

THE UNIVERSITY OF HULL

**Acquired brain injury: The public's understanding of survivors and
survivors' perceptions of stigma.**

being a Thesis submitted for the Degree of

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by

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A: Overview

The portfolio has three parts: a systematic literature review, an empirical paper and a set of appendixes.

Part 1 is a systematic literature review, in which the empirical literature assessing the public's knowledge of acquired brain injury (ABI) and attitudes towards survivors is reviewed and critically evaluated. The review aims to identify the misconceptions commonly endorsed by the public and identify their attitudes towards survivors, to determine whether the stigmatisation of this population is likely.

Part 2 is an empirical paper which aimed to explore whether survivors of ABI perceived stigma and anticipated discrimination. To achieve this, participants with ABI completed either an online ($n= 114$) or paper version ($n= 36$) of a questionnaire designed to assess their level of perceived stigma. This study further aimed to determine whether perceived stigma was associated with reduced self-efficacy and unemployment, given their negative impact on rehabilitation outcomes, continued recovery and quality of life post-injury. The findings and clinical implications are discussed and highlight the need for government and media campaigns to prioritise fighting the stigma of ABI and promoting the inclusion of survivors.

Part 3 comprises the appendixes, including a reflective account of the research process and additional information relating to Part 1 and Part 2 of the portfolio.

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Part One: Systematic Literature Review

This paper is written in the format ready for submission to the journal Brain Injury.

Please see appendix 2.1 for the 'Guidelines for Authors'.

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Survivors of brain injury through the eyes of the public: A systematic review

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Abstract¹

Background: It is known that knowledge and attitudes are important in determining whether society stigmatise and discriminate against specific groups. However, there has been no systematic review of the literature measuring the public's knowledge or attitudes regarding acquired brain injury (ABI).

Objective: This study aimed to systematically evaluate the literature measuring the public's (1) knowledge of ABI, and (2) attitudes towards survivors.

Methods: Four databases were searched between December 2011 and March 2012. Studies meeting the selection criteria were included and a manual search of studies' reference lists undertaken to identify any remaining. The quality of studies was assessed using an adapted tool.

Results: 20 studies were reviewed, with quality assessment ratings ranging from 47.83% to 91.3%. The public lacked awareness of some post-injury symptoms. Misconceptions concerning recovery, memory difficulties and vulnerability to second injuries were also commonly endorsed. The public demonstrated more negative attitudes towards survivors of ABI than those with other injuries, particularly if deemed responsible for their ABI.

Conclusions: The findings of the studies reviewed suggest that survivors of ABI are vulnerable to stigma and discrimination. It is therefore essential that Government and media campaigns prioritise educating the public about ABI and promote the inclusion of survivors.

Key words: Brain injury, public, knowledge, attitudes, prejudice, stigma.

¹ Journal guidelines: Structured abstract must be no longer than 200 words (word count: 200 words).

Introduction

‘I am tired of fighting people’s perceptions of me as stupid’, Survivor [1].

‘My friends all thought I was mad’, Survivor [2].

‘...I felt so lonely at times. My friends stayed away’, Survivor [3].

275 in every 100,000 individuals within the UK are estimated to sustain an acquired brain injury (ABI) that requires hospital admission each year [4]. ABIs are considered the world’s leading cause of death and disability worldwide [5] and can cause significant impairments impeding the survivor’s physical, behavioural, cognitive, emotional, social and vocational functioning [6, 7]. Survivors are faced with the sudden and unexpected need to adjust to life post-injury, which can result in the onset of secondary difficulties, including depression and anxiety [8, 9].

ABI is sometimes considered an ‘invisible disability’ given that some post-injury symptoms provide no outward indication that the survivor is suffering from a problem. Therefore survivors are faced with the challenging dilemma of choosing whether to disclose their injury to others. Ultimately, this decision determines whether survivors will be defined as somebody who has acquired a brain injury or not [7]. Survivors report that their post-injury symptoms elicit stigma from society and evoke feelings of shame and embarrassment, which pose a barrier to their ability to reintegrate in to society post-injury [2, 10]. Survivors describe concealing their injury from others in an attempt to protect themselves from the anticipated discrimination [2]. However, concealing an injury is likely to have a significant impact on the survivor’s ability to adjust to life post-injury, given the value of any existing relationships is likely to be diminished due to lack of authenticity, and survivors are prohibited from engaging in support services established specifically for survivors [7].

Stigma was defined by Goffman [11] as society's application of 'deeply discrediting' labels to those who deviate from what they consider to be normal. The consequences of the stigma experience have been widely researched in the mental health literature and conclude that devastating effects can result, including reduced self-esteem and quality of life, loss of social relationships and many discriminatory experiences, including reduced employment opportunities [12-14]. This has attracted much government and media attention, and caused an increase in the number of campaigns fighting the stigma of mental illness and promoting the inclusion of those with mental health difficulties (e.g. 'Time to Change National Campaign' [15]).

Corrigan and Watson [16] proposed a social-cognitive model of 'public stigma' in an attempt to understand society's response to those they perceive to belong to a stigmatised group. Public stigma was understood to comprise of three concepts: stereotypes, prejudice and discrimination. Stereotypes describe the knowledge structures and beliefs held by society about the stigmatised group; individuals are not necessarily in agreement with these beliefs, but adopt them for their functional purpose in enabling quick impressions and expectations of those belonging to stigmatised groups to be generated [17]. The term prejudice is used when individuals agree with these beliefs, considered similar to attitudes. Prejudice can ultimately lead to discrimination, the behavioural consequences of prejudice. This theory extends understanding of the effects of public stigma for those who belong to the stigmatised group and also perceive the stigmatising attitudes as legitimate. Corrigan and Watson [16] proposed that these individuals internalise the public stigma; a concept referred to as 'self-stigma'. This leads to negative emotional reactions and subsequent behaviours which aim to protect individuals from the anticipated discrimination [12, 13]. Ajzen and Fishbein's Theory of Planned Behaviour [18] can be drawn upon to further understand the role of societal attitudes in determining subsequent behaviours. This theory posits that attitudes which

reflect underlying beliefs about an act, together with society's approval of the act predict behaviours. Therefore in relation to stigma, if an individual perceives discriminatory behaviour towards a survivor as acceptable as a result of holding negative attitudes towards survivors, and expects society to similarly perceive this as acceptable, they are more likely to engage in discriminatory behaviours.

Although research has explored the public's knowledge of ABI and their attitudes towards survivors, there is no review that systematically evaluates this literature. Given the importance of knowledge and attitudes in determining discriminatory behaviours, it is necessary that this is undertaken in order to design effective interventions to reduce stigma and discrimination [16]. Stigma is likely to have far-reaching consequences for the survivor and their families as evidenced by existing research in the field of mental health, in addition to increasing the likelihood of survivors choosing to conceal their injury [12, 13, 19]. Stigma could not only have significant implications at a clinical level, but also at a service and Government level: stigma may prevent survivors and their families from engaging in rehabilitation programmes and additional support services, and may result in fewer survivors and their family members returning to employment bringing about additional costs for the Government.

This review aims to systematically evaluate the literature measuring public knowledge of ABI and exploring their attitudes towards survivors. By definition, this review considers all terminology pertaining to ABI, including head injury, brain injury and post-concussion syndrome (PCS). This review would identify specific areas of knowledge that is lacking and determine whether educating the public about ABI needed to be prioritised. It would further determine whether it was time for government

and media campaigns to focus on fighting the stigma of ABI and promoting the inclusion of survivors, in order to create an environment that fosters their recovery.

Research questions:

1. (a) What is known about the public's knowledge of ABI?
(b) What factors influence the public's level of knowledge?
2. (a) What is known about the public's attitudes towards survivors of ABI?
(b) What factors influence the public's attitudes?

Method

Data sources and search strategy

An extensive literature search was performed to identify relevant published articles using the PsychINFO, MEDLINE, CINAHL and Web of Science databases up to and including March 2012. Databases were chosen which provided access to a wide range of international articles in the field of psychology and related disciplines.

An initial scoping search was performed to ensure the selected search terms were effective in identifying articles relevant to the research questions. The keywords listed by relevant articles were reviewed to enable further search terms to be identified and increase the likelihood of identifying all relevant articles. Article titles and abstracts were searched using the following search terms:

head injur* OR brain injur* OR TBI OR ABI OR concussion OR
post-concussion* syndrome OR postconcussion* syndrome

AND

attitude* OR view* OR misconception* OR perception* OR belie* OR opinion* OR
understand* OR knowledge* OR point N3 view OR prejudice* OR stigma* OR
expectation*

AND

public* OR general population* OR communit* OR layperson* OR child*

Specific limits were applied to database searches where possible to ensure that all articles selected were published in the English language as to prevent bias and misunderstanding at the point of translating qualitative data, and to ensure that all articles were published in peer-reviewed journals and hence of a reputable standard. No limits regarding publication date were set. An additional search was conducted to determine whether a review of this type had already been carried out; this confirmed that the literature measuring the public's knowledge of ABI and their attitudes towards survivors had not yet been systematically reviewed.

Articles were included if they met all the inclusion criteria and none of the exclusion criteria.

Inclusion criteria

- Studies that explored participant's knowledge of ABI.
- Studies that explored participant's attitudes towards survivors of ABI.
- Studies where participants were selected for the primary purpose of being members of the general public and were recruited from a public, educational or occupational site.
- Studies with various sub-groups of participants (e.g. general public and health professionals) where participants from at least one sub-group were members of the general public².
- Studies published in the English language.
- Studies published in peer-reviewed journals.

Exclusion criteria

- Studies that did not focus on exploring participant's knowledge of ABI or participants' attitudes towards survivors of ABI.
- Studies exploring participant's attitudes towards the services and treatments available for ABI.
- Studies specifically referring to stroke³.
- Studies where participants were not recruited from a public, educational or occupational site despite being labelled as 'members of the general public'

² The findings of sub-groups that were not members of the general public were not included or evaluated in the review.

³ Studies explicitly referring to knowledge of stroke symptoms were excluded on the basis that recent media campaigns have aimed to educate the public about stroke symptoms, to encourage quick responses in such situations (e.g. ACT F.A.S.T campaign [62]). Studies evaluating the effectiveness of such campaigns were considered irrelevant to the research questions.

(e.g. brain rehabilitation centres⁴).

- Studies where participants were selected on the basis of having personal or professional experience of ABI.
- Studies where participants were health or educational professionals (Trainee or qualified).
- Studies including various sub-groups of participants, where no sub-group were selected for the primary purpose of being members of the general public.
- Studies published in a language other than English.
- Studies not published in a peer reviewed journal.
- Case reports; literature reviews; conference presentations or unpublished studies.

Data extraction

Data from the selected studies was extracted using data extraction forms designed specifically for this review. Separate forms were designed for qualitative and quantitative studies (Appendix 4.1 and 4.2).

⁴ Although authors identified individuals attending brain injury rehabilitation centres as general members of the public, it was thought that these individuals would have easy access to information regarding brain injury and an enhanced motivation to learn about ABI if they were visiting a friend or family member in the centre. The knowledge and attitudes of this group was therefore considered irrelevant to the research questions.

Quality Assessment

The methodological quality of studies was assessed to allow the strength of the findings to be taken in to consideration during data analysis. A quality assessment tool was designed specifically for the research questions because no existing quality assessment tool was deemed appropriate. A large proportion of existing assessment tools are specifically intended for experimental designs [20], however the majority of included studies employed a cross-sectional survey design and those studies remaining varied greatly in their research design.

A quality assessment tool appropriate for quantitative studies was designed based on the quality checklists by Fowkes and Foulton [21], Downs and Black [22] and the National Institute for Health and Clinical Excellence (NICE) [23, 24]. The modified assessment tool consisted of 23 criteria considered relevant for assessing the quality of cross-sectional survey designs and independent group designs (Appendix 4.3). Items pertaining to the quality of the sampling strategy, representativeness of the sample, use of comparison groups and the choice of measures to assess knowledge or attitudes were deemed of particular importance given the research questions. A slightly different version of this modified assessment tool was used for assessing the quality of qualitative studies (Appendix 4.4).

Studies were awarded a score of one on the quality assessment tool for meeting each criterion adequately. Criteria could also be omitted from the assessment if deemed inappropriate to the research design, allowing a percentage score to be calculated regarding the number of criteria considered appropriate. This enabled direct comparisons of quality between studies utilising different research designs. A maximum score of 23 and 21 could be achieved on the quantitative and qualitative assessment tools respectively. An independent rater, blinded to the Researcher's quality

ratings, scored each study to ensure reliability. The inter-rater reliability of quantitative studies was assessed using the Kappa statistic: the average inter-rater reliability was found to be $Kappa = 0.729$, which is considered a substantial level of agreement [25] (Appendix 4.5).

Data analysis

The extracted data was analysed using a qualitative approach due to the heterogeneity of the studies with regards to research design and methodology.

