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# iPad Application for Pain Assessment in Youths with Developmental Disabilities and Complex Communication Needs

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IPAD APPLICATION FOR PAIN ASSESSMENT IN YOUTHS WITH DEVELOPMENTAL  
DISABILITIES AND COMPLEX COMMUNICATION NEEDS

by

Alyssa Guard

A Thesis Submitted in  
Partial Fulfillment of the  
Requirements for the Degree of

Master of Science  
in Occupational Therapy

at

The University of Wisconsin-Milwaukee

August 2016

## ABSTRACT

### IPAD APPLICATION FOR PAIN ASSESSMENT IN YOUTHS WITH DEVELOPMENTAL DISABILITIES AND COMPLEX COMMUNICATION NEEDS

by

Alyssa Guard

The University of Wisconsin-Milwaukee, 2016  
Under the Supervision of Professor Joyce M. Engel, PhD

**Aims:** Development of a new pain assessment for youths with communication challenges. The Guard-Putzer Pain Assessment Domains (gPAD) for the iPad was designed and tested as a more universally accessible way for youths, ages 7-to-12 years, with a developmental disability (DD) to express their private pain experiences through self-report. **Methods:** A two-phase process developed the design for an app, created an interactive prototype, and tested its face validity and user interface. This work included a review of current assessments and pain apps as well as completed a survey to obtain descriptive data on clinical practicality of the gPAD. Fifteen occupational therapists reviewed the gPAD assessment design and reported their experience. **Results:** Thirteen respondents agreed to the statement that they would use the gPAD for this population. School-based practitioners seemed to identify the most significant need for such a new app. **Conclusions:** Advancement of this app could mainstream the assessment of pain in youths with DD.

**Keywords:** Pain assessment, developmental disabilities, nonverbal, technology

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## **Introduction**

The purpose of this study is to design an application for pain assessment that can be used by youths with developmental disabilities (DD) that have complex communication needs. Jensen (2010) stated that “No measure of pain is perfect. No one measure assesses all pain domains, nor is any single measure useful in all settings and with all populations. Moreover, because of the imperfection of available instruments, it is theoretically possible to modify any existing measure to improve it further, or to develop new and better measures to replace existing ones,” (p.251). This statement reinforces the purpose and desire to create a new pain assessment for youths with complex communication needs that can be used in a variety of clinical settings in order to provide client-centered care.

According to the International Association for the Study of Pain (1994, p.209), pain is a sensory and emotional experience that is unpleasant and associated with tissue damage and is described in the terms of that damage. Acute and chronic are the two basic types of pain, each with varying definitions. Acute pain serves a biological purpose and alerts the person that there is tissue damage or irritation. Chronic pain no longer serves this biological purpose, and in turn is a persistent pain that involves an intricate physiologic, psychological, and social factor interaction (Chambliss, Heggen, Copelan, & Pettignano, 2002). A person who is experiencing chronic pain will have the persisting pain extend beyond the three months it takes for damaged tissue to heal (International Association for the Study of Pain, 2003).

As proposed by this author and Konz (Appendix 12) and based on the continued research conducted by Konz (2016), there is limited research on the effectiveness of self-report pain assessments for chronic pain in youths who have complex communication needs with a DD. A study involving nurses treating youths with intellectual disabilities found that pain is a common

everyday experience, but it is rarely treated. This is alarming as people with intellectual disabilities have health problems 2 to 5 times more than their peers without an intellectual disability (Zwakhalen van Dongen, Hamers, & Abu-Saad, 2003). It has been found that children who had any level of cognitive impairment were more likely to receive fewer doses of pain medication, have their pain assessed less frequently, and given fewer opportunities to self-report than their peers without a cognitive impairment (Malviya, Voepel-Lewis, Tait, Merkel, Lauer, Munro & Farley, 2001). The lack of treatment for pain experiences by those with an intellectual disability is a notable one as a youth with DD may also have some level of an intellectual disability (Zwakhalen van Dongen et al., 2003). This only increases the communication barrier in regards to being able to express his or her pain.

### ***Population of Interest***

The Centers for Disease Control and Prevention (2015) define DD as conditions caused from physical, learning, language or behavioral impairments. A youth is a large age span ranging from dependent childhood to the independence of adulthood (United Nations Department of Economic and Social Affairs, 2013). This includes middle childhood, meaning at 7-8 chronological years a youth begins to understand the quality of pain (Case-Smith & O'Brien, 2010; Ratnapalan et al., 2010). There are important differences to note in understanding what language impairments may be involved. A youth who has complex communication needs means they cannot communicate through the conventional methods widely used as a result of cognitive, speech, or language impairments. This can include impairments of receptive and expressive skills, meaning non-readers or those whose reading comprehension cannot be determined due to communication limitations (Pearson Education Inc., 2006). Terms of nonverbal or non-vocal do not accurately depict the actual communication capabilities of a youth as they may suggest that

the youth has no noise or sound utterances, when they may in fact have some limited speech abilities (Glennen & DeCoste, 1997). Many studies tend to use verbiage that does not follow these definitions to encompass non-readers in addition to those who cannot speak. This made it difficult to find research of assessments being used with this specific population, however, many studies were able to provide information on the nonverbal population which is included in the complex communication needs. These communication, motoric and cognitive factors affect how this focused population can provide a self-report.

It is however, possible to gain reliable and valid self-reports within this population even with communication and cognitive barriers. An exploration study completed by Conrad, Farurik, Harrison, Koh and Tomerun (1998) found that 50% of youths with borderline cognitive impairment and 35% of youths with mild cognitive impairment were able to correctly use the Numeric Pain Rating Scale (NRS; McCaffery, & Pasero, 1999). The NRS is an 11-point rating scale with 0 meaning no pain and 10 meaning the worst pain the person could experience (McCaffery & Pasero, 1999).

Often a child who is nonverbal or has communication barriers and has a cognitive disability is not given the opportunity to self-report and instead overt or motoric behaviors are used to assess pain. The **F**ace, **L**egs, **A**ctivity, **C**ry, and **C**onsolability (rFLACC; Merkel, Voepel-Lewis, Shayevitz & Malviya, 1997), allows parents and caregivers to provide information about that child's behavior at each level of pain intensity. The Noncommunication Children's Pain Checklist (NCCPC; Breau, Camfield, McGrath, Rosmus & Finley, 2000) has a checklist of common pain behaviors for youths who are nonverbal. This checklist includes categories of vocalizations, eating and sleeping, socialization and personality, facial expressions, activity, body and limb movements, and physiologic pain behaviors. Observation is required by a

healthcare professional in order to determine which behaviors in each category may indicate the youth is experiencing pain. The rFLACC is shown to have short administration time, however, heavily relies on accuracy from the caregiver or professional to understand how the child displays his or her pain (Chen-Lim et al., 2012). It also can become more difficult to assess this way if a child begins to adapt to their chronic pain and reduce their overt pain behaviors (Engel, 1988). Similarly, proxy reporting is a report given by parent or caregiver to assess youths' pain experiences (Irwin et al., 2012). Information provided by this method, however, may not be equivalent to that reported directly by the individual experiencing pain. The proxy-reporters often felt they did not have enough information to accurately answer, because of the inability to be present during every moment of the youths' day (Irwin et al., 2012). Observation methods of assessing pain cannot replace the youth's personal experience, and in addition to the behavioral measures, self-report is essential in order to ensure appropriate treatment (Johnson, Nilsson & Adolfsson, 2015). These overt measures alone do not work for this population to gain the in-depth perspective needed of their pain.

Youths who have varying communication abilities and have a cognitive impairment should be given the opportunity to self-report just the same as their speaking peers, as self-report is the "gold standard" for pain assessment (Conrad et al., 1998). It is evident that there are no self-report measures that cater to this population, and they are often denied the opportunity due to their limited abilities to answer a self-report in the way many of these researched assessments require (i.e. responding to questions in interview or questionnaire format, ability to read and comprehend questions). Allowing a youth with a cognitive disability or who has complex communication needs with an opportunity to self-report their pain experience can also create a



greater sense of control over the youths' lived experience and self-determination, increasing their independent functioning (de Knegt, Lobbezoo, Schuengel, Evenhuis & Scherder, 2015).

### ***Importance of Pain Assessment***

There is a large importance to assessing pain besides that its assessment helps increase independent functioning. Chronic pain is a serious developmental health concern that can interfere significantly with daily functioning (Chambers et al., 2011). Youths who experience pain early in life show long-term changes in pain perception and related behaviors (Ratnapalan, Schneewiess & Srouji, 2010). It is important for healthcare professionals to assess, address, and reduce the pain and associated anxiety and suffering as much as possible because pain interferes with the youth's daily activities and long-term psychosocial development. If chronic pain starting in early life persists into adulthood it results in continued poorer quality of life (QoL) and increased psychological distress (Hunfeld et al., 2000). This is an even more important to address for these youths with DD due to their already compromised health and possible limited participation in activities from health status and development.

Location of the youths' pain can also predict activities they may be limited in participating in. Students with abdominal pain and headaches are more likely to miss school, "hanging out" with friends, and have a greater loss of appetite than those who have back or limb pain. Youths with headache or abdominal pain are at a higher risk in adulthood to develop depression, anxiety, and recurrent illnesses related to pain (Roth-Isigkeit, Thyen, Stoven, Sxhwarzanberger & Schumucker, 2005). Pain interference has been studied and results show that restrictions from pain included: absence from school, decreased or withdrawal from socialization, loss of appetite, disturbances in sleep, and inability to pursue hobbies (Chambers et al., 2011; Roth-Isigkeit et al., 2005). Negative consequences that chronic pain can exert on

youths include: reduced QoL, more likely to use pain medication and a higher risk for internalizing symptoms in response to pain (Chambers et al.; Huguet & Miro, 2007). A youth in pain is more likely to be less cooperative with medical treatment because of the anxiety and fear of pain, which can result in limited participation from the child in treatment planning and being successful with treatment goals (Turnquist & Engel, 1994). Clinicians and researchers need to be able to understand all aspects of a youth's life with a DD, including their pain, in order to help them further their development and improve their QoL as the youth ages and may continue to experience pain and its effects on life and participation. This is even more critical for children who have a DD with complex communication needs as they are challenged in their ability to communicate with ease when compared to their vocal and able-bodied peers. It is apparent current assessments are not able to be adapted to allow for expression of pain for youths who have complex communication needs with DD, a new more universally accessible assessment is needed in practice. The inadequate usability across populations of the pain assessments available is exacerbated when using these assessments for youths with DD and have communication barriers as there is no effective way to communicate their experience through these assessments.

### ***Context and Limitations of Current Apps***

The idea for the new assessment is to use a platform that is going to increase accessibility of that assessment in order to adapt to the varying abilities that a youth who has DD with complex communication needs would possess. Youths are frequently exposed to this technology and other forms. In 2008, 98% of U.S. public elementary schools had internet access, suggesting this technology is able to be widely used, and has continued to grow over the years (National Center for Educational Statistics, 2010). Approximately 55% of adults in the U.S. have a mobile phone, which translates into youths having access to these devices by association (Price et al.,

2013). Mobile applications themselves are being used on average for 2.8 hours each day with 25 billion downloads in the Apple App Store in 2015 (Dogtiev, 2015). The Apple iPad has many features that allows for a universally designed mode of assessing pain, such as switch connection and selection modes, VoiceOver, increase in contrast, zoom, and AssistiveTouch (Apple Inc., 2015).

The Apple App Store presents various types of pain apps, as seen in Table 1. Some apps are free, with options to upgrade the app for a small cost while others can cost approximately \$42. It was analyzed which domains each app identified includes, as pain is a multidimensional experience and should include as many domains as possible for a holistic view of one's pain (Jensen, 2010). Each app is a self-report allowing the user to input information specific to his or her pain experience. Only two apps were developed specifically for children, one for children with cancer pain aged 8-18 years, another for general pain for those 7 years and older (Culbert, Fitzgerald, Sullwold Ristau, & Harrington, 2012; The Hospital for Sick Children, 2015). When looking at the domains of pain location, frequency, duration, intensity, alleviators/aggravators, and interference none of the apps cover the domain of pain interference. Chronic Pain Tracker and My Pain Diary (Chronic Stimulation, LLC, 2014; Lynn, 2013) are apps to cover the duration of pain. All apps, except the Healing Buddies Comfort Kit<sup>TM</sup>, covers intensity using a variation of the NRS (Austin, 2015; Chronic Stimulation, LLC, iHealth Ventures LLC, 2012; Lynn, 2013; Sanovation AG, 2012; WebMD LLC, 2014). With exception to the two apps tailored towards children, the majority of the researched apps are tailored towards adults. The way the apps are presented with different charts and longer descriptions interferes with the ability for youths between the ages of 7-and-12 years old to use them. Also, the apps that use a body diagram use

an adult body, which is more developed and shows more detail than children would be able to understand and relate to.

Accessibility of the apps was tested using an iPad Air 2 (Table 2). To be considered to have adequate function of each accessibility features, the app needed to be able to accurately speak button's titles or describe images and use the functions without limiting use of the app (i.e., does not hinder selection, typing, and zooming). The most common accessibility feature to work effectively within each app was the TouchAccommodations. This includes the hold duration on a button before it will register and ignoring repeat touches. One app that it was difficult to decipher if it was ignoring repeat touches was the Pain Squad app as the app is very simplistic with few buttons and options, it appeared as though it was allowing for selection of the second button before the 5 second time delay. Most apps had VoiceOver and speak screen functions that did not read buttons or images appropriately and instead were spoken as "button" or another combination of letters or error phrases. The apps with the best VoiceOver function were Healing Buddies Comfort Kit<sup>TM</sup> and My Pain Diary as they able to read all button titles on the screen. In Healing Buddies Comfort Kit, when selecting a button to move to a new screen it would often immediately read the "back" button at the top of the screen instead of the heading of the new screen. In this app, the VoiceOver function was able to read through scrolled material without stopping even if the content continued past what was visible on screen. When attempting to use gestures specific to other apps to zoom on body mapping pictures and color for pain location with VoiceOver on, it limited usability or completely made that portion of the app inoperable. This occurred in the Pain Diary & Community, Pain Tracker, Chronic Pain Tracker and Web MD Pain Coach Apps. Often times using the speak screen function it would not read in the order of sections on screen but instead from left to right. This was confusing and difficult to

follow. In My Pain Diary, it would not register the pop-up screens to read with screen reader. Switch capabilities for the apps varied with it limiting the function of the Pain Diary & Community, WebMD Pain Coach, and Chronic Pain Tracker. In these apps, using a switch eliminated control of sliders to rate pain intensity and color on body outlines. The Chronic Pain Tracker app allowed for using sliding scales and was easy to select from scrolling lists, however, it still did not allow for coloring on a body diagram for pain location. It is evident that of the apps available to the public to track their pain experiences there is not one single app that would be accessible to all persons, no matter their language development, cognitive, and motoric abilities.

### ***Need for New Assessment***

It is evident based on the literature that youths who are living with pain, whether they can express it verbally or not, are experiencing disruptions in their daily activities. Every child's perception of pain is going to vary, even if they all are exposed to the same noxious stimulus (Chambliss et al., 2002). A new assessment is needed due to: (a) limited accessibility and accesses of current assessments, (b) one assessment has not been found to address all pain domains including the available mobile apps, (c) not all pain assessments have high reliability and validity with the youths who have complex communication needs with DD, and (d) none of the iPad apps have any research on their reliability and validity. Self-reports of pain are the gold standard for assessment, and there are few opportunities for this vulnerable population to provide such reports (Chambliss et al.). The importance of being able to address the pain appropriately can help reduce or eliminate pain, pain interference, and suffering, ultimately allowing the child to experience an improved QoL. A valid and reliable assessment is necessary in determining the need for intervention, and to understand the mechanisms of those effects (Jensen, 2010). Current

self-report measures do not cover all pain domains and are most often pen and paper type self-report assessments, which limits the universal access to increase the opportunity of self-report for youths of all abilities, including those with DD (Konz, 2016). As well as, pain is not being as readily assessed as it should be in practice with 63% (n=12; 63%) stating they do not assess pain, the majority of OT practitioners stating they do not assess pain identified as a school-based practitioner (n=11, 92%) (Konz, 2016). This is alarming considering how detrimental chronic pain can be to a youths' development. School is where a youth spends most of his or her time, and to not have this addressed effectively and frequently suggests it is only continuing to hinder their active scholastic participation. A new assessment for youths who have complex communication needs with DD, including a variety of pain dimensions, will allow clinicians to give their pediatric patients a client-centered approach towards improving their daily activities, participation, and QoL. If this assessment is made with this population in mind, it will result in a universally designed assessment that can be made accessible to all.

An assessment with broad age coverage may make it difficult for healthcare professionals to decide which pain assessment to use. Also, having an age requirement and cognitive skill requirement for an assessment will allow for an increase in the reliability and validity of the assessment. Youths at roughly 7-to-8 years of chronological age able to understand their pain and may begin to describe how it is affecting their life (Ratnapalan et al., 2010). At this level, fine motor skills include good dexterity with small objects and precision and motor planning that is needed to use possible communicative devices, such as an iPhone or iPad. The cognitive abilities for this age range include demonstration of flexible problem solving, solving of complex problems, and abstract reasoning (Case-Smith & O'Brien, 2010). Based on the developmental involvement of DD defined by the CDC (2015), individuals with a DD may have limited ability

to complete tasks within their expected developmental range. This was taken into consideration when creating the assessment for youths with a DD. Both verbal and nonverbal reports require a certain level of cognitive and language development for the youth to understand and provide reliable responses (Ratnapalan et al., 2010). It was found that youths with moderate to greater levels of cognitive impairment did not consistently pass an entire self-report evaluation due to inability to respond to a self-report assessment for pain or accurately show understanding of magnitude and ordinal position concepts needed for self-reporting of pain, meaning they were unable to determine what items or concepts are larger or greater than others and understanding gradation of size. Youths who had mild cognitive impairment or less consistently showed magnitude and ordinal position concepts to accurately self-report (Conrad et al., 1998). It is these statements that narrowed the targeted population for the development of the prototyped app. The intended population is a youth aged 7-to-12 years of chronological age who have complex communication needs with a DD and has no more than a mild cognitive impairment.

Using a mobile application has benefits of its use including: (a) the information and assessment can be accessed anywhere at any time, (b) they provided immediate feedback of information, and (c) they are more accessible and easier to adapt to each youths varying abilities. The proposed pain app's aim is to be easier to comprehend and not to include charts that can be confusing to understand with no verbal or audible explanation. It also will aim to include how the pain is interfering in the youth's day, as this is going to be helpful for clinicians, parents, and youths to understand how pain is impacting daily life. The use of other mediums besides pen and paper self-reports will also aim to increase access for clinicians which will result in an increase in the assessment of pain in clinical practice. Using touch screens with this population is

effective as there is often little difficulty for a person with DD to operate these devices (de Knecht et al., 2015).

This leads one to ask how do occupational therapists rate the usefulness of a created prototyped iPad application to assess pain in youths who have a DD and complex communication needs? Based on the literature and the constant use of technology in today's society it is hypothesized that creating an iPad app will allow a clinician to gain a broader perspective on youth's pain experiences. Ultimately, using this medium will allow not only the clinician, but the youth, to adapt how the app and user selects, reads, sees, and hears the questions and answers. These features will be important as this can increase the population that will be able to self-report with ease. If pain is not being addressed effectively when healthcare providers have the opportunity to intervene the youth with chronic pain can grow into adulthood with chronic pain and as a result may experience anxiety, depression, and decreased overall QoL. Based on research findings two things should occur: (a) a new app should be designed and (b) it should be designed with clinicians and youths with a DD who have complex communication needs in mind as these factors will help create an app that is a better design.

