEMA web-based portal, item responses that were not selected by the participant were not identified in the

extracted file. For instance, if a participant never selected “working” for the *Activity* item it was not present in the extracted file. To accurately analyze all participants as a group it was necessary to identify unrepresented item responses and manually input them into the data file. Also, when participants selected “other” for an item they were prompted by the mEMA application to explain further by typing in a description. A research team member identified each instance “other” was selected and recoded it as an appropriate corresponding item response when available. For instance, a participant who selected “other” for the *Activity* item wrote “taking pills” was recoded as the *Activity* item response of “self-care.”

#### **4.2.8 Analytic Plan**

Due to the exploratory nature of this study, descriptive statistics were used to examine all data collected. Also, due to small sample size we visually examined group and individual data using graphs. The specific analyses utilized are discussed in the following sections. All statistical analyses were conducted using the Statistical Package for the Social Sciences Software (SPSS, v 23).

##### **4.2.8.1 Feasibility**

###### ***Compliance***

To examine compliance with scheduled assessments we examined both the sample as a whole and by participant. We used descriptive statistics to examine compliance rate, which was defined as the percent of assessments completed out of the total number scheduled. To determine if compliance changed over time or by time period it was examined visually using line

graphs. The following compliance variables for the sampling time-frame of 4 weeks, by week, and by time period were examined using descriptive statistics: number of prompts delivered, number of prompts completed, number of missed prompts, and compliance. Due to our small sample size we also examined the compliance variables listed above for the sampling time-frame, by week and by time period for each participant separately. Additionally, line graphs were used to visually examine data.

### ***Usability and Acceptability***

To examine preliminary usability and acceptability, means and standard deviations were computed to examine participant satisfaction with the mEMA application and the mPAT. Descriptive statistics was also used to examine participants' responses to ease of use and learnability, and interface quality of the mEMA application and the ease of use and learnability of the mPAT.

### ***Participation***

To examine the feasibility of EMA techniques to capture the construct of participation, the following variables will be examined over the total observation time-frame, by week and by time period: number of observations, number of observations coded as not participation, number of observations coded as participation and the mPAT Participation Score. Means, standard deviations and frequencies were used to explore participation. Coding of observations as participation or not participation was based on the developed scoring algorithm. These participation variables were examined for the group and by individual due to the small sample size. Additionally, line graphs were used to visually examine data.

## **4.3 RESULTS**

### **4.3.1 Participants**

Participant 1 (P1) was a 34-year-old Caucasian female with a Bachelor's degree. She was single and was not currently employed but reported volunteering on a regular basis. Her traumatic brain injury was a result of a motorcycle accident five years and 10 months ago. At the time of baseline assessments, she was involved in counseling for both depression and anxiety. Participant 2 (P2) was a 30-year-old Caucasian male with an Associate's degree. He was single and was not currently employed at the time of baseline assessment completion. His traumatic brain injury was a result of a motor vehicle accident 12 years and 10 months ago. At the time of baseline assessments, he was involved in counseling and taking medication for both depression and anxiety. Participant 3 (P3) was a 46-year-old Caucasian male with a high school degree. He was married and was not currently employed. His traumatic brain injury was a result of a fall three years and two months ago. At the time of baseline assessments, he was involved in counseling and taking medication for depression, anxiety, and bipolar disorder. Additional screening and baseline information is presented in Table 15. Participants varied by level of cognitive impairment, and experience with smartphones.

**Table 15.** Participant screening and baseline information

	<b>P1</b>	<b>P2</b>	<b>P3</b>
Cognistat MCI Index	6	2	3
PHQ-9	12	8	18
GAD-7	11	2	11
PART			
Objective Score	13.37	13.67	14.00
Subjective Score	7.57	5.27	6.57
Barthel Index Total Score	90	100	95
Smartphone			
Type	Android	Android	iPhone
Yrs current	1-2	< 6 months	1-2
Total years w/smartphone	4-5	> 5 years	> 5
Use per day (min)	> 60	> 60	> 60

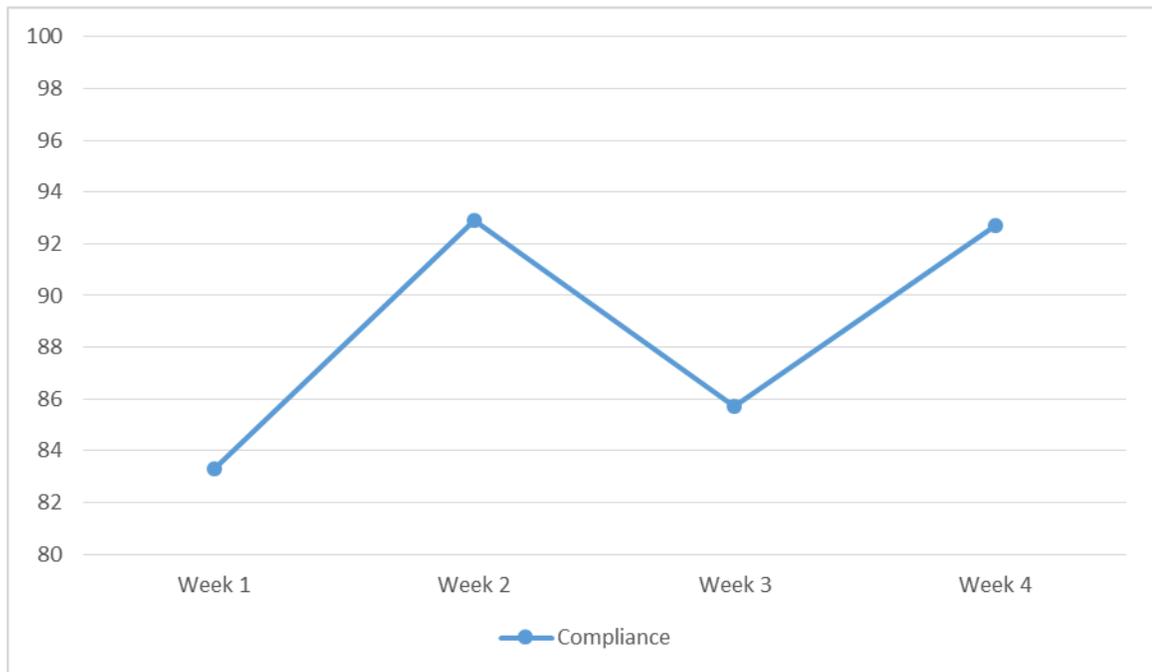
### 4.3.2 Feasibility

#### 4.3.2.1 Compliance

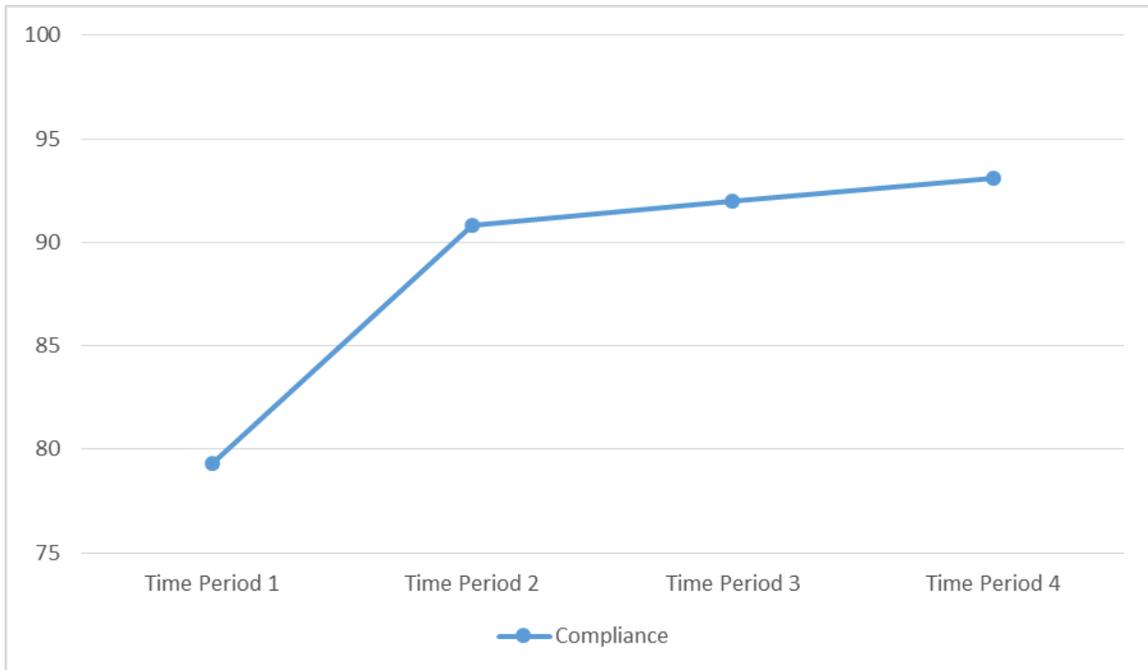
Participants ( $n = 3$ ) were scheduled to complete the mPAT via the mEMA application four times a day over a four-week period. During the study 348 prompts were delivered. Compliance with the mEMA delivered assessments over the four-week sampling time period was excellent. The average compliance for the group was 88.8% ( $SD = 6.88$ ). Table 16 presents the compliance variables for the overall sampling time-frame, by week and by time period. When compliance was examined by week some variation was found. As can be seen in Figure 8, compliance rate increases at week two from the first week of sampling and falls during the third week, but increases again during the final week. Similarly, when compliance was examined by time period variation was found. As shown in Figure 9, compliance is lowest at time period 1 (8:00am – 12:00pm) but increases through each subsequent time period.

**Table 16.** Group compliance data

	<b># Prompts delivered</b>	<b># Assessments completed</b>	<b># Assessments missed</b>	<b>Compliance (%)</b>
Overall	348	309	39	88.8
By Week				
Week 1	84	70	14	83.3
Week 2	84	78	6	92.9
Week 3	84	72	12	85.7
Week 4	96	89	7	92.7
By Time Period				
Time Period 1	87	69	18	79.3
Time Period 2	87	79	8	90.8
Time Period 3	87	80	7	92.0
Time Period 4	87	81	6	93.1



**Figure 8.** Group compliance by week



**Figure 9.** Group compliance by time period

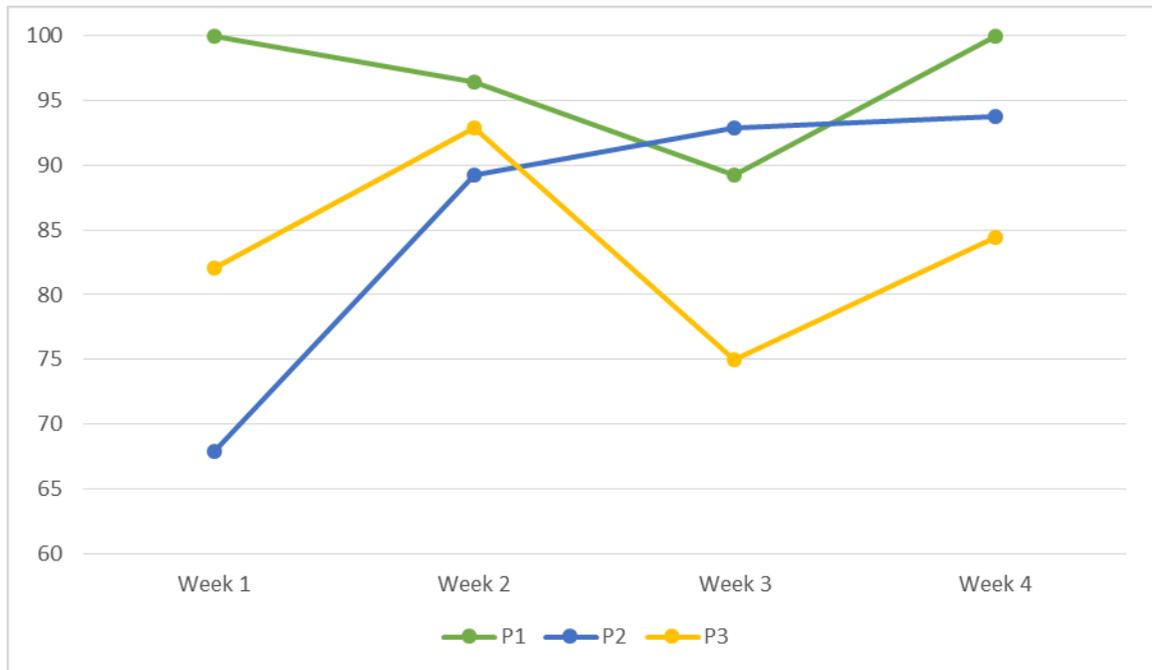
These trends found when examining the data as a group remained when looking at participants individually, as seen in Tables 17, 18, and 19, and Figures 10 and 11. Overall compliance was excellent for all three participants and ranged from 83.6% to 96.6%. Compliance by week was also variable with P1 and P3 following the same trends as the group data. P2 was the only participant to have an increase in compliance rate for each of the four weeks. Compliance by time period was also variable for all participants with all participants having the lowest compliance rate at time period 1 (8am-12pm). P2 and P3 showed an increase in compliance as the time periods grew later (Table 19 and Figure 11).

**Table 17.** Individual overall compliance

<b>Subject</b>	<b># Prompts delivered</b>	<b># Assessments completed</b>	<b># Assessments missed</b>	<b>Compliance (%)</b>
P1	116	112	4	96.6
P2	116	100	16	86.2
P3	116	97	19	83.6

**Table 18.** Individual compliance by week

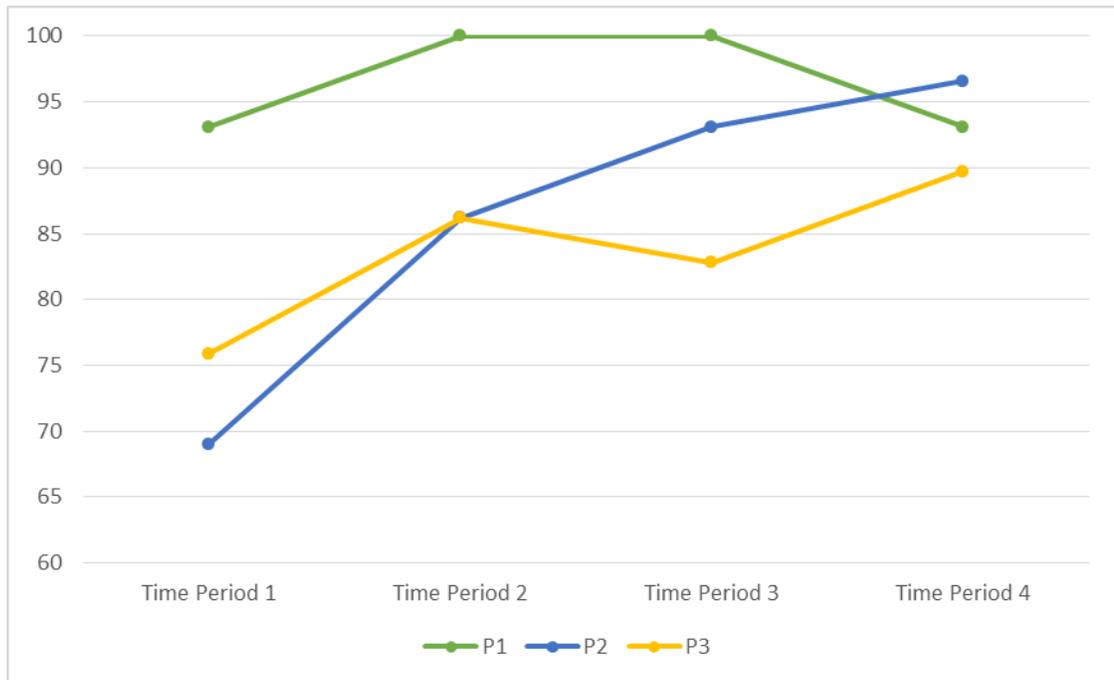
Subject	# Prompts delivered	# Assessments completed	# Assessments missed	Compliance (%)
<b>P1</b>				
Week 1	28	28	0	100
Week 2	28	27	1	96.4
Week 3	28	25	3	89.3
Week 4	32	32	0	100
<b>P2</b>				
Week 1	28	19	9	67.9
Week 2	28	25	3	89.3
Week 3	28	26	2	92.9
Week 4	32	30	2	93.8
<b>P3</b>				
Week 1	28	23	5	82.1
Week 2	28	26	2	92.9
Week 3	28	21	7	75.0 </td
Week 4	32	27	5	84.4



**Figure 10.** Individual weekly compliance rate

**Table 19.** Individual compliance by time period

Subject	# Prompts delivered	# Assessments completed	# Assessments missed	Compliance (%)
<b>P1</b>				
Time Period 1	29	27	2	93.1
Time Period 2	29	29	0	100
Time Period 3	29	29	0	100
Time Period 4	29	27	2	93.1
<b>P2</b>				
Time Period 1	29	20	9	69.0
Time Period 2	29	25	4	86.2
Time Period 3	29	27	2	93.1
Time Period 4	29	28	1	96.6
<b>P3</b>				
Time Period 1	29	22	7	75.9
Time Period 2	29	25	4	86.2
Time Period 3	29	24	5	82.8
Time Period 4	29	26	3	89.7



**Figure 11.** Individual compliance by time period

#### 4.3.2.2 Usability and Acceptability

Weekly and follow-up telephone calls and surveys provided data regarding participants' views on the usability and acceptability of the mEMA application for delivery of the mPAT. Usability and acceptability data was also provided through these methods for the mPAT. During weekly phone calls participants were able to notify the research team of any mEMA application issues

Means and standard deviations were examined for the mPAT ease of use and learnability, as well as satisfaction with the measure. Participants were asked to rate their level of agreement (1 = Strongly disagree, 2 = Disagree, 3 = Neither agree or disagree, 4 = Agree, 5 = Strongly agree) with statements. In regards to ease of use and learnability, participants strongly agreed that it was simple to use the mPAT ( $M = 5.00$ ,  $SD = 0.00$ ), and agreed that it was easy to learn to use the mPAT ( $m = 4.67$ ,  $SD = 0.58$ ). Additionally, participants agreed that the instructions for the mPAT were clear ( $M = 4.67$ ,  $SD = 0.58$ ). Participants strongly agreed that the mPAT was simple and easy to understand ( $M = 5.00$ ,  $SD = 0.00$ ). Furthermore, on average participants agreed that the mPAT was an acceptable way to measure their participation ( $M = 4.67$ ,  $SD = 0.58$ ), and that overall they were satisfied with the mPAT as a measure of their participation ( $M = 4.67$ ,  $SD = 0.58$ ).