Results

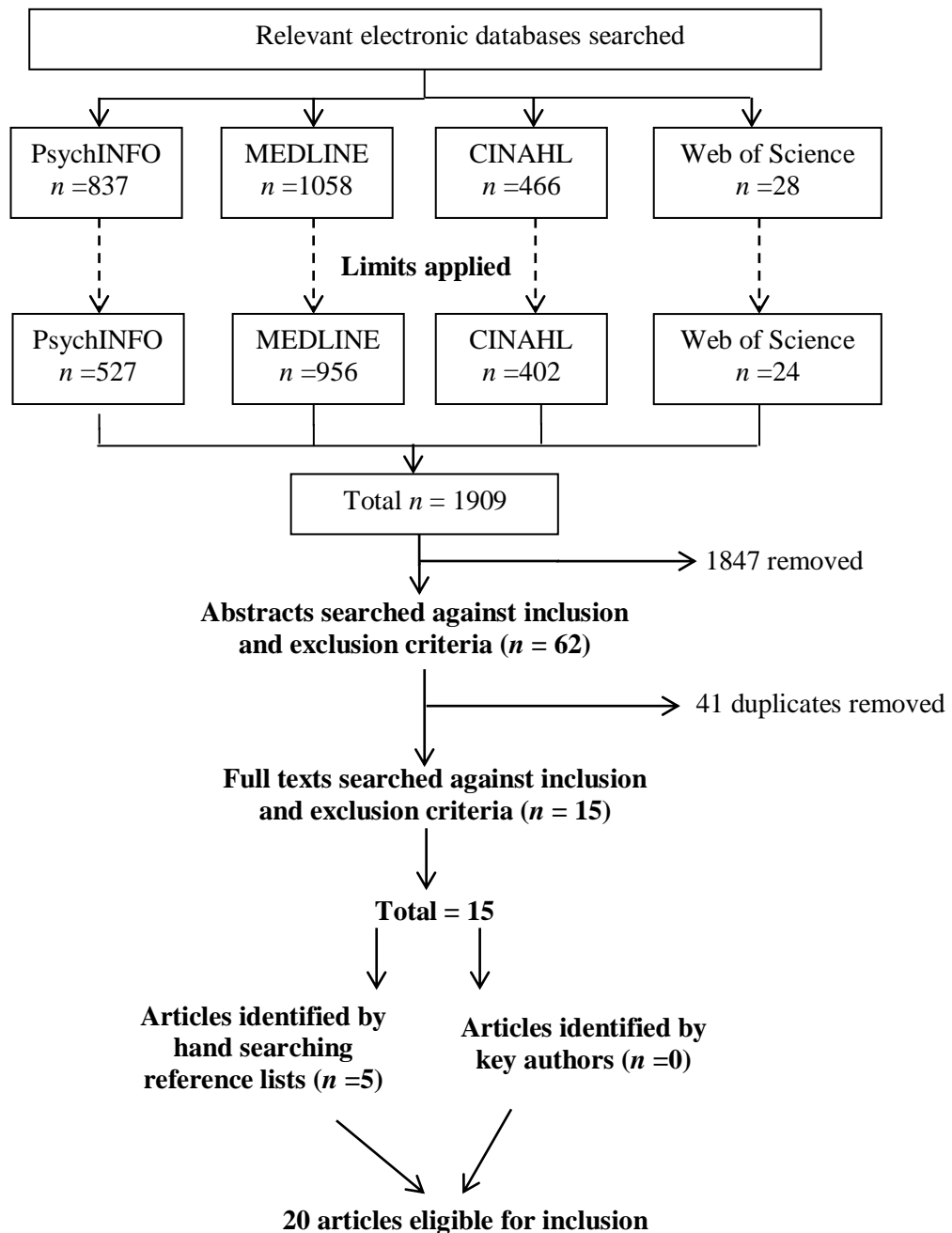
Overview of article selection

1909 articles were identified by the search strategy. The abstracts of all 1909 articles were reviewed against the inclusion and exclusion criteria, leaving 62 articles. The full texts of the 62 articles were obtained and similarly reviewed against the inclusion and exclusion criteria. 41 duplicates were removed and a further 6 articles were removed based on the criteria, resulting in 15 articles being accepted for review. The reference lists of accepted studies were hand-searched to identify any remaining studies relevant to the research questions and were subsequently accepted for review ($n=5$).

Additionally, key authors defined as having published more than one article in the field were contacted to determine whether any additional studies that had not been identified by the search strategy existed. No studies were identified by key authors that had not

yet been accepted for review. This process resulted in a total of 20 articles being accepted for review, a summary of which can be found in figure 1.

Figure 1: Overview of article selection process



Overview of included studies

20 studies published between 1988 and 2011 were accepted for review; 19 employed a quantitative methodology and one employed a qualitative methodology. Studies utilised public samples from different worldwide locations: eight studies were undertaken in the USA across seven different states, two in Canada, two in New Zealand and a further nine were undertaken in the UK, six of which were located in Northern Ireland. Sample sizes of quantitative studies ranged from 30 to 1123 participants and 16 participated in the qualitative study.

Framework for analyses

Studies were divided and analysed on the basis of their measured outcomes: knowledge of ABI ($n=14$) or attitudes towards survivors ($n=8$). Two studies measured both knowledge and attitudes and were therefore considered in both analyses [26, 27]. An overview of each study and their main findings can be found in table 1 and table 2.

1. Overview of studies measuring knowledge

Five studies specifically assessed symptom knowledge of mild brain injury.

Terminology used to describe mild brain injury varied within the literature, including concussion and post-concussional syndrome. The study methodology required participants to either select or self-report symptoms they would expect following an ABI described by a vignette ($n=4$) or an ABI that participants were asked to simulate themselves ($n=1$).

Eight studies assessed the public's general knowledge of ABI across the severity spectrum using a questionnaire, in which participant's reported the accuracy of items.

Six studies used adaptations of the original 17 item questionnaire devised by Gouvier, Prestholdt and Warner [28]. In five instances, the questionnaire was administered as a structured interview whereby multiple response categories were read to participants, allowing quantitative data to still be collated. The remaining two studies employed questionnaires designed by the study authors. A further study utilised semi-structured interviews to assess public knowledge of ABI and collate qualitative data. These eight studies reported the most common misconceptions endorsed by the public.

2. Overview of studies measuring attitudes

Eight studies utilised a variety of measures to assess public attitudes towards survivors of ABI: four adapted existing scales, including the Community Attitudes to Mental Illness (CAMI; [29]) ($n=1$), the Prejudicial Evaluation Scale (PES; [30]) and Social Interaction Scale (SIS; [30]) ($n=2$), the Friendship Activity Scale (FAS; [31]) ($n=1$) and the Implicit Associations Test (IAT; [32]) ($n=1$). These studies required participants to read a vignette depicting a survivor of ABI and subsequently respond to items on the scale. The three remaining studies designed their own measures, which required participants to indicate the degree to which they associated a list of attributes with survivors. The study utilising semi-structured interviews similarly assessed participants' attitudes.

Table 1: Overview of included studies measuring public knowledge of ABI (*Notes: K= Knowledge; A= Attitudes*)

Study (Location)	Recruitment site (Sample size)	Design	Methodology/ Measure	Additional factors explored	Key findings (% of sample that endorsed misconception)	Quality rating
Gouvier et al. (1988) [28] Louisiana, USA	Shopping mall (221)	Cross sectional questionnaire	25-item questionnaire devised by study authors	<ul style="list-style-type: none"> • Age; • Personal experience of ABI 	K: Misconceptions endorsed regarding amnesia (55.43%), recovery (49.65%), and unconsciousness (44.53%); personal experience of ABI and age did not consistently influence knowledge; participants who had personal experience of ABI were significantly more likely to have had conversations with health professionals.	76.20%
Aubrey et al. (1989) [33] Alberta, Canada	Psychology undergraduate course (245)	<i>Not reported</i>	Symptom-reporting methodology	<ul style="list-style-type: none"> • Loss of consciousness; • Different terminology 	K: Physical symptoms judged more likely to be expected post-ABI than any other category of symptoms; cognitive symptoms judged as likely to occur as distractor symptoms; social, sexual and financial difficulties post-ABI not expected; all symptoms and outcomes judged to be more likely to occur when consciousness was lost at time of injury.	47.80%
Mittenberg et al. (1992) [34] Florida, USA	Local businesses, shopping centres, apartments and colleges (223)	<i>Not reported</i>	Symptom-reporting methodology - compared responses to actual symptoms reported by survivors	-	K: 22/30 symptoms were expected post-injury by participants at frequencies that did not significantly differ from those reported by survivors; survivors reported significantly more difficulties concerning irritability, fatigue and memory than participants expected.	68.20%

Willer et al. (1993) [35] Western New York, USA and Southern Ontario, Canada	Shopping mall and health-care centre (245)	Cross sectional questionnaire with comparison groups	Adapted 9-item version of questionnaire devised by Gouvier et al. [28]	<ul style="list-style-type: none"> • Compared to findings by Gouvier et al. [28]* 	K: Misconceptions endorsed regarding memory difficulties (89% and 82.4%) and vulnerability to future head injuries (81.2% and 88.2%); misconceptions similar to those reported by Gouvier et al. [28].	52.40%
Vaughn et al. (1993) [36] Missouri, USA	via telephone (1123)	Cross sectional questionnaire with comparison groups	108-item questionnaire devised by study authors	<ul style="list-style-type: none"> • Age; • Gender; • Education level; • Income; • Race; • Marital status; • No. in household; • Personal experience of ABI 	K: Knowledge of symptoms was poor; significant effect of education level on type of symptoms expected to occur post-ABI; no other factors influenced knowledge.	77.30%
Lees-Hayley & Dunn (1994) [37] Southern California, USA	Undergraduate psychology course (98)	Cross sectional questionnaire	Symptom-reporting methodology	-	K: 63.3% of participants correctly identified at least half or more of the symptoms commonly suffered following mild brain injury; no information provided about the type of symptoms reported.	50.00%

<p>O'Jile et al. (1997) [38] Louisiana, USA</p>	<p>Psychology undergraduate course (217)</p>	<p>Cross sectional questionnaire with comparison groups</p>	<p>Adapted 26-item version of questionnaire devised by Gouvier et al. [28]</p>	<ul style="list-style-type: none"> • Compared to findings by Gouvier et al. [28] and Willer et al. [35]* • Personal experience of ABI 	<p>K: Misconceptions endorsed regarding vulnerability to future head injuries (83.41%), recovery from severe brain injury (67.74%) and unconsciousness (67.28%); fewer misconceptions endorsed than those reported by Gouvier et al. [28] and Willer et al.[35]; personal experience of ABI had significant effect on knowledge on some items.</p>	<p>72.70%</p>
<p>Guilmette & Paglia (2004) [39] Providence, Rhode Island, USA</p>	<p>Motor Vehicles Office (179)</p>	<p>Cross sectional questionnaire with comparison groups</p>	<p>Adapted 19-item version of questionnaire devised by Gouvier et al. [28]</p>	<ul style="list-style-type: none"> • Compared to findings by Gouvier et al. [28] and Willer et al.[35]; • Age; • Gender; • Education level; • Personal experience of ABI 	<p>K: Misconceptions endorsed regarding memory difficulties (75%), vulnerability to future head injuries (68.1%) and recovery (61.9%); no overall significant difference in misconceptions endorsed by current sample and those reported by Gouvier et al. [28] or Willer at al. [35]; age, gender and education level did not significantly effect knowledge; personal experience of ABI had a significant effect on knowledge measured by one item.</p>	<p>72.70%</p>
<p>McKenzie & McMillan (2005) [40] Glasgow</p>	<p>Higher education provision (30)</p>	<p><i>Not reported</i></p>	<p>Symptom-reporting methodology</p>	<ul style="list-style-type: none"> • IQ; • Free recall vs. Use of checklist 	<p>K: Knowledge of PCS symptoms was very poor when asked to free recall; 40% expected no symptoms post-injury; significantly less physical than cognitive or emotional symptoms were identified when using the checklist; presence of bogus symptoms did not effect participants' accurate reporting of symptoms.</p>	<p>72.70%</p>

<p>Hux et al. (2006) [41] Nebraska, USA</p>	<p>Shopping mall (318)</p>	<p>Cross sectional questionnaire with comparison groups</p>	<p>Adapted 17-item version of questionnaire devised by Gouvier et al. [28]</p>	<ul style="list-style-type: none"> • Compared to findings by Gouvier et al. [28] and Willer et al. [35]* • Age; • Gender; • Education level; • Personal experience of ABI 	<p>K: Misconceptions endorsed regarding memory difficulties (93.4%), recovery from severe ABI (72.01%) and vulnerability to future head injuries (67.92%); fewer misconceptions endorsed on some items compared to Gouvier et al. [28]; gender and personal experience of ABI had a significant effect on knowledge on four items.</p>	<p>85.70%</p>
<p>Mulhern & McMillan (2006) [42] Glasgow</p>	<p>Higher education provision (171)</p>	<p><i>Not reported</i></p>	<p>Symptom-reporting methodology</p>	<ul style="list-style-type: none"> • Free recall vs. Use of checklist; • Personal experience of ABI 	<p>K: Few accurate symptoms of PCS reported when asked to free-recall ($M=1.90$, $SD=1.35$); Number of symptoms reported increased when using PCSC checklist ($M=5.24$, $SD=3.09$); 61% identified memory problems, 63% concentration difficulties, 57% anxiety, 78% headaches following mild brain injury using checklist; personal experience of ABI did not influence symptom reporting.</p>	<p>81.80%</p>
<p>Chapman & Hudson (2010) [43] Britain</p>	<p>Snowball sampling (322)</p>	<p>Cross sectional questionnaire with comparison groups</p>	<p>Adapted 17-item version of questionnaire devised by Gouvier et al. [28]</p>	<ul style="list-style-type: none"> • Compared to findings by Hux et al. [41]; • Age; • Education level; • Personal experience of ABI 	<p>K: Misconceptions endorsed regarding memory difficulties (91.4%), unconsciousness (77.1%) and recovery from severe brain injury (73.1%); misconceptions of eight items endorsed significantly more by present sample; gender had significant effect on knowledge on two items; no significant effect of personal experience of ABI.</p>	<p>81.80%</p>

