## DEVELOPMENT AND VALIDATION OF THE CEREBRAL PERFORMANCE CATEGORIES-EXTENDED (CPC-E)

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University of Pittsburgh, 2014

Optimizing resuscitation efforts post sudden cardiac arrest (CA) and improving mortality have received a great deal of attention while efforts to measure and understand functional outcomes post CA have not been adequately addressed. The Cerebral Performance Category (CPC) is considered the "gold" standard outcome measurement tool after CA yet it lacks psychometric validation. The purpose of this project was to develop and establish the psychometric properties of the revised CPC: the CPC-Extended (CPC-E). The specific aims were to establish the CPC-E's content validity, and to test its reliability, and feasibility in the hospital setting. We established content validity by identifying existing Domains in the CPC and adding additional Domains to be included in the CPC-E by conducting a systematic review of the literature, and by engaging a panel of CA and Rehabilitation experts. We identified 10 Domains to be included in the CPC-E: Alert, Logical Thinking, Attention, Short-Term Memory, Motor, Basic Activities of Daily Living (BADL), Mood, Fatigue, Complex Activities of Daily Living (CADL), and Return to Work (RTW). We tested the CPC-E's intra-rater reliability (IR) percent agreement (n = 30; range = 73.3% - 100%) and inter-rater reliability (IRR) (n = 50; range = 60% - 100%) using retrospective chart reviews of the electronic medical records, and its feasibility in a "live" hospital setting (n = 11; range = 90.9% - 100%). For both IR and IRR chart reviews, ICC scores could not be calculated for Mood, Fatigue and CADL Domains due to lack of variance in the For both IR and IRR chart reviews, 5/10 Domains had large amounts of missing data data.

while Mood, Fatigue and CADL Domains had missing data 100% of the time. In contrast, no data were missing for the IRR-Hospital for any of the 10 Domains. We established and developed content validity for each of these unique domains and demonstrated the CPC-E's excellent reliability via "live" administration, in contrast to retrospective medical chart reviews. The CPC-E yields more efficient, reliable and meaningful ratings.

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#### PREFACE

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#### **1.0 INTRODUCTION**

#### **1.1 BACKGROUND**

Sudden Cardiac Arrest (CA) takes the lives of nearly half a million Americans and nearly half of those deaths occur outside the hospital.<sup>1</sup> Of those individuals who are admitted to the hospital, survival to hospital discharge is highly variable with rates ranging from 5% to 33 %. <sup>2-9</sup> Once discharged, long-term survival rates from out-of-hospital cardiac arrest (OHCA) are reported to be 88% after 1 year, 81% after 3 years, 77% after 5 years and 73% after 7 years.<sup>10</sup> These individuals, however, may experience affective, cognitive and physical impairments post CA that interfere with their ability to function and participate in everyday life.<sup>11-17</sup>

#### **1.2 PURPOSES OF DISSERTATION**

CA is characterized by the loss of blood flow to the brain with resultant loss of consciousness and concomitant neuronal injury.<sup>18, 19</sup> While physicians have focused on improving immediate CA care by optimizing the rate of return of spontaneous circulation and improving mortality, functional outcomes post CA have received little attention. In order to evaluate the outcomes of resuscitation efforts, assessment of neurological and disability status of CA survivors has becoming increasingly important. The Cerebral Performance Category (CPC) is considered the standard outcome measurement tool after CA.<sup>20</sup> The CPC is typically completed at discharge as a recommended part of resuscitation outcome studies.<sup>21</sup> Despite lacking established psychometric properties, clinicians base their clinical care decisions on CPC scores. Because short- and long-term clinical recommendations may be made based on this unvalidated tool, the patient's needs and recovery may be compromised. In this dissertation, we have developed an expanded version of the CPC tool – the CPC-Extended (CPC-E) – by establishing its content validity and testing its intra- and inter-rater reliability. It is believed that the CPC-E will inform the clinician and signal the need for further clinical assessment and recommendations.

The purpose of this project was to develop and establish the psychometric properties of the revised CPC-E. The specific aims were to:

- 1) Establish the content validity;
- 2) Test the intra-rater reliability of the CPC-E;
- 3) Test the inter-rater reliability of the CPC-E;
- 4) Test the feasibility of the CPC-E tool in the hospital setting to determine time necessary to complete the tool, comprehensiveness of data, and ease of administration.

#### **1.3 ORGANIZATION OF DISSERTATION**

This dissertation is presented in five chapters. Chapter one provides a brief introduction on the significance and magnitude of sudden CA, and the aims of this study. Chapter two describes the limitations of the CPC and provides the literature review in support of existing or new domains selected for the CPC-E. Chapter three addresses the methods used to establish content validity,

intra- and inter-rater reliability and feasibility. Chapter four discusses the psychometric properties of the CPC-E. Chapter five summarizes the findings of this dissertation, including limitations and suggestions for future research considerations.

#### 2.0 BACKGROUND AND LITERATURE REVIEW

Cardiac arrest (CA) is the sudden, unexpected cessation of effective cardiac pumping function due to either ventricular dysfunction (electrical or mechanical failure) or disorganization (pulseless ventricular tachycardia/ ventricular fibrillation).<sup>22, 23</sup> CA can also result from progressive respiratory failure or shock. CA manifests clinically as sudden cardiac death, which is an unexpected natural death from a cardiac cause within 1 hour of onset of symptoms.<sup>24</sup> Sudden cardiac death is a major clinical problem, resulting in approximately 250,000 to 450,000 deaths annually and accounts for 63% of all cardiac deaths.<sup>4, 8, 25</sup> Because of the increasing and aging population, the incidence of sudden cardiovascular death has remained constant or increased despite an overall decrease in cardiovascular mortality.

Most CAs occur outside the hospital. Historically, survival rates among patients who have an out-of-hospital CA (OHCA) vary from 5% to 21%, depending on the presenting rhythm.<sup>2, 4 5 8</sup> The resultant neurological sequelae range from complete recovery, to coma with brain death.<sup>8, 14</sup>

However, aggressive treatment for CA, including early cardiopulmonary resuscitation, defibrillation and advanced life support has led to improved survival after CA.<sup>23 21, 26</sup> Over the past decade, improved neurologic outcomes and reduced mortality have been reported in patients with out-of-hospital ventricular fibrillation CA who have been treated with mild hypothermia.<sup>27-</sup>

<sup>30</sup> In-hospital CA is common and estimated to be 0.17 ( $\pm$  0.09) per bed per year.<sup>25</sup> Between 2001 and 2009, in-hospital CA mortality rates have decreased by nearly 12% in the United States. <sup>31</sup> With more individuals surviving to discharge the need to appropriately assess quality of life, including mood, cognition, and functional status is becoming increasingly important. <sup>11-17</sup>

Attempts have been made to standardize post CA reporting, yet validated outcome assessment tools following CA have been lacking. <sup>21, 23, 26</sup> Ideally, outcome assessment post-CA should address both functional and neurological status. Historically, post-CA evaluation of outcomes focused primarily on survival/non-survival, with short- and long-term impairment (deficits in body structures and functions) and disability outcomes (difficulties experienced in the execution of everyday activities and involvement in life situations) receiving little attention. With improved survival rates post-CA, accurate assessment of short-term outcomes is critical for decision-making regarding discharge disposition, rehabilitation, and support services, while long- term outcomes are critical for evaluating the efficacy of traditional and emerging post-CA interventions.

The Cerebral Performance Categories (CPC) scale<sup>32, 33</sup> is the current gold standard used to assess short and long term impairment (neurological sequelae) and disability outcomes post-CA. The Utstein Style, which is the uniform reporting of data from pre-hospital cardiac arrests, recommends the use of the CPC as an outcome measure.<sup>34</sup> CPC scores, typically completed by physicians at discharge based on observation and chart review, are also used to establish patient care management recommendations, thus influencing both short- and long-term outcomes such as disability and quality of life (QOL).<sup>35</sup> The CPC was created by the Brain Resuscitation Clinical Trial 1 Study Group (BRCTSG)<sup>32</sup> to be a subjective evaluation of performance, and was modified from a brain damage scale by Jennet and Bond.<sup>33, 36, 37</sup> Despite its widespread adoption,

the CPC has not been thoroughly tested for its psychometric properties. Concerns remain with the CPC based on its inherent subjectivity, its questionable validity and inter-rater reliability, its instability between time and settings, and its failure to adequately discriminate between subgroups of patients with neurological deficits.<sup>20, 38-40</sup> In contrast, the Glasgow Coma Scale (GCS), which was also developed by BRCTSG at the same time as the CPC, assesses short-term neurological function and recovery, has distinct categories and has been validated. However, the GCS is not used beyond the first week or two of hospitalization.<sup>38</sup>

The original CPC scale<sup>41</sup> and a current modification of the scale<sup>39</sup> are shown in Table 1. In both versions of the scale, the authors have combined impairment and disability descriptors. Although the descriptors are addressed at one level, they may not be mentioned again at subsequent levels (i.e., transportation, food preparation, memory changes, and cranial nerve abnormalities).

Score	<b>Original scale</b> <sup>41</sup>	Modified scale <sup>39</sup>
CPC 1.	Good Cerebral Performance: Conscious, alert, able to work, might have mild neurologic or psychological deficit.	<b>1. Good Cerebral Performance (Normal Life):</b> Conscious, alert, able to work and lead a normal life. May have minor psychological or neurologic deficits (mild dysphasia, non-incapacitating hemiparesis, or minor cranial nerve abnormalities).
CPC 2.	Moderate Cerebral Disability: Conscious, sufficient cerebral function for independent activities of daily life. Able to work in sheltered environment	Moderate Cerebral Disability (Disabled but Independent): Conscious. Sufficient cerebral function for part-time work in sheltered environment or independent activities of daily life (dress, travel by public transportation, food preparation). May have hemiplegia, seizures, ataxia, dysarthria, dysphasia, or permanent memory or mental changes.
CPC 3.	Severe Cerebral Disability: Conscious, dependent on others for daily support because of impaired brain function. Ranges from ambulatory state to severe dementia or paralysis.	Severe Cerebral Disability (Conscious but Disabled and Dependent): Conscious; dependent on others for daily support (in an institution or at home with exceptional family effort). Has at least limited cognition. This category includes a wide range of cerebral abnormalities, from patients who are ambulatory but have severe memory disturbances or dementia precluding independent existence to those who are paralyzed and can communicate only with their eyes, as in the locked-in syndrome.
CPC 4.	Coma or Vegetative State: Any degree of coma without the presence of all brain death criteria. Unawareness, even if appears awake (vegetative state) without interaction with environment; may have spontaneous eye opening and sleep/awake cycles. Cerebral unresponsiveness.	Coma/Vegetative S State (Unconscious): Unconscious, unaware of surroundings, no cognition. No verbal or psychological interaction with environment.
CPC 5.	<b>Brain Death:</b> apnea, areflexia, EEG silence, etc. Note: If patient is anesthetized, paralyzed, or intubated, use "as is" clinical condition to calculate scores.	<b>Brain Death</b> (Certified brain dead or dead by traditional criteria)

 Table 1. Original and Modified Cerebral Performance Categories Scale

In addition to inconsistent descriptors, there are four major issues with the current versions of the CPC that limit their reliability and utility for measuring short-term and long-term outcomes. First, only subjective and minimal criteria are provided for each score. For example, options such as "may have minor psychological or neurologic deficits," or "may have limited cognition" can compromise inter-rater and test-retest reliability, although neither have been thoroughly studied or reported. A study by Ajam et al.<sup>40</sup> reported variable inter- and intra-rater agreement with the CPC in classifying favorable (CPC 1 and 2) versus unfavorable (CPC 3 and 4) neurological status for hospitalized patients. The generalizability of this study, however, was limited because of its methodology, and number of eligible subjects. Anecdotally, the reviewers in this study were able to rate the CPC with greater ease and confidence when reports from additional rehabilitation services (e.g., physical therapy, occupational therapy, speech therapy) were available.

Second, validity studies have not been conducted with large populations, and existing reports suggest that validity is inadequate.<sup>20, 38, 39</sup> In 1996, Hsu et al.<sup>38</sup> were the first to examine the relationship between the CPC and functional status and subjective quality-of-life (QOL). This study compared CPC scores at discharge to CPC scores and QOL (Functional Status Questionnaire (FSQ)) scores at follow-up 12 - 24 months later. The FSQ is a structured, reliable and validated instrument in ambulatory and chronically ill populations attending outpatient clinics.<sup>42</sup> The FSQ is designed to assess six aspects of well-being: physical health, mental health, psychological function, social activities, work performance, and quality of interactions.<sup>43-45</sup> Hsu et al.<sup>38</sup> found poor correlations between discharge and follow-up CPC scores ( $R^2 = .32$ ), and discharge CPC scores and follow-up QOL scores ( $R^2 = .13$ ). These authors found that, within each CPC category, there was a great deal of variation and overlap in the objective test scores of

the FSQ, and poor prediction of follow-up QOL with the two best CPC categories (CPC 1 and CPC 2).<sup>38</sup> Even when considering all 5 levels of the CPC (including comatose and dead patients), the correlation of CPC at discharge and at follow-up was only modest, thus demonstrating its limited accuracy for predicting even gross outcomes after hospital discharge.

It is also important to note that despite the large number of studies reporting long-term outcomes post-CA, many researchers fail to evaluate or report the quality of long-term neurologic outcomes. Furthermore, in most studies, the CPC score assigned at discharge is often used to describe long-term outcomes, yet these scores were rarely reassessed after hospital discharge. Hsu et al.<sup>38</sup> were the first to report the lack of a strong relationship between traditionally used neurological outcome measures in cardiac arrest (e.g., clinical neurological exam, GCS, Mini Mental State Examination) and validated indexes of functional disability (e.g., FSQ and The Sickness Impact Profile). The results of their study questioned the meaningfulness of the CPC as a neurological outcome measure, and the reliance on it alone for assessment of outcome, as many studies have done in the past.

Third, the CPC is not stable across times and settings. Raina et al.<sup>20</sup> examined the relationship between discharge CPC scores and CPC and QOL (Health Utilities Index Mark 3 (HUI3)) scores 1 month post-CA. Twenty-one CA survivors participated in the study. A medical chart review was completed at the time of discharge to determine the CPC and Modified Rankin Scale (mRS) scores, while a 1-month in-person interview was conducted to collect mRS and HUI3 scores. Data collected during the interview were used to determine follow-up CPC scores. The mRS is a reliable and valid instrument for measuring the degree of disability or dependence in the daily activities of people following a stroke,<sup>46</sup> brain injury<sup>47</sup> or neurosurgical patients with in-hospital CA.<sup>48</sup> The HUI3 is a 41 item self- or proxy report interviewer-administered

instrument which links QOL to disability by assessing 8 attributes of health: vision, hearing, speech, mobility, dexterity, emotion, cognition, and pain. The HUI3 has adequate reliability and validity in stroke and rheumatologic populations,<sup>49, 50</sup> including survivors of CA.<sup>51, 52</sup> The 1month time point was chosen by the authors because it was close enough to capture the neurological sequelae of the CA, but far enough that it allowed the patients to be medically stable. Despite fair to good correlation coefficients at discharge and 1 month, further examination of the scatter plots revealed substantial variability and a wide distribution of mRS scores obtained from chart review, and 1-month mRS and HUI3 scores obtained from interviews within each CPC category. Ratings of moderate cerebral performance at 1 month, for example, were associated with participant HUI3 scores ranging from severe disability to no disability. CPC scores obtained through chart review were significantly better than the CPC 1-month scores, thus overestimating the participants' cognitive and disability status at discharge compared to 1 month later. Similarly, Tiainen et al.<sup>15</sup> found unexpected results with 93% of the participants rated as having a "good" outcome (CPC 1 or CPC 2) at discharge, yet neuropsychological testing identified 34% of the participants as having moderate to severe cognitive deficits.

Fourth, the CPC fails to discriminate between subgroups of patients with neurological deficits. As previously noted, the wide variability and overlap of scores within and between the CPC reported by Raina et al.,<sup>20</sup> suggests that it lacks the ability to discriminate between differences in impairments and disability among persons with good, moderate, and severe cerebral involvement. The lack of sensitivity may be attributable to the criteria associated with each CPC category, and the attention given by physicians to focus primarily on the cognitive and neurological aspects of each category, while ignoring the functional or disability aspects. For

example, a CPC of 2 (moderate cerebral performance) is "Conscious. Sufficient cerebral function for part-time work in sheltered environment or independent activities of daily life (dress, travel by public transportation, food preparation). May have hemiplegia, seizures, ataxia, dysarthria, or permanent memory or mental changes." In this category, the constructs of neurological impairments and disability are combined together and encompass multiple domains (e.g., consciousness, everyday activities, work), preventing an accurate assessment of each domain, as well as the participant's cognitive impairment and level of disability. In contrast, the HUI3 successfully measures cognition and seven other distinct attributes of health and permits the participant to choose the level that best reflects their condition post-CA. As a result, the CPC violates the psychometric criterion of unidimensionality of a measure since it uses a single digit to measure multiple constructs of impairment and disability.<sup>53-55</sup> Inter-rater bias is also more likely due to the clinician's focus on documenting impairment domains of consciousness and cognition, while mostly ignoring disability outcomes. Moreover, combining domains can lead to an underestimation or overestimation of the patient's impairment and disability, with the former not sufficiently utilizing referrals to rehabilitation services, or failing to provide adequate disability support services related to employment, while the latter may result in services that are not needed.

Stiell et al.<sup>39</sup> concluded that the CPC was only able to grossly dichotomize CA survivors into no-mild impairment/disability versus moderate-severe impairment/disability. Their results suggest that the CPC does not discriminate well between those individuals at the higher end of the scale who have no to mild impairment/disability, nor does it discriminate between those with moderate to severe impairment/disability. Failure to accurately distinguish between individuals with varying degrees of impairment/disability lessens the likelihood that appropriate and varied

rehabilitation services (e.g. cardiac, cognitive, work-hardening) would reach those individuals who would be best suited to benefit from them.

The inability of the CPC to discriminate between patients with varied degrees of impairment/ disability may be attributed in part to the criteria for grading each CPC category. As noted earlier, each CPC criterion level combines distinct impairment and disability concepts disparate concepts that do not allow for an accurate estimation of patients' cognitive, physical, or motor impairment or level of disability. This representation of multiple constructs in a single score also violates the psychometric criterion of unidimensionality of a measure. Specifically, a unidimensional measure assesses a single construct or variable, is free from rater bias, and is more likely to be responsive to change in the construct over time.<sup>46, 56, 57</sup> Participants at the Consensus on Outcomes for Resuscitation Science Conference sponsored by the American Heart Association determined that the complex nature of CA recovery demands classification of the variable patterns of impairment and disability and that a global measure may not suffice.<sup>40</sup> As a result, there is interest in the development of a multi-domain tool similar to the Glasgow Coma Scale, with discrete unidimensional subscales for impairment (e.g., consciousness, motor, sensory) and disability (activities of daily living, work activities) indicators that are scored separately, and which could lead to a more accurate measurement of short- and long-term outcomes after CA. The goal of the proposed project is to develop and test the psychometric properties of relevant domains for a Cerebral Performance Categories - Extended (CPC-E) tool which would more accurately measure the extent and severity of post-CA impairment and disability.

#### 2.1 SUPPORT FOR DOMAINS IN THE CPC-E

CA survivors often experience impairments and disabilities that are not adequately addressed by the current CPC tool. These post CA effects may include impaired cognition (e.g., impaired memory, attention, and executive functioning); impaired affect (e.g., anxiety and depression); and impaired physical mobility. When considered separately or collectively, these impairments can limit activity and participation in society; thus, negatively affecting quality of life.<sup>14, 17, 20, 58, 59</sup> Support for developing discrete CPC-E Domains and related scoring criteria can be found in the CA literature, as well as literature on myocardial infarction and individuals implanted with defibrillators. This section describes and defines the Domains most relevant to the assessment of CA survivors.

#### 2.1.1 Arousal Domain:

Impaired level of consciousness and cognition are perhaps the most studied and reported impairment post CA justifying their continued attention in the CPC.<sup>52, 60-63</sup> Cognitive impairments have been reported in 11-50% of CA survivors<sup>17, 61, 64</sup> with deficits still present in up to half of all survivors 6 months after cardiac arrest.<sup>64</sup>

In a classic work on the diagnosis and treatment of stupor and coma, Plum and Posner<sup>65</sup> describe consciousness as an "awareness of self and environment" involving two aspects: the "content of consciousness," or the sum of mental functions, and arousal, which is closely associated with the appearance of wakefulness. Young and Pigott<sup>66</sup> further expanded the "content of consciousness" to include attention, sensation and perception, explicit memory, executive function, and motivation, with arousal often interchanged with wakefulness. The

relationship between awareness and arousal is hierarchical: Awareness cannot occur independently of wakefulness, but wakefulness may be observed in the absence of awareness (e.g., the vegetative state).<sup>67</sup>

An alert patient has a normal state of arousal. Confusion or "clouding of consciousness is a state of reduced wakefulness or awareness that in its minimal form includes excitability and irritability alternating with drowsiness.

In this state, the patient may be startled by minor stimuli and be easily distracted. Comprehension is frequently delayed and diminished. With advanced confusion, stimuli are consistently misinterpreted and the attention span is shortened. Bewilderment and difficulty following commands are often observed along with minor disorientation with person, place or time. Memory is negatively affected as demonstrated by problems with short story retention and recall or by limitations in backward number counting (at least a four or five number count is expected in normal state of arousal).<sup>65</sup> (p. 4)

In the clinical states of coma and stupor, responsiveness can be impaired (or absent) when the patient is presented with external stimulation, and patients are difficult to arouse or are unarousable. Coma is characterized by the total absence of arousal and of awareness and must last  $\geq 1$  hr.<sup>68</sup> According to Plum and Posner,<sup>65</sup> coma is defined as "unarousable unresponsiveness." This definition is consistent with earlier descriptions of coma that noted "... the absence of any psychologically understandable response to external stimulus or inner need."<sup>69</sup> (p. 162) Sleep-wake cycles are lacking and comatose patients have no eye opening or spontaneous speaking or movement functions. Additionally, comatose patients do not follow commands, and when provoked by a noxious stimulus their eyes remain closed, vocalization is limited or absent, and motor activity is absent or abnormal and reflexive, rather than purposeful or defensive.<sup>70</sup> Coma is typically a transitional state, evolving toward recovery of consciousness, the vegetative state, the minimally conscious state, or brain death.

The terms stupor, lethargy, somnolent, and obtundation refer to states between alertness and coma and are viewed as imprecise terms and; thus, are generally discouraged from use unless accompanied by further qualification. A lethargic or obtunded patient is a " ... sleepy patient who responds to being addressed verbally or to light shaking, or one who responds verbally to more intense mechanical stimulation."<sup>70</sup> (p. 40) The use of the term stupor is supported by Plum and Posner's definition as "...unresponsiveness from which the subject can be aroused only by vigorous and repeated stimuli."<sup>65</sup> (p. 5) In this instance, a stuporous patient's best response to deep pain would be an attempt to push the examiner's arm away with localizing responses.

#### 2.1.2 Attention Domain:

The concept of attention playing a central role in human performance dates back to the late 1800s in the emerging field of experimental psychology.<sup>71</sup> Research on attention eventually focused on behavioral studies of normal adults or individuals with brain injury until the advances in neuroimaging (i.e., positron emission tomography), pharmacology, and electrophysiology converged on the emerging field of cognitive-neuroscience. For the first time, researchers were able to study mental processes, including attention, by simultaneously gathering information on human behavior, physiology and anatomy of the brain.

In 1990, Petersen and Posner were the first to speculate that attention adhered to some sort of organized pattern that allowed it to function as part of a larger, more unified system in the control of mental processes.<sup>72</sup> Imaging of the brain subsequently indicated that attention involves a bilaterally distributed network whose components were asymmetrically represented in both hemispheres. The authors' original descriptions of three independent components or

networks of attention, each specializing in particular processes, have been updated following additional advances in imaging,<sup>72, 73</sup> while neurotransmitter and gene studies have led to further differentiation.<sup>74 75</sup> Currently, the three neural networks of attention, each subserving a different type of function include: achieving and maintaining an alert state, orienting to sensory events, and monitoring and resolving conflicts between alternative actions.

The alerting network focuses on arousal and sustained vigilance (tonic alertness). The study of alerting, or phasic alerting, involves presenting a warning signal prior to a target event in an effort to produce a change from the resting state to a new state. The alerting network prepares and readies the system for an expected signal. Phasic alertness is studied by measuring the influence on reaction time of a signal thereby providing temporal information. Tonic alertness, or vigilance, refers to a sustained activation over a period of time. Historically connected to the study of tasks related to radar operators, vigilance is usually measured by having participants attend to very monotonous situations (critical stimuli having a very low frequency of occurrence) but then imposing high demands on their attention level by introducing a stimulus. Both classical lesion data and recent imaging data confirm that the right hemisphere and thalamic set of areas are largely specialized for the alerting network involving both phasic and tonic alerting<sup>76</sup> while other researchers have observed more pronounced involvement of the left hemisphere.<sup>77, 78</sup>

With respect to the physiology and pharmacology underlying the alerting network, the neurotransmitters norepinephrine and acetylcholine play key roles by facilitating shifts in attention, responding to cues from the environment, and maintaining attention.<sup>79</sup> With the activation of the alerting system, activation of the locus coeruleus in the brain stem, the source of

norepinephrine, is observed. Hence, drugs that decrease or increase norepinephrine can suppress or enhance the alerting system of attention, respectively.

Executive control, involving conflict monitoring, conflict resolution (ability to overcome distracting stimuli), and response selection represents the third neural network of attention. Functional magnetic resonance imaging suggests a dual-networks model of control between the fronto-parietal and cingulo-opercula regions of the brain. The fronto-parietal component is believed to initiate and adjust control on a trial-to-trial basis while the cingulo-opercular component provides stable maintenance of goals during the course of multiple trials of a task and across task performance as a whole.<sup>80</sup>

#### 2.1.3 Assessment of Attention

Visual search tasks, widely used to study orienting of visual spatial attention were first introduced by Posner.<sup>81</sup> The task includes a visual cue, often represented by an arrow in the center of the visual field (pointed right or left). The arrow provides a special clue of the location of an upcoming target stimulus whereby the subject then predicts the location of the target, and voluntarily pays attention to that location. These visual search tasks are known to involve interactions between the two cortical visual pathways: A dorsal pathway that is concerned with spatial perception and visuo-motor performance and a ventral pathway that underlies object recognition.<sup>82</sup>

Attentional executive control is measure by employing tasks that deal with conflict, handling novelty, and detecting errors.<sup>83</sup> For example, in the Stroop task,<sup>84</sup> an individual may have difficulty verbalizing the color of a word, printed in colored ink, when the printed word itself identifies a different color (e.g., the word 'blue' printed in red ink). The distraction

produced by the task-irrelevant stimulus in the Stroop task depends on previously learned associations between printed words and their meaning (i.e., reading required). Stroop, spatial conflict tasks, pictorial conflict tasks (reading not required), and flanker-type conflict resolution tasks<sup>85</sup> (identifying a target item that is flanked by incongruent options) have been used to measure the ability to select the less dominant response. Imaging results suggest that these conflicts selectively engage the anterior cingulate cortex<sup>86</sup> and anterior insula,<sup>87</sup> and left prefrontal cortex.<sup>87, 88</sup>

Involvement of the anterior cingulate cortex not only has an important role in cognition (focused problem-solving, error recognition, and adaptive or strategic response to changing conditions), but to emotional self-control and motor control.<sup>86, 89</sup> The common involvement of the anterior cingulate in attention and both emotion and cognitive control has provided support for the argument that the executive attention network is critical to these various functions.

