Development and psychometric properties of the Patient-Head Injury Participation Scale (P-HIPS) and the Patient-Head Injury Neurobehavioral Assessment Scale (P-HINAS): patient and family determined outcomes scales

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Objective: To develop a measure to assess post-acute outcome following from traumatic brain injury (TBI) with particular emphasis on the emotional and the behavioral outcome. The second objective was to assess the test–retest reliability, internal consistency, and factor structure of the newly developed patient version of the Head Injury Participation Scale (P-HIPS) and Patient-Head Injury Neurobehavioral Scale (P-HINAS).

Method: Thirty-two TBI individuals and 27 carers took part in in-depth qualitative interviews exploring the consequences of the TBI. Interview transcripts were analyzed and key themes and concepts were used to construct the 49-item P-HIPS. A postal survey was then conducted on a cohort of 113 TBI patients to 'field test' the P-HIPS and the P-HINAS.

Results: All individual 49 items of the P-HIPS and their total score showed good test–retest reliability (0.93) and internal consistency (0.95). The P-HIPS showed a very good correlations with the Mayo Portland Adaptability Inventory-3 (MPAI-3) (0.87) and a moderate negative correlation with the Glasgow Outcome Scale-Extended (GOSE) (–0.51). Factor analysis extracted the following domains: 'Emotion/Behavior,' 'Independence/Community Living,' 'Cognition' and 'Physical'. The 'Emotion/Behavior' factor constituted the P-HINAS, which showed good internal consistency (0.93), test–retest reliability (0.91) and concurrent validity with MPAI subscale (0.82).

Conclusions: Both the P-HIPS and the P-HINAS show strong psychometric properties. The qualitative methodology employed in the construction stage of the questionnaires provided good evidence of face and content validity.

Keywords: traumatic brain injury, neurobehavioral outcome measure, P-HIPS, P-HINAS, psychometrics

Introduction

Traumatic brain injury (TBI) constitutes a major public health problem with the yearly incidence rate ranging between 1620 and 3489 per 100,000 (UK and US population) (see Deb 1999). Despite recent medical advances, a large number of patients with TBI continue to suffer from long term consequences (Moscato et al 1994). There have been many longitudinal studies of patients with TBI; some of the recent ones include Cifu et al (1997), Hellawell et al (1999), Kersel et al (2001), Levin et al (1990), and Novack et al (2001). Outcome studies show that TBI can lead to individuals experiencing chronic physical and mental health difficulties (Deb et al 1998, 1999a, 1999b; Thornhill et al 2000) that often include hidden psychological, cognitive, and behavioral problems (Deb et al 1999a, 1999b; Stilwell et al 1999;

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Thornhill et al 2000). These problems have implications for the individuals in terms of their ability to work, maintain family relationships, and take part in social activities (Deb et al 1999a). These problems can have a serious impact on the quality of life not only for the TBI individuals, but also for their families (Oddy et al 1978; Brooks et al 1986; Prigatano and Schacter 1991). Although initial severity of brain injury is an important prognostic factor for the long term outcome many recent studies including those of Chiang et al (2003), Kreutzer et al (2003), Franulic et al (2004), Slewa-Younan et al (2004), and Wilde et al (2004) have highlighted the influence of psychosocial and many demographic variables on the outcome of TBI.

The influence of cognitive factors in the overall functional outcome following TBI has been emphasized in recent studies by Rassovsky et al (2006a, 2006b). The authors found that neurocognitive deficits showed a stronger association with functional outcome than emotional and behavioral difficulties among 87 patients with moderate to severe TBI (Rassovsky et al 2006a). Within the neurocognitive deficits, frontal lobe deficits, particularly manifested through impaired speed of information processing, was a more important prognostic factor for social and occupational functioning than other problems such as verbal memory problem (Rassovsky et al 2006b). Similarly, the role of emotional adjustment as a coping strategy to improve psychosocial rehabilitation following TBI was emphasized in a recent study by Anson and Ponsford (2006).