<i>Linden & Boylan (2010)</i> [26]** Northern Ireland	Participants known to study authors (16)	Cross sectional semi-structured interviews	Interview schedule developed by authors	-	K: Public demonstrated awareness of physical, cognitive, emotional and behavioural impairments post-injury; expected survivors to always have some physical impairment; A: Negative language used to describe survivors; language became more positive when asked to describe how others perceive survivors.	81%
<i>McKinlay et al. (2011)</i> [27]** Christchurch, NZ	Numerous workplaces (103)	Cross sectional questionnaire	10-item questionnaire devised by study authors and 15 attributes listed to assess attitudes	<ul style="list-style-type: none"> • Terminology; • Personal experience of ABI 	K: 58.6% of those who reported having had concussion did not identify themselves as having sustained a head injury; evidence of uncertainty regarding public's knowledge of what constituted as concussion; A: Terminology used to describe head/brain injury had significant effect on attributes participants assigned to injury; participants with personal experience of ABI were more likely to attribute the terms hard-working, trustworthy and positive to survivors.	82.60%

Notes: **K** = Knowledge; **A** = Attitudes; PCS = Post-concussion syndrome; PCSC = Post-Concussional Screening Checklist (PCSC; [50])

* Comparisons between studies made without conducting statistical analyses

** Studies measured both knowledge and attitudes

Table 2: Overview of included studies measuring public attitudes towards survivors (*Notes: K = knowledge; A = attitudes*)

Study (Location)	Recruitment site (Sample size)	Design	Methodology/ Measure	Additional factors explored	Key findings	Quality rating
Redpath & Linden (2004) [44] Belfast	Psychology undergraduate course (96)	Independent groups design	Adapted versions of the PES and SIS; Willingness to help scale (seven point item devised by study authors)	<ul style="list-style-type: none"> • Degree of responsibility in acquiring ABI • Gender of vignette 	A: Individuals deemed responsible for their ABI were perceived more negatively than those not responsible; gender of survivor had no significant effect on attitudes displayed.	82.60%
Linden et al. (2005) [45] Northern Ireland	Classes of four local high schools (179)	Independent groups design	Adapted version of the CAMI	<ul style="list-style-type: none"> • Gender of participants • SES • Religion 	A: Females held significantly less tolerant attitudes towards survivors across all factors on measure (Authoritarianism; Social Restrictiveness; Benevolence; Community Ideology) ; Protestant males more positive than Catholic males on Social Restrictiveness factor; Males with higher SES more positive than males with lower SES on Benevolence factor.	90.90%
Linden & Crothers (2006) [46] Northern Ireland	Psychology undergraduate course (169) and unknown public location (159)	Independent groups design	20 item measure with five point Likert scale designed by study authors	<ul style="list-style-type: none"> • Sample (student vs. public) • Gender of participants • SES 	A: Students were significantly more positive towards survivors than public sample; Gender or SES had no significant effect on the attitudes displayed.	77.30%

Crothers et al. (2007) [47] Belfast	Local high school (50) and primary school (50)	Independent groups design	FAS	<ul style="list-style-type: none"> • Age of participants • Gender of participants 	A: Females significantly more willing to befriend a peer with ABI than males across both age groups; males became significantly more positive towards peers with ABI with age.	86.40%
Linden et al. (2007) [48] Belfast	Psychology undergraduate course (173) and unknown public location (152)	Independent groups design	Adapted versions of the PES and SIS	<ul style="list-style-type: none"> • Degree of responsibility in acquiring ABI • ABI aetiology • Sample (student vs. public) • Gender of participants • Personal experience of ABI 	A: Survivors deemed responsible for their ABI were perceived significantly more negatively; evidence for a hierarchy of aetiology found when survivors deemed responsible for their ABI: drugs (most prejudice), recreation, RTA, alcohol and aneurism (least prejudice); student sample significantly more positive towards survivors on PES than public sample; public sample significantly more likely to desire social interaction with survivors than students as measured by SIS; males significantly more negative and desired less contact with survivors.	91.30%
McLellan et al. (2010) [49] Canterbury, NZ	Numerous workplaces (103)	Independent groups design	IAT and an explicit attitudes measure devised by authors: Participants rate whether 10 attributes are associated with ABI	<ul style="list-style-type: none"> • Type of injury • Terminology used • Personal experience of ABI 	A: Brain/head injuries perceived more negatively than limb injuries: perceived as less mature, intelligent, flexible and employable; term 'brain' injury perceived more negatively than 'head' injury; participants with personal experience were significantly less negative towards brain/head injury on explicit measures and those without personal experience displayed a negative implicit bias.	73.90%

Notes: **K** = Knowledge; **A** = Attitudes; SES = Socio-economic status; CAMI = Community Attitudes to Mental Illness [29]; PES = Prejudicial Evaluation Scale [30]; SES = Social Interaction Scale [30]; FAS = Friendship Activity Scale [31]; IAT = Implicit Associations Test [32].

Quality assessment

Given that some criteria listed by the quality assessment tool were not applicable to some research designs and therefore omitted, a percentage was calculated for each study taking in to account the number of relevant criteria. The most commonly omitted criteria concerned participants being randomly allocated to groups (kappa value=1, $p=0.025$), given this was only relevant to five studies with independent groups designs.

The results of the quality assessment are presented in Appendices 4.6 and 4.7. Quality assessment ratings for the quantitative studies ranged between 47.83% and 91.3%. In particular, Aubrey, Dobbs and Rule [33] failed to achieve eight criteria by failing to adequately report specifics concerning the abstract, research questions, research design, sampling methodology, participant demographics and actual probability values.

Overall, the criteria most commonly met, with an almost perfect level of agreement between raters concerned the adequate reporting of the data collection method (met by 97.37% of studies) and that achieved if the findings and conclusions were related to the initial research questions (met by 100% of studies) [25]. The criteria that the majority of studies failed to meet, with a substantial level of agreement between raters concerned the adequate reporting of response rates (met by 5.26% of studies, with a kappa value=1, $p<0.001$) and actual probability values (met by 47.06% of studies, with a kappa value=0.767, $p=0.001$) [25]. Importantly, the majority of quantitative studies employed measures with unknown psychometric properties, therefore the accuracy and reliability of these measures was questionable (met by 23.68% of studies, with a kappa value=0.855, $p<0.001$). The majority of studies were also considered to inadequately meet the criterion relating to the reporting of sampling methodology,

however the level of agreement between raters was only fair (kappa value=0.24, $p=0.107$) [25].

The mean quality assessment rating for the qualitative study was 83.33%. Similarly this study failed to adequately report the sampling methodology and the response rate. Specific to the quality of qualitative studies, it failed to discuss the underpinning values and assumptions of the methodological approach adopted.

Main findings

Public knowledge of ABI

The findings from studies assessing symptom knowledge by means of symptom-reporting methodology and those identifying the most commonly endorsed misconceptions about ABI by questionnaire are reported separately.

Symptom knowledge of mild brain injury

Two studies concluded that participants' ability to free-recall symptoms that they expected to occur post-ABI described in a vignette, was very poor, with the mean number of accurate symptoms reported being 1.90, SD=1.35 [40, 42]. In these instances, symptoms were considered accurate if they were consistent with research criteria for PCS. MacKenzie and McMillan [40] reported that 40% of participants expected no symptoms post-ABI. In both studies, the number of symptoms accurately reported in the presence of bogus symptoms (e.g. heart problems) increased when responses were prompted by means of the Post-Concussional Screening Checklist (PCSC; [50]) [40, 42]. Alternatively, Lees-Hayley and Dunn [37] considered symptoms to be accurate if they were reported by a sample of survivors. Over half of the

symptoms reported by survivors were selected by 63.3% of participants. However, this checklist failed to include bogus items and failed to provide any specifics regarding the symptoms that were identified, which limited the quality of this study.

Using qualitative methodology, Linden and Boylan [26] found participants to be competent in describing symptoms from a range of symptom categories, including physical, cognitive, emotional and behavioural. The majority of participants in this study expected survivors to always have some form of physical impairment, indicating that participants failed to recognise ABI as an invisible disability. In addition, one quantitative study concluded that physical symptoms were more frequently expected post-ABI than any other category of symptoms [33]. Other symptom categories were expected less frequently: one study reported that less than half of the participants expected social difficulties and cognitive difficulties were expected no more likely than distractor symptoms (e.g. heart trouble) post-injury [33]. Moreover, symptoms pertaining to emotional and memory difficulties were endorsed at a frequency that was significantly lower than that actually reported by survivors [34].

In contrast, one study found that participants reported physical symptoms significantly less than cognitive or emotional symptoms. However, for this analysis the public sample was grouped with samples of GPs and survivors, who may have been more knowledgeable about symptoms of a less visible nature than the general public [40].

Common misconceptions about ABI

What constitutes a brain injury? There was some recognition that brain damage can be incurred when there is no ‘blow to the head’ or loss of consciousness at the time of injury when using questionnaire methodology [27, 38, 41, 43]. In contrast, when

participants were required to disclose and categorise their own experiences of any previous injuries, 58.6% of those identifying themselves as having experienced concussion reported that they had not sustained a brain injury [27].

Outward indicators of brain injury. The item, ‘most people with brain damage look and act disabled’ listed in Gouvier et al.’s [28] original questionnaire received a misconception rate of 30.77% in 1988 and rates between 5.97% and 7.37% on studies since 1997 [28, 38, 41, 43]. This may suggest that the public are increasingly recognising ABI as an ‘invisible disability’, which is inconsistent with the conclusions drawn from studies utilising symptom-reporting methodology and qualitative methodology [26, 33].

Loss of consciousness. The item, ‘when people are knocked unconscious, most wake up shortly after with no lasting effects’ was deemed false by questionnaire studies and misconception rates between 48.11% and 77.1% were reported [28, 38, 41, 43]. Hence, questionnaire studies concluded that the public lacked knowledge regarding the lasting effects of unconsciousness. Conversely, symptom reporting methodology employed by Aubrey, Dobbs and Rule [33] found that participants expected a survivor to experience significantly more symptoms if consciousness was lost, than cases where consciousness was not lost. Hence, the majority understood unconsciousness to determine the frequency of long-lasting effects [33].

Memory difficulties. Inaccurate knowledge of memory difficulties was consistently found across studies, with between 75% and 93.4% of participants believing that survivors could forget who they were and others around them but be perfect or normal ‘in every other way’ [28, 35, 39, 41, 43]. Interestingly, a much lower misconception

rate of 5.53% was found amongst a student sample in Louisiana, USA, which was understood by the study's authors to result from cohort effects [38].

Moreover, between 25.9% and 46.54% of participants believed that a second brain injury could restore lost memories in survivors with amnesia [28, 35, 39, 41, 43].

Recovery. Between 49.48% and 70.1% believed that speed of recovery post-ABI was dependent on the survivor's efforts [28, 35, 38, 39, 41, 43]. Moreover, the majority of participants disagreed that 'complete recovery from a severe head injury was not possible, no matter how badly the person wants to recover', with between 60.3% and 73% answering this item incorrectly since 1997 [38, 39, 41, 43]. This demonstrates the public's expectation of complete recovery following severe brain injury, if the survivor is willing to strive for recovery. Interestingly, much lower misconception rates of 14.7% and 17.6% were reported in 1993 in New York and Southern Ontario respectively [35]. Differences in participant's exposure to severe brain injury may explain the difference in findings, given this latter study failed to report the sample's personal experiences of ABI.

Vulnerability to future injuries. The public consistently failed to recognise that survivors were more vulnerable to sustaining further head injuries, with between 67.92% and 89.4% of participants scoring incorrectly on the associated item [28, 35, 38, 39, 41, 43]. However, there was an increased understanding of a survivor's limited ability to withstand a second head injury should they sustain a second one [28, 35, 38, 39, 41, 43].

Misconceptions over time

Five studies compared their findings to previous levels of public misconceptions, however only two studies did this reliably using statistical analysis [35, 38, 39, 41, 43].

Guilmette and Paglia [39] reported that the overall frequency of misconceptions found in 2004 did not differ significantly from those reported by earlier studies [28, 35]. However, this study proposed that knowledge specific to mild brain injury may have increased; the misconception rate for the item ‘whiplash injuries to the neck can cause brain damage even if there is no direct blow to the head’ decreased from 45.3% in 1988 to 35.7% in 2004 [28, 39]. Furthermore, the misconception rate for the item ‘a head injury can cause brain damage even if the person is not knocked out’ decreased from 27.2% in 1988 to 8.3% in 2004 [28, 39]. This increase in knowledge regarding mild brain injury is further supported by Hux, Schram and Goeken [41] who reported misconception rates of 9.75% and 1.26% on these items in 2006.

Hux, Schram and Goeken [41] further highlighted slight improvements in knowledge pertaining to the recovery process post-ABI, but did not perform statistical analyses. For example, knowledge regarding the role of effort in the recovery process appeared to have increased, with misconception rates decreasing from 70.1% in 1988 [28], to 52.52% in 2006 [41] and 49.8% in 2010 [43]. However, despite this decrease, the current misconception rate continues to be of concern.

Of two of the more recent studies, overall responses demonstrated a greater degree of misconceptions amongst the British sample compared to the USA sample [41, 43]. The British sample scored significantly lower on eight of 17 items pertaining to unconsciousness, amnesia, ability to learn and risk of further injuries post-injury [43].

Participant factors influencing levels of knowledge

Nine of the fourteen studies explored whether knowledge was influenced by different participant variables, namely age ($n=5$), gender ($n=4$), education level ($n=3$) and personal experience of ABI ($n=8$). The findings of each are presented in turn:

- *Age.* None of the five studies found participants' age to consistently influence public knowledge [28, 36, 39, 41, 43].

Three studies found age to be significantly associated with some questionnaire items, whereas two studies found no significant effect [36, 39]. One study divided participants in to four age bands and concluded that the 15-20 year old group were most likely to believe that recovery was mostly dependant on the survivor's effort [28]. A second study divided participants in to three age bands and reported that younger participants were significantly more likely to be educated about comas, but failed to provide the cut-off points used to define 'younger' [41]. This study further found 'middle-aged' adults to be significantly more likely to correctly identify that remaining 'inactive' throughout recovery was poor advice [41]. Gouvier et al. [28] further reported that participants aged above 60 years were significantly more likely to agree that a 'little brain damage' didn't matter.