While the three attentional networks have been defined in anatomical and functional terms, reaction time measures can be used to quantify the processing efficiency within each network. Posner and associates developed the Attention Network Test, a single, 30-minute computerized battery session that examines the effects of cues and targets within a single reaction time task as a way to explore the efficiencies of each network.<sup>89</sup> In each trial, a fixation cross appears in the center of the screen throughout while various cues (none, center or spatial) appear for 200ms. Following a variable length of time, the target (center arrow) left and right flankers (congruent or non-congruent) appear until the subject responds to a button press after which additional trials begin again. Studies using the Test have suggested that it is a reliable measure, capable of evaluating each of the three networks independently of one another.<sup>74, 75, 90</sup>

Methods of assessing cognition and attention were reported in a systematic review of cognitive impairments in post-OHCA survivors.<sup>14</sup> The majority of the 28 studies that were included in the review noted a neuropsychological battery without noting which specific tests were selected. Four studies also included the Mini-Mental State Examination, with one study relying on this measurement exclusively. Six of the 28 studies that were noted to be of good or excellent quality typically had a larger repertoire of measurement tools such as: Neurobehavioural Cognitive Status Examination, Wechsler Adult Intelligence Scale, tests of reasoning, motor speed, and memory verbal fluency. While the Attention Network Test has not been specifically identified in the literature for assessing attention in survivors of CA, three of the top six tools incorporated the following attention measurement instruments: Stroop Color Word Test, Symbol-Digit Modalities Test, visual scanning task, and the Trail Making Test A and B. The Trail-Making Test is generally listed under the executive function domain and it tests sequencing, divided attention, mental flexibility and shifting, speed of processing and manual skills. Although not listed in this review, digit span tests the Attention Domain with subdomains of immediate recall, short-term memory, working memory and concentration. In digit span tasks, the subject repeats a series of digits that are represented orally in 1-second intervals. The second part requires the subject to reverse the order of digits mentally and to repeat the number series backwards.

The Montreal Cognitive Assessment (MoCA©) is a screening instrument for mild cognitive impairment and more severe cognitive deficits.<sup>91</sup> It is also an interviewer-administered questionnaire in which the respondent performs certain tasks, such as drawing and counting, to assess various cognitive Domains, such as attention, memory, orientation, language, conceptual thinking and planning.

Section Six of the MoCA<sup>©</sup> tests the Attention Domain by examining the following:

- <u>Forward Digit Span</u>: At a pace of one digit per second, the examiner reads a five-number sequence and then asks the patient to repeat the sequence in the exact order. Backward Digit Span includes another set of numbers but it requires that the patient repeat the numbers in reverse sequence.
- <u>Vigilance</u>: At a pace of one per second, the examiner reads a list of letters. The patient is asked to tap his or her hand upon hearing a specific letter while not responding (no tapping) when the other letters are read.
- <u>Serial 7s</u>: The examiner asks the patient to subtract seven from 100 until asked to stop.

To summarize, attention is often viewed as a system organized into three neural networks: alerting, spatial orienting, and executive conflict resolution. Each of the attentional networks involves a number of anatomically separated but highly connected structures which are largely distributed within the two hemispheres. Advances in technology are providing unique insights into the understanding of attention.

#### 2.1.4 Memory Domain:

The primary purpose of any clinical test of memory is to detect memory impairments.<sup>92</sup> Memory impairments may occur in short-term memory, long-term memory, and working memory. Short-term memory refers to an individual's ability to store or maintain information over a limited time period, whereas long-term memory involves the storage and recall of information over a long period of time (as days, weeks, or years). In contrast, working memory refers to the ability to hold information in mind while manipulating, and integrating other information towards a cognitive goal,<sup>93, 94</sup> or "the ability to hold in mind information in the face of potentially

interfering distraction in order to guide behavior.<sup>95</sup> (p. 39) <sup>96</sup> While there is some degree of overlap between short-term and working memory definitions, working memory is considered to be the broader concept. Working memory involves short-term memory components dedicated to the storage of information, but it also includes other systems responsible for the coordination and processing of information.<sup>97, 98</sup>

In 2009, Moulaert et al.<sup>14</sup> conducted a systematic review of cognitive impairments in survivors of OHCA. From an initial pool of 286 articles, 28 studies were selected for final review. The authors used a 10-point rating scale with a score ranging from 0 (very poor) to 10 (excellent). Of those 28 studies selected for review, only 6 were ranked 7 or higher with only one study rated a 10. In most instances, the low quality of studies could be attributed to several methodological weaknesses in areas related to population bias (study populations may have also included in-hospital arrest, respiratory arrest or carbon monoxide poisoning; previously identified subjects with cognitive impairments or exclusion of severely cognitively-impaired individuals); small sample size; absence of a standard protocol for testing cognitive function in this population limited comparisons between studies (measurement of cognitive function differed in each study; some included insensitive tools for this population (i.e., Mini-Mental State Examination or inappropriate selection of battery of neuropsychological tests).

The studies with the highest quality rankings reported cognitive problems in 40% to 50% of CA survivors. One of these studies by Sauve et al.<sup>64</sup> examined cognitive outcomes in 45 sudden CA survivors over a 6 month period post arrest. The authors selected the following assessments: Profile of Mood States, to assess the psychological status of subjects over time; Neurobehavioral Cognitive Status Examination, a screening test that assesses intellectual function in several ability areas with subscales selected for orientation, memory and reasoning;

Symbol-Digits Modalities Test (similar to Wechsler's Digit Symbol Substitution Test); Rey's Auditory Verbal Learning Test, which consists of 5 presentations with multiple recall trials of a 15-word list over a 20 minute period; and three computerized task: the Tapping Test, which required the subject to tap quickly and repeatedly; the Memory Scanning task, that requires the respondent to match the numbers presented earlier and the Visual Scanning Task in which the subject searches for a specific target with increasing complexity. At 6 months, 50% of the subjects experienced impairments in one or more of the following: 14 in delayed recall, 11 in recognition, 11 in early recall, and 5 in immediate memory. Of these individuals, half had significant impairments in 2 or more outcome variables related to memory and/or cognitive areas such as psychological (tension, anger or depression), orientation, attention, reasoning, or motor (speed, regularity).

Another highly ranked study by Roine et al.<sup>52</sup> examined 68 CA survivors at 3 months and 12 months post discharge using the Wechsler Adult Intelligence Scale categories of Verbal Intelligence Quotient and Performance Intelligence Quotient, the Wechsler Memory Scale and subcategories Memory Quotient and Delayed Recall, and the Mini-Mental State Examination. Sixty percent of the survivors experienced moderate to severe cognitive deficits at 3 months, decreasing to 48% at 12 months. Other neurological sequelae included deficits in: reading, writing, memory, dyscalculia, or visuoconstructive dyspraxia.

The third and final study with the highest ranking examined cognitive impairment in survivors of OHCA at 6 months after resuscitation.<sup>61</sup> The neuropsychological examination included the following tests of memory, attention and executive functioning: Rey's Auditory Verbal Learning Test (immediate and delayed memory); Stroop Color Word Test (selective attention and response inhibition); Trail Making A and B (divided attention, mental flexibility

and motor speed); Controlled Oral Word Association Test (verbal fluency); and the 6-point Rankin scale (level of independence) scored by the research nurse. Depending on the test, between 11% and 28% of the subjects were found to be impaired in cognitive functioning: Trail Making B (11%); Rey's delayed recall (12%); verbal fluency (21%); Rey's Auditory Verbal Learning Test immediate (19%); with the highest 3 scores reported in the Stroop card 1 - 3 (28%). Eighty-one percent of the subjects were ranked as minimally or not limited in daily life, while 12% had restrictions but were able to take care of themselves (Rankin score 3), and 7% were partially or totally dependent on others (Rankin score  $\geq 4$ ).

In a 2010 Cochrane review to assess the effectiveness of therapeutic hypothermia in patients post CA, it was reported that of all patients from industrialized nations where resuscitation was attempted, 14% to 40% achieved return of spontaneous circulation and were admitted to a hospital.<sup>99-103</sup> Of those patients admitted to a hospital, only between 7% to 30% were discharged with good neurologic outcome.<sup>101, 104-109</sup> These findings are in contrast to two reports in Scotland in which good neurological outcomes were found in approximately 70% of CA survivors <sup>110</sup> or defined as normal or mildly impaired at discharge in 89% of CA survivors.<sup>111</sup>

Caution is warranted, however, when interpreting neurological function in some studies of CA survivors since 'good neurologic outcome' may be poorly defined or unsupported by specific or objective neurological testing. As recommended by the Task Force in 1991 for uniform reporting of data from OHCA: the "Utstein style" neurological outcome is often measured by the Glasgow-Pittsburgh CPC.<sup>112</sup> In a 2011 systematic review of quality of life and other patient-centered outcomes following CA survival, 34 of 69 studies reported using the CPC as an outcome measurement with 9 using it exclusively.<sup>113</sup> As previously noted, a CPC score of 1 or 2 is frequently regarded as a 'good outcome' although it includes subjects with 'mild to

moderate' cognitive impairments, such as dysphasia and permanent memory or mental changes. Good neurological outcomes have been presumably determined by some study authors based on the survivor fitting into a previously undefined category of 'moderate, mild, or no disabilities,' or 'the best score of the Glasgow outcome scale at one month.'<sup>114</sup> Also, authors make assumptions since the survivor of CA "has good neurologic function to be sent home to a rehabilitation facility, or a long-term nursing facility at discharge."<sup>28</sup>(p. 563)

Several CA studies have reported significant cognitive deficits, including memory impairment, in survivors more than 6 months after cardiac arrest.<sup>52, 115-117</sup> Grubb et al.<sup>116</sup> conducted a study to identify the nature, prevalence, and severity of memory impairment in two distinct groups of cardiac patients: OHCA and status post myocardial infarction (MI). The researchers found that chronic impairment of episodic long term memory was a clinically important problem among 35 individuals who had a cardiac arrest outside a hospital. Based on their performance on the Rivermead Behavioral Memory Test (RBMT), a test of episodic longterm memory, 38% of OHCA survivors sustained significant impairment of long-term memory while there was no difference in short-term memory recall between cases and controls. In contrast, none of a comparison group of MI patients had significant long-term memory impairment. The authors used the digits forward and backward subtests from the revised Wechsler Memory Scale as measures of primary short-term working memory.<sup>118</sup> Thirteen of the OHCA subjects performed poorly in tests of spatial and verbal memory and recall of instructions which the authors noted would likely impair the subjects' ability to successfully complete daily functioning tasks.

O'Reilly, Grubb and Carroll<sup>119</sup> built upon the earlier findings by their colleagues by assessing the prevalence and severity of memory deficits in a group of patients who survived an

in-hospital cardiac arrest (IHCA) in comparison with patients resuscitated outside-the-hospital, and patients with acute MI. Thirty-five IHCA survivors, 35 OHCA survivors, and 35 patients who had suffered MI uncomplicated by cardiac arrest were assessed 8.2 (±4.5) months after the event for current affective state using the Hospital Anxiety and Depression Scale, pre-morbid intelligence (National Adult Reading Test), short-term memory (Digit Span Test) and long-term episodic memory (RBMT). Performance on the backwards Digit-Span sub-scale of the Wechsler Memory Scale did not differ between the three groups although there was a significant difference between the groups on the Digits Forwards subscale. This difference was driven by the IHCA group which performed more poorly than both control groups; however, all 3 groups scored in the range expected in unimpaired adults. With respect to long-term memory, their results indicated that IHCA patients scored lower on the RBMT than MI controls but their scores did not significantly differ from those of the OHCA subjects. These results suggest that experiencing an IHCA did not offer any additional protection against long-term cognitive outcome. However, moderate or severe long-term memory impairment was found in 26% of the IHCA group and 38% of the OHCA group while none of the MI group experienced this degree of impairment.<sup>119</sup> While the difference in prevalence of long-term memory impairment between the two CA groups was not statistically significant, both arrest groups had significantly greater memory impairment than the MI control group. Furthermore, follow up to the original OHCA group 3 years post arrest found no improvement in memory performance, but rather a continuation of ageassociated deterioration.<sup>120</sup> Scoring poorly on the RBMT is of concern since this test is specifically designed to identify memory difficulties in impaired populations and focuses on areas in which individuals may encounter difficulties during daily living.<sup>121</sup>

Noting the collective research findings aforementioned, memory deficits that take place post CA are persistent, significant and may be underreported. Drysdale et al.,<sup>120</sup> concluded that "cognitive impairment is a serious and under diagnosed complication of prolonged cardiac arrest" resulting in considerable barriers in resuming activities of daily living (p. 31). Failure by most researchers to adequately address this problem is supported in part by the Heartstart Scotland program in which clinicians only identified cognitive deficits in less than 10 % of CA survivors in their discharge summaries.<sup>111</sup>

## 2.1.5 Memory assessments relevant for CA survivors

In addition to short-term memory, long-term memory and working memory, there are assessments of verbal memory, visual memory and overall general memory which includes several cognitive Domains, such as attention, memory, orientation, language, conceptual thinking and planning. The following are examples of memory assessments, which have been used to assess memory impairments in CA survivors although as previously noted, there is no universal standard assessment protocol in place.<sup>14</sup>

#### 2.1.5.1 Short-term memory assessment

Digit Span, an interviewer-administered test that is part of the Wechsler Adult Intelligence Scale®, Fourth Edition, measures the ability of the respondent to process and retrieve information associated with short-term memory.<sup>122</sup> Other Indexed scores in the Scale include auditory memory, visual memory, visual working memory, and delayed memory. Participants are presented with a list of verbal or visuo-spatial items that need to be recalled in correct serial

order. Individuals are tested on their ability to maintain this information in the short-term, but they are not required to process or manipulate information in any meaningful way. The digit span includes a forwards and backwards subtest. In the forwards subtest the participant listens to single digit numbers presented in series of increasing lengths and then repeats the long string of numbers in the correct sequence until the task becomes impossible. The maximum length (i.e., maximum number of numbers) that a participant repeats correctly constitutes a "span." In the backwards condition the participant is required to repeat the strings of numbers backwards.

#### 2.1.5.2 Long-term episodic memory assessment

Long-term episodic memory can be assessed by the RBMT, a short, reliable, and valid test of everyday memory problems.<sup>121, 123</sup> This test is specifically designed to identify memory difficulties in impaired populations and focuses on areas in which patients might encounter difficulties during daily living. Scores on the RBMT correlate with observer ratings of memory impairment in the moderate to severe impairment range, <sup>121</sup> and impairment on the test corresponds to difficulties in functioning in "real-life." Memory function using the RBMT is measured with several subtests using varying time delays. For example, objects and faces from picture cards are tested following a 3-4 min delay; whereas, the ability to remember a name, the location of a hidden personal item, or an appointment is tested after a 20 minute delay. Other tasks such as remembering a news report or a short route is tested immediately and following a delay.

Each subtest is scored between 0 and 2 points, giving a maximum total score ("profile" score) of 24 points. Performance is divided into four categories according to the profile score/normal memory, followed by mild, moderate, or severe memory impairment.

#### 2.1.5.3 Visual memory assessment

The Visual Reproduction Test, a subset of the Wechsler Memory Test, measures the ability of the respondent to remember cards with images. Two types of recall are tested: immediate recall and delay recall. In immediate recall, the examiner shows the respondent a series of pictures for 10 seconds then asks the respondent to draw them from memory. In delayed recall, and after a lapse of a pre-identified period of time, the examiner asks respondents to reproduce as many pictures as they can recall, and to identify the order in which they were shown the pictures. The test includes cards with images, paper for respondents to draw the images and a copy of the scoring instructions. The protocol includes scoring instructions that account for accuracy and speed.

#### 2.1.5.4 Verbal memory assessment

The Verbal Memory Test, a component of the Wechsler Memory Test on Logical Memory, measures the ability of the respondent to recall words and specific details about a story. It measures a respondent's total range of function with respect to verbal memory by testing two types of recall: immediate and delay. In the former, the examiner reads the respondent a short story and asks the respondent to repeat details of the story from memory. In the latter, the examiner waits a predetermined time before asking the respondent to recall details about the story. This section ends with the respondent answering multiple choice questions about the story content. The protocol includes scoring instructions that account for specific versus paraphrased details.

The MoCA<sup>©</sup> is an instrument designed for rapid screening of mild cognitive dysfunction.<sup>91</sup> It is also an interviewer-administered questionnaire in which the respondent performs certain tasks, such as drawing and counting, to assess various cognitive Domains, such as attention, orientation, language, conceptual thinking and planning, and memory. The subset section related to memory employs 3 trials: First, the examiner reads a short list of words to the respondent whereupon the respondent repeats as many words as can be recalled. This trial is repeated twice but only the second trial is scored. At the end of the test, the third trial requires the respondent to once again recall the list of 5 words, which is then scored.

In summary, memory impairment post CA remains a serious, yet under-diagnosed effect of cerebral hypoxia for many cardiac arrest survivors. With one in four of IHCA and four out of ten OHCA survivors experiencing moderate to severe memory impairment,<sup>119</sup> patients' functional capacity in real life settings (home, work and social settings) can be compromised. Even among patients who regain independence following CA, cognitive dysfunction and memory impairment may limit complete neurological recovery. In a review of common syndromes after hypoxic-ischemic encephalopathy, it was argued that in such patients, "...it is often necessary to include neuropsychological screening and detailed testing of memory to detect subtle deficits."<sup>124</sup> (p. 428)

# 2.1.6 Fatigue Domain:

Fatigue has been described in broad terms such as "the reduction in performance with either prolonged or unusual exertion."<sup>125</sup> (p. 320) Definitions of fatigue are frequently based on subjective reports of tiredness or exhaustion, and/or an objective measure of performance. Fatigue can include a physical component that interrupts and prevents task completion, and a

mental component in which one's attention to an activity is lessened (i.e., failure to initiate or sustain engagement). It is generally agreed upon however, that fatigue interferes with an individual's ability to function at his or her normal capacity.<sup>126</sup> Reduced tolerance to activity in turn leads to further muscle deconditioning, thus exacerbating the symptoms of fatigue.

Fatigue can range from mild to complete exhaustion, and while it is frequently a common complaint within the general population, it is often viewed as an inevitable consequence of advancing age and deteriorating health.<sup>127, 128</sup> While fatigue can be associated with exertion or be a byproduct of effort, its presence "in the absence of any excessive expenditure of energy or effort as cause"<sup>129</sup> (p. 147) is of most concern in this review.

Despite the high number of annual incidents of CA researchers have not thoroughly studied the fatigue experience of post-CA survivors. In Rochester, MN, long-term outcomes were collected from patients who were neurologically intact (defined as good overall capability or moderate overall disability) at discharge following an OHCA from ventricular fibrillation.<sup>130</sup> Mean length of follow-up was  $4.8\pm 3.0$  years post CA. Fifty of 60 patients completed SF-36 surveys at the end of follow-up that were compared with age- and sex-matched controls from the general U.S. population. There were no significant differences between the groups on the majority of quality of life measures with the exception of reduced vitality (e.g., "I tire easily or feel worn out") (p = 0.01). Energy levels were also significantly decreased (p = 0.0001) in a Swiss study looking at long-term survivors of OHCA in seven towns (mix of urban and rural populations) using the Nottingham Health Profile questionnaire.<sup>59</sup> However, researchers also reported no significant differences in vitality in the same study using the Psychological General Well-Being Index.

Researchers from Holland evaluated fatigue in 63 patients surviving, on average, 3 years post CA.<sup>17</sup> Using the Fatigue Severity Scale (FSS), over 50% of participants reported severe fatigue. In addition, 74% of the patients experienced a low participation level in society compared with the general population, 38% reported feelings of anxiety and/or depression and 24% noted a decreased quality of life.

While fatigue has not been adequately addressed in post-CA adults, fatigue is frequently associated with depression, physical and emotional health in the elderly and those with chronic illnesses, such as cancer, multiple sclerosis, systemic lupus erythematous, heart failure, and stroke.<sup>131-134</sup> In these populations, fatigue negatively affects performance in basic and instrumental activities of daily living, quality of life, and overall survival rates. In particular, patients with heart failure were reported to have a higher level of fatigue and eight times greater risk of having fatigue symptoms than healthy people.<sup>135</sup>

MI is another heart condition that frequently results in fatigue. Alsén, Brink, and Persson<sup>136</sup> performed in-depth interviews to understand fatigue and its impact in 19 individuals with a recent history of MI. Participants reported physical, cognitive, and emotional fatigue that restricted their ability to perform activities of daily living such as housekeeping, gardening, driving a car, or working. McGowan et al.,<sup>137</sup> found significant correlations among fatigue, depression, and co-morbid illnesses in post-MI patients. Similarly, Spijkerman, van den Brink, Jansen, Crijns, and Ormel<sup>138</sup> found a significant relationship between exhaustion and late-onset depressive symptoms. In addition, Lee, Kohlman, Lee, and Schiller<sup>139</sup> found that patients who experienced an MI showed five patterns of change in fatigue at various stages of their recovery: decreasing fatigue, increasing fatigue, unchanged low fatigue, high fatigue, and a curvilinear pattern with low fatigue.

Only three studies have adequately addressed long-term outcomes such as fatigue post-CA. Yet, the rate of fatigue post-CA is comparable to that which is documented in other chronic diseases. Anecdotally, in our previous work with CA survivors, fatigue was a common complaint among participants.<sup>20, 140</sup> Furthermore, a study examining fatigue in 13 post-CA survivors found that participants with chronic fatigue had the most difficulty implementing instrumental activities of daily living.<sup>141</sup> Additionally, perception of their performance and participation in daily activities were not altered significantly in posttest measurements even when they were provided with energy-conservation interventions. We propose that fatigue post CA is likely prevalent, a major barrier to completion of activities of daily life and achievement of a satisfactory quality of life, and inadequately addressed by clinicians; thus, warranting its inclusion as a new Domain in the CPC-E.

## 2.1.6.1 Measurement of Fatigue

In 2004, Dittner et al.<sup>129</sup> argued that due to the subjective experience of fatigue, multiple and often unclear etiologies connected to fatigue, and lack of an agreed upon definition of fatigue, "a gold standard" measurement tool is likely to remain elusive.<sup>129</sup> Nonetheless, many have attempted to measure fatigue by visual analogue scales, and self-report questionnaires which often address multiple dimensions such as temporal characteristics, severity and impact, and qualities of fatigue that are physical, cognitive, emotional or behavioral in nature.

#### 2.1.6.2 Visual Analogue Scale for Fatigue (VAS-F)

The VAS- $F^{142}$  is a quick and simple measure of fatigue and energy levels that has been studied in patients with HIV, cancer, brain injury and stroke.<sup>143-148</sup> It consists of a number of visual analogue scales organized into energy and fatigue categories.

#### 2.1.6.3 Fatigue Severity Scale (FSS)

As noted earlier, the FSS questionnaire has been used in the post-CA population. This scale however, has been studied more extensively in patients with multiple sclerosis, systemic lupus erythematosus, sleep-wake disorder, Parkinson's disease, and chronic hepatitis C, with evidence to support its reliability and validity for measuring fatigue.<sup>149-154</sup> Developed by Krupp et al. in 1989,<sup>152</sup> the FSS questionnaire begins with either an individual or an examiner reading nine items requiring a response to a 7-point scale ranging from 1 (strongly disagree) to 7 (strongly agree). The estimated time to administer the FSS is 5 minutes. The total score of the FSS is the mean of scores from the nine items: a higher score indicates more severe fatigue.<sup>152</sup>

## 2.1.6.4 The Modified Fatigue Impact Scale (MFIS)

The MFIS, a modification of the Fatigue Impact Scale, is a self-report instrument which examines how fatigue has affected performance in functional activities.<sup>155</sup> The MFIS is the short version of the 40-item Fatigue Impact Scale (FIS) Survey.<sup>154</sup> It has 21 items that provide information on three different aspects of fatigue: physical (9 items), cognitive (10 items), and psychosocial (2 items).<sup>156, 157</sup> The MFIS has been used in various populations, including multiple

sclerosis, traumatic brain injury, Parkinson's disease and heart failure.<sup>158-161</sup> Reliability, reproducibility, and validity of the MFIS have been established.<sup>157</sup> The MFIS uses a 5-point scale rating scale ranging from 0 (never) to 4 (almost always).

In summary, a number of visual analogue scales, validated questionnaires and fatigue scores have attempted to assess the physical and/or mental component of fatigue, its temporal relationship to exertion changes over time, and how it impacts the patient's day-to-day activities. However, nearly all studies have focused on other diagnostic populations. While the assessment of fatigue has not been adequately addressed in the post-CA population, based on its prevalence and debilitating effects in other chronic diseases, it seems reasonable that it may also be a common, yet overlooked symptom in post-CA recovery. Inclusion of fatigue in the CPC-E screening process may alert the clinician to follow-up with a more comprehensive and/or different management approach. As additional information on fatigue post-CA is collected, its negative impact on quality of life and return to work post-CA, for example, may be mitigated if it is measured and treated early.

# 2.1.7 Motor Domain:

Venkatesan and Frucht<sup>162</sup> reviewed movement disorders caused by cerebral hypoxia after CA. The authors commented on a wide range of movement disorders observed after CA that may be a result of metabolic disturbances associated with hypoxic-ischemic damage to the liver or kidney, medications administered to treat other complications of CA, or from cardioembolic ischemic stroke as a result of a compromised myocardium or cardiac valve. Examples of rare, but debilitating movement disorders described by the authors after hypoxic-ischemic brain injury include parkinsonism, dystonia, chorea, tics, athetosis, tremor, and myoclonus. One criticism of

the original CPC instrument is that major deficits such as hemiplegia are considered "mild" and are part of a CPC score of 2.

#### 2.1.8 Affective Domain: Mood

Survivors of CA also report symptoms of depression,<sup>58</sup> dependency on others for daily functioning,<sup>58</sup> and decreased participation in society with only 13–58% of patients returning to work,<sup>17, 59, 60, 130</sup> and a lower quality of life.<sup>58, 59</sup> In one study, quality of survival after cardiopulmonary resuscitation (CPR) was significantly more impaired in patients aged 70 years or older and those with a noncardiac reason for admission.<sup>58</sup> Prolonged coma also negatively affected overall quality of life. Of the 10% of survivors who survived CPR post CA, approximately 16% reported depression. The hospital admission diagnosis was the most important factor that explained the differences in the quality of life. The authors concluded that differences in disease leading to CPR, rather than differences in CPR and recovery itself, contributed to the quality of life after CPR.