Despite the existence of a plethora of outcome measures following TBI, it has been argued that there is a lack of established or well validated measures to measure post-acute outcome in this population (Fleminger and Powell 1999; Stilwell et al 1999). The psychometric properties of many of the existing scales are poor or have not been properly assessed (Hall 1992; Hart and Hayden 1986; Lezak 1993; Wade 1998). At present most available outcome measures used in this population are devised by professionals with little or no input from TBI individuals and their families.

Also, despite the prominence of behavioral and emotional problems in the post-acute stage of TBI, proper assessment scales for these domains in the post acute stage are lacking. The neurobehavioral scale devised by Levin et al (1987) has been validated among people with TBI, but includes items related to both psychiatric symptoms such as hallucinations and delusions, and neurobehavioral symptoms such as lack of motivation. Similarly, the Neuropsychiatric Inventory (NPI) (Cummings et al 1994), which is designed for neurodegenerative disorders, also combines items relating to psychiatric symptoms with behavioral and emotional symptoms. Both these scales use symptoms-based ratings.

The aim of the current study was to develop a post-acute outcome measure with items generated from unconstrained accounts of the consequences of the TBI from the TBI individuals and their families, with particular emphasis on producing a neurobehavioral scale.

Method

Stage 1: Development of the questionnaire: Qualitative study

Qualitative information regarding perceptions of the consequences of TBI was gathered from a group of 59 individuals; 32 TBI patients and 27 family, friends, or paid carers. Potential interviewees were identified via TBI services in the Cardiff area in Wales, UK. Actual level of disability was subsequently determined using the Glasgow Outcome Scale. Purposive sampling was used in order to get views from individuals with a mix of disability levels according to the Glasgow Outcome Scale (Jennett and Bond 1975), and a mix of gender and age at injury. All interviews were conducted at least one year post injury.

Semi-structured interviews that focused on narratives of personal experience were conducted with individuals and their carers. Interviewees were asked to describe their lives prior to the injury and then to describe the consequences of TBI that had been most important to them. Open-ended questions were designed to collect as much information as possible on the impacts of the injury on the lives of patients and their carers, and to identify those areas, which interviewees considered to be particularly significant. These interviews were all recorded onto minidisk and transcribed in full.

Initially, a simple concordance program was used (a) to identify a list of the most frequent terms used in the interviews, and (b) to highlight differences of word use in patient and carer interviews. Following that, the interview transcripts were read repeatedly in combination with listening to the recorded interviews. The coding process was akin to that described by Strauss and Corbin (1990), and was later facilitated by the use of NUDI*ST (N5) (Qualitative Solutions and Research Pty Ltd, Melbourne, Australia), a qualitative software data analysis package (Richards 2000). The key categories were then used as nodes for use. The themes and topics derived from this analysis were later refined and set as questions for inclusion in the questionnaire. On the basis of information gathered in the first stage, 49 questions were collated for inclusion in the draft Patient-Head

Injury Participation Scale (P-HIPS). These questions were worded by using language and phrases taken directly from the transcripts wherever possible. The aim was to collate a minimum number of questions under a minimum number of dimensions and to create a questionnaire, which should not take long to complete. From subsequent use of the P-HIPS among the clinic population we found that both patients and carers found the question on sexual relationships too sensitive to answer, therefore we would advise exclusion of this item for day to day use of the scale.

The same ranking system (eg, '0' = not a problem, '1' = mild problem, '2' = moderate problem, and '3' = serious problem) has been used for all questions. The emphasis was on assessing 'participation' and thereby the impact of each symptom on the individual rather than simply rating the presence of symptoms.