- *Gender.* Two of the four studies reported that gender was not significantly associated with any questionnaire items [36, 39]. However, males were shown to consistently outperform females on items pertaining to knowledge of damage sustained from mild brain injuries and the lack of awareness survivors experience during unconsciousness by two studies [41, 43]. One study further found that males responded significantly more accurately than females on two items regarding survivors'

vulnerability to further brain injuries and the inability of those with severe brain injuries to achieve complete recovery [41]. In this study, females were also shown to outperform males on two items, namely those concerning the consequences of unconsciousness and the importance of remaining active throughout recovery [41].

- *Education level.* One of three studies found no significant effect of participants' education level on knowledge [39]. However Vaughn et al. [36] reported that education level had a significant effect on the type of symptoms that participants expected survivors to experience post-injury, however this study failed to provide definitions of 'lower' and 'higher' educational levels. A further study found that participants with a degree were significantly more likely to recognise that a second blow to the head cannot help a survivor restore lost memories [43].

- *Personal experience of ABI.* Eight studies explored the effects of personal experience of brain injury on knowledge, defined as participants having either sustained an ABI themselves or a relative/close friend with an ABI. The percentage of participants disclosing some form of personal experience of ABI ranged from 39.9% to 56.61% [27, 41, 43], with between 5.35% and 41% of those identifying themselves as a survivor [41-43]. Three of the eight studies found that personal experience of brain injury had no significant effect on participants' knowledge [28, 42, 43]. Interestingly, one study reported that those with personal experience of ABI were significantly more likely to have obtained their knowledge through discussions with professionals, despite this not influencing the accuracy of their knowledge [28].

Five studies found personal experience of ABI to be associated with increased knowledge on some questionnaire items, however this was not consistently found. For example, inconsistent findings were found for the item 'people in a coma are not usually

aware of what is going on around them' [38, 41]. Moreover, O'Jile et al. [38] reported that survivors were significantly more knowledgeable about the physical symptoms post-injury. This study proposed that survivors lacked knowledge of non-physical symptoms because the sample was likely to have had minimal experience of these issues given their injuries were mild in severity. However contrary to this proposition is the finding that survivors were significantly less likely to identify walking difficulties as a symptom when the survivor had experienced this difficulty themselves. Hence, experience of a symptom did not necessarily improve knowledge [36].

Public attitudes towards survivors

One study reported that survivors were perceived significantly more negatively than individuals with limb injuries across seven of ten attributes listed by the study authors: survivors were perceived as less sociable, friendly, mature, intelligent, flexible, polite and employable [49]. These findings alone do not necessarily equate to the conclusion that the public hold a negative view of survivors, but that they are perceived more negatively than other groups. However, the findings of two further studies demonstrate that the public hold a negative view of survivors [26, 45]. A thematic analysis concluded that participants solely used negative language in their descriptions of survivors, using the terms 'not normal', 'unfortunate', 'handicap' and 'sad' [26].

Linden et al.'s [45] use of the modified version of the CAMI appeared to provide further support; although, it must be acknowledged that the study's authors concluded that participants' attitudes were generally positive. However, closer inspection of the means and standard deviations of participant responses on the four factors of the CAMI revealed that participants' attitudes were slightly negative. Negative attitudes are reflected by high scores on the Authoritarian and the Social

Restrictiveness factors. Conversely, negative attitudes are demonstrated by low scores on the Benevolence and Community Ideology factors of the CAMI. Across all participant groups, mean scores on the Authoritarian and the Social Restrictiveness factors were greater than the scale mid-point and mean scores on the Benevolence and Community Ideology factors were below the scale mid-point. The scores indicated that participants were more likely to endorse the institutionalisation of survivors and to maintain social distance from survivors due to their dangerousness, and were more likely to display an unwillingness to become personally involved.

One study further explored whether these attitudes were implicitly held by means of a computerised version of the IAT [32, 49]; participants showed stronger associations between negative attributes and brain injury than those and limb injury, however this was not significant [49].

Factors influencing attitudes

All six quantitative studies further aimed to explore whether specific factors influenced the attitudes displayed by participants. For the purpose of this review, the factors were divided and analysed on the basis of whether they related to participant demographics or specifics of the brain injury.

Participant demographic factors

- *Gender.* Three of the four studies demonstrated a significant effect of gender on participant attitudes, however the direction of this effect was not consistent [45, 47, 48]. The remaining study reported no significant differences between males and females [46].

Two studies found that females held significantly more positive attitudes and were significantly more likely to befriend survivors using adapted versions of the PES, SIS and FAS [47, 48]. One of these studies was undertaken using a sample of children and found that the difference in male and female attitudes narrowed as children grew older, with males becoming more willing to befriend survivors with age [47].

In contrast, a study utilising the CAMI found that males held significantly more tolerant attitudes than females towards survivors [45]. However, this study recruited participants between the ages of 17 and 22 years only and therefore cannot be generalised to individuals across the age range.

- *Public vs. student sample.* Two studies recruited a student sample of psychology undergraduates in addition to a public sample [26, 28]. Both studies found the student sample to hold significantly more positive attitudes than the public, as measured by overall scores on the PES and a 20 attribute measure devised by study authors [46, 48]. Significant differences between the two samples were found on 15 of the 20 individual attributes listed by Linden and Crothers [46]. Specifically, the public demonstrated greater disagreement with all 11 positive attributes, indicating that they perceived survivors to be less caring, responsible, useful or productive members of society. Whereas, the student sample demonstrated greater agreement with negative attributes, perceiving survivors as significantly more violent, unpredictable, and demanding than the public. Moreover, scores on the SIS demonstrated that the student sample had less desire to interact socially with survivors than the public [48].

However, examination of demographic data revealed that both student samples consisted of more female than male participants, and were younger on average than the public samples [46, 48]. These variables were not controlled in the analyses and

therefore may partially explain the differences in attitudes between public and student samples.

- *Socio-economic status (SES)*. Two studies determined participant's SES using postcodes and grouped participants according to low, moderate or high SES [45, 46].

Neither study found a significant main effect of SES on participant's attitudes.

However, one study found a significant interaction between SES and gender on the Benevolence factor of the CAMI [45], with males of high SES scoring significantly higher than males of low SES demonstrating more positive attitudes.

- *Religion*. One study explored the effect of religion on participant's attitudes, although no main effect was found [45]. However, a significant interaction between religion and gender was found on the Social Restrictiveness factor, with Catholic males scoring significantly higher than Protestant males demonstrating more negative attitudes.

- *Personal experience of ABI*. Two of the three studies that explored the effect of personal experience reported that 24% and 62.75% of their samples had sustained an ABI themselves or knew a survivor [27, 48]. The remaining study failed to report the percentage of participants with personal experience of ABI [49].

Two studies reported that participant's personal experience of ABI was significantly associated with more positive attitudes on both explicit and implicit measures [27, 49]. Participants with personal experience were significantly more likely to rate survivors as kind, hard-working, trustworthy and positive [27].

The third study found no significant effect of personal experience [48].

ABI specific factors

- *Gender.* One study manipulated the gender of the survivor described in the vignette, however this was found to have no significant effect on participant's attitudes, as measured by the PES and SIS [44].
- *Degree of responsibility in acquisition of ABI.* Two studies randomly allocated participants to one of two conditions, which manipulated the survivor's degree of responsibility in acquiring the brain injury depicted in a vignette [44, 48]. Both studies found a significant effect of responsibility on the attitudes displayed using the PES, but only one study found this effect using the SIS. In all instances, participants displayed more negative attitudes and a greater reluctance to interact socially with survivors, when they were considered responsible for their brain injury [44, 48].

Linden, Hanna and Redpath [48] further explored whether the event in which the brain injury was acquired influenced participants' attitudes towards survivors. No main effect of aetiology was found, however, a significant main effect of aetiology was evident for the 'responsibility' condition when the two conditions were separated. More specifically, when the survivor was considered responsible for their injury, they were perceived most negatively if the injury was acquired by means of drugs, followed by alcohol then an aneurism as a result of ignoring medical advice.

- *Terminology.* Two studies explored the effects of the terminology used to describe ABI [27, 49]. The Likert scale employed by McLellan, Bishop and McKinlay [49] was considered superior to the dichotomous scale used by McKinlay, Bishop and McLellan [27] as it enabled a greater variability in participant responses.

This study found that a survivor described as having a ‘brain injury’ was rated significantly more negative than a survivor with a ‘head injury’. Specifically, survivors of ‘brain injury’ were rated as significantly less mature, intelligent, flexible, polite, employable and likeable [49]. In contrast, McKinlay Bishop and McLellan [27] found survivors described as having acquired ‘brain injuries’ were rated as significantly more kind, eager and diligent than survivors of ‘head injury’. Survivors of ‘brain injuries’ were also significantly more likely to be associated with the attributes distractible and negative.

Discussion

Overview of research findings

This review aimed to systematically evaluate the literature exploring the public’s knowledge of ABI and their attitudes towards survivors. A total of 20 studies were reviewed that utilised a range of methodologies, 14 of which assessed the public’s knowledge and eight explored their attitudes towards survivors.

Public knowledge of ABI

The findings suggest that although public knowledge of ABI, particularly of mild brain injury may have increased since the initial study in 1988, the public continue to endorse a number of misconceptions [39, 41]. The global nature of these misconceptions was highlighted, with comparable levels of misconceptions being identified across samples recruited in the UK, USA, Canada and New Zealand. Knowledge of ABI was not found to be consistently related to specific participant demographics or participants’ personal experience of ABI.

A misconception consistently endorsed by the public was that survivors' speed of recovery was dependant on effort [28, 35, 38, 39, 41, 43]. The public also held the expectation that all survivors could achieve complete recovery regardless of severity [35, 38, 39, 41, 43]. This has significant implications for those who continue to experience persistent difficulties post-injury, given they are likely to be perceived as 'effortless' and 'lazy' due to the public's misunderstanding of recovery. Consistent with the social-cognitive model of public stigma, individuals who hold these negative beliefs and stereotypes are likely to display prejudice and discrimination towards survivors [16]. For example, one may predict that employers who endorse these stereotypes would be less likely to employ survivors. This is consistent with the mental health literature, which reports that employers were concerned about hiring those with mental illness because they were similarly assumed to be 'lazy', 'sluggish' and 'not hard-working' [51]. Moreover, individuals who endorse these stereotypes may be less likely to befriend and offer support to survivors, negatively impacting on the survivor's ability to reintegrate in to the community post-injury.

The pivotal role of perceived effort in recovery may be understood by drawing upon society's wider moral beliefs about one's ability to influence and control illness. Believing that one has the power to influence recovery may enable individuals to be better able to accept and cope with the concept of illness. More specifically, society may be better able to accept and relate to individuals who continue to experience difficulties recovering from an illness, if they believe that the individual was in control of their illness outcome. In this way, survivors who continue to experience persistent difficulties post-injury are understood to be responsible and almost 'deserving' of these difficulties [52]. These societal beliefs may serve to; firstly enable individuals to more easily accept without feelings of guilt that some continue to suffer post- injury. And secondly to reassure individuals that they are invulnerable and therefore protected from

experiencing these difficulties given those who do suffer, are understood to be responsible and therefore ‘deserving’ of their suffering. Conversely, these beliefs have significant implications for survivors, given society’s placing of responsibility on the survivor has the potential to generate feelings of shame, which is strongly associated with stigma [53].

This review also highlighted the public’s lack of knowledge concerning post-injury symptoms beyond those that are physically visible [33, 34]. This is likely to result in the public failing to understand and recognise the difficulties experienced by survivors as legitimate. This is consistent with survivors’ personal accounts of their experiences of returning to employment post-injury; they describe feeling that other colleagues doubted their need for the additional support that they received because colleagues couldn’t ‘see’ their injuries [54]. In these instances, the public are likely to expect the same performance from survivors as those who haven’t acquired a brain injury. Therefore, any survivors who experience difficulties meeting these expectations are likely to be perceived in a negative light.

Interestingly, questionnaire studies understood most survivors to suffer ‘lasting effects’ when knocked unconscious and concluded from participants’ responses that the public lacked knowledge about this [28, 38, 41, 43]. However, this item was thought to be ambiguous given participants could have varied greatly in their interpretation of the duration of unconsciousness and what they understood to constitute ‘lasting effects’. In addition, this review argues that many individuals who experience a brief loss of consciousness suffer no long-term effects, and therefore questions the validity of the item ‘when people are knocked unconscious, most wake up shortly after with no lasting effects’ being considered false. Interestingly, a study using symptom-reporting methodology demonstrated that the public expected a survivor to experience more

symptoms following an injury in which consciousness was lost for ten minutes, as opposed to an injury in which consciousness was not lost [33]. Therefore, an accurate and reliable understanding of the public's knowledge of unconsciousness across the severity range is unknown, given the majority of studies attempted to measure this using a questionnaire item that was considered ambiguous.

In addition, the public lacked knowledge regarding the vulnerability of survivors to further head injuries [28, 35, 38, 39, 41, 43]. This may result in the carers of survivors and survivors themselves being less cautious day-to-day and therefore increase the likelihood of survivors sustaining a second injury. Furthermore, this research highlighted the public's inaccuracies' concerning what constitutes a mild brain injury, which may hinder their ability to recognise when a brain injury has been acquired. This would result in the public being unaware of the need to seek medical treatment resulting in further damage and difficulty.

Public attitudes towards survivors

The research demonstrated that the public continue to hold and explicitly voice negative attitudes towards survivors, with survivors being described as 'unfortunate', 'handicapped' and 'sad' [26]. When compared to individuals with different injuries, survivors of brain injuries were perceived more negatively [49]. These findings are of great concern given prejudice is known to lead to discrimination [16].