#### 2.1.9 Everyday Activities Domain

Basic Activities of Daily Living (BADLs) encompass six basic human functions: bathing, dressing, toileting, transfer, continence, and feeding.<sup>163</sup> These fundamental human functions provide an objective method of classifying groups of people with chronic illnesses, disabilities and impairments into various stages of independence (or dependency). Assessment of BADLs is also useful in describing the patient's progress following an illness, and for justifying the rehabilitation support necessary for new or continued care. Instrumental activities of daily living

include: Shopping, food preparation, housekeeping, traveling, mode of transportation (e.g., drives, takes public transportation, does not travel), responsibility for own medications, ability to handle finances.<sup>164</sup> Functional independence post CA is variable with Wachelder et al.<sup>17</sup> reporting that 86% of patients were functioning independently, compared to 23–32% of patients who were unable to live at home independently up to 1 year after the cardiac arrest.<sup>58, 60, 62</sup>

#### **2.1.10 Return to Work Domain:**

Wachelder et al.<sup>17</sup> noted that while 56% patients were working before the cardiac arrest, nearly half were able to fully return to work; whereas, a study by Lundgren-Nilsson et al.<sup>60</sup> reported only 13% of patients working 1 year post CA. In another study of 50 OHCA survivors, 19 (38%) returned to work although the amount of hours was significantly reduced.<sup>59</sup>

#### 2.1.11 Participation Domain:

Over a period of 1 to 6 years post CA, Wachelder et al.<sup>17</sup> noted that the majority of patients had a lower participation level in society than the general population, although comparable with that of individuals with post traumatic brain injury.<sup>165</sup> While 24% of participants showed a lower quality of life (SF-36), overall, the health related quality of life was just below average when compared to a reference group of the general population.<sup>166</sup> However, it should be noted that the mean age of the patients in this study was higher as compared to the general population, and older age had a negative effect on participation in society.

# 2.1.12 Social Support Domain:

Having a solid social network that can be relied upon for assistance and emotional support can attenuate the negative effects of stress and protect patients from physical and emotional illness during a crisis.<sup>167</sup> Social support has been described as any exchange of resources between two or more individuals perceived by each to enhance the well- being of the recipient, and it plays a significant role in managing the extended course of chronic illness.<sup>168</sup>

Three types of social support are commonly described and include: (1) Emotional support involving comforting by physical affection or expressing concern for well-being; (2) Guidance support involving giving knowledge of how to do something or suggesting some action; (3) Tangible support involving the provision of housing, money, transportation, or physical assistance.

Support networks can be formal (e.g., occupational therapists, visiting nurse and nutritional services) and informal (e.g., spouse, parents, children and friends). The presence of a spouse and having social contacts outside the home are positively related to physical recovery, and during these periods of physical limitation, families are the major source of instrumental and emotional support for older adults.<sup>169, 170</sup> Furthermore, in a study by Cummings,<sup>171</sup> older adults who had more social support reported a more complete recovery of function than those with fewer members in their social support network.

A study of 2320 male survivors of acute MI by Ruberman et al.<sup>172</sup> identified two variables that were strongly associated with an increased 3-year mortality risk. Controlling for other prognostic factors, patients classified as being socially isolated and having a high degree of life stress had more than four times the risk of death when compared to men with low levels of both isolation and stress. An inverse relationship between education and mortality was also

observed with social isolation and high levels of stress being most prevalent among the leasteducated men and least prevalent among the best educated. The increase in risk associated with social isolation and stress applied both to total deaths and to sudden cardiac deaths.

Studies addressing social support post CA are nearly absent in the literature. A study by Dougherty et al.<sup>173</sup> examined coping strategies following sudden CA and internal cardioverter defibrillator implantation. During the first year of recovery, CA survivors and their families had reduced coping strategies with the spousal group reporting significantly lower levels of acquiring familial support.

Addressing social support networks in the CPC-E may offer additional insight into the appropriate needs (e.g., referral to a psychologist for cognitive-retraining or to an occupational therapist for a home assessment) of both the CA survivor and the individual(s) providing care (e.g., referral to respite or other support services).

#### 3.0 CONTENT VALIDITY AND RELIABILITY

## 3.1 BACKGROUND AND SIGNIFICANCE

The Cerebral Performance Category (CPC) has been the traditional, although unvalidated, standard for measuring neurological outcome for survivors of Cardiac Arrest (CA).<sup>32, 33</sup> The CPC is a 5-category scale for measuring neurological status after CA. The 5 categories include: CPC 1, conscious and alert with good cerebral performance; CPC 2, conscious and alert with moderate cerebral performance; CPC 3, conscious with severe cerebral disability; CPC 4, comatose or in persistent vegetative state; and CPC 5, dead.<sup>32, 57</sup> A review of the literature identified concerns with the CPC scale related to its poorly defined, subjective criteria, and the lack of information regarding its psychometric properties.<sup>34, 38</sup>

Because outcome measurements and long-term patient management decisions post CA are based on this tool with potential flaws, it is critical to first address its psychometric properties. The usefulness of any measurement tool is dependent upon two prerequisites: validity and reliability. Validity ensures that the tool is measuring what it was developed to measure.<sup>174, 175</sup> An instrument is said to have content validity if "it covers all parts of the content of the universe and reflects the relative importance of each part"<sup>174</sup> (p. 101). In this study we derived and established content validity of a new instrument, the CPC-E, by identifying relevant

Domains through a literature review and by engaging a panel of CA experts. The extent to which a measurement is consistent and free of errors is the underlying principle defining reliability.<sup>176</sup> Reliability ensures that measurement is stable over time and raters.<sup>176, 177</sup> In this study, performance of the CPC-E was established by measuring intra-rater and inter-rater reliability on chart reviews, and inter-rater reliability during "in-person" testing of CA survivor patients in the hospital setting. Additionally, we also tested the clinical feasibility of the CPC-E tool in CA survivors.

This study addresses a need that has been overlooked in post-CA care: developing a valid and reliable outcome measurement tool that informs clinicians about potential problems/concerns, thereby influencing which Domains warrant further attention and intervention. It is reasonable to presume that if a clinician can better understand the concerns and needs of CA survivors, his/her recommendations for managing both short- and long-term care will be enhanced. A well-developed and well-validated CPC-E has great potential to impact how and what is currently measured during post-CA care. A valid and reliable tool will likely influence which interventions, treatments, or services should be recommended. We will address one aspect of validity in this dissertation by developing and establishing the CPC-E's content validity, followed by testing the tool's intra- and inter-rater reliability.

## 3.2 METHODS: CONTENT VALIDITY

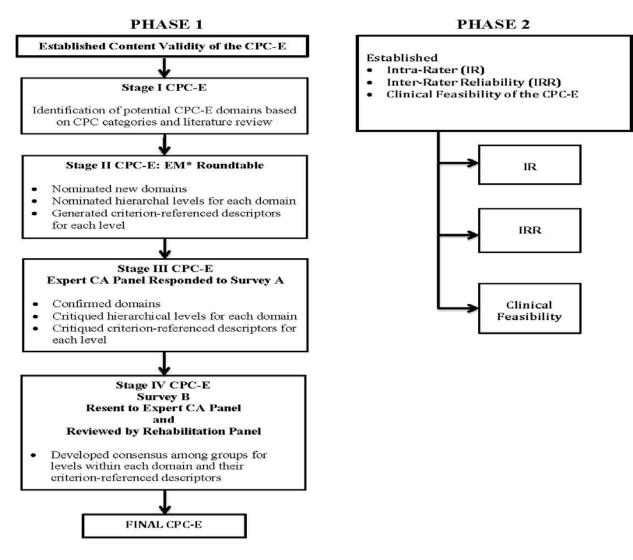
#### **3.2.1** Overview of the Development of the CPC-E tool

One method of establishing content validity is to use a panel of experts who are knowledgeable about the subjects being studied. This approach is consistent with Kirshner and Guyatt's methodological framework for developing and evaluating measurement health status tools.<sup>178</sup> The authors outlined the following steps: (1) Identification of a specific patient population; (2) Item generation; (3) Item reduction; (4) Pretesting of the final tool; (5) Determination of validity, reliability, and responsiveness.

A similar step-wise process was used in developing the CPC-E. Item generation followed by item reduction was largely achieved by a thorough review of the literature in support of each proposed Domain of the CPC-E, and by following a structured and iterative process with a team of experts. We used a series of questionnaires or "rounds" to assess the extent of agreement (consensus measurement) and to resolve disagreements (consensus development) among a panel of experts. At the end of each round, individual responses from the panel were summarized, and redistributed among panel members for feedback. Because the experts' views were collated individually, the panel members neither met one another nor knew the source of the opinions expressed by other members. This method has several advantages. First, it minimizes the risk of panel members influencing one another's opinions, thus encouraging a full spectrum of opinions to be expressed. Second, the panel members do not need to be in the same geographical location to participate in the process of consensus development. Third, panel members can change their opinions in consecutive stages of the process, based on the systematic feedback from the results of the previous rounds. According to Saliba and Schnelle (2002),<sup>35</sup> if panel members adequately represent the field under study, then content validity of the instrument can be assumed. There are several benefits to engaging a diverse and external expert jury. For example, a heterogeneous panel of experts with substantially different perspectives on a problem is more likely to produce a higher proportion of high quality, highly acceptable solutions than a homogeneous group.<sup>179-181</sup> This chapter will describe the development of the CPC-E beginning with its content validity and the methods used to establish its reliability and feasibility.

The CPC and CPC-E were designed to assess the extent and severity of impairment and disability in adults aged 18 years of age or older who are survivors of in-hospital or out-of-hospital CA. The CPC-E was designed to be a criterion-referenced tool for use by practitioners and researchers to measure impairment and disability Domains post CA. The CPC-E extracted criteria and expanded upon the content included in the original CPC scale, and in other instances new Domains (i.e., Fatigue, Mood, Social Support) were created. An iterative process ultimately yielded 10 Domains (i.e., item generation) that were scaled using the original CPC 5-point ordinal scaling system. Once the Domains were developed and operationally defined based on a review of the literature, and following input from clinicians, draft protocols were developed. In addition to the 10 Domains, written instructions on procedures, materials, item scales, and scoring interpretation were developed. While the CPC was intended to be completed in its entirety prior to hospital discharge following CA, and/or via chart review, it became evident that several of the CPC-E Domains would be more appropriately assessed post-discharge.

Systematic identification of the preliminary domains of the CPC-E tool was accomplished in two phases (see Figure 1). In Phase I, relevant Domains were identified, developed and further refined (i.e., item reduction) for the CPC-E tool thus establishing its content validity. In Phase II, intra-rater reliability (IR), inter-rater reliability (IRR) were established, and a clinical feasibility study was conducted.



\*EM= Emergency Medicine

Figure 1. Staged Development of the CPC Extended Tool (CPC-E)

#### **3.2.2 Stage I: Identification of Potential Domains**

The original CPC tool encompassed multiple constructs within each category that needed to be disentangled. These constructs included impairment and disability indicators for multiple Domains. To identify the Domains for the CPC-E tool, descriptors in the original CPC tool were identified. They were: (1) <u>Consciousness</u> (e.g., conscious, coma, vegetative state, brain death); (2) <u>Alertness</u> (e.g., alert, aware, unaware); (3) <u>Memory</u> (e.g., mild to severe dementia); (4) <u>Motor involvement</u> (e.g., hemiplegia to severe paralysis, ataxia, dysarthria); (5) <u>Independence in activities of daily life</u> (e.g., dressing, traveling by public transportation, food preparation, living "normal life" to living in an institution); and (6) <u>Employment</u> (e.g., able to work full-time, working part-time, working in sheltered environment, no interactions with environment).

Phase I, Stage I of the content validity process then proceeded with an in-depth literature review of other possible impairment and disability Domains that were overlooked or not represented in the original CPC. Identification of additional Domains for the CPC-E were expected due to advances in medical treatment and rehabilitation, along with changes in survival rates and short- and long-term outcomes in the CA population since the original scale was first developed. Furthermore, support from the literature for additional Domains was complemented by the investigative team's clinical and research expertise in emergency medicine, occupational (OT) and physical therapy (PT), and historic contributions from researchers associated with the initial publication of the CPC. As a result of this initial approach, Stage I revisions of the CPC-E tool included 9 Domains beginning with: (1) Arousal; (2) Attention; (3) Short Term Memory; (4)Motor; (5) Fatigue; (6) Mood; (7) Everyday Activities; (8) Return to Work, and; (9) Social Support (family, friends and community). (see Table 2)

## 3.2.3 Stage II: EM Roundtable

In Phase 1, Stage II, a committee of local experts in the field of CA further disentangled the various descriptors in the CPC-E. Six Emergency Medicine (EM) physicians met in a roundtable discussion format to discuss the proposed CPC-E. All physicians were experienced in treating patients post CA at the University of Pittsburgh Medical Center (UPMC) and had published extensively in the CA resuscitation field. During this meeting, clinicians were asked to comment on the revisions made to the Stage I CPC-E tool (see Table 2).

### Table 2. Stage 1 CPC-E

		1.1	1.2	1.3	1.4	1.5	1.6	1.7	1.8	1.9
Domain Levels		Arousal	Attention	Short Term Memory*	Motor	Fatigue	Mood	Everyday Activities	Return to Work	Social Support
Best Indicator	1	Alert and Oriented	No errors with Vigilance (tapping)	5 words recalled	Moves all 4 limbs	Strongly agree	Strongly agree	Independent in §BADL & IADL	Currently full-time; returned to same job or was retired pre CA <sup>non</sup>	Strong: Spouse/ family/ friend that resides in same household
	2	Confused	1 error with Vigilance (tapping)	4 words recalled	Moves only 3 limbs	Agree	Agree	Independent in §BADL but partially dependent in IADL	Currently working full- time, with restrictions or in a lesser skilled job	Good: Adult child, parent, family or friend is identified as an available caregiver
	3	Lethargic or Obtunded	2 errors with Vigilance (tapping)	3 words recalled	Moves only 2 limbs	Neither agree nor disagree	Neither agree nor disagree	Independent in §BADL but totally dependent in IADL	Currently working part-time in same or lesser skilled job	Adequate: Family member or friend can be available if needed
	4	Stuporous	3 errors with Vigilance (tapping)	2 words recalled	Moves only 1 limb	Disagree	Disagree	Partially dependent in §BADL & totally dependent in IADL	Currently being evaluated for job or SSDI <sup>4</sup>	Poor: Family and/or friends unavailable or unwilling to fulfill caregiving role
	5	Comatose	4 errors with Vigilance (tapping)	l or no words recalled	Can only lift head up and off bed or cannot move	Strongly Disagree	Strongly Disagree	Totally dependent in §BADL & totally dependent in IADL	Currently unable to work	Minimal/ Absent: Family/ friends cannot be identified or do not respond to requests for help
Worst Indicator	6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported

Table 1. Proposed Impairment and Disability Domains of the CPC-E

© 2013, Holm-Raina-Balouris-Rittenberger-Rogers & Callaway, All Rights Reserved. Scoring is based on the delayed recall trial. Scoling is based on the delayer recarries. BADL: Basic Activities of Daily Living. \*\*CA: Cardiac Arrest <sup>1</sup>SSDI: Social Security Disability Insurance

At the Stage II EM Roundtable, the CPC-E included 9 impairment and disability Domains rated from 1 to 5 with 1 being the best indicator to 5 being the worst, and a 6th level option of "not reported." Each Domain/column had corresponding second level descriptors tables that provided additional details on administration and content for each of the 5 levels (See Appendix A).

The EM Roundtable nominated new Domains, new levels for each Domain, and the criterion-referenced descriptors of each level (see Tables 3 - 6). Discussion and feedback addressed the structure, format, additions and subtractions, and supporting references associated with each Domain. Changes were made to the Stage I CPC-E and the supporting sublevel tables based on the feedback received from the EM Roundtable Discussion group. Only the significant changes leading to the Stage II CPC-E will be highlighted in the following text.

## **3.2.3.1** Alert and Arousal Domains

Beginning with the Alert and Arousal Domains, Table 3, column 1.1, a significant amount of the discussion was devoted to distinguishing between arousal, alertness and orientation, and the corresponding second level descriptors for each. The group decided in favor of referring to column 1.1 as the Alert Domain versus the Arousal Domain. The Arousal Domain and its associated second level descriptors were replaced with the Alert Domain and new supporting descriptors. These new descriptors addressed the patient's response to an observer entering the room and response to different type of stimuli (e.g., auditory, physical) as noted in Table 3.

		Original: 1.1	Revised: 1.1
Domain Lev	els	AROUSAL	ALERT
Best Indicator	1	Alert and Oriented	Spontaneously responds to person entering room
$\bigwedge$	2	Confused	Responds to verbal stimulus
	3	Lethargic or Obtunded	Responds to light touch
	4	Stuporous	Responds to noxious stimulus
Worst	5	Comatose	No response to voice or physical stimulation; may observe abnormal reflex or posturing
	6	Not Reported	Not Reported

# Table 3. Stage II: Modifications to Alert and Arousal Domains

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# **3.2.3.2 Disorganized Thinking Domain**

The Disorganized Thinking Domain was added (see Table 4) and included 4 questions from the Confusion Assessment Model for the ICU (CAM-ICU), a delirium monitoring instrument for ICU patients. <sup>182-184</sup> The CAM-ICU is a quick, valid, and reliable instrument for diagnosing delirium in the ICU setting. <sup>182</sup>

# 3.2.3.3 Attention Domain

The reference to "vigilance" was removed from each level in the Attention Domain, and the Attention sub-scale of the Montréal Cognitive Assessment (MoCA)<sup>©91</sup> was presented and accepted by the EM Discussion group as noted in Table 4. The MoCA<sup>©</sup> was developed as a brief screening instrument for mild cognitive impairment and mild Alzheimer disease to address limitations of the The Mini-Mental State Examination. The MoCA<sup>©</sup> is divided into 7 subscores: visuospatial/executive; naming; memory; attention; language; abstraction; and orientation.

		New: 1.2	Original: 1.2	Revised: 1.3
Domain Levels		<u>DISORGANIZED</u> <u>THINKING</u>	<u>ATTENTION</u>	<u>ATTENTION</u>
Best Indicator	1	Correctly answers all 4/4 questions	No errors with Vigilance (tapping)	No errors with tapping
	2	Correctly answers all 3/4 questions	1 error with Vigilance (tapping)	1 error with tapping
	3	Correctly answers all 2/4 questions	2 errors with Vigilance (tapping)	2 errors with tapping
	4	Correctly answers 1/4 questions	3 errors with Vigilance (tapping)	3 errors with tapping
Worst Indicator	5	0/4: Does not answer any question correctly	4 errors with Vigilance (tapping)	4 or more errors with tapping
	6	Not Reported	Not Reported	Not Reported

 Table 4. New Disorganized Thinking Domain and Revisions to Attention Domain

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# 3.2.3.4 Short-Term Memory Domain

There were no changes to the Short-Term Memory Domain.

# **3.2.3.5** Motor Domain

The Motor Domain was changed to include language and instructions (in second level descriptors; See Appendix A) that reflected the "drift test" of the National Institutes of Health's Stroke Scale as noted in Table 5.

		Original: 1.4	Revised: 1.4
Domain Lev	rels	MOTOR	MOTOR
Best Indicator	1	Moves all 4 limbs	Drifting observed in 0 limbs
	2	Moves only 3 limbs	Drifting observed in 1 limb
	3	Moves only 2 limbs	Drifting observed in 2 limbs
	4	Moves only 1 limb	Drifting observed in 3 limbs
V Worst Indicator	5	Can only lift head up and off bed or cannot move	Drifting observed in 4 limbs/Does not move limbs
	6	Not Reported	Not Reported

Table 5.	Stage II:	<b>Modifications</b>	to Motor	Domain
I ubic 5.	Duge III	mouncations		Domain

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#### **3.2.3.6 Fatigue Domain**

There were no changes to the Fatigue Domain.

## 3.2.3.7 Mood Domain

There were no changes to Mood Domain.

# 3.2.3.8 Everyday Activities Domain

The EM Roundtable Discussion group recommended separating the Everyday Activities Domain into the Basic Activities of Daily Living Domain and the Instrumental Activities of Daily Living Domain to better reflect the *current* level of independence in these respective Domains. Additional details on rating independence were provided for each basic human activity (i.e., independence with feeding, dressing, transferring and toileting) and each instrumental activity (i.e., independence with medication management, food preparation, shopping or transportation). The IADL was also moved to post discharge since these activities cannot be assessed adequately during hospitalization (see Table 6).

Original: 1.7 (combined)							
Domain Lev	els	Basic Activities of Daily Living (BADLs): Six basic human functions: Bathing, dressing, toileting, transfer, continence, and feeding	Instrumental Activities of Daily Living (IADLs): Shopping, food preparation, housekeeping, traveling, mode of transportation (drives, public transportation, does not travel), responsible for own medications, able to handle finances				
Best Indicator	1	Independ	lent in BADLs and IADLs				
	2	-	DLs but partially dependent in IADLs DLs but totally dependent in IADLs				
	4	Partially dependent in BADLs and totally dependent in IADLs					
Worst Indicator	5	Totally dependent in BADLs and totally dependent in IADLs Not Reported					
	Revi	ised: Separated into 1.8 (BA	ADLs) and 1.10 (IADLs)				
Domain Levels		<u>BADLs</u>	IADLs				
Best Indicator	1	Independent in 4/4	Independent in 4/4				
	2	Independent in 3/4	Independent in 3/4				
	3	Independent in 2/4	Independent in 2/4				
	4	Independent in 1/4	Independent in 1/4				
↓ Worst Indicator	5	0/4: Not Independent in BADLs	a any 0/4: Not Independent in any IADLs				
	6	Not Reported	Not Reported				

Table 6. Changes to CPC-E Table for Everyday Activities, BADLs, and IADLs Domains

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# 3.2.3.9 Return to Work Domain

The Return to Work Domain (RTW) was moved to post discharge assessment and minor changes were made to reflect nuances related to work-readiness (i.e., changes in medical status post CA, ability to complete complex activities of daily living, etc.). (see Table 7)

		Original: 1.8	Revised: 1.11
Domain Lev	rels	<u>RETURN TO WORK</u>	<u>RETURN TO WORK</u>
Best Indicator	1	Currently full-time; returned to same job or was retired <i>pre</i> CA	Currently full-time or has returned to <i>pre</i> CA job
	2	Currently working full-time, with restrictions or in a lesser skilled job	Currently working full-time with restrictions or in a lesser skilled job
	3	Currently working part-time in same or lesser skilled job	Currently working part-time in same or lesser skilled job
	4	Currently being evaluated for job or SSDI	Currently being evaluated for work
Worst Indicator	5	Currently unable to work	Currently unable to work due to change in medical status since CA
	6	Not Reported	Not Reported

# Table 7: Return to Work

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# 3.2.3.10 Social Support Domain

There were no changes to the Social Support Domain.

Based on a lengthy discussion with the EM Roundtable, the Stage II CPC-E was generated (see Table 8).

# Table 8. Stage II CPC-E

			1.1	1.2	1.3	1.4	1.5	1.6	1.7	1.8	1.9	1.10	1.11
	Domain Levels		Alert	Disorganize d Thinking	Attention	Short Term Memory*	Motor	Fatigue	Mood	Basic Activities of Daily Living (BADLs)	Social Support	Instrumental Activities of Daily Living (IADLs) <sup>¢</sup>	Return to Work <sup>¢¢</sup>
Ir	Best dicator	1	Spontaneously responds to person entering room	Correctly answers all 4 questions	No errors with tapping	5 words recalled	Drifting observed in 0 limbs	Strongly agree	Strongly agree	Independent in 4/4 (feeding, dressing, transferring and toileting)	Strong: Spouse, family member and/or friend that resides in same household	Independent in 4/4 (medication management, food preparation, shopping and transportation)	Currently full- time or has returned to <i>pre</i> CA job§
		2	Responds to verbal stimulus	Correctly answers 3/4 questions	1 error with tapping	4 words recalled	Drifting observed in 1 limb	Agree	Agree	Independent in 3/4 (feeding, dressing, transferring or toileting)	Good: Adult child, parent, family member or friend is identified as an available caregiver	Independent in 3/4 (medication management, food preparation, shopping or transportation)	Currently working full- time, with restrictions or in a lesser skilled job
		3	Responds to light touch	Correctly answers 2/4 questions	2 errors with tapping	3 words recalled	Drifting observed in 2 limbs	Neither agree nor disagree	Neither agree nor disagree	Independent in 2/4 (feeding, dressing, transferring or toileting)	Adequate: Family member or friend available if needed	Independent in 2/4 (medication management, food preparation, shopping or transportation)	Currently working part- time in same or lesser skilled job
		4	Responds to noxious stimulus	Correctly answers 1/4 questions	3 errors with tapping	2 words recalled	Drifting observed in 3 limbs	Disagree	Disagree	Independent in 1/4 (feeding, dressing, transferring or toileting)	Poor: Family and/or friends unavailable or unwilling to fulfill caregiving role	Independent in 1/4 (medication management, food preparation, shopping or transportation)	Currently being evaluated for work
	Worst	5	No response to voice or physical stimulation; may observe abnormal reflex or posturing	0/4: Does not answer any question correctly	4 or more errors with tapping	l or no words recalled	Drifting observed in 4 limbs/Does not move limbs	Strongly Disagr <b>ee</b>	Strongly Disagree	0/4: Not independent in any BADLs	Minimal/ Absent: Family/ friends cannot be identified or do not respond to requests for help	0/4:Not independent in any IADLs	Currently unable to work due to change in medical status since CA
		6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported

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\*Scoring is based on the delayed recall trial (page 13).
 \*IADLs: This Domain will <u>not</u> to be administered in the hospital.
 \*Return to Work: This Domain will <u>not</u> to be administered in the hospital.
 \*CA: Cardiac Arrest

#### **3.2.4** The Content Validity Process

The next step in the content validity process was to submit the Stage II CPC-E to an external jury. A nominated expert panel of external jury members was identified to provide feedback on the proposed domains, levels and descriptors. The expert panel included established researchers in the field of CA that were identified by EM faculty members at the University of Pittsburgh.

We used a web-based survey since it has been shown to be feasible, cost effective and efficient, and better accepted by users than traditional paper-based approaches.<sup>185, 186</sup> To ensure security and confidentiality, each panel member received a personal link to a web page specifically designed and programmed for the present study (www.surveymonkey.com). The questionnaire was completed online by each panel member.

We employed two rounds of feedback until an agreement was reached by the majority of the panel. Survey A and Survey B were repeated with the same Expert CA Panel of 10 CA researchers from North America while a separate review of Survey B, was completed by rehabilitation personnel with expertise in cardiac rehabilitation (Stage IV – Rehabilitation Panel) as depicted in Figure 2. The Rehabilitation Panel members were a sample of convenience of local therapists and physicians with experience working in cardiac rehabilitation. Additional rounds of feedback were impractical mainly due to panel members' limited availability over an extended period of time. Changes to the CPC-E in Survey A and Survey B resulted from a consensus approach based on written comments by the Expert CA Panel, and calculations of their mean, median and mode scores. In addition, comments from the Rehabilitation Panel were also scored and incorporated into the final revisions of the CPC-E.