Before finalizing, the P-HIPS was sent for comment to all the original sample of TBI patients who took part in the qualitative stage of the study, their carers, and some professionals working with TBI patients. In the light of the comments and feedback received, the draft version of the questionnaire underwent minor revisions in content. It was also decided that the questionnaire should be printed in large font in landscape format, as this was the preferred format of most of the TBI individuals. The large font was designed to help those with visual impairments to read the questionnaire. The formatting reduced the amount of information on the page, which was found beneficial by individuals with memory and concentration difficulties. We checked whether participants were consistently missing any particular item or providing the same answer. We also checked for possible floor or ceiling effect from the spread of overall scores from all participants.

Stage 2: Field testing of the questionnaire: Quantitative study

The P-HIPS was field-tested on a cohort of 113 TBI patients. Inclusion criteria were as follows: a) Patients must have experienced TBI at least one year prior to taking part in the study, and b) Patients must have had their TBI whilst aged over 16. Participants were recruited from TBI services nationwide in the UK. This was done in the anticipation that those patients who are in touch with various service agencies will experience post-acute consequences. All participants were asked to complete the P-HIPS by post, in conjunction with a postal version of the Glasgow Outcome Scale-Extended (GOSE) (Wilson et al 2002) and Mayo Portland Adaptability Inventory-3 (MPAI-3) (Malec et al 2000). Once these were returned the P-HIPS was sent out again. Eighty-nine patients sent the completed P-HIPS back twice, which helped to calculate the test retest reliability of the P-HIPS.

The West Midlands Multi-centre Research Ethics Committee (MREC), UK, granted ethical approval for this study. Consent forms, information sheets, and self-addressed envelopes were distributed to interested individuals via TBI services nationwide in the UK, primarily through regional Headways (a charity dedicated to providing services and information to TBI individuals). Participants who returned their consent forms to the research team were sent the P-HIPS along with the GOSE and the MPAI-3 to complete.

Results

Only the data relating to the P-HIPS and the Patient – Head Injury Neurobehavioral Assessment Scale (P-HINAS) are presented in this paper. The data related to the carer version, namely the Carer – Head Injury Participation Scale (C-HIPS) and the Carer – Head Injury Neurobehavioral Assessment Scale (C-HINAS), are presented in a separate paper (Deb et al 2007).

Psychometric properties

Construct validity

We examined the construct validity of the scale by using a factor analysis method (Field 2005). Principal components analysis using varimax rotation was conducted to explore the factor structure of the 49 scored items of the questionnaire. The Keiser Meyer Olkin statistic for sampling adequacy was 0.87, suggesting that if factor analysis is conducted, the factors extracted will account for substantial amount of variance. Scree plot analysis identified four factors for rotation, accounting for 52.84% of the total variance (see Table 1). As shown in Table 1, Factor 1 is the biggest factor, and consists of 20 items related to emotion and behavior. The items of this factor are put in a separate scale, P-HINAS. Factor 2 is the second biggest factor, and consists of 13 items relating to independence and community living. These include preparing meals, travel, and lack of independence. Factor 3 consists of 9 cognitive items. Factor 4 is the smallest and consists of 7 items related to physical handicap.

Internal consistency

Cronbach's alpha was used to measure the internal consistency of the P-HIPS. Analyses revealed a coefficient of 0.96 for the total score. The coefficients of the four P-HIPS domains are 0.94 for the P-HINAS, 0.91 for