The literature measuring public's attitudes towards survivors similarly highlighted the importance of perceived responsibility. Survivors deemed responsible for the acquisition of their injury were consistently perceived more negatively than those not deemed responsible [44, 48]. This research further highlighted that the degree of negativity displayed by the public may be partially dependent on the way in which

the ABI was acquired [48]. As already outlined, perceived responsibility has significant implications relating to the degree of stigma experienced and subsequent shame felt by the individual [53]. In addition, this is likely to influence the survivor's likelihood of disclosing their injury to others and disclosing how their injury was acquired. In line with previous research, survivors who anticipate society to perceive them as responsible for their injury are more likely to conceal their injury in an attempt to avoid the anticipated stigma and discrimination [19]. This is of concern given that concealing an injury is likely to negatively impact on survivors' ability to adjust to life post-injury and prohibit them from engaging in community support services established for survivors in the community [7].

Interestingly, female children aged between eight and 13 years, and female adults were found to hold significantly more positive attitudes towards survivors and were more likely to befriend survivors than their male counterparts [47, 48]. This is consistent with the mental health literature, and is understood to result from the greater role of social relationships in the formation of females' self-concepts relative to males' [55, 56]. However, this effect was reversed amongst young adults aged between 17 and 22 years, with males demonstrating more positive attitudes towards survivors in one study using the CAMI [45]. This observed trend may suggest that females perceive themselves to be more vulnerable to threat and danger during their teenage years and as a result desire greater distance between themselves and survivors, who they perceive to be potentially threatening. However, the conclusions drawn about the variation in male and female attitudes across the age range utilised different measures, therefore the accuracy of comparing findings is questionable.

Moreover, males of low SES demonstrated more negative attitudes towards survivors as indicated by low scores on the Benevolence factor of the CAMI, which

reflects their reluctance to sympathise and display kindness towards survivors [45]. Brain injuries are common amongst males with low SES and therefore the finding by Linden, Rauch and Crothers [45] has implications for their social reintegration. These survivors are likely to desire social relationships with those of similar age and background, the very group of society that have been found to display less kindness towards survivors. However, it could be argued that high scores on the Benevolence factor reflect reverse discrimination, given that high scores represent a respondent's belief in the need to sympathise and display kindness towards survivors because of their injury, which may not necessarily be welcomed by survivors [57].

Catholic males perceived survivors as more dangerous and therefore desired more social distance than Protestant males as measured by the Social Restrictiveness factor of the CAMI [45]. This was understood by the study authors in terms of social dominance [45, 58]. It was suggested that Catholic males expressed high social dominance, which defines individuals who disregard democratic beliefs and show a preference for hierarchical systems. Hence, Catholic males displayed a preference to distance themselves from other groups and emphasise differences. This suggests that survivors may be vulnerable to stigmatisation from groups who similarly identify themselves as high in social dominance.

Consistent with the mental health literature, personal experience was significantly associated with more positive towards survivors in two out of three studies [27, 49, 59]. This may have ramifications for those with severe brain injuries, who are likely to have more severe impairments that limit their ability to live independently in the community. Hence society may have reduced exposure to severe brain injury, which may suggest that survivors of severe brain injury are at greater risk of prejudice.

Future research based on limitations of included studies

The methodological quality assessment highlighted a number of limitations that were common to the majority of studies included in the review.

Sampling methodology

16 of 20 studies used convenience sampling to recruit participants from public locations⁵. Given the aims of these studies were to assess the knowledge and attitudes of the general public convenience sampling may be considered appropriate. However, the limitation associated with this self-selecting methodology still applies; it could be argued that those interested in participating were more knowledgeable of ABI, questioning the representativeness of the sample. Two studies employed quota sampling and stratified sampling respectively, which strengthened their sampling methodology [28, 36].

A further limitation concerns the lack of information provided by studies regarding the recruitment process; 19 of 20 studies failed to report the number of individuals declining to take part or withdrawing from the research. Future research should be sure to report the study response rate to determine how representative the samples are of the whole population.

Of those studies assessing attitudes ($n=8$), six were conducted in Northern Ireland, therefore the generalizability of these findings to other geographical areas is questionable. This highlights the need for future research to assess public attitudes towards survivors of ABI outside of Northern Ireland.

⁵ 11 of studies failed to identify the sampling method used therefore sampling methods were determined on the basis of the information provided.

Study methodology

The heterogeneity of the measures and methodologies used to assess knowledge complicated the process of making comparisons across studies. Five studies utilised adaptations of Gouvier, Prestholdt and Warner's [28] original 25-item measure and created nine and 17-item versions; their rationales for omitting such items were considered weak given the potential for researcher's to exert bias during this process. The reliability and validity of all versions of this questionnaire ($n=6$) and the two additional questionnaires devised by study authors were unknown and therefore the ability of these questionnaires to assess knowledge accurately and reliably is unknown. Future research should be sure to assess and report the validity and reliability of the measures used to assess knowledge of ABI in order to enhance the quality of the research findings.

There are several limitations associated with the symptom-reporting methodology used to infer public knowledge by five studies. Three of these studies required participants to read a vignette describing somebody sustain a brain injury prior to being asked to report symptoms, two of which did not control for the gender of the survivor described. The survivor described by both studies was male, therefore the generalizability of these findings to female survivors is limited [27, 42]. A second limitation concerns the potential for factors other than knowledge to influence symptom-reporting. For example, connotations associated with the gender of the survivor described, may have biased participants' reporting of symptoms. Females are thought to be more emotionally expressive than males, therefore participants may have been more likely to report depression as a symptom experienced by a male survivor than a female survivor. One study required participants to imagine having sustained an ABI themselves as an alternative to reading a vignette about a survivor [34]. This

methodology may have been influenced by the participant's personal experience of symptoms. Hence, a participant prone to suffering headaches may be more likely to report this symptom after imagining themselves having an ABI than reading a vignette about a survivor. Therefore, the validity of these symptom-reporting methodologies in assessing knowledge of ABI is questionable.

Vignettes were also used by three studies to assess participant's attitudes towards survivors. Similarly, the generalizability of two of these is limited given the survivor was depicted as male [47, 48]. The methodology employed by Redpath and Linden [44] was strengthened, given attitudes towards male and female survivors was explored. Future research employing vignettes to assess knowledge or attitudes should aim to control for the gender of the survivor described.

Limitations of review

The inclusion criteria was limited to including studies that recruited participants from public, occupational and educational sites only, to ensure that the knowledge and attitudes of the general public were reviewed. Therefore a decision was made to exclude studies that recruited participants for the primary purpose of having personal experience with ABI (e.g. survivors; relatives of survivors; health professionals). It was assumed that these groups would be motivated to seek additional learning with regard to ABI and therefore would be more knowledgeable than the general public. However, the majority of studies failed to provide information regarding participants' professions, therefore it proved difficult to assess studies against this criteria. Undoubtedly a proportion of those recruited from public locations and therefore included in the review were survivors themselves, relatives or health professionals, which may be considered a limitation of the review. However, it is reasonable to argue

that survivors, relatives of survivors and health professionals are ultimately members of the general public and therefore need not be screened out of public samples.

Two quality assessment tools were devised to assess the quality of quantitative and qualitative studies separately. Although this allowed for studies to be assessed against items that were relevant to the study methodology, it proved difficult to compare the quality ratings of quantitative and qualitative studies reliably.

Lastly, although the review encompasses studies conducted across the UK, USA, Canada and New Zealand, it is important to acknowledge that these countries constitute the western, developed society. Therefore the generalizability of these conclusions to other developing countries is questionable.

Conclusions and Clinical implications

The misconceptions endorsed by the public have a significant role in increasing the likelihood of survivors being discriminated against and excluded from society [16]. Specifically, the public's misunderstanding of the recovery process and lack of awareness of post-injury symptoms beyond those physically visible may result in survivors being perceived as lazy and effortless, and their symptoms as illegitimate. This is consistent with the research concluding that the public hold and explicitly voice negative attitudes towards survivors [26, 49]. In addition survivors' anticipation of discrimination is likely to lead them to conceal their injury from others and withdraw from society, which has far-reaching consequences for the survivor and their families [7].

It is vital that the problem of stigma surrounding ABI is addressed. Interventions that educate the public about ABI world-wide are essential in order to

create an environment for survivors and their families that fosters their recovery.

Education aims to reduce stigma and shift attitudes by means of providing contradictory evidence, which has been found to be effective in reducing stigmatising attitudes towards mental illness [60, 61]. Encouragingly, the explicit nature of the public's attitudes may suggest that they are susceptible to change [49]. Education could take the form of both specific educational programmes in addition to global media campaigning, which has been used to fight the stigma of mental illness and promote the inclusion of those with mental health difficulties (e.g. 'Time to Change National Campaign' [15]).

Educating the public would have further implications concerning the health and safety of survivors and the general public. It would improve the public's ability to recognise ABIs and the need to seek medical treatment to prevent further damage and difficulty. This would ultimately reduce the likelihood of survivors enduring further damage, reduce the frequency of ABIs and reduce the number of these going unnoticed in society.

This review identifies the most common misconceptions and recommends that these are addressed in future educational plans. Education is required regarding what constitutes an ABI, knowledge about recovery and survivors increased vulnerability to future injuries in addition to the common symptoms experienced post-ABI, specifically of the cognitive, emotional and social type. The specific evidence highlighting poorer knowledge amongst certain sub-groups of the public would suggest the need to prioritise educating some sub-groups over others. However, this review concludes that these associations were not consistently found and therefore emphasises the need for further research in order to determine the validity and reliability of these findings. Given personal experience of ABI was significantly associated with holding more positive attitudes towards survivors in two out of three studies, increasing society's

contact with survivors may be effective in augmenting the effects of education in reducing stigmatising attitudes [27, 49, 61]. Therefore, it may be valuable to encourage and support those with personal experience of ABI to have active roles in educational programmes or campaigns. This would aim to increase the audience's personal experience of ABI and foster more positive attitudes towards survivors.

Future research

This review has highlighted various directions for future research. Firstly, this review concludes that the public demonstrate some knowledge of the difficulties experienced by survivors post-injury. However, further studies that explore the public's knowledge of the acute and longer-term effects of brain injury would be valuable to determine whether the public appreciate the long-term impact of some injuries. In addition, some studies included in this review focussed specifically on mild brain injury however future studies should aim to assess the public's knowledge of mild, moderate and severe brain injury independently. This would enable a more comprehensive understanding of the public's knowledge and attitudes towards survivors of brain injury across the severity spectrum and determine whether the public hold accurate and realistic expectations following mild, moderate and severe brain injury.

Additionally, further research that explores the direct relationship between public attitudes and their actual behaviours towards survivors would be valuable in furthering our understanding of the types of attitudes that are likely to lead to discrimination and rejection. This would provide valuable information for the planning of educational programmes and media campaigns, which aim to fight the stigma of ABI and promote the inclusion of survivors.

References

1. Nochi M. "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science and Medicine* 1998;46:869-78.
2. Simpson G, Mohr R, Redman A. Cultural variations in the understanding of traumatic brain injury and brain injury rehabilitation. *Brain Injury* 2000;14:125-40.
3. Chamberlain DJ. The experience of surviving traumatic brain injury. *Journal of Advanced Nursing* 2006 May;54:407-17.
4. Royal College of Physicians. Rehabilitation following acquired brain injury: National clinical guidelines. London, UK: Royal College of Physicians & British Society of Rehabilitation Medicine; 2003.
5. Brain injury facts. [Internet]: International Brain Injury Association [cited 2012 May 03]. Available from: <http://www.internationalbrain.org/?q=Brain-Injury-Facts>.
6. Zasler N, Martelli M. Mild traumatic brain injury: Impairment and disability assessment caveats. *Neuropsychological Rehabilitation* 2003;13:31-42.
7. Jones JM, Jetten J, Haslam SA, Williams WH. Deciding to disclose: The importance of maintaining social relationships for well-being after acquired brain injury. In: J. Jetten, C. Haslam, A. Haslam, editors. *The social cure: Identity, health and well-being*. Hove: Psychology Press; 2012. p.255-72.
8. Rao V, Lyketsos C. Neuropsychiatric sequelae of traumatic brain injury. *Psychosomatics* 2000;41:95-103.
9. Ashman T, Spielman L, Hibbard M, Silver J, Chandna T, Gordon W. Psychiatric challenges in the first 6 years after traumatic brain injury: Cross-sectional analyses of axis I disorders. *Archives of Physical Medicine and Rehabilitation* 2004;85:S36-42.

10. Lefebvre H, Cloutier G, Levert M. Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury* 2008;22:535-43.
11. Goffman E. *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice Hall; 1963.
12. Link B, Phelan J. Conceptualizing stigma. *Annual Review of Sociology* 2001;27:363-85.
13. Link BG, Struening EL, Neese-Todd S, Asmussen S, Phelan JC. The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services* 2001;52:1621-6.
14. Penn D, Wykes T. Stigma, discrimination and mental illness. *Journal of Mental Health* 2003;12:203-8.
15. Time to change: Lets end mental health discrimination. [Internet] [cited 2012 May 03]. Available from: <http://www.time-to-change.org.uk/>.
16. Corrigan PW, Watson AC. The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice* 2002;9:35-53.
17. Hamilton D, Sherman J. Stereotypes. In: RS Wyer, TK Srull, editors. *Handbook of social cognition*, vol. 1: Basic processes. 2nd ed. Hillsdale, NJ: Erlbaum; 1994.
18. Ajzen I. The theory of planned behavior. *Organizational Behavior and Human Decision processed* 1991;50:179-211.
19. Bos AER, Kanner D, Muris P, Janssen B, Mayer B. Mental illness stigma and disclosure: Consequences of coming out of the closet. *Issues in Mental Health Nursing* 2009;30:509-13.
20. Katrak P, Bialocerkowski AE, Massy-Westropp N, Kumar S, Grimmer KA. A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology* 2004;4:22-22.