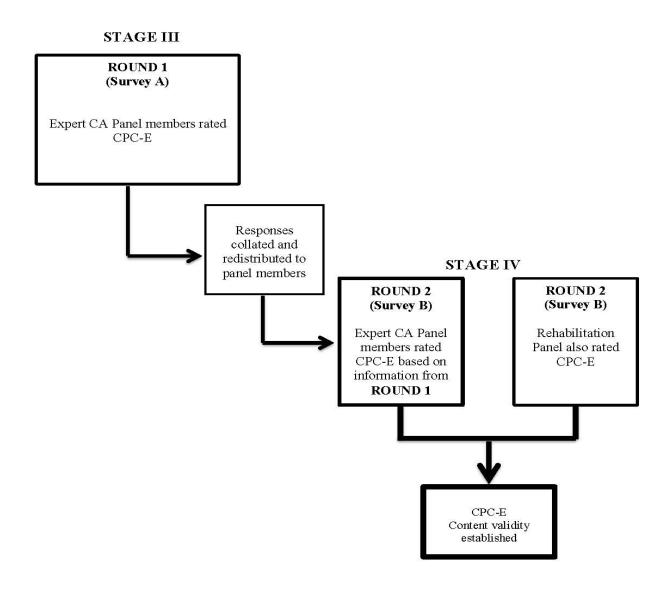


Figure 2. Rounds by Expert CA Panel and Rehabilitation Panel

Panel members with expertise in the areas of emergency medicine, resuscitation, and disability outcome measurement were recruited. Additionally, panel members who were content experts in certain Domains, such as neuropsychologists for the cognition and the affective Domains, and occupational therapists for the everyday activities and return to work Domains

were recruited. As a result, the members of this panel were expected to produce a comprehensive list of Domains for the CPC-E. To identify appropriate panel members, the collaborating investigators of the internal committee (Rittenberger, Raina, Callaway, Rogers, and Holm) and three Directors of UPMC's Inpatient Center for Rehabilitation Services recommended a total of 28 experts. Experts were contacted initially via e-mail to explain the scope of the project. The time commitment required of each panel member was clearly specified. Twenty of the 28 identified experts agreed to participate as noted in Table 8 (10 Expert CA Panel) and Table 9 (10 Rehabilitation Panel).

# Table 9. Expert CA Panel

Reviewer	Specialization/Clinical Research Interests
1	• Health services research in EM; Most effective programs for treating OHCA cardiac arrest, major trauma, respiratory distress, and chest pain; economic evaluation of pre-hospital care Management of cardiac arrest (CA), particularly in the pre-hospital setting
2	• Neurointensivist (neurological intensive care); ultra-early hemostatic therapy for brain hemorrhage; therapeutic hypothermia, multimodality brain monitoring, noninvasive ICP (intracranial Pressure) monitoring, and status epilepticus
3	• Observational and randomized single-center and multi-center studies of interventions intended to reduce the sequelae of ischemia-reperfusion injury in patients with acute, life-threatening illness; resuscitation; defibrillation; cost-effective procedures for the patient
4	• Randomized controlled trials; development of clinical decision rules, knowledge translation implementation trials; systematic reviews and meta-analyses: patient safety in emergency medical services; evaluation of systems of care; knowledge translation networks
5	• Cardiopulmonary resuscitation; emergency management/preparedness and disaster response

# Table 9 (continued).

Reviewer	Specialization/Clinical Research Interests
6	• Clinical trials and clinical investigations in septic shock and cardiac arrest; multi-center clinical trials; microcirculatory dysfunction post-arrest; evaluation of the human metabolome in sepsis and post CA (cardiac arrest; and severity of illness scoring systems in post-CA patients
7	Critical Care Medicine; Anesthesiology
8	• Emergency Medical Service research and management; pre-hospital care and safety; pre-hospital resuscitation medicine with special emphasis on traumatic shock and CA; air medical transport of critically ill patients; pre- hospital airway management, point of care testing of lactate, and tissue oximetry to identify shock
9	Emergency medicine clinical service and research
10	• Neurointensivist; traumatic brain injury and advanced monitoring in neurocritical care; management of severe traumatic brain injury, medical management of subarachnoid hemorrhage and management of status epilepticus

**Table 10. Rehabilitation Panel** 

Reviewer	Title/Profession	% Time Focused on Research
1	Occupational Therapist	25%
2	Occupational Therapist	None
3	Occupational Therapist	25%
4	Occupational Therapist	None
5	Occupational Therapist	None
6	Physical Therapist	None
7	Physical Therapist	None
8	Physical Therapist	None
9	Neurologist	None
10	Physiatrist	75%

## 3.2.4.1 Stage III: Expert CA Panel: Round 1, Survey A

Fourteen experts (Expert CA Panel) in cardiac arrest resuscitation and outcomes were originally contacted to provide input on the CPC-E. Ten of the 14 individuals agreed to participate. Each member of the Expert CA Panel was contacted via email and provided with a unique personal identifier to access Survey A and the Stage II CPC-E, via Survey Monkey. Reviewers evaluated and responded to the proposed Domains and language for each descriptor at each level of the CPC-E Survey A. The complete Round 1, Survey A CPC-E Table with its corresponding second-level descriptors is shown in Appendix B.

In Round 1 (Survey A), Expert CA Panel members rated each Domain on the following three questions:

(1) Is the Domain named correctly?

(2) What is the importance of this Domain for measuring outcomes after a CA?

(3) Second Level Descriptors: Do the criteria for each level of the Domain allow for appropriate differentiation of a patient's current status?

An exemplar summary of the reviewers' comments on the Alert Domain is presented in Table 11. Space was provided below each question, for the experts to explain their ratings. The Expert CA Panel also had the opportunity to suggest additional Domains. Revisions were then made to the main table of the CPC-E and the corresponding second-level descriptors based on the collective feedback of Expert CA Panel 1, and as evaluated by the investigative team. In some instances, content remained the same or it was modified, moved to post-discharge, or deleted altogether (see Table 12).

For example, while the MoCA<sup>®</sup> was presented and accepted by the EM Discussion group in Phase 1, Stage 2, we were not granted permission from the developers to extract only a portion of the test. As a result, the MoCA<sup>®</sup> attention item was subsequently replaced with SAVEAHAART, a section of CAM-ICU that addresses inattention.<sup>184</sup>

# Table 11. Exemplar of Expert Panel 1 Summary for Alert Domain

	1. Is the Alert Domain named correctly? 0 = No 1 = Maybe 2 = Yes	<ul> <li>2. What is the importance of the Alert Domain for measuring outcomes after a CA?</li> <li>0 = Not important at all</li> <li>1 = Somewhat important</li> <li>2 = Important</li> <li>3 = Very important</li> </ul>	<ul> <li>3. Second Level Descriptors: Do the criteria for each level of the Alert Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
	2	3	2
	2	3	O§
	2	2	2
	2	$1^{\pm}$	18
	2	2	2
	2	3	2
	$0^{\epsilon}$	3	O <sup>§</sup>
	2	3	2
	$1^{\epsilon}$	3	O <sup>§</sup>
	2	3	2
Mean	1.7	2.6	1.3
Median	2	3	2
Mode	2	3	2

#### **Comments:**

#### <sup>€</sup> Two Reviewers responsed to Ouestion 1:

- The assessment of whether the patient is awake, alert, and appropriately responsive generally requires more than mere tracking to establish. Although other portions of the proposed scale address appropriateness of response, I would favor a Best Indicator which more stringently requires the patient to attend to conversation rather than merely track.
- Alert 'and Arousable' instead?

<sup>±</sup>One Reviewer responded to Ouestion 2:

Simple to do and complements prior categories so important for implementation

#### <sup>§</sup> Three Reviewers responsed to Ouestion 3:

- What does respond mean?
- I don't understand the phrase "to attend." I also do not understand how to comment on "sleep wake cycles" motor activity is 'reflexive' would be hard to reproduce across observers - suggest more clarity through examples if you wish to use this.
- No for the reasons above.
- Level 5: Too complex. For instance, it is difficult to assess sleep-wake cycles. Would it be clearer
  to state 'does not attend to noxious stimulus'? The portion beginning with, 'no eye opening....' is

Table 12. Survey A Results: Summary of Reviewers' Comments to CPC-E

1.1 Alert Domain	<ul> <li>Criterion 1: While one reviewer suggested adding "attends to conversation," we felt this domain is intended to capture the basic level of alertness while the next two domains address higher levels of cognition; therefore, descriptor 1 remains unchanged.</li> <li>Criteria 2 - 4: As per several comments, we replaced "Requires" with "Orients or Responds to."</li> <li>Criterion 5: As per several comments, "sleep-wake cycles are lacking" was deleted.</li> </ul>
1.2 Disorganized Thinking Domain	<ul> <li>As per the reviewers' feedback concerning the title of this domain it was renamed to <i>Logical Thinking</i> Domain.</li> <li>Criteria 1 - 4: Kept "as is" in light of the CPC-E being used as a <i>screening</i> tool.</li> <li>In response to a reviewer's concern for patients that are hard of hearing, deaf or aphasic, additions were added to "Administration" to include asking the proposed questions in written form. Reword And for patients who have a tracheostomy: Thumbs up = Yes; Thumbs down= No</li> </ul>
1.3 Attention Domain	<ul> <li>Several reviewers voiced concern over only four "A's" with SAVEAHAART and therefore only four opportunities to respond. While we were hoping to replace it with the longer list of letters from the MoCA, the test developers did not grant us permission to use the Attention sub-section. Hence, we have retained the Attention section from the CAM-ICU.</li> <li>It may not be possible to test this domain if the patient is hard of hearing (first check for a hearing aid) deaf or aphasic; therefore, an additional, "not testable" was added in Table 1.</li> <li>While adding the Psychomotor Vigilance Testing was suggested, many clinical settings may not have the resources to administer this test. In keeping with the notion of the CPC-E as a <i>screening</i> tool, performance of this item may signal the need for additional follow-up testing and/or referral.</li> </ul>
1.4 Short Term Memory Domain	<ul> <li>The test developers did not grant us permission to use the Short-term Memory sub-section of the MOCA. Using a randomly generated table of numbers, we selected among a list of the most commonly used 4 letter words in the English language.</li> <li>This item has been adapted for patients with a tracheostomy as suggested.</li> <li>It may not be possible to test this domain if the patient is hard of hearing (first check for a hearing aid) deaf or aphasic; therefore, an additional, "not testable" was added in Table 1.</li> </ul>
1.5 Motor Domain	• Our intent is to quickly assess movement in the upper and lower extremities. In response to the methods of motor assessment and reference to the NIH stroke scale, we replaced the 5 criterion ranging from ambulates without assistance to activity is limited to moving in bed.
1.6 Fatigue Domain	<ul> <li>Based on feedback, this domain was moved to post-discharge and renumbered as 1.7.</li> <li>Fatigue has not been adequately studied or addressed in post-CA survivors although there is compelling evidence that it is a significant problem for this population. Four references (B through E) were added to support the importance of measuring this domain in individuals post CA.</li> </ul>

# Table 12 (continued).

1.7 Mood Domain	<ul> <li>Following a reviewer's comment about how the questions were phrased, the questions were rewritten to reflect a patient's current mood state.</li> <li>This domain is intended to be a quick <i>screen</i> which may warrant a more detailed mood assessment. While patients who are post myocardial infarction, post stroke or post spinal cord injury are routinely evaluated for depression, per our experience many patients post cardiac arrest are not comparably treated. Consequently, these patients may not receive any follow up services for assessment of mood post discharge which can significantly hinder their progress and alter their quality of life.</li> </ul>
1.8 Basic Activities of Daily Living Domain	<ul> <li>As per a reviewer's suggestion, the definition of independence was added and defined as "no assistance from another person."</li> <li>In response to a comment about the need for current references, an additional BADL reference was provided; however, definitions of BADLs have remained the same since the Katz reference, which is still regarded as a classic. However, we did replace "Feeding" with "Eating," which eliminates any confusion about dependency in performing this activity. In addition, BADL activities included in the scale are considered obligatory activities - universally expected of all individuals.</li> </ul>
1.9 Social Support Domain	Deleted due to majority of comments questioning its role in CA outcomes.
1.10 Instrumental Activities of Daily Living Domain	<ul> <li>Renumbered as 1.9 and renamed Complex Activities of Daily Living.</li> <li>As per a reviewer's suggestion, the definition of independence was added and defined as "no assistance from another person."</li> <li>Comment about the need for current references. While an additional IADL reference was provided, definitions of BADLs have remained the same since the Lawton reference, which is still regarded as a classic.</li> </ul>
1.11 Return to Work Domain	<ul> <li>Renumbered as 1.10.</li> <li>While the Department of Labor dichotomizes return to work as either working or not working, the CPC-E administration statement was changed to minimize ambiguity and to reflect concerns about performing pre-CA work tasks, including that of a retiree, or homemaker. According to return to work literature, the complexity of work is not the main focus but rather the endpoint, i.e., working or not working at the pre-morbid status.</li> <li>Criteria 1 – 5: New options include percentages of the patient's ability to perform pre-CA work tasks at 100%, 75 %, 50%, 25% and 0% levels, respectively. If a patient reports a number within 2 categories, choose the lower number.</li> </ul>

# 3.2.5 Stage IV: Expert Panel and Rehabilitation Panel

Based on comments by Panel 1 from Survey A, the CPC-E was revised (see Table 13; Stage III CPC-E) and presented to Panel 1 for a second and final time. The same 10 reviewers responded to the revised Domains and language for each descriptor at each level.

# Table 13. Stage III CPC-E

		1.1	1.2	1.3	1.4	1.5	1.6	1.7	1.8	1.9	1.10
Domain Levels		Alert	Logical Thinking	Attention	Short Term Memory*	Motor	Mood	Basic Activities of Daily Living (BADLs)	Fatigue <sup>¢</sup>	Complex Activities of Daily Living (CADLs) <sup>¢</sup>	Return to Work <sup>¢</sup>
Best Indicator	1	Spontaneously orients or responds to person entering room	Correctly answers all 4 questions	No errors	4 words recalled	Ambulates without assistance	I feel positive and hopeful most of the time	Independent in 4/4 (eating, dressing, transferring and toileting)	Strongly agree	Independent in 4/4 (medication management, food preparation, shopping and transportation)	Currently performing 100% <i>pre</i> CA <sup>§</sup> work tasks <sup>¢¢</sup>
	2	Requires verbal stimulus to orient or respond	Correctly answers 3/4 questions	1 error	3 words recalled	Ambulates with assistance	I feel positive and hopeful some of the time	Independent in 3/4 (eating, dressing, transferring or toileting)	Agree	Independent in 3/4 (medication management, food preparation, shopping or transportation)	Currently performing 75% <i>pre</i> CA <sup>§</sup> work tasks <sup>¢¢</sup>
	3	Requires light touch to orient or respond	Correctly answers 2/4 questions	2 errors	2 words recalled	Comes to sit without assistance but needs assistance to stand	I feel positive or hopeful occasionally	Independent in 2/4 (eating, dressing, transferring or toileting)	Neither agree nor disagree	Independent in 2/4 (medication management, food preparation, shopping or transportation)	Currently performing 50% pre CA <sup>§</sup> work tasks <sup>¢¢</sup>
	4	Requires noxious stimulus to orient or respond	Correctly answers 1/4 questions	3 errors	1 word recalled	Unable to sit without assistance	I feel positive or hopeful rarely	Independent in 1/4 (eating, dressing, transferring or toileting)	Disagree	Independent in 1/4 (medication management, food preparation, shopping or transportation)	Currently performing 25% <i>pre</i> CA <sup>§</sup> work tasks <sup>¢¢</sup>
Worst	5	No response to voice or physical stimulation; may observe abnormal reflex or posturing	0/4: Does not answer any question correctly	4 errors	No words recalled	Activity limited to moving in bed	I feel positive or hopeful none of the time	0/4: Not independent in any BADLs	Strongly Disagree	0/4:Not independent in any CADLs	0%: Currently unable to perform any <i>pre</i> CA <sup>§</sup> work tasks <sup>¢¢</sup>
	6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported
	7		Not Testable	Not Testable	Not Testable						

# Table 1. Proposed Impairment and Disability Domains of the CPC-E

\*Scoring is based on the delayed recall trial (page 12).

<sup>#</sup>These Domains will <u>not</u> to be administered in the hospital: Fatigue, CADLs, and Return to Work. <sup>##</sup>Includes retiree or homemaker.

<sup>§</sup>CA: Cardiac Arrest

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In Round 2 (Survey B), Expert Panel members rated each Domain on the following questions:

(1) Should the Domain be kept as described? (Yes or No)

- (2) Please tell us why you would like to delete this Domain?
- (3) Please suggest additional modifications, if any.

An exemplar of the Alert Domain is listed in Table 14. Space was provided below each question for the experts to explain their decisions to delete the Domain, note any concerns, or suggest additional modifications to the Domain. At the end of the survey, a final opportunity to comment about the proposed CPC-E was provided. An overall assessment by the Expert CA Panel is provided in Table 15. The complete assessment is listed in Appendix C.

Reviewer	Should the Alert Domain be kept as described? No or Yes	Please tell us why you would like to delete this domain?	Please suggest additional modifications, if any.
1	Yes		
2	Yes		
3	Yes		
4	Yes		None
5	Yes		By 'orient,' you do not mean oriented to anytime or place, just to examiner, correct?
6	Yes		None
7	Yes		
8	Yes		
9	Yes		
10	Yes		
	10/10 or 100% responded "Yes "		

Table 14. Round II, Survey B: Exemplar of Expert CA Panel 1 Responses to Alert Domain

Reviewer	Please add any additional comments or concerns about the proposed CPC-E. If you have none, please type "none." To finish and exit the survey, please select the "done" button after you enter your response.
1	My difficulty with all of this is that this provides additional layers, but still requires a holistic or gestalt assessment. I think a stronger approach is to use a structured questionnaire EG MRS- I understand what you are trying to do- I just do not think that it is going to have greater reliability or validity.
2	none
3	done
4	none
5	none
6	none
7	It is difficult to predict whether and to what degree some clinical investigators may wish to substitute the CPC-E for CPC in CPC's original purpose, i.e., as an outcome measure. It will take a careful explanation to firmly make clear that the CPC-E is designed as an instrument to facilitate rehabilitation planning and further testing/evaluation, rather than as an end-point.
8	Thank you
9	none
10	none

 Table 15. Round II, Survey B: Overall Assessment by Expert CA Panel 1

Several comments were noted about the difficulty in accurately assessing mood and fatigue during hospitalization; as a result, both of these Domains were moved to post-discharge. Only a few overall comments concerning the CPC-E were offered as noted in Table 15. One Expert CA Panel member stated that the CPC-E "...provides additional layers, but still requires a holistic or gestalt assessment. I think a stronger approach is to use a structured questionnaire such as the Modified Rankin Score." Another reviewer, who was involved in the development of the original CPC noted, "It is difficult to predict whether and to what degree some clinical investigators may wish to substitute the CPC-E for CPC in CPC's original purpose, i.e., as an outcome measure. It will take a careful explanation to firmly make clear that the CPC-E is designed as an instrument to facilitate rehabilitation planning and further testing/evaluation, rather than as an end-point."

# **3.2.5.1 Panel 2: Rehabilitation Panel, Survey**

While the Expert CA Panel was assessing the CPC-E via Survey B, the Rehabilitation Panel was recruited to evaluate the CPC-E via Survey B (i.e., same questions were posted via a separate Survey Monkey administrative link). The Rehabilitation Panel consisted of 10 local UPMC clinicians who had experience working with patients post CA. The Panel consisted of a physical medicine rehabilitation physician (PMR), a neurologist, three physical therapists (PTs), and five occupational therapists (OTs). The composition of the Rehabilitation Panel is presented in Table 16.

Profession§	Gender	1.00	Years	Number	Percent of	Clinical
Profession	Gender	Age Category	of	of Post-	Time	Subspecialty
		Category	Practice	CA	Focused	Affiliations *
			Practice	Patients	on	Amnations *
				Treated	Research	
				Per	Research	
				Month		
ОТ	Female	30-39	6-10	11-15	25%	Neuro unit;
01	remaie	30-39	0-10	11-15	2370	ICU; Inpt
						Cardiac Rehab
ОТ	Male	30-39	16-20	1-5	None	Not reported
OT	Female	40-49	16-20	1-5	25%	ER; Trauma;
01	Female	40-49	16-20	1-5	25%	Neuro; ICU
						Cardiac ICU;
						Cardiac Medical
						Unit; Oncology;
						Medicine; Plastics
OT	F 1	30-39	6-10	> 15	DT.	
ОТ	Female	30-39	6-10	> 15	None	ER; Trauma;
						Neuro; ICU
						Acute Inpt
						Cardiac Rehab;
						Transitional care
						unit (mixed Dx);
						Inpt Rehab
OT	Trans 1	30-39	11.15	1.5	N	(mixed Dx)
OT	Female		11-15	1-5	None	Not reported
PT	Female	50-59	11-15	1-5	None	Inpt Cardiac
DT	<b>D</b> 1	20.20	11.15	1.5	21	Rehab
PT	Female	30-39	11-15	1-5	None	Neuro; ICU
PT	Male	20-29	1-5	1-5	None	ICU; Inpt
37 1 1 2	<b>D</b> 1	20.20	6.10		21	Cardiac Rehab
Neurologist	Female	30-39	6-10	1-5	None	Not reported
Physical	Male	50-59	16-20	1-5	75%	Neuro
Medicine and						
Rehabilitation				L		

# Table 16. Composition of Panel 2: Rehabilitation Panel

<sup>§</sup> Occupational Therapy (OT); Physical Therapy (PT)

\* Cardiac Rehabilitation (cardiac rehab); Diagnosis (Dx); Emergency Room (ER) Inpatient (Inpt); Intensive Care Unit (ICU); Neurology unit (Neuro); Outpatient (Outpt); Plastic Surgery (Plastics)

Three reviewers were male; seven were female. The Rehabilitation Experts were both mature and seasoned clinicians: half had been practicing in their respective fields for 11-15 or more years. Six were between the ages of 30-39; two were 50-59; and one was between the ages of 20-29 and 40-49, respectively. Seven clinicians treated, on average, 1-5 post-CA patients per

month with three treating between 11-15 patients, and one treating greater than 15 patients per month. Seven were full-time clinicians with only three reporting some involvement with research: two individuals estimated 25% and one individual estimated 75% of their time was devoted to research. The group often identified with more than one clinical affiliation: emergency room/trauma, neurology, intensive/cardiac intensive care unit and/or inpatient cardiac rehabilitation.

# **3.2.5.2 Final Version of CPC-E**

Feedback from both groups for Survey B was collected and analyzed separately in a similar format to that of the Expert CA Panel (percentage agreement and summary of comments) to yield the final version of the CPC-E (see Table 17).

			ASSESSED PRIOR TO DISCHARGE						ASSESS	SED POST DISCHARGE	
		1.1	1.2	13	1.4	1.5	1.6	1.7	1.8	1.9	1.10
Domain Levels		Alert	Logical Thinking	Attention	Short Term Memory	Motor	Basic Activities of Daily Living (BADLs)	Mood	Fatigue	Complex Activities of Daily Living (CADLs)	Return to Work
Best Indicator	1	Spontaneously orients or responds to person entering room	Correctly answers all 4 questions	No errors	4 words recalled	Ambulates without assistance	Independent in 4/4 (eating, dressing, transferring and toileting)	I feel positive and hopeful most of the time	I feel fatigued none of the time	Independent in 4/4 (medication management, food preparation, shopping and transportation)	Currently performing 100% pre CA <sup>§</sup> work tasks <sup>¢¢</sup>
	2	Requires only verbal stimulus to orient or respond to observer	Correctly answers 3/4 questions	1 error	3 words recalled	Ambulates with assistance	Independent in 3/4 (eating, dressing, transferring or toileting)	I feel positive and hopeful some of the time	I feel fatigued rarely	Independent in 3/4 (medication management, food preparation, shopping or transportation)	Currently performing 75% pre CA <sup>§</sup> work tasks <sup>66</sup>
	3	Requires light touch and verbal stimulus to orient or respond to observer	Correctly answers 2/4 questions	2 errors	2 words recalled	Needs assistance to stand	Independent in 2/4 (eating, dressing, transferring or toileting)	I feel positive and hopeful occasionally	I feel fatigued occasionally	Independent in 2/4 (medication management, food preparation, shopping or transportation)	Currently performing 50% pre CA <sup>§</sup> work tasks <sup>66</sup>
	4	Requires noxious stimulus to orient or respond to observer	Correctly answers 1/4 questions	3 errors	1 word recalled	Unable to sit without assistance	Independent in 1/4 (eating, dressing, transferring or toileting)	I feel positive and hopeful rarely	I feel fatigued some of the time	Independent in 1/4 (medication management, food preparation, shopping or transportation)	Currently performing 25% pre CA <sup>§</sup> work tasks <sup>¢¢</sup>
	5	No response to voice or physical stimulation; may observe abnormal reflex or posturing	0/4: Does not answer any question correctly	4 crrors	No words recalled	Activity limited to moving in bed	0/4: Not independent in any BADLs	I feel positive and hopeful none of the time	I feel fatigued most of the time	0/4:Not independent in any CADLs	0%: Currently unable to perform any <i>pre</i> CA <sup>§</sup> worf tasks <sup>66</sup>
	6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported
	7		Not Testable	Not Testable	Not Testable						

## Table 17. Stage IV: Final CPC-E Impairment and Disability Domains

Abbreviated Scoring Sheet: Impairment and Disability Domains of the CPC-E

Scoring is based on the delayed recall trial (Refer to directions on page 2). Cardiac Arrest. # Includes retiree or homemaker. © 2014, Holm-Raina-Balouris-Rittenberger-Rogers-Callaway, All Rights Reserved.

# **3.3 METHODS: RELIABILITY**

## 3.3.1 Overview of Reliability

The clinical utility of a tool used in clinical practice and research depends upon the extent to which clinicians and researchers can rely on its data to be accurate and meaningful indicators of the content universe being measured. The first requirement of any measurement tool is that it needs to be reliable (i.e., the extent to which multiple raters are in agreement and the ratings from the tool are stable).<sup>176</sup> Reliability of clinical tools is usually measured using intra-rater reliability (IRR) and/or test-retest reliability.<sup>177</sup> IR is defined as the degree of

agreement among repeated scores by a single rater, and IRR is agreement between two or more raters who measure the same group of subjects within the same time frame.<sup>187</sup> Because the CPC data are usually gathered from chart reviews for research purposes, reliability for this study was delimited to IR and IRR based on medical chart data.

# 3.3.2 Reliability Study Raters: Record Review

Two occupational therapists were involved in the collection of the reliability data. Both raters (AB) and (PB) were trained by a member of the investigative team (KR) in the medical chart review process. Retrospective medical chart reviews were conducted to determine CPC-E scores. Raters extracted medical entries from the Post-CA Service (PCAS) database at the University of Pittsburgh and the electronic medical records (EMR) portal (CERNER) at UPMC. Data collected from the EMR included: Demographics, co-morbidities, details of resuscitation, location of CA, initial CA rhythm, hypothermia treatment, rehabilitation services received, length of stay, CPC, mRS, and discharge disposition. Additional information on post-CA neurological dysfunction was determined using the Full Outline of Unresponsiveness score (FOUR)<sup>188</sup> motor and brainstem components.

In addition, all 10 Domains of the CPC-E were extracted, which included: Alert, Logical Thinking, Attention, Short-Term Memory, Motor, BADLs, Mood, Fatigue, Complex Activities of Daily Living (CADL), and Return to Work. Raters were directed to search the physician, nursing, and rehabilitation notes for specific data related to residual symptoms and participants' ability to understand instructions, perform toileting and self-care, transfers, ambulation, and perform BADLs.

Decision rules for IR and IRR were established *a priori* and included the following: When specific data in the clinical notes were conflicting, the Raters were instructed to assume the worst outcome. Data that was not available was coded as missing. If a subject was transferred to an inpatient rehabilitation facility then the Raters were instructed to use the intake assessment by OT, PT, speech language pathology, and nutrition as opposed to earlier assessments, provided no interventions occurred in between hospital discharge and rehabilitation admission. In addition to noting discharge disposition, and extracting information closest to discharge from entries by rehabilitation professionals, Raters chose entries that are generally considered Domain-specific for each profession. For example, while both PT and OT may have commented on motor activity assessment for ambulation, transfers and moving in bed, the rater selected from the PT notes. Likewise, OT assessments of BADLs were selected over PT entries. Independence with eating was determined mainly by reviewing speech language pathology and nutrition notes with support from OT if records were incomplete.