## **Methods**

This study is comprised of two phases (Figure 4): (a) research and development for the prototyped app and testing of the software and (b) surveying occupational therapists (OT) who currently treat clients who are chronologically aged 7-12 years who have complex communication needs with a DD. In the first phase of the study, research of the psychometric properties was completed on existing self-report assessments for pain that fit within the criteria for age level and nonspeaking/nonverbal or DD if applicable. When searching, the keyword nonverbal was used due to the limited results with the term complex communication needs in



relation to pain assessment. This aided in the development of the prototyped app, it was then tested with a small sample of graduate students to determine usability of the app with a general user. In the second phase a survey was distributed to OTs who are in practice with the targeted population for the app. The goal of the survey was to determine if the app would be well received by clinicians and if they would find use for it with youths who have complex communication needs and have a DD.

### ***Project Design & Procedures***

The development and testing phases for the design of the new app included various steps within each phase. The development and testing was completed in collaboration with the needs assessment completed in a previous study by Konz (2016). The development phase comprised of steps to ensure a complete prototype these included: (a) research of existing self-report assessments and their psychometric properties in relation to the targeted population, (b) identified the format in which the app should be created and stylistic content, and (c) determined the outline and creation of the prototype. It was these detailed steps that lead to the creation of the prototype of the Guard-Putzer Pain Assessment Domains (gPAD). The testing phase comprised of: (a) recruiting “talk over” participants and (b) making edits and changes to the app based on feedback and observed use of the app to first time users.

### ***Development***

First, research was completed on the various forms of self-report, what they included, and their psychometric properties to ensure high reliability and validity in the intended population. The NRS has shown adequate test-retest reliability when testing pain intensity each week for two weeks, and excellent test-retest reliability when testing intensity at least two days during one week and at least two days the following week in a population with chronic pain (Jensen &

McFarland, 1993). Content validity was high when studied with people who acquired a spinal cord injury. The NRS was voted by participants as being used first over the Visual Analogue Scale (VAS; White & Snow, 1985), and was a valid measure in a minimum data set and valid for children aged 5 years and older (Bryce et al., 2007; Shields, Cohen, Harbeck-Weber, Powers & Smith, 2003). The NRS is the recommended method for assessment of pain intensity (Dworkin et al., 2005). Because of these reasons, the NRS is what the intensity rating will be based on in the app (Appendix 2). The Varni-Thompson Pediatric Pain Questionnaire (PPQ; Varni & Thompson, 1985) includes a body chart to mark and color code pain areas. Good test-retest reliability was found when testing at intervals of 1 week, 3 weeks, and 6 months. This assessment has also been used to assess children with chronic pain, beside the original intended populations of juvenile rheumatoid arthritis and sickle cell disease. It demonstrates the utility and generalization that is possible across pediatric populations (Cohen et al., 2008). This assessment aids in the body mapping for pain locations (Appendix 3). The Adolescent Pediatric Pain Tool (APPT; Savedra, Tesler, Holzemer & Ward, 1992; Appendix 4) is adequate for children 8-to-17 years and is appropriate for both genders and individuals from diverse cultural groups (Jacob, Mack, Savedra, Van Cleve, & Wilkie, 2014). This assessment is shown to have adequate content, construct, and criterion validity, test-retest reliability, alternate forms reliability, inter-rater reliability, and internal consistency reliability. Sensitivity to reduction in pain was also found with this assessment when used over five days postoperatively (Jacob et al., 2014). This assessment will aid in providing different ideas for domains to be considered with the new app and the body map also will help with implementing a body into the app to determine the location of the child's pain. The Brief Pain Inventory (BPI; Appendix 5, Cleeland & Ryan, 1994) includes an 11-point rating scale of interference of pain on daily activities and participation. Similarly, the PROMIS

assessment (Appendix 9, Health Organization & PROMIS Cooperative Group, 2012), developed for youths aged 8-17 years, asks the respondent to rate effect of pain on daily participation with a 5-point scale. The BPI has shown significant correlation with pain intensity and is a valid and reliable measure for determining pain interference (Tyler, Jensen, Engel, & Schwartz, 2002). These aided in ratings and topics of pain interference.

The format in which the prototype should be created was easily determined through using the parameters of the Prototyping on Paper (POP) app and website (WOOMOO Inc., 2014). POP allows the user to upload photos using the camera on the iPad and create links from one page to the next. The user of POP needs to draw or construct what they envision on paper first before taking the picture. POP's website has templates that lay out gridlines for Apple and Android devices to ensure the user is placing items to scale to be easily seen on the app. Creating a POP account was free, but does have a two upgrade options to pay per month allowing projects to be shared among multiple users and for multiple projects to be saved. In order to keep some similarity with pictures for the youths taking the assessment, Boardmaker symbols were used when applicable (Tobii Dynavox, 2015). Many youths who may complete the pain assessment may also have their own communication board or iPad and be familiar with these symbols. In some instances, these symbols were used as buttons to link to following pages (Figure 1), and others they were used to help describe the topic or words displayed (Figure 2). Another style feature to increase accessibility included making buttons uniform with high contrast using a yellow background with black lettering if there were no Boardmaker symbols (Figure 3).

A decision tree (Appendix 1) was developed to determine an appropriate order for all of the domains of pain being assessed. The count of pages for the gPAD totals 57. This includes a start page with options for instructions for use of the app and to start the assessment. The

assessment ends with options to continue the assessment to describe another pain location, or to end the assessment to which it brings up an “end of assessment” screen. Some pages are entered in multiple times to the app in order to have smooth linking from one domain to the next and to ensure accurate use of the “back” button to take the user back to the previously answered question. Using POP the Guard-Putzer Pain Assessment Domains (gPAD) was created (Appendix 11). The app can be viewed through a preview mode at:

<https://popapp.in/w/projects/54eb9e7ed06ba63914cefeab/preview>

### *Testing*

A testing phase, named the talk over phase, was completed after the initial prototype was completed. This phase recruited 10 graduate occupational therapy students, a convenience sample, to review the app and share candidly their thoughts and thinking process while moving through the app. Each talk over phase participant was asked to participate through verbal contact and informed consent was obtained (Appendix 8) upon meeting to audio record each participant while they used the gPAD. All 10 participated separately from each other in a room with the author of this study and similar study over the course of 1 week (Konz, 2016). Feedback and observed difficulties while talk over phase participants were using the app allowed for improvements to be made before further steps in the study were completed.

Changes made to the gPAD during this phase allowed for improved utility of the app and increased understanding of what a first time user may experience when interacting with the gPAD through POP. A back button was suggested to be added to each page, and adding more Boardmaker symbols. It was noticed during many of the meetings with the participants they often overlooked the “more options” button. This prompted the changing of the placement of the button on the screen to increase sight of the button when scanning the page. Some participants

suggested changes that were not feasible for the prototype phase of the app and the limitations that exist with POP. These suggestions for changes included: eliminating the “more options” and allowing for scrolling of the page or using VoiceOver for each page.

### ***Survey Design & Procedures***

After these improvements were made to the prototyped gPAD, the survey phase of the study was completed. This included the steps of (a) creation of a survey outline and determining format for administration, (b) reviewing of outline, and (c) recruitment of participants. The outline was created and contained questions pertaining to a similar study by Konz (2016). The survey consisted of 11 questions relating to this study with 5 preliminary questions connecting to practice setting and years of experience and the remaining 6 questions linking to the gPAD after participants had reviewed it via a link provided in the survey. The survey outline was created (Appendix 6) and it was determined that the use of nonverbal in the survey in questions about the targeted population would be more widely understood than complex communication needs. This was important as participants needed to be able to understand survey questions independently. Then, the outline was reviewed by two OTs and one speech and language pathologist (SLP).

After approval, the survey was recreated on Qualtrics Survey Software to increase ease of dissemination and collection of responses. Survey questions were formatted to obtain informed consent immediately at the start of the survey, to end the survey if a participant gave an answer causing them to fit into the exclusion criteria of the study, as well as, skip over the portion pertaining to the other study of pain assessment if they do not currently assess pain in their field of practice. Questions related to information and feedback on the gPAD application were completed after respondents followed the external link on the survey to review the gPAD at their leisure. Questions included: personal perceived competency with an iPad and accessibility

features, if they believe they would use the gPAD in practice and why, if the app is easy to understand, clear and concise, and a section for respondents to provide their overall thoughts and feedback. This allowed the data collected to be descriptive in nature. Questions varied from open-ended to provide feedback to dichotomous closed-ended questions to respond yes/no to in terms of their understanding of app content and determination if the app was clear and concise.

Survey participants were recruited and a convenience sample and was obtained through the Wisconsin Occupational Therapy Association's (WOTA) annual conference and through emails to OTs whose contact information has been provided through the University of Wisconsin-Milwaukee's Evidenced-Based Technology Integration program, and other university faculty and staff who have connections to OTs that may meet the inclusion criteria.

### **Ethical Approval**

The survey, talk over phase and data collection with all corresponding materials for this study were reviewed by the University of Wisconsin-Milwaukee Institutional Review Board (IRB). The IRB granted Exempt Status under Category 2 by 45 CFR 46.101(b) on October 5, 2015 (see Appendix 10).

### **Participants**

Inclusion criteria for survey participants included needing to currently work in a pediatric setting with youth's aged 7-12 years old who have a developmental disability and are nonverbal or have complex communication needs. Exclusion criteria included anyone who is not currently a registered occupational therapist (OTR) and if she or he did not have experience with the targeted population of youths. The majority of participants were Wisconsin OTs (n=13) with 2 respondents completing the survey in Kansas. The 15 participants of the survey provided all practice setting areas in which they work, with only 3 participants identifying multiple practice

areas. The majority consisted of 9 school-based practitioners, 4 outpatient or private practice practitioners, and 4 working in acute hospital settings. Years of experience varied with most respondents having 2-4 years (n=6) and 10 or more years (n=4), as is seen in Table 3.

### **Survey Data Analysis**

Qualtrics Survey Software was used to collect survey responses anonymously. Survey participants were only identifiable by IP address and general location the survey was completed, keeping them anonymous but allowing to determine which method of recruitment they participated from. Results were taken from Qualtrics and imported into Microsoft Excel 2016 to complete cross-tabulations and the analysis of written feedback from the survey participants.

### **Survey Results**

Of 20 survey responses, 15 were completed and counted for data analysis, 4 respondents dropped out before completion of the survey, nullifying their responses and 1 respondent did not identify as a registered occupational therapist automatically excluding them from participation. This created a 25% dropout rate. Raw data are displayed in Table 6. The majority of data were collected in person at an annual state OT conference (n=11) and additional via email (n=4). General reviews of the app were positive with 13 respondents believing that if the app was available for commercial use and they had access to an iPad, they would use it to assess pain. Two participants (13.3%) did not find the gPAD to be useful for their work both had identified as working in a school setting. All 15 participants agree that the app was easy to follow and understand, and 13 believed it was generally clear and concise. The two participants that disagreed with this statement identified as working in the acute setting. The majority of participants (n=10) stated they are competent with the use of the iPad and would be able to adapt the app to use appropriate accessibility features to increase the effectiveness of the use of the

app. The rest of participants stated (n=5) they would at least be able to download, operate, and delete a new app. Of the participants identifying as having 5 or more years of experience (n=7), 5 stated they are very competent. Participants identifying as having 4 years or less of experience (n=8), 5 stated they were very competent (Table 4). When analyzing if a correlation was present between competence with accessibility features and practice setting, 8 of 9 school-based practitioners rated themselves as very competent. Across all other settings excluding school-based, a total of 4 out of 11 identified as being very competent. No one had identified in any setting as having little knowledge of iPad use (Table 5).

Responses from feedback given in the descriptive portions of the survey provided insightful and constructive direction for further development of the gPAD. Of the respondents (n=13) who believed the gPAD would be useful in clinical practice, they explained that “it’s always good to have an easy tool” and “using an app like this to help communicate would be useful”. One respondent stated “sometimes we know that something is bothering the child but we are unable to determine what” and another stating that they rely on pictures to teach their nonverbal and essentially nonverbal children to make relationships with words, items, feelings and activity processes. Those who disagreed stated that students that they have who have complex communication needs and are in pain “might find that particular survey very long and become even more frustrated” and another stating that “it’s too long”. The concern of length with the gPAD was also evident in responses when asking for overall feedback at the end of the survey. Additionally, multiple responses suggested adding more visuals and pictures for non-readers. One respondent suggested a scale of 1-5 for the pain interference portion of the survey as “some of the kids I work with get overwhelmed when they are presented with a lot of



choices.” Another participant suggests long-term tracking of responses from the youth on the app, which is a goal of the gPAD if fully developed.

## **Discussion**

The alarmingly high percentage of school-based OTs who noted to not assess pain in practice suggests there is disconnect to assessing pain in the population of youths with a DD and complex communication needs. Additionally, those who identified to not find the app useful also stated they were school-based practitioners. This could be due to a lack of education of its importance, as well as, lack of emphasized importance compared to the hospital settings. The general lack of assessing pain within this population was also evident in the literature. The survey development and design was repeated and tested to be able to display a working and interactive app prototype, even without full functioning of accessibility features and ability to record responses for a finalized report. The design phase of the app was successful and this process seemed to help produce an acceptable app prototype for non-technical developers and would be recommended for any future studies with similar aims.

One prominent theme from written feedback in the surveys is to shorten the assessment, however, this would be difficult to do as it could then mean eliminating domains from the assessment that are important to cover in order to obtain as much information about the youth’s private pain experience. Adding a simplified version of the question when rating the pain interference portion to each page would be a useful addition and increase the comprehension and understanding of that portion of the assessment. Participants who had disagreed about the gPAD being concise both identified as working in acute care, this could suggest that the fast nature of their setting and limited treatment time spent with patients has them seeing the use of this 5-minute assessment too long. Suggestions of using a 5-point scale instead of 11-point scale during

the end interference portion of the gPAD would not be supported by the evidence. This also suggests that there could be a lack of education on the evidence behind the use of appropriate pain scales for the targeted population, and pediatric population in general, however, general assumptions cannot be made due to the small sample size. A goal of the gPAD would be to have an initial long version on first assessment with abbreviated versions for reassessment.

Having this app allows a youth with disability-related pain the opportunity to self-report what he or she is experiencing. This provides opportunities for clinicians to expand their knowledge of their clients, as well as, allow them to increase their individualization of care. The next step that should be taken for this pain assessment is conducting evidence-based research on this app in the targeted population. The design goals of the gPAD if fully developed are to allow it to be as universally designed and accessible as possible. These would include the ability for the gPAD to be compatible with switches for various methods of scanning and selecting, compatible with the iPad's VoiceOver feature and others under the Accessibility section of the iPad, such as AssistiveTouch, larger text, and zoom. Other goals include allowing the gPAD to connect to the internet for cloud use to track and save reports of pain for tracking and sharing purposes among parents, caregivers, and all clinicians who would benefit from the vital information of the youth's pain experience. As well as, having a short version for reassessment.

Using the feedback from the survey participants and the design goals to alter the app again and fully developing the app so the accessibility features of the iPad can be fully used when a youth completes the assessment would be the first task before conducting a subsequent study. Also, having other health professionals outside of OT provide their review of the iPad and thoughts on the clinical practicality of using this app needs to be completed. There is a need to

establish validity and reliability for the given population before there can be testing on other ages and populations.

## **Limitations**

There are two areas of limitations within this study. One area of limitations revolves around administration and data collection from the survey. A second area of limitations are those associated with the project which include development and execution of the app.

Limitations to the study include: (a) using a survey, (b) participant size, (c) and limited geographical representation. A survey can often result in drop-outs and the biases or fidelity of the participants' responses is unknown. Additionally, the participants were expert therapists, not the intended users of the app for self-reporting, the youths with DD and complex communication needs. Participant size and limited geographical representation does not allow for general assumptions of how clinicians of a large variety of practice settings view the applicability and utility of the gPAD, as well as, if it is common in most of the United States that school-based practitioners are over-looking pain assessment. Of the participants that did not complete the survey, this could have been a result of compatibility of the link to review the gPAD with their internet browser as it was discovered that some places of employment had blocked the website on his or her servers causing one participant to email stating their inability to view and finish the survey.

Limitations of the app include: (a) the use of the Prototyping on Paper app, (b) using an iPad, and (c) understanding use of accessibility features. POP was a great way to get a rough prototype for a non-technical developer, but in order to complete any pilot studies or begin to test the psychometrics of this assessment the time needs to be taken to collaborate with software designers to fully develop the app. In addition, POP only allows for partial use of the needed

features for an accessible app. Using the medium of the iPad itself can be a limitation as individuals who cannot afford an iPad or do not have access to one would be unable to access the gPAD. If the user is not technologically savvy, this could result in their inability to use this app. If they are unable to enable switch capability or other accessible features that could limit the intended population from effectively using the app.

## **Conclusion**

Based on feedback from this study, the gPAD, as a new pain assessment, seems to have promise in a clinical setting. The prototype works but warrants complete and full development in order for full testing to be completed with the intended population. When fully developed, subsequent reliability and validity focused studies can be completed to support the use of this mobile application in practice.

## **Declaration of Interest**

The author reports no declaration of interest.