21. Fowkes FG, Fulton PM. Critical appraisal of published research: Introductory guidelines. *British Medical Journal* 1991;302:1136-40.
22. Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health* 1998;52:377-84.
23. National Institute for Health and Clinical Excellence (NICE). The guidelines manual. London: National Institute for Health and Clinical Excellence; 2007.
24. National Institute for Health and Clinical Excellence (NICE). The guidelines manual. London: National Institute for Health and Clinical Excellence; 2009.
25. Landis J, Koch G. The measurement of observer agreement for categorical data. *Biometrics* 1988;33:159-74.
26. Linden MA, Boylan A-. 'To be accepted as normal': Public understanding and misconceptions concerning survivors of brain injury. *Brain Injury* 2010;24:642-50.
27. McKinlay A, Bishop A, McLellan T. Public knowledge of 'concussion' and the different terminology used to communicate about mild traumatic brain injury (MTBI). *Brain Injury* 2011;25:761-6.
28. Gouvier W, D., Prestholdt PH, Warner MS. A survey of common misconceptions about head injury and recovery. *Archives of Clinical Neuropsychology* 1988;3:331-43.
29. Taylor SM, Dear MJ. Scaling community attitudes toward the mentally ill. *Schizophrenia Bulletin* 1981;7:225-40.
30. Kelly JA, St. Lawrence JS, Smith S, Hood HV. Medical students' attitudes toward AIDS and homosexual patients. *Journal of Medical Education* 1987;62:549-56.

31. Siperstein G. Adjective checklist (ACL) and friendship activity scale (FAS):
Instruments for measuring children's attitudes. Boston: University of
Massachusetts, Center for the Study of Social Acceptance; 1980.
32. Greenwald AG, McGhee DE, Schwartz JLK. Measuring individual differences in
implicit cognition: The implicit association test. *Journal of Personality and Social
Psychology* 1998;74:1464-80.
33. Aubrey JB, Dobbs AR, Rule BG. Laypersons' knowledge about the sequelae of
minor head injury and whiplash. *Journal of Neurology, Neurosurgery & Psychiatry*
1989;52:842-6.
34. Mittenberg W, DiGiulio DV, Perrin S, Bass AE. Symptoms following mild head
injury: Expectation as aetiology. *Journal of Neurology, Neurosurgery and
Psychiatry* 1992;55:200-4.
35. Willer B, Johnson WE, Rempel RG, Linn R. A note concerning misconceptions of
the general public about brain injury. *Archives of Clinical Neuropsychology*
1993;8:461-5.
36. Vaughn SL, Frank RG, Leach LR, O'Neal GO. The public perception of head injury
in Missouri. *Brain Injury* 1994;8:149-58.
37. Lees-Haley PR, Dunn JT. The ability of naive subjects to report symptoms of mild
brain injury, post-traumatic stress disorder, major depression, and generalized
anxiety disorder. *Journal of Clinical Psychology* 1994;50:252-6.
38. O'Jile JR, Ryan LM, Parks-Levy J, Gouvier WD, Betz B, Haptonstahl DE, Coon
RC. Effects of head injury experience on head injury misconceptions. *International
Journal of Rehabilitation and Health* 1997;3:61-7.
39. Guilmette TJ, Paglia MF. The public's misconceptions about traumatic brain injury:
A follow up survey. *Archives of Clinical Neuropsychology* 2004;19:183-9.

40. Mackenzie JA, McMillan TM. Knowledge of post-concussional syndrome in naive lay-people, general practitioners and people with minor traumatic brain injury. *British Journal of Clinical Psychology* 2005;44:417-24.
41. Hux K, Schram CD, Goeken T. Misconceptions about brain injury: A survey replication study. *Brain Injury* 2006;20:547-53.
42. Mulhern S, McMillan TM. Knowledge and expectation of postconcussion symptoms in the general population. *Journal of Psychosomatic Research* 2006;61:439-45.
43. Chapman RCG, Hudson JM. Beliefs about brain injury in Britain. *Brain Injury* 2010;24:797-801.
44. Redpath SJ, Linden MA. Attitudes towards behavioural versus organic acquisition of brain injury. *Brain Injury* 2004;18:861-9.
45. Linden MA, Rauch RJ, Crothers IR. Public attitudes towards survivors of brain injury. *Brain Injury* 2005;19:1011-7.
46. Linden MA, Crothers IR. Violent, caring, unpredictable: Public views on survivors of brain injury. *Archives of Clinical Neuropsychology* 2006;21:763-70.
47. Crothers IR, Linden MA, Kennedy N. Attitudes of children towards peers with acquired brain injury (ABI). *Brain Injury* 2007;21:47-52.
48. Linden MA, Hanna D, Redpath SJ. The influence of aetiology and blame on prejudice towards survivors of brain injury. *Archives of Clinical Neuropsychology* 2007;22:665-73.
49. McLellan T, Bishop A, McKinlay A. Community attitudes toward individuals with traumatic brain injury. *Journal of the International Neuropsychological Society* 2010;16:705-10.

50. Gouvier WD, Cublic B, Jones G, Brantley P, Cutlip Q. Postconcussional symptoms and daily stress in normal and head injured college populations. *Archives of Clinical Neuropsychology* 1992;7:193-211.
51. Tsang HWH, Angel B, Corrigan PW, Lee Y, Shi K, Lam CS, Jin S, Fung KMT. A cross-cultural study of employers' concerns about hiring people with psychotic disorder: Implications for recovery. *Social Psychiatry and Psychiatric Epidemiology* 2007;42:723-33.
52. Weiner B. On sin versus sickness: A theory of perceived responsibility and social motivation. *American Psychologist* 1993;48:957-65.
53. Lewis M. Shame and stigma. In: P. Gilbert, B. Andrews, editors. *Shame: Interpersonal behaviour, psychopathology and culture*. New York: Oxford University Press; 1998. p.126-40
54. Gilworth G, Eyres S, Carey A, Bhakta BB, Tennant A. Working with a brain injury: Personal experiences of returning to work following a mild or moderate brain injury. *Journal of Rehabilitation Medicine* 2008;40:334-9.
55. Cross SE, Madson L. Models of the self: Self-construals and gender. *Psychological Bulletin* 1997;122:5-37.
56. Ng P, Chan K. Sex differences in opinion towards mental illness of secondary school students in Hong Kong. *International Journal of Social Psychiatry* 2000;46:79-88.
57. Fajardo DM. Author race, essay quality, and reverse discrimination. *Journal of Applied Social Psychology* 1985;15:255-68.
58. Pratto F, Sidanius J, Stallworth LM, Malle BF. Social dominance orientation: A personality variable predicting social and political attitudes. *Journal of Personality and Social Psychology* 1994;67:741-63.

59. Corrigan PW, Edwards AB, Green A, Diwan SL, Penn DL. Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin* 2001;27:219-25.
60. Tanaka G, Ogawa T, Inadomi H, Kikuchi Y, Ohta Y. Effects of an educational program on public attitudes towards mental illness. *Psychiatry and Clinical Neurosciences* 2003;57:595-602.
61. Rüsç N, Angermeyer MC, Corrigan PW. Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry* 2005;20:529-39.
62. Stroke - ACT F.A.S.T. [Internet]: NHS Choices [cited 2012 May 03]. Available from: <http://www.nhs.uk/actfast/pages/stroke.aspx>.

Part Two: Empirical Paper

This paper is written in the format ready for submission to the Journal of

Head Trauma Rehabilitation.

Please see appendix 2.2 for the 'Guidelines for Authors'.

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Perceived stigma amongst employed and unemployed survivors of acquired brain injury

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Abstract⁶

Background: Individuals with a range of health problems have been found to perceive stigma from society, and this is associated with negative consequences.

Objective: To explore whether survivors of acquired brain injury (ABI) perceive stigma, and whether perceived stigma is associated with reduced self-efficacy and unemployment.

Research design: The main analysis employed an independent groups design.

Participants: 150 participants with ABI were recruited by opportunity sampling; 114 participants submitted questionnaires online and 36 returned questionnaires by post.

Main measures: Perceived Devaluation and Discrimination Scale, Traumatic Brain Injury Work Instability Scale, and Independence and Employability subscales of the Bigelow Quality of Life Questionnaire.

Results: Survivors perceived stigma as a result of their ABI. Perceived stigma was found to be unrelated to post-injury employment status, but was significantly associated with the number of work-related difficulties reported by survivors in unsupported employment. Perceived stigma was significantly associated with reduced self-efficacy and reduced employment-related self-efficacy.

Conclusions: The findings demonstrate that survivors perceive stigma because of their injury and outlines the negative consequences for survivors in terms of recovery and quality of life. The need to educate the public, healthcare providers and policy-makers about survivors' experiences post-injury and the negative consequences of stigma is emphasised.

Key words: *Brain injury, stigma, employment, self-efficacy.*

⁶ Journal guidelines: Structured abstract must be no longer than 200 words (word count: 200 words)

Introduction

Acquired brain injury (ABI)

Within the UK, 275 in every 100,000 individuals are estimated to sustain an acquired brain injury (ABI) that requires hospital admission each year ¹. ABI can be extremely debilitating, with a vast range of injury-related impairments impeding the survivor's physical, cognitive, emotional, behavioural, social and vocational functioning ^{2,3}.

Survivors and their families are faced with the sudden and unexpected need to adjust to these changes, which can be complex and chronic.

Defining stigma

Stigma was defined by Goffman⁴ as society's application of 'deeply discrediting' labels to an individual who is perceived to deviate from the norm, and tends to become the dominant identity by which they are known. This was expanded by Corrigan and Watson's⁵ social-cognitive model of 'public stigma', which comprises three concepts: stereotypes, prejudice and discrimination. Stereotypes concern the general knowledge structures and beliefs held by society about the stigmatised group. These are not necessarily endorsed by individuals, but have a functional purpose in enabling expectations of the stigmatised group to be generated quickly ⁶. The term prejudice becomes relevant when individuals endorse and agree with these beliefs, considered similar to attitudes, and discrimination refers to the behavioural consequences of prejudice.

Research concludes that society explicitly voices negative attitudes towards survivors of ABI, describing them as 'unfortunate' and 'handicapped'⁷. In line with the

social-cognitive model of public stigma, survivors have reported experiences of stigma and discrimination post-injury^{5,8}.

Perceived stigma

The modified labelling theory (MLT; ⁹) outlines the negative consequences experienced by individuals who later come to suffer from the stigmatised condition themselves. In these instances, the beliefs that are already held about the stigmatized condition become personally relevant¹⁰. As a result, individuals perceive stigma and fear devaluation and discrimination from society. MLT proposes that individuals engage in specific coping strategies, namely secrecy and withdrawal, in an attempt to protect them from the anticipated discrimination. However, in doing so, individuals disconnect themselves from potential sources of support and avoid a wide range of opportunities; limiting their education, employment and treatment prospects, which result in further negative consequences^{11,12}.

Research in the field of mental illness provides support for the multitude of negative consequences faced by individuals who perceive stigma. Perceived stigma has been found to be significantly associated with anxiety, depression, reduced self-esteem, reduced self-efficacy and reduced life satisfaction¹²⁻¹⁶. Perceived stigma has further been associated with negative psychosocial outcomes; lower education, unemployment and social limitation¹².

Perceived stigma and ABI

The concept of perceived stigma has not yet been explored amongst survivors of ABI. Applying MLT to survivors would be valuable, given the specific consequences of

employing the aforementioned coping strategies for this population. Firstly, ABI is sometimes considered an ‘invisible disability’. Therefore, like individuals with mental illness, survivors are faced with the complex dilemma of choosing whether to disclose their injury or not³. The relevance here is that should survivors anticipate discrimination from society, one would expect survivors to be more likely to choose to conceal their injury¹⁷. Although nondisclosure may protect survivors from experiencing discrimination, there can be negative consequences; survivors have to continually live with anxiety associated with ‘being found out’ and are prohibited from seeking additional support as a result of their injury³. Secondly, survivors may withdraw from a wide range of opportunities and situations, including social activity and rehabilitation programmes and employment; the latter two being of particular importance to this population which constitute the focus of this current research study.

Importance of rehabilitation and employment

A wide range of rehabilitation interventions are available to survivors post-injury which aim to optimise their physical, cognitive, emotional, social and vocational functioning¹. Self-efficacy has been found to significantly influence rehabilitation outcomes¹⁸; defined by Bandura¹⁹ as an individual’s belief in their ability to perform or achieve future goals. Research in the field of mental illness has shown that perceived stigma is significantly associated with reduced self-efficacy^{15,17}. Therefore, should a similar association be identified amongst survivors, one would predict this to negatively impact on survivors’ rehabilitation outcomes.

Return to work (RTW) is considered one of the most important goals of brain injury rehabilitation due to the magnitude of benefits associated with employment, including increased quality of life and community integration^{20,21}. RTW continues to be

a major challenge to survivors and this study questions whether perceived stigma is related to this. Employment-related self-efficacy is a sub-component of self-efficacy and is defined as an individual's belief in their ability to seek and secure employment or successfully carry out work-related activities ²². It is unknown whether perceived stigma is similarly associated with reduced employment-related self-efficacy, which is important given its association with current employment status ²³. Research in the field of mental illness has shown that perceived stigma is significantly associated with unemployment ¹², which is understood to be a consequence of an individual's use of avoidant styles of coping ⁹. However, it may be useful to consider this relationship as bidirectional: individuals who perceive stigma may be less likely to seek employment opportunities and thus remain unemployed, and in addition individuals may perceive stigma as a result of failed attempts to gain employment.