# 3.3.3 Intra-Rater Reliability: Chart Review

Rater 1 (AB) was involved in the collection of the IR data. Rater 1 independently reviewed and scored the CPC-E using 30 randomly selected medical charts of patients who were admitted with a CA between January 2010 – November 2013. Rater 1 rescored the charts following an interval period of two days. The Rater was masked to the results of the first scoring.

## **3.3.4** Inter-Rater Reliability: Record Review

Rater 1 independently evaluated 50 charts from the PCAS database, and the EMR portal (CERNER). Likewise, Rater 2 independently repeated the process on the same 50 charts. Rater 1 was masked to Rater 2, and vice versa.

# 3.4 METHODS: CLINICAL FEASIBILITY AND INTER-RATER RELIABILITY: HOSPITAL

Clinical feasibility and IRR of the CPC-E was tested in the hospital on 11 patients. Subjects were eligible to participate in the study if they were  $\geq 18$  years of age and resuscitated following either in-hospital cardiac arrest (IHCA) or OHCA. We defined cardiac arrest as a loss of pulse requiring chest compressions, rescue shock, or both. Cardiac arrests that occurred in the emergency department were classified as OHCA. To consent to participation in the study, patients had to answer three questions correctly: (1) Why are you in the hospital? (2) Are you  $\geq$  18 years of age? and (3) What is the purpose of the study? If a patient could not answer all three questions, a proxy consent was sought.

Domains 1.1 - 1.6 of the CPC-E were administered close to hospital discharge by a member of the post-CA clinical service while the author (SB), or a second member of the post-CA clinical service, simultaneously scored the CPC-E. The scores of Rater 1 were masked to the scores of Rater 2 and vice versa. These six Domains included: Alert, Logical Thinking, Attention, Short-Term Memory, Motor, and BADLs. Domains 1.7 - 1.10 were collected via phone by the author (SB) between 7 - 32 days (mean of  $15.7 \pm 7.9$ ) post discharge. One patient

was an outlier at 32 days due to re-hospitalization. These four Domains included: Fatigue, Mood, CADLs, and Return to Work. The CPC-E was assessed for time to complete, comprehensiveness of data, and ease of administration.

# 3.5 DATA ANALYSIS OF CONTENT VALIDITY

Responses by Survey A (Expert CA Panel) and by Survey B (Expert CA Panel and Rehabilitation Panel) were collected in <u>www.surveymonkey.com</u> then downloaded and recorded. Qualitative data was downloaded by Domain, level, and descriptor, and then summarized by response themes. For Panel 1 Survey A, mean, median and mode were calculated for the reviewers' response to each of the three survey questions. For Survey B, the frequency of "Yes" or "No" responses were tabulated for both the Expert CA Panel and Rehabilitation Panel responses to three additional survey questions.

# 3.6 **RESULTS: CONTENT VALIDITY**

The results from Survey A (Expert CA Panel) and Survey B (Expert CA Panel and Rehabilitation Panel) are presented in Tables 18, 19 and 20, respectively. See Appendix D for the full report for all Surveys and corresponding Panel members' responses. Highlights for both surveys are presented here.

			1.1.4	2 With set is the	2.6
			1. Is the	2. What is the	3. Second Level
			Domain	importance of this	Descriptors: Do the
			named	Domain for measuring outcomes after a CA?	criteria for each level of
			correctly?	outcomes after a CA?	this Domain allow for
			0 = No	$0 = N_{eff}$ important at all	appropriate differentiation of a
			0 = No 1 = Maybe	0 = Not important at all $1 = Somewhat$ important	patient's current status?
			1 = Maybe 2 = Yes	2 = Important	0 = No
			z - res	3 = Very important	1 = Maybe
Doma	ain			5 – very important	2 = Yes
1.1	Alert	Mean	1.7	2.6	1.3
	Alon	Median	2	3	2
		Mode	2	3	2
1.2	Disorganized	Mean	1.2	2.2	1.4
1.2	Thinking	Median	1.2	2.2	1.5
	Thinking	Mode	2	3	2
1.3	Attention	Mean	1.8	2	1.4
1.5	Attention	Median	2	2	1.4
		Mode	2	2	1
1.4	Short Term	Mean	1.9	2.6	1.9
1.4	Memory	Median	2	3	2
	Memory	Mode	2	3	2
1.5	Motor	Mean	1.9	2.2	1
1.5	Motor	Median	2	2.2	1
		Mode	2	2	1
1.6	E-kinne			1.5	1.2
1.6	Fatigue	Mean	1.7	1.5	
		Median	2		1
1.7		Mode	2	2	2
1.7	Mood	Mean	1.8	1.9	1.1
		Median	2	2	1
		Mode	2	2	2
1.8	Basic	Mean	2	2.8	1.7
	Activities of	Median	2	3	2
	Daily Living	Mode	2	3	2
1.9	Social	Mean	1.9	1.5	1.2
	Support	Median	2	1.5	1.5
	-	Mode	2	0	2
1.10	Instrumental	Mean	1.7	2.5	1.8
	Activities of	Median	2	3	2
	Daily Living	Mode	2	3	2
1.11	Return to	Mean	1.9	2.2	1.4
	Work	Median	2	2.5	1.5
	Domain	Mode	2	3	2

# Table 18. Panel 1 Survey A Expert CA Panel Results

For Panel 1 Survey A, mean, median and mode were calculated for the reviewers' response to each of the three survey questions (refer to Table 18). Question 1 regarding feedback on naming of the Domain received a mode scoring of "2" (Yes – correctly named) for each of the

eleven Domains. For question 2, the importance of the Domain, 4 of the CPC-E Domains received a mode score of "2" (Important) while 6 Domains received a mode score of "3" (Very important). The reviewers only deemed one of the proposed Domains, the Social Support Domain, as "not being an important Domain for measuring outcomes after CA" (i.e., a mode score of "0" was calculated). As a result, the Social Support Domain was removed from the CPC-E Table. For question 3 regarding differentiation of each level of the second level descriptors, 9 of the Domains received a mode score of "2" (Yes) and 2 Domains received a mode score of 1 (Maybe). Subsequent modifications at this stage included: refinements to the Alert Domain second-level descriptors; renaming of the Disorganized Thinking Domain to Logical Thinking; administration considerations related to intubated patients; determination of a quick and appropriate motor assessment; definition of independence in activities; and return to work descriptors. Since the reviewers expressed a need for a greater distinction between BADLs and IADLs, IADLs was renamed as the CADL Domain.

Results from Panel 1 and Panel 2 Survey B reviewers are presented in Tables 19 and 20, respectively. In response to the question for keeping the Domain as described, Panel 1 Expert CA Panel had a mean "Yes" score of 92% (see Table 19), while Panel 2 Survey B Rehabilitation Panel had a mean "Yes" score of 96% (see Table 20).

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Domain Doma as des		Should Domain as descr (Yes or	ı be kept ribed?	Please tell us why you would like to delete this domain.	Please suggest additional modifications, if any.
1.1	Alert	% Yes	100 %		
1.2	Logical	% Yes	80 %		
1.2	Thinking	% No	20%	Too abstract; Too redundant;	
		% Yes	90 %		Consider alternative method if patient
1.3	Attention	% No	10~%	Complex task- requires both attention and motor response	unable to squeeze hand; is immobilized
	Short-Term	% Yes	90 %		Option for
1.4	Memory	% No	10 %	Not good option for intubated patient	tracheostomy patients to write or point to something
1.5	Motor	% Yes	100 %		Some instances patient may be immobile
	Basic	% Yes	90 %		
1.6	Activities of Daily Living	% No	10 %	Poor discrimination: expect most patients to score 0/0 or 4/4	
		1	POST-DIS	CHARGE ASSESSMENT	
		% Yes	90 %		How should intubated
1.7	Mood	% No	10 %	Too subjective	respond? Responding to "today" is too restrictive; consider longer timeframe
1.8	Fatigue	% Yes	100 %		Clarify the scale; Rephrase options to be similar to Mood Domain
1.9	Complex Activities of Daily Living	% Yes	100 %		
		% Yes	80 %		Suggest reframing as
1.10	Return to Work Domain	% No	20 %	Not appropriate for majority older patients who do not work; depends on socioeconomic factors and depression mostly	"return to normal daily activities" to encompass recreation etc.
AVERAGE MEAN YES SCORE FOR PANEL 1			92%		

Table 19. Panel 1 Survey B Expert CA Panel Results and Feedback

Domain		be kept describ	ed?	Please tell us why you would like to delete this domain.	Please suggest additional modifications, if any.
			es or No)		
1.1	Alert	% Yes	90 %		
		% No	10 %	Not pertinent	
1.2	Logical Thinking	% Yes	100 %		
1.2	10 A	% Yes	90 %		
1.3	Attention	% No	10 %	Too complicated; too long	
1.4	Short-Term	% Yes	90 %		Add option for
1.4	Memory	% No	10 %	Too many words/commands	tracheostomy patients to write
1.5	Motor	% Yes	100 %		Rephrase: Patient may only need help with coming to sitting but not with walking
1.6	Basic Activities of Daily Living	% Yes	100 %		
		PO	ST-DISCHAR	3E ASSESSMENT	
		% Yes	90 %		
1.7	Mood	% No	10%	Fluctuates in this setting	-
1.8	Fatigue	% Yes	100 %		Clarify scale; Avoid double negative terms
1.9	Complex Activities of Daily Living	% Yes	100 %		
1.10	Return to Work Domain	% Yes	100 %		Difficult to assess in hospital
AVERAGE MEAN YES SCORE FOR PANEL 2			96 %		

Table 20. Panel 2 Survey B Rehabilitation Results and Feedback

Based on the collective feedback from the reviewers, additional refinements were incorporated into the final version of the CPC-E (see Stage IV Table 17). For example,

administration of the Attention Domain was changed to reflect reviewers' comments about ensuring the participation of an immobilized patient. Similarly, changes were made to the administration section of the Short-Term Memory Domain to permit an intubated patient to write a response. Following comments from several physical therapists, a second-level descriptor of the Motor Domain was changed from "unable to sit without assistance," to "patient needs assistance to stand;" since, based on their experience, it is not unusual for a patient to require assistance when moving in bed to a seated position, yet be independent with walking. Some of the most significant changes were made to the Fatigue Domain. The second-level options were simplified and restated to reflect the style of the Mood Domain. For example, option 1 of the second-level Fatigue Domain descriptor, "I *strongly agree* with the statement: I feel no fatigue at all," was replaced with "I feel fatigued...none of the time."

# 3.7 DATA ANALYSIS OF RELIABILITY

Quantitative data were transferred to SPSS 20.0 for Windows (Chicago, IL). Descriptive statistics were used to analyze demographics and medical chart data, and the distribution of scores for each CPC-E Domain. Power analysis for the ICCs, with an alpha of .05, a power of .80, and a correlation coefficient of .70 yielded a minimum sample size of 11.

Owing to the criterion-referenced characteristics of the CPC-E tool, it was clinically relevant to measure decision consistency among raters based on a mutual ability to collect information from the chart retrospectively, not the probabilistic reliability of estimating a subject's "true" score. <sup>189-191</sup> However, because the original CPC was scored primarily using medical chart review, we also chose to do medical chart reviews for intra- and inter-rater

reliability. Therefore, the decision consistency of the two raters was reported in three ways: Number of agreements/number of possible agreements, mean percent agreements, and intraclass correlation coefficients (ICC). Percent agreement provides information on rater consistency. The strength of the agreement has been defined as 0–0.20 as slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1 as almost perfect agreement.<sup>192</sup> ICC provides additional information since it has the ability to analyze other factors affecting reliability such as between-subject variance, between-rater variance and error variance. A guideline by Portney and Watkins suggests that ICCs greater than 0.90 represents high reliability, above 0.75 represents good reliability, and those below 0.75 represent poor to moderate reliability.<sup>193</sup> Intrarater reliability (IR) data were analyzed using one rater (AB) and the ICC (3, 1). With one rater and 30 charts, the goal was to achieve an ICC between 0.5 (moderate reliability) and 0.75 or above (good to high reliability). Inter-rater reliability (IRR) data were analyzed using ICC (2, k (2)).

# 3.8 **RESULTS: RELIABILITY**

Demographic and medical data are presented in Table 21. Mean age was 55.07, 55.34 and 53.45 years for IR, IRR and IRR-Hospital, respectively, and the majority of subjects were Caucasian. The majority of subjects were male for the IR and IRR; in contrast, only 27.3% were male for the IRR-Hospital sample. The majority of subjects were OHCA survivors and ventricular dysrhythmia was most common presenting dysrhythmia. Use of hypothermia was similar for IR and IRR, 20 (n = 30, 66.7%) and 31 (n = 50, 62%), respectively, compared to only 1 (n = 11,

9.1%) in the IRR-Hospital group. Median length of hospital stay was similar at 15.4 days, 15.0 days, and 13.73 days for all three groups, respectively. The CPC mode was a CPC 1 ("good" cerebral function) for IR (n = 11, 36.7%); for IRR the mode was CPC 1 and CPC 2 ("moderate" cerebral function, n = 18, 36.0%); and a score of CPC 3 ("severe" cerebral function) was the mode for IRR-Hospital (n = 4, 36.4%). The mRS mode was mRS 2 (slight disability) and mRS 4 (moderately-severe disability) for IR (n = 7, 23.3%); mRS 2 for IRR (n = 16, 32%); and mRS 4 for IRR-Hospital (n = 5, 45.5%). The mode discharge disposition for IR was bimodal: Home – No Services and Long-Term Acute Care (n = 8, 26.7% for each); for IRR, Home – No Services (n = 22, 44%), and for IRR Hospital, Home No – Services (n = 5, 37.8%).

	Intra-rater reliability	Inter-rater reliability -	Inter-rater reliability – Hospital
	(n = 30)	Medical record review	(n = 11)
		(n = 50)	
Age, years, mean (SD)	55.07 (17.4)	55.34 (14.5)	53.45 (19.4)
Male, n (%)	17 (56.7)	32 (64)	3 (27.3)
Race, n (%)			
White	23 (76.7)	42 (84)	7 (63.6)
Black	3 (10.0)	3 (6)	1 (9.1)
Other			1 (9.1)
OHCA, n (%)	22 (73.3)	37 (74)	9 (81.8)
Hypothermia Treatment, n (%)	20 (66.7)	31 (62)	1 (9.1)
Rhythm, n (%)			
VF/VT	22 (73.3)	37 (74.0)	9 (81.8)
PEA	7 (23.3)	8 (16.0)	1 (9.1)
Asystole	1 (3.3)	3 (6.0)	1 (9.1)
Unknown	0	2 (4.0)	0
	FOUR	1	
Motor Score, n (%)			
0	1 (3.3)	4 (8.0)	1 (9.1)
1	0	0	0
2	14 (46.7)	19 (38.0)	3 (27.3)
3	0	0	0
4	10 (33.3)	19 (38.0)	6 (54.5)
Brainstem Score, n (%)			
0	1 (3.3)	1 (2.0)	0
1	0	0	0
2	1 (3.3)	8 (16.0)	1 (9.1)
3	0	0	0
4	23 (76.7)	34 (68.0)	7 (63.6)
Length of stay, days, mean (SD)	15.40 (9.15)	15.0 (10.6)	13.73 (7.94)
CPC, n (%)			
1	10 (33.3)	18 (36.0)	0
2	11 (36.7)	18 (36.0)	3 (27.3)
3	9 (30.0)	13 (26.0)	4 (36.4)
4	0	0	0
5		1 (2.0)	0
mRS, n (%)			
0	4 (13.3)	5 (10.0)	0
1	6 (20.0)	9 (18.0)	0
2	7 (23.3)	16 (32.0)	2 (18.2)
3	6 (20.0)	12 (24.0)	3 (27.3)
4	7 (23.3)	7 (14.0)	5 (45.5)
5	0	0	
6		1 (2.0)	
Discharge Disposition, n (%)			
Home- No Services	8 (26.7)	22 (44.0)	5 (45.5)
Home- Care	7 (23.3)	11 (22.0)	2 (18.2)
Acute Care Hospital	2 (6.7)	1 (2.0)	1 (9.1)
Skilled Nursing Facility	5 (16.7)	7 (14.0)	2 (18.2)
Long-term Acute Care	8 (26.7)	8 (16.0)	1 (9.1)

Table 21. Demographic Information and IR and IRR Results

N.B. When n is less than sample number, data could not be found.

For the Mood, Fatigue and CADL Domains for IR and IRR chart review, data were missing 100% of the time (see Table 22). Five additional Domains for IR had missing data 40%

to 76% of the time (Logical Thinking, Short-Term Memory, Attention, BADLs, and Return to Work). For IRR, five Domains had missing data 58% to 84% of the time (Short-Term Memory, Attention, Logical Thinking, BADL and Return to Work). In contrast, no data were missing for the IRR-Hospital for any of the 10 Domains.

	Intra-rater reliability (IR) (n = 30)	Inter-rater reliability (IRR) – Medical record review (n = 50)	Inter-rater reliability – Hospital (n = 11)
Alert, n (%)			
1	29 (96.7)	47 (94.0)	10 (90.9)
2			1 (9.1)
3			
4			
5			
Data not found	1 (3.3)	3 (6.0)	
Logical Thinking			
1	13 (43.3)	1 (20.0)	10 (90.9)
2	1 (3.3)	1 (2.0)	1 (9.1)
3			
4			
5	4 (13.3)	4 (8.0)	
Data not found	12 (40.0)	35 (70.0)	
Attention			
1	9 (30.0)	17 (34.0)	8 (72.7)
2		1 (2.0)	3 (27.3)
3		1 (2.0)	
4			
5			
Data not found	21 (70.0)	31 (62.0)	
Short-Term Memory			
1	9 (30.0)	12 (24.0)	7 (63.6)
2	4 (13.3)	3 (6.0)	1 (9.1)
3		2 (4.0)	
4	3 (10.0)	2 (4.0)	2 (18.2)
5	2 (6.7)	2 (4.0)	1 (9.1)
Data not found	12 (40.0)	29 (58.0)	
Motor			
1	6 (20.0)	9 (18.0)	6 (54.5)
2	1 (3.3)	10 (20.0)	4 (36.4)
3	13 (43.3)	15 (30.0)	1 (9.1)
4	10 (33.3)	12 (24.0)	
5			
Data not found		4 (8.0)	
Basic Activities of Daily Living			
1	3 (10.0)	3 (6.0)	8 (72.7)
2			1 (9.1)
3		1 (2.0)	
4	2 (6.7)	2 (4.0)	2 (18.2)
5	2 (6.7)	4 (8.0)	
Data not found	23 (76.7)	40 (80.0)	

# Table 22. Distribution of CPC-E Scores

Table 22 (continued).

	Intra-rater reliability (IR)	Inter-rater reliability (IRR) -	Inter-rater reliability – Hospital
	(n = 30)	Medical record review	(n = 11)
		(n = 50)	
Mood			
1			6 (54.5)
2			3 (27.3)
3			1 (9.1)
4			
5			1 (9.1)
Data not found	30 (100)	30 (100)	
Fatigue			
1			4 (36.4)
2			
3			
4			4 (36.4)
5			3 (27.3)
Data not found	30 (100)	30 (100)	
CADLs			
1			3 (27.3)
2			3 (27.3)
3			
4			4 (36.4)
5			1 (9.1)
Data not found	30 (100)	30 (100)	
Return to Work			
1	6 (20.0)	7 (14.0)	2 (18.2)
2			2 (18.2)
3			1 (9.1)
4			4 (36.4)
5	1 (3.3)	1 (2.0)	2 (18.2)
Data not found	23 (76.7)	42 (84.0)	

IR reliability data for the CPC-E (n=30) is presented in Table 23. The percent agreement ranged from substantial (73.3 %) for the Motor and Short-Term Memory Domains, to perfect agreement (100%) for the Alert, Mood, Fatigue and CADL Domains. Of the scores that could be calculated, ICC ranged from poor to moderate (.46), for the BADLs Domain to high (1.0) for the Alert Domain. ICC scores could not be calculated for the Mood, Fatigue and CADL Domains due to lack of variance in the data.

Domain	Missing Data (%)	Decision Consistency	Percent Agreement	Intraclass Correlation Coefficient (ICC)
Alert	3.3	30/30	100	1.00
Logical Thinking	40	25/30	83.0	0.90
Attention	70	28/30	93.3	0.92
Short-Term Memory	40	22/30	73.3	0.80
Motor	0	22/30	73.3	0.78
Basic Activities of Daily Living	76.7	26/30	86.7	0.46
Mood	100	30/30	100	-
Fatigue	100	30/30	100	-
Complex Activities of Daily Living	100	30/30	100	-
Return to Work	76.7	23/30	76.7	0.61

 Table 23. Intra-Rater Reliability Data for the CPC-E (n = 30)

Note. - = ICC could not be calculated due to lack of variance.

IRR reliability data for the CPC-E (n=50) is presented in Table 24. The percent agreement ranged from moderate (60%; Attention Domain), to perfect agreement (100%; Mood, Fatigue and CADL Domains). ICCs ranged from a poor to moderate for the RTW Domain (-0.16), and high (0.93) for the Motor Domain. While raters agreed 80% of the time for RTW, the negative variance reflected the divergent scores of the two raters on the remaining 20% of the data that were scored. ICC scores could not be calculated for the Mood, Fatigue and CADL Domains due to lack of variance in the data.

Domain	Missing Data (%)	Decision Consistency	Percent Agreement	Intraclass Correlation Coefficient (ICC)
Alert	6	46/50	92	0.63
Logical Thinking	70	34/50	68	0.62
Attention	62	30/50	60	0.37
Short-Term Memory	58	33/50	66	0.54
Motor	8	46/50	92	0.93
Basic Activities of Daily Living	80	44/50	88	0.64
Mood	100	50/50	100	-
Fatigue	100	50/50	100	-
Complex Activities of Daily Living	100	50/50	100	-
Return to Work	84	40/50	80	16

Table 24. Inter-Rater Reliability Data for the CPC-E (n = 50)

Note. - = ICC could not be calculated due to lack of variance.

IR reliability data for the hospital CPC-E (n=11) is presented in Table 25. Agreement among raters ranged from 90.9% for the Alert, Logical Thinking, Attention, and BADLs Domains (almost perfect), to 100% for the Short-Term Memory and Motor Domains (perfect agreement). The ICC for the In-Hospital IRR ranged from 0.78 (Logical Thinking; good) to 1.00 (Short-Term Memory and Motor; high ). The ICC could not be calculated for the Alert Domain due to lack of variance in the data.

Domain	Missing (%)	Decision Consistency	Percent Agreement	Intraclass Correlation Coefficient (ICC)
Alert	0	10/11	90.9	-
Logical Thinking	0	10/11	90.9	0.78
Attention	0	10/11	90.9	0.87
Short Term Memory	0	11/11	100	1.00
Motor	0	11/11	100	1.00
Basic Activities of Daily Living	0	10/11	90.9	0.79

 Table 25. Inter-Rater Reliability Data for the Hospital CPC-E (n = 11)

Note. - = ICC could not be calculated due to lack of variance.

# 3.9 **RESULTS: FEASIBILITY**

We collected the time to complete the CPC-E, comprehensiveness of the data, and the ease of its administration in the hospital setting.

# **3.9.1** Time to Complete

Time to complete all of the in-hospital Domains, columns 1.1 to 1.6, ranged from 4 minutes, 57 seconds to 7 minutes, 17 seconds, with a mean of 6.03 minutes. The Rater administering the questions to the patient waited approximately four to five minutes before returning to complete and score the Short-Term Memory Domain.

# 3.9.2 Comprehensiveness of Data

Thoroughness of data was achieved during the hospital room visit with additional information being extracted from CERNER. Patient reports of independence in Motor and BADLs activities were compared to the PT, OT and/or nursing notes. In three instances, adult family members were present to comment on the subject's state of attention, logical thinking and memory (i.e., if each of the three Domains being tested were "normal" for their family member).

# 3.9.3 Ease of Administration

All Raters (n = 6) found the CPC-E to be quick and easy to administer. To improve efficiency, and to ensure at least 4 minutes of re-testing time, suggestions were made to re-order the sequence of the Short-Term Memory Domain (currently 1.4) to be placed second, following the 1.1 Alert Domain.

## 4.0 DISCUSSION

The methodological framework for developing and evaluating measurement tools that assess health and quality of life has been well defined and includes five major steps: 1) identification of a specific patient population, 2) item generation, 3) item reduction, 4) pretesting of the final instrument, and 5) determination of the validity, reliability, and responsiveness.<sup>194</sup> Since there is no "gold standard" with which the CPC-E tool can be compared, we have attempted to follow an approach that other researchers have taken when attempting to determine if their health assessment tools are really valid.<sup>178, 195</sup> One strategy involves a vigorous process of construct validation that is achieved by progressing through this series of five steps. An understanding of the common health concerns that post-CA patients experience, combined with what other peer investigators are trying to measure, allows predictions to be made about how the CPC-E tool will relate to other measures. If the predictions are confirmed in the population of interest then this strengthens the evidence for validity. Furthermore, if the CPC-E performs as expected over time in varied settings then one can be more confident of its validity.

Each stage and corresponding round of the CPC-E resulted in improvements to the tool. Second-level descriptors and administrative instructions underwent an iterative process based on feedback from a variety of expert reviewers and the expertise of the Dissertation Committee Members. Criteria for each of the second-level descriptors and administrative directions were critiqued and refined at each of the four stages of Phase 1, until near consensus was reached for each Domain.

Phase 2 in this study examined retrospective data analysis of IR, and IRR and the feasibility of the CPC-E. Because the original CPC was scored primarily using medical chart review, we also chose to do retrospective medical chart reviews for intra- and inter-rater reliability to determine if they differed from the "live" administration of the CPC-E. IR and IRR raters achieved moderate to perfect decision consistency when rating subjects retrospectively on the CPC-E. However, for several Domains, they agreed that the data were missing. In particular, both raters had difficulty finding data to support criteria for rating the following Domains: Logical Thinking, Attention, Short-Term Memory and Return to Work. Likewise, neither found any data for Mood, Fatigue and CADL Domains resulting in 100% agreement. In some instances, while the raters also achieved moderate to perfect decision consistency, the ICCs could not be determined due to lack of variance in the data.

It is also of note that even when decision consistency was almost perfect (46/50; 0.92 percent agreement), the ICC statistic varied between 0.63 and 0.93. This difference reflects the difference in what is being measured. Decision consistency and percent agreement only address agreement among raters. However, the ICC reflects the variance between patients, between raters, and the error variance. The difference between the ICC of 0.63 and the 0.93 also reflected the magnitude of the rater difference (i.e., a rating of 1 vs. 6 [0.63] in contrast to a rating of 2 vs. 3 [0.93]).

Of particular interest, even for data related to BADL and Motor Domains, which one would presumably find in the chart (i.e., PT, OT, SLP and nutrition notes), the retrospective analysis did not yield reliable data. For each of these Domains, there was lower decision

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consistency and lower percent agreement despite *a priori* decision rules and identification of EMR entries. Even though the same charts were not sampled, the IR data mirrored the IRR data in terms of data availability and percent agreement.