Table 1 Factor analysis of the P-HIPS

		Emotion / Behaviour (P-HINAS)	Independence / Community living	Cognition	Physical
	Eigen value	**16.75**	**4.01**	**2.76**	**2.38**
	% variance	**34.18**	**8.18**	**5.63**	**4.85**
	Cronbach's α coefficient	**0.93**	**0.91**	**0.89**	**0.81**
28	Temper / irritable	0.696			
29	Social behavior	0.665			
31	Lack of motivation	0.679			
32	Difficulty with feeling tired / fatigued	0.434			0.463
33	Difficulty with sleep	0.415			
34	Feeling scared	0.670			
35	Paranoia	0.716			
36	Feelings of loss	0.716			
37	Frustration	0.677			
38	Worrying about things	0.685			
39	Crowds	0.584			
40	Loss of confidence	0.598			
41	Depression	0.800			
42	Arguments with close family	0.649			
43	Reduced interest in family	0.442			0.470
44	Strain on family	0.495			
46	Don't see friends as often as would like	0.524			
47	Lack of good friends	0.652			
48	Lack of understanding from others	0.442			
50	Lack of people to talk to	0.588			
09	Difficulty with mobility		0.724		
10	Lack of independence		0.782		
11	Sports activities		0.675		
12	Leisure activities		0.489		
13	Preparing meals		0.696		
14	Travel		0.820		
16	Shopping		0.589		
17	Physical self-care		0.498		
18	Local environment		0.806		
23	Difficulty with balance		0.620		
24	Physical appearance		0.450		
25	Difficulty with eyesight		0.426		
45	Sex life		0.472		
02	Group conversations			0.540	
03	Difficulty reading			0.465	
04	Difficulty speaking			0.371	
05	Difficulty with recent memory			0.653	
06	Difficulty with concentration			0.737	
07	Difficulty with planning / organisation			0.693	
08	Difficulty with multi-tasking			0.580	
15	Dealing with money			0.683	
30	Safety risks			0.448	
01	Difficulty hearing				0.586
19	Difficulty with headaches				0.564
20	Pain other than headaches				0.467
21	Difficulty with epilepsy or fits				0.207
22	Difficulty with feeling dizzy / faint				0.622
26	Difficulty with buzzing noise in the ear				0.526
27	Difficulty with sensitivity to noise/light				0.715

Abbreviations: P-HIPS, Patient-Head Injury Participation Scale (P-HIPS).

'Independence/Community Living', 0.89 for 'Cognition', and 0.81 for 'Physical'.

Criterion-related validity – GOSE

The correlation between the P-HIPS's total scores and the GOSE category ratings was –0.51 ($p < 0.001$, N = 100). The GOSE category ratings spanned a wide range of scores on the patient questionnaire.

Criterion-related validity – MPAI-3

The correlation between the P-HIPS's total scores and the MPAI-3's total scores was 0.87 ($p < 0.001$, N = 111). Table 2 illustrates the comparisons between the domains of the P-HIPS and those of the MPAI-3. The correlations between the domains of both questionnaires were all significant (see Table 2), however correlations above 0.7 were found between the P-HINAS and the MPAI-3 'Pain/Emotion' Score (r = 0.82), the P-HIPS 'Independence/Community Living' scale and the MPAI-3 'Social Participation' Score (r = 0.77). The P-HIPS 'Cognition' scale correlated best with the MPAI-3 'Physical/Cognition' Score (r = 0.73), whereas the P-HIPS 'Physical' scale had its highest correlations with the MPAI-3 'Pain/Emotion' Score (r = 0.65). The MPAI-3 Total Score correlated significantly with all four domains of the P-HIPS (r = 0.60–0.76, $P < 0.01$).

Test–retest reliability

The P-HIPS total scores for the 49 items showed a test–retest reliability of 0.93 ($p < 0.001$, N = 89), with individual item's reliability ranging from 0.60 to 0.91 ($p < 0.001$, N = 85–89). The test–retest reliability of the four domains were 0.91 ($p < 0.001$, N = 89) for the P-HINAS, 0.91 ($p < 0.001$, N = 89) for 'Independence/Community Living', 0.88 ($p < 0.001$, N = 89) for 'Cognition', and 0.93 ($p < 0.001$, N = 89) for 'Physical'.

Discussion

This is the first study to use a qualitative methodology to assess the unconstrained views of patients and carers concerning the consequences of TBI in their daily lives and then apply this information to develop a patient and family determined outcome measure and more particularly a neurobehavioral assessment scale. By focusing solely on the perspectives of patients and their carers, the hope was to elicit areas of outcome that had not previously been considered by health professionals, but that were viewed as important consequences for the individuals and their family (Morris et al 2005). This method of development has provided the questionnaire with good content and face validity. The P-HIPS and the P-HINAS were constructed to measure 'participation' as defined by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (WHO 2001).