Survivors who RTW are often at risk of failing due to a mismatch between their abilities and work-demands, which often causes difficulties (termed 'work instability') ^{24,25}. Supported employment placements provide survivors with on-going support and regular progress evaluations in the workplace, and have been shown to be effective ^{26,27}. However, it is unknown whether experiencing difficulties in the workplace or receiving additional support affects how survivors predict society will perceive them. This would provide a valuable insight into survivors' experience of RTW post-injury.

Current study

Although research has acknowledged that survivors are vulnerable to stigma and discrimination, little research has focussed on stigma from the survivor's perspective. More specifically, no study to date has explored whether survivors perceive stigma and this study aimed to address this gap in the literature. It further aimed to determine

whether perceived stigma was associated with unemployment and reduced self-efficacy, as found amongst those with mental illness^{12,15,17}.

This study aimed to explore the following research questions:

1. Do survivors perceive a similar level of stigma to those with mental illness as reported by Link et al.²⁸? It is hypothesized that survivors would perceive an equal level of stigma as those with mental illness.
2. (i). Is perceived stigma and current employment status related? It is hypothesized that unemployed survivors would report the highest level of perceived stigma.

(ii). Is perceived stigma and 'change' in employment status from pre- to post-injury related? It is hypothesized that survivors who were employed pre-injury and unemployed post-injury would report the highest level of perceived stigma.

(iii). Amongst survivors currently employed, is perceived stigma and perceived work difficulty related? It is hypothesized that a positive correlation would be found.
3. (i). Is perceived stigma and self-efficacy related? It is hypothesized that a negative correlation would be found.

(ii). Is perceived stigma and employment-related self-efficacy related? It is hypothesized that a negative correlation would be found.

Method

Design

The part of the study designed to explore research questions one, two (i) and two (ii) employed an independent groups design. The between subjects factor for research question one was the sample type, which comprised of two levels, namely the current ABI sample and a previous mental health sample studied by Link et al.²⁸. The between subjects factor for research question two (i) was post-injury employment status, which comprised of four levels: unemployment, unsupported employment, supported employment and full-time higher education. Finally, the between subjects factor for research question two (ii) was the ‘change’ in employment status from pre- to post-injury. This factor similarly had four levels: pre-injury unemployment to post-injury unemployment, pre-injury unemployment to post-injury employment, pre-injury employment to post-injury unemployment and lastly pre-injury employment to post-injury employment.

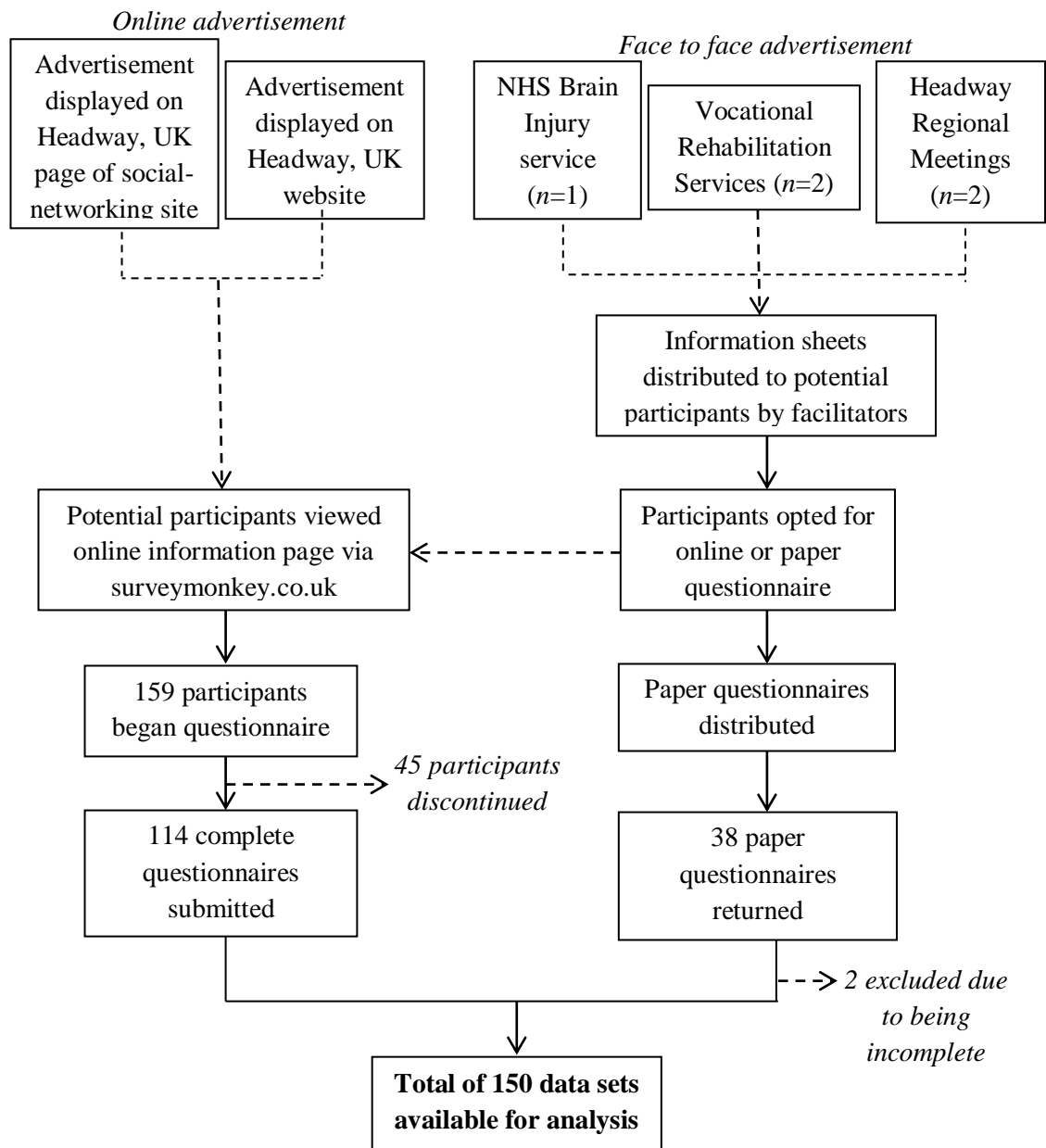
The study also employed a cross-sectional correlational design to explore the relationships between perceived stigma and perceived work difficulty (research question two (iii)), and perceived stigma and self-efficacy (research question three (i)) and employment related self-efficacy (research question three (ii)).

Recruitment process

Ethical approval was granted by the North East National Research Ethics Service Committee. Recruitment took the form of two procedures, via brain injury

rehabilitation and support services, and online via the Headway, UK website⁷. The recruitment process is detailed in figure 1.

Figure 1: Participant recruitment process



⁷ Headway is a UK based charity that aims to promote understanding about brain injury and provide information and support to survivors, their families and carers.

An advertisement and a web-link to the online version of the questionnaire were displayed on the Headway, UK website and the Headway page of a social networking site (Facebook; ²⁹) (Appendix 5.1). When clicked, the web-link directed users to an online information sheet providing detailed information about the study, hosted by surveymonkey.co.uk (Appendix 5.2). Online participants were responsible for determining whether they fit the inclusion criteria and indicating their consent to participate before being eligible to complete the questionnaire (Appendix 5.3).

Potential participants were also identified by facilitators at three brain injury rehabilitation services in Yorkshire and Manchester and two regional Headway meetings. Facilitators provided those meeting the inclusion criteria with a participant information sheet and an opportunity to ask questions (Appendix 5.4). Participants had the option of completing the questionnaire immediately or at a later date, and by paper or online (the identical web-link to the questionnaire described above, hosted by surveymonkey.co.uk was provided on a flyer (Appendix 5.5)). Participants were required to indicate their consent before being eligible to take part and were supported to complete the paper version of the questionnaire where necessary. Paper questionnaires were returned by freepost.

Procedure

After indicating consent, the questionnaire required participants to provide demographic information, including age, gender, educational status, time since injury, pre-injury employment status and post-injury employment status. The questionnaire then required participants to answer questions pertaining to the six measures detailed below, taking approximately 25 minutes to complete (Appendix 5.6).

Measures

Perceived stigma

Perceived stigma was assessed using the Perceived Devaluation and Discrimination scale (PDD; ¹¹). It requires individuals to rate their degree of agreement with 13 items using a four point Likert Scale. A total score (χ) is obtained by summing all 13 items (six items are reverse-scored) and dividing by 13 ($1 < \chi < 4$). A high level of perceived stigma is indicated by a high score on the scale. Previous studies have reported good reliability ($\alpha = 0.88$ at baseline and 0.88 at 12-month follow-up) and good internal consistency ($\alpha = 0.88$) ^{15,30}. This scale was designed for use with individuals with mental illness; therefore items were modified for the purpose of this study: ‘serious mental illness’ was replaced with ‘brain injury’ and ‘psychiatric hospital’ was replaced with ‘rehabilitation unit’.

Self-efficacy

The Independence subscale (IND) of the Bigelow Quality of Life Questionnaire (BQQ;³¹) was used to measure self-efficacy. The IND is an eight item self-report scale, which requires individuals to rate each item using a four point likert scale. Items concern the individual’s confidence in completing tasks of daily-living and decision-making. A total measure of self-efficacy (χ) is ascertained by summing all eight items (four items are reverse scored), where higher scores indicate greater self-efficacy ($8 < \chi < 32$). Previous research demonstrates adequate reliability for five of the items amongst an ABI population (Cronbach’s alpha = 0.71) ²².

Employment-related Self-efficacy

The Perceived Employability subscale (PEM) of the BQQ³¹ was used to measure employment-related self-efficacy. This measure similarly consists of eight-items and

requires individuals to respond using a four point Likert scale. Items concern the individual's confidence in seeking and maintaining employment, and their knowledge of ways of finding employment. Item scores are similarly summed to ascertain a total measure of employment-related self-efficacy, where higher scores indicate greater employment-related self-efficacy ($8 < \chi < 32$). Six of the eight items have demonstrated adequate internal consistency amongst an ABI population (Cronbach's alpha = 0.72) ²².

Perceived work difficulties

The number of difficulties participants perceived in the workplace was measured using the Traumatic Brain Injury Work Instability Scale (TBI-WIS; ²⁴). Only those who were currently employed were required to complete the TBI-WIS. The TBI-WIS is a 36-item self-report scale, each requiring a true or false response. This scale is used to ascertain a 'total score' that estimates the mismatch between an individual's cognitive and functional abilities, and their work demands where higher scores indicate a greater mismatch and an increased likelihood of difficulties being experienced ($0 < \chi < 36$).

Measures included in the analysis as covariates:

Emotional Distress⁸

Participants' level of emotional distress was assessed by combining participants' scores on the anxiety and depression subscales of the Hospital Anxiety and Depression Scale (HADS; ³²). The HADS is a 14-item self-report measure that requires participants to indicate their degree of familiarity with both positive and negative feelings using a four

⁸ Emotional distress was included in the analysis as a covariate because both anxiety and depression have been shown to be related to greater perceived stigma ^{16,52}.

point Likert scale. Greater scores reflect a greater degree of current emotional distress ($0 < \chi < 42$). Cronbach's alphas ranging from 0.67 to 0.90 have been reported³³.

*Perceived injury severity*⁹

Participants' perceived injury severity was measured using the Awareness Questionnaire (AQ;³⁴). The AQ was designed to measure an individual's insight in to their post-injury impairments, by comparing self-reported scores with those reported by significant others or clinicians. In this study, it is the participant's *perceived* injury severity that is of interest and therefore data from significant others and clinicians were not collated.

The AQ is a 17-item scale that requires individuals to rate their current functioning compared to their pre-injury functioning concerning their ability to live independently, perform cognitive tasks and remain in control of their emotions. Individuals are required to respond using a five point Likert scale ranging from 'much worse' (1) to 'much better' (5). A maximum score of 85 can be achieved, indicating all areas of functioning are perceived to be superior post-injury relative to pre-injury. This scale is used routinely in brain injury rehabilitation and has good internal consistency (Cronbach's alpha = 0.88)³⁵.

Participants

The study comprised of an opportunity sample. Data regarding the online recruitment process revealed that between May 2011 and March 2012 the advertisement displayed on the Headway, UK website was viewed 72 times and approximately 4000 impressions

⁹ Perceived injury severity was included as a covariate because awareness of injury has been found to be related to greater emotional distress⁵³.

of the advertisement were displayed on Facebook²⁹. Data regarding the number of times impressions were clicked on is unknown.

159 participants across the UK started the questionnaire advertised online and approximately 100 paper forms of the questionnaire were distributed across Manchester and Yorkshire in the UK between May 2011 and December 2011. 114 completed questionnaires were submitted online and 38 questionnaires were returned by post. Two of the paper questionnaires were excluded due to being incomplete, resulting in a total number of 150 participants. Data were not available for participants whose questionnaires were incomplete.

Participants must have sustained an ABI. Participants were also required to be proficient in English, to communicate to the level required to complete the questionnaire and be aged 18 or over. Participants were excluded if they lacked capacity to consent to the research and were unable to communicate to the level required to complete the questionnaire.

Sample size calculation

There was no published research available that could be drawn upon to accurately estimate effect sizes in the current study. To estimate effect sizes with four employment groups for the main analysis, assumptions were made on the basis of Alonso et al.'s¹² findings regarding the difference in perceived stigma scores found between employed and unemployed participants. The following was therefore assumed: a within-group standard deviation of 0.95, where unemployed participants scored higher on the PDD

than those in unsupported employment and higher education by 0.5¹⁰, and also unemployed participants scored higher than those in supported employment by 1. A power calculation indicated that, with 21 participants in each group, an effect size of 0.37 could be detected with 81% power using a one-way analysis of variance with a 5% significance level.