Means and standard deviations were examined for the mEMA application's ease of use and learnability, as well as satisfaction with the application. Participants were asked to rate their level of agreement (1 = Strongly disagree, 2 = Disagree, 3 = Neither agree or disagree, 4 = Agree, 5 = Strongly agree) with statements. In regards to ease of use and learnability, on average participations agreed that they could easily access assessments using the mEMA application ( $m = 4.33$ ,  $SD = 0.58$ ). Participations on average agreed that it was simple to use the mEMA application ( $M = 4.67$ ,  $SD = 0.58$ ), that it was easy to learn to use the mEMA application ( $M =$

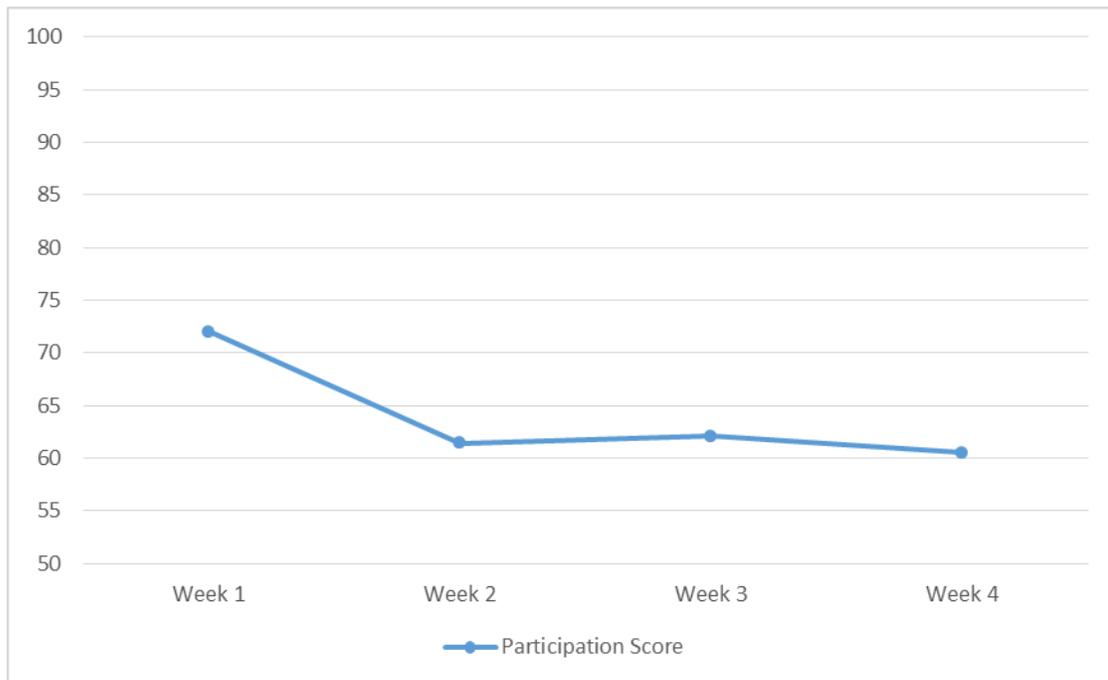
4.67, SD = 0.58), and that it was simple and easy to understand (M = 4.33, SD = 0.58). Additionally, on average participants strongly agreed that they felt comfortable answering questions using the application (M = 5.00, SD = 0.00, and agreed that it was an acceptable way to answer questions (M = 4.33, SD = 0.58). Participants on average strongly agreed that they would use the mEMA application again (M = 5.00, SD = 0.00), and overall were satisfied with the application (M = 4.67, SD = 0.58). However, all participants reported having difficulty hearing the prompts to complete scheduled assessments. As a result, all three participants reported setting additional reminders to alert them of scheduled assessments.

#### **4.3.2.3 Participation**

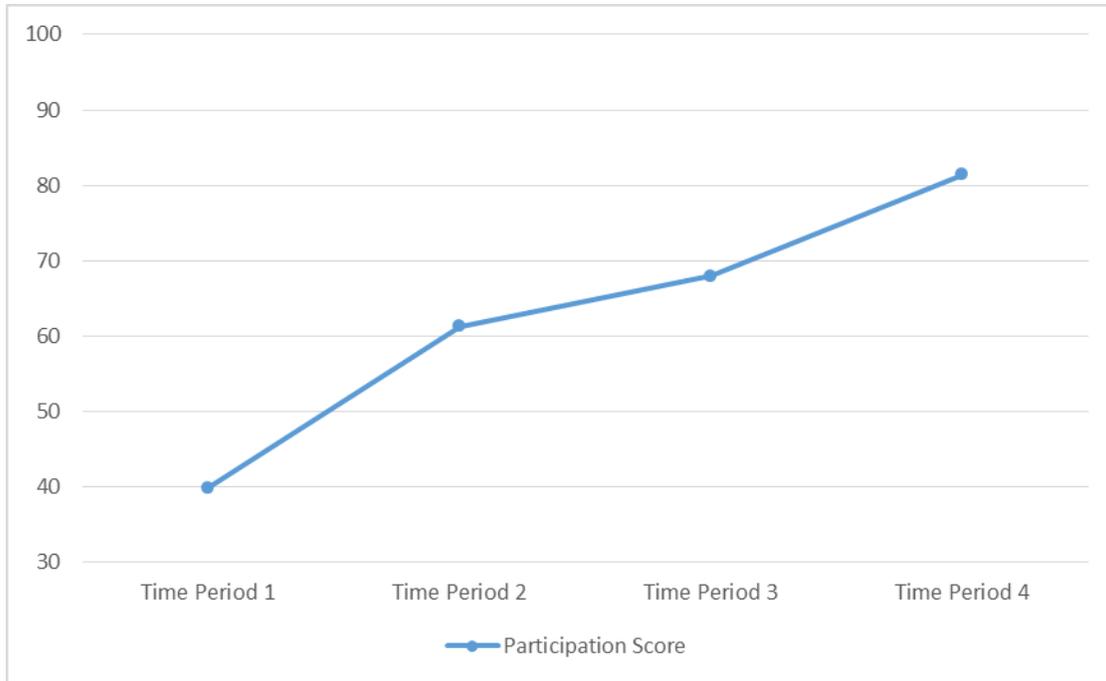
For the analyses of participation, as measured by the mPAT via the mEMA application, we examined the three scores produced by the mPAT and the developed scoring algorithm. The Participation Score was obtained using the revised scoring algorithm. Participation scores were examined for the overall sampling time frame, by week and by time period for the group. Table 20 shows the participation variables examined including number of observations, number of not participation observations, number of participation observations, and Participation Score. There were 309 observations made using the mPAT. Of those, 212 were coded as being representative of participation. The average Participation Score over the sampling time frame was 63.5% (SD = 7.6). The average Participation Score by week does vary by week, as shown in Figure 12. The highest average Participation score was observed during the first week (M = 72.0%, SD = 13.5) and the lowest average score was observed during the fourth week (M = 60.5%, SD = 24.2). Likewise, the average Participation Score differs between the four time periods. The lowest average Participation Score was observed at time period 1 (M = 39.9%, SD = 19.6), but the average score increases throughout the day, as shown in Figure 13.

**Table 20.** Group participation observations of participation and participation scores

	# Observations	# Not Participation	# Participation	Participation Score (%)
Overall	309	112	197	63.5 (7.6)
Week				
1	70	20	50	72.0 (13.5)
2	78	30	48	61.4 (8.1)
3	72	28	44	62.1 (13.2)
4	89	34	55	60.5 (24.2)
Time Period				
1	69	41	28	39.9 (19.6)
2	79	30	49	61.3 (12.8)
3	80	26	54	68.1 (9.6)
4	81	15	66	81.4 (16.4)



**Figure 12.** Group participation score by week



**Figure 13.** Group participation score by time period

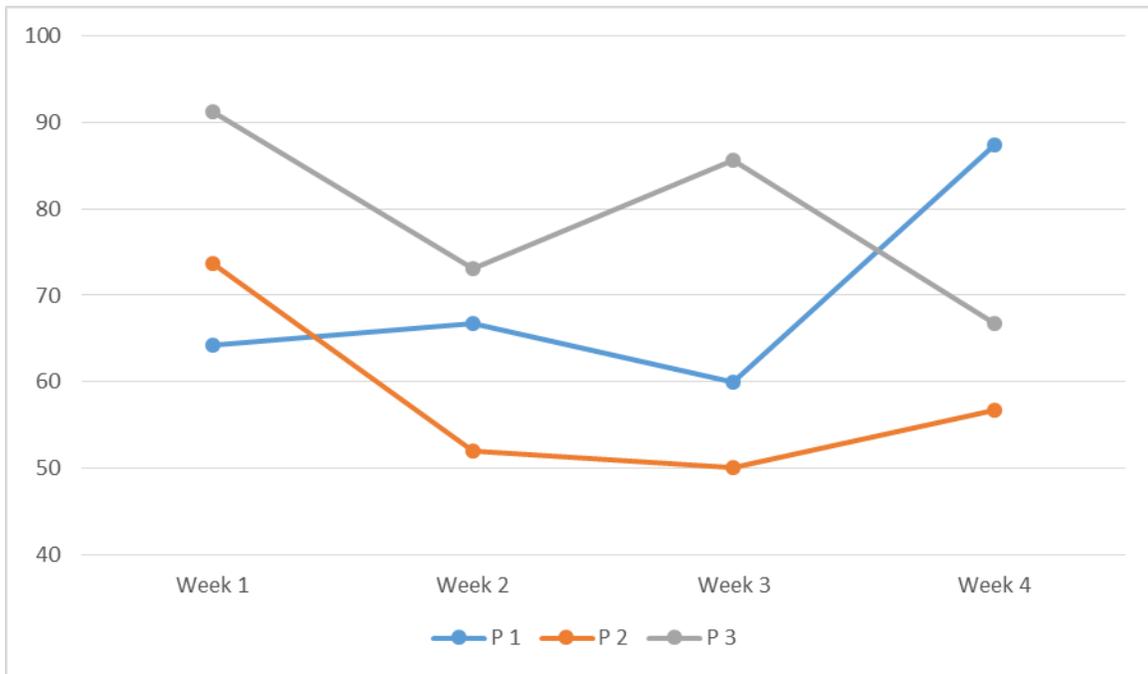
When we examined Participation Scores by individual we found similar trends as when reviewed by group. As shown in Table 21, the overall Participation Scores range from 55% (P2) to 69.6% (P1). Similar to the group Participation Score by week the scores by week for each participant vary as well, as shown in Table 22 and Figure 14. Finally, participation scores continue to increase from time period 1 to time period 4 for participants with some deviation between participants, as displayed in Table 23 and Figure 15.

**Table 21.** Individual participation observations of participation and participation scores

Participant	# Observations	# Not Participation	# Participation	Participation Score (%)
P1	112	34	78	69.6
P2	100	45	55	55.0
P3	97	33	64	66.0

**Table 22.** Individual observations of participation and participation scores by week

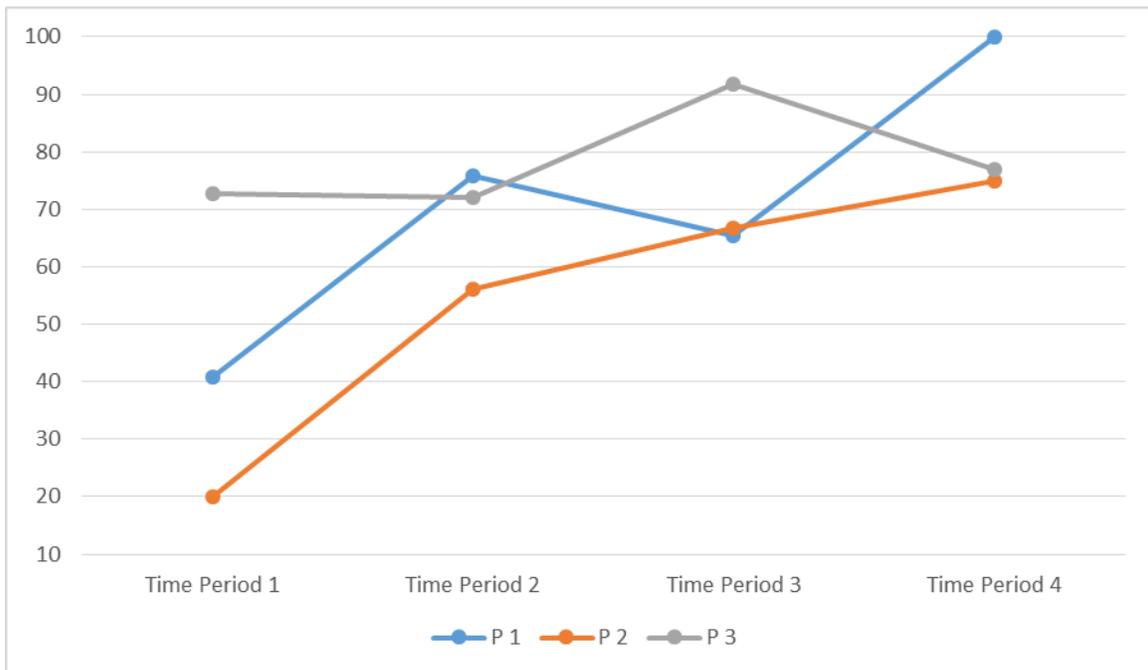
Participant	# Observations	# Not Participation	# Participation	Participation Score (%)
P1				
Week 1	28	11	17	60.7
Week 2	27	9	18	66.7
Week 3	25	10	15	60.0
Week 4	32	4	28	87.5
P2				
Week 1	19	6	13	68.4
Week 2	25	12	13	52.0
Week 3	26	13	13	50.0
Week 4	30	14	16	53.3
P3				
Week 1	23	3	20	87.0
Week 2	26	9	17	65.4
Week 3	21	5	16	76.2
Week 4	27	16	11	40.7



**Figure 14.** Individual participation score by week

**Table 23.** Individual observations of participation and participation scores by time period

Participant	# Observations	# Not Participation	# Participation	Participation Score (%)
<b>P1</b>				
Time Period 1	27	16	11	40.7
Time Period 2	29	7	22	75.9
Time Period 3	29	11	18	62.1
Time Period 4	27	0	27	100
<b>P2</b>				
Time Period 1	20	16	4	20.0
Time Period 2	25	12	13	52.0
Time Period 3	27	10	17	63.0
Time Period 4	28	7	21	75.0
<b>P3</b>				
Time Period 1	22	9	13	59.1
Time Period 2	25	11	14	56.0
Time Period 3	24	5	19	79.2
Time Period 4	26	8	18	69.2



**Figure 15.** Individual participation score by time period

## 4.4 DISCUSSION

Our study aimed to examine the preliminary feasibility of the mPAT's assessment of participation via the mEMA application in order to determine the optimal sampling approach. We addressed three primary questions: (1) is compliance acceptable over the sampling duration and frequency? (2) are the mPAT and mEMA application usable and acceptable to participants? and (3) does the mPAT capture observations of participation over the sampling duration and frequency? The data preliminarily suggests that it is feasible to assess participation using the mPAT via the mEMA application. Compliance over the sampling time-frame was comparable to previous research examining the feasibility of EMA in a TBI population, and rates were indicative of good compliance (Juengst, et al., 2015). When compliance was examined by week and time period, despite an observed variation, rates remained suggestive of good compliance. Additionally, when compliance was examined by participant, rates continued to be high and participants followed similar trends, despite the variability in participant characteristics (e.g. level of cognitive impairment). These findings suggest that similar compliance over the sampling time-frame may be found in a larger sample of individuals with TBI.

In regards to the usability and acceptability of the mEMA application and the mPAT participants reported finding both easy to learn and use, and were satisfied with both. Participants agreed that the mPAT was an acceptable way to measure participation, and overall were satisfied with the assessment tool. All participants reported issues with the mEMA application, but reported that they would use the application again, and overall were satisfied with the application. These findings suggest that the mEMA application is an acceptable way to deliver the mPAT, and that the mPAT is an acceptable measure of participation.

Finally, the mPAT and our sampling approach were able to identify observations of participation using the revised scoring algorithm. While the overall average Participation Score was found to be 63.5%, variation was observed when the score was examined by week and by time period. These findings preliminary support the idea that participation is a dynamic construct, and support the duration and frequency of our sampling strategy to assess participation using the mPAT. Therefore, we concluded that a four-week sampling period at a rate of four times per day was feasible and acceptable to assess participation. However, further research is necessary to support these findings.

#### **4.4.1 Limitations**

This study had several limitations. These data represented a very small sample of individuals with TBI and cognitive impairment and thus cannot be confirmatory of the sampling approach, nor can the findings be generalized to the TBI population. While the data does support the feasibility of our sampling approach, further research is needed to confirm our initial findings.

Additionally, all participants reported difficulty hearing the prompt initiated by the mEMA application. Despite several attempts to increase the volume or change the default tone, all participants continued to report this issue for the duration of the sampling period. All participants reported setting additional reminders in order to complete the mPAT as scheduled. Due to participants having access to their daily schedule they were able to do this, but it should be noted that they were not asked by the researchers to do so. This significantly increased the burden on participants, which may impact compliance rate as well as satisfaction with and usability of this type of assessment in future studies.

Finally, our findings in regards to the preliminary feasibility of the mPAT to capture observations of participation rely heavily on the accuracy of the developed scoring algorithm. While the compliance and usability data support the sampling approach further research is needed to confirm the reliability and validity of the scoring algorithm to accurately identify observations of participation. However, despite these limitations, this study was a critical phase in a larger research project. Establishing preliminary feasibility was necessary to ensure that our sampling approach could be supported in future research.

## **5.0 STUDY 3 PILOT STUDY: PRELIMINARY EXAMINATION OF THE VALIDITY, FEASIBILITY AND USABILITY OF THE mPAT DELIVERED VIA EMA TECHNIQUES**

In previous studies of this project we have developed a measure of participation to be delivered via EMA techniques and methodologies and an accompanying scoring algorithm. Preliminary content validity of the mPAT and reliability of the scoring algorithm were established. A time-based sampling approach for a duration of four weeks and frequency of four times per day was examined in a small sample of individuals with TBI. Results of the previous study supported this sampling approach. The next steps of this project were to establish preliminary construct validity of the mPAT, examine the feasibility of EMA techniques and methods in a TBI population, and to examine participation in TBI as assessed by the mPAT. The specific aims, procedure, and results of this study are detailed in the following chapter.