In the past, measuring the patient's own perspective of their injury has been criticized due to the lack of insight and memory problems that are commonly experienced by TBI individuals, and therefore proxy reports were deemed as more accurate and reliable (Teasdale et al 1997). However, it is argued that carers will not be able to report patient's inner feelings and may interpret patient's behavior using their own explanation which may be different from patient's own interpretation of events. The reports of carers may also be biased by their emotional status, the severity of patient's problems, and familiarity with the patient (Kreutzer et al 1996). The carers, however, are likely to report certain behaviours such as aggression more frequently than the patients themselves. In fact Teasdale et al's (1997) study showed that relatives rated difficulties related to brain injury as significantly greater than patients. More recently attention has turned to eliciting patient reports, identifying what they feel are the difficulties

Table 2 Comparison between the domains (Spearman correlation coefficient) of the P-HIPS, including the P-HINAS and the MPAI-3 domains (N = 111)

		MPAI-3		
	Physical / Cognition Score	**Pain / Emotion Score**	**Social Participation Score**	**Total Score**
P-HIPS				
Emotion / Behavior (**P-HINAS**)	0.54	0.82	0.66	0.71
Independence / Community living	0.69	0.39	0.77	0.74
Cognition	0.73	0.53	0.65	0.60
Physical	0.55	0.65	0.50	0.76
Total Score	0.75	0.75	0.82	0.87

Note: All p values are <0.01.

Abbreviations: MPAI-3, Mayo Portland Adaptability Inventory-3; P-HINAS, Patient-Head Injury Neurobehavioral Assessment Scale; P-HIPS, Patient – Head Injury Participation Scale.

that they encounter following from their injury. A number of more recently developed instruments, such as the European Brain Injury Questionnaire (EBIQ), ask for the patient's own views of their injury (Teasdale et al 1997). It is argued that these reports are highly important and the information that they provide about patients' own emotions and interests would otherwise go unnoticed (Teasdale et al 1997; Martin et al 2001). We have therefore decided to develop both patient and carer versions of our scale.

The second phase of the study has established good psychometric properties of the P-HIPS and the P-HINAS. The P-HIPS was also compared with the MPAI-3 and GOSE to establish its criterion-related validity. There is no accepted 'gold standard' in this area (Eames 1999) therefore two instruments were selected that were deemed to be most appropriate for the purposes of this investigation. Concurrent validity of the P-HIPS with the MPAI-3 showed a good relationship between the total and domain scores. There is therefore a trend for patients to report similar levels of problems, despite individual differences in the layout, wording, and structure of the two questionnaires. This however does not mean that the two scales are similar in their 'item content', factor structure, and effectiveness to measure change in outcome. Throughout the development of the P-HIPS, emphasis has been placed on developing a user-friendly questionnaire, with particular attention being paid to the layout, wording, and phraseology. This design is believed to aid individuals with cognitive and visual difficulties that are frequently present in this population. Furthermore, with the identification of novel 'symptoms/outcomes' following injury in the qualitative interviews, such as 'being sensitive about changes in physical appearance due to scarring or weight change', 'difficulties with group conversations,' and a 'sense of loss for the individual's life before the injury' (Morris et al 2005), it is believed that the P-HIPS and the P-HINAS will be more sensitive to changes in outcome following intervention than the existing scales. This is because it should detect changes in areas that have not previously been considered. A high correlation between the P-HINAS score and the MPAI-3 'Pain/Emotion' domain score provided good criterion related validity for the P-HINAS.

When comparing the GOSE category ratings with the P-HIPS, there is a negative association, which is significant but low in comparison with the MPAI-3. A moderate correlation between the GOSE and the P-HIPS was expected due to the categorical nature of the GOSE and its broad outcome categories. It has also been demonstrated that although a patient may have a severe disability rating on the GOSE, the range of scores that are present in the P-HIPS vary across a wide range of total scores.