Compared to the retrospective chart review, "live" in-hospital data were complete for all of the Domains compared to only 1/10 Domains in the IR (Motor), and 0/10 Domains in the IRR-Chart Review. Our findings suggest that retrospective chart reviews are more ambiguous than one would expect, and more open to interpretation. Retrospective review of the charts is inherently prone to problems such as difficulty knowing where to locate the data in the EMR and how to find the latest data entry. There is a temporal component that threatens accuracy of data as well since it is not unusual, for example, for therapists to chart several days after seeing a patient. Adding to these shortcomings is the uneven skill set among clinicians. While Raters 1 and 2 were instructed to default to the Domain commonly associated with a particular profession (i.e., ambulation with PT, BADLs with OT), this may not have reflected the most thorough and appropriate assessment. In contrast, "live" hospital CPC-E administration permits the rater to access the data in real time, efficiently and immediately prior to discharge.

Because the primary approach to completing the CPC has been via retrospective chart review, we chose a similar method with both the IR and IRR (n = 50) review. Our results suggest, however, that this approach is flawed for the multi-domain CPC-E and yields unreliable results largely owing to the difficulty in locating discrete information in the electronic medical records. In contrast, results of the IRR-hospital CPC-E feasibility study suggest that a "live" approach with a more finely textured tool, such as the CPC-E, yields more complete information. In all instances, the data were available and complete for all Domains via this method. The decision consistency, and percent agreement among reviewers was substantial (.62 and .74) in two Domains, Logical Thinking and Attention, respectively, and almost perfect (.99, 1.0, and 1.0) in three Domains, BADLs, Motor and Short-Term Memory. The Alert Domain was the only Domain in which ICC could not be calculated due to lack of variance in the data. The findings of the Phase 2 portion of this study support the use of "live" testing of the CPC-E to arrive at meaningful ratings, as opposed to a retrospective review of the chart. We have demonstrated that the administration of the CPC-E via this method is a viable alternative to the more conventional medical chart review owing to its excellent reliability, ease of use, and comprehensiveness of data.

## 5.0 CONCLUSION

This dissertation addressed four aims. The first aim was to establish the content validity of the CPC-E by identifying the Domains that should be represented in the CPC-E based on an extensive review of the literature, and by involving a panel of CA experts. Our second and third aims tested the intra-rater reliability (IR) and inter-rater reliability (IRR) of the CPC-E. The fourth aim was to test the feasibility of the CPC-E tool in the hospital setting to determine its time to complete, comprehensive of data, and ease of administration.

For Aim 1, we developed the CPC-E tool with 10 Domains that assess disability and impairment post CA. We sought feedback from a panel of CA experts and rehabilitation experts with experience working with CA survivors that resulted in near complete consensus for the final tool. The findings of this study identify shortcomings and decreased reliability with retrospective determination of the CPC-E via chart reviews. In contrast, reliability is consistent and high for using the CPC-E in a "live" hospital setting. The CPC-E is quick, easy to use and complete in terms of thoroughness of finding needed information in the hospital setting.

Limitations of this study include a small sample size to test the feasibility of the tool's use, testing at only one regional Level 1 Trauma hospital setting, and including only 1 decisionally-impaired subject. We will be actively recruiting a more heterogeneous population in future studies, which will test for greater ranges for each Domain, as well as ceiling and floor effects for each Domain. Since survival rates post CA can vary depending on regional

differences,<sup>8</sup> future testing of the CPC-E in multiple locations would also be desirable. Step five of the tool development process<sup>178</sup> recommends including input from the population of interest (i.e., individuals who sustained a CA or their caregivers). However, while anecdotal evidence from previous interactions with post-CA survivors contributed to the Fatigue Domain addition, direct participation of CA survivors or their caregivers was not specifically sought. In future studies of the CPC-E, we plan to include a panel of post CA survivors and their caregivers.

One advantage of the multi-domain CPC-E tool is that it will yield a profile of current impairments and disabilities at the time of discharge. The CPC-E profile also has the potential to "signal" a referral to rehabilitation, or a clinical or community support service associated with a particular Domain. Additionally, the potential use of the CPC-E as an outcome measure has the potential to drastically alter our current approach to measuring and understanding outcomes post-CA. We anticipate that the CPC-E will offer an efficient, yet comprehensive approach to systematically tracking associations between specific CA interventions and/or treatments that will provide us with new insights about how CA interventions may influence specific Domains and meaningful quality of life outcomes.

The development and establishment of the content validity of the CPC-E and its systematic assessment of its intra- and inter-rater reliability, and feasibility, will now provide the framework for further psychometric testing. The more discrete information provided by the 10 unique Domains still must be tested. For example, future studies will address its sensitivity to measure changes within, and between the Domains. The ability of the CPC-E to accurately measure change in patient status over time is of particular interest; specifically, its ability to detect clinically important changes over time<sup>196</sup> (i.e., Minimal Detectable Difference and

Minimal Clinically Important Difference). Additionally, we plan to compare and contrast the CPC-E's psychometric properties to the psychometric properties of the original CPC.

Recommendations for future research also include repeating this study with a larger number of subjects, and testing the inter-rater reliability of the CPC-E when administered by different clinicians such as PTs, OTs, and nurses. The utility of the tool will be enhanced if it can be used by multiple individuals with varied backgrounds in a consistent and effortless manner. These three groups are especially of interest because they are frequently involved in pre- and post-discharge care in the hospital, home, and/or in an assisted living facility setting.

Future validity studies will include cross-validation with other tools with established construct validity for each Domain of the CPC-E. Also, a convergent and divergent validity study will establish the discriminative ability of each Domain. It is also recommended that the post-discharge follow-up time be extended to longer intervals (i.e., 1 month, 3 months, 1 year, etc.). This will allow for the assessment of changes, by Domain, over time, as well as the ability to test the predictive validity of the tool. Furthermore, tracking over time may reveal patterns of impairment and disability that will improve our understanding of the sequelae of post CA survival, as well as if there are patterns associated with initial lower or higher scores on specific Domains, such as the Alert Domain. Additionally quality improvement studies with the CA population will be explored, as well as the utility of the CPC-E with other populations such as patients in the intensive care unit and those with traumatic brain injury.

While capturing and measuring responsiveness of the CPC-E is desired, interpretation of scoring is another area of future interest in tool development. Determination of a composite or single-Domain scoring system will require a thoughtful approach since each Domain is currently viewed and scored separately, while a global score may not identify particular impairments or

disabilities that require further action. While a summative score is frequently preferred by clinicians to reference current status against "norms," or to measure change over time, further examination is needed to address this issue.

The results of this study are encouraging and it builds on previous work by Becker, et al.,<sup>197</sup> Raina, et al.,<sup>20</sup> and Rittenberger, et al.,<sup>140</sup> who identified the need to develop a comprehensive outcome measurement for CA survivors that incorporates functional impairment and disability assessment to reflect the International Classification of Functioning, Disability and Health (ICF). Future studies will test the CPC-E on a more heterogeneous population; explore how it will be best scored and interpreted, and how its psychometric properties will compare to the original scale.

**APPENDIX A** 

### **CEREBRAL PERFORMANCE CATEGORY-EXTENDED: EM ROUNDTABLE**

		1.1	1.2	1.3	1.4	1.5	1.6	1.7	1.8	1.9
Domain Levels		Arousal	Attention	Short Term Memory*	Motor	Fatigue	Mood	Everyday Activities	Return to Work	Social Support
Best Indicator	1	Alert and Oriented	No errors with Vigilance (tapping)	5 words recalled	Moves all 4 limbs	Strongly agree	Strongly agree	Independent in §BADL & IADL	Currently full-time; returned to same job or was retired pre CA <sup>#+#</sup>	Strong: Spouse/ family/ friend that resides in same household
	2	Confused	1 error with Vigilance (tapping)	4 words recalled	Moves only 3 limbs	Agree	Agree	Independent in §BADL but partially dependent in IADL	Currently working full- time, with restrictions or in a lesser skilled job	Good: Adult child, parent, family or friend is identified as an available caregiver
	3	Lethargic or Obtunded	2 errors with Vigilance (tapping)	3 words recalled	Moves only 2 limbs	Neither agree nor disagree	Neither agree nor disagree	Independent in §BADL but totally dependent in IADL	Currently working part-time in same or lesser skilled job	Adequate: Family member or friend can be available if needed
	4	Stuporous	3 errors with Vigilance (tapping)	2 words recalled	Moves only 1 limb	Disagree	Disagree	Partially dependent in §BADL & totally dependent in IADL	Currently being evaluated for job or SSDI <sup>±</sup>	Poor: Family and/or friends unavailable or unwilling to fulfill caregiving role
	5	Comatose	4 errors with Vigilance (tapping)	l or no words recalled	Can only lift head up and off bed or cannot move	Strongly Disagree	Strongly Disagr <b>ee</b>	Totally dependent in §BADL & totally dependent in IADL	Currently unable to work	Minimal/ Absent: Family/ friends cannot be identified or do not respond to requests for help
<b>U</b> orst Indicator	6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported

Presented to EM Roundtable February 12, 2013 Table 1. Proposed Impairment and Disability Domains of the CPC-E

\* Scoring is based on the delayed recall trial.

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§BADL: Basic Activities of Daily Living and IADL: Instrumental Activities of Daily Living. \*\*\*CA: Cardiac Arrest

<sup>1</sup>SSDI: Social Security Disability Insurance

# Table 1. 1. Second Level Descriptors for the Arousal Domain

1.	Aleı	rt and Oriented	Orientated X 3 (person, place, time-including year, season, and month).				
2.	Con	fused	Attends & responds to orientation questions but answers are muddled/wrong. May demonstrate excitability and/or irritability, alternating with drowsiness.				
3.		nargic or unded	Sleepy; Responds to being addressed verbally or after light shaking, or responds verbally to more intense mechanical stimulation.				
4.	Stuporous		Unresponsive; can be aroused only by vigorous and repeated stimuli. Best response to deep pain is pushing examiner's arm away.				
5.	Comatose		Sleep-wake cycles are lacking; no eye opening or spontaneous speaking; does not follow commands, and when provoked by a noxious stimulus eyes remain closed, motor activity is absent or abnormal and reflexive, rather than purposeful or defensive.				
References	Α.	Jennet B. Revie	w Article: Development of Glasgow Coma and Outcome. <i>Nepal J of Neuroscience.</i> 2005;2:24-28.				
	В.	Plum F, Posner	JB. The Diagnosis of Stupor and Coma. 1995, 2nd Ed, FA Davis, Philadelphia. pgs. 4-5.				
	C.	Plum F, Posner JB: <i>The Diagnosis of Stupor and Coma. Contemporary Neurology Series.</i> 2007, 4th Ed, FA Davis, Philadelphia, p. 4					
	D.		JB. <i>The Diagnosis of Stupor and Coma</i> . 1995, 2nd Ed, FA Davis, Philadelphia, p. 5 and 4 <sup>th</sup> Ed. " <i>Best response to deep pain is ner's arm away</i> ," p. 40.				
	Ε.	The Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state (1). <i>N Engl J Med.</i> 1994;330:1499–1508. PMID: 7818633					
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#### Table 1. 2. Second Level Descriptors for the Attention Domain

(Vigilance) Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: "I am going to read a sequence of letters. Every time I say the letter 'A,' tap your hand once. If I say a different letter, do not tap your hand." [An error is a tap on a wrong letter or a failure to tap on letter "A."]

# <u>FBACMNAAJKLBAFAKDEAAAJAMOFAAB</u>

1.	No errors with tapping	The patient taps correctly when the letter "A" is mentioned.
2.	1 error with tapping	The patient taps incorrectly when the letter "A" is mentioned: either an error with tapping on a wrong letter or a failure to tap on letter "A."
3.	2 errors with tapping	The patient taps incorrectly twice when the letter "A" is mentioned: a combination of either an error with tapping on a wrong letter and/or a failure to tap on letter "A."
4.	3 errors with tapping	The patient taps incorrectly three times when the letter "A" is mentioned: combinations of either an error with tapping on a wrong letter and/or a failure to tap on letter "A."
5.	4 or more errors with tapping	The patient taps incorrectly four or more times when the letter "A" is mentioned: combinations of either an error with tapping on a wrong letter and/or a failure to tap on letter "A."
Reference	The Montreal Cognitive A	ssessment: MoCA© 2003 to 2010 (need to secure written permission for research purposes)
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#### Table 1.3. Second Level Descriptors for the Short-term Memory Domain

#### Administration:

The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: "This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them." [Mark a check in the allocated space for each word the subject produces for Trial 1.]

Not Scored	Train	Egg	Hat	Chair	Blue
Trial 1					
Trial 2					

When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a *second* time with the following instructions: I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time. Put a check in the allocated space for each word the subject recalls after the second trial. (see Trial 2 above) At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, "I will ask you to recall those words again at the end of the test."

Scoring: No points are given for Trials One and Two. Scoring is based on the delayed recall trial, which will be the last page.

1.	5 words recalled	Able to recall all 5 words.					
2.	4 words recalled	Able to recall 4 words.					
3.	3 words recalled	Able to recall 3 words.					
4.	2 words recalled	Able to recall 2 words.					
5.	1 or no words recalled	Able to recall 1 word or unable to recall any words.					
Reference	MoCA: The Montreal Cognitive Assessment <sup>©</sup> 2003 to 2010. (need to secure written permission for research purposes)						
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# Table 1.4. Second Level Descriptors for the Motor Domain

Administrat The examin	nistration: examiner states: "I want you to lift each arm off of the bedand now lift each leg off of the bedand now lift your head off of the pillow."								
1.	Moves all limbs	Patient can raise all 4 limbs (i.e., both arms and both legs off of the bed)							
2.	Moves 3/4 limbs	Patient can raise only 3/4 extremities.							
3.	Moves 2/4 limbs	Patient can raise only 2/4 extremities.							
4.	Moves 1/4 limbs	Patient can raise only 1/4 extremities.							
5.	Can only move head off pillow or cannot move	Patient can only raise head off of the pillow or cannot move.							
Reference	Adapted from	n the National Institutes of Health's Stroke toolkit							
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#### Administration: The examiner asks the patient: "How would you respond to the following statement: 'I feel no fatigue at all'. Do you: (1) Strongly agree (2) Strongly disagree (3) Or Somewhere in between" 1. Strongly agree "I strongly agree with the statement: I feel no fatigue at all." 2. Agree If the patient responds "Somewhere in between," offer the following three responses: (2) Agree 3. (3) Neither agree nor disagree Neither disagree nor agree (4) Disagree 4. Disagree 5. "I strongly disagree with the statement: I feel no fatigue at all." Strongly disagree Adapted from: ASCPRO Recommendations for the assessment of fatigue as an outcome in clinical trials. Barsevick AM, Cleeland CS, Reference Manning DC, O'Mara AM, Reeve BB, Scott JA, and Sloan JA. Journal Pain Symptom Manage. Author manuscript; available in PMC 2011 June 1. Published in final edited form as: J Pain Symptom Manage. 2010 June; 39(6): 1086–1099. PMCID: PMC2909842 NIHMSID: NIHMS207733 doi: 10.1016/j.jpainsymman.2010.02.006 © 2013, Holm-Raina-Balouris-Rittenberger-Rogers & Callaway, All Rights Reserved

### Table 1.5. Second Level Descriptors for the Fatigue Domain

# Table 1.6. Second Level Descriptors for the Mood Domain

Administrat	ion:									
The Examin	The Examiner asks the patient: "How would you respond to the following statement: 'I feel positive and hopeful' Do you:									
			<ul><li>(1) Strongly agree</li><li>(2) Strongly disagree</li><li>(3) Or Somewhere in between"</li></ul>							
1.	Strongly a	agree	"I strongly agree with the statement: I feel positive and hopeful."							
2.	Agree		If the patient responds "Somewhere in between," offer the following three responses:							
3.	l neither a	agree nor disagree	(2) Agree (3) Neither agree nor disagree							
4.	Disagree		(4) Disagree							
5.	Strongly o	disagree	"I strongly disagree with the statement: I feel positive and hopeful."							
Reference	A.	Kroenke K, Spitzer RL. The F	PHQ-9: a new depression and diagnostic severity measure. <i>Psychiatric Annals</i> . 2002;32: 509-521.							
	В.	depression screening in pat	Elderon L, Smolderen KG, Na B, Whooley MA. Accuracy and prognostic value of American Heart Association: Recommended depression screening in patients with coronary heart disease: data from the Heart and Soul Study. <i>Circ Cardiovasc Qual Outcomes.</i> 2011. Sep;4(5):533-40. doi: 10.1161/CIRCOUTCOMES.110.960302. Epub 2011 Aug 23.							
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### Table 1.7. Second Level Descriptors for the Everyday Activities Domain:

Administration: The examiner records the CURRENT level of basic independence in both activities of daily living (BADLs) and instrumental activities of daily living (IADLs). Both measures provide an objective method of classifying groups of people with chronic illnesses, disabilities and impairments, and of describing their health needs and outcomes. It may be necessary to refer to the Occupational Therapy notes in the patient's chart.

			Activities of Daily Living (ADLs):	Instrumental Activities of Daily Living (IADLs):				
			Six basic human functions: Bathing, dressing, toileting, transfer, continence, and feeding	Shopping, food preparation, housekeeping, traveling, mode of transportation (drives, public transportation, does not travel), responsible for own medications, able to handle finances				
1.	Indep & IAD	endent in §BADL PL	Independent	Independent				
2.	Independent in BADL but partially dependent in IADL		Independent	Partially dependent				
3.	Independent in BADL but totally dependent in IADL		Independent	Totally dependent				
4.	BADL	Illy dependent in & totally ndent in IADL	Partially dependent	Totally dependent				
5.	BADL	y dependent in & totally ndent in IADL	Totally dependent	Totally dependent				
References	A.	Katz S, Akpom, C	A. Index of ADL. <i>Medical Care.</i> 1976;14(5 Suppl):116-8.PN	ИID: 132585				
	В.		Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. <i>The Gerontologist.</i> 1969;9(3 Part 1):179-186 PMID:5349366					
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# Table 1.8. Second Level Descriptors for the Return to Work Domain:

Administrati	on: The	e examiner asks the patient for his or her CURRENT work status.							
1.	Curre	Currently working full-time or has returned to same job post CA as full-time employee, or was already retired pre CA.							
2.	Curre	Currently working full-time with restrictions or in a lesser skilled job.							
3.	Curre	Currently working part-time in same or lesser skilled job.							
4.	Curre	Currently being evaluated for work or Social Security Disability Insurance (SSDI).							
5.	Curre	ntly unable to work.							
References	А.	MacEachen E, Clarke J, Franche RL, Irvin E. Systematic review of the qualitative literature on return to work after injury. Scandinavian Journal of Work, Environment & Health. 2006;257-269.							
	В.	Krause N, Dasinger LK, Neuhauser F. Modified work and return to work: a review of the literature. <i>Journal of Occupational Rehabilitation</i> . 1998;8(2):113-139.							
	C.	Saner H, Borner RE, Kummer-Bangerter A, Schuppel R, von Planta M. Quality of life in long-term survivors of out-of-hospital cardiac arrest. <i>Resuscitation</i> . 2002;53:7-13.							
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# Table 1.9. Second Level Descriptors for the Social Support Domain

	Administration: The examiner asks the patient to answer the stated questions below or selects the appropriate statements as indicated.									
1.	Strong	Strong Does your spouse, family and/or a friend reside with you in the same household?								
2.	Good	Good Is there an adult child, parent, or other family member or friend who is identified as an available caregiver?								
3.	Adequate Is a family member or friend available if needed?									
4.	Poor	Are family and/or friends unavailable or unwilling to fulfill a caregiving role?								
5.	Minimal/ Absent	Are you unable to identify any family or friends, or if you can they do not respond to requests for help?								
Reference	Holt-Lunstad J, Smith, TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. <i>PLoS Med</i> . 2010. Jul 27;7(7):e1000316. doi: 10.1371/journal.pmed.1000316.									
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# Table 1.3. Second Level Descriptors for the Short-term Memory Domain

Administra "I read son	ition: ne words to you earli	er, which I asked yo	u to remember. Tell	me as many of thos	e words as you can i	remember"				
[Mark a ch	eck in the allocated s	pace for each word	the subject produce.	s for DELAYED]						
Not Score	ed Train	Egg	Hat	Chair	Blue					
DELAYED										
Scoring: N	o points are given for	Trials One and Two	Scoring is based on	the delayed recall t	rial only					
5coning. 14					indi oniy.					
1.	5 words recalled Able to recall all 5 words.									
2.	4 words recalled	Able to recall 4 words.								
3.	3 words recalled	Able to recall 3 words.								
4.	2 words recalled	Able to recall 2 v	vords.							
5.	1 or no words Able to recall 1 word or unable to recall any words.									
Reference	MoCA: The Montre	al Cognitive Assessr	ment© 2003 to 2010	D. (need to secure w	ritten permission for	research purposes)				
		MoCA: The Montreal Cognitive Assessment© 2003 to 2010. (need to secure written permission for research purposes) © 2013, Holm-Raina-Balouris-Rittenberger-Rogers & Callaway, All Rights Reserved								

# **APPENDIX B**

## **ROUND I, SURVEY A**

		1.1	1.2	1.3	1.4	15	1.6	1.7	1.8	1.9	1.10	1.11
Domain Levels		Alert	Disorganized Thinking	Attention	Short Term Memory	Motor	Fatigue	Mood	Basic Activities of Daily Living (BADLs)	Social Support	Instrumental Activities of Daily Living (IADLs) <sup>¢</sup>	Return to Work <sup>¢¢</sup>
Best Indicator	1	Spontaneously responds to person entering room	Correctly answers all 4 questions	No errors with tapping	5 words recalled	Drifting observed in 0 limbs	Strongly agree	Strongly agree	Independent in 4/4 (feeding, dressing, transferring and toileting)	Strong: Spouse, family member and/or friend that resides in same household	Independent in 4/4 (medication management, food preparation, shopping and transportation)	Currently full- time or has returned to pre CA job§
	2	Responds to verbal stimulus	Correctly answers 3/4 questions	1 error with tapping	4 words recalled	Drifting observed in 1 limb	Agree	Agree	Independent in 3/4 (feeding, dressing, transferring or toileting)	Good: Adult child, parent, family member or friend is identified as an available caregiver	Independent in 3/4 (medication management, food preparation, shopping or transportation)	Currently working full- time, with restrictions or in a lesser skilled job
	3	Responds to light touch	Correctly answers 2/4 questions	2 errors with tapping	3 words recalled	Drifting observed in 2 limbs	Neither agree nor disagree	Neither agree nor disagree	Independent in 2/4 (feeding, dressing, transferring or toileting)	Adequate: Family member or friend available if needed	Independent in 2/4 (medication management, food preparation, shopping or transportation)	Currently working part- time in same or lesser skilled job
	4	Responds to noxious stimulus	Correctly answers 1/4 questions	3 errors with tapping	2 words recalled	Drifling observed in 3 limbs	Disagree	Disagree	Independent in 1/4 (feeding, dressing, transferring or toileting)	Poor: Family and/or friends unavailable or unwilling to fulfill caregiving role	Independent in 1/4 (medication management, food preparation, shopping or transportation)	Currently being evaluated for work
Worst Indicator	5	No response to voice or physical stimulation; may observe abnormal reflex or posturing	0/4: Does not answer any question correctly	4 or more errors with tapping	l or no words recalled	Drifting observed in 4 limbs/Does not move limbs	Strongly Disagree	Strongly Disagree	0/4: Not independent in any BADLs	Minimal/ Absent: Family/ friends cannot be identified or do not respond to requests for help	0/4:Not independent in any IADLs	Currently unable to work due to change in medical status since CA
	6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported

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\*Scoring is based on the delayed recall trial (page 13). \*IADLs: This Domain will <u>not</u> to be administered in the hospital. #Return to Work: This Domain will <u>not</u> to be administered in the hospital.

<sup>6</sup>CA: Cardiac Arrest

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#### Table 1.1 Second Level Descriptors for the Alert Domain

1.	Spontaneously responds to person entering room		Patient spontaneously responds to observer (i.e., tracks with eyes/turns head toward person entering room).		
2.	Responds to verbal stimulus		Patient requires verbal stimulus to attend.		
3.	Resp toucl	onds to light	Patient requires light touch to attend.		
4.		onds to ous stimulus	Patient requires noxious stimulus to attend.		
5.	or ph stimu obse	esponse to voice hysical hlation; may rve abnormal x or posturing	Sleep-wake cycles are lacking; no eye opening or spontaneous speaking; does not follow commands, and when provoked by a noxious stimulus eyes remain closed. Motor activity is absent or abnormal and reflexive, rather than purposeful or defensive.		
Ref. A. Sessler CN, Gosnell M, Grap MJ, Brophy GT, O'Nea			nell M, Grap MJ, Brophy GT, O'Neal PV, Keane KA et al. The Richmond Agitation- validity and reliability in adult intensive care patients. <i>Am J Respir Crit Care Med</i>		
JD, Farber MO, Ely W, Boustani MA. Comparison and agreement between the Richmond Agitation-Sedation Scale a Sedation-Agitation Scale in evaluating patients' eligibility for delirium assess <i>Chest.</i> 2012 Jul;142(1):48-54. doi: 10.1378/chest.11-2100.CEly EW, Truman B, Shintani A, Thomason JWW, Wheeler AP, Gordon S et a status over time in ICU patients: the reliability and validity of the Richmond Agitation			agreement between the Richmond Agitation-Sedation Scale and the Riker on Scale in evaluating patients' eligibility for delirium assessment in the ICU.		
			n B, Shintani A, Thomason JWW, Wheeler AP, Gordon S et al. Monitoring sedation patients: the reliability and validity of the Richmond Agitation Sedation Scale		
			w Article: Development of Glasgow Coma and Outcome. Nepal J of Neuroscience.		
	F.	Plum F, Posner JB. <i>The Diagnosis of Stupor and Coma</i> . 1995, 2nd Ed, FA Davis, Philadelphia. pgs. 4-5.			
	G.	G. Plum F, Posner JB: <i>The Diagnosis of Stupor and Coma. Contemporary Neurology Series.</i> 2007, 4th Ed, FA Davis, Philadelphia, p. 40.			
H. The Multi-S			Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state (1). <i>N Engl J</i> 1994;330:1499–1508.		
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## Table 1.2 Second Level Descriptors for the Disorganized Thinking Domain

Administrati	ministration: Ask the patient to answer the following 4 questions:*				
	<ol> <li>Will a stone float on water? (Correct answer is "No")</li> <li>Are there fish in the sea? (Correct answer is "Yes")</li> <li>Does one pound weigh more than two? (Correct answer is "No")</li> <li>Can you use a hammer to pound a nail? (Correct answer is "Yes")</li> </ol>				
1.	Correctly answers all 4 questions.				
2.	Correctly answers 3/4 questions.				
3.	Correctly answers 2/4 questions.				
4.	Correctly answers 1/4 questions.				
5.	0/4: Does not answer any question correctly.				
References	A. Adapted from: Confusion Assessment Method for the ICU (CAM-ICU): The CAM-ICU is a delirium monitoring instrument for ICU patients. * Copyright © 2002, E. Wesley Ely, MD, MPH and Vanderbilt University, all rights reserved				
	B. Ely EW, Inouye SK, Bernard GR, Gordon S, Francis J, May L, Truman B, Speroff T, Gautam S, Margolin R, Hart RP, Dittus R. Delirium in mechanically ventilated patients: validity and reliability of the confusion assessment method for the intensive care unit (CAM-ICU). JAMA. 2001;286(21):2703–2710. doi: 10.1001/jama.286.21.2703				
	C. Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. Ann Intern Med. 1990;113:941–8.				
	E. Vanderbilt University Medical Center website. CAM-ICU Training Manual and Instructional Video. Accessed February 21, 2013 from http://www.mc.vanderbilt.edu/icudelirium/index.html.				
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 Table 1.3 Second Level Descriptors for the Attention Domain

 Administration: The examiner reads the list of letters at a rate of one per second, after giving the following
 instruction: "I am going to read a sequence of letters. Every time I say the letter 'A,' tap your hand once. If I say a different letter, do not tap your hand." [An error is a tap on a wrong letter or a failure to tap on letter "A."]\*\*

1.	No errors with tapping		The patient taps correctly when the letter "A" is mentioned.	
2.	1 error with tapping		The patient taps incorrectly when the letter "A" is mentioned: either an error with tapping on a wrong letter or a failure to tap on letter "A."	
3.	2 errors with tapping		The patient taps incorrectly twice when the letter "A" is mentioned: a combination of either an error with tapping on a wrong letter and/or a failure to tap on letter "A."	
4.	3 errors with tapping		The patient taps incorrectly three times when the letter "A" is mentioned: combinations of either an error with tapping on a wrong letter and/or a failure to tap on letter "A."	
5.		re errors with apping	The patient taps incorrectly four or more times when the letter "A" is mentioned: combinations of either an error with tapping on a wrong letter and/or a failure to tap on letter "A."	
References	A.	The Montreal Cognitive Assessment: MoCA© 2003 to 2010 (need to secure written permission for research purposes)		
	В.	Adapted from: Confusion Assessment Method for the ICU (CAM-ICU): The CAM-ICU is a delirium monitoring instrument for ICU patients. ** Copyright © 2002, E. Wesley Ely, MD, MPH and Vanderbilt University, all rights reserved		
	C.	Vanderbilt University Medical Center website. CAM-ICU Training Manual and Instructional Video. Accessed February 21, 2013 from http://www.mc.vanderbilt.edu/icudelirium/index.html. © 2013, Holm-Raina-Balouris-Rittenberger-Rogers & Callaway, All Rights Reserved		

### Table 1.4 Second Level Descriptors for the Short-term Memory Domain

#### Administration:

The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: "This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them." [Mark a check in the allocated space for each word the subject produces for Trial 1.]