The mPAT was developed to be delivered via EMA techniques and methods, and as such it is necessary to ensure that the assessment is valid (Mokkink et al., 2009). Therefore, the first aim of this study was to examine the preliminary construct validity of the mPAT delivered via EMA techniques to individuals with TBI. We examined the construct validity by assessing the mPAT's convergent validity with a validated participation measure in TBI, and discriminant validity with an assessment of activities of daily living (ADL). Because the existing knowledge of the use of EMA techniques in the TBI population, and especially those individuals with

cognitive impairment, is limited our second aim was to examine the feasibility and usability of EMA techniques to assess participation to be delivered four times per day for four weeks in individuals with TBI. Finally, we aimed to examine participation as measured with the mPAT delivered via EMA techniques in individuals with TBI.

## **5.1 METHODS**

### **5.1.1 Overview of study**

This study used a multimethod approach to (1) assess the construct validity of the mPAT, (2) assess the feasibility and usability of EMA techniques to deliver the mPAT in a TBI population, and (3) examine participation as measured by the mPAT. The data collection modalities included an in-person interview, self-report questionnaires, a brief neuropsychological assessment, telephone interviews, and a four-week long interval time-based EMA sampling via the ilumivu mEMA application on participant's personal smartphones. A prospective repeated measures design was used.

### **5.1.2 Sample**

Eligible participants (1) were at least 18 years of age, (2) of working age (18-66 years old), (3) English speaking, (4) capable of providing informed consent, (5) had an eligible smartphone with a data plan and be capable of using the device independently, (6) had a history of sustaining a TBI, and (7) demonstrated, at minimum, mild cognitive impairment, as assessed by a brief

neuropsychological assessment. Individuals who (1) do not have a smartphone with a data plan, (2) history of TBI is undeterminable, (3) are involved in active litigation, (4) diagnosis limited to concussion only, or (5) had been hospitalized due to psychiatric issues or had suicidal ideations within the last 6 months were excluded from participation. To determine preliminary eligibility participants were screened over the phone by a member of the research staff (KG). Twelve individuals with TBI were recruited to participate in this study through local TBI support groups, and local community agencies specializing in working with individuals with TBI.

### **5.1.3 Procedure**

Corresponding with the previous beta testing study, this study consisted of four phases: screening, baseline, active tracking, and follow up (Figure 16). The screening and baseline phases were conducted in-person in a private clinical setting. During the screening phase participants completed the Cognistat assessment to determine presence and level of cognitive impairment. MCI index of 2 or higher are suggestive of mild cognitive impairment. The Cognistat is further discussed in section **5.15 Measures**. Demographic information (i.e. age, gender, time since injury) was also collected as part of the screening phase. If at least mild cognitive impairment was present ( $MCI \geq 2$ ), the baseline phase began immediately following the screening.



**Figure 16.** Timeline of study listing the assessments that will be conducted during each of the four phases.

Data collected during the baseline phase included: mobile device experience, affect (PHQ-9 and GAD-7), a traditional measure of participation (PART-OS), and a measure of activities of daily living (Barthel Index). A full description of all measures used is provided in section **5.1.5 Measures**. Also, during the in-person baseline phase, training and instructions on the mEMA application and the mPAT were provided. A full description of the training is provided in section **5.1.4 Training**. It was determined that the training developed and provided in the previous study was sufficient to provide participants with an understanding of the mobile app and mPAT.

During the “Active Tracking” phase of this study, momentary data collection occurred via participants’ personal smartphones. The ilumivu application, mEMA, was downloaded on to participants’ personal smartphones at the completion of the baseline in-person interview. The application was programmed specifically for our data collection needs. The length of data collection was determined based on findings in the previous study (**4.0 Study 2 Beta Testing: Determination of Optimal Sampling Approach to Assess Participation in a TBI Population Using EMA Techniques**). This decision was based on the researcher’s review of feasibility, participants’ feedback on disruptiveness and burden, and the observations of participations gathered by week and by time frame

Random time-based prompts were initiated by the web-based application to the participant's personal smartphone. Time-based prompts were delivered four times per day, during a 14-hour timeframe to include one assessment in the morning (8a-12p), afternoon (12p-4p), evening (4p-8p), and late evening (8p-10p). At these times the mEMA application signaled the participant to begin the mPAT. Each prompt was date and time-stamped and was recorded as completed or missed. Participants were given a 15-minute window to complete scheduled prompts. During that time two additional prompts were sent to remind participants to complete the mPAT. For instance, if a prompt was scheduled for 2:00pm, the initial alert would be sent at 2:00pm. If the participant missed or ignored this alert, a follow up alert would be sent at 2:05pm. If this alert was missed or ignored a final alert would be sent at 2:10pm. The participant would have from 2:00pm to 2:15pm to begin the assessment. Missed prompts were those that were not completed during the 15-minute window.

Participants were called on a weekly basis to check in for any issues and remind participants to sync the mEMA application to the online server. Syncing of the mEMA application occurred when the participant pressed the "Upload" button on the mEMA app. This sent stored survey responses to the online portal. Detailed notes of phone conversations were kept to track questions and issues that arose.

Following completion of the active tracking phase, the follow up phase began. During this phase, participants were called within 3 days of the final active tracking day to collect usability and satisfaction measures of the mPAT and assessment delivery method (mEMA application), as well as complete the PART-OS. All research efforts were approved by the University of Pittsburgh Institutional Review Board (IRB) prior to conducting any research activities (#PRO15110547). Additionally, once the previous study was completed we continued

to recruit for this study using the same approved protocol since the previous study did not indicate the necessity of alterations to the protocol.

#### **5.1.4 Training**

At the conclusion of the baseline interview a researcher (KG) assisted the participant in downloading the mEMA application on to his/her personal smartphone. Each participant completed training on the use of the mEMA application on his/her personal smartphone. Training lasted for 30 minutes to one hour, depending on the individual need. Participants were provided with a pamphlet developed by the research team that provided step by step instructions for downloading the mEMA application and completing the mPAT assessment. Participants were able to take the training pamphlet with them to reference if needed. The training pamphlet is provided in Appendix C. During the training the following information was covered (1) downloading and installing of the mEMA application, (2) navigating the application (accessing assessments, manual synchronization of device, alerts), (3) responding to prompts, and 4) completing assessments. The mPAT was also reviewed during training. The purpose of the assessment and instructions for answering questions was reviewed with participants. Each item and item response for the mPAT was also reviewed with each participant. For the *Surrounding People* item, participants were instructed to only select people with whom they were engaged. For example, if they were at home and their spouse was at home also, but in another room and they were not engaged they would not select “spouse/partner” for the *Surrounding People* item. However, if they were engaged with them, such as having a conversation, they were directed to select “spouse/partner” for this item. At the conclusion of the training period, participants were asked to complete the mPAT using the mEMA application to ensure that they could

independently navigate the application and assessment as well as successfully upload a completed assessment.

## **5.1.5 Measures**

### **5.1.5.1 Screening**

Two measures were used during the screening phase to determine study eligibility. The Cognistat was used to determine presence and level of cognitive impairment. The Cognistat is a cognitive screening assessment that measures orientation, attention, language, spatial skills, memory, constructions and reasoning (Kiernan, Mueller, Langston, & Van Dyke, 1987). The assessment provides a mild cognitive impairment (MCI) index. The MCI index is derived from the subtests of memory and constructions and is adjusted for the patient's age and education level to provide an index level. There are seven index levels: 0 = no indication of cognitive impairment, 1 = raises the question of MCI, 2 = suggests MCI, 3 = strongly suggests MCI, 4 = raises the question of a dementia syndrome, 5 = suggests a dementia syndrome, 6 = strongly suggests a dementia syndrome. The Cognistat has been shown to be a reliable assessment of level of cognitive status in community dwelling individuals with TBI (Doninger et al., 2006). Participants who's MCI index was 2 or higher were eligible for this study. Demographic information was also collected. Information collected included: date of birth, age, gender, race/ethnicity, marital status, education level, employment status, nature of injury, time since injury, current psychiatric diagnosis and current treatment if applicable.

### **5.1.5.2 Baseline**

During the baseline phase, several interview based and self-report measures were utilized to describe the sample. Participant's affect was assessed using the Patient Health Questionnaire – 9 (PHQ-9) and Generalized Anxiety Disorder – 7 (GAD-7). The PHQ-9 assesses frequency of nine symptoms of a major depressive episode over the previous two weeks. Total scores range from 0-27, with interpretation cut-off scores of 0-4 (none), 5-9 (mild), 10-14 (moderate), 15-19 (moderately severe) and >20 (severe) (Kroenke et al., 2001). The PHQ-9 has been validated to measure depressive symptoms in individuals with TBI (Fann et al., 2005). The GAD-7 assesses frequency of seven symptoms of generalized anxiety disorder over the previous two weeks (Spitzer et al., 2006). Total scores range from 0-21, with interpretation cut-off scores of 0-4 (none), 5-9 (mild), 10-14 (moderate) and >15 (severe) (Spitzer et al., 2006). Additionally, participants were asked questions in regards to experience with mobile devices. This included questions regarding type of smartphone used, experience with their current smartphone and previous experience, as well as comfort using the device.

Participants' frequency and satisfaction with participation was assessed using the Participation Assessment with Recombined Tools – Objective/Satisfaction (PART-OS). The PART-OS is divided into two sections with the first, "O," being an objective measure of participation and the second, "S," measuring the subjective experience and satisfaction with participation for individuals with TBI (Whiteneck et al., 2011). The "O" section contains 24 questions that can be calculated into a total score that indicates an individual's level of participation, with higher scores indicating a higher level of participation. The "S" section contains eleven domains of participation, but individuals can add additional areas that they find important. Satisfaction is rated on a scale of 0-10 and a mean satisfaction score is calculated to

produce a participation satisfaction score. Higher satisfaction scores indicate higher levels of satisfaction. The PART-OS was developed to incorporate the strengths of previously utilized measures of participation. These include the Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF), Community Integration Questionnaire version 2 (CIQ-2), and Participation Objective, Participation Subject (POPS) objective scale, all of which the PART-OS is highly correlated with (Whiteneck et al., 2011). The PART-O was found to have construct and concurrent validity (Whiteneck et al., 2011). The PART-OS was used to evaluate the convergent validity of the mPAT Participation Score and Satisfaction Score.

The Barthel Index was used to evaluate discriminant validity of the mPAT. The Barthel Index assesses an individual's performance on 10 ADLs and measures functional ability (Mahoney & Barthel, 1965). It has been found to have inter-rater reliability, test-retest reliability and validity (Mahoney & Barthel, 1965). Each item of the Barthel Index is rated based on how much physical assistance the individual requires to complete or perform a task, and items are summed to produce a score that ranges from 0-100. Lower scores indicate higher levels of assistance are needed.

### **5.1.5.3 Active Tracking**

During the Active tracking phase, the mPAT version 2 (Appendix B) was utilized to assess participation, importance of participation and satisfaction with participation. The mPAT was delivered via the mEMA application. The mPAT consists of five items: *Activity*, *Location*, *Surrounding People*, *Importance*, and *Satisfaction*. The mPAT provides a Participation Score that is the percent of participation (total number of participation observations divided by the total number of observations collected over the sampling time frame), and Importance Score (average importance of participation observations) and Satisfaction Score (average satisfaction of

participation observations). Higher scores are indicative of higher frequency of participation, and higher levels of importance of participation and satisfaction with participation. Scores were computed for overall (total sampling period), by week and by time period. It should be noted that the interpretability of the scores produced by the mPAT is unknown at this time, and was used to examine the preliminary feasibility of the tool and sampling approach used in this study. Further research is needed to examine the interpretability of the scores produced by the mPAT.

#### **5.1.5.4 Follow-up**

During the follow up phase of the study participants' participation was reassessed using the PART-OS. The PART-OS was re-administered to examine the convergent validity of the mPAT. Additionally, a Usability and Satisfaction Questionnaire was utilized to assess the usability and acceptability of the mEMA application and mPAT. The questionnaires were developed by the research team utilizing an existing measure (Telehealth Usability Questionnaire (TUQ) – Parmanto et al., 2016) and modifying wording to address usability and satisfaction of the mEMA application and the mPAT. The questionnaire consisted of items addressing the following: satisfaction, ease of use, learnability, and interface quality. Responses were on a Likert scale, and participants were able to provide additional comments. Higher ratings indicate better ratings of usability and acceptability.

#### **5.1.6 Data Collection**

Confidentiality was maintained by assigning all data collected a study specific identification number. EMA data collection, this identification number was used when creating individual profiles on the mEMA web-based portal. Once a profile was created and schedule of

assessments created by a research team member (KG), participants were provided with a unique mobile code to be entered into the mEMA application. The mobile code allowed participants to download the assigned schedule of assessments. When an assessment was completed and the participant pressed “upload” on the mEMA application, the data was sent to the mEMA web-based portal. No identifiable information, such as phone number or name, was transmitted. Instead, the mEMA web-based portal assigned a unique identification number to all assessment data linked to the mobile code. In order to distinguish between completed and missed assessments, the mEMA web-based portal coded each scheduled assessment as “true” for completed or “false” for missed.

#### **5.1.7 EMA Data Management**

The management of the EMA data involved extraction and cleaning. Extraction of data was completed for each participant individually as he/she completed the active tracking phase of the study. A research team member (KG) extracted data by logging on to the mEMA web-based portal and selecting the appropriate participant identifiable number. Data were downloaded in a long file form as a Microsoft Excel file. Cleaning of data included coding of scheduled assessments by week and time period. Additionally, when a participant’s data were extracted from the mEMA web-based portal item responses that were not selected by the participant were not identified in the extracted file. For instance, if a participant never selected “working” for the *Activity* item it was not present in the extracted file. To accurately analyze all participants as a group, it was necessary to identify unrepresented item responses and manually input them into the data file. Also, when participants selected “other” for an item, they were prompted by the mEMA application to explain further by typing in a description. A research team member

identified each instance “other” was selected and recoded it as an appropriate corresponding item response when available. For instance, a participant who selected “other” for the *Activity* item wrote “taking pills.” This was recoded as the *Activity* item response of “self-care.” Several participants identify pets as their response for the *Surrounding People* item, this was the only instance where an appropriate recode of an “other” response was unavailable. Finally, some participant data files contained errors, including duplicate item response columns and reporting of unscheduled assessments. A research team member contacted ilumivu for support to report these instances and to ensure that they were errors of the web-based portal. After confirming that the errors were a result of programming they were corrected by a research team member.

Four participants reported that the mEMA application failed on several occasions, resulting in no prompts being sent for scheduled assessments. These application failures were documented and will be discussed further in section **5.2.3.2 Usability and Acceptability**. The application failures resulted in scheduled assessments that were coded as missed; however, because the assessment was not missed due to the participant, as the error was in the application, the research team decided to remove these instances from the participant’s data. This resulted in an unequal number of observations across individuals. We did not exclude any subjects who took part in the active tracking phase of the study due to the completeness of their data. Specifically, individuals who had observations removed because the app failed to send a notification were not removed from the final analysis.

### **5.1.8 Analytic Plan**

Due to the exploratory nature of this study, descriptive statistics were used to examine all data collected. All statistical analyses were conducted using the Statistical Package for the Social

Sciences Software (SPSS, v 23). Frequencies, means and standard deviations were used to describe participant demographic information and baseline measurement data for all participants (n = 12). The analytic plan utilized to examine construct validity, feasibility and participation is presented in the following sections **5.1.8.1 Construct Validity**, **5.1.8.2 Feasibility**, and **5.1.8.3 Participation**.

#### **5.1.8.1 Construct Validity**

Construct validity is the degree to which the scores of an instrument are consistent with a priori hypotheses, which are based on the assumption that the instrument validity measures the construct of interest (Mokkink et al., 2009). Construct validity was assessed through an analysis of correlations between scores on the mPAT and PART-OS and Barthel Index. In order to establish construct validity, we examined both convergent validity and discriminant validity. Convergent validity holds that two measures believed to assess the same construct will be highly correlated (Portney & Watkins, 2009). Discriminant validity holds that measures that are believed to assess different constructs will have a low correlation (Portney & Watkins, 2009). The PART-OS was used because it is a measure of both frequency of participation and satisfaction with participation and is a valid and reliable measure in individuals with TBI (Whiteneck et al., 2011). The Barthel Index was selected because it is a measure of ADLs (Mahoney & Barthel, 1965). A correlation coefficient was used to examine the magnitude of the relationship between measures. Due to the small sample size of our study and the presence of outliers, we computed correlations using Spearman's rho, which does not require the assumption of normality (Hauke & Kossowski, 2011).

Spearman's rho correlation coefficients were computed between the mPAT Participation and Satisfaction Score and the PART-OS objective and subjective score (baseline, follow-up)

and the mPAT Participation Score and Barthel Index. A priori hypotheses were formulated, following COSMIN guidance (Mokkink et al., 2010a; Mokkink et al., 2010b). We hypothesized that there would be a strong positive relationship between the mPAT Participation Score and the PART-OS objective score (baseline, follow-up), and the mPAT Satisfaction Score and the PART-OS subjective score (baseline, follow-up), as both measures assess frequency of participation and satisfaction with participation. However, we hypothesized that the strength of the relationship between the mPAT scores and the PART-OS scores would be stronger for the PART-OS scores obtained at follow-up, as participants would be more mindful of their level of participation after the four-week active tracking phase. Because the mPAT and Barthel Index measure different constructs, we hypothesized that there would be a weak relationship between the mPAT Participation Score and the Barthel Index score. Effect sizes were also calculated. Effect sizes were interpreted using the following: 0.10 = small; 0.30 = medium; 0.50 = large (Cohen, 1992). Only participants who took part in the active tracking phase (n=10) of the study were used in these calculations.

#### **5.1.8.2 Feasibility**

##### ***Compliance***

Compliance rates were calculated as an indicator of the feasibility of EMA and our sampling approach. Compliance was defined as the number of completed assessments relative to the total number of prompted assessments, and resulted in a percentage. Means, standard deviations or frequencies were used, when appropriate, to examine compliance. The following variables overall, by week, and time period (Time Period 1, 8:00am – 12:00pm; Time Period 2, 12:00pm – 4:00pm; Time Period 3, 4:00pm – 8:00pm; and Time Period 4, 8:00pm – 10:00pm) were

examined: number of prompted assessments, number of assessments completed, number of missed assessments, and compliance rate. Based on findings of earlier research, a compliance rate of at least 70% was considered acceptable and supported the feasibility of our sampling approach (Dunbar, Scharf, Kirchner, & Shiffman, 2010; Kirk et al., 2013; Garcia et al., 2014; Juengst et al., 2015).