## Tables and Figures



Figure 1: Boardmaker as Buttons Screenshot

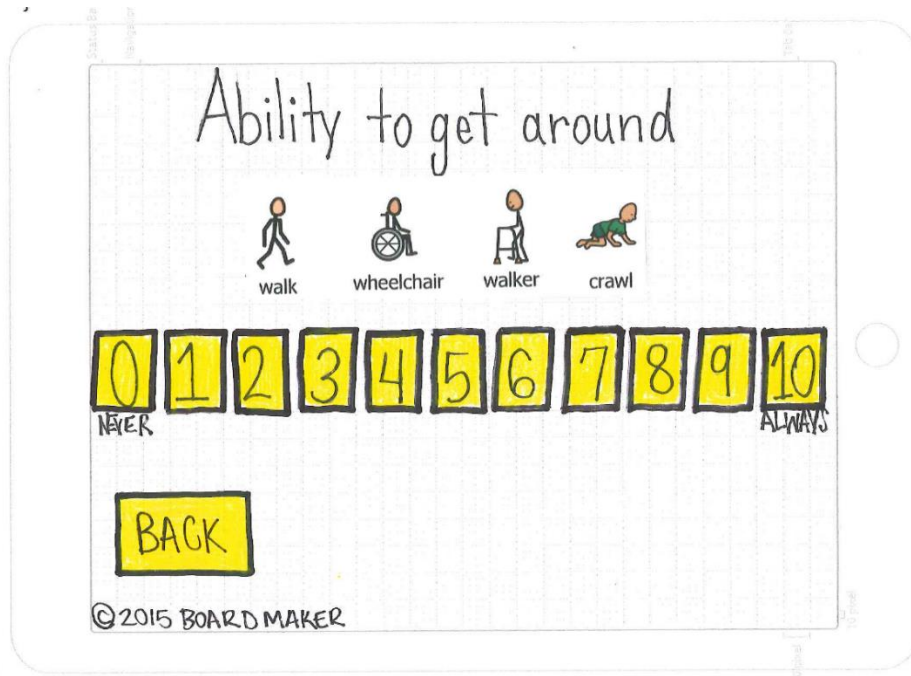


Figure 2: Boardmaker as Descriptors Screenshot

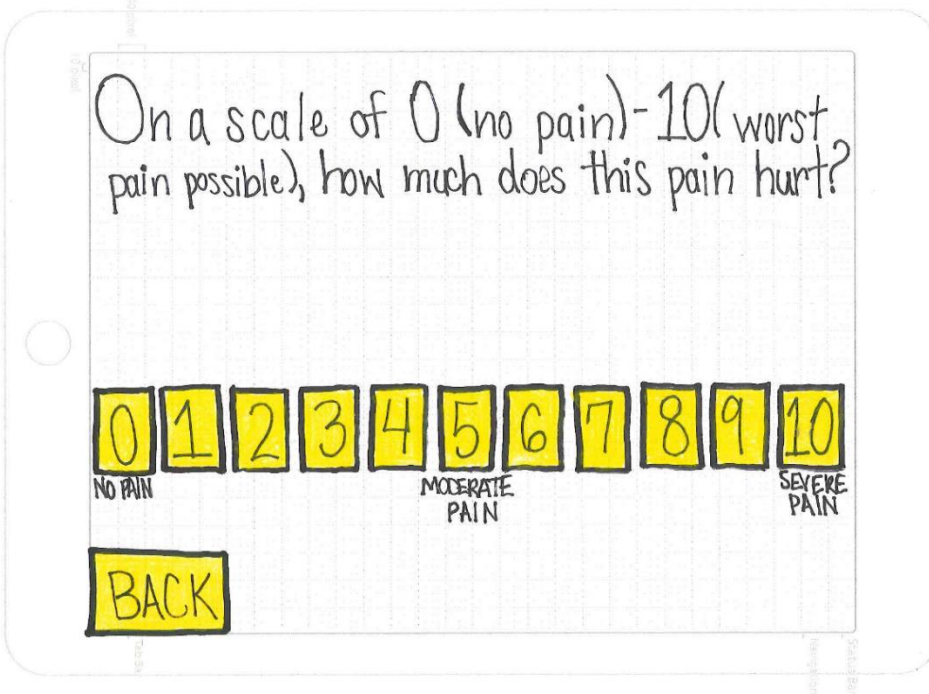


Figure 3: High Contrast Buttons Screenshot

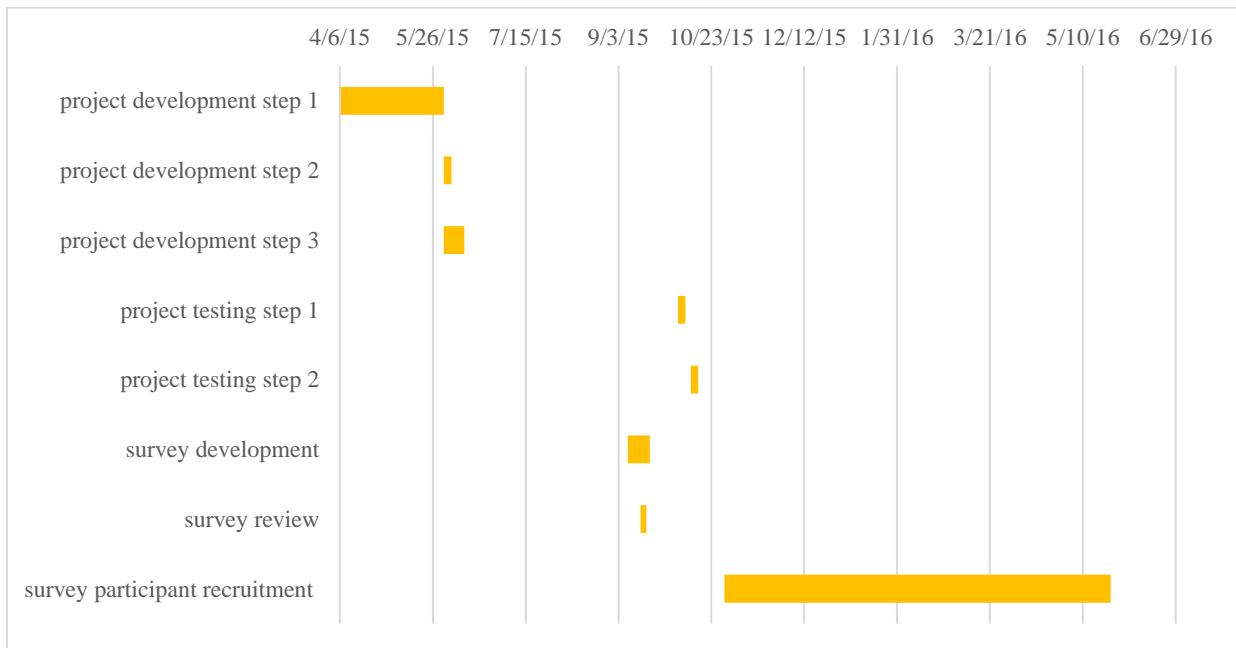


Figure 4: Methods Timeline

Table 1: Current pain applications available for individuals to track various pain domains.

App Title	Location	Frequency	Duration	Intensity	Alleviate/aggravators	Interference	Age	Pain Type
Web MD Pain Coach	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	17+ yr.	Chronic
My Pain Diary	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	17+ yr.	Chronic/ CRPS
Pain Diary & Community-CatchMyPain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12+ yr.	Not specified
Chronic Pain Tracker	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	4+ yr.	Chronic
Pain Tracker	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	4+ yr.	Not specified
Healing Buddies Comfort Kit™	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	7+ yr.	Not specified
Pain Logger	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4+ yr.	Not specified
Pain Squad	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8-18 yr.	Cancer

Table 2: Accessibility Functions of Current Pain Apps

App Title	VoiceOver	Zoom	Speak Screen	Switch Control	Hold Duration (0.50 sec)	Ignore repeat (0.50 sec)
Web MD Pain Coach	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My Pain Diary	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Pain Diary & Community-CatchMyPain	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Chronic Pain Tracker	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Pain Tracker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Healing Buddies Comfort Kit™	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Pain Logger	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Pain Squad	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Table 3: Survey participant demographics (N=15)

Characteristics	N(%)
Practice Setting <sup>1</sup>	
School-based	9(60)
Acute hospital	4(26.7)
Outpatient	3(20)
Private practice	1(6.7)
Inpatient	2(13.3)
Home health	1(6.7)
Years of Experience	
<1	1(6.7)
1-2	1(6.7)
2-4	6(40)
5-10	3(20)
10+	4(26.7)

<sup>1</sup>subjects may work in multiple settings

Table 4: Level of Competence v. Years of Experience (N=15)

		Level of Competence		
		Not	Somewhat	Very
<b>years of experience</b>	<1	0	1	0
	1to2	0	1	0
	2to4	0	1	5
	5to10	0	0	3
	10+	0	2	2
Total		0	5	10



Table 5: Level of Competence v. Setting (N=15)

		<b>Level of Competence</b>		
		Not	Somewhat	Very
<b>Practice Setting<sup>1</sup></b>	Acute Hospital	0	3	1
	Inpatient Rehab	0	2	0
	Outpatient	0	1	2
	Home Health	0	0	1
	Private Practice	0	1	0
	Day or Community program	0	0	0
	School	0	1	8
	Other	0	0	0
Total		0	8	12

<sup>1</sup> Subjects may work in multiple settings

Table 6: Raw data

Particip.*	Q2	Q4	Q5	Q14	Q15 & Comments	Q16	Q17	Q18	Recuritment method
1	school	<1	N	somewhat	Y	Y	Y		WOTA
2	home health	10+	Y	very	Y	Y	Y	Use the word example for the activity pictures so they do not select those.	WOTA
3	school	2-4	Y	very	Y; if the technology is available	Y	Y	no	WOTA
4	acute, inpt, outpt	10+	Y	somewhat	Y; It looks like a useful means of gathering more info	Y	Y	no	WOTA
5	school	2-4	N	very	Y; It gives another method to communicate with nonverbal students on how they are feeling instead of just using yes no questions	Y	Y	Add pictures to all sections if possible for those who cannot read	WOTA
6	acute, inpt	2-4	Y	somewhat	Y; Easy to access tools as needed based on patient profile	Y	Y	More young child friendly	WOTA
7	school	5-10	N	very	Y; I think the more visual, with fewer words, you can make it the better.	Y	Y	Use visuals and pictures for all questions	WOTA
8	outpt	5-10	Y	very	Y; Kids are already on the iPad and tech is a great way track data	Y	Y	Long term uses for tracking change would be great, maybe more graphics and less words for non readers	WOTA

9	private practice	10+	Y	somewhat	Y; It's always good to have an easy tool . I don't currently use an iPad app for this purpose.	Y	Y		WOTA
10	acute, outpt, school	2-4	N	very	N; But the app is a good idea however I think it's too long	Y	N	I needed some explanation Questions are a little confusing	WOTA
11	acute	1-2	Y	somewhat	Y; Yes.givesus another way to assess pain	Y	N	Too many questions	WOTA
12	school	2-4	N	very	Y; Any method that can be used to help a non-verbal student articulate their experience would be helpful in my line of work. While pain management is not something that is a large part of my work, using an app like this to help communicate would be useful.	Y	Y	on certain menu's (i.e. communication) a reminder of why you are selecting a number would be a nice cue. Otherwise, it just appears as a topic (ex: communication) and a scale to choose a number which could be confusing in terms of "does my pain get worse during ____? does my pain get better during ____?"	email
13	school	2-4	N	very	N; My students who are non verbal who are in pain might find that particular survey very long and become even more frustrated.	Y	Y	It's clear it is just way too long for children in that age range.	email
14**	school	5-10	N						
15**	school	1-2	N						

16	school	10+	N	very	Y; For our non-verbal and essentially non-verbal children, we rely on pictures to teach them to make relationships with words, items, feelings and activity processes.	Y	Y	Might explore the use of voice-over to speak the text while children look at the pictures.	email
17**	school	5-10	N						
18**	school	5-10	N						
19	school	5to10	N	very	Y; Sometimes we know that something is bothering the child but are unable to determine what.	Y	Y	I am wondering if having a scale 1-5 may be an alternative option. Some of the kids I work with get overwhelmed when they are presented with a lot of choices. Otherwise like the ease of use.	email

\*Does not include respondent who did not identify as an OTR

\*\*Participants who did not finish survey and are not counted data analysis

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## APPENDICIES

### *Appendix A: Decision Tree*

Pg. 1: “Name of Assessment” “start”; instructions page

#### Location

Pg. 2: Front of body picture “Pick your worst pain location”

Pg. 3: Dependent on selection made on page 2

- Head and neck: “Pick the exact location of your pain”
  - Close up of head and neck
    - Possible selections: ears, eyes, nose, mouth, teeth, forehead, chin, cheeks
    - Side of head and neck
    - Back of head and neck
- Torso: “Pick the exact location of your pain”
  - Side of torso
  - Back of torso
- Arm: “Pick the exact location of your pain”
  - Possible selections: fingers, hand, forearm, elbow, upper arm, shoulder
- Leg: “Pick the exact location of your pain”
  - Possible selections: toes, foot, ankle, shin, calf, knee, thigh, hip

#### Frequency

Pg. 4: “How often do you have this pain?” “Everyday” “weekly” “monthly” “constant”

Pg. 5: Dependent on selection made on page 4

- Weekly possible selections: 1 time per week, 2-3 times per week, 3-4 times per week, 4-5 times per week, and 5 or more times per week
- Monthly possible selections: 1-2 times per month, 2-3 times per month, 3-4 times per month, 4-5 times per month, and 5 or more times per month

#### Duration

Pg. 6: “How long does this pain last?”

- Possible selections: 1 minute, 5 minutes, 10 minutes, 30 minutes, 60 minutes, 1-5 hours, 6-10 hours, 11-15 hours, 16-20 hours, and 21-23 hours; Constant

#### Intensity

Pg. 7: “On a scale of 0 (no pain)-10 (worst pain possible), how much does this pain hurt?”

- Possible selections: 0,1,2,3,4,5,6,7,8,9,10

#### Helps pain

Pg. 8: “What helps your pain?”

- Possible selections: “nothing” “exercise/movement” “concentrating/relaxing” “medication” “changing thoughts” “heat” “cold” “stretching”

#### Aggravators of Pain

Pg. 9: “What makes your pain worse?”

- Possible selections: “nothing” “exercise/movement” “stress” “depression” “walking” “sitting” “laying down” “heat” “cold”

### Interference of Pain

Pg. 10: “On a scale of 0 (no pain)-10 (worst pain possible), how much does your pain interfere with the following activities?”

- Pg. 11: “General Activities” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 12: “Mood” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 13: “Ability to get around” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 14: “School work and participation” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 15: “Socializing” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 16: “Sleep” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 17: “Playing recreational activities” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 18: “Self-cares” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 19: “Communication with others” “0 1 2 3 4 5 6 7 8 9 10”

Pg. 20: “Do you have any other pain locations?”

- Possible selections: “yes” “no”

Pg. 21: Dependent on answer to page 20

- Yes: start back at page 2 and repeat the entire process for a new pain location
- No: “End of Assessment” “Thank you”

## Appendix B: Numeric Pain Rating Scale (NRS)

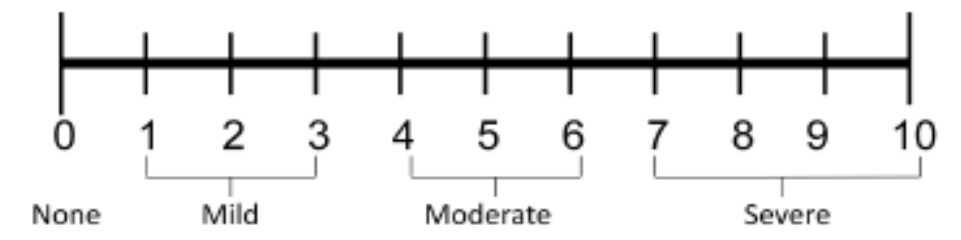
### The Numeric Pain Rating Scale Instructions

#### General Information:

- The patient is asked to make three pain ratings, corresponding to current, best and worst pain experienced over the past 24 hours.
- The average of the 3 ratings was used to represent the patient's level of pain over the previous 24 hours.

#### Patient Instructions (adopted from (McCaffery, Beebe et al. 1989):

*"Please indicate the intensity of current, best, and worst pain levels over the past 24 hours on a scale of 0 (no pain) to 10 (worst pain imaginable)"*



#### Reference:

McCaffery, M., Beebe, A., et al. (1989). Pain: Clinical manual for nursing practice, Mosby St. Louis, MO.

*Appendix C: Pediatric Pain Questionnaire (PPQ)*

## Pediatric Pain Questionnaire

### *Understanding your pain*

This questionnaire is to help us learn about your pain. We want to understand your past pain so we can diagnose and treat you.

This questionnaire and any information given in interviews will remain private. If you do not wish to answer a question, write, "do not wish to answer" in the space provided.

Please print or write clearly.

Today's date: \_\_\_\_\_

Your name: \_\_\_\_\_ Age: \_\_\_\_\_



What words would you use to describe your pain or hurt? \_\_\_\_\_

---

---

---

Circle the words below that best describe your pain, or the way you feel when you are in pain.

cutting	pounding	tingling	tiring	deep
squeezing	throbbing	horrible	stabbing	burning
pulling	sickening	biting	screaming	scraping
aching	uncomfortable	cold	miserable	stretching
pricking	hot	scared	lonely	jumping
pinching	unbearable	sad	itching	grabbing
stinging	sharp	sore	flashing	pins and needles

From the words you wrote or circled, which three words best describe the pain you are feeling right now?

---

---

---

Rate **how you feel now**. If you have no pain put a mark at the end of the line by the happy face. If you have some pain, put a mark near the middle of the line. If you have a lot of pain, put a mark by the sad face.



Not hurting  
No discomfort  
No pain



Hurting a whole lot  
Very uncomfortable  
Severe pain

Rate **the worst pain you had this week**. If you had no pain this week, put a mark at the end of the line by the happy face. If the pain you had was some hurting, put a mark by the middle of the line. If the worst pain you had was a whole lot of pain, put a mark by the sad face.



Not hurting  
No discomfort  
No pain



Hurting a whole lot  
Very uncomfortable  
Severe pain

*From Hockenberry MJ, Wilson D, Winkelstein ML: Wong Essentials of Pediatric Nursing, ed 7, St. Louis, 2005, p. 1259. Used with permission. Copyright Mosby.*



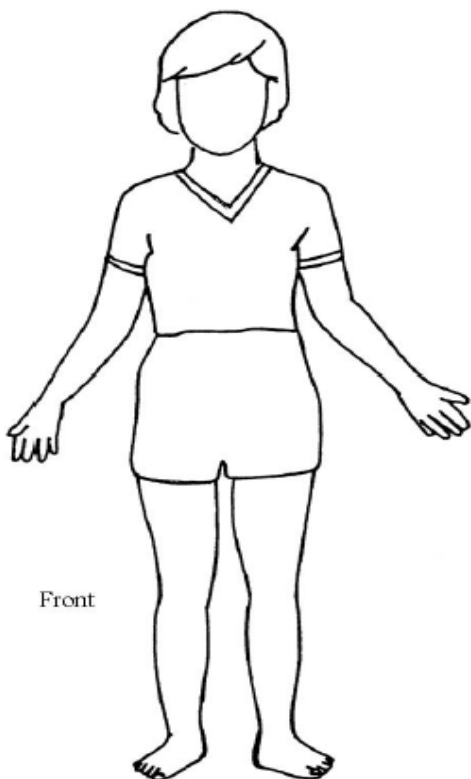
Pick colors that mean **no hurt**, **a little hurt**, **more hurt**, and **a lot of hurt** to you and color in the boxes.  
Now, using those colors, color in the body to show how you feel.

No pain  
No hurt

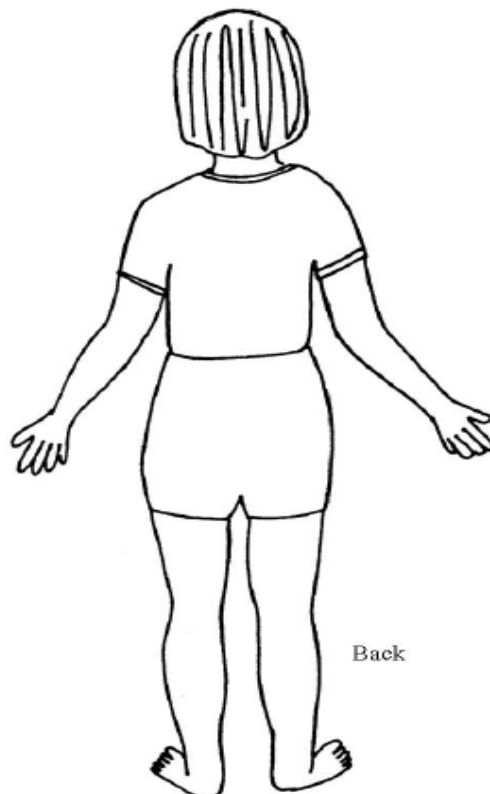
Mild pain  
A little hurt

Moderate pain  
More hurt

Severe pain  
A lot of hurt



Front



Back

**Children's**  
Hospital & Regional Medical Center

4800 Sand Point Way NE, PO Box 5371, M/S 9G-1  
Seattle, WA 98105-0371  
Phone 206-987-2704  
Fax: 206-987-3935

© 2008 Source: Varril, J.W., & Thompson, K.L. (1985).  
The Varril/Thompson Pediatric Pain Questionnaire: Form C (Child), unpublished manuscript.  
Modified for Children's Hospital and Regional Medical Center, Seattle, Washington.  
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## Appendix D: Adolescent Pediatric Pain Tool (APPT)

CODE \_\_\_\_\_

DATE \_\_\_\_\_

**ADOLESCENT PEDIATRIC PAIN TOOL (APPT)**

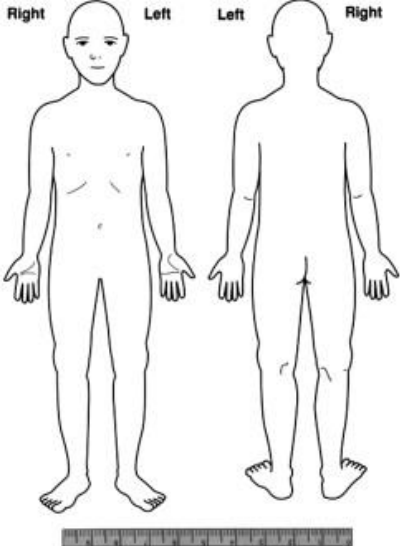
**INSTRUCTIONS:**

1. Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.