Cronbach's alpha for the total and domain scores of the P-HIPS including the P-HINAS were found to be high, with all coefficients above 0.8. This indicates that these questionnaires have good internal consistency. The results further demonstrate that the test–retest reliability of the P-HIPS's total scores and domain scores including the P-HINAS are good (all >0.87). The results are broadly comparable to the test–retest coefficients for the domain and total scores for the Community Integration Questionnaire (CIQ) (all >0.83) (Willer et al 1993) when it was administered to 16 patients with TBI. However, this is a relatively low cohort number for the assessment of test–retest reliability. The Disability Rating Scale (DRS) showed a test–retest coefficient of 0.95 when raters assessed 40 patients with TBI (Gouvier et al 1987). However, 3 other TBI-specific outcome measures, namely GOSE (Wilson et al 2002), The Rivermead Head Injury Follow Up Questionnaire (RHFUQ) (Crawford et al 1996) and Community Outcome Scale (COS) (Stilwell et al 1998) do not provide any information on their test–retest reliability properties. Similarly Brain Injury Community Rehabilitation Outcome-39 (BICRO-39) was validated using a small cohort size of 33 (Powell et al 1998). Although Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) showed good inter-informant reliability (intraclass correlation coefficient [ICC]: 0.85 for FIM and 0.83 for FAM) (Hall et al 1993), they show ceiling effects when used at the end of rehabilitation (Beckers et al 1999) and one year post-injury (Wilson et al 2002). No data are available on FIM/FAM's predictive value. There are no data available on EBIQ's concurrent validity and test retest reliability (Teasdale et al 1997). The test retest reliability of the total score and individual items according to the P-HIPS and the P-HINAS are between good and very good.

Kreutzer and colleagues (1996) reported validation data on their Neurobehavioral Functioning Inventory (NFI). Although 72 items included in this scale have similarities with items in the P-HIPS, the authors did not describe in detail how they developed the questionnaire. The authors stated that the items for the NFI were taken from a bigger scale, The General Health and History Questionnaire (GHHQ) and the items were originally formulated and compiled from interviews with patients with TBI and family members, and from thorough reviews of the brain injury literature. However, it is unlikely that they have used the same rigor and qualitative methodology to analyse data collected from interviews with patients and carers. Kreutzer and colleagues

(1996) also had to exclude 35 of the original 105 items from the final version of the NFI as they did not meet strong statistical criteria for inclusion in the scale; nevertheless the authors thought many of these items were clinically important. In the validation study (Kreutzer et al 1996), the authors did not provide any data on reliability of the NFI, which is an important aspect of psychometric properties of any scale. The authors have compared the NFI scores with a personality scale such as the Minnesota Multiple Personality Inventory (MMPI) (Greene 1991) score but not with any standardized neurobehavioral outcome measure such as the one produced by Levin et al (1987). However, in subsequent studies the authors have compared the NFI (Johnston et al 2006) with functional measure such as FIM (Hall et al 1993). The same group also compared the depression subscale scores of the NFI with a clinical diagnosis of depression according to the DSM-IV (APA 1994) criteria (Kennedy et al 2005) and the Beck Depression Inventory (BDI) (Beck et al 1988) scores (Seel and Kreutzer 2003) among 172 outpatient clinic attendants with TBI.

We made sure that the cohort represented participants with all levels of severity of outcome and all ages and different causes of TBI. However, although our postal questionnaire survey allowed us to recruit a relatively large number of participants, which would not have been possible otherwise, the disadvantage was the lack of control over certain things. For example, we could not exclude the possibility that in a certain proportion of cases patients may have had help from their carers in completing the questionnaire. Although the P-HIPS and the P-HINAS will be useful in day to day assessment of outcome of patients with brain injury, it is worth pointing out here that an accurate impression of consequences of brain injury requires blending information collected from several sources (Campbell and Fiske 1959). These include data from various tests, outcome scales, direct observation combined with patient interview and examination (Hartlage et al 1987). We could not assess the sensitivity/predictive value of the P-HIPS and the P-HINAS to detect change from a 'real world' intervention. This needs to be tested in a future prospective study.