### ***Usability and acceptability***

As additional means of examining the feasibility of our sampling approach, as well as the delivery method (mEMA application), and measure (mPAT), we examined usability and acceptability. To examine preliminary usability and acceptability, means and standard deviations were computed to examine participant satisfaction with the mEMA application and the mPAT. Descriptive statistics were used to examine participants' responses to ease of use and learnability, and interface quality of the mEMA application and the ease of use and learnability of the mPAT.

#### **5.1.8.3 Participation**

Due to the exploratory nature of this study, descriptive statistics were used to examine participation as assessed using the mPAT and the dynamic aspects of participation. For the purpose of this study, the dynamic aspects were defined as variation in participation over time and by time of day. Descriptive statistics were used to examine the three scores of the mPAT: Participation Score, Importance Score, and Satisfaction Score. Means, standard deviations were used to explore the overall scores produced by the mPAT, and variation of scores over time and time of day. Frequency of responses to each item of the mPAT was examined. Frequency of

responses were used to examine types of participation participants are engaged in, but also to support the use of an item response list and potential revisions for future versions of the mPAT.

## 5.2 RESULTS

### 5.2.1 Participants

Twelve participants were enrolled in the study. Ten participants completed the study. One participant dropped out due to being unable to download the mEMA application on to his personal smartphone, and one was removed from the study because the mEMA application was not compatible with his smartphone. Because the protocol was not altered from the previous study, the three participants, from the beta testing study, were included in the analyses of this study. The demographic information for all participants (n = 12) are presented below in Table 24.

**Table 24.** Participant demographic information

	Frequency (%)	Means (SD)
<b>Age</b>		38.50 (13.53)
<b>Gender</b>		
Male	8 (66.7)	
Female	4 (33.3)	
<b>Race</b>		
Asian	1 (8.3)	
African American	1 (8.3)	
Caucasian	10 (83.3)	
<b>Marital Status</b>		
Single, never married	8 (66.7)	
Married or domestic partnership	4 (33.3)	

**Table 24. (continued)**

<b>Highest level of education</b>		
High school graduate	1 (8.3)	
Some college credit, no degree	3 (25.0)	
Trade/technical training	1 (8.3)	
Associate's degree	3 (25.0)	
Bachelor's degree	3 (25.0)	
PhD, law or medical degree	1 (8.3)	
<b>Employment status</b>		
Employed – Full time	1 (8.3)	
Employed – Part time	2 (16.7)	
Out of work - looking for work	2 (16.7)	
Out of work - not currently looking for work	7 (58.3)	
<b>Nature of Injury</b>		
Fall	6 (50%)	
Motor vehicle accident	6 (50%)	
<b>Time since injury (months)</b>		100.67 (154.78)
<b>Current treatment for depression</b>	6 (50.0)	
<b>PHQ – 9</b>		11.33 (4.87)
<b>Current treatment for anxiety</b>	7 (58.3)	
<b>GAD-7</b>		7.92 (5.12)
<b>Cognistat – MCI</b>		
MCI 2	5 (41.7)	
MCI 3	2 (16.7)	
MCI 5	1 (8.3)	
MCI 6	4 (33.3)	

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A majority of the participants (66.6%) owned their current smartphone for more than a year. Three participants (25%) reported their current smartphone to be their first smartphone. One participant did not own a smartphone, but had access to a smartphone. Of those participants who had previously owned a smartphone, a majority (90%) reported using a smartphone for three or more years. Seven participants (58.3%) reported using an Apple iPhone and five

(41.7%) reported using an Android smartphone. Ten participants (83.3%) reported using their smartphone for more than 60 minutes a day. All participants reported using their smartphone to make phone calls. Frequency of reported uses of smartphones for additional activities is presented in Table 25. Additionally, participants reporting using their smartphones for things such as taking notes, setting alarms, checking the time, navigation, and setting reminders or using the calendar application. Most participants (75%) agreed that their smartphone was easy to learn to use, that they were comfortable using their current smartphone (83.3%), were satisfied with the functionality their current smartphone (83.3%), and liked their smartphone (75%).

**Table 25.** Additional smartphone activities

<b>Activity</b>	<b>Frequency (%)</b>
Texting	11 (91.7)
Taking photos	11 (91.7)
Sending/checking Email	11 (91.7)
Browsing the internet	10 (83.3)
Listening to music	10 (83.3)
Managing daily activities	10 (83.3)
Playing games	8 (66.7)
Social networking	8 (66.7)

### 5.2.2 Construct Validity

Table 26 presents Spearman rho correlation coefficients between the mPAT Participation and Satisfaction scores and PART-OS (baseline, follow-up) and Barthel Index scores. A weak and non-significant correlation was found between the mPAT Participation Score and the baseline PART-OS objective score. Additionally, the effect size of the correlation was small ( $r^2 = .087$ ). However, the direction of the correlation was positive, indicating that as scores on the PART-OS increased, scores on the mPAT increased. A stronger correlation was found between

Participation Scores on the mPAT and follow-up PART-OS objective scores. Although the relationship was not statistically significant, the effect size was close to moderate ( $r^2 = 0.22$ ), suggesting that the PART-OS and the mPAT were measuring similar constructs. Additionally, the direction of the correlation was positive, again indicating that as objective scores on the PART-OS increase, Participation scores on the mPAT increased. As hypothesized, a stronger relationship was observed between the follow-up PART-OS objective score and the mPAT Participation Score.

**Table 26.** Correlation coefficients between the mPAT and PART-OS and Barthel Index

mPAT Score	PART-OS Objective (Baseline)	PART-OS Subjective (Baseline)	PART-OS Objective (Follow-up)	PART-OS Subjective (Follow-up)	Barthel Index
Participation Score	.295		.467		.195
Satisfaction Score		.539		.103	

A moderate-to-strong relationship was observed between Satisfaction Scores on the mPAT and the baseline PART-OS subjective scores. The effect size of this correlation ( $r^2 = .290$ ) was approaching a medium effect. Additionally, the direction of the correlation was positive, which indicates that as subjective scores on the PART-OS increase, Satisfaction Scores on the mPAT increased and findings support our hypothesis in part. However, there was a weak relationship between Satisfaction Scores on the mPAT and the follow-up PART-OS subject scores, and the effect size of this relationship ( $r^2 = .011$ ) was small. Findings do not support our hypothesis that the relationship would be stronger at follow-up.

As hypothesized, a weak relationship was found between mPAT Participation Scores and Barthel Index total scores ( $r_s = .195$ ,  $p = .590$ ). The effect size of this correlation was small ( $r^2 = .038$ ). Findings support that the two measures are assessing different constructs.

## 5.2.3 Feasibility

### 5.2.3.1 Compliance

Participants completing the active tracking phase of the study (n = 10) were scheduled to complete the mPAT via the mEMA application four times a day over a four-week period, for a total of 116 scheduled assessments per participant. As reported in section **5.1.7 EMA Data Management**, some notifications were not sent to participants due to mEMA application failure. Because participants were not prompted to complete assessments, these instances were removed from the final EMA data analysis. This resulted in an unequal number of observations; however, an equal number of observations were not necessary to complete the planned analyses.

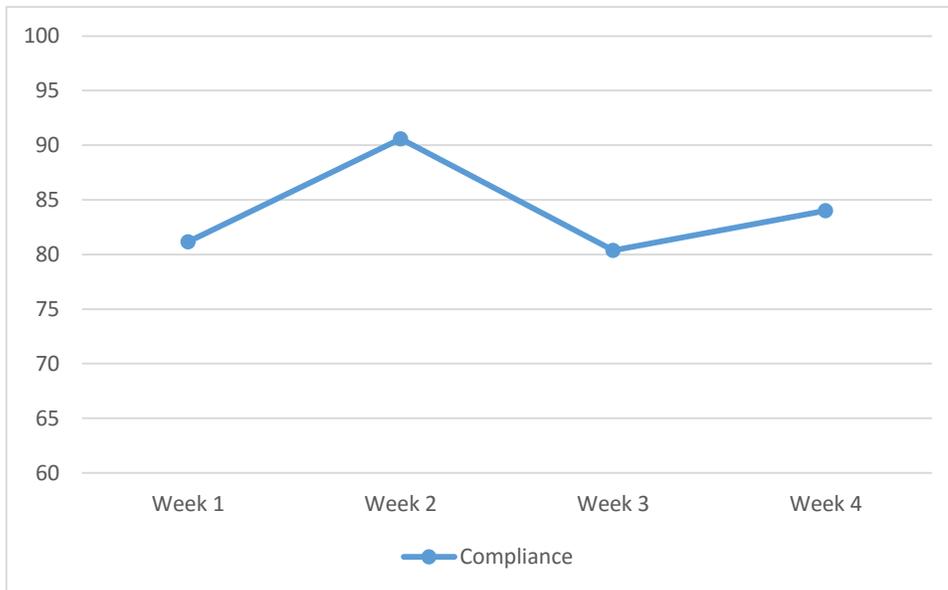
Compliance with the mEMA delivered prompts over the four-week sampling time period was good. The total number of prompts to complete the mPAT delivered to participants was 1067. The average number of prompts delivered per participant was 106.70 (SD = 15.26, Range = 72-116), with an average of 89.30 (SD = 21.09, Range = 48-112) of those answered, resulting in an average compliance rate of 82.92% (SD = 11.81, Range = 53.3- 96.6%). Table 27 shows the indices of compliance for the entire sampling period. When compliance was examined by week, some variation in compliance was observed. Table 28 shows the compliance indices by week. As can be seen from Figure 17, which presents compliance rates for each week, compliance rate increases at week two from the first week of sampling and falls again during the third week, but ultimately increases again during the final week of sampling. When weekly compliance rate is examined by participant (Figure 18), compliance rate does vary by week. However, with the exception of one participant, compliance rates remain strong for each week.

**Table 27.** Compliance variables

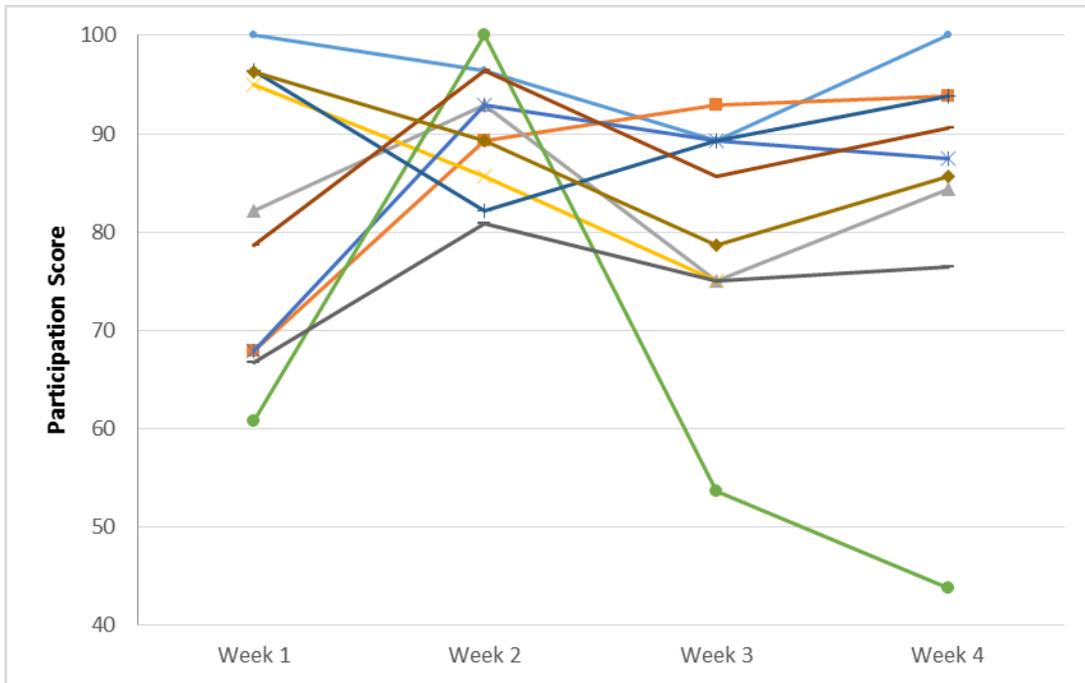
	<b>Means (SD)</b>
# of prompts	106.70 (15.26)
# of assessments answered	89.30 (21.09)
# of assessments missed	17.40 (10.29)
Compliance (%)	82.92 (11.81)

**Table 28.** Weekly compliance

	<b>Week1 Means (SD)</b>	<b>Week 2 Means (SD)</b>	<b>Week 3 Means (SD)</b>	<b>Week 4 Means (SD)</b>
# of prompts	27.00 (2.49)	25.20 (8.18)	27.60 (1.26)	29.89 (5.01)
# of assessments answered	21.80 (4.02)	22.60 (7.47)	22.20 (3.55)	25.22 (7.01)
# of assessments missed	5.20 (4.18)	2.60 (1.71)	5.40 (3.24)	4.67 (5.22)
Compliance (%)	81.16 (14.88)	90.58 (6.34)	80.37 (11.69)	84.01 (16.50)



**Figure 17.** Compliance rate by week

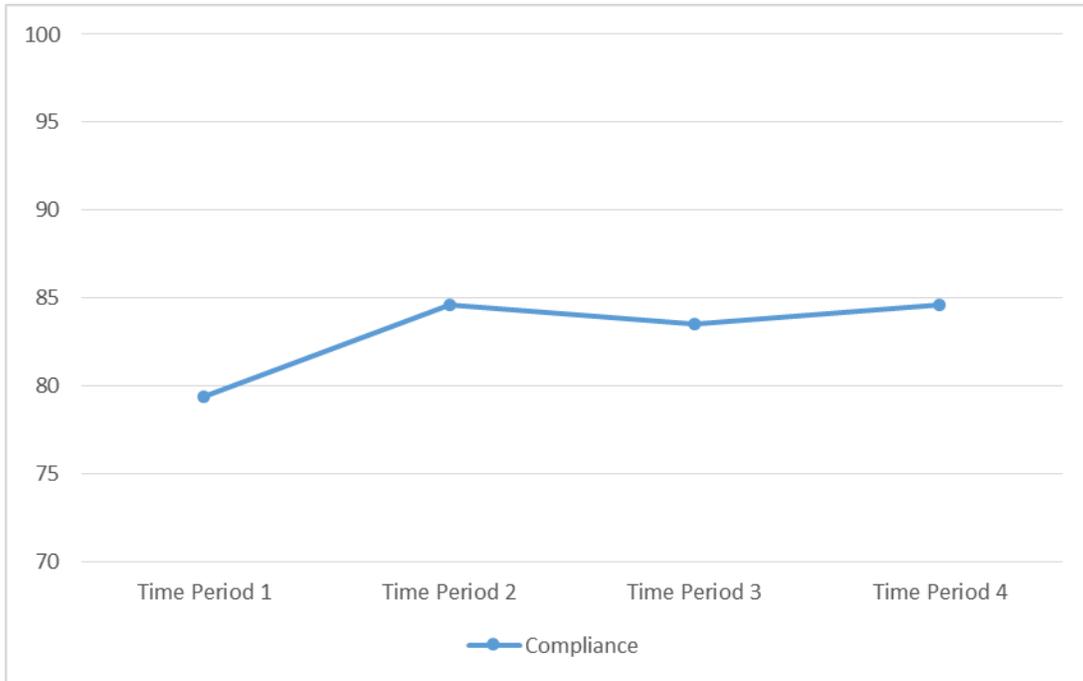


**Figure 18.** Compliance rate by week for all participants

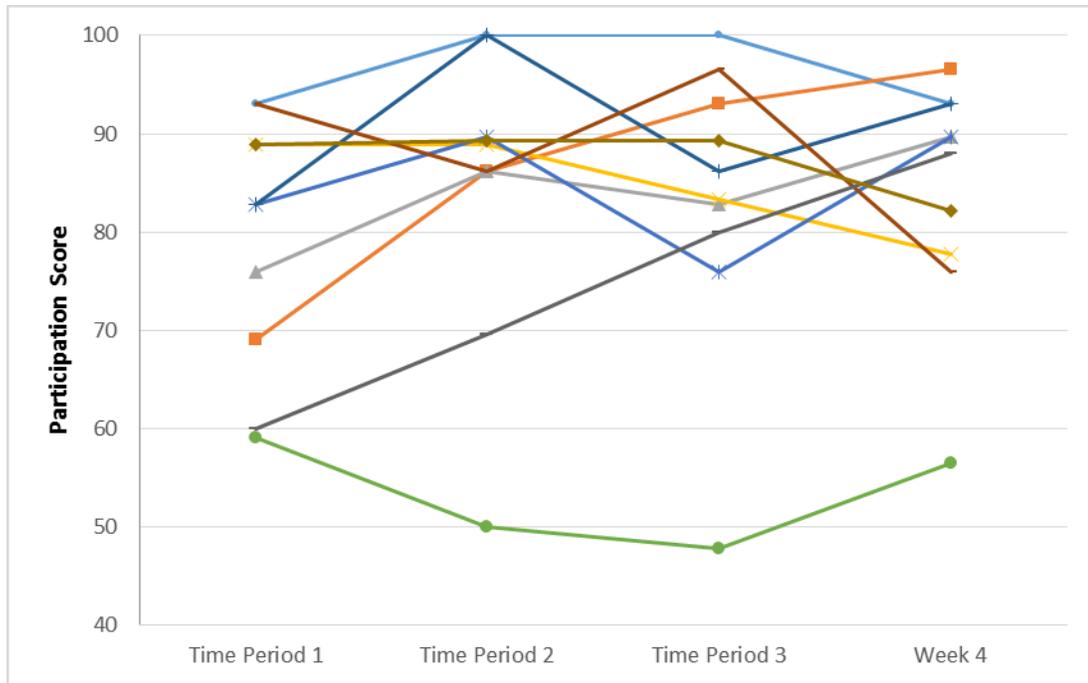
We also examined compliance by time period. Table 29 presents the compliance variables by time period. As shown in Table 29, the lowest compliance rate was seen during time period 1, which was between the hours of 8:00am and 12:00pm. This compliance rate ( $M = 79.36$ ;  $SD = 12.86$ ) was almost 4% lower than the average compliance rate for the group. The compliance rate for the remaining time periods are higher than the overall compliance rate, and is highest at time period 2 (12:00pm to 4:00pm). As seen in Figure 19, which presents compliance rates by time period, compliance rate is lowest at time point 1, but remains indicative of good compliance. However, when compliance rate by time period is examined for individual participants (Figure 20), the variability of compliance rates is more visible. Specifically, two participants (green and navy lines) do not follow the trends of other participants and the group.