Trial 1 Trial 2	Not Scored	Train	Egg	Hat	Chair	Blue
Trial 2	Trial 1					
	Trial 2					

When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a *second* time with the following instructions: "I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time." Put a check in the allocated space for each word the subject recalls after the second trial. (see Trial 2 above) At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, "I will ask you to recall those words again at the end of the test."

Scoring: No points are given for Trials One and Two. Scoring is based on the delayed recall trial, which will be on the last page, page 13.

1.	5 words recalled	Able to recall all 5 words.		
2.	4 words recalled	Able to recall 4 words.		
3.	3 words recalled	Able to recall 3 words.		
4.	2 words recalled	Able to recall 2 words.		
5.	1 or no words recalled	Able to recall 1 word or unable to recall any		
words.				
References MoCA: The Montreal Cognitive Assessment© 2003 to 2010. (need to secure written permission for research purposes)				
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### Table 1.5 Second Level Descriptors for the Motor Domain

Gross screening of motor weakness of the upper extremity (UE) and lower extremity (LE) is the "drift test." "Drifting" will occur if one (or more) limbs are weak.				
Administration:				
	Begin with <b>UE only:</b> In a conscious patient, have the patient hold his/her arms outward at 90 degrees from the body with palms facing up. The examiner instructs the patient to: "Close your eyes and hold for 10 seconds." Observe for drift in <i>each</i> arm.			
	Proceed to <b>LE:</b> In a conscious patient, the examiner places his/her hand at approximately 30 degrees above the patient's legs and says to the patient: "I want you to lift your right leg to my hand and hold it for 5 seconds." Observe for drift. Repeat instructions with left leg.			
1.	Drifting observed in 0 limbs.			
2.	Drifting observed in 1 limb.			
3.	Drifting observed in 2 limbs.			
4.	Drifting observed in 3 limbs.			
5.	Drifting observed in 4 limbs/Does not move limbs.			
Reference	Adapted from the National Institutes of Health's Stroke Scale: Rev 10/1/2003.			
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### **Table 1.6 Second Level Descriptors for the Fatigue Domain**

Administration:

The examiner asks the patient: "How would you respond to the following statement: 'I feel no fatigue at all.' Do you:

(1) Strongly agree

(2) Strongly disagree,

Or (3) Somewhere in between?"

1.	Strongly agree	"I strongly agree with the statement: I feel no fatigue at all."				
2.	Agree	If the patient responds "Somewhere in				
3.	Neither disagree nor agree	between," offer the following				
4.	Disagree three responses: (2)					
5.	Strongly disagree with the statement: I feel no fatigue at all."					
Reference	Adapted from: ASCPRO Recommendations for the assessment of fatigue as an outcome in clinical trials. Barsevick AM, Cleeland CS, Manning DC, O'Mara AM, Reeve BB, Scott JA, and Sloan JA. <i>Journal Pain Symptom Manage</i> . Author manuscript; available in PMC 2011 June 1. Published in final edited form as: <i>J Pain Symptom Manage</i> . 2010 June; 39(6): 1086–1099. PMCID: PMC2909842 NIHMSID: NIHMS207733 doi: 10.1016/j.jpainsymman.2010.02.006					

### **Table 1.7 Second Level Descriptors for the Mood Domain**

Administration:

The Examiner asks the patient: "How would you respond to the following statement: 'I feel positive and hopeful.' Do you:

- (1) Strongly agree,
- (2) Strongly disagree,
- or
- (3) Somewhere in between?"

1.	Strongly agree	If the patient responds "Somewhere in between," offer the following three responses:
2.	Agree	(2) Agree
3.	I neither agree nor disagree	<ul><li>(3) Neither agree nor disagree</li><li>(4) Disagree</li></ul>
4.	Disagree	
5.	Strongly disagree	"I strongly agree with the statement: I feel positive and hopeful."

References	А.	Kroenke K, Spitzer RL. The PHQ-9: a new depression and diagnostic severity measure. Psychiatric Annals. 2002;32: 509-521.
	B.	Elderon L, Smolderen KG, Na B, Whooley MA. Accuracy and prognostic value of American Heart Association: Recommended depression screening in patients with coronary heart disease: data from the Heart and Soul Study. Circ Cardiovasc Qual Outcomes. 2011. Sep;4(5):533-40. doi: 10.1161/CIRCOUTCOMES.110.960302. Epub 2011 Aug 23.

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# Table 1.8 Second Level Descriptors for the Basic Activities of Daily Living (BADLs) Domain

	er records th	e CURRENT level of independence in basic activities of daily living (BADLs). It may the OccupationalTherapy notes in the patient's chart.	
		Basic Activities of Daily Living (BADLs) Four basic human activities: Feeding, dressing, transferring and toileting	
1.	Independent in 4/4 (feeding, dressing, transferring and toileting).		
2.	Independent in 3/4 (feeding, dressing, transferring or toileting).		
3.	Independent in 2/4 (feeding, dressing, transferring or toileting).		
4.	Independent in 1/4 (feeding, dressing, transferring or toileting).		
5.	0/4: Not independent in any BADLs.		
References	А.	Katz S, Akpom, CA. Index of ADL. Medical Care. 1976;14(5 Suppl):116-8.PMID:	
	В.	Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. The Gerontologist. 1969;9(3 Part 1):179-186 PMID:5349366	
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#### **Table 1.9 Second Level Descriptors for the Social Support Domain**

7	able 1.9 Second Devel Descriptors for the Social Support Domain			
	Administrat	ion:		
	The examination of the	ner asks the patient to answer the stated questions below or selects the appropriate statements as		
	indicated.	licated.		
	1.	Strong Does your spouse, family member and/or a friend reside with you in the same household?		
	2.	Good Is there an adult child, parent, other family member or friend who is identified a available caregiver?		
	3.	Adequate         Is a family member or friend available if needed?		
	4.	Poor	Are family and/or friends unavailable or unwilling to fulfill a caregiving role?	
	5.	Minimal/ Absent Are you unable to identify any family or friends, or if you can they do not resp to requests for help?		
	Reference	Holt-Lunstad J, Smith, TB, Layton JB. Social relationships and mortality risk: a meta-analytic review <i>PLoS Med.</i> 2010. Jul 27;7(7):e1000316.doi: 10.1371/journal.pmed.1000316.		

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# Table 1.10 Second Level Descriptors for the Instrumental Activities of Daily Living (IADLs) Domain

Administration: *Not* administered in the hospital.

The examiner records the CURRENT level of independence in instrumental activities of daily living (IADLs).

#### Instrumental Activities of Daily Living (IADLs):

Responsible for own medication (medication management), food preparation, shopping and transportation (drives or uses public transportation)

1.	Independent in 4/4 (medication management, food preparation, shopping and transportation).		
2.	Independent in 3/4 (medication management, food preparation, shopping or transportation).		
3.	Independent in 2/4 (medication management, food preparation, shopping or transportation).		
4.	Independent in 1/4 (medication management, food preparation, shopping or transportation).		
5.	0/4: Not independent in any IADLs.		
References	A.	Katz S, Akpom, CA. Index of ADL. Medical Care. 1976;14(5 Suppl):116-8.PMID: 132585	
	В.	Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. <i>The Gerontologist</i> . 1969;9(3 Part 1):179-186 PMID:5349366	
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### Table 1.11 Second Level Descriptors for the Return to Work Domain

Administration: Not administered in the hospital. The examiner asks the patient "Were you employed immediately prior to your cardiac arrest?" Circle response: YES/ NO

# If YES, ask patient for his or her CURRENT work status. If NO, DO NOT COMPLETE THIS ITEM.

1.	Currently working full-time or has returned to pre-CA job.			
2.	Currently working full-time, with restrictions or in a lesser skilled job.			
3.	Currently working part-time in same or lesser skilled job.			
4.	Currently being evaluated for work.			
5.	Currently unable to work due to change in medical status since CA.			
References				
А.	MacEachen E, Clarke J, Franche RL, Irvin E. Systematic review of the qualitative			
	literature on return to work after injury. Scandinavian Journal of Work, Environment & Health. 2006;257-269.			
В.	Krause N, Dasinger LK, Neuhauser F. Modified work and return to work: a review of the literature. Journal of Occupational Rehabilitation. 1998;8(2):113-139.			
С.	Saner H, Borner RE, Kummer-Bangerter A, Schuppel R, von Planta M. Quality of life in long-term survivors of out-of-hospital cardiacarrest. Resuscitation. 2002;53:7-13.			
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### Table 1.4 Second Level Descriptors for the Short-term Memory Domain

#### Administration:

The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: "This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them." [Mark a check in the allocated space for each word the subject produces for Trial 1.]

Not Scored	Train	Egg	Hat	Chair	Blue
Trial 1					
Trial 2					
Irial 2					

When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a *second* time with the following instructions: "I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time." Put a check in the allocated space for each word the subject recalls after the second trial. (see Trial 2 above) At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, "I will ask you to recall those words again at the end of the test."

Scoring: No points are given for Trials One and Two. Scoring is based on the delayed recall trial, which will be on the last page, page 13.

1.	5 words recalled	Able to recall all 5 words.			
2.	4 words recalled	Able to recall 4 words.			
3.	3 words recalled	Able to recall 3 words.			
4.	2 words recalled	Able to recall 2 words.			
5.	1 or no words recalled	Able to recall 1 word or unable to recall any			
	words.				
Reference	References MoCA: The Montreal Cognitive Assessment© 2003 to 2010. (need to secure written permission for research purposes)				
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# **B.1.1 POST SURVEY A: SUMMARY OF REVIEWERS' COMMENT**

#### 1.1 ALERT DOMAIN

Subject	1. Is the Alert Domain named correctly? 0 = No 1 = Maybe 2 = Yes	<ul> <li>2. What is the importance of the Alert Domain for measuring outcomes after a CA?</li> <li>0 = Not important at all</li> <li>1 = Somewhat important</li> <li>2 = Important</li> <li>3 = Very important</li> </ul>	<ul> <li>3. Second Level Descriptors: Do the criteria for each level of the Alert Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	З	2
2	2	3	0
3	2	2	2
4	2	1	1
7	2	2	2
8	2	3	2
10	0	з	0
11	2	3	2
12	1	3	0
14	2	3	2
Mean	1.7	2.6	1.3
Median	2	3	2
Mode	2	3	2

#### Comments:

#### Question 1:

**Subject 10**: The assessment of whether the patient is awake, alert, and appropriately responsive generally requires more than mere tracking to establish. Although other portions of the proposed scale address appropriateness of response, I would favor a Best Indicator which

more stringently requires the patient to attend to conversation rather than merely track.

Subject 12: Alert 'and Arousable' instead?

#### Question 2:

Subject 4: simple to do and complements prior categories so important for implementation

#### Question 3:

Subject 2: What does respond mean?

Subject 4: i don't understand the phrase " to attend" i alson don understand how to comment on "sleep wake cycles" motor activity is 'reflexive' would be hard to reproduce across observers - suggest more clarity through examples if you wish to use this.

Subject 10: No for the reasons above.

**Subject 12**: level 5: too complex. for instance, difficult to assess sleep-wake cycles. would it be more clear to state 'does not attend to noxious stimulus'? The portion beginning with, 'no eye opening....' is useful, i think.:

#### 1.2 DISORGANIZED THINKING DOMAIN

Subject	4. Is the Disorganized Thinking Domain named correctly? 0 = No 1 = Maybe 2 = Yes	<ul> <li>5. What is the importance of the Disorganized Thinking Domain for measuring outcomes after a CA?</li> <li>0 = Not important at all</li> <li>1 = Somewhat important</li> <li>2 = Important</li> <li>3 = Very important</li> </ul>	<ul> <li>6. Second Level Descriptors: Do the criteria for each level of the Disorganized Thinking Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	3	2
2	1	2	1
3	2	1	1
4	0	2	2
7	2	2	2
8	1	2	2
10	0	1	0
11	2	3	2
12	1	3	1
14	1	3	1
Mean	1.2	2.2	1.4
Median	1	2	1.5
Mode	2	3	2

#### Comments:

#### Question 4:

**Subject 4:** this is the only domain which implies the negative - all other domains are either positively phrased (basic activities of daily living, social support) or a symptom without implying a bad outcome (fatigue, mood, motor, fatigue, short term memory, attention) - suggest complex thought processes instead of disorganized thinking.

**Subject 8:** I am not sure that failure to answer these questions represents "disorganized thinking" as opposed to failure to process or basic cognition. I am not sure what the right term would be but I tend to think of disorganized thinking in terms of people who might be able to answer simple yes/no questions but would be disorganized with higher end thought process. All that being said, I am not familiar with the specific literature in this area.

Subject 10: The unwarranted assumption here is that the patient has no component of receptive aphasia, which may be true in ICU delirium in the complete absence of structural brain injury. In patients after CA, however, receptive aphasia may be a component of the problem and disorganized thinking is too vague a term to be useful. Subject 12: would 'organized thinking' be more correct and positive?

Subject 14: Initially not clear what the questions are that this is referring to. Once the questions are stated (page 3), this domain makes better sense.

#### Question 5:

Subject 3: Complex attribute, likely tapping into multiple domains.

Subject 10: Receptive aphasia should be distinguished from failure of executive function. While the domain itself is extraordinarily important, the

totally inadequate test applied sharply diminishes the importance of the domain in the context of this instrument.

#### Question 6:

Subject 2: Will likely be all or none. If you can get just one correct that's not too different from getting 2 or 4. Subject 3: requires intact hearing, cortical function, limb function.

Subject 10: No for the reasons above.

Subject 12: is there a caveat for unable to hear, see, etc.?

**Subject 14**: The questions are similar, thus the ability to answer focuses on fairly specific cognitive processing and may not adequately reflect other aspects of problem solving.

#### **1.3 ATTENTION DOMAIN**

		8. What is the importance of	9. Second Level Descriptors: Do the
	7. Is the	the Attention Domain for	criteria for each level of the Attention
	Attention	measuring outcomes after a	Domain allow for appropriate
	Domain named	CA?	differentiation of a patient's current
	correctly?	0 = Not important at all	status?
	0 = No	1 = Somewhat important	0 = No
	1 = Maybe	2 = Important	1 = Maybe
Subject	2 = Yes	3 = Very important	2 = Yes
1	2	2	2
2	2	1	1
3	1	1	1
4	2	2	1
7	2	2	2
8	2	2	1
10	2	3	1
11	2	2	2
12	2	3	1
14	1	2	2
Mean	1.8	2	1.4
Median	2	2	1
Mode	2	2	1

#### Comments:

Question 7:

Subject 3: requires intact hearing, cortical function and motor.

**Subject 12**: Yes but, could be confusing for a novice with table 1.1 where is uses the term 'attends' **Subject 14**: This is not just attention, but also concentration and a measure of impulsivity.

#### Question 8:

**Subject 2**: Will correlate with and might be redundant to the organized thinking domain **Subject 3**: complex attribute correlation with function unclear

#### Question 9:

Subject 3: complex attribute

**Subject 4:** just wondering how this is scored - is a single rater is noting this on paper in front of the patient while giving out the letters I would suspect it may be anxiety provoking for the patient and may impact on performance - there would have to be a way to score this without antagonizing the patient or affecting his/her

performance. This comment applies to all the domains. **Subject 8**: Probably ok but with the same task required for each measurement (i.e.., tapping to the letter), you

run the risk of having a predominately dichotomous split meaning that either they tap or they do not and will spread the results between 1 and 5.

Subject 10: I would favor Psychomotor Vigilance Testing (of the variety used in fatigue research) as more sensitive and specific index. This has the disadvantage of not being readily available in most clinical settings. The so-called tapping test has the disadvantage, however, that it is hearing and language dependent.
Subject 12: the MoCA allows for a much longer string of letters. CAM-ICU only asks < or > 2 errors, I believe. Asking for 1,2,3,4 or > errors on such a short string may be too detailed.

#### 1.4 SHORT TERM MEMORY DOMAIN

Subject	10. Is the Short Term Memory Domain named correctly? 0 = No 1 = Maybe 2 = Yes	<ul> <li>11. What is the importance of the Short Term Memory Domain for measuring outcomes after a CA?</li> <li>0 = Not important at all</li> <li>1 = Somewhat important</li> <li>2 = Important</li> <li>3 = Very important</li> </ul>	<ul> <li>12. Second Level Descriptors: Do the criteria for each level of the Short Term Memory Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	3	2
2	2	3	2
3	2	2	2
4	2	2	2
7	2	2	2
8	2	3	2
10	2	3	1
11	2	2	2
12	1	3	2
14	2	3	2
Mean	1.9	2.6	1.9
Median	2	3	2
Mode	2	3	2

#### Comments: <u>Question 10:</u> Subject 12: "Delayed Recall" used in the other scales.

#### Question 11: No comments reported

#### Question 12:

Subject 4: we use something like this in daily practice and it is meaningful in my opinion.

**Subject 8**: I think this is ok for differentiation - my only comment on this test is that this will require phonation on the part of the patient which is ok if testing is being done after recovery from the acute period of the arrest. If, however, this is intended to be done while in-hospital, probably consider that there will be some patients with good memory who might have a tracheostomy in place or even an endotracheal tube and therefore cannot speak. How will they be graded? Again, if this is not intended for that population, then not a problem.

**Subject 10**: Same problem as above with receptive aphasia. There should be category for "does not appear to understand either commands involved in the test or the specific words used."

#### 1.5 MOTOR DOMAIN

Subject	13. Is the Motor Domain named correctly? 0 = No 1 = Maybe 2 = Yes	the Motor Domain for measuring outcomes after a CA? 0 = Not important at all	15. Second Level Descriptors: Do the criteria for each level of the Motor Domain allow for appropriate differentiation of a patient's current status? 0 = No 1 = Maybe 2 = Yes
1	2	2	1
2	2	3	2
3	1	2	1
4	2	2	2
7	2	1	0
8	2	3	1
10	2	3	0
11	2	2	1
12	2	2	2
14	2	2	0
Mean	1.9	2.2	1
Median	2	2	1
Mode	2	2	1

#### Comments:

#### Question 13:

Subject 3: what if hemiplegic? what is decreased LOC

#### Question 14:

Subject 4: Used in stroke triage and seems to implementable and reproducible and similar in interpretation across users

**Subject 7**: The problem is that this proposed domain is for STROKE, in which gross motor abnormalities are COMMON. They are exceptionally UNCOMMON following global ischemia/cardiac arrest. At VCU, we are doing extensive 8 hr neuropsych testing on these patients. We are finding FINE MOTOR abnormalities, not gross motor changes. I believe this category needs to test fine motor

#### Question 15:

Subject 3: again, measuring multiple attributes than a single one

Subject 7: See my comments under #14.

Subject 8: drift test for upper extremities is good. I am not as sure about "drift" in the lower extremities as much as capacity to keep the leg up for 5 seconds.

Subject 10: The single test applied is not an adequate assessment of motor function. Furthermore, the neurologic examination after cardiac arrest differs radically from that after stroke because global and focal cerebral ischemia differ radically as mechanisms of injury. Thus, derivation of a test from the NIH Stroke Scale is inappropriate. Subject 11: Will the instructions account for previous injury or disability? If the patient has a know spinal cord injury or previous deficit from a CVA how is that accounted for?

Subject 14: It does not account for spontaneous, semi-purposeful movements in patients who are not able to follow commands. It is too "language based" - the patient must understand the instructions.

#### 1.6 FATIGUE DOMAIN

Subject	16. Is the Fatigue Domain named correctly? 0 = No 1 = Maybe 2 = Yes	<ul> <li>17. What is the importance of the Fatigue Domain for measuring outcomes after a CA?</li> <li>0 = Not important at all</li> <li>1 = Somewhat important</li> <li>2 = Important</li> <li>3 = Very important</li> </ul>	<ul> <li>18. Second Level Descriptors for the Fatigue Domain: Do the criteria for each level of the Fatigue Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	2	2
2	0	0	0
3	2	1	2
4	2	2	0
7	2	0	2
8	1	1	2
10	2	3	1
11	2	3	1
12	2	2	1
14	2	1	1
Mean	1.7	1.5	1.2
Median	2	1.5	1
Mode	2	2	2

#### Comments:

Question 16:

Subject 2: It really is "can you answer a question"

**Subject 8**: I am not as sure of the importance of fatigue for in-hospital patients and perhaps even discharged patients in the early period after cardiac arrest; at least probably not as important as some of the other domains

#### Question 17:

Subject 1: sounds more like a health-related quality of life question

Subject 3: I don't recognize or recall fatigue as being a common compliant among survivors of CA Subject 8: see previous answer

Subject 14: Fatigue can be caused by a large number of factors, not specific enough.

#### Question 18:

Subject 2: It is a "can you answer a question" item, and there is no response level for people who cannot do so Subject t 4: the middle category is too confusing - somewhere in between is appropriate for patients - suggest just leaving it at that or alternatively providing all 5 categories initially including a neutral category for sometimes I feel tired and other times I am energetic as the feeling of fatigue may not be constant.

**Subject 10:** This set of questions does not adequately distinguish between acute fatigue and chronic fatigue, nor does it distinguish between fatigue of central origin (which is the focus of the CPC) and fatigue from extracranial causes (which is the focus of the OPC). It also fails to assess fatigue as a consequence of chronic pain, disordered sleep, or depression. In this sense, it differs little from the general question "How are you feeling today?"

**Subject 11:** Is there a difference between a persons perception of fatigue and their limitation at performing tasks related to fatigue?

Subject 12: concerned about the 'double negative' asking patients if they agree or disagree with a negative statement (I feel no fatigue at all). I am not up to date on this literature. It seems that a patient could misinterpret.Subject 14: This is a very subjective, non-specific measure.

#### 1.7 MOOD DOMAIN

Subject	19. Is the Mood Domain named correctly? 0 = No 1 = Maybe 2 = Yes	20. What is the importance of the Mood Domain for measuring outcomes after a CA? 0 = Not important at all 1 = Somewhat important 2 = Important 3 = Very important	<ul> <li>21. Second Level Descriptors: Do the criteria for each level of the Mood Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	3	1
2	1	0	0
3	2	2	2
4	2	2	0
7	1	2	2
8	2	1	1
10	2	2	0
11	2	3	2
12	2	3	2
14	2	1	1
Mean	1.8	1.9	1.1
Median	2	2	1
Mode	2	2	2

#### Comments:

Question 19: No comments reported

#### Question 20:

Subject 7: At VCU, we are finding (as expected) significant mood changes in these patients, so it is an appropriate measure from our perspective. However, we are finding a DIFFERENT pattern on hospital discharge vs. at 2 months. Early we are seeing anxiety relating to inability to recall events of the arrest and early hospital treatment (our psychiatrists have termed this "reverse PTSD" in which the "missing time" causes anxiety similar to what occurs in regular PTSD when a traumatic event has occurred) resulting in "flock back behavior" in which they return to the ICU and ask for a tour so they can reconnect with what has occurred. Later we are seeing significant IMPULSIVITY as well.

**Subject 8**: I think mood is important but they way this question is phrased, I selected "somewhat important" because the question is open-ended without a time period and might simply reflect the day of which this testing is provided rather than overall good feeling about their current condition. Could the question be rephrased in some way that it quantifies an overall feeling as opposed to at that time point - for example, "I feel positive and hopeful" but with the responses being "Most of the time", "some of the time", blah blah.

Subject 14: Multiple factors may contribute to mood disorders, this may not reflect a direct CA outcome.

#### Question 21:

Subject 1: unsure what this will tell us
Subject 2: If you can respond and say that you feel depressed, you have already had a good outcome considering that you were already dead!
Subject 4: same comments as per fatigue
Subject 7: See #20
Subject 10: I would favor a more detailed mood assessment tool, such as those used in the ALASCA trial.
Subject 14: Too subjective

## 1.8 BASIC ACTIVITIES OF DAILY LIVING DOMAIN

Subject	22. Is the Basic Activities of Daily Living Domain named correctly? 0 = No 1 = Maybe 2 = Yes	the Basic Activities of Daily Living Domain for measuring	<ul> <li>24. Second Level Descriptors: Do the criteria for each level of the Basic Activities of Daily Living Domain allow for appropriate differentiation of a patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	3	1
2	2	3	1
3	2	2	2
4	2	3	2
7	2	2	2
8	2	3	2
10	2	3	1
11	2	3	2
12	2	3	2
14	2	3	2
Mean	2	2.8	1.7
Median	2	3	2
Mode	2	3	2

#### Comments:

Question 22: No comments reported

#### Question 23:

Subject 10: The degree of independence is a key outcome for patients, families, and investigators.

#### **Question 24:**

Subject 1: unsure how this will play out with these CA patient

Subject 2: You better define INDEPENDENT very clearly!

**Subject 10:** It is a little difficult for me to believe that no substantive progress have been made in the assessment of Basic ADLs since the Katz paper cited. I would add a few more items to the list based on more modern work.

#### 1.9 SOCIAL SUPPORT DOMAIN

	25. Is the Social Support Domain named correctly? 0 = No 1 = Maybe	for measuring outcomes after a CA? 0 = Not important at all 1 = Somewhat important 2 = Important	27. Please refer to Second Level Descriptors: Do the criteria for each level of the Social Support Domain allow for appropriate differentiation of a patient's current status? 0 = No 1 = Maybe
Subject	2 = Yes	3 = Very important	2 = Yes
1	2	2	2
2	2	0	0
3	1	1	2
4	2	3	0
7	2	2	2
8	2	0	1
10	2	0	0
11	2	3	2
12	2	3	2
14	2	1	1
Mean	1.9	1.5	1.2
Median	2	1.5	1.5
Mode	2	0	2

#### Comments:

#### Question 25:

Subject 3: what if i need social support but do not have friends or family?