2. Place a straight, up and down mark on this line to show how much pain you have.

3. Point to or circle as many of these words that describe your pain.

Right Left Left Right



No Pain Little Pain Medium Pain Large Pain Worst Possible Pain

1 annoying  
2 aching  
3 beating  
4 biting  
5 blistering  
6 burning  
7 cramping  
8 crushing  
9 like a pinch  
10 pinching  
11 pressure  
12 itching  
13 like a scratch  
14 like a sting  
15 scratching  
16 stinging  
17 shocking  
18 shooting  
19 splitting  
20 numb  
21 stiff  
22 swollen  
23 tight  
24 awful  
25 deadly  
26 dying  
27 killing  
28 crying  
29 frightening  
30 screaming  
31 terrifying  
32 dizzy  
33 sickening  
34 suffocating  
35 never goes away  
36 uncontrollable  
37 always comes and goes  
38 comes on all of a sudden  
39 constant  
40 continuous  
41 forever  
42 off and on  
43 once in a while  
44 sneaks up  
45 sometimes  
46 steady

If you like, you may add other words:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

For office use only.

BSA: \_\_\_\_\_

IS: \_\_\_\_\_

#S (2-9) \_\_\_\_\_ / 37 = \_\_\_\_\_ %

#A (10-12) \_\_\_\_\_ / 11 = \_\_\_\_\_ %

#E (1-13) \_\_\_\_\_ / 8 = \_\_\_\_\_ %

#T (14-15) \_\_\_\_\_ / 11 = \_\_\_\_\_ %

Total \_\_\_\_\_ / 67 = \_\_\_\_\_ %

(Savedra, Tesler, Holzemer & Ward, 1992)

## Appendix E: Brief Pain Inventory

### 31. BRIEF PAIN INVENTORY

For the next set of questions, choose the one number that describes how, during the past week, pain has interfered with the following activities. Please use the 0 to 10 scale where a 0 means that "pain does not interfere" with that activity and a 10 means that "pain completely interferes." (KEY 3)

	Does not interfere	0	1	2	3	4	5	6	7	8	9	10	Completely interferes
a) General Activity.....		0	1	2	3	4	5	6	7	8	9	10	
b) Mood.....		0	1	2	3	4	5	6	7	8	9	10	
c) Mobility (ability to get around).....		0	1	2	3	4	5	6	7	8	9	10	
d) Normal Work (includes both work outside the home and housework) ....		0	1	2	3	4	5	6	7	8	9	10	
e) Relations With Other People.....		0	1	2	3	4	5	6	7	8	9	10	
f) Sleep.....		0	1	2	3	4	5	6	7	8	9	10	
g) Enjoyment Of Life.....		0	1	2	3	4	5	6	7	8	9	10	
h) Self Care (taking care of your daily needs).....		0	1	2	3	4	5	6	7	8	9	10	
i) Recreational Activities.....		0	1	2	3	4	5	6	7	8	9	10	
j) Social Activities.....		0	1	2	3	4	5	6	7	8	9	10	
k) Communication With Others.....		0	1	2	3	4	5	6	7	8	9	10	
l) Learning New Information or Skills.....		0	1	2	3	4	5	6	7	8	9	10	

(Cleeland & Ryan, 1994)

## ***Appendix F: Qualtrics Survey Outline***

The purpose of this survey is to gather knowledge on how registered occupational therapists (OTR) are currently assessing pain in the pediatric population and to gain expert review of a new pain assessment iPad app. Please keep in mind the clientele being discussed is youths chronologically aged 7-to-12 years old when answering the following questions. Response to this survey is voluntary and will be kept confidential. Thank you for completing this survey and we appreciate you contributing to our study.

1. Are you currently a Registered Occupational Therapist (OTR) in a pediatric setting?

- ☐ Yes
- ☐ No

[If response is no: end of survey]

[If response is yes: next question]

2. In what type setting(s) do you work? (Select all that apply)

- ☐ Acute Hospital
- ☐ Inpatient Rehabilitation
- ☐ Outpatient
- ☐ Home Health
- ☐ Private Practice
- ☐ Day or Community Program
- ☐ School
- ☐ Other

3. Do you have experience working with youths (ages 7-12 years chronologically) who are nonspeaking and have a developmental disability?

- ☐ Yes
- ☐ No

[If response is no: end of survey]

[If response is yes: next question]

4. How many years of experience do you have working with this population?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 2-4 years
- ☐ 5-10 years
- ☐ 10 or more years

5. Do you currently assess pain with your clients?

- ☐ Yes
- ☐ No

[If response is no: go to gPad section]

[If response is yes: next question-data for Konz, 2016]

The goal of the gPAD is to provide a new and concise measure for youths who are nonspeaking and have a developmental disability to self-report their pain experience. The following questions will pertain to the gPAD application on the iPad.

Please take the time to review the gPAD application on the given iPad or external link.

14. What is your level of competency regarding using the iPad?

- ☐ Not competent (have never used iPad)
- ☐ Somewhat competent (know how to download and open apps)
- ☐ Very competent (able to download and use apps, and change accessibility settings on the iPad)

15. Do you believe this developed iPad app would be useful in your line of work?

- ☐ Yes
- ☐ No
  - ☐ Why?\_\_\_\_\_

16. Is the app presented easy to follow and understand?

- ☐ Yes
- ☐ No

17. Are the questions given in the app clear and concise?

- ☐ Yes
- ☐ No

18. Overall, what could be improved upon? Please provide clear and concise feedback. ?

---

## ***Appendix G: Survey Consent***

### **University of Wisconsin – Milwaukee Consent to Participate in Online Survey Research**

**Study Title:** Pain Assessment of Nonverbal Youths with Developmental Disabilities & Survey of Assessing Pain in Clinical Practice and Applicability of a New Assessment

**Person Responsible for Research:** Alyssa Guard, OTS, Michelle Putzer, OTS and Joyce Engel, PhD, OT

**Study Description:** The purpose of this study is to determine how pediatric occupational therapists assess pain in nonverbal youth's with a developmental disability. Consequently, we will establish the clinical utility of the developed pain iPad app. Approximately 50 subjects will participate in the study. If you agree to participate, you will be asked to complete a brief written survey. This survey will ask you questions about your practice area and age of clients served, how information on a client's pain is collected and used, and feedback on the utility of demonstrated iPad application. This will take approximately 15 minutes of your time.

**Risks / Benefits:** Risks to participants are considered minimal. Collection of data and survey responses using the internet involves the same risks that a person would encounter in everyday use of the internet, such as breach of confidentiality. While the researchers have taken every reasonable step to protect your confidentiality, there is always the possibility of interception or hacking of the data by third parties that is not under the control of the research team.

There will be no costs for participating. There are no benefits to you other than to further research.

**Limits to Confidentiality** Identifying information such as your name, email address, and the Internet Protocol (IP) address of this computer will not be asked or available to the researchers. Data will be retained on the Qualtrics website server for 10 months and will be deleted by the research staff after this time. However, data may exist on backups or server logs beyond the timeframe of this research project. Data transferred from the survey site will be saved on a password protected computer for 10 months. Only Alyssa Guard, Michelle Putzer, and Joyce Engel will have access to the data collected by this study. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

**Voluntary Participation:** Your participation in this study is voluntary. You may choose to not answer any of the questions or withdraw from this study at any time without penalty. Your decision will not change any present or future relationship with the University of Wisconsin Milwaukee.

**Who do I contact for questions about the study:** For more information about the study or study procedures, contact Alyssa Guard ([arguard@uwm.edu](mailto:arguard@uwm.edu)), Michelle Putzer ([mrputzer@uwm.edu](mailto:mrputzer@uwm.edu)), or Joyce Engel ([engel@uwm.edu](mailto:engel@uwm.edu)).

**Who do I contact for questions about my rights or complaints towards my treatment as a research subject?** Contact the UWM IRB at 414-229-3173 or [irbinfo@uwm.edu](mailto:irbinfo@uwm.edu)

#### **Research Subject's Consent to Participate in Research:**

By entering this survey, you are indicating that you have read the consent form, you are age 18 or older and that you voluntarily agree to participate in this research study.

Thank you!

## ***Appendix H: Talk Over Consent***

### **University of Wisconsin – Milwaukee Consent to Participate in Research**

**Study Title:** Pain Assessment of Nonverbal Youths with Developmental Disabilities & Survey of Assessing Pain in Clinical Practice and Applicability of a New Assessment

**Person Responsible for Research:** Alyssa Guard, OTS, Michelle Putzer, OTS and Joyce Engel, PhD, OT

**Study Description:** The purpose of this research study is to determine changes that need to be made to the gPAD iPad application through participants honestly talking about their interactions with the app. Approximately 5 subjects will participate in this study. If you agree to participate, you will be asked to play with the gPAD app and say everything that they are thinking while being audio recorded. This will take approximately 30 minutes of your time.

**Risks / Benefits:** Risks that you may experience from participating are considered minimal. There are no costs for participating. There are no benefits to you other than to further research.

**Confidentiality:** Identifying information such as your name will be collected for research purposes to identify separate recordings. Your responses will be treated as confidential and all reasonable efforts will be made so that no individual participant will be identified with his/her answers. The research team will remove your identifying information 1 month after the date of recording and all study results will be reported without identifying information so that no one viewing the results will ever be able to match you with your responses. Data from this study will be saved on password protected smartphones for 1 month from the date of recording. Only Alyssa Guard, Michelle Putzer, and Joyce Engel will have access to your information. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

**Voluntary Participation:** Your participation in this study is voluntary. You may choose not to take part in this study, or if you decide to take part, you can change your mind later and withdraw from the study. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with the University of Wisconsin Milwaukee. There are no known alternatives available to participating in this research study other than not taking part.

**Who do I contact for questions about the study:** For more information about the study or study procedures, contact Alyssa Guard ([arguard@uwm.edu](mailto:arguard@uwm.edu)), Michelle Putzer ([mrputzer@uwm.edu](mailto:mrputzer@uwm.edu)), or Joyce Engel ([engel@uwm.edu](mailto:engel@uwm.edu)).

**Who do I contact for questions about my rights or complaints towards my treatment as a research subject?** Contact the UWM IRB at 414-229-3173 or [irbinfo@uwm.edu](mailto:irbinfo@uwm.edu).

#### **Research Subject's Consent to Participate in Research:**

To voluntarily agree to take part in this study, you must be 18 years of age or older. By signing the consent form, you are giving your consent to voluntarily participate in this research project.

---

Printed Name of Subject/Legally Authorized Representative

---

Signature of Subject/Legally Authorized Representative

---

Date

## Appendix I: PROMIS Pediatric Pain Interference

PROMIS® Pediatric Item Bank v1.0 – Pain Interference

### Pediatric Pain Interference

Please respond to each item by marking one box per row.

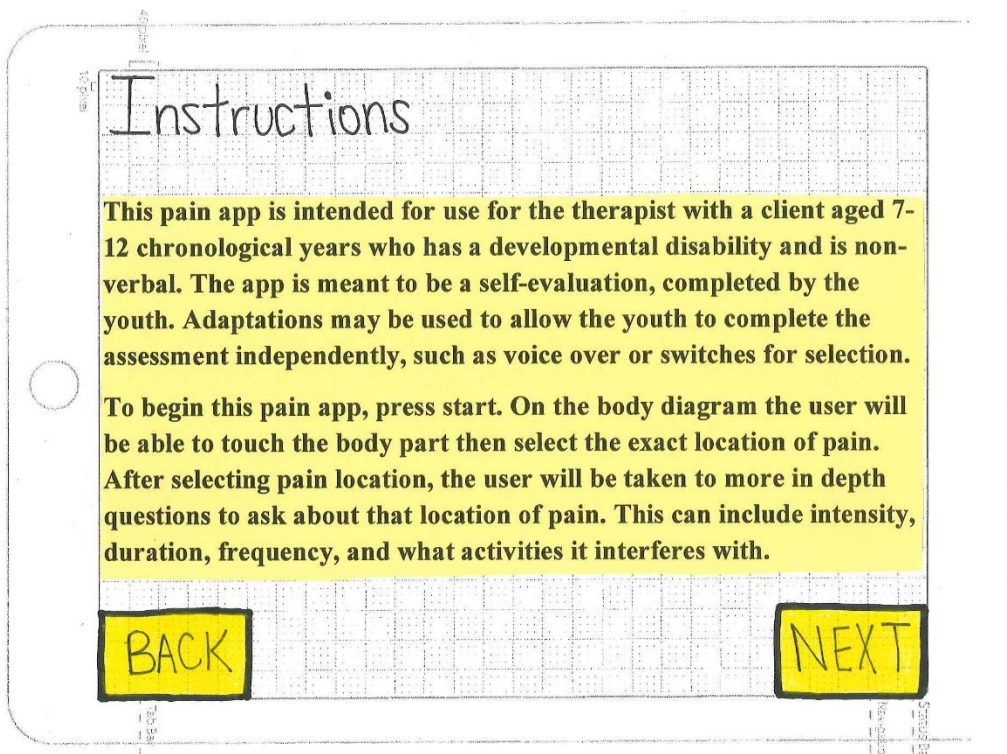
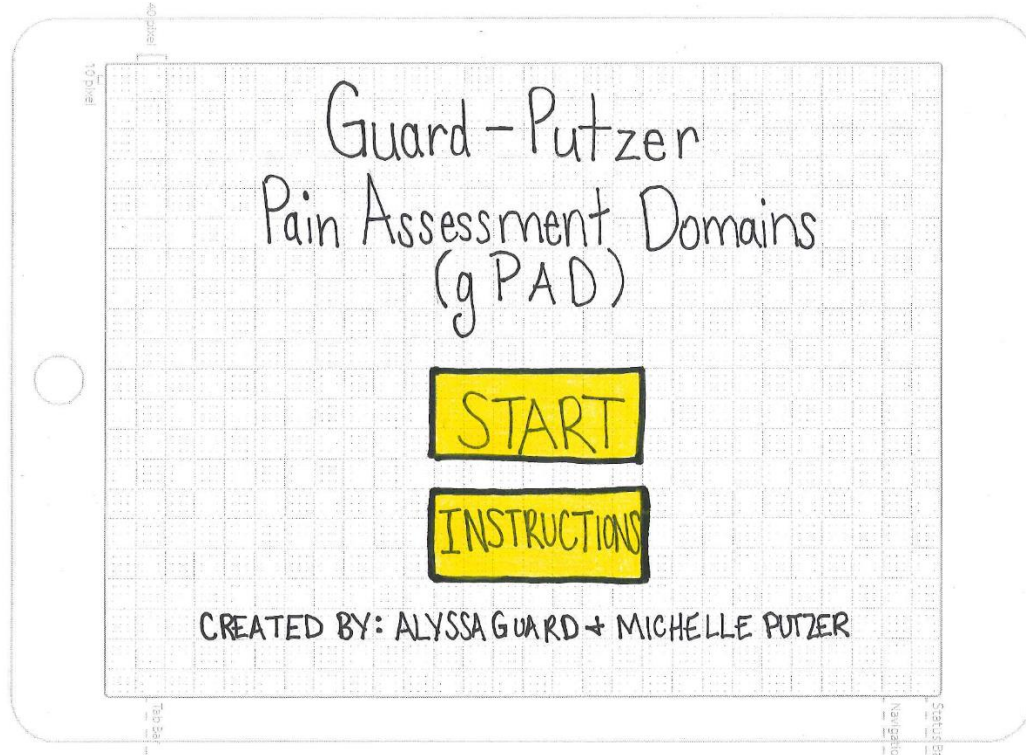
In the past 7 days. . . .		Never	Almost Never	Sometimes	Often	Almost Always
1696bR1	I felt angry when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2035R1	I had trouble doing schoolwork when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3793R1	I had trouble sleeping when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9004	It was hard for me to pay attention when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2045R1	It was hard for me to run when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2046R1	It was hard for me to walk one block when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
1703R1	It was hard to have fun when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2180R1	It was hard to stay standing when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3582R1	I hurt a lot.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9009	I hurt all over my body.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2032R1	I missed school when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9007	It was hard for me to remember things when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
1701R1	It was hard to get along with other people when I had pain.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4



## Appendix J: IRB Approval-Exempt Status

<b>▼ Study</b>					
<b>Study:</b>	16.094	<b>Sponsor(s):</b>	f. NOT FUNDED (Primary)		
<b>Committee:</b>	Exempt Committee	<b>Sponsor Id:</b>			
<b>Category:</b>	d. Health Services	<b>Grants:</b>			
<b>Agent Types:</b>	A. Data/Record/Chart Analysis • C. Questionnaires/Surveys • E. Audio, Video, Photo Taping • F. Internet Research • X. Device (Non-Medical)				
<b>Study Title:</b>	iPad Application for Nonverbal Youths with a Developmental Disability Survey of Assessing Pain in Clinical Practice and Applicability of a New Assessment		<b>Year:</b>	2015	
<b>Department:</b>	Occupational Science and Technology	<b>Funding Agency:</b>	N/A		
<b>Level of Risk:</b>	Minimal Risk	<b>Student Project:</b>	Yes		
<b>Tags:</b>	Exempt Study				
<b>Comments:</b>					
<b>▼ Study Reference Documents (5)</b>					
Name	Type	Active	Inactivated		
Online Survey Consent Form	Consent Form #1	10/05/2015			
Talk-Over Phase Consent Form	Consent Form #2	10/05/2015			
Pain Assessment Survey	Data Collection Instrument #1	10/05/2015			
IRB Protocol Form	Protocol Form	12/11/2015			
Email Survey Body	Recruitment Material #1	12/11/2015			
<b>Study-Site</b>					
<b>Site(s):</b>	UWM - UWM Only	<b>PI:</b>	Engel, Joyce		
<b>Status:</b>	Active	<b>Additional:</b>	N		
<b>Approval:</b>	October 05, 2015	<b>Expiration:</b>	Exempt - October 04, 2018		
<b>Initial Approval:</b>	October 05, 2015	<b>Other Expirations:</b>			
<b>Comments:</b>					
<b>▼ Contacts (2)</b>					

**Appendix K: gPAD pages**



# Instructions

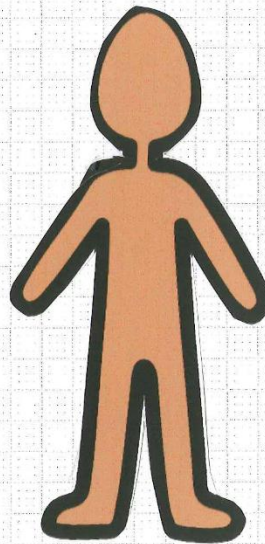
Some questions may have further selection on another page. This can be reached by selecting "more options". Near the end of the assessment it will ask if the user has more pain locations, by selecting "yes" the user will be taken back to the body diagram to select the location and corresponding answers about that location.