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Patient – Head Injury Participation Scale (P-HIPS)

Name of the patient:

Patient's date of birth:

Place where the scale was administered:

Name of the person administering the scale:

The role of the person administering the scale:

Date of completion:

The cause of brain injury:

The time of brain injury:

The initial severity of brain injury (eg, length of coma, PTA or the lowest GCS score):

Current treatments:

Patient – Head Injury Participation Scale (P-HIPS)

We are interested in the things that cause you problems in your day-to-day life.
Each question asks whether a particular symptom has been either 'not a problem', or a 'mild', 'moderate' or 'serious' problem for you in your day-to-day life during the past four weeks.

There are 48 questions in total and they all follow the same format.

Example Question

One question asks whether your hearing has caused you problems over the last four weeks.

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty Hearing (Loss of hearing)	☐ Either the symptom is not present or the symptom is present but does not cause difficulties	☐ The symptom causes some mild problems with day-to-day life, but these are manageable	☐ The symptom causes problems that have a moderate impact upon day-to-day life	☐ The symptom causes problems that have a serious impact upon day-to-day life

Therefore for the 'Difficulty Hearing' Question:

If you do not have any difficulty hearing, then tick the 'Not a Problem' box. Or, if you do have difficulty hearing, but this does not cause any problems for you (even if it is a bit worse), then tick the 'Not a Problem' box

If it causes some mild problems, but these are manageable, then tick the 'Mild Problem' box

If it causes problems that have a moderate impact upon your life, then tick the 'Moderate Problem' box

If it causes problems that have a serious impact upon your life, then tick the 'Serious Problem' box

Please tick ☑one box only

We have used large text to make the questions easier to read

Please note that questions are printed on both sides

Patient – Head Injury Neurobehavioral Assessment Scale (P-HINAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Temper / Irritable (Loss of temper, more aggressive, irritable, etc.)	☐	☐	☐	☐
Social Behavior (Too loud, causing offence, acting childishly, saying the wrong thing, etc.)	☐	☐	☐	☐
Lack of Motivation (Difficulty getting round to doing things, giving up too easily, etc.)	☐	☐	☐	☐
Difficulty with Feeling Tired / Fatigued (Feeling tired, drained or exhausted, having less energy, etc.)	☐	☐	☐	☐
Difficulty with Sleep (Sleeping a lot or not sleeping, nightmares, etc.)	☐	☐	☐	☐
Feeling Scared (Frightened, panic attacks, etc.)	☐	☐	☐	☐
Paranoia (Feeling more suspicious about people, etc.)	☐	☐	☐	☐
Feelings of Loss (Troubled by loss of previous life or how life could have been, etc.)	☐	☐	☐	☐
Frustration (Because of not being able to do things you would like to, etc.)	☐	☐	☐	☐
Worrying About Things (Feeling anxious or worried, etc.)	☐	☐	☐	☐
Crowds (Feeling uneasy in large crowds or amongst strangers, etc.)	☐	☐	☐	☐

Please answer all questions

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Loss of Confidence (Less confident in unfamiliar situations or when doing things you used to do, etc.)	☐	☐	☐	☐
Depression (Feeling down or isolated, suicidal thoughts, etc.)	☐	☐	☐	☐
Arguments with Close Family (Arguments with partner, children, parents, etc.)	☐	☐	☐	☐
Reduced interest in family (less loving, less caring, less affectionate etc.)	☐	☐	☐	☐
Strain on Family (tension, stress or depression amongst family members etc.)	☐	☐	☐	☐
Don't See Friends as Often as Would Like	☐	☐	☐	☐
Lack of Good Friends (Close friends)	☐	☐	☐	☐
Lack of Understanding from Others (People don't understand your situation, people judge or label you, etc.)	☐	☐	☐	☐
Lack of people to talk to (Social interaction, people to confide in)	☐	☐	☐	☐