#### Question 26:

Subject 1: This seems like a totally different domain, not intrinsic to the status of the patient

## Subject 3: See above.

Subject 8: I am not sure this is helpful in grading recovery from cardiac arrest if that is the goal. A patient who is homeless or with social issues prior to the arrest could have complete medical recovery from the event but score poorly on the support side of things. However, scoring poorly on social support seems to have little to do with the recovery that an individual has from an arrest.

Subject 14: This is not directly related to the affects of the CA. This is related more to psychological condition after the event.

#### Question 27:

Subject 2: This is irrelevant

Subject 4: the highest level goes for proximity i.e. lives with them whereas this may not imply support - many of us support elder parents very well and do not live with them - I think this top category should be does the individual identified by you as the best caregiver reside with you implying that post arrest it is understood they will need immediate support 24-7 by a high quality caregiver to have the best recovery.

**Subject 10:** This IS NOT an assessment of the patient. It is an assessment of the patient's environment. Social and economic circumstances will differ vastly pre-arrest as well as post-arrest. Therefore, by definition, this is neither a valid or nor a reliable assessment of the sequelae of cardiac arrest. This measure has no more role in the assessment of outcome than should pre-arrest income, state of residence, or race and gender for that matter. **Subject 14:** Some people may have support but chose not to use it.

Subject	28. Is the Instrumental Activities of Daily Living Domain named correctly? 0 = No 1 = Maybe 2 = Yes	29. What is the importance of the Instrumental Activities of Daily Living Domain for measuring outcomes after a CA? 0 = Not important at all 1 = Somewhat important 2 = Important 3 = Very important	30. Second Level Descriptors for the Instrumental Activities of Daily Living Domain: Do the criteria for each level of the Instrumental Activities of Daily Living Domain allow for appropriate differentiation of a patient's current status? 0 = No 1 = Maybe 2 = Yes
1	2	3	2
2	2	3	2
3	1	1	1
4	0	3	2
7	2	2	2
8	2	2	2
10	2	3	1
11	2	2	2
12	2	3	2
14	2	3	2
Mean	1.7	2.5	1.8
Median	2	3	2
Mode	2	3	2

## 1.10 INSTRUMENTAL ACTIVITIES OF DAILY LIVING DOMAIN

#### Comments:

#### Question 28:

Subject 3: relationship between BADL and IADL unclear

**Subject 4:** I am not sure what instrumental means and I would have a hard time remembering this domain - perhaps just call it complex activities of daily living to build on basic domain prior.

### Question 29:

Subject 3: see aboveSubject 4: essential for independent living.Subject 10: Again, the degree of independence is a key outcome for patients, families, and investigators.

### Question 30:

Subject 3: overlap with basic ADL. Subject 10: This is an OK start, but it is difficult to believe that no progress has been made since Lawton.

#### 1.11 RETURN TO WORK DOMAIN

Subject	31. Is the Return to Work Domain named correctly? 0 = No 1 = Maybe 2 = Yes	<ul> <li>32. What is the importance of the Return to Work Domain for measuring outcomes after a CA?</li> <li>0 = Not important at all</li> <li>1 = Somewhat important</li> <li>2 = Important</li> <li>3 = Very important</li> </ul>	<ul> <li>33. Second Level Descriptors: Do the criteria</li> <li>for each level of the Return to Work Domain</li> <li>allow for appropriate differentiation of a</li> <li>patient's current status?</li> <li>0 = No</li> <li>1 = Maybe</li> <li>2 = Yes</li> </ul>
1	2	3	2
2	2	1	2
3	2	1	2
4	2	3	0
7	2	2	2
8	2	1	1
10	1	3	1
11	2	2	1
12	2	З	1
14	2	3	2
Mean	1.9	2.2	1.4
Median	2	2.5	1.5
Mode	2	3	2

Comments:

Question 31:

Subject 10: There is a huge difference between having a job, and returning to your pre-arrest job as a doctor, lawyer, or rocket scientist.

Question 32:

Subject 3: what if patient retired before CA?

Subject 4: speaks to societal impact of recovery.

Subject 8: I think it is important to know if someone has the 'capacity' to return to work though I wonder if this question answers that component. In other words, this question would be answered with the lowest score by an unemployed individual even if they can work. The question attempts to differentiate this slightly I think by asking if a job was held prior to the event so maybe this would cover it but I am not sure - wonder if there could be a way to examine capacity to return to work...

Subject 10: As Ake Grenvik is fond of saying, a successful resuscitation returns the patient to taxpayer status (assuming that was their pre-arrest status).

#### Question 33:

Subject 4: i am not convinced that full time with restrictions or part time equates to full time in a lesser skilled job - example - a neurosurgeon who returns to the operating room 3 days a week with an assistant assigned should be scored higher as it speaks to a full recovery over the same individual taking a part time job working starbucks and using this scale - both would select 3.

Subject 7: Not appropriate for this group of questions, but since the survey does not ask for what is missing, I will state my concerns here. We are finding significant defects in executive function, visuospatial, and long-term memory (in addition to short-term memory which is most affected) domains early. These can be tested quickly and easily using the RBANS scale. Suggest you consider adding these elements.

Subject 8: may reflect someone's capacity to get a full or part time job as opposed to their capacity to work a full or part time job.

Subject 10: I would reword Item 1 to read "Currently working fulltime at exactly the same job as pre-CA." Subject 11: How is this modified for persons working in the home or retired?

Subject 12: should there be a qualifier if not employed prior instead of giving a 6?

**OVERALL COMMENT:** Subject 1\*\* OVERALL - surprised not more emphasis on Ambulation and Speech my answers may have been submitted twice.

## APPENDIX C

## SURVEY B COMMENTS

Custom Data	Should the Alert Domain be kept as described?	Please tell us why you would like to delete this domain.	Please suggest additional modifications, if any.
3	Yes		
1	Yes		
4	Yes		
10	Yes		none
0	Yee		By 'orient', you do not mean oriented to any time or
9	Yes		place, just to examiner, correct?
8	Yes		none
7	Yes		
2	Yes		
6	Yes		
5	Yes		
	Yes=10		

Alert Domain COMMENTS FROM EXPERT PANEL TO SURVEY B (JULY 2013 CPC-E)

Logical Thinking Domain COMMENTS FROM EXPERT PANEL TO SURVEY B (JULY 2013 CPC-E)

Custom Data	Should the Logical Thinking Domain be kept as described?	Please tell us why you would like to delete this domain.	Please suggest additional modifications, if any.
3		too abstract	
1	Yes		
4	Yes		
10	Yes		none
9	Yes		
8	Yes		none
7 2 6 5	Yes Yes Yes	redundant	These questions are really more a test of long term memory and simple language than real tests of logical thinking. Given that the stated purpose of the CPC-E is as a screening tool for more detailed testing (rather than the original purpose of the CPC, which was to serve as an outcome measure for both humans and large animals), this set of questions may be OK.
	Yes = 8	No = 2	

APPENDIX D

## FINAL CPC-E IMPAIRMENT AND DISABILITY DOMAINS

		ASSESSED PRIOR TO DISCHARGE							ASSESS	SED POST DISCHARGE	
		1.1	1.2	13	1.4	15	1.6	1.7	1.8	19	1.10
Domain Levels		Alert	Logical Thinking	Attention	Short Term Memory	Motor	Basic Activities of Daily Living (BADLs)	Mood	Fatigue	Complex Activities of Daily Living (CADLs)	Return to Work
Best Indicator	1	Spontaneously orients or responds to person entering room	Correctly answers all 4 questions	No errors	4 words recalled	Ambulates without assistance	Independent in 4/4 (eating, dressing, transferring and toileting)	I feel positive and hopeful most of the time	I feel fatigued none of the time	Independent in 4/4 (medication management, food preparation, shopping and transportation)	Currently performing 100% pre CA <sup>\$</sup> work tasks <sup>\$6</sup>
	2	Requires only verbal stimulus to orient or respond to observer	Correctly answers 3/4 questions	1 error	3 words recalled	Ambulates with assistance	Independent in 3/4 (eating, dressing, transferring or toileting)	I feel positive and hopeful some of the time	I feel fatigued rarely	Independent in 3/4 (medication management, food preparation, shopping or transportation)	Currently performing 75% pre CA <sup>§</sup> work tasks <sup>66</sup>
	3	Requires light touch and verbal stimulus to orient or respond to observer	Correctly answers 2/4 questions	2 errors	2 words recalled	Needs assistance to stand	Independent in 2/4 (eating, dressing, transferring or toileting)	I feel positive and hopeful occasionally	I feel fatigued occasionally	Independent in 2/4 (medication management, food preparation, shopping or transportation)	Currently performing 50% pre CA <sup>§</sup> work tasks <sup>66</sup>
	4	Requires noxious stimulus to orient or respond to observer	Correctly answers 1/4 questions	3 errors	1 word recalled	Unable to sit without assistance	Independent in 1/4 (eating, dressing, transferring or toileting)	I feel positive and hopeful rarely	I feel fatigued some of the time	Independent in 1/4 (medication management, food preparation, shopping or transportation)	Currently performing 25% pre CA <sup>§</sup> work tasks <sup>66</sup>
Worst Indicator	5	No response to voice or physical stimulation; may observe abnormal reflex or posturing	0/4: Does not answer any question correctly	4 errors	No words recalled	Activity limited to moving in bed	0/4: Not independent in any BADLs	I feel positive and hopeful none of the time	I feel fatigued most of the time	0/4:Not independent in any CADLs	0%: Currently unable to perform any pre CA <sup>§</sup> work tasks <sup>66</sup>
	6	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported
	7		Not Testable	Not Testable	Not Testable						

Abbreviated Scoring Sheet: Impairment and Disability Domains of the CPC-E

\* Scoring is based on the delayed recall trial (Refer to directions on page 2). SCA: Cardiac Arrest # Includes retiree or homemaker. © 2014, Holm-Raina-Balouris-Rittenberger-Rogers-Callaway, All Rights Reserved.

1.	resp	ntaneously orients or bonds to person ering room	Patient spontaneously orients or responds to observer (i.e., tracks with eyes/turns head toward person entering room).	
2.	Requires only verbal stimulus to orient or respond to observer		Patient requires only verbal stimulus to orient or respond to observer.	
3.	verk	uires light touch and pal stimulus to orient or pond to observer	Patient requires light touch and verbal stimulation to orient or respond to observer.	
4.	to o	uires noxious stimulus rient or respond to erver	Patient requires noxious stimulus to orient or respond to observer.	
5.	No response to voice or physical stimulation; may observe abnormal reflex or posturing		No eye opening or spontaneous speaking. Does not follow commands, and when provoked by a noxious stimulus eyes remain closed. Motor activity is absent or abnormal and reflexive, rather than purposeful or defensive.	
References	A.	Sessler CN, Gosnell M, Grap MJ, Brophy GT, O'Neal PV, Keane KA et al. The Richmond Agitation-Sedation Scale: validity and reliability in adult intensive care patients. <i>Am J Respir Crit Care Med</i> 2002;166:1338-1344.		
	В.	Khan BA, Guzman O, Campbell NL, Walroth T, Tricker J, Hui SL, Perkins A, Zawahiri M, Buck JD, Farber MO, Ely W, Boustani MA. Comparison and agreement between the Richmond Agitation-Sedation Scale and the Riker Sedation-Agitation Scale in evaluating patients' eligibility for delirium assessment in the ICU. <i>Chest</i> . 2012 Jul;142(1):48-54. doi: 10.1378/chest.11-2100.		
	C.	Ely EW, Truman B, Shintani A, Thomason JWW, Wheeler AP, Gordon S et al. Monitoring sedation status over time in ICU patients: the reliability and validity of the Richmond Agitation Sedation Scale (RASS). <i>JAMA</i> . 2003; 289:2983-2991.		
	E.	Jennet B. Review Article: Development of Glasgow Coma and Outcome. <i>Nepal J of Neuroscience</i> . 2005;2:24-28.		
	F.	Plum F, Posner JB. <i>The Diagnosis of Stupor and Coma.</i> 1995, 2nd Ed, FA Davis, Philadelphia. pgs. 4-5.		
	G.	Plum F, Posner JB: <i>The I</i> 4th Ed, FA Davis, Philad	Diagnosis of Stupor and Coma. Contemporary Neurology Series. 2007, elphia, p. 40.	
	H.			

 Table 1.1 Second Level Descriptors for the Alert Domain

## Table 1.2 Second Level Descriptors for the Logical Thinking Domain

Administration: Ask the patient to answer the following 4 questions:\*

1. Will a stone float on water? (Correct answer is "No")

2. Are there fish in the sea? (Correct answer is "Yes")

3. Does one pound weigh more than two? (Correct answer is "No")

4. Can you use a hammer to pound a nail? (Correct answer is "Yes")

If the patient is hard of hearing, deaf or aphasic, attempt the questions in written form. If the patient has a tracheostomy: Thumbs up = Yes; Thumbs down= No.

1.	Cor	Correctly answers all 4 questions.					
2.	Cor	rectly answers 3/4 questions.					
3.	Cor	rectly answers 2/4 questions.					
4.	Cor	rectly answers 1/4 questions.					
5.	0/4: Does not answer any question correctly.						
References	Α.	Adapted from: Confusion Assessment Method for the ICU (CAM-ICU): The CAM-ICU is a delirium monitoring instrument for ICU patients. * Copyright © 2002, E. Wesley Ely, MD, MPH and Vanderbilt University, all rights reserved					
	В.	Ely EW, Inouye SK, Bernard GR, Gordon S, Francis J, May L, Truman B, Speroff T, Gautam S, Margolin R, Hart RP, Dittus R. Delirium in mechanically ventilated patients: validity and reliability of the confusion assessment method for the intensive care unit (CAM-ICU). JAMA. 2001;286(21):2703–2710. doi: 10.1001/jama.286.21.2703					
	C.	Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. Ann Intern Med. 1990;113:941–8.					
	D.	Vanderbilt University Medical Center website. CAM-ICU Training Manual and Instructional Video. Accessed February 21, 2013 from <u>http://www.mc.vanderbilt.edu/icudelirium/index.html</u> .					
		© 2014, Holm-Raina-Balouris-Rittenberger-Rogers-Callaway, All Rights Reserved.					

## Table 1.3 Second Level Descriptors for the Attention Domain

Administration: Say to the patient, "I am going to read you a series of 10 letters. Whenever you hear the letter 'A,' squeeze my hand." \* Read letters from the following list in a normal tone, 3 seconds apart.\*\*

## SAVEAHAART

Errors are counted when patient fails to squeeze on the letter "A" and when the patient squeezes on any letter other than "A."

If the patient is hard of hearing (first check for hearing aide), deaf or aphasic, this domain may not be testable. (Select number 7 under the Attention Domain in Table 1). \*

\* Clinician needs to select a consistent, reproducible response if the patient is unable to squeeze clinician's hand.

1.	No errors with squeezing		The patient correctly squeezes only when the letter "A" is mentioned. (i.e., correctly squeezes 4/4 times when the letter "A" is mentioned)	
2.	1 error with squeezing		The patient squeezes on a wrong letter or fails to squeeze on the letter "A."	
3.	2 errors with squeezing		The patient squeezes on 2 wrong letters and/or fails to squeeze on the letter "A" twice, or a combination of errors.	
4.	3 errors with squeezing		The patient squeezes on 3 wrong letters and/or fails to squeeze on the letter "A" three times, or a combination of errors.	
5.	4 or more errors with squeezing		The patient squeezes on 4 wrong letters and/or fails to squeeze on the letter "A" four times, or a combination of errors.	
References	Α.	Adapted from: Confusion Assessment Method for the ICU (CAM-ICU): The CAM-ICU is a delirium monitoring instrument for ICU patients. **Copyright © 2002, E. Wesley Ely, MD, MPH and Vanderbilt University, all rights reserved.		
	В.	Vanderbilt University Medical Center website. CAM-ICU Training Manual and Instructional		
		Video. Accessed February 21, 2013 from		
		http://www.mc.vanderbilt.edu/icudelirium/index.html.		
	© 2014 Halm Daine Delaurie Dittenhangen Degene Calleman. All Dichte Degenund			

## Table 1.4 Second Level Descriptors for the Short-term Memory Domain

## Administration:

<u>Part 1:</u> Tell the patient, "Listen carefully. This is a memory test. I am going to read a list of words that I want you to remember. I will ask you to repeat these words now and later on, at the end of my visit. When I am through, tell me as many words as you can remember." (*While pausing at least 1 second between each word*), Say: "The words are: **Book, goat, dirt, and hand**. Repeat the words to me." [For each word that is repeated, place a check in the Part 1 box **but do not score**.]

	Part 1	Part 2	Part 3
	(Record but do not	(Record but do not	Completed and scored at the end of your visit
	score)	score)	
Book			
Goat			
Dirt			
Hand			

<u>Part 2:</u> After the subject has recalled all, or as many as words as (s)he can remember, read the list a *second* time with the following instructions: "I am going to read the same list again. Try to remember and tell me as many words as you can. The words are: Book, goat, dirt, and hand. Repeat the words to me." [For each word that is repeated by the patient, place a check in the Part 2 box above **but do not score.**]

Now inform the patient that (s)he will be asked to recall these words again by saying, "I will ask you to recall those words again at the end of my visit."

If the patient has a tracheostomy and you are unable to lip read, ask the patient to write the correct word or

read from the list of words below<sup>\*</sup> and ask for a hand gesture or eye closure: Tell the patient, "Lift your hand (or close your eyes) when you hear the word that I mentioned earlier." While pausing between words, say:

- 1) "Is the correct word: Pen, desk, or book?
- 2) "Is the correct word: Horse, goat or lamb?
- 3) "Is the correct word: Dirt, sand or rock?
- 4) "Is the correct word: Foot, hand or head?

\*List of word options will be on the back of Table 1

Scoring: No points are given for Parts 1 and 2. <u>Scoring is based on the delayed recall trial (Part 3). A prompt</u> will appear on page 12, the last page of this document.

<u>1 AN1 3 (300</u>	cored at the end of your visit					
1.	4 words recalled	Able to recall all 4 words.				
2.	3 words recalled	Able to recall 3 words.				
3.	2 words recalled	Able to recall 2 words.				
4.	1 word recalled	Able to recall 1 word.				
5.	No words are recalled Unable to recall any words.					
Reference	From the most frequently used 1-2-3-4 letter words in the English language:					
	http://www.alphabeticalist.com/9000%20foldera/all1-2-3-4-words.html					

## PART 3 (scored at the end of your visit)

## Table 1.5 Second Level Descriptors for the Motor Domain

Gross screer	ning of motor weakness.	
	on: Check either the nursing, physical therapy or occupational therapy notes. If the patient has a ay, select the highest level of tolerated activity.	
1.	Patient ambulates without assistance. (assistance equals help from another individual)	
2.	Patient ambulates with assistance. (assistance equals help from another individual)	
3.	Patient needs assistance to stand. (assistance equals help from another individual)	
4.	Patient is unable to sit without assistance. (assistance equals help from another individual)	
5.	Patient's activity is limited to moving in bed.	
Reference	Adapted from: Said CM, Morris ME, Woodward M, Churilov L, Bernhardt J. Enhancing physical activity in older adults receiving hospital based rehabilitation: A phase II feasibility study. BMC Geriatr. 2012 Jun 8; 12:26. doi: 10.1186/1471-2318-12-26. PMID:22676723 [PubMed - in process]	

# Table 1.6 Second Level Descriptors for the Basic Activities of Daily Living (BADLs)Domain

## Administration:

The examiner records the CURRENT level of independence in basic activities of daily living (BADLs). Independence is defined as no assistance from another person. *It may be necessary to refer to the nursing and occupational therapy notes in the patient's chart.* 

		Basic Activities of Daily Living (BADLs) Four basic human activities: Eating, dressing, transferring and toileting	
1.	Independent in 4/4 (eating, dressing, transferring and toileting).		
2.	Independent in 3/4 (eating, dressing, transferring or toileting).		
3.	Independent in 2/4 (eating, dressing, transferring or toileting).		
4.	Independent in 1/4 (eating, dressing, transferring or toileting).		
5.	0/4: Not independent in any BADLs.		
References	Α.	Katz S, Akpom, CA. Index of ADL. Medical Care. 1976;14(5 Suppl):116-8.PMID: 132585	
	В.	Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. The Gerontologist. 1969;9(3 Part 1):179-186 PMID:5349366	
	C.	Tamaru, A, McColl, MA, Yamasaki, S. Understanding 'independence': perspectives of occupational therapists. Disabil Rehabil. 2007 Jul 15;29(13):1021-33. PMID:17612987 © 2014. Holm-Raina-Balouris-Rittenberger-Rogers-Callaway. All Rights Reserved.	

## Table 1.7 Second Level Descriptors for the Mood Domain

Administrat	ion: <u>Not</u> administered in the hospital.	
Using the 5 hopeful"	options below, the Examiner asks the patient to complete this sentence: "Today, I feel positive and	
1.	Most of the time.	
2.	Some of the time.	
3.	Occasionally.	
4.	Rarely.	
5.	None of the time.	
Reference	Kroenke K, Spitzer RL. The PHQ-9: a new depression and diagnostic severity measure. <i>Psychiatric Annals.</i> 2002;32: 509-521.	

	Administration: <u>Not</u> administered in the hospital. Using the 5 options below, the Examiner asks the patient to complete this sentence: "I feel fatigued"		
1.	None of the time		
2.	Rarely		
3.	Occasionally		
4.	Some of the time		
5.	Most of the time		
References	Α.	Adapted from: ASCPRO Recommendations for the assessment of fatigue as an outcome in clinical trials. Barsevick AM, Cleeland CS, Manning DC, O'Mara AM, Reeve BB, Scott JA, and Sloan JA. <i>Journal Pain Symptom Manage</i> . Author manuscript; available in PMC 2011 June 1. Published in final edited form as: <i>J Pain Symptom Manage</i> . 2010 June; 39(6): 1086–1099. PMCID: PMC2909842 NIHMSID: NIHMS207733 doi: 10.1016/j.jpainsymman.2010.02.006	
	В.	Norberg EB, Boman K, Lofgren B. Activities of daily living for old persons in primary health care with chronic heart failure. Scandinavian journal of caring sciences 2008;22:203-10.	
	C.	Evangelista LS, Moser DK, Westlake C, Pike N, Ter-Galstanyan A, Dracup K. Correlates of fatigue in patients with heart failure. Progress in cardiovascular nursing 2008;23:12-7.	
	D.	Saner H, Rodriguez EB, Kummer-Bangerter A, R. S, von Planta M. Quality of life in long- term survivors of out-of-hospital cardiac arrest. Resuscitation 2002; 2002:7-13.	
	E.	Appels A, Golombeck B, Gorgels A, de Vreede J, van Breukelen G. Behavioral risk factors of sudden cardiac arrest. Journal of Psychosomatic Research 2000; 48:463-9 © 2014 Holm-Baina-Balouris-Rittenberger-Rogers-Callaway. All Rights Reserved	

## Table 1.8 Second Level Descriptors for the Fatigue Domain

# Table 1.9 Second Level Descriptors for the Complex Activities of Daily Living (CADLs) Domain

Administration: <u>Not</u> administered in the hospital. The examiner asks the patient: "Do you need assistance from another person to manage your medications, prepare your food, shop, drive, or use public transportation?"

The examiner records the CURRENT level of independence in complex activities of daily living (CADLs). Independence is defined as no assistance from another person.

Responsit	ble for d	<u>Complex Activities of Daily Living (CADLs):</u> own medication (medication management), food preparation, shopping and transportation (drives or uses public transportation)	
1.	Independent in 4/4 (medication management, food preparation, shopping and transportation).		
2.	Independent in 3/4 (medication management, food preparation, shopping or transportation).		
3.	Independent in 2/4 (medication management, food preparation, shopping or transportation).		
4.	Independent in 1/4 (medication management, food preparation, shopping or transportation).		
5.	0/4: Not independent in any CADLs.		
References	А.	Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. <i>The Gerontologist.</i> 1969;9(3 Part 1):179-186 PMID:5349366	
	В.	Dunlop, DD, Hughes, SL, Manheim, LM. Disability in activities of daily living: Patterns of change and hierarchy of disability. American Journal of Public Health. 1997;87(3):378-383cn	

## Table 1.10 Second Level Descriptors for the Return to Work Domain

Administration: <u>Not</u> administered in the hospital. The examiner asks the patient "Were you employed, a retiree, or a full-time homemaker, immediately prior to your cardiac arrest?"

Circle response: YES/ NO

If YES, ask patient for his or her CURRENT status: "If so, what percent of your pre-CA work tasks are you currently able to perform?"

Select the lower score if a patient gives you a number between one of the 5 options. For example, if the patient reports "About ~30%," select 25% (number 4).

1.	100%	Currently performing 100% of pre-CA work tasks (includes retiree/homemaker).
2.	75%	Currently performing 75% of pre-CA work tasks (includes retiree/homemaker).
3.	50%	Currently performing 50% of pre-CA work tasks (includes retiree/homemaker).
4.	25%	Currently performing 25% of pre-CA work tasks (includes retiree/homemaker).
5.	0%	Currently unable to perform any of pre-CA work tasks (includes retiree/homemaker).
References	A.	MacEachen E, Clarke J, Franche RL, Irvin E. Systematic review of the qualitative literature on return to work after injury. <i>Scandinavian Journal of Work, Environment &amp; Health.</i> 2006;257-269.
	В.	Krause N, Dasinger LK, Neuhauser F. Modified work and return to work: a review of the literature. <i>Journal of Occupational Rehabilitation</i> . 1998;8(2):113-139.
	C.	Saner H, Borner RE, Kummer-Bangerter A, Schuppel R, von Planta M. Quality of life in long-term survivors of out-of-hospital cardiac arrest. <i>Resuscitation</i> . 2002;53:7-13.

## If NO, DO NOT COMPLETE THIS ITEM.

## Table 1.4 Second Level Descriptors for the Short-term Memory Domain

## Administration:

"Earlier in my visit, I asked you to remember a few words. Please tell me as many words as you can remember." Place a check in the space next to each word in Part 3 Delayed Recall:

If the patient has a tracheostomy and you are unable to lip read, ask the patient to write the correct word or read from the list of words below and ask for a hand gesture or eye closure: Tell the patient, "Lift your hand (or close your eyes) when you hear the word that I mentioned earlier." While pausing between words, say:

- 1) "Is the correct word: Pen, desk or book?
- 2) "Is the correct word: Horse, goat or lamb?
- 3) "Is the correct word: Dirt, sand or rock?
- 4) "Is the correct word: Foot, hand or head?

## List of word options will be on the back of Table 1.

Scoring: No points are given for Parts One and Part Two. Scoring is based on the Part 3 Delayed Recall trial only. Record below and refer to the 1-5 scoring levels below.

	Part 3: Delayed Recall (Score and Record)
Book	
Goat	
Dirt	
Hand	

1.	4 words recalled	Able to recall all 4 words.	
2.	3 words recalled	Able to recall 3 words.	
3.	2 words recalled	Able to recall 2 words.	
4.	1 word recalled	Able to recall 1 word.	
5.	No words are recalled	Unable to recall any words.	
Reference	From the most frequently used 1-2-3-4 letter words in the English language : http://www.alphabeticalist.com/9000%20foldera/all1-2-3-4-words.html		
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