During the developmental stage of this app, clinicians should follow along and take notes on the responses of the youth using the app. Until this app has been developed further it does not provide a comprehensive report at the end.

BACK

BACK TO  
START

Pick the area  
with  
your worst  
pain



BACK

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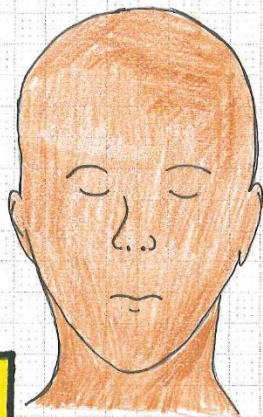


Where on your head is your pain?

FRONT:

CHANGE VIEW:

BACK



TOP

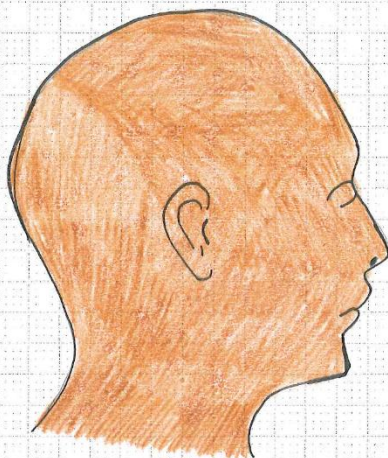
BACK

SIDE

Where on your head is your pain?

Side:

BACK



Which side of your head is the pain located?

RIGHT SIDE

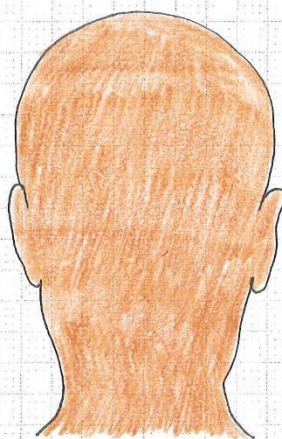
LEFT SIDE

BOTH

BACK

Where on your head is your pain?

Back:

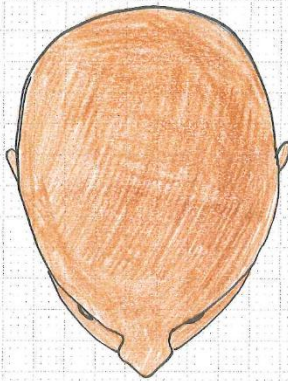


BACK



Where on your head is your pain?

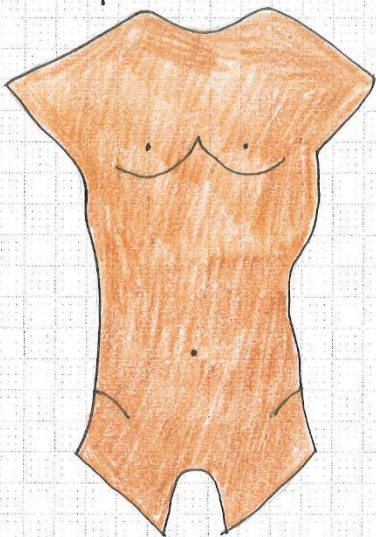
Top:



BACK

Where on your torso is your pain?

FRONT:



CHANGE VIEW:

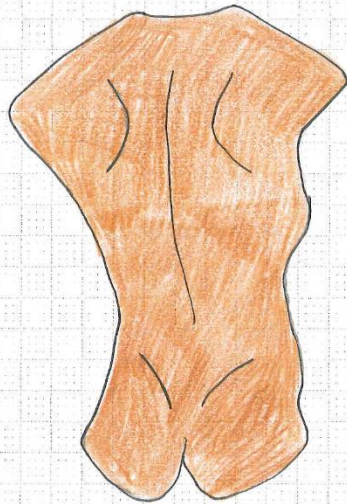
BACK

SIDE

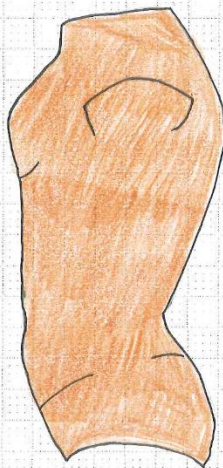
BACK



Where on your back is your pain?



Where on your side is your pain?





Which side of your torso is your pain located?

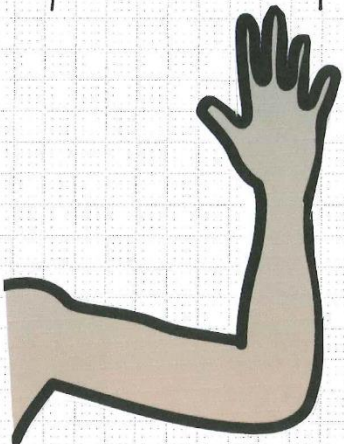
RIGHT

LEFT

BOTH

BACK

Where on your arm is your pain?



BACK

© 2015 BOARDMAKER



Which side of your arm is your pain?

BACK

(opposite side of palm)

FRONT

(same side as palm)

BACK



Which arm is your pain located in?

RIGHT

LEFT

BOTH

BACK

Where on your leg is your pain?

FRONT

BACK

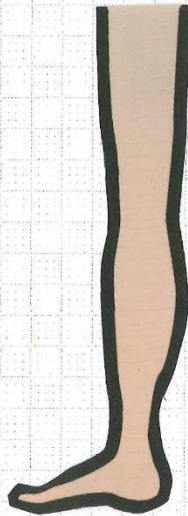
SIDE

BACK



Where on your leg is your pain?

BACK



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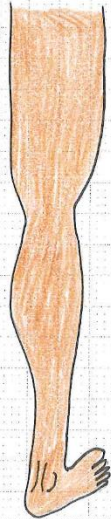
Which side of your leg is your pain?

INSIDE

OUTSIDE

BACK

Where on your leg is your pain?



BACK

Where on your leg is your pain?



BACK

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Which leg is your pain located in?

RIGHT

LEFT

BOTH

BACK



Which leg is your pain located in?

RIGHT

LEFT

BOTH

BACK

How often do you typically have this pain?

EVERYDAY

WEEKLY

MONTHLY

CONSTANT

BACK

How many times per week?

1 time per week

2-3 times per week

3-4 times per week

4-5 times per week

5 or more times per week

BACK

How many times per month?

1-2 times per month

2-3 times per month

3-4 times per month

4-5 times per month

5 or more times per month

BACK



How long does this pain last?

MORE  
OPTIONS

1 minute

5 minutes

10 minutes

30 minutes

60 minutes

BACK

How long does this pain last?

1-5 hours

6-10 hours

11-15 hours

16-20 hours

21-23 hours

BACK

CONSTANT

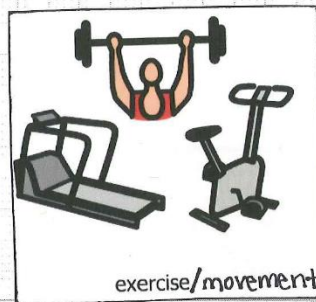
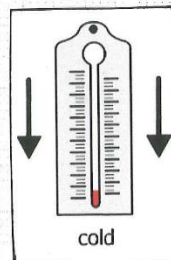
On a scale of 0 (no pain)-10 (worst pain possible), how much does this pain hurt?



BACK

What helps your pain the most?

MORE  
OPTIONS

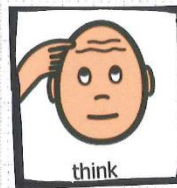


BACK

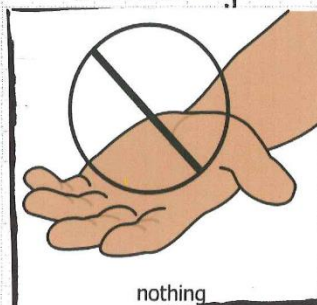
© 2015 BOARDMAKER



What helps your pain the most?



(about something else)

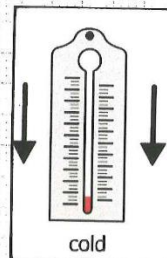
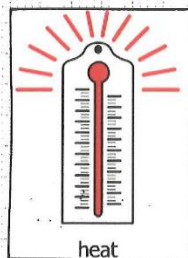
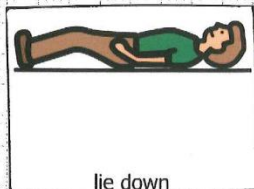


BACK

© 2015 BOARDMAKER

What one activity makes your pain worse?

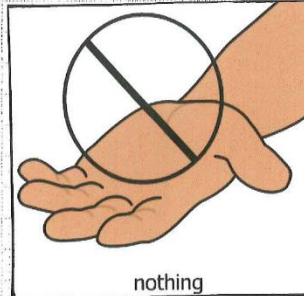
MORE  
OPTIONS



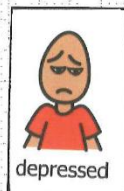
BACK

© 2015 BOARDMAKER

What one activity makes your pain worse?



BACK



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On a scale of 0 (never gets in the way) - 10 (always gets in the way), how much does your pain get in the way of the following activities?

Touch  
to  
Continue

BACK



# General Activities



0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

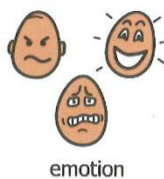
NEVER

ALWAYS

BACK

©2015 BOARDMAKER

# Mood



0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

NEVER

ALWAYS

BACK

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# Ability to get around



walk



wheelchair



walker



crawl

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

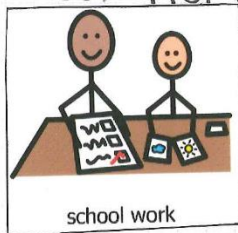
NEVER

ALWAYS

BACK

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# School work and Participation



school work

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

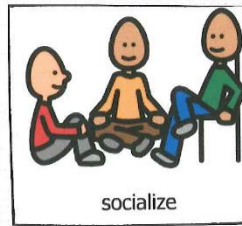
NEVER

ALWAYS

BACK

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# Socializing



0 1 2 3 4 5 6 7 8 9 10

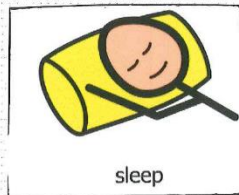
NEVER

ALWAYS

BACK

©2015 Board maker

# Sleep



0 1 2 3 4 5 6 7 8 9 10

NEVER

ALWAYS

BACK

©2015 Board maker



Status Bar

Navigation

Tab Bar

# Playing recreational activities

recreation

0

1

2

3

4

5

6

7

8

9

10

NEVER

ALWAYS

BACK

© 2015 BOARDMAKER

10 pixel

Status Bar

Navigation

Tab Bar

# Self-cares

brush teeth

get dressed

shower

go to bathroom

0

1

2

3

4

5

6

7

8

9

10

NEVER

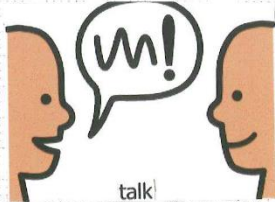
ALWAYS

BACK

© 2015 BOARDMAKER

10 pixel

Communication with others



talk

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

NEVER ALWAYS

BACK

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Do you have any other pain locations?

YES

No

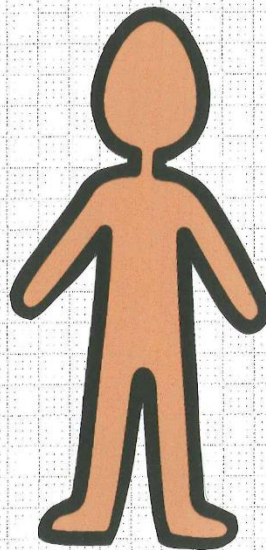
BACK



End  
of  
Assessment!  
Thank  
you

BACK

Pick the  
next  
pain  
location



BACK

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*Appendix L: Study Proposal Draft*

PAIN ASSESSMENT OF NONVERBAL CHILDREN WITH DEVELOPMENTAL  
DISABILITIES

by

Alyssa Guard & Michelle Putzer

A Project Submitted in Fulfillment of the Requirements for the degree of

Master of Science

In Occupational Therapy

at

The University of Wisconsin-Milwaukee

July 2015

## **Abstract**

# **PAIN ASSESSMENT OF NON VERBAL CHILDREN WITH DEVELOPMENTAL DISABILITIES**

By

Alyssa Guard and Michelle Putzer

The University of Wisconsin-Milwaukee, 2016

Under the supervision of Dr. Joyce Engel

(Name of App) is an application that was designed to be a pain assessment for nonverbal children experiencing a developmental disability to self-report their pain. The app was developed by two University of Wisconsin-Milwaukee Master of Science Occupational Therapy students. The purpose of this app is to allow children to express their pain experiences in a variety of domains and give their caregivers an opportunity to understand their child's pain. Healthcare professionals working with these children will also be able to discover the way pain interferes with the child's daily life and can further work with the child to reduce pain and pain interference. Seven pain domains were used to create this app. They include pain location, frequency, duration, intensity, alleviators and aggravators of pain, and pain interference. Based on the research and current pain apps, these domains were found to be the most important and beneficial to identifying a child's pain through self-report. Moving further this app could be developed and mainstreamed into the use by nonverbal children with developmental delays experiencing pain in everyday life.

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© Copyright by Alyssa Guard & Michelle Putzer .....	<b>Error! Bookmark not defined.</b>
All Rights Reserved .....	<b>Error! Bookmark not defined.</b>
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## **Purpose of the Study**

The purpose of this study is to design a communication board that can be used by non-verbal youths with developmental disabilities in order for therapists to understand their pain experiences. Jensen (2010) stated that “No measure of pain is perfect. No one measure assesses all pain domains, nor is any single measure useful in all settings and with all populations. Moreover, because of the imperfection of available instruments, it is theoretically possible to modify any existing measure to improve it further, or to develop new and better measures to replace existing ones,” (p.251). This statement reinforces our purpose and desire to create a new pain assessment for children that can be used in many clinical settings in order to provide client-centered care.

The communication board being designed in this study will include a variety of different domains of pain that are not included in most pediatric pain assessments. The domains of pain will include detailed locations, intensities, durations, pain interference, and activities that may aggravate or reduce the pain. The assessment will allow individuals to select different body parts they feel experience pain. As Jensen stated, “Patients often have more than one pain problem,” (p. 252) we feel it is necessary that patients are given the opportunity to report more than one pain problem. Intensity of pain will be reported in this assessment to allow patients to rate which pain problems are the most severe and also gives them the opportunity to express how much the pain affects them. The duration domain will give clinicians the sense of how long the individual’s pain is interfering in daily life and allows the client the opportunity to express if the pain occurs all day or for only periods of time. The last domain being evaluated with this assessment is profoundly important to give the patient the moment to express in which activities they experience pain the most. This will give clinicians a crucial look into which activities may

be aggravating their pain and the activities that should be adapted or minimized to lessen the experience of pain. This assessment will also provide a more timely approach to save quality treatment time for more implementation of interventions, rather than lengthy evaluation.

## **Literature Review**

### ***Pain***

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage,” (International Association for the Study of Pain, 1994). There are two basic types of pain, acute and chronic. Acute pain serves a biological purpose to alert the person that tissue irritation or damage is occurring. In contrast, chronic pain is persistent pain that is no longer serving a biological purpose (Chambliss et al., 2002). Chronic pain persists beyond the normal tissue healing time, which is usually 3 months (International Association for the Study of Pain, 2003). Chronic pain involves a complex interaction of physiologic, psychological, and social factors (Chambliss et al., 2002).

### ***Prevalence of Pain***

The prevalence of chronic pain in American youths is an important topic to address for the realization of the importance of this study. Huguet and Miro (2007) conducted an epidemiological study to provide information on the prevalence of pediatric pain. Participants included 561 children between the ages of 8 and 16 chronological years. Results of the study showed that 37.3% of the children reported having chronic pain. This study further concluded that chronic pain is highly prevalent in the youth community (Huguet & Miro). Because chronic pain does have a large prevalence, it is important to continue to address the pain experiences of youths as they go through therapy.

Zwakhallen van Dongen, Hamers, and Abu-Saad (2003) reported everyday pain in people with intellectual disabilities is common yet is rarely treated. Also, people with intellectual disability appear to have 2 to 5 times more health problems than people without intellectual disability (Zwakhallen van Dongen et al.). The limited amount of research makes it difficult to accurately determine pain prevalence in individuals with intellectual or developmental disabilities. This is important to remember as a child with a developmental disability may also have an intellectual disability, creating more communication barriers for them to express their pain. The above statements can help us to conclude that pain is prevalent in this population and should be widely recognized as an issue these individuals are experiencing.

### ***Pain Interference***

The interference of pain is important to research for this study to help us gather information as to how pain may be affecting the youths that may be using the communication board. This will also help us gather information to incorporate into our project. In a study done by Roth-Isigkeit, Thyen, Stoven, Schwarzanberger, & Schumucker (2005) examining the effects of chronic pain on daily activities, they found 68.2% of the youths responding reported having restrictions in completing daily activities due to pain. This can include absence from school, missing out on meeting up with friends, loss of appetite, disturbances in sleep, and inability to pursue hobbies. Of the youths responding, 53.6% reported to experience sleep disturbances in a range of sometimes to always as a result of their pain. Of the sample indicated, 53.3% reported that they are unable to pursue hobbies because of the experienced of pain. Absence from school was often or always occurring in 13% of students and sometimes occurring for 35.8% of students. Students with abdominal pain and headaches are more likely to miss school than those who have back pain. This same group of children with abdominal pain and headaches are also

more likely to miss "hanging out" or meeting up with friends than youths who have back or limb pain. They also reported to experience a loss of appetite due to pain more than those with pain in their back or limbs. In this study, as age increased so did pain interference (Roth-Isigkeit et al.).

Similarly, Chambers, Huguet, King, MacDonald, MacNevin, McGrath, & Parker (2011) performed a systematic review of chronic recurrent pain in youths to determine individual factors related to pain. This systematic review included 41 published papers. The study found that complaints of chronic pain were significantly correlated with several variables: chronic health problems, frequent change of residence, poor performances at school, frequent television watching, and fewer interactions with other children. The children described in this study were also found to miss school, withdraw from social activities, and are at risk of developing internalizing symptoms in response to their pain (Chambers et al.). The pain prevalence study mentioned previously by Huguet et al. (2007), also discussed negative consequences that chronic pain can exert on youths. The study participants reported consequences that included reduced quality of life, missing days from school, and were more likely to use pain medication.

It is evident based on the literature that youths who are experiencing pain, whether they can express it verbally or not, are experiencing disruptions in their daily activities. The importance of being able to address the pain appropriately can help reduce or eliminate pain interference ultimately allowing the child to pursue desired activities.

### ***Importance of Assessing Pain***

Jensen (2010) has written extensively on the importance of pain assessment. He stated that "valid and reliable pain assessment is essential for successful pain care," (pp. 251). This statement supports the idea that adequate assessment is necessary to determining the need for intervention, and to understand the mechanisms of those effects. Clinicians and researchers need



to be able to understand all aspects of a child's life, including their pain intensities, in order to help them further their development and improve their quality of life. The systematic review completed by Chambers et al. (2011) demonstrated the need to assess pain because chronic pain is a serious developmental health concern that can interfere significantly with daily functioning. It is important for clinicians and researchers to consider the issues related to pediatric pain so they can develop effective strategies to improve the possible problems.