**Table 29.** Time period percent compliance

	<b>Time Period 1 Means (SD)</b>	<b>Time Period 2 Means (SD)</b>	<b>Time Period 3 Means (SD)</b>	<b>Time Period 4 Means (SD)</b>
# of prompts	26.60 (3.84)	26.50 (4.01)	26.80 (3.74)	26.80 (3.74)
# of assessments answered	21.20 (5.01)	22.70 (6.13)	22.60 (5.80)	22.80 (5.35)
# of assessments missed	5.40 (3.17)	4.80 (5.27)	4.20 (3.43)	4.00 (2.71)
Compliance (%)	79.36 (12.86)	84.61 (14.80)	83.50 (14.61)	84.25 (11.87)



**Figure 19.** Compliance rate by time period



**Figure 20.** Compliance rate by time period for all participants

### 5.2.3.2 Usability and Acceptability

Weekly and follow-up telephone calls and surveys provided data regarding participants' views on the usability and acceptability of the mEMA application for delivery of the mPAT. Usability and acceptability data was also provided through these methods for the mPAT. During weekly phone calls participants were able to notify the research team of any mEMA application issues or failures. Table 30 presents the issues reported by participants. Of the 10 participants taking part in the active tracking phase of the study, four reported failures where the application stopped working. Application failure was reported five times. The date and times of application failure were documented and these instances were removed from the final EMA data analysis. An additional issue that was reported by several participants was the inability to hear the tone. Participants attempted to reset the default mEMA prompt tone, but reported being unable to change the default tone. The research team contacted mEMA application support requesting

guidance on changing the default prompt tone; however, no resolution was reached. As a result four participants scheduled additional alarms on their smartphone.

**Table 30.** Participant reported mEMA application issues and failures

Description of issue or failure	# times reported
Reports hearing the tone for the prompt but notification is not displayed on the screen	1
Prompt going off several minutes after it is scheduled	3
Notification “mEMA has stopped working”	1
Responding to the prompt on the smartphone did not open the mPAT questionnaire	1
Unable to hear the prompt tone	6
Not receiving scheduled prompts	6
mEMA application has frozen and unable to access	5

Means and standard deviations were examined for the mPAT ease of use and learnability, and satisfaction with the measure. Participants were asked to rate their level of agreement (1 = Strongly disagree, 2 = Disagree, 3 = Neither agree or disagree, 4 = Agree, 5 = Strongly agree) with statements. In regards to ease of use and learnability, participants reported on average that it was simple to use the mPAT (M = 4.80, SD = 0.42), and that it was easy to learn to use the mPAT (M = 4.50, SD = .527). Additionally, participants agreed that the instructions for the mPAT were clear (M = 4.90, SD = 0.32). Participants strongly agreed that the mPAT was simple and easy to understand (M = 5.00, SD = 0.00). Furthermore, on average participants agreed that the mPAT was an acceptable way to measure their participation (M = 4.30, SD = 1.06), and that overall they were satisfied with the mPAT as a measure of their participation (M = 4.20, SD = 1.03).

Participants provided feedback on additional items for the mPAT, including the addition of an item assessing level of enjoyment with what they are doing, and an item assessing mood at the time of assessment. For the *Activity* item, participants provided feedback on additional

possible response, including reading, cooking, texting, emailing, and taking pills. For the *Location* item, participants suggested the addition of volunteering location, sibling’s house, and grocery store. Several participants identified the addition of pets to the *Surrounding People* item. Other suggested responses for the *Surrounding People* item included, in laws, siblings and volunteers. Additional suggested changes to the mPAT included, 1) listing responses in alphabetical order, 2) ability to report how many people you are engaged with, 3) ability to just type in answers as opposed to list of responses, 4) have the opportunity to provide additional detail, 5) ability to explain why an assigned assessment was missed, and 6) additional response options for the satisfaction item. Participants also reported that the ability to select “other” for the *Activity*, *Location*, and *Surrounding People* items was helpful. Additional feedback on the mPAT is presented in Table 31.

**Table 31.** Participant verbal feedback on the mPAT

<b>Feedback</b>
Very well structured
The knowing it was going to be four times a day it was a good mental exercise. Motivated to do things throughout the day
The list is fairly comprehensive. It was a great idea to have an “other” option.
I didn’t understand why the satisfaction question was there
I would like to have it go longer.
It would be a good thing for my therapist to see how I’m doing. She would have a big picture of who my life is going.
It was clear cut
Didn’t catch everything you’re doing in a day, but might get it next time
It’s a good measuring tool of when people are doing something and when they aren’t

Means and standard deviations were examined for the mEMA application’s ease of use and learnability, as well as satisfaction with the application. In regards to ease of use and

learnability, on average participants somewhat agreed that they could easily access assessments using the mEMA application (M = 3.80, SD = 1.03). Participants on average agreed that it was simple to use the mEMA application (M = 4.30, SD = 1.25), that it was easy to learn to use the mEMA application (M = 4.50, SD = 0.71), and that it was simple and easy to understand (M = 4.40, SD = 0.70). Additionally, on average participants agreed that they felt comfortable answering questions using the application (M = 4.60, SD = 0.52), and that it was an acceptable way to answer questions (M = 4.60, SD = 0.52). Participants on average also agreed that they would use the mEMA application again (M = 4.10, SD = 1.29), and overall were satisfied with the application (M = 4.00, SD = 1.16). Participants' feedback on the mEMA application is presented in Table 32.

**Table 32.** Participant verbal feedback on the mEMA application

Feedback
Nice that you could go back and read the instructions
The volume of the app is not as loud
Sometimes it worked, sometimes it didn't
Unreliable
Things are working well
The first notification didn't always come when the assessment was scheduled
Would recommend using a different app
Not very user friendly
Very frustrated with the app
Pretty straight forward
It's going smooth

#### 5.2.4 Participation

We were interested in examining the construct of participation, as assessed by the mPAT and EMA methods. For the analyses we focused on the three scores: Participation Score, Importance Score, and Satisfaction Score. The Participation Scores are derived by the developed scoring

algorithm. As with the feasibility analyses, there was an unequal number of observations across participants; however, because the final scores are expressed as either a percentage or mean, an equal number of observations were not necessary to proceed with the planned analyses.

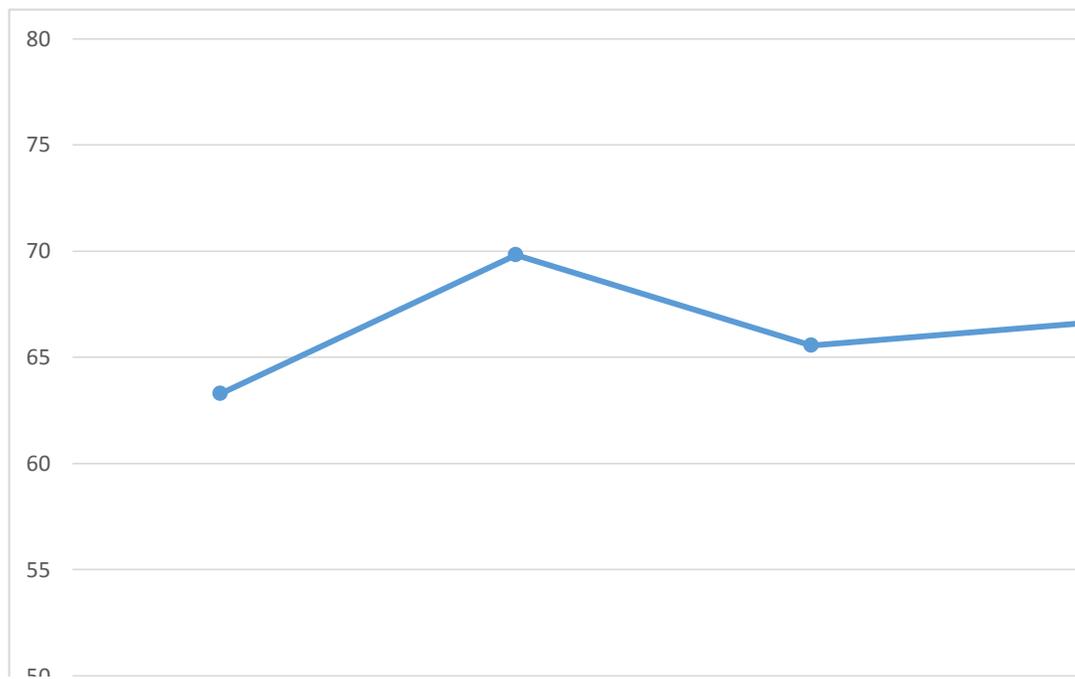
#### **5.2.4.1 mPAT Participation Score**

The mPAT was completed a total of 893 times and of those observations 590 (66.1%) were coded by the scoring algorithm as being representative of participation. The number of mPAT observations, observations coded as not participation and participation, as well as Participation Scores were calculated for each participant ( $n = 10$ ). Participants completed an average of 89.30 ( $SD = 21.09$ ) mPAT observations. Of these observations the scoring algorithm coded an average of 30.30 ( $SD = 12.32$ ) as not participation and 59.00 ( $SD = 24.28$ ) as participation. The average Participation Score for participants was observed to be 63.50% ( $SD = 19.76$ , Range = 31.3-90.4%).

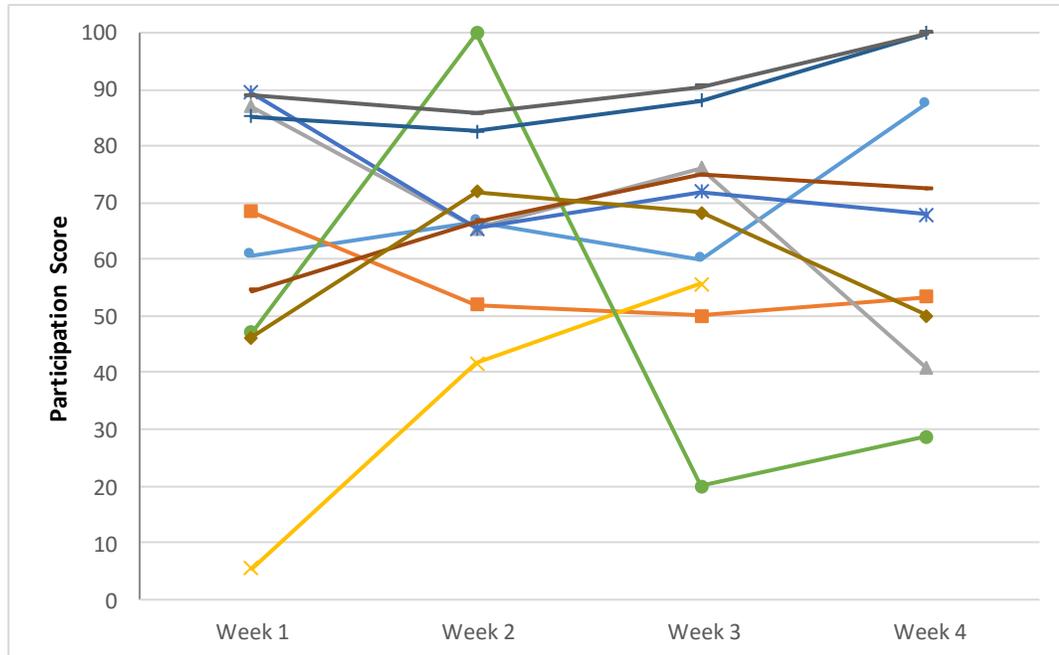
Participation scores were also examined by week and time period. mPAT observations means and standard deviations, by week and by time period, are presented in Table 33 and Table 34 respectively. The highest average Participation Score is seen in the second week of sampling, and is over six percentage points higher than the Participation Score for the entire sampling period. Additionally, weeks three and four are also higher than the Participation Score for the sampling period. As shown in Figure 21, the average Participation Score varies by week. Additionally, participation score variability by week for each participant, as shown in Figure 22, shows that this variation was also present between participants.

**Table 33.** Participation by week

	<b>Week 1</b>	<b>Week 2</b>	<b>Week 3</b>	<b>Week 4</b>
	<b>Means (SD)</b>	<b>Means (SD)</b>	<b>Means (SD)</b>	<b>Means (SD)</b>
# of observations	21.80 (4.02)	22.60 (7.47)	22.20 (3.55)	25.22 (7.01)
# of not participation observations	7.90 (5.45)	7.60 (4.22)	7.30 (3.59)	8.11 (5.75)
# of participation observations	13.90 (6.26)	15.00 (5.35)	14.90 (5.34)	17.11 (8.34)
Participation Score	63.28 (26.69)	69.82 (16.66)	65.55 (20.61)	66.71 (25.67)



**Figure 21.** Participation score by week

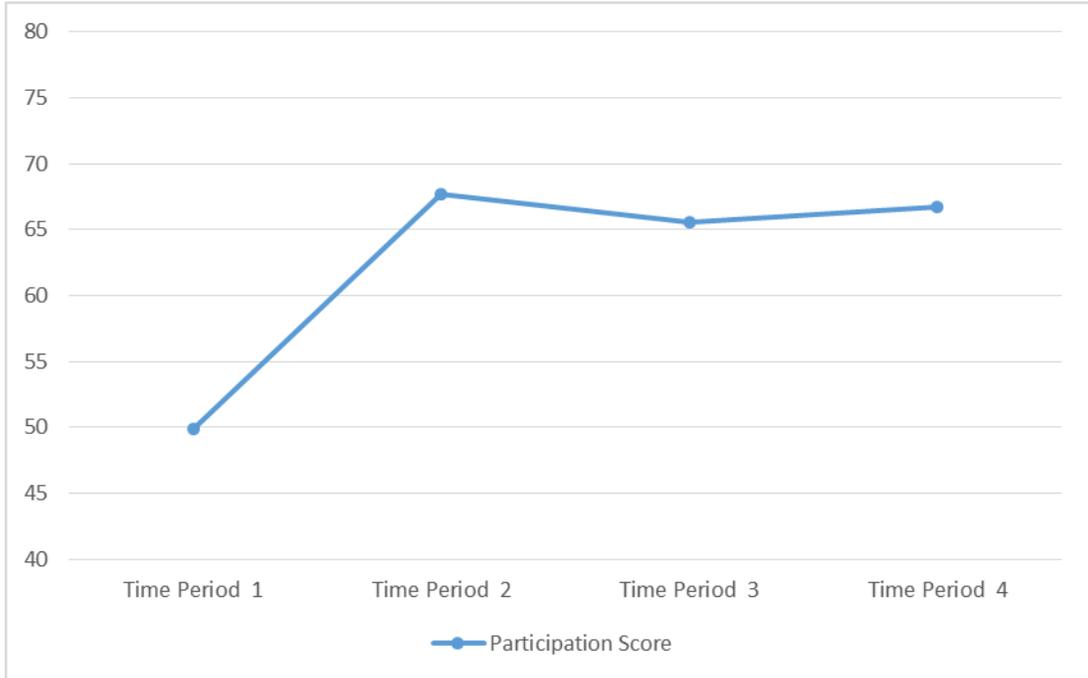


**Figure 22.** Participation score by week for each participant

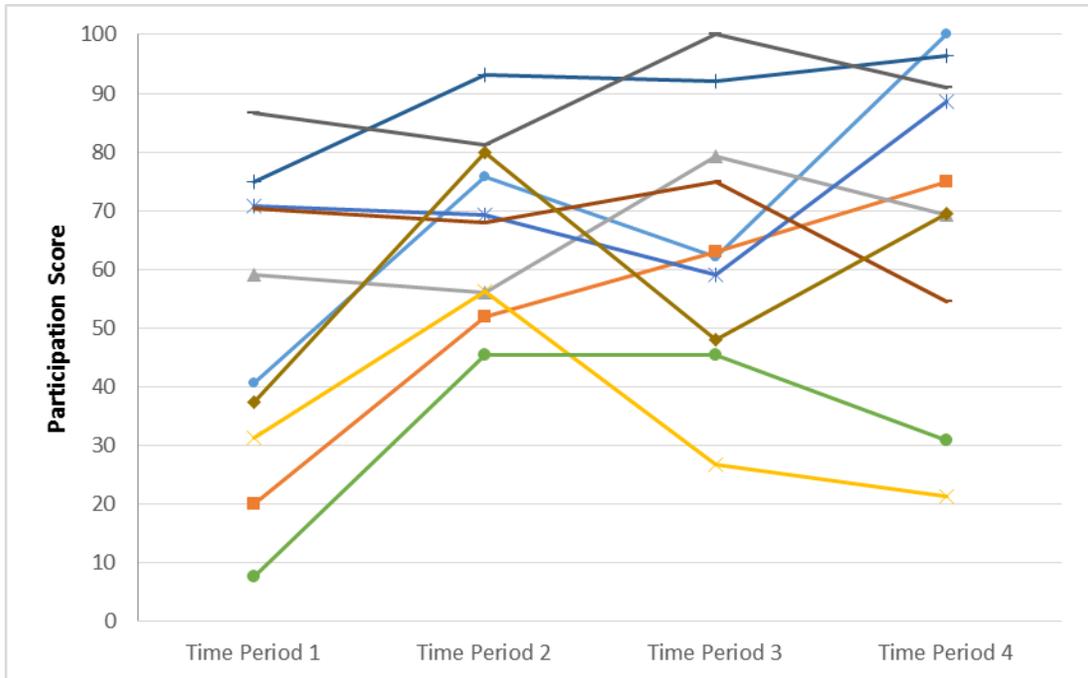
Participation Scores also differed by time period. The lowest average Participation Score was observed at time period 1 (8:00am to 12:00pm), and is nearly 14 percentage points lower than average Participation Score for the sampling period. The highest average Participation Score was seen at time period 4 (8:00pm to 10:00pm). As shown in Figure 23, the average Participation Score varied by time period. Additionally, participation score variability by time period for each participant, as shown in Figure 24, shows that this variation was also present between participants.