Patient – Head Injury Community Living Scale (P-HICLS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with Mobility (Getting around places, going up stairs, getting in and out of bed, etc.)	☐	☐	☐	☐
Lack of Independence (Rely upon help from others, unable to live by yourself, etc.)	☐	☐	☐	☐
Sports Activities (Restrictions in playing sports)	☐	☐	☐	☐
Leisure Activities (Restrictions in taking part in leisure activities eg, pub, going out for meals, cinema, etc.)	☐	☐	☐	☐
Preparing Meals (Preparing / cooking meals, etc.)	☐	☐	☐	☐
Travel (Getting around local area, travelling to shops, visiting friends, going out, etc.)	☐	☐	☐	☐
Shopping (Buying food, clothes etc. for everyday needs, etc.)	☐	☐	☐	☐
Physical Self-care (Washing, dressing, etc.)	☐	☐	☐	☐
Local Environment (Restriction due to steps or kerbs in local area, lack of ramps, handrails, etc.)	☐	☐	☐	☐
Difficulty with Balance (Loss of balance, standing/sitting upright, walking, etc.)	☐	☐	☐	☐
Physical Appearance (Changes to physical looks due to paralysis or scars, weight change, etc.)	☐	☐	☐	☐
Difficulty with Eyesight (Limited or blurred vision, can't see things properly, etc.)	☐	☐	☐	☐

Patient – Head Injury Cognitive Assessment Scale (P-HICAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Group Conversations (Difficulty following conversations when several people speak at the same time, etc.)	☐	☐	☐	☐
Difficulty Reading (Difficulty reading letters, bills, newspapers, books, etc.)	☐	☐	☐	☐
Difficulty Speaking (Words come out jumbled, you have to concentrate harder on speech, or people can't understand you properly, etc.)	☐	☐	☐	☐
Difficulty with Recent Memory (Short term memory, forgetting things: eg, what day it is, what happened yesterday, etc.)	☐	☐	☐	☐
Difficulty with Concentration (Focusing on reading newspapers, TV, doing tasks, easily distracted, etc.)	☐	☐	☐	☐
Difficulty with Planning / Organisation (Doing things in the right order, allowing enough time, etc.)	☐	☐	☐	☐
Difficulty with Multi-tasking (Doing more than one thing at a time: eg, walking and talking, etc.)	☐	☐	☐	☐
Dealing with Money (Paying bills, knowing how much change you should get, etc.)	☐	☐	☐	☐
Safety Risks (Leaving gas/oven on, not safe crossing roads, using electrical goods, etc.)	☐	☐	☐	☐
Difficulty Hearing (Loss of hearing, etc.)	☐	☐	☐	☐

Patient – Head Injury Physical Assessment Scale (P-HIPAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with Headaches	☐	☐	☐	☐
Difficulty with Pain other than headaches (Pain in body, legs, arms, etc. Not headaches)	☐	☐	☐	☐
Difficulty with Epilepsy / Fits (Blackouts, seizures, absences, etc.)	☐	☐	☐	☐
Difficulty with Feeling Dizzy / Faint (Feeling as if head is spinning, vertigo, dizziness, feeling giddy, etc.)	☐	☐	☐	☐
Difficulty with Buzzing Noise in Ear (Tinnitus etc.)	☐	☐	☐	☐
Difficulty with Sensitivity to Noise / Light (Cannot tolerate noise or light, etc.)	☐	☐	☐	☐

ADDITIONAL COMMENTS

(You may attach additional sheets if necessary)

Thank you for taking the time to complete this questionnaire

Please check that you have answered all of the questions