Breau, Camfield, McGrath, & Finley (2007) completed a comparison study with 63 children and their caregivers to determine whether pain reduced the adaptive functioning of youths with severe intellectual disabilities. The authors addressed the issue that at the time of the study pain was found to interfere with functioning of typical children, but no studies had been completed with children with pre-existing intellectual disabilities. They believed that an understanding of the impact of pain on the daily lives of children will assist caregivers in minimizing the consequences of pain and assisting with development of rehabilitation programs that focus on where pain is most problematic. 64% of youths displayed their possible abilities during pain-free days and only 53% did this during days of experiencing pain. These results suggest that children displayed significantly more abilities when pain-free than when pain was present. The pain was found to impact all areas of functioning, including communication, daily living, social and motor skills. The study concluded that youth's long-term functioning could be affected because of reduced practice of skills, when faced with chronic pain from an early age (Breau et al., 2007). Ratnapalan, Schneewiess, & Srouji (2010) completed a thorough literature review that supports why it is important to assess pain. Pain in infants, children, and adolescents is often underestimated and therefore undertreated. Another topic addressed concluded that youths who experience pain in early life show long-term change in terms of pain perception and

related behaviors (Ratnapalan et al.). These statements help justify that it is important for healthcare professionals to assess, address, and reduce the pain and associated anxiety as much as possible because pain interferes with the youth's daily life and long-term psychosocial development.

Overall pain is important to assess in all patients that may be experiencing pain. It is one's right to receive pain reduction and suffering. Our belief closely follows the International Association of the Study of Pain's Declaration of Montreal (IASP, 2015). The title of this declaration is the "Declaration that Access to Pain Management Is a Fundamental Human Right." One of the main objectives of this declaration is as follows:

"The obligation of all health care professionals in a treatment relationship with a patient, within the scope of the legal limits of their professional practice and taking into account the treatment resources reasonably available, to offer to a patient in pain the management that would be offered by a reasonably careful and competent health care professional in that field of practice. Failure to offer such management is a breach of the patient's human rights," (IASP).

This bold statement helps healthcare professionals, to realize how important it is to allow youths and other patients the opportunity to express their pain, and receive pain evaluation, and receive intervention to help manage the pain itself.

### ***How Pain is Assessed***

There are three main methods for measuring pain: self-report, behavioral, and physiological measures. Self-report measures are found to be the most valid and optimal, however, they are dependent on individual's cognitive development and language skills. Conrad, Fanurik, Harrison, Koh, and Tomerun (1998) completed an exploratory study of self-report skills

with 47 children with borderline-to-profound cognitive impairment between the ages of 7-8 years. This study was completed to determine the extent to which children with cognitive impairment understand a simple pain intensity scale or their skills underlying its use. The authors discussed how the "gold standard" for pain assessment is self-report, (Conrad, Fanurik, Harrison, Koh, & Tomerun). However, proxy report by a parent is often used in pediatric health care services to help determine pain a child is having when they are unable to report the information themselves. In past research, it is well documented that in both adult and children information provided by proxy respondents is not equivalent to that reported directly by the patient (Irwin, Gross, Stucky, Thissen, DeWitt, Lai, Antmann, Khastou, Varni, & DeWalt, 2012).

Behavioral measures include: assessment of crying, facial expressions, body postures, and movements. This type of measurement is most often used with neonates, infants, and younger children where communication is difficult. Physiological measures include assessment of heart rate, blood pressure, respiration, oxygen saturation, palmar sweating, and sometimes neuroendocrine responses. These methods are only valid for acute pain and differ depending on the general health and maturational age of the infant or child (Ratnapalan et al., 2010). Based on the research done, it can be concluded that self-report is the best way to approach assessment of the private experience of pain. Self-report will be the main focus of the following review of assessments as this is the method of pain assessment that is going to be used to build the communication board. The review of standardized pain instruments will begin with ones used by all children, and then will focus in on our desired population.

Type of Measure	Measures	Standardized Instruments
<b>Self-Report</b>	Pain intensity	Wong-Baker FACES Pain Rating Scale (Wong DL, Hackenberry-Eaton

		M, Wilson D, Winkelstein ML, Schwartz P., 2001).
		Pieces of Hurt (Poker Chip Tool) (Hester, Foster, and Kristensen, 1990).
		Colored Analog Scale (McGrath, Seifert, Speechley, Booth, Stitt, and Gibson, 1996)
<b>Behavioral</b>	Physical discomfort and pain intensity	The Faces Legs Activity Cry Consolability Scale (FLACC) (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997)
	Pain-related distress	Observational Scale of Behavioral Distress (OSBD) (Jay, Ozolins, Elliot, & Caldwell, 1983)
<b>Physiological</b>	Blood Pressure	Blood pressure cuff

**Table 1:** Additional assessment resources for pediatric children between the ages of 7 to 12 years not mentioned in the literature of this review.

A review of pain measurements done by Ratnapalan et al. (2010), found a self-report measurement that is widely used for children experiencing pain within the chronological ages of 7-to-12-years-old. These include the Adolescent Pediatric Pain Tool (APPT; Savedra, Tesler, Holzemer, & Ward, 1992). APPT is a valid all-encompassing pain assessment tool used for individual pain assessments and measures intensity, location, and quality of pain in youths older than 8 years of age. This tool is most useful with children and adolescents who are experiencing refractory pain. It consists of a body diagram to allow youths to point to the location(s) of pain on their body and a word graphic scale to measure pain intensity (Ratnapalan et al., 2010). This assessment is important to consider in our research to see what is provided in a comprehensive self-report of pain.

Two questionnaires have been commonly used for youths to help them self-report their pain. The Varni-Thompson Pediatric Pain Questionnaire (Varni, Thompson, & Hanson, 1987) includes a visual analog scale (VAS; White & Snow, 1985) a body outline, a color coded scale for determining distress and discomfort from the pain, questions regarding family history, pain

descriptors, and questions relating to socio-environmental factors to help assess chronic or recurrent pain. The VAS is a straight line with two ends that are defined as the limits of the sensation being measured. VAS is a cross-modality matching in which the length of the line is adjusted to match the strength of the perception. This self-report measure can be used for pain intensity and has been found to be reliable for children 5 years of age and older (Shields, Cohen, Harbeck-Weber, Powers, & Smith, 2003). This questionnaire has three versions allowing parents to report for children, a version for adolescent aged children to self-report and for children less than 7 years old to answer. The Children's Comprehensive Pain Questionnaire uses open-ended questions with the VAS to assess chronic and recurrent pain (Chambliss et al., 2002). It is unknown if a child with a mild cognitive impairment can reliably answer these questionnaires, and cognition should be considered and tested with the assessment we create.

To be more precise on the ways pain is assessed with our population, further research was done on pain assessments for nonverbal children with or without cognitive disability. All of these assessments do not include self-report. One way the Children's Hospital of Philadelphia has found to be beneficial in assessing pain for children with a severe or profound cognitive disability is through the revised version of the Face, Legs, Activity, Cry and Consolability (rFLACC; Merkel, Voepel-Lewis, Shayevitz & Malviya, 1997) pain assessment. This assessment was reported to have clinical practicality and allowed for parents and caregivers to enter in individualized information about the child's pain behaviors. For example, if a child was frequent to have a clenched jaw or quivering chin the child would score a 2 in the face section. A score of 1 would constitute occasional grimacing or frowning and a 0 is no particular expression. High scores of the rFLACC suggest a child is experiencing pain. This assessment takes about a minute

to complete according to registered nurses testing the assessment at the hospital (Chen-Lim, Zarnowsky, Green, Shaffer, Holtzer, & Ely, 2012).

The Noncommunication Children's Pain Checklist (NCCPC; Breau, Camfield, McGrath, Rosmus & Finley, 2000) is a 30-item checklist of common pain behaviors of youths who are nonverbal. They are categorized into vocal, eating or sleeping, social or personality, facial expression of pain, activity, body or limbs, and physiologic pain behaviors. A postoperative version was created, eliminating the eating or sleeping category. Both versions of this assessment have been noted to be time consuming to complete as they require observation time.

The Individualized Numeric Rating Scale (INRS; Curley, 2003) is another form of assessing pain in a youth who is nonverbal. In this assessment caregivers are asked to rate pain behaviors as a result of the intensity of pain to the corresponding level of intensity. This instrument is used if the child is above the chronological age of 3 years and has a cognitive disability (Solodiuk & Curley, 2003). Both of these assessments have been found to have convergent validity between their total scores and ratings. The INRS ratings were higher before a pain intervention and lower after, indicating reduced pain as to be expected. This was not dependent on the type of rater, supporting the assessment's construct validity (Solodiuk, Scott-Sutherland, Meyers, Myette, Shusterman, Karian, Harris, & Curley, 2010).

The rFLACC, NCCPC, and INRS assessments rely on observations and accuracy of the rater in the child's presentation of each area, instead of the child self-reporting these pain behaviors and the level of severity that corresponds. The study mentioned earlier by Conrad et al. (1998) also noted that there are pain assessment scales available that have been developed and validated for children with limited verbal and comprehensions skills, such as the Faces Pain Scale (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990), the Poker Chip tool (Hester, Foster,

& Kristensen, 1990), and the Oucher (Beyer, Villarruel, & Denyes, 2009). However, none of these have been studied in youths with cognitive impairments. Having all of this research on different ways that pain is currently assessed in our population, we can note that a new self-assessment would be useful because most of these assessments cannot be used with non-verbal children with developmental disabilities. This research will also help us in designing and creating a communication board to assess pain.

### ***Project Population***

We want to make a communication board for youths who are nonverbal and have a developmental disability. Both verbal and nonverbal reports require a certain level of cognitive and language development for the child to understand and give reliable responses (Ratnapalan et al., 2010). However, it should be tested as to what cognitive level our assessment would be appropriate for considering it is difficult to determine a child's cognition when they are non-verbal as well. This population has limited research, and it is mostly concerned about the intensity of pain or broad location of the pain.

An exploration study completed by Conrad et al. (1998) found that 50% of children with borderline and 35% of children with mild cognitive impairment were able to correctly use the Numeric Pain Rating Scale (NRS; McCaffery, M, Pasero, C., 1999). Half of the children with cognitive impairment demonstrated skills, such as magnitude and ordinal position, which may allow them to use simpler pain rating methods. Children with moderate to greater levels of cognitive impairment did not pass the entire self-report evaluation (Conrad et al., 1998). However, having an assessment that allows for a comprehensive self-report of their pain experiences will allow for better understanding and treatment of it by the clinician, even if the child cannot complete the assessment in its entirety. Adaption can be made to how a child

responds to the questions, with a switch or head stick, or how they have the questions read to them, audibly or independently.

The Ratnapalan et al. study (201) on the review of pain assessments contributed to our narrowing of inclusion criteria. The authors stated that infants and children present a unique challenge that require consideration of their chronological age, developmental level, cognitive and communication skills, previous pain experiences, and associated beliefs. It was stated that healthcare professionals depend on self-report from school-aged children, and we agree. The authors also mentioned that children at roughly 7 to 8 years of age begin to understand the quality of pain. Children at this age are able to understand their pain and may begin to tell how it is affecting their life. Self-report, visual analogues, and numerical scales are effective in this age group. Children's capability to describe pain increases with age, experience, and changes throughout their developmental stages (Ratnapalan et al., 2010). These statements helped us decide to make a chronological age requirement of 7-12 years. An assessment with broad age limits may make it difficult for healthcare professionals to decide which pain assessment to use. Also, having an age requirement for an assessment will allow for an increase in the reliability and validity of the assessment.

One particular age group that stood out in our decision of age inclusion criteria was 6 to 10 years, or middle childhood. At this level, fine motor skills include good dexterity with small objects and precision and motor planning that is needed to use possible communicative devices, such as an iPhone or iPad. The cognitive abilities for this age range include demonstration of flexible problem solving, solving of complex problems, and abstract reasoning. These cognitive skills are important for this study because of the in-depth questions asked of the child to answer,



however adaptations will be made to allow for the use of the communication device with children who may have a cognitive impairment (Case-Smith & O'Brien, 2010).

The Centers for Disease Control and Prevention (2015) define developmental disability as a “group of conditions due to impairment in physical, learning, language, or behavior areas.” Based on the developmental levels mentioned above, individuals with a developmental disability may have an interference with or have limited ability to complete tasks within their expected developmental range. This is important to consider when creating our assessment for children with a developmental disability.

### ***Current Pain Applications***

When searching the Apple App Store, various pain applications are presented. Some apps are able to be downloaded for free, with options to upgrade the app for a small cost while others have a price tag of up to \$42, approximately. The Web MD app allows users with a chronic pain condition to track how frequently throughout the day they are experiencing pain in relation to their diagnosis, along with triggers for their pain and a section to journal each day (WebMD, LLC, 2014). The My Pain Diary app allows a user to upload photos and print or email the tracking of their pain to share for medical purposes. It also costs \$4.99 to download, with no additional cost after the initial download to use various app features (Lynn, 2013). The Chronic Pain Tracker is an app that costs \$9.99 and has multiple features to allow users to track their pain history. The features include pain location mapping on a diagram of a body and allows users to have a section in which they can input information they wish to share with their doctor (Chronic Stimulation, LLC, 2014). Pain Tracker is another app that is an interface to record information about an individual's pain and monitors the changes over time. The app is sold for \$0.99 and all of the upgrades are included for free (iHealth Ventures LLC, 2012). Pain Logger is an app that

gives you the option to get a lite edition for free, otherwise costs \$0.99. The Pain Logger app helps users track their pain intensity levels over time and allows users to insert multiple pain locations (Astin, 2015).

All of these apps are a great way for individuals to track their pain intensity levels and location over time. However, the majority of the apps available in the Apple store are tailored more towards adults. The way the apps are presented with different charts and longer descriptions interferes with the ability for children between the ages of 7 and 12 years old to use this app. Also, the apps that use a body diagram use an adult body which is more developed and show more details than children would be able to understand.

One app that is tailored toward children ages 7 years and older is the Healing Buddies Comfort Kit™. In this application children can choose one of the 5 feelings of worried, sick, tired, pain, awake. Based on the selection, it leads the children into a definition of what they are feeling and why as well as a list of what they can do to feel better. Each of these skills is able to be spoken to the child by them hitting the speaker button. It also has additional tips and instructions for kids and a section for parents to learn how they can contribute to helping their child feel better. This app is free with no additional charges for other features inside the app (Culbert, Fitzgerald, Sullwold Ristau, & Harrington, 2012). Although it is a great tool for providing tips and tricks for alleviating a child's pain and other side effects from any medical condition it does not go as in depth to provide enough information about the child's pain as well as information a clinician can use.

Pain Squad is another app that is geared toward children between the ages of 8 and 18 that allows them to track their pain within a 12 hour span. The app has a police theme to help the kids "put pain where it belongs...behind bars". Mainly the app is meant for children with cancer

to track their pain each day during treatment, and has an option to set up reminders so they do not forget to track. Besides providing a body map and intensity scale, it also includes a section to select pain descriptors and a chart of their pain intensity over time (The Hospital for Sick Children, 2015).

Researching all of these current applications has given us a good understanding on features our app should include. Our pain app will need to be easier to comprehend and not include charts that can be confusing to understand with no verbal or audible explanation. It will also include how the pain is interfering in the youth's day, as this is going to be helpful for clinicians and children to understand how their pain is hindering their daily life.

App Title	Location	Frequency	Duration	Intensity	Alleviate/aggravators	Interference
Web MD Pain Coach	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My Pain Diary	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain Diary & Community-CatchMyPain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chronic Pain Tracker	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain Tracker	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Healing Buddies Comfort Kit <sup>TM</sup>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain Logger	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain Squad	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Table 2:** Current pain applications available for individuals to track various pain domains.

### ***Need for New Assessment***

Every child's perception of pain is going to vary, even if they all are exposed to the same noxious stimulus. This further supports the need for self-report of pain experiences of the child, which as stated earlier is the current "gold standard" for pediatric pain assessment. Forms of self-report can include interviews, questionnaires, pain rating scales, and pain diaries recording events causing pain onset, intensity, and duration (Chambliss et al., 2002).

Every assessment is different and allows for variability in understanding pain for certain individuals. However, many assessments available today for nonverbal children with developmental disabilities do not provide a subjective view the youth's private experience of pain. A new universally designed assessment, including a variety of pain dimensions, will allow clinicians to give their pediatric patients a subjective client-centered approach towards improving their daily activities and quality of life. The pain dimensions added into the communication board are important in understanding the whole person and will give clinicians more detailed information about their patients' pain experiences. These dimensions are important because past research has found that "pain is a multidimensional experience that includes a number of measurable qualities" (Jensen, 2010).

### **Methods**

#### ***Design***

An extensive review of the pain assessments currently available for youths has been completed in order to develop a new pain assessment. Each assessment that promotes self-report of the child's pain experience and has been studied to have strong psychometric properties will be considered in the development of a more universal and comprehensive pain assessment. Each

assessment used to help in the development of the pain assessment app is listed in Appendices 2, 3, and 4.

### ***Procedures***

To ensure that the developed iPad application and assessment have content validity, expert reviewers will complete a survey and provide feedback on the utility and ease of the assessment in clinical practice in addition to the content. These expert reviewers will not be contributing to the initial development; instead the supporting advisor and committee members of the project will be providing feedback on the app. Then, the expert reviewers can provide information on how practical they feel the use of the app would be in the clinic and if the app covers topics they find most important to assess.

Development of the app is made possible through the use of Prototyping on Paper, an iPad app that will take a picture of the hand drawn page and allow the user to create links to other pages creating the feel of an app (WOOMOO, Inc., 2014). This will be useful in creating our own prototype to see if this is feasible in the population we hope to use this assessment with after its development. In order to keep some similarity with pictures for the youths taking the assessment, Boardmaker symbols will be used when applicable (Tobii Dynavox, 2015). Many of the youths who may be taking the pain assessment, may also have their own communication board and be familiar with these symbols. Universal design concepts, such as voice over, high contrast, and Boardmaker symbols are being used during this entire process. The Apple iPad has many great features that allows for creating a universally designed app that will not limit which children will be able to use the pain assessment app once developed.

A decision tree (Appendix 1) has been written out and developed before creating each page of the app on Prototyping on Paper's app and website. Following the decision tree,

drawings and symbols will be put together on grid paper following the dimensions of the app. Every sheet will then be scanned onto the iPad using the Prototyping on Paper's app. Setting up direct links will make new locations for the app to go to based off what the user selects and for order of questions within the app being developed. Once this process is completed, then expert review and suggestions will be considered to cover any errors or possible improvements that could be made to the completed app.

In Appendix 2 the Numeric pain rating scale is depicted. The Numeric Pain Rating Scale has shown to have adequate test-retest reliability when using one assessment to test the pain intensity each week for two weeks, and excellent test-retest reliability when testing two or more days during the first week compared to testing the pain level two or more days during the second week. This was with a population experiencing chronic pain (Jensen and McFarland, 1993). Content validity, when studied with people who acquired a spinal cord injury, was voted by participants as being used first over the visual analogue scale, and was voted to be a valid measure to be a part of a minimum data set (Bryce, 2007). This is what the intensity rating will be based on in the app development.