**Table 34.** Participation by time period

	Time Period 1 Means (SD)	Time Period 2 Means (SD)	Time Period 3 Means (SD)	Time Period 4 Means (SD)
# of observations	21.20 (5.01)	22.70 (6.13)	22.60 (5.80)	22.80 (5.35)
# of not participation observations	10.20 (4.66)	6.90 (3.14)	7.40 (4.20)	5.80 (3.97)
# of participation observations	11.00 (6.20)	15.80 (6.41)	15.20 (6.56)	17.00 (8.39)
Participation Score	49.92 (26.22)	67.73 (15.12)	65.06 (22.21)	69.62 (26.94)



**Figure 23.** Participation Score by time period



**Figure 24.** Participation score by time period for each participant

#### 5.2.4.2 mPAT Importance Score

Importance was rated on a five point Likert scale (1 = not important, 2 = slightly important, 3 = moderately important, 4 = important, 5 = very important). The average Importance Score of participation observations was 3.95 (SD = 1.24) and is representative of ratings of importance between moderately important to important. Importance Scores were also examined by week and by time period and are presented in Table 35 and Table 36 correspondingly. The average Importance Score was lowest during the third week of sampling and highest at the final week. Additionally, the average Importance score was lowest during time period 4 (8:00pm to 10:00pm) and highest for time period 1 (8:00am to 12:00pm).

**Table 35.** Importance score by week

	<b>Mean (SD)</b>
Week 1	4.01 (1.29)
Week 2	3.92 (1.30)
Week 3	3.71 (1.33)
Week 4	4.15 (0.99)

**Table 36.** Importance score by time period

	<b>Mean (SD)</b>
Time Period 1	4.23 (1.11)
Time Period 2	4.04 (1.17)
Time Period 3	3.84 (1.28)
Time Period 4	3.78 (1.30)

#### 5.2.4.3 mPAT Satisfaction Score

Satisfaction was rated on a five point Likert scale (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied or dissatisfied, 4 = satisfied, 5 = very satisfied). The average Satisfaction Score of participation observations was 4.06 (SD = .084). Average Satisfaction Scores were also examined by week and by time period and are presented in Table 37 and Table 38

correspondingly. The average satisfaction score was highest during the final week of sampling and during time period 1 (8:00am to 12:00pm), while the lowest average Satisfaction Scores was observed during the third week and time period 2 (12:00pm to 4:00pm) and time period 3 (4:00pm to 8:00pm).

**Table 37.** Satisfaction score by week

	<b>Mean (SD)</b>
Week 1	4.04 (0.83)
Week 2	4.10 (0.91)
Week 3	3.98 (0.80)
Week 4	4.12 (0.79)

**Table 38.** Satisfaction score by time period

	<b>Mean (SD)</b>
Time Period 1	4.12 (0.78)
Time Period 2	4.03 (0.88)
Time Period 3	4.03 (0.85)
Time Period 4	4.08 (0.82)

#### **5.2.4.4 Frequency of responses**

We examined the frequency of responses for the mPAT items of *Activity*, *Location*, and *Surrounding People*. For the *Activity* item the most selected response was watching television (23.2%), followed by other (16.4%), communicating/conversation (13.1%), and resting/sleeping (11.6%). Table 39 presents the frequency with which each response was selected for the *Activity* item. All possible responses were selected at least twice by participants.

**Table 39.** Frequency of activity

<b>Activity</b>	<b>Frequency (%)</b>
Watching television	207 (23.2)
Other	146 (16.4)
Communicating/conversation	117 (13.1)
Resting/sleeping	104 (11.6)
Travel – riding in or driving a vehicle	99 (11.1)
Working	96 (10.8)
Eating	93 (10.4)
Listening to music	67 (7.5)
Socializing	54 (6.0)
Self-care	52 (5.8)
Doing a hobby	47 (5.3)
Using the internet	37 (4.1)
No activity	33 (3.7)
Rehabilitation/therapy appointment	29 (3.2)
Preparing a meal	29 (3.2)
Watching sports	25 (2.8)
Playing (i.e. board game, video game, cards, etc.)	25 (2.8)
Engaging with pet(s)	24 (2.7)
Shopping	24 (2.7)
Studying	22 (2.5)
Doing housework	19 (2.1)
Exercising	19 (2.1)
Doing homework	14 (1.6)
Assisting others	13 (1.5)
Playing sports/recreation	12 (1.3)
Learning	10 (1.1)
Medical/dental appointment	8 (0.9)
Volunteering	7 (0.8)
Doing a craft	6 (0.7)
Attending religious/spiritual service	6 (0.7)
Attending an arts or cultural event	4 (0.4)
Paying bills	3 (0.3)
Attending religious/spiritual event	2 (0.2)
Caring for children	2 (0.2)
Physical intimacy	2 (0.2)

For the *Location* item, home (57.2%) was the most selected response, followed by transportation vehicle (12.1%), outside (11.5%), and work (6.4%). The following responses were never selected by participants: library, movie theater, museum and art gallery. Table 40 presents the frequency with which each response was selected for the *Location* item.

**Table 40.** Frequency of location

<b>Location</b>	<b>Frequency (%)</b>
Home	511 (57.2)
Transportation vehicle	108 (12.1)
Outside	103 (11.5)
Work	57 (6.4)
Relative's home	57 (6.4)
Shop/store	42 (4.7)
Other	39 (4.4)
Rehabilitation facility	37 (4.1)
Block/neighborhood	16 (1.8)
Friend's home	14 (1.6)
Restaurant	14 (1.6)
Hospital/medical facility	11 (1.2)
Gym	11 (1.2)
Religious facility	8 (0.9)
Distant relative's home	2 (0.2)
Sporting event venue	2 (0.2)
Coffee shop	1 (0.1)
Bar	1 (0.1)
School	1 (0.1)
Theater	1 (0.1)
Movie theater	0 (0)
Museum	0 (0)
Library	0 (0)
Art gallery	0 (0)

For *Surrounding People*, alone (42.2%) was the most frequently selected response, followed by family (20.4%), spouse/partner (14.7%) and significant other (11.2%). Each response for the *Surrounding People* item was selected at least once. Table 41 presents the frequency of each response selected for the *Surrounding People* item.

**Table 41.** Frequency of surrounding people

<b>Surrounding people</b>	<b>Frequency (%)</b>
Alone	377 (42.2)
Family	182 (20.4)
Spouse/partner	131 (14.7)
Significant other	100 (11.2)
Friend(s)	75 (8.4)
Unknown people	43 (4.8)
Other	38 (4.3)
Acquaintance(s)	34 (3.8)
Professional(s)	29 (3.2)
Peer(s)	20 (2.2)
Medical professional(s)	17 (1.9)
Caregiver (paid)	10 (1.1)
Distant relative	7 (0.8)
Coworker(s)	7 (0.8)
Classmate(s)	1 (0.1)

### **5.3 DISCUSSION**

Recent advances in smartphone application technology provide new opportunities for efficient and effective ecologically valid assessment of a variety of outcomes. Our study aimed to examine the use of a participation assessment developed specifically to be delivered via EMA techniques and methodologies in individuals living in the community following TBI. We addressed three primary questions with the EMA data: (1) does the mPAT demonstrate construct validity? (2) can EMA techniques and methodologies be used in a TBI population? and (3) what does participation as measured by the mPAT look like in a TBI population? Our hypotheses in regards to the construct validity of the mPAT were partially supported. The data suggested that individuals with TBI who were found to have cognitive impairment can adhere to EMA, and that it was a usable and acceptable means to assess participation. Additionally, evaluation of mPAT

participation scores preliminarily supports the measurement of participation as a dynamic construct.

### **5.3.1 Insights Gained from EMA**

#### **5.3.1.1 Construct Validity**

We hypothesized that there would be a strong and positive relationship between scores on the mPAT and the PART-OS, and that there would be a weak relationship between mPAT Participation Scores and the Barthel Index scores. Data supported our discriminant validity hypothesis, as a weak relationship was found between the mPAT Participation Scores and Barthel Index scores. This suggests that the two assessments measure different constructs.

The correlations between the mPAT scores of participation and satisfaction and the PART-OS objective and subjective scores were not as straightforward. A positive relationship was found between scores on both measures, indicating that as scores increased correspondingly. However, the strength of the relationship did not fully support our hypothesis. We hypothesized a strong correlation, but found moderate and weak correlations between the scores on the measures. Nevertheless, as hypothesized, we did observe a stronger correlation between the mPAT Participation Scores and the PART-OS objective scores obtained at follow-up. Conversely, we observed a weaker correlation between the mPAT Satisfaction Scores and the PART-OS subject scores obtained at follow-up.

Our findings may be explained by the different types of memory relied upon to complete the measures. EMA measures are proposed to rely on episodic memory, while traditional recall-based measures rely on semantic memory (Robinson & Clore, 2002; Stone et al., 2007). The different types of memory used to report on the construct may result in different views of the

same construct. Stone and colleagues (2007) suggest that further research is needed to better understand the mechanism of the differences found between EMA and recall-based assessment approaches.

Our findings may be further explained by the ways in which participation and satisfaction with participation are measured by the mPAT and the PART-OS. While both tools assess frequency of participation and average satisfaction, the approach is different. The PART-OS aggregates “typical” frequency of participation in a variety of domains (Whiteneck et al., 2011). This means that if an individual does not engage in a wide variety of participation domains that his/her score can be affected. For instance, an individual who engages in work and familial socializing at a high rate may have a lower score than someone who engages in a wide range of participation domains infrequently. On the other hand, the mPAT Participation Score is not impacted by variety of participation, but is impacted by the sampling method’s ability to sample moments of participation.

Similarly, differences in how satisfaction is assessed by these tools, may explain the strength of the relationships. The PART-OS assess satisfaction by asking individuals to rate their satisfaction with a variety of activities, regardless of whether or not the individual is currently engaged in them (Whiteneck et al., 2011). For example, individuals who rate having paid or unpaid work as important are asked how satisfied they are with this area of their life. If the individual is unemployed, they may rate their level of satisfaction as low, which would result in a lower subjective score on the PART-OS. On the other hand, the mPAT assess satisfaction with only participation activities the individual is currently engaged in.

Type of memory used to answer questions and assessment approach may explain why only moderate correlations were found between the mPAT and PART-OS. The positive

direction and moderate correlation found in this study are promising indicators that the mPAT is assessing the intended construct of participation and satisfaction with participation.

We hypothesized that the strength of the relationship between scores on the mPAT and PART-OS would be stronger at follow-up as compared to baseline. An individual's ability to accurately and unbiased recall is questionable (Stone, Shiffman, & DeVries, 2000). A wide range of heuristic strategies (e.g. recency, state biases, aggregation) are used by individual's to recall information (Stone et al., 2007). We believed that these would have a greater impact on the individual's report at baseline administration of the PART-OS, resulting in a lower correlation with scores on the mPAT. On the other hand, we believed that the heuristic strategies of availability and recency would result in a stronger correlation between scores on the mPAT and the follow-up administration of the PART-OS (Joffe, MacDonald, & Kutcher, 1989; Shiffman et al., 1997). While our hypothesis was supported for the mPAT Participation Scores and PART-OS objective scores, we did not find an increase in relationship strength for the mPAT Satisfaction Scores and PART-OS subjective scores.

Our findings may be explained by the same heuristic strategies we believed would support our hypothesis. Follow-up administration of the PART-OS may be impacted by the availability and recency of information the individual is being asked to recall. Because participants were asked to answer questions about their participation and satisfaction with participation four times a day for four weeks, they may be better able to recall this information at follow-up. The weaker relationship between satisfaction scores at follow-up may be a result of participant's being more aware of their frequency of participation and as a result impact their report of satisfaction with domains of participation they are or are not engaged in.

### **5.3.1.2 Feasibility**

Compliance over the sampling time-frame was comparable to previous research, and indicative of good compliance (Dunbar et al., 2010; Kirk et al., 2013; Garcia et al., 2014; Juengst et al., 2015). Despite observed variation in compliance when examined by week and time period, rates remained suggestive of good compliance. These findings preliminarily suggest that the sampling method and approach used in this study is feasible in individuals with TBI, who demonstrate at minimum mild levels cognitive impairment.

However, when individual compliance rates were examined by time period, the variation of compliance rates was more distinct, with participants showing different patterns of compliance. For the majority of participants, compliance rates remained good despite variation. However, for two participants low compliance rates were found. This may be due to individual differences in routine and schedule. For instance, one participant reported that the late evening time period (8:00pm to 10:00pm) was inconvenient due to his medication schedule. In order to increase compliance, and thus increase the utility of the mPAT, future studies should employ a sampling strategy that takes the individual's routine and daily schedule into account by asking participants to identify a time-frame that is conducive with his/her daily schedule.

Additionally, despite reported issues with the mEMA application participants reported agreement with the usability and acceptability of the mEMA application as a delivery system and the mPAT as a measure of participation. This study demonstrates the initial feasibility of the use of EMA techniques and methodologies to assess participation in a TBI population living in the community with cognitive impairment.

### **5.3.1.3 Participation**

The mPAT was scheduled to be completed 116 times over a four week period at a rate of four times each day. This means that the mPAT had had the potential to capture an observation of participation 116 times per individual. The highest Participation Score possible is 100, in our sample the average Participation Score was 63.50%. Findings of this study provide initial support for the ability of the mPAT to assess participation, and the mPAT's ability to detect variation in participation rates over time and throughout the day. A wide range of Participation Scores were found between individuals, and variation was also observed over time and time periods.

Furthermore, the average Participation Score varied somewhat by sampling week and time period, reasonably indicating that rates of participation may vary over time and time of day. The mPAT was able to identify variability of participation by week, suggesting that frequency of participation is dynamic over time. At any given time-frame someone could be participating more or less. However, the minimal difference in Participation Scores from week to week in our sample support the use of an average score and our sampling approach as a means of assessing participation. In addition, the differences in participation by time period are an intriguing finding. In our sample participation was lowest between 8:00am and 12:00pm but increased over the remaining time periods, suggesting that participation is variable throughout the day. When we look at participants individually, the variation by week and time period is even more apparent. This suggests that not only is participation variable over time, but it is variable between individuals over time. This supports the use of the mPAT in future studies, as well as its potential to detect change over time.

Interpretation of the Participation Score should be tempered by the Importance and Satisfaction Scores. While it might be simple to say that a higher Participation Score is intrinsically better, how important participation is and how satisfied an individual is with their participation is also meaningful. For instance, an individual who is a single mother, working 60 hours a week may have an mPAT Participation Score of 90%, an Importance Score of 4.5, but a Satisfaction score of 2.3, indicating that on average they are not satisfied with their participation. Using the information collected by the mPAT, we could then find what the individual is doing when she rates her satisfaction as low but importance as high. This information could be used by researchers and clinicians in the development of interventions, individual goal setting and treatment, and as a means of measuring the effectiveness of intervention.

As found in our sample the average mPAT Participation Score of 63.50% was accompanied by an average Importance Score of 3.95 and average Satisfaction Score of 4.06. The average Importance Score falls in the range of moderately important to important and the Satisfaction Score is indicative of feeling satisfied. This would suggest that while the average Participation Score may appear low, in comparison to the highest possible score, that our sample felt their participation was important and were satisfied with their participation. We would caution that these findings are preliminary and from a small sample of individuals, and as such further research is needed to accurately interpret the scores produced by the mPAT.

Finally, in our sample, individuals most frequently reported being at home and being alone, which supports previous EMA measurement of participation study findings (Seekins et al., 2007). Engaging with family, a spouse/partner or significant other represented 46.3% of the *Surrounding People* reports. For our sample, this suggests that individuals with TBI are most

often home, and alone or with a close family member or significant other and not engaged in the community or social engagement outside of those closest to them.

Frequency of item response reporting supports the use of a list of responses as well as the use of an “other” response option, as it allows participants to explain activities, locations, or people they are engaged with in further detail if it is not represented on the list. The frequency rates can also be used to re-order lists to have those responses most frequently selected at the top of each response list.

### **5.3.2 Insights Gained from Participants**

Participants provided a wealth of information and feedback in regards to the usability and acceptability of the mEMA application as a delivery system and the mPAT as a measure of participation. Overall, participants supported the use of the mPAT as a means of assessing their participation. Their suggestions to add possible item responses or questions will be useful in future versions of the mPAT. Of interest, was the number of times participants reported pets as the “other” descriptor for the *Surrounding People* item. It raises the question of whether or not engaging with pets is representative of participation?

Despite several issues with the mEMA application (e.g. volume of prompt tone, application failure), participants reported willingness to use the application again, or as one participant suggested finding a more reliable application for assessment. Only one participant reported that the time-frame for assessment was a burden, but future studies should consider employing an individualized time-frame for assessment.

### **5.3.3 Insights Gained from Ilumivu**

The ilumivu mobile application and web-based portal were selected for use in this study because it was an “off the shelf” system that when purchased participants could download the mobile application for free. Additionally, the system was designed specifically to deliver and collect EMA assessments. Furthermore, it was advertised to have all of the features necessary to deliver our tool and appeared to be a good fit for our population. Unfortunately, for some participants the mEMA application was unreliable, resulting in unreliable data collection. Also, the data extraction and cleaning process was labor intensive and would not translate easily to clinical use. Each time a data file for a participant was downloaded a member of the research team spent a minimum of 30 minutes cleaning the data and ensuring that the date and time stamps were the same as the originally scheduled assessments.

### **5.3.4 Limitations**

There are several limitations to this study. These data represented a small sample of adults with TBI, living in the community with evidence of cognitive impairment. Therefore, generalization to the broader TBI population should be cautioned and results should be validated in a largest sample. Of the 12 participants involved in this study, a greater representation of individuals who demonstrated mild cognitive impairment (58.4%) on assessment took part in this study. Future research should be conducted among those experience more severe cognitive impairments to determine the feasibility of EMA in TBI. Additionally, investigation of the interaction between cognitive impairment and feasibility of EMA and participation in a TBI population is necessary.

Application issues and failures may have impacted the compliance of some participants. While weekly phone calls made by a research team member allowed us to identify and fix issues as they arose, in some cases a number of days went by before we were made aware of the issue. Additionally, some participants contacted the research team to report issues. This increased the burden of participants and may impact compliance with this type of assessment.

The sampling approach employed in this study does not provide a complete picture of every instance of participation, but an average over a time period. It is possible that moments of participation were missed, or that the same act of participation was sampled more than once. Additionally, the reliance on the reliability of the scoring algorithm to accurately code observations as participation or not participation is a limitation of this study. The definition of participation used in this study was the driving force of the development of the scoring algorithm and may be skewed by the research team and the expert review panel. Therefore, it may be beneficial to further examine the reliability and validity of the mPAT and scoring algorithm. .