Appendix 3 contains the Varni-Thompson Pediatric Pain Questionnaire. This includes a body chart for children to mark and color code pain areas. The psychometrics for this assessment, along with its parent and physician questionnaire counterparts, has good test-retest reliability when testing at intervals of 1 week, 3 weeks, and 6 months. This assessment has also been used to assess children with chronic pain, beside the original intended populations of juvenile rheumatoid arthritis and sickle cell disease. The shows the utility and generalization that is possible across pediatric populations (Cohen, Lemanek, Blount, Dahlquist, Lim, Palermo, McKenna, and Weiss, 2008). This assessment is aiding in the body mapping for pain locations.

In Appendix 4 the Adolescent Pediatric Pain Tool is displayed. This assessment is shown to have adequate content, construct, and criterion validity, test-retest reliability, alternate forms reliability, inter-rater reliability, and internal consistency reliability. Sensitivity to reduction in pain was also found with this assessment over five days postoperatively. The psychometric properties of the APPT indicate that it is adequate for children between the ages of 8 to 17 years old. Boys and girls are both also found to be appropriate for this assessment, as well as individuals from diverse cultural groups (Jacob, Mack, Savedra, Van Cleve, & Wilkie, 2014). This assessment will aid in providing different ideas for domains to be considered with the new app and the body map also will help with implementing a body into the app to determine the location of the child's pain.

The part of the pain app that includes the rating of the interference of pain on daily activities was pulled from the assessment in Appendix 5. This assessment was developed with previous students being supervised under Dr. Engel.

### ***Participants***

The intended population for this application is for youth's ages 7-12 years old that have a developmental disability and are non-verbal to use as a way to express their pain experience to a therapist or caregiver. Until further research has been conducted children who are younger than this developmental age group should not be considered to use this app effectively. Also, it should only be used on an iPad.

### ***Materials***

The main materials of this study are a pen, pencil, colored pencils, sharpie markers, tape, scissors, paper, and iPad. To make the assessment the pen, pencil, colored pencils, and paper are going to be needed to draw up the various screens for the app. The tape and scissors will serve

the purpose to cut Boardmaker symbols to the correct size and tape them onto assigned grid papers to fit the Prototyping on Paper's layout. Then the iPad is needed to take pictures of the pages and upload them to the Prototyping on Paper account.

### **Limitations**

One limit to this study is that this pain assessment will be entirely designed on an iPad. This hinders the use of the pain assessment for individuals who cannot afford an iPad or do not have access to an iPad. Children who do have access to an iPad, this app will contribute in giving them the opportunity to express their experiences with pain to their caregiver and therapist in a manner that allows for potential insight into new ways to decrease the amount of pain experienced daily. Overall, this will increase the individual's amount of occupations they can participate in and quality of daily life. Another limitation to this study is that individuals may not be technologically savvy, resulting in inability to use this app based on a technology device. This can extend to not understanding how to set up voice over, or connect a switch or scanning method for selecting buttons on the app. Not having enough adaptations available may be another limitation for individuals who may be visually impaired or illiterate. This limitation can be address by the accessibility given by the iPad product, which includes adaptations for the visually impaired and illiterate individuals.

### **Future Implications**

The next step that should be taken for this pain assessment is conducting evidence-based research on this app. The research should include completing a survey to mail out to expert reviewers, which could be health care professionals working with children with developmental disabilities. The healthcare professionals could be occupational therapist, physical therapists, speech language pathologists, or professionals specializing in assistive technology devices. The



step after completing the survey would be to take the results and implicate them into the development of the full app to be accessible in the iTunes store for Apple products. Further research could then be done using the app in clinical trials to ensure the reliability and validity of this pain assessment. Future research should also be conducted to determine if the pain app is improving healthcare professional's ability to better understand nonverbal children's pain and help alleviate pain and pain interference of daily life.

## **Discussion**

The medium in which this app is developed on can be both an asset and setback to the administration of a pain assessment. Apple has many universal design features that allow for children with a variety of abilities to use the app successfully. However, until the app is fully developed beyond the prototype it is difficult to use all of the universal design features on the iPad. Based on the input from the expert reviewers...

### Appendix 1

#### Pain Assessment

Pg. 1: "Name of Assessment" "start"

#### Location

Pg. 2: Front of body picture "Pick your worst pain location"

Pg. 3: dependent on selection made on page 2

- Head and neck: "Pick the exact location of your pain"
  - Close up of head and neck
    - possible selections: ears, eyes, nose, mouth, teeth, forehead, chin, cheeks
  - Side of head and neck
  - Back of head and neck
- Torso: "Pick the exact location of your pain"
  - Side of torso
  - Back of torso
- Arm: "Pick the exact location of your pain"
  - possible selections: fingers, hand, forearm, elbow, upper arm, shoulder
- Leg: "Pick the exact location of your pain"
  - possible selections: toes, foot, ankle, shin, calf, knee, thigh, hip

#### Frequency

Pg. 4: “How often do you have this pain?” “Everyday” “weekly” “monthly” “constant”

Pg. 5: dependent on selection made on page 4

- Weekly possible selections: 1 time per week, 2-3 times per week, 3-4 times per week, 4-5 times per week, and 5 or more times per week
- Monthly possible selections: 1-2 times per month, 2-3 times per month, 3-4 times per month, 4-5 times per month, and 5 or more times per month

#### Duration

Pg. 6: “How long does this pain last?”

- Possible selections: 1 minute, 5 minutes, 10 minutes, 30 minutes, 60 minutes, 1-5 hours, 6-10 hours, 11-15 hours, 16-20 hours, and 21-23 hours; Constant

#### Intensity

Pg. 7: “On a scale of 0(no pain)-10(worst pain possible), how much does this pain hurt?”

- Possible selections: 0,1,2,3,4,5,6,7,8,9,10

#### Helps pain

Pg. 8: “What helps your pain?”

- Possible selections: “nothing” “exercise/movement” “concentrating/relaxing” “medication” “changing thoughts” “heat” “cold” “stretching”

#### Aggravators of Pain

Pg. 9: “What makes your pain worse?”

- Possible selections: “nothing” “exercise/movement” “stress” “depression” “walking” “sitting” “laying down” “heat” “cold”

#### Interference of Pain

Pg. 10: “On a scale of 0 (no pain)-10 (worst pain possible), how much does your pain interfere with the following activities?”

- Pg. 11: “General Activities” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 12: “Mood” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 13: “Ability to get around” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 14: “School work and participation” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 15: “Socializing” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 16: “Sleep” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 17: “Playing recreational activities” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 18: “Self-cares” “0 1 2 3 4 5 6 7 8 9 10”
- Pg. 19: “Communication with others” “0 1 2 3 4 5 6 7 8 9 10”

Pg. 20: “Do you have any other pain locations?”

- Possible selections: “yes” “no”

Pg. 21: dependent on answer to page 20

- Yes: start back at page 2 and repeat the entire process for a new pain location
- No: “End of Assessment” “Thank you”

## Appendix 2

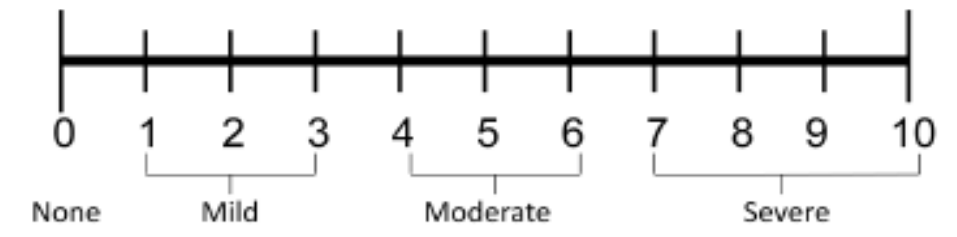
### The Numeric Pain Rating Scale Instructions

#### General Information:

- The patient is asked to make three pain ratings, corresponding to current, best and worst pain experienced over the past 24 hours.
- The average of the 3 ratings was used to represent the patient's level of pain over the previous 24 hours.

#### Patient Instructions (adopted from (McCaffery, Beebe et al. 1989):

*"Please indicate the intensity of current, best, and worst pain levels over the past 24 hours on a scale of 0 (no pain) to 10 (worst pain imaginable)"*



#### Reference:

McCaffery, M., Beebe, A., et al. (1989). Pain: Clinical manual for nursing practice, Mosby St. Louis, MO.

## Appendix 3

# Pediatric Pain Questionnaire

## *Understanding your pain*

This questionnaire is to help us learn about your pain. We want to understand your past pain so we can diagnose and treat you.

This questionnaire and any information given in interviews will remain private. If you do not wish to answer a question, write, "do not wish to answer" in the space provided.

Please print or write clearly.



Today's date: \_\_\_\_\_

Your name: \_\_\_\_\_ Age: \_\_\_\_\_

What words would you use to describe your pain or hurt? \_\_\_\_\_

---

---

---

Circle the words below that best describe your pain, or the way you feel when you are in pain.

cutting	pounding	tingling	tiring	deep
squeezing	throbbing	horrible	stabbing	burning
pulling	sickening	biting	screaming	scraping
aching	uncomfortable	cold	miserable	stretching
pricking	hot	scared	lonely	jumping
pinching	unbearable	sad	itching	grabbing
stinging	sharp	sore	flashing	pins and needles

### Appendix 3

From the words you wrote or circled, which three words best describe the pain you are feeling right now?

---

---

---

Rate **how you feel now**. If you have no pain put a mark at the end of the line by the happy face. If you have some pain, put a mark near the middle of the line. If you have a lot of pain, put a mark by the sad face.



Not hurting  
No discomfort  
No pain



Hurting a whole lot  
Very uncomfortable  
Severe pain

Rate **the worst pain you had this week**. If you had no pain this week, put a mark at the end of the line by the happy face. If the pain you had was some hurting, put a mark by the middle of the line. If the worst pain you had was a whole lot of pain, put a mark by the sad face.



Not hurting  
No discomfort  
No pain



Hurting a whole lot  
Very uncomfortable  
Severe pain

*From Hockenberry MJ, Wilson D, Winkelstein ML: Wong Essentials of Pediatric Nursing, ed 7, St. Louis, 2005, p. 1259. Used with permission. Copyright Mosby.*

### Appendix 3

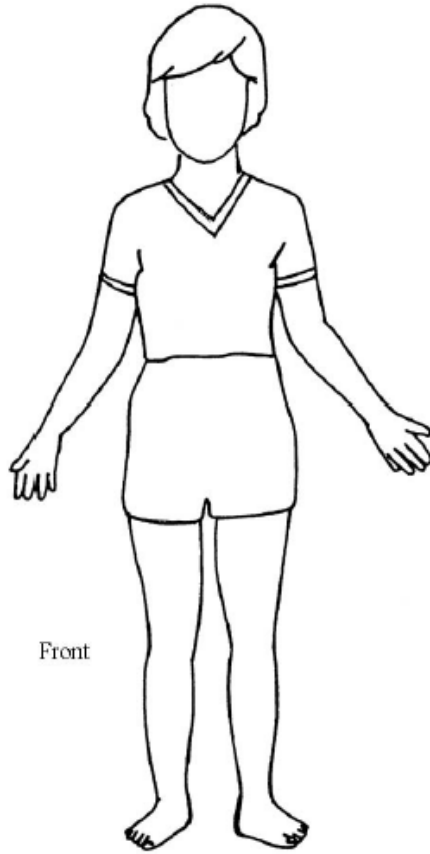
Pick colors that mean **no hurt**, **a little hurt**, **more hurt**, and **a lot of hurt** to you and color in the boxes. Now, using those colors, color in the body to show how you feel.

No pain  
No hurt

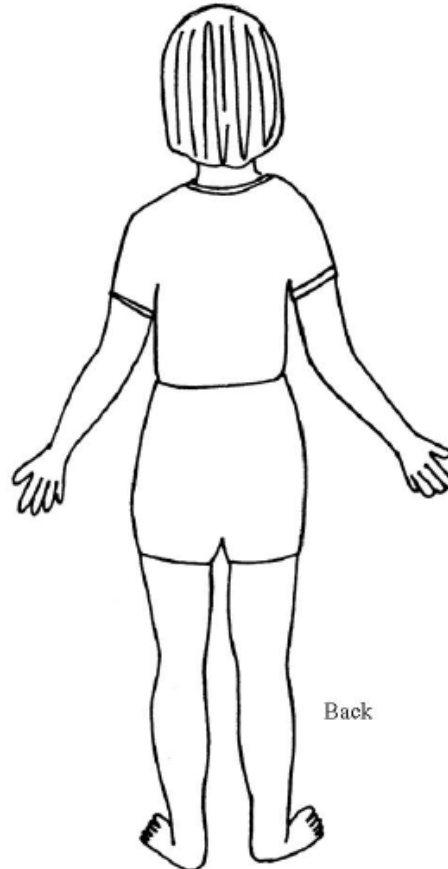
Mild pain  
A little hurt

Moderate pain  
More hurt

Severe pain  
A lot of hurt



Front



Back

**Children's**  
Hospital & Regional Medical Center

4800 Sand Point Way NE, PO Box 5371, M/S 9G-1  
Seattle, WA 98105-0371  
Phone 206-987-2704  
Fax: 206-987-3935

© 2008 Source: Varni, J.W., & Thompson, K.L. (1985).  
The Varni/Thompson Pediatric Pain Questionnaire: Form C (Child), unpublished manuscript.  
Modified for Children's Hospital and Regional Medical Center, Seattle, Washington.  
All Rights Reserved.

## Appendix 4

CODE \_\_\_\_\_

DATE \_\_\_\_\_

**ADOLESCENT PEDIATRIC PAIN TOOL (APPT)**

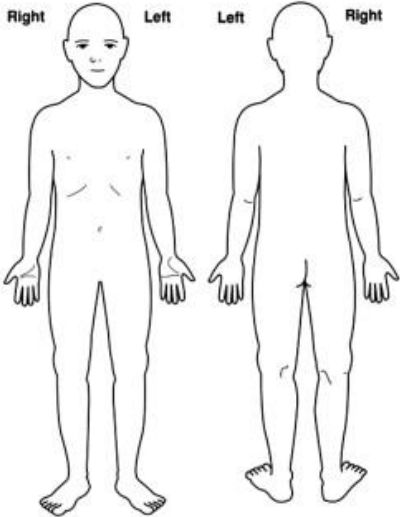
**INSTRUCTIONS:**

1. Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.

2. Place a straight, up and down mark on this line to show how much pain you have.

3. Point to or circle as many of these words that describe your pain.

Right Left Left Right



No Pain Little Pain Medium Pain Large Pain Worst Possible Pain

1 annoying  
2 bad  
3 horrible  
4 miserable  
5 terrible  
6 uncomfortable  
7 aching  
8 hurting  
9 like an ache  
10 like a hurt  
11 sore  
12 beating  
13 hitting  
14 pounding  
15 punching  
16 throbbing  
17 biting  
18 cutting  
19 like a pin  
20 like a sharp knife  
21 pin like  
22 sharp  
23 stabbing

5 blistering  
6 burning  
7 hot  
8 cramping  
9 crushing  
10 like a pinch  
11 pinching  
12 pressure  
13 itching  
14 like a scratch  
15 like a sting  
16 scratching  
17 stinging  
18 shocking  
19 shooting  
20 splitting  
21 numb  
22 stiff  
23 swollen  
24 tight

10 awful  
11 deadly  
12 dying  
13 killing  
14 crying  
15 frightening  
16 screaming  
17 terrifying  
18 dizzy  
19 sickening  
20 suffocating  
21 never goes away  
22 uncontrollable  
23 always  
24 comes and goes  
25 comes on all of  
26 a sudden  
27 constant  
28 continuous  
29 forever

15 off and on  
16 once in a while  
17 sneaks up  
18 sometimes  
19 steady

If you like, you may add other words:

For office use only.

BSA: \_\_\_\_\_  
IS: \_\_\_\_\_

#S (2-9) \_\_\_\_\_ / 57 = \_\_\_\_\_ %  
#A (10-12) \_\_\_\_\_ / 11 = \_\_\_\_\_ %  
#E (1-13) \_\_\_\_\_ / 8 = \_\_\_\_\_ %  
#T (14-15) \_\_\_\_\_ / 1 = \_\_\_\_\_ %  
Total \_\_\_\_\_ / 87 = \_\_\_\_\_ %

(Jacob, Mack, Savedra, Van Cleve, & Wilkie, 2014)

## Appendix 5

Dr. Engel's assessment

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## ***Appendix M: Equivalent Text Descriptions for Tables and Figures***

### ***Figure 1***

Brief: PDF of gPAD asking “what helps your pain the most?”

Essential: A PDF of a landscape page in the gPAD that resembles the outline of the iPad with gridlines where the screen would be. It is asking the question at the top most part of the page “What helps your pain the most?” with two rows of 3 buttons each reading left to right as: more options, heat, cold, back, relax, and exercise/movement. The heat, cold, relax, and exercise/movement buttons are larger squares with Boardmaker pictures, the word listed immediately under the picture to help with association, and each pair is outlined in black to signify the ability to tap the picture as a button. The bottom left corner shows a copy right symbol with 2015 Boardmaker after.

Summary: A PDF page in landscape resembling the outline of an iPad with faint gridlines in the background where the screen would be. The topmost part of the “screen” states “What helps your pain the most?” and is written in black. Underneath this heading there are two buttons in a column on the left hand side of the page, one stating more options, the other back. The more options and back buttons are outlined thick in black with the text written in black. To the right of these buttons are larger pictures with a descriptive word underneath. From left to right, top to bottom these are: (a) a thermometer with the red mercury meter all the way to the top of the numbers and many red lines coming out of the top to signify heat, the descriptive word, (b) a thermometer with an arrow pointing down on the left and right of the thermometer and the red mercury line close to the bottom of the unnumbered temperature scale to signify cold, the descriptive word below, (c) a black stick figure with a face that is smiling is sitting on a yellow chair with its hands up behind its head showing a relaxed posture to describe the word relax (d)

clockwise starting at the top of the circle are three pictures one is a small picture of a person from their chest up holding a bar with weights on the ends, then a stationary bike, then a treadmill all to symbolize the descriptive word of exercise/movement. Each of these buttons are outlined in thin black. The bottom left corner shows a copy right symbol with 2015 Boardmaker written in black.

### *Figure 2*

Brief: PDF of gPAD page stating “Ability to get around” from pain interference portion.

Essential: A PDF of a landscape page in the gPAD that resembles the outline of the iPad with gridlines where the screen would be. It is stating at the top most part of the page “Ability to get around”. Below the written text is a series of 4 Boardmaker symbols with pictures depicting each action with a stick-figure. These actions and words include: walk, wheelchair, walker, and crawl. These Boardmaker symbols are not outlined to be used as a button but rather as a description for the topic of the page. Below the Boardmaker symbols is a row of 11 buttons. Each button represents a number from 0 to 10 in order with “never” anchoring the 0 and “always” anchoring the 10. Below the 0 and 1 buttons on the left side of the page is a back button. All buttons are outlined thick in black with the text written in black. The bottom left corner shows a copy right symbol with 2015 Boardmaker.

Summary: A PDF page in landscape resembling the outline of an iPad with faint gridlines in the background where the screen would be. The topmost part of the “screen” states “Ability to get around” in black writing. Beneath the writing are a row of small pictures of stickfigures performing various tasks relating to ability to get around and each have their descriptive word typed below. From left to right these are: walk, a stick figure sitting in a wheelchair to depict wheelchair, a stick figure standing with a walker to depict walker, and a person on hands and



knees to describe crawling. Immediately below these pictures are a row of 11 buttons running from left to right from 0 to 10. Each button is outlined in thick black with the number written in thin black and yellow for the button background. Under the 0 is the word never, and under 10 the word always. A small space separates each button. On the left side, below the 0, 1 and 2 buttons is another thickly lined button with black written in thin black and a yellow button background. Below this in the left bottom corner of the screen outlines is the copyright symbol with 2015 Boardmaker written after it.