## **6.0 SUMMARY**

The current project aimed to develop and provide support for a novel measure of participation that could be delivered through EMA techniques and methodologies and to develop an accompanying scoring algorithm for individuals with TBI. The Mobile Participation Assessment (mPAT) version 2 and revised scoring algorithm were developed throughout the course of these dissertation studies. The preliminary psychometric properties of the mPAT and scoring algorithm are promising and support further research of this tool. Additionally, feasibility of employing EMA techniques in a TBI population was further supported by this project. Individuals with TBI demonstrated good compliance and supported the usability and acceptability of the mPAT and a smartphone application as a means of delivering the measure.

The mPAT was able to detect observations of participation in individuals with TBI living in the community when the revised scoring algorithm was applied to collected observations. Additionally, the sampling method employed showed preliminary support for the dynamic nature of participation. These findings lend preliminary support for future research of the mPAT as well as the implementation of the mPAT as a measure of participation following TBI.

## **6.1 IMPLICATIONS**

### **6.1.1 Ecological Momentary Assessment of Participation**

EMA of participation via the mPAT is a promising means of assessing this important outcome. The rehabilitation process is often highly individualized. However, our current methods of measuring outcomes are rigid and often compare individuals to a typical population. As a result, meaningful improvements in important outcomes may be undetected or underrepresented. Utilizing EMA techniques and methodologies to assess participation may allow us to gain a more ecologically valid assessment of construct as well as provide additional contextual information that may have mediating effects. The mPAT and this project are a preliminary step in determining the feasibility of EMA of participation.

### **6.1.2 Clinical Utility**

The ability to assess clients in real-time, in their natural environment allows clinicians to gather a wealth of information. A tool such as the mPAT may be able to be used as a way to monitor participation more effectively and accurately than traditional measures. The mPAT provides information about frequency of participation, importance of participation to the individual, and the individual's level of satisfaction with their participation. Additionally, contextual information such as where individuals are participating and with whom they are participating is also gathered using the mPAT. This depth and scope of information is unique to the mPAT and sets it apart from traditional measures. Furthermore, the ability to review data in real-time is a unique and potentially valuable aspect of the tool. Clinicians would be able to monitor or review

client's responses to the mPAT in real-time and prior to scheduled appointments. This could allow clinicians to be proactive in developing treatment plans and goals to review with clients.

Information gathered using the mPAT could be used to inform clinical decision making, and goal setting and as a means of measuring goal attainment. However, in its current format and means of delivery the mPAT is labor intensive and would require a significant amount of attention from clinicians. Therefore, further research and development is necessary before the mPAT is ready for clinical use.

## **6.2 FUTURE DIRECTIONS**

Results from this project provide preliminary support for both the use of EMA in TBI and the EMA of participation in this population, and as such supports further research. Potential future directions for this project are listed in the following sections.

### **6.2.1 Secondary Data Analysis**

Prior to conducting new research protocols, the current dataset can be used to further examine findings in the form of a secondary data analysis. Secondary analysis of this dataset allows for the further examination of the sampling approach and of the scores produced by the mPAT. This dataset allows for further examination of the EMA sampling approach, specifically examination of the differences observed in compliance and participation over time and by time of day. The diversity of our sample also allows for the examination of the effect of participant specific information on Participation Scores. For example, do mPAT scores differ between levels of

cognitive impairment, presence of depression, or time since injury? Compliance rate could also be examined by these participant characteristics.

The mPAT produces three scores (Participation, Importance, and Satisfaction), this dataset can be used to examine the relationship between participation and importance and participation and satisfaction, and the evaluation of differences between importance and satisfaction ratings of non-participation observations. Finally, the scoring algorithm produces the final Participation Score by identifying two levels of participation and not participation. This dataset allows for the examination of frequency of these levels and frequency of observations coded as more than one level. These analyses could further inform our understanding of participation after TBI.

### **6.2.2 Future Research**

Findings of this project support future research of the mPAT as a measure of participation. The mPAT has the potential to become a widely used measure participation and fill a gap in our understanding of participation. However, further examination of the measurement properties of the mPAT is a necessary next step. Following COSMIN guidance, the responsiveness and interpretability of the mPAT should be examined (Mokkink et al., 2009). Responsiveness is an important measurement property in an outcome score, as it is an indicator of the tools ability to detect when the individual is experiencing relevant clinical change (Mokkink et al., 2010a; Mokkink et al., 2010b). Interpretability of scores, or the degree to which qualitative meaning can be assigned to scores produced by the tool, is an equally important next step (Mokkink et al., 2009). Floor and ceiling scores for the three mPAT scores are possible, indicating a possibility

to measure improvements and decline in participation, importance, and satisfaction over time. However, further research is needed in order to establish these measurement properties.

Additionally, examination of the sampling approach, including the duration and frequency of sampling as well as the sampling method (i.e. time-based versus event-based sampling), is necessary to ensure the measure is accurately and reliably capturing the construct. A larger-scaled replication study to address the sampling approach as well as the measurement properties discussed above would be the next step in supporting the use of the mPAT as a measure of participation.

If the measurement properties and feasibility of the mPAT can be replicated and further established, the next phase would be development of a mPAT specific platform to include a smartphone app and web-based portal. A platform specific to mPAT delivery and data collection would allow for the implementation of real-time coding of observations using the mPAT scoring algorithm. This would increase the clinical applicability and utility of the measure and allow researchers to conduct research more efficiently.

A mPAT specific platform could be used to conduct additional research using the mPAT. While the mPAT was developed with a TBI population in mind, participation is a universal rehabilitation and disability outcome. Future studies should examine the measurement properties of the mPAT and its feasibility in other rehabilitation and disability populations.

### **6.3 CONCLUSION**

Participation is an important outcome in health, disability, and rehabilitation research and practice; however, the breadth of measures available to investigators and clinicians, as well as

the breadth of what these measures assess, makes choosing an appropriate measure difficult. Additionally, the reliance on self-reporting is a limitation of current measures of participation for disability populations (e.g. TBI) for who the accurate and reliable recall may be impaired. EMA techniques and methodologies allow investigators and clinicians an enhanced ecologically valid means of assessing participation. The measurement properties examined in this project provide preliminary support of the mPAT for the assessment of participation in individuals with TBI. The ecological focus and unique information collected and presented by the mPAT support further studies using the tool and implementation of the mPAT as a measure of participation.

## APPENDIX A

### MOBILE PARTICIPATION ASSESSMENT TOOL VERSION 1

#### **Participation**

Participation is defined by the dynamic relationship between an individual's involvement in an activity within an environmental and social context.

#### **Instructions**

You will be prompted by your phone to complete the Participation Measure 3-4 times a day. Wait for the prompt before completing the assessment. Once you receive the prompt you will be asked to provide responses to the following items: Activity, Location, Surrounding People, and Satisfaction. Your response should be for moment you are filling out the assessment.

You will be able to choose from a list of responses for each question. You can select more than one response for Activity, Location, and Surrounding People. For example, your *Surrounding People* may be "Family" and "Friends." If none of the responses fit you can select "other", but you must provide more information. For example if you select "other" for Location you could write "amusement park" or "airport."

## Items

### Activity

What are you doing at this moment? (select all that apply)

- Learning/studying
- Working
- In class
- Communicating/conversation
- Exercising
- Using transportation
- Self-care
- Eating
- Shopping
- Preparing a meal
- Housework
- Assisting others
- Socializing
- Play
- Sports – playing
- Arts and culture
- Crafts
- Hobby
- Attending religious/spiritual event or service
- Internet communication
- Travel – ride in or driving vehicle
- Volunteering
- Watching television
- Listening to music
- Resting/sleeping
- No activity
- Other (explain) \_\_\_\_\_

### Location

Where are you at this moment? (select all that apply)

- Home
- Friend's home
- Relative's home
- Medical institution
- Work
- Shop/store
- Restaurant
- Block/neighborhood
- School
- Transportation vehicle
- Religious facility
- Bar
- Sporting event venue
- Gym
- Movie theater
- Museum
- Art gallery
- Theater
- Other (explain) \_\_\_\_\_

### Surrounding People

Who are you with at this moment? (select all that apply)

- Alone
- Family
- Friends
- Peers
- Coworkers
- Professionals
- Unknown people
- Spouse/partner
- Significant other
- Other (explain) \_\_\_\_\_

Satisfaction

How satisfied are you with what you are doing right now? (*select one*)

1 – Very dissatisfied

2 – Dissatisfied

3 – Neither

4 - Satisfied

5 – Very satisfied

.

## **APPENDIX B**

### **MOBILE PARTICIPATION ASSESSMENT TOOL VERSION 2**

#### **Participation**

Participation is defined by the dynamic relationship between an individual's involvement in an activity and the environmental and social context in which it occurs.

#### **Instructions**

You will be notified by your phone to complete the Participation Survey. Wait for the notification before completing the survey. Once you receive the notification you will be asked to answer questions like what you are doing, or who you are with. Your answers should be for the moment you are filling out the assessment.

You will be given a list of answers to choose from and should select all that apply. For example, when asked who you are with, you may be with family members and friends. You should select answers that reflect this. If none of the responses fit you can select "other", but you must provide more information. For example if you select "other" for where you are, you could write "amusement park" or "airport."

## Items

### Activity

What are you doing at this moment? (select all that apply)

- Working
- Volunteering
- Learning
- Studying
- Doing homework
- Medical/dental appointment
- Rehabilitation/therapy appointment
- Communicating/conversation
- Socializing
- Travel – riding in or driving a vehicle (i.e. car, bus, train, airplane)
- Self-care
- Eating
- Preparing a meal
- Doing housework
- Paying bills
- Assisting others
- Caring for children
- Engaging with pet(s)
- Exercising
- Shopping
- Playing (i.e. board game, video game, cards, etc.)
- Playing sports/recreation
- Watching sports
- Attending a arts or cultural event
- Doing a craft
- Doing a hobby
- Attending religious/spiritual service
- Attending religious/spiritual event
- Using the internet
- Watching television
- Listening to music
- Resting/sleeping
- Physical intimacy
- No activity
- Other (explain) \_\_\_\_\_

Location

Where are you at this moment? (select all that apply)

- Work
- School
- Home
- Friend's home
- Relative's home
- Distant relative's home
- Hospital/medical facility
- Rehabilitation facility
- Shop/store
- Library
- Coffee shop
- Restaurant
- Bar
- Block/neighborhood
- Outside
- Personal transportation vehicle
- Public transportation vehicle
- Religious facility
- Sporting event venue
- Gym
- Movie theater
- Museum
- Art gallery
- Theater
- Other (explain) \_\_\_\_\_

## Surrounding People

*Who are you with at this moment? (select all that apply)*

- Alone
- Spouse/partner
- Significant other
- Family
- Distant relative
- Friend(s)
- Peer(s)
- Acquaintance(s)
- Classmate(s)
- Coworker(s)
- Professional(s)
- Medical professional(s)
- Caregiver (paid)
- Unknown people
- Other (explain) \_\_\_\_\_

## **Importance**

Considering what you are doing, where you are, and who you are with, how **important** to you is what you are doing right now? (*select one*)

- 1 – Not Important
- 2 – Slightly Important
- 3 – Moderately Important
- 4 – Important
- 5 – Very important

## **Satisfaction**

Considering what you are doing, where you are, and who you are with, how **satisfied** are you with what you are doing right now? (*select one*)

- 1 – Very dissatisfied
- 2 – Dissatisfied
- 3 – Neither satisfied or dissatisfied
- 4 - Satisfied
- 5 – Very satisfied

## APPENDIX C

### PARTICIPATION LEVEL 2 CASES

#### Learning

##### Location:

- If learning is selected and library
- If learning is selected and coffee shop
- If learning is selected and restaurant
- If learning is selected and bar
- If learning is selected and shop/store
- If learning is selected and outside
- If learning is selected and block/neighborhood
- If learning is selected and transportation vehicle
- If learning is selected and hospital/medical facility
- If learning is selected and rehabilitation facility

##### Surrounding People:

- If learning is selected and spouse/partner
- If learning is selected and significant other
- If learning is selected and family
- If learning is selected and distant relative
- If learning is selected and friends
- If learning is selected and peers
- If learning is selected and acquaintances
- If learning is selected and classmates
- If learning is selected and coworkers
- If learning is selected and professionals

- If learning is selected and medical professionals
- If learning is selected and unknown people

## Studying

Location:

- If studying is selected and library
- If studying is selected and coffee shop
- If studying is selected and restaurant
- If studying is selected and bar
- If studying is selected and shop/store
- If studying is selected and outside
- If studying is selected and block/neighborhood
- If studying is selected and transportation vehicle
- If studying is selected and hospital/medical facility
- If studying is selected and rehabilitation facility

Surrounding People:

- If studying is selected and spouse/partner
- If studying is selected and significant other
- If studying is selected and family
- If studying is selected and distant relative
- If studying is selected and friends
- If studying is selected and peers
- If studying is selected and acquaintances
- If studying is selected and classmates
- If studying is selected and coworkers
- If studying is selected and professionals
- If studying is selected and medical professionals
- If studying is selected and unknown people

## Doing homework

Location:

- If doing homework is selected and shop/store
- If doing homework is selected and library
- If doing homework is selected and coffee shop
- If doing homework is selected and restaurant

- If doing homework is selected and bar
- If doing homework is selected and outside
- If doing homework is selected and block/neighborhood
- If doing homework is selected and transportation vehicle
- If doing homework is selected and hospital/medical facility
- If doing homework is selected and rehabilitation facility

Surrounding people:

- If doing homework is selected and spouse/partner
- If doing homework is selected and significant other
- If doing homework is selected and family
- If doing homework is selected and distant relative
- If doing homework is selected and friends
- If doing homework is selected and peers
- If doing homework is selected and acquaintances
- If doing homework is selected and classmates
- If doing homework is selected and coworkers
- If doing homework is selected and professionals
- If doing homework is selected and medical professionals
- If doing homework is selected and unknown people

### **Travel – riding in or driving a vehicle**

Location:

- If travel is selected and transportation vehicle

Surrounding people:

- If travel is selected and spouse/partner
- If travel is selected and significant other
- If travel is selected and family
- If travel is selected and distant relative
- If travel is selected and friends
- If travel is selected and peers
- If travel is selected and acquaintances
- If travel is selected and classmates
- If travel is selected and coworkers
- If travel is selected and professionals
- If travel is selected and medical professionals
- If travel is selected and unknown people

## Eating

### Location:

- If eating is selected and shop/store
- If eating is selected and library
- If eating is selected and coffee shop
- If eating is selected and restaurant
- If eating is selected and bar
- If eating is selected and outside
- If eating is selected and block/neighborhood
- If eating is selected and transportation vehicle
- If eating is selected and hospital/medical facility
- If eating is selected and rehabilitation facility

### Surrounding People:

- If eating is selected and spouse/partner
- If eating is selected and significant other
- If eating is selected and family
- If eating is selected and distant relative
- If eating is selected and friends
- If eating is selected and peers
- If eating is selected and acquaintances
- If eating is selected and classmates
- If eating is selected and coworkers
- If eating is selected and professionals
- If eating is selected and medical professionals
- If eating is selected and unknown people

## Preparing a meal

### Location:

- If preparing a meal is selected and shop/store
- If preparing a meal is selected and library
- If preparing a meal is selected and coffee shop

- If preparing a meal is selected and restaurant
- If preparing a meal is selected and bar
- If preparing a meal is selected and outside
- If preparing a meal is selected and block/neighborhood
- If preparing a meal is selected and transportation vehicle
- If preparing a meal is selected and hospital/medical facility
- If preparing a meal is selected and rehabilitation facility

#### Surrounding People:

- If preparing a meal is selected and spouse/partner
- If preparing a meal is selected and significant other
- If preparing a meal is selected and family
- If preparing a meal is selected and distant relative
- If preparing a meal is selected and friends
- If preparing a meal is selected and peers
- If preparing a meal is selected and acquaintances
- If preparing a meal is selected and classmates
- If preparing a meal is selected and coworkers
- If preparing a meal is selected and professionals
- If preparing a meal is selected and medical professionals
- If preparing a meal is selected and unknown people

#### Doing housework

Location:

Surrounding people:

- If Doing a housework is selected and spouse/partner
- If Doing a housework is selected and significant other
- If Doing a housework is selected and family
- If Doing a housework is selected and distant relative
- If Doing a housework is selected and friends
- If Doing a housework is selected and peers
- If Doing a housework is selected and acquaintances
- If Doing a housework is selected and classmates
- If Doing a housework is selected and coworkers
- If Doing a housework is selected and professionals
- If Doing a housework is selected and medical professionals
- If Doing a housework is selected and unknown people

## Engaging with pets

Location:

- If engaging with pets is selected and shop/store
- If engaging with pets is selected and library
- If engaging with pets is selected and coffee shop
- If engaging with pets is selected and restaurant
- If engaging with pets is selected and bar
- If engaging with pets is selected and outside
- If engaging with pets is selected and block/neighborhood
- If engaging with pets is selected and transportation vehicle
- If engaging with pets is selected and hospital/medical facility
- If engaging with pets is selected and rehabilitation facility

Surrounding people:

- If engaging with pets is selected and spouse/partner
- If engaging with pets is selected and significant other
- If engaging with pets is selected and family
- If engaging with pets is selected and distant relative
- If engaging with pets is selected and friends
- If engaging with pets is selected and peers
- If engaging with pets is selected and acquaintances
- If engaging with pets is selected and classmates
- If engaging with pets is selected and coworkers
- If engaging with pets is selected and professionals
- If engaging with pets is selected and medical professionals
- If engaging with pets is selected and unknown people

## Exercising

Location:

- If exercising is selected and outside
- If exercising is selected and block/neighborhood

Surrounding people:

- If exercising is selected and spouse/partner
- If exercising is selected and significant other
- If exercising is selected and family
- If exercising is selected and distant relative
- If exercising is selected and friends
- If exercising is selected and peers
- If exercising is selected and acquaintances
- If exercising is selected and classmates
- If exercising is selected and coworkers
- If exercising is selected and professionals
- If exercising is selected and unknown people

## Shopping

Location:

- If shopping is selected and shop/store
- If shopping is selected and library
- If shopping is selected and coffee shop
- If shopping is selected and restaurant
- If shopping is selected and bar
- If shopping is selected and outside
- If shopping is selected and block/neighborhood
- If shopping is selected and transportation vehicle
- If shopping is selected and hospital/medical facility
- If shopping is selected and rehabilitation facility

Surrounding People:

- If shopping is selected and spouse/partner
- If shopping is selected and significant other
- If shopping is selected and family
- If shopping is selected and distant relative
- If shopping is selected and friends
- If shopping is selected and peers
- If shopping is selected and acquaintances
- If shopping is selected and classmates

- If shopping is selected and coworkers
- If shopping is selected and professionals
- If shopping is selected and medical professionals
- If shopping is selected and unknown people

## Playing

Location:

- If playing is selected and shop/store
- If playing is selected and library
- If playing is selected and coffee shop
- If playing is selected and restaurant
- If playing is selected and bar
- If playing is selected and outside
- If playing is selected and block/neighborhood
- If playing is selected and transportation vehicle
- If playing is selected and hospital/medical facility
- If playing is selected and rehabilitation facility

Surrounding People:

- If playing is selected and spouse/partner
- If playing is selected and significant other
- If playing is selected and family
- If playing is selected and distant relative
- If playing is selected and friends
- If playing is selected and peers
- If playing is selected and acquaintances
- If playing is selected and classmates
- If playing is selected and coworkers
- If playing is selected and professionals
- If playing is selected and medical professionals
- If playing is selected and unknown people

## Watching sports

Location:

- If watching sports is selected and shop/store
- If watching sports is selected and library
- If watching sports is selected and coffee shop
- If watching sports is selected and restaurant
- If watching sports is selected and bar
- If watching sports is selected and outside
- If watching sports is selected and block/neighborhood
- If watching sports is selected and transportation vehicle
- If watching sports is selected and hospital/medical facility
- If watching sports is selected and rehabilitation facility

#### Surrounding People:

- If watching sports is selected and spouse/partner
- If watching sports is selected and significant other
- If watching sports is selected and family
- If watching sports is selected and distant relative
- If watching sports is selected and friends
- If watching sports is selected and peers
- If watching sports is selected and acquaintances
- If watching sports is selected and classmates
- If watching sports is selected and coworkers
- If watching sports is selected and professionals
- If watching sports is selected and medical professionals
- If watching sports is selected and unknown people

#### Doing a craft

##### Location:

- If Doing a craft is selected and shop/store
- If Doing a craft is selected and library
- If Doing a craft is selected and coffee shop
- If Doing a craft is selected and restaurant
- If Doing a craft is selected and bar
- If Doing a craft is selected and outside
- If Doing a craft is selected and block/neighborhood
- If Doing a craft is selected and transportation vehicle
- If Doing a craft is selected and hospital/medical facility
- If Doing a craft is selected and rehabilitation facility

Surrounding people:

- If Doing a craft is selected and spouse/partner
- If Doing a craft is selected and significant other
- If Doing a craft is selected and family
- If Doing a craft is selected and distant relative
- If Doing a craft is selected and friends
- If Doing a craft is selected and peers
- If Doing a craft is selected and acquaintances
- If Doing a craft is selected and classmates
- If Doing a craft is selected and coworkers
- If Doing a craft is selected and professionals
- If Doing a craft is selected and medical professionals
- If Doing a craft is selected and unknown people

## Doing a hobby

Location:

- If Doing a hobby is selected and shop/store
- If Doing a hobby is selected and library
- If Doing a hobby is selected and coffee shop
- If Doing a hobby is selected and restaurant
- If Doing a hobby is selected and bar
- If Doing a hobby is selected and outside
- If Doing a hobby is selected and block/neighborhood
- If Doing a hobby is selected and transportation vehicle
- If Doing a hobby is selected and hospital/medical facility
- If Doing a hobby is selected and rehabilitation facility

Surrounding people:

- If Doing a hobby is selected and spouse/partner
- If Doing a hobby is selected and significant other
- If Doing a hobby is selected and family
- If Doing a hobby is selected and distant relative
- If Doing a hobby is selected and friends
- If Doing a hobby is selected and peers
- If Doing a hobby is selected and acquaintances
- If Doing a hobby is selected and classmates

- If Doing a hobby is selected and coworkers
- If Doing a hobby is selected and professionals
- If Doing a hobby is selected and medical professionals
- If Doing a hobby is selected and unknown people

## Using the internet

Location:

- If Using the internet is selected and shop/store
- If Using the internet is selected and library
- If Using the internet is selected and coffee shop
- If Using the internet is selected and restaurant
- If Using the internet is selected and bar
- If Using the internet is selected and outside
- If Using the internet is selected and block/neighborhood
- If Using the internet is selected and transportation vehicle
- If Using the internet is selected and hospital/medical facility
- If Using the internet is selected and rehabilitation facility

Surrounding people:

1. If Using the internet is selected and spouse/partner
2. If Using the internet is selected and significant other
3. If Using the internet is selected and family
4. If Using the internet is selected and distant relative
5. If Using the internet is selected and friends
6. If Using the internet is selected and peers
7. If Using the internet is selected and acquaintances
8. If Using the internet is selected and classmates
9. If Using the internet is selected and coworkers
10. If Using the internet is selected and professionals
11. If Using the internet is selected and medical professionals
12. If Using the internet is selected and unknown people

## Watching television

Location:

- If Watching television is selected and shop/store

- If Watching television is selected and library
- If Watching television is selected and coffee shop
- If Watching television is selected and restaurant
- If Watching television is selected and bar
- If Watching television is selected and outside
- If Watching television is selected and block/neighborhood
- If Watching television is selected and transportation vehicle
- If Watching television is selected and hospital/medical facility
- If Watching television is selected and rehabilitation facility

Surrounding people:

- If Watching television is selected and spouse/partner
- If Watching television is selected and significant other
- If Watching television is selected and family
- If Watching television is selected and distant relative
- If Watching television is selected and friends
- If Watching television is selected and peers
- If Watching television is selected and acquaintances
- If Watching television is selected and classmates
- If Watching television is selected and coworkers
- If Watching television is selected and professionals
- If Watching television is selected and medical professionals
- If Watching television is selected and unknown people

## **Listening to music**

Location:

- If Listening to music is selected and shop/store
- If Listening to music is selected and library
- If Listening to music is selected and coffee shop
- If Listening to music is selected and restaurant
- If Listening to music is selected and bar
- If Listening to music is selected and outside
- If Listening to music is selected and block/neighborhood
- If Listening to music is selected and transportation vehicle
- If Listening to music is selected and hospital/medical facility
- If Listening to music is selected and rehabilitation facility

Surrounding people:

- If Listening to music is selected and spouse/partner
- If Listening to music is selected and significant other
- If Listening to music is selected and family
- If Listening to music is selected and distant relative
- If Listening to music is selected and friends
- If Listening to music is selected and peers
- If Listening to music is selected and acquaintances
- If Listening to music is selected and classmates
- If Listening to music is selected and coworkers
- If Listening to music is selected and professionals
- If Listening to music is selected and medical professionals
- If Listening to music is selected and unknown people

## **Resting/sleeping**

Location:

Surrounding people:

- If Resting/sleeping is selected and spouse/partner
- If Resting/sleeping is selected and significant other
- If Resting/sleeping is selected and family
- If Resting/sleeping is selected and distant relative
- If Resting/sleeping is selected and friends
- If Resting/sleeping is selected and peers
- If Resting/sleeping is selected and acquaintances
- If Resting/sleeping is selected and classmates
- If Resting/sleeping is selected and coworkers
- If Resting/sleeping is selected and professionals
- If Resting/sleeping is selected and medical professionals
- If Resting/sleeping is selected and unknown people

## **No activity**

Location:

Surrounding people:

- If No activity is selected and spouse/partner
- If No activity is selected and significant other
- If No activity is selected and family
- If No activity is selected and distant relative
- If No activity is selected and friends
- If No activity is selected and peers
- If No activity is selected and acquaintances
- If No activity is selected and classmates
- If No activity is selected and coworkers
- If No activity is selected and professionals
- If No activity is selected and medical professionals
- If No activity is selected and unknown people

## APPENDIX D

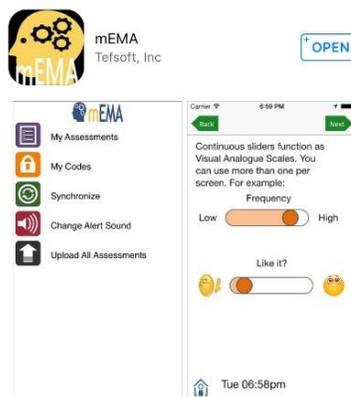
### REFERENCE GUIDE FOR THE mEMA SMARTPHONE APPLICATION

#### Download and Installment

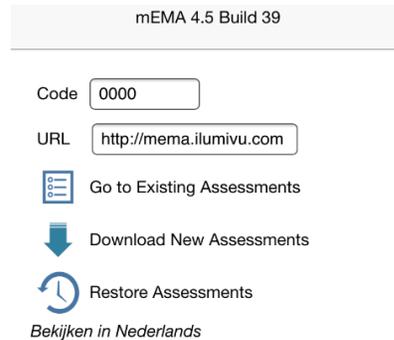
The mEMA smartphone application is free for download on Android and iOS (Apple) smartphone devices through the Google Play Store and App Store



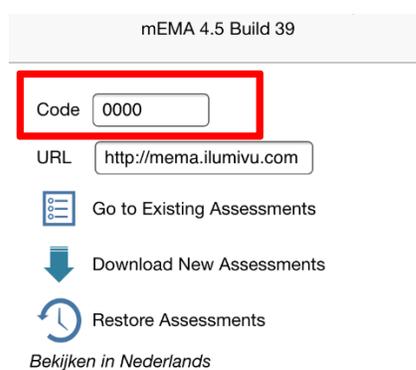
Type “**mEMA**” into the search bar after opening the Google Play or App Store on your phone.



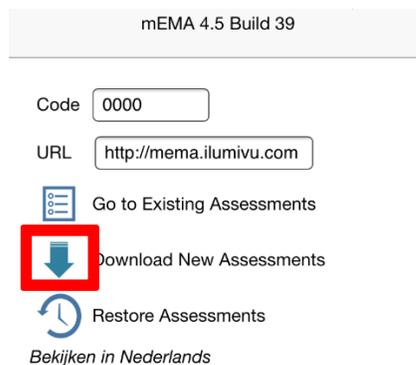
Install the mEMA app on your smartphone. This may take a few minutes depending on your cellular service or connection to wifi. Once the mEMA app has been installed on your phone tap the icon to open the app. You will be brought to the following screen:



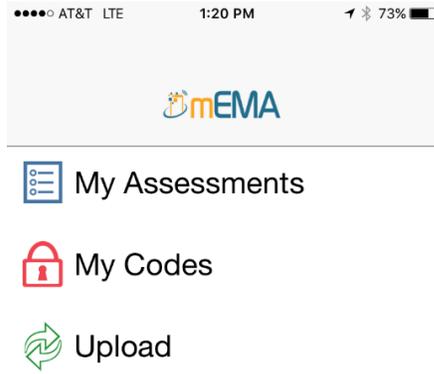
The research staff member will provide you with a unique code to be entered:



After you have entered your code press the [blue arrow](#) beside “Download New Assessments”

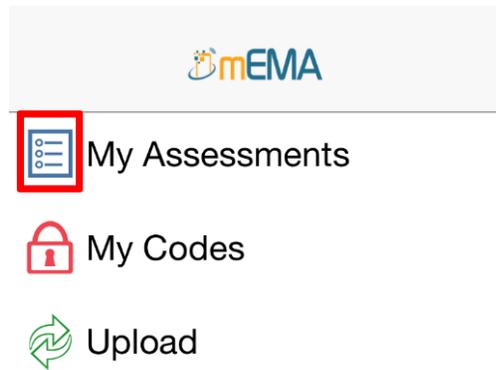


You will now be brought to the home screen of the mEMA app

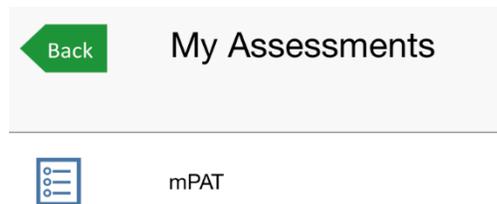


## Using the mEMA app

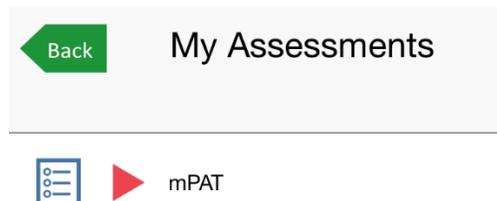
You can navigate the mEMA app using the home screen pictured above. To complete your assessments press the [blue notebook](#) beside “My Assessments”



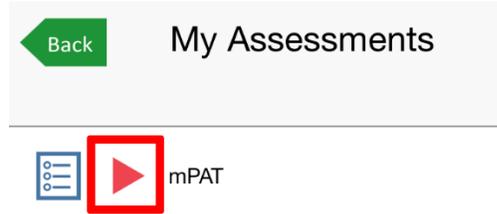
If you do not have any assessments scheduled the screen will appear as follows:



However, when you have an assessment to complete your screen should appear as follows:



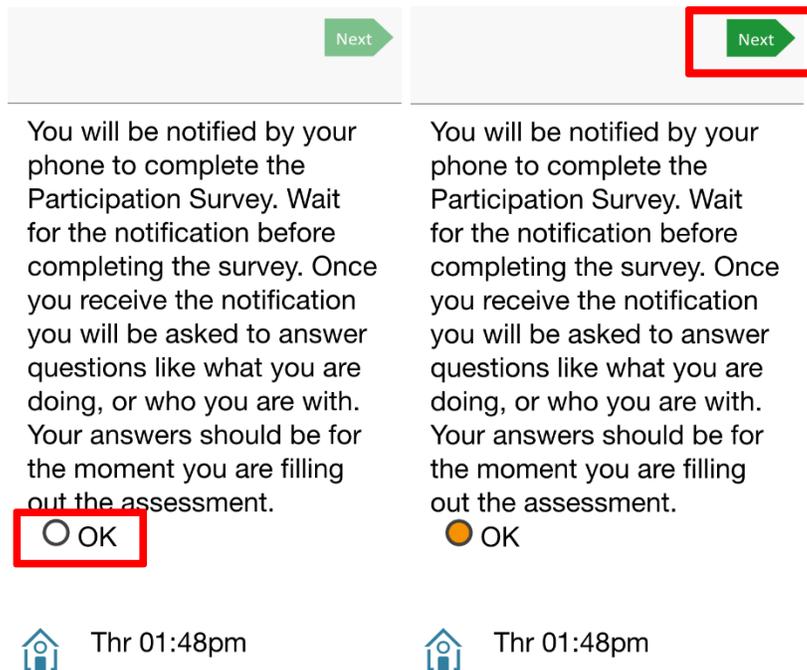
You can complete a survey by pressing the **red triangle** beside “mPAT”



### How to complete the mPAT

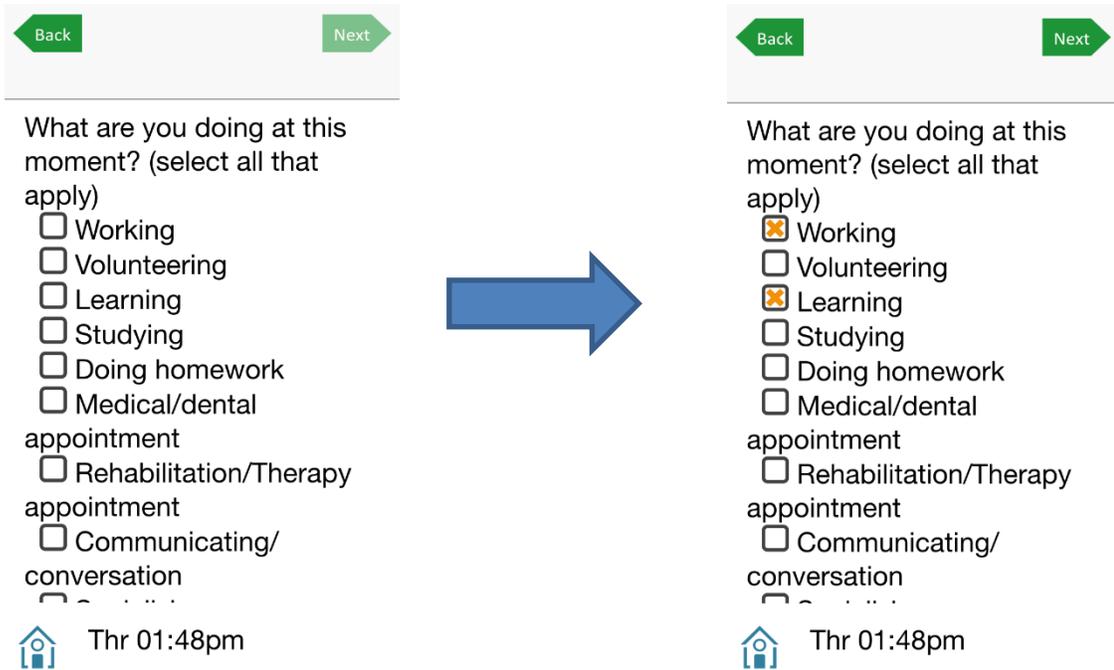
The instructions for the mPAT survey will appear each time you complete the survey.

Press the circle next to “Ok” and “Next” to move to the next section.



To select a response to a question tap the box next to the item you would like to select.

An **Orange** “x” will appear in the box



Press “Next” at the top of the screen once you have answered the question



If the response you would like to make is not listed you can select other

Back Next

- Coffee shop
- Restaurant
- Bar
- Block/neighborhood
- Outside
- Transportation vehicle
- Religious facility
- Sporting event venue
- Gym
- Movie theater
- Museum
- Art gallery
- Theater
- Other

 Thr 01:48pm

When you press “Next” you will be directed to the following screen:

Back Next

Other: Explain

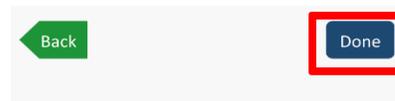
Type your response into the box and then press “Next” to move to the next question.



Other: Explain

Riding roller coasters

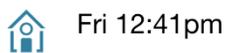
When you come to the final question you will press the “Done” button at the top of the screen once you have answered the question.



Considering what you are doing, where you are, and who you are with, how satisfied are you with what you are doing right now?

(select one)

- Very dissatisfied
- Dissatisfied
- Neither satisfied or dissatisfied
- Satisfied
- Very satisfied



You will be returned to the home screen. Press the **green arrows** next to “Upload” to upload your answers.

 My Assessments

 My Codes

 Upload

The **organe** bar will appear to indicate your answers are being upladed.

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