### *Figure 3*

Brief: PDF of gPAD page asking about pain intensity.

Essential: A PDF of a landscape page in the gPAD that resembles the outline of the iPad with gridlines where the screen would be. It is asking the question at the top most part of the page “On a scale of 0 (no pain)-10 (worst pain possible), how much does this pain hurt”? In the middle of the page running horizontally is a row of 11 buttons. Each button represents a number from 0 to 10 in order. Below the 0 and 1 buttons on the left side of the page is a back button. All buttons are outlined thick in black with the text written in black. The button background is yellow to assist with high contrast. The bottom left corner shows a copy right symbol with 2015 Boardmaker after.

Summary: A PDF page in landscape resembling the outline of an iPad with faint gridlines in the background where the screen would be. The topmost part of the “screen” states “On a scale of 0 (no pain)- 10 (worst pain possible), how much does this pain hurt?” There is a large empty space before reaching a row of 11 buttons running horizontally with a number representing each button from 0 to 10. Each button is outlined in thick black with the number written in thin black and yellow for the button background. Under the 0 button “no pain” is written, “moderate pain” is

written under the “5” button and “severe pain” is written under the 10. These anchors are written below the corresponding number. In the left bottom corner is another button outlined in thick black with the word back written in its borders with thin black lettering. The background of the button is yellow.

*Figure 4*

Brief: Gantt Chart of procedures in methods of study.

Essential: This graph displays a Gantt Chart to show the timeline of the various phases and methods the x-axis at the top most part of the graph, listing dates: 4/6/15, 5/26/15, 7/15/16, 9/3/15, 10/23/15, 12/12/15, 1/31/16, 3/21/16, 5/10/16, 6/29/16. The y-axis lists vertically the steps to the methods described in the paper which include from top to bottom: project develop step 1, step 2 and step 3, project testing step 1 and 2, survey development, survey review, and survey participant recruitment. The graph shows that all project development steps were completed before 7/15/15, then survey development and review steps were completed, followed by project testing steps 1 and 2. Lastly, survey participant recruitment was completed starting after 10/23/15 and shortly after 5/10/16.

Summary: This is a horizontal bar graph, with the x-axis listed at the top part of the graph and the y-axis on the left side of the bars in the graph. The x-axis lists the dates: 4/6/15, 5/26/15, 7/15/16, 9/3/15, 10/23/15, 12/12/15, 1/31/16, 3/21/16, 5/10/16, 6/29/16 and the y-axis lists the steps to completing the development of the gPAD and the survey as described by the steps in the methods portion. These steps listed from top to bottom are: project development step 1, project development step 2 and project development step 3, project testing step 1 and project testing step 2, survey development, survey review, and survey participant recruitment. The graph is

displayed as horizontal yellow bars that extend the length of the y-axis. Their length is dependent upon the time it took to complete the task.

The first bar starts at project development step 1 with the yellow bar starting at 4/6/15 and extending just past the 5/26/16 line. Then the bars for project development steps 2 and 3 start immediately after, with step 2 ending before step 3. Step 3 extends to the halfway point between 5/26/15 and 7/15/15. There is a gap with no bars between the end of step 3 and the start of the bar for survey development shortly after the marker for 9/3/15. This bar ends roughly at the halfway point between 9/3/15 and 10/23/15. There is a short bar for survey review that overlaps with the end of the survey development bar. After survey development ends, then begins the project testing step 1 bar with project testing step 2 immediately following. Both are located in the latter half of the space between 9/3/15 and 10/23/15. Lastly, the survey participant recruitment bar starts after the 10/23/15 marker and extends into the space between 5/10/16 and 6/29/16.

*Table 1*

Brief: Table describing available apps and domains covered.

Essential: This table lists each app by title in the left most column with following column titles including: location, frequency, duration, intensity, alleviate/aggravators, interference, age, and pain type. Within each row for each app there is a check box to depict with the app associated with that row has questions or portions of their app that include those pain domains along with age and pain type listed on the top row. Of the apps listed which include from top to bottom: Web MD Pain Coach, My Pain Diary, Pain Diary & Community-CatchMyPain, Chronic Pain Tracker, Pain Tracker, Healing Buddies Comfort Kit™, Pain Logger, and Pain squad, none of them have a check in the interference column. The Web MD Pain Coach and My Pain Diary are

for people 17+ years. The Chronic Pain Tracker, Pain Tracker, and Pain Logger are for people 4+ years. The Pain Diary & Community-CatchMyPain is for people 12+ years old.

Summary: This table lists each app by title in the left most column with following column titles including: location, frequency, duration, intensity, alleviate/aggravators, interference, age, and pain type. Within each row for each app there is a check box to depict with the app associated with that row has questions or portions of their app that include those pain domains along with age and pain type listed on the top row. Of the apps listed which include from top to bottom: Web MD Pain Coach, My Pain Diary, Pain Diary & Community-CatchMyPain, Chronic Pain Tracker, Pain Tracker, Healing Buddies Comfort Kit™, Pain Logger, and Pain squad.

The Web MD Pain Coach has frequency, intensity, alleviate/aggravators checked is for 17+ years and assesses chronic pain. The My Pain Diary app has location, frequency, duration, intensity, and alleviate/aggravators checked, is for 17+ years and assesses chronic pain, specifically Chronic Regional Pain Syndrome (CRPS). Pain Diary and Community-CatchMyPain has location, frequency and intensity checked, it is aimed for those 12+ years old and does not specify pain type it is meant for. Chronic Pain Tracker has location, duration, intensity, and alleviate/aggravators checked is for anyone 4+ years and is meant for chronic pain tracking. Pain Tracker has frequency, intensity, alleviate/aggravators checked and is for 4+ years and does not specify the type of pain it is ideal for tracking. Healing Buddies Comfort Kit™ has duration, intensity and alleviate/aggravators checked, was noted to be for people 7 years and older and does not have a pain type it is meant to track. Pain logger has location and intensity checked is identified to be good for any 4 years an older and does not specify the pain type it can be used for. Lastly, Pain Squad has location and intensity checked, is meant for people aged 8-18 years and helps track pain related to cancer.

*Table 2*

Brief: Table describing current pain apps and their accessibility features.

Essential: This table lists the pain apps by title in the left most column. The top row lists various accessibility features tested with these apps on the iPad which include: VoiceOver, zoom, speak screen, switch control, hold duration for .5 seconds and ignore repeat for .5 seconds. The apps included from top to bottom are: Web MD Pain Coach, My Pain Diary, Pain Diary & Community-CatchMyPain, Chronic Pain Tracker, Pain Tracker, Healing Buddies Comfort Kit™, Pain Logger, and Pain squad. The two columns with the fewest apps having compatibility with accessible features are the VoiceOver column with the My Pain Diary and Healing Buddies Comfort Kit™ and the only app that had effective use of the speak screen function was again Healing Buddies Comfort Kit™.

Summary: This table lists the pain apps by title in the left most column. The top row lists various accessibility features tested with these apps on the iPad which include: VoiceOver, zoom, speak screen, switch control, hold duration for .5 seconds and ignore repeat for .5 seconds. The apps included from top to bottom are: Web MD Pain Coach, My Pain Diary, Pain Diary & Community-CatchMyPain, Chronic Pain Tracker, Pain Tracker, Healing Buddies Comfort Kit™, Pain Logger, and Pain squad.

The Web MD Pain Coach app has zoom and hold duration checked. My Pain Diary has VoiceOver, zoom, switch control, hold duration and ignore repeat checked. Pain Diary and Community-CatchMyPain has zoom, hold duration, and ignore repeat checked. Chronic Pain tracker has zoom, hold duration and ignore repeat checked. Pain Tracker has only hold duration and ignore repeat checked. Health Buddies Comfort Kit™ has all items checked, which are VoiceOver, zoom, speak screen, switch control, hold duration, and ignore repeat. Pain Logger

has zoom, switch control, hold duration, and ignore repeat checked. Pain Squad has zoom, switch control and hold duration checked.

*Table 3*

Brief: Total participants in each practice setting and years of experience

Essential: This table depicts the two sets of characteristics from the survey with one topic being practice setting and the other years of experience. These topics are followed by a column to the right with the N, number of responses, and percent of the total 15 respondents that the N represents. There is a footnote for practice settings to indicate that participants were able to select as many of the practice settings that they identify with. Practice settings include: school-based, acute hospital, outpatient, private practice, inpatient, and home health. The years of experience is broken down into 5 categories of: less than 1 year, 1 to 2 years, 2 to 4 years, 5 to 10 years, and more than 10 years.

Summary: This table depicts the two sets of characteristics from the survey with one topic being practice setting and the other years of experience. Practice settings include: school-based, acute hospital, outpatient, private practice, inpatient, and home health. The years of experience is broken down into 5 categories of: less than 1 year, 1 to 2 years, 2 to 4 years, 5 to 10 years, and more than 10 years. These topics are followed by a column to the right with the N, number of responses, and percent of the total 15 respondents that the N represents.

Under practice setting 9 participants or 60 percent identified as school-based, 4 or 26.7 percent identified as working in acute care, 3 or 20 percent identified as working in outpatient, 1 person which is 6.7 percent identified with private practice. 2 participants which is 13.3 percent identified as working in an inpatient setting and 1 person at 6.7 percent of the participants identified as working in home health. For the years of experience one person, 6.7 percent, stated

they have less than 1 year experience, another 1 participant said they have 1 to 2 years, 6, or 40 percent, identified as having 2 to 4 years, 3, 20 percent, said they have 5 to 10 years and 4, 26.7 percent said they have 10 or more years of experience. The practice setting header has a subscript 1 after it which draws attention to the footnote written at the bottom of the table, which states “subjects may work in multiple settings”. This accounts for the number of participants not totaling to 15 in this section.

#### *Table 4*

Brief: Comparison of years of experience with level of iPad competency.

Essential: This table shows a cross-tabulation of years of experience compared to participant responses to level of competency with an iPad. The competency levels are listed at the top of the table as: not, somewhat and very. None of the participants identified as not have any understanding of the use of an iPad. One person each from less than 1 year experience, 1 to 2 years’ experience, and 2 to 4 years’ experience identified as being somewhat competent. Two people who identified as having 10 or more years of experience stated they are somewhat competent. Five people from the 2 to 4 year experience bracket identified as being very competent, as well as 3 from the 5 to 10 year experience group and 2 from the 10 or more years’ experience group.

Summary: This table shows a cross-tabulation of years of experience compared to participant responses to level of competency with an iPad. The competency levels are listed at the top of the table as: not, somewhat and very. The years of experience are broken down into divisions of: less than 1 year, 1 to 2 years, 2 to 4 years, 5 to 10 years, and more than 10 years.

No one across all years of experience identified to be “not” competent with an iPad. The less than 1 year experience participant stated they are somewhat competent, the participant who

had 1 to 2 years of experience also said they were somewhat competent. One participant in the 2 to 4-year row said they are somewhat competent and the other 5 stated they were very competent. No one who identified as having 5 to 10 year's experience said they were somewhat competent, all 3 identified as being very competent with an iPad. For those who had 10 or more years of experience 2 said they were somewhat competent, and 2 said they were very competent. In the total row beneath the listing of the years of experience this leaves 0 in the not column, 5 in the somewhat column, and 10 in the very column.

#### *Table 5*

Brief: Comparison of practice setting with level of iPad competency.

Essential: This table shows a cross-tabulation of practice setting compared to participant responses to level of competency with an iPad. The competency levels are listed at the top of the table as: not, somewhat and very. None of the participants identified as not have any understanding of the use of an iPad. There is a footnote for practice settings to indicate that participants were able to select as many of the practice settings that they identify with. Four identified as working in acute with 3 somewhat competent and 1 very competent. Two work in inpatient rehabilitation with both being somewhat competent. Three work in outpatient, 1 is somewhat competent, 2 are very. One identified with home health and stated they are very competent. One identified with private practice and is only somewhat competent. Nine people identified as to working in schools, with 1 being somewhat competent and 8 being very competent. No one identified to work in a day or community setting or listed an "other" setting.

Summary: This table shows a cross-tabulation of practice setting compared to participant responses to level of competency with an iPad. The competency levels are listed at the top of the table as: not, somewhat and very. The practice settings listed from top to bottom are: acute



hospital, inpatient rehab, outpatient, home health, private practice, day or community program, school and other.

Across all settings no one identified as not being competent with an iPad. Those who identified as being in an acute setting 3 stated they were somewhat competent and 1 was very competent. The only 2 participants who identified as being in inpatient rehab, both stated they were somewhat competent. One participant who said they work in outpatient said they were somewhat competent and 2 said they were very competent and identified as working in this setting. The one participant who identified as working in home health said they are very competent. A participant who works in private practice said they are somewhat competent. No one identified as working in a day or community program, leaving zeros for each level of competency. One participant who identified as a school-based practitioner said they are somewhat competent, while the other 8 participants said they are very competent. No participants had stated they work in a setting not listed by choosing other, resulting in zeros for each level of competency. The total row listed under the practice settings shows a zero for not competent, 8 for somewhat competent and 12 for very competent. A subscript 1 is listed at the end of the practice setting header and the footnote is indicated at the bottom of the graph stating “subjects may work in multiple settings”. This accounts for the total between all competency levels that is greater than the 15 participant total.

#### *Table 6*

Brief: The raw data of each participant’s response to all questions of study.

Essential: There is a chart of the raw data with the number of participants being listed in the left-most column and the top most column listing each question by number. The right most column lists the recruitment method of the participants. In columns 6 and 9 there are text paragraphs of

how the respondent answered to the question in the survey. There is a footnote for participants stating the raw data does not include the participant that did not identify as an OTR in the survey. A second footnote is indicated for participants 14, 15, 17, and 18 stating that these were the participants to drop out of the survey. Each participant only answered up to question 5 before dropping out.

Summary: There is a chart of the raw data with the number of participants being listed in the left-most column and the top most column listing each question by number. The right most column lists the recruitment method of the participants. There is a subscript asterisk after the participant header, and a subscript double asterisk after participant numbers 14, 15, 17, and 18. The first footnote states “Does not include respondent who did not identify as an OTR” and the second says “Participants who did not finish survey are not counted for data analysis.”

Participant 1 identified as school-based has less than 1-year experience, does not assess pain in practice, is somewhat competent with an iPad, thinks the gPAD is useful, agrees that it is easy to understand, clear and concise. They were recruited through WOTA. Participant 2 works in home health with 10 or more years of experience, they do assess pain in practice are very competent with an iPad, find the gPAD useful, also agree it is easy to understand, clear and concise. Feedback given was “use the word example for the activity pictures so they do not select those” and was recruited at WOTA. Participant 3 works in schools has 2 to 4-years of experience does assess pain in practice, is very competent with an iPad, finds the gPAD useful “if the technology is available”, agrees that the app is easy to understand, clear and concise and was recruited at WOTA. Participant 4 works in acute, inpatient and outpatient settings with more than 10 years of experience and does assess pain when practicing. They are somewhat competent with the iPad and think the gPAD is useful as “it looks like a useful means of gathering more

info". They agree that it is easy to understand, clear and concise and participated at WOTA.

Participant 5 works in schools with 2-to-4 years experience, they do not assess pain, are very competent, and agree the gPAD is useful as "it gives another method to communicate with nonverbal students on how they are feeling instead of just using yes no questions." They agree that it is easy to understand, clear and concise and participated at WOTA. Overall feedback included to "add pictures to all sections if possible for those who cannot read." Participant 6 worked in acute and inpatient settings with 2-to-4 years experience, they assess pain, are somewhat competent and think the gPAD is useful stating "easy to access tools as needed based on patient profile." They agree that it is easy to understand, clear and concise and participated at WOTA. Overall feedback included "more young child friendly." Participant 7 identified as working in schools with 5-to-10 years of experience and they do not assess pain with clients, they are very competent with the iPad and think the gPAD is useful adding "I think the more visual, with fewer words, you can make it the better." They agreed that it is easy to understand, clear and concise and participated at WOTA. Additional feedback included "use visuals and pictures for all questions." Participant number 8 works in outpatient, has 5-to-10 years experience, assess pain currently, and is very competent with the iPad and agree the gPAD would be useful stating "kids are already on the iPad and tech is a great way to track data. He or she agreed that it is easy to understand, clear and concise and participated at WOTA. Feedback included "long term uses for tracking change would be great, maybe more graphics and less words for non readers." For participant 9, he or she stated they work in private practice with more than 10 years of experience and that they do assess pain, are somewhat competent with the iPad and agree the gPAD would be useful as "it's always good to have an easy tool. I don't currently use an iPad app for this purpose." He or she agreed that it is easy to understand, clear

and concise and participated at WOTA. Participant 10 stated working in acute, outpatient and school-based practices with 2-to-4 years of experience and that they are not assessing pain but are very competent with an iPad. He or she did not think the gPAD would be useful stating “but the app is a good idea however I think it’s too long.” This participant agreed that the app was easy to understand but was not clear and concise. These responses were collected at WOTA with additional feedback of “I needed some explanation questions are a little confusing.” Participant 11 identified as working in acute care with 1-to-2 years of experience and that they do assess pain currently in practice, are somewhat competent with an iPad, and they agree the gPAD is useful as “yes gives us another way to assess pain.” He or she agrees that the app is easy to understand but that it is not clear and concise with overall feedback stating “too many questions” They were the last participant to be recruited at WOTA. Participant 12 identified as working in schools with 2-to-4 years of experience, stating pain is not assessed, they are very competent, and that the gPAD would be useful because “any method that can be used to help a non-verbal student articulate their experience would be helpful in my line of work. While pain management is not something that is a large part of my work, using an app like this to help communicate would be useful.” He or she agreed that the app is easy to understand, clear and concise. This participant was recruited through email. Participant 13 also worked in a school setting with 2-to-4 years of experience, stated pain is not assessed and they are very competent. They did not think the gPAD would be useful because “My students who are non verbal who are in pain might find that particular survey very long and become even more frustrated.” This participant did agree that the gPAD was easy to understand, clear, and concise. He or she stated “it’s clear it is just way too long for children in that age range.” This response was collected via email recruitment. Participants 14 and 15 dropped out of the study with both participants identifying as school

practitioners with 14 having 5-to-10 years experience and 15 having 1-to-2 years, both stated pain is not assessed. Participant 16 worked in a school setting with more than 10 years experience, stating pain is not assessed and they are very competent with the iPad. They agree that the gPAD would be useful to them “For our non-verbal and essentially non-verbal children, we rely on pictures to teach them to make relationships with words, items, feelings and activity processes.” This participant agreed that the gPAD is easy to understand, clear, and concise with additional feedback stating “Might explore the use of voice-over to speak the text while children look at the pictures.” This response was collected from email recruitment. Both participants 17 and 18 dropped out and identified as being school-based practitioners with 5-to-10 years experience and stating pain is not assessed. Lastly, participant 19 works in schools with 5-to-10 years of experience, he or she does not assess pain, is very competent with an iPad and agrees the gPAD would be useful stating “Sometimes we know that something is bothering the child but are unable to determine what.” He or she agreed that the gPAD is easy to understand, clear and concise with additional feedback stating “I am wondering if having a scale 1-5 may be an alternative option. Some of the kids I work with get overwhelmed when they are presented with a lot of choices. Otherwise like the ease of use.” This last participant was recruited through email.