¹⁰ Participants in unsupported employment and higher education were expected to score similarly on the PDD because both are typically unstructured and require individuals to work independently towards deadlines.

Results

Statistical analysis

Statistical analyses were performed using SPSS version 19.0. Initial independent *t*-tests were performed to determine whether the mean perceived stigma score differed significantly from the PDD mid-point and the mean perceived stigma score reported by a sample of participants diagnosed with mental illness²⁸. Analyses of covariance were conducted to explore the effects of post-injury employment status and the 'change' in employment status from pre- to post-injury on levels of perceived stigma, whilst partialling out the effects of emotional distress, perceived functioning and time since injury¹¹. Correlational analyses were performed to explore the degree of relationship between perceived work-difficulty and perceived stigma for the supported and unsupported employment groups independently. Additional correlational analyses were performed to explore the degree of relationship between self-efficacy, employment-related self-efficacy and perceived stigma.

Preliminary analyses

A series of independent *t*-tests and chi-square tests were carried out to test for significant differences between participants recruited by online and paper methods. Independent *t*-tests revealed no significant differences between these groups for the variables age ($t=-1.858$, $df=148$, $p=0.065$), perceived injury severity ($t=-0.569$, $df=148$, $p=0.570$), perceived stigma ($t=1.417$, $df=148$, $p=0.159$), self-efficacy ($t=-0.432$, $df=148$, $p=0.667$) and employment-related self-efficacy ($t=0.970$, $df=148$, $p=0.334$). A

¹¹ Time since injury was also included as a covariate because a longer time since injury has been found to be associated with greater adaptation to injury-related impairments⁵⁴

significant difference in emotional distress was evident between groups; those recruited online reported a significantly higher degree of distress than those recruited by paper ($t=2.084$, $df=148$, $p=0.039$).

A series of chi-square tests showed no significant differences between these groups for the variables gender ($\chi^2(1, N=150)=0.476$, $p=0.490$), pre-injury employment status ($\chi^2(2, N=150)=0.397$, $p=0.820$), post-injury employment status ($\chi^2(2, N=150)=2.578$, $p=0.276$) and time since injury ($\chi^2(2, N=150)=1.331$, $p=0.514$). However, a significant effect of educational level was found ($\chi^2(2, N=150)=9.906$, $p=0.007$). Participants recruited online appeared more educated with 45.6% attending University compared to 16.7% of those recruited by paper methods.

Given the few differences between the groups, the data collated from the two recruitment methods were combined for further analyses.

Participant characteristics

An overview of participant characteristics by post-injury employment group can be found in table 1. Given only two participants reported themselves as students post-injury, the student group was combined with the unsupported employment group. The working environment of a student was thought to be most similar to unsupported employment given both require individuals to work independently to complete tasks and meet deadlines, and organise their own time in an unstructured environment. Hence, there were three post-injury employment groups for all further analyses.

A one way between-subjects analysis of variance (ANOVA) revealed that there was a significant difference between groups in age ($F(2, 147)=8.867$, $p<0.001$).

Bonferroni post-hoc comparisons on all group pairs showed that the unemployed group

were significantly older than the unsupported employment group ($p=0.004$) and the supported employment group ($p=0.006$). Age was considered a covariate for all further analyses given older participants may be retired or approaching retirement, which may have influenced their perceptions of stigma. The unsupported and supported employment groups did not significantly differ in age ($p=1$). A series of chi-square tests showed no significant differences between groups in gender ($\chi^2(2, N=150)=1.723, p=0.422$), education level ($\chi^2(4, N=150)=1.864, p=0.761$) and pre-injury employment status ($\chi^2(4, N=150)=7.682, p=0.104$). Time since injury was found to be of borderline significance ($\chi^2(4, N=150)=9.170, p=0.057$).

Table 1: Participant characteristics by post-injury employment status

Characteristic	Unemployment (<i>n</i>=106)	Unsupported employment (<i>n</i>=30)	Supported employment (<i>n</i>=14)
Age, Mean (SD)	47.81yrs (11.41)	40.07yrs (11.87)	37.64yrs (10.41)
Gender, <i>n</i> (%)			
Male	60 (56.6)	13 (43.3)	7 (50.0)
Female	46 (43.4)	17 (56.7)	7 (50.0)
Educational level, <i>n</i> (%)			
High school or less	34 (32.1)	7 (23.3)	5 (35.7)
College/sixth form	30 (28.3)	12 (40.0)	4 (28.6)
University level	42 (39.6)	11 (36.7)	5 (35.7)
Time since injury, <i>n</i> (%)			
0-2 years	23 (21.7)	8 (26.7)	8 (57.1)
3-5 years	36 (34.0)	12 (40.0)	2 (14.3)
6 years +	47 (44.3)	10 (33.3)	4 (28.6)
Pre-injury employment status, <i>n</i> (%)			
Student	8 (7.5)	5 (16.7)	3 (21.4)
Unemployment	10 (9.4)	0 (0)	0 (0)
Employment	88 (83.0)	25 (83.3)	11 (78.6)

Perceived stigma

Although the p-value of 0.023 for the Kolmogorov-Smirnov test of normality suggested some evidence against a normal distribution, examination of the histogram for perceived stigma suggested that the distribution was both symmetrical and unimodal. Therefore in line with previous studies, an independent t-test was performed to determine whether the overall mean score on the PDD differed significantly from the scale mid-point^{15,28}. The overall mean score on the PDD was 2.58 ($SD=0.45$), which was significantly above the scale mid-point of 2.5 ($t=2.280$, $df=149$, $p=0.024$).

A difference in mean PDD scores between the current sample and a sample of participants diagnosed with mental health problems reported previously²⁸ was identified ($t=-2.666$, $df=218$, $p=0.008$). Participants diagnosed with mental health problems perceived significantly more stigma ($M=2.76$, $SD=0.50$) than participants in the current study, with ABI ($M=2.58$, $SD=0.45$)²⁸.

Perceived stigma and employment

The mean PDD scores reported by each post-injury employment group can be found in table 2.

Table 2: Mean scores on PDD by post-injury employment status

	<i>n</i>	PDD	
		<i>M</i>	<i>SD</i>
Unemployment	106	2.63	0.41
Unsupported employment	30	2.48	0.61
Supported employment	14	2.44	0.28

An analysis of covariance of perceived stigma was conducted, with post-injury employment status as the between subjects factor and age, perceived injury severity, emotional distress and time since injury as covariates. After controlling for covariates, there was no significant difference in perceived stigma scores between post-injury employment groups ($F(2,143)=1.195, p=0.306$). Further inspection of parameter estimates revealed significant effects of all three covariates; as participant's emotional distress increased by one unit, PDD scores were found to increase by 0.015 ($SE=0.005$), $p=0.004$. Similarly, as participant's time since injury increased by one unit, PDD scores were found to increase by 0.098 ($SE=0.038$), $p=0.012$. Alternatively, as scores on the AQ increased by one unit, reflecting a decrease in perceived injury severity, PDD scores were shown to decrease by 0.015 ($SE=0.004$), $p=0.001$.

A plot of residuals against predicted values showed no pattern, demonstrating that the modelling assumption of a common residual variance was met. A histogram of the residuals and Kolmogorov-Smirnov test of normality demonstrated that the modelling assumption concerning the residuals being normally distributed was also met ($p>0.2$).

The above analysis was repeated to explore whether the 'change' in participant's employment status from pre- to post-injury was associated with perceived stigma. The data was re-categorised, such that the student group (pre-injury) was combined with the pre-injury employment group ($n=140$), and both supported and unsupported post-injury employment groups were combined to form an overall post-injury employment group ($n=44$). Four groups were created for the purpose of this second analysis as depicted in table 3, which displays an overview of the mean PDD scores for each group.

Table 3: Mean scores on PDD by ‘change’ in employment group.

	<i>n</i>	PDD	
		<i>M</i>	<i>SD</i>
Unemployed pre-injury and unemployed post-injury	10	2.72	0.53
Unemployed pre-injury and employed post-injury	0	-	-
Employed pre-injury and unemployed post-injury	96	2.62	0.40
Employed pre-injury and Employed post-injury	44	2.47	0.53

Preliminary analyses were conducted to explore whether participant demographics differed significantly amongst the re-categorised groups. A one way between-subjects analysis of variance (ANOVA) revealed that there was a significant difference between groups in age ($F(2, 147)=8.765, p<0.001$). Bonferroni post-hoc comparisons on all group pairs showed that participants who were employed pre-injury and unemployed post-injury were significantly older ($M=47.99$ yrs, $SD=11.59$ yrs) than those employed pre-injury and employed post-injury ($M=39.3$ yrs, $SD=11.36$ yrs) ($p<0.001$). No other pairwise comparisons were significant. In line with previous analyses, age was considered a covariate. The re-categorised groups did not significantly differ in gender ($\chi^2(2, N=150)=1.746, p=0.418$), education level ($\chi^2(4, N=150)=2.648, p=0.618$) or time since injury ($\chi^2(4, N=150)=3.998, p=0.406$).

An analysis of covariance of perceived stigma was conducted, with ‘change’ in employment status from pre- to post-injury as the between subjects factor and age, perceived injury severity, emotional distress and time since injury as covariates. No significant effect of ‘change’ in employment status was identified when covariates were controlled ($F(2, 143)=1.106, p=0.334$). Parameter estimates demonstrated significant effects of all three covariates; as participant’s emotional distress increased by one unit,

PDD scores were found to increase by 0.015 ($SD= 0.005$), $p=0.005$. Similarly, as participant's time since injury increased by one unit, PDD scores were found to increase by 0.095 ($SD= 0.038$), $p=0.014$. Conversely, as participant's AQ scores increased by one unit, reflecting a decrease in participant's perceptions of their injury severity, PDD scores were shown to decrease by 0.015 ($SD=0.004$), $p<0.001$.

The modelling assumption of a common residual variance was met, as shown by no pattern in the plot of residuals against predicted values. A histogram of residuals and Kolmogorov-Smirnov test of normality further demonstrated that the modelling assumption concerning the residuals being normally distributed was met ($p>0.2$).

Perceived stigma and perceived work-difficulty amongst those currently employed

Participants currently in supported employment scored higher on the TBI-WIS ($M=22.86$, $SD=10.11$) than participants currently in unsupported employment ($M=22.63$, $SD=11.21$), however this difference was not significant ($t=-0.064$, $df=42$, $p=0.950$).

Subsequent, bivariate correlations (Pearson's r) were performed to explore the relationship between perceived stigma and perceived work-difficulty, as measured by the TBI-WIS. Correlational analyses were performed for the supported and unsupported employment groups separately, given participants may have perceived stigma as a result of needing support in the workplace to manage difficulties. A significant moderate positive correlation was found between perceived stigma and perceived work-difficulty amongst those currently in unsupported employment ($r=0.498$, $n=30$, $p=0.005$, two-tailed). There was no evidence of a significant

correlation between these two variables amongst those currently in supported employment ($r=0.016$, $n=14$, $p=0.957$, two-tailed).

Perceived stigma, self-efficacy and employment-related self-efficacy

Additional bivariate correlations (Pearson's r) were performed to explore the relationship between self-efficacy and perceived stigma, and employment-related self-efficacy and perceived stigma. Significant moderate negative correlations between self-efficacy and perceived stigma ($r=-0.412$, $N=150$, $p<0.001$, two-tailed) and employment-related self-efficacy and perceived stigma were identified ($r=-0.389$, $N=150$, $p<0.001$, two-tailed).

Post-hoc analyses

Post-hoc analyses were conducted to explore levels of self-efficacy and employment-related self-efficacy amongst the three post-injury employment groups. Examination of histograms for self-efficacy and employment-related self-efficacy, and Kolmogorov-Smirnov tests of normality demonstrated that both measures were normally distributed, therefore indicating the appropriate use of parametric tests for these analyses.

The mean scores on the IND and PEM subscales of the BQQ by post-injury employment group are displayed in table 4.

Table 4: Mean scores on IND and PEM subscales of BQQ by post-injury employment group.

	<i>n</i>	IND		PEM	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Unemployment	106	20.92	5.71	19.8	5.56
Unsupported employment	30	21.87	4.31	21.63	3.37
Supported employment	14	19.93	5.39	22.14	3.76

Two analyses of covariance were conducted, with post-injury employment status as the between subjects factor and age, perceived injury severity, emotional distress and time since injury as covariates. After controlling for covariates, there was no significant difference in self-efficacy between post-injury employment groups ($F(2,143)=2.657$, $p=0.074$). Further inspection of parameter estimates revealed significant effects of two of the covariates; as participant's emotional distress increased by one unit, IND scores were found to decrease by 0.247 ($SE=0.049$), $p<0.001$. Moreover, as scores on the AQ increased by one unit, reflecting a decrease in the participant's perception of their injury severity, IND scores were shown to increase by 0.250 ($SE=0.042$), $p<0.001$.

A plot of residuals against predicted values showed no pattern, demonstrating that the modelling assumption of a common residual variance was met in regard to self-efficacy. A histogram of residuals and Kolmogorov-Smirnov test of normality demonstrated that the modelling assumption concerning the residuals being normally distributed was also met ($p>0.2$).

After controlling for covariates, a significant difference in employment-related self-efficacy was found between post-injury employment groups ($F(2,143)=3.295$, $p=0.040$). On closer inspection of mean PEM scores, the largest difference in

employment-related self-efficacy existed between the unemployment and supported employment groups. However, this itself and no other pairwise comparisons were significantly different when conducting Bonferroni post-hoc comparisons on all group pairs. Moreover, parameter estimates similarly revealed significant effects of two covariates; as participant's emotional distress increased by one unit, self-efficacy scores were found to decrease by 0.162 ($SE=0.054$), $p=0.003$ whereas an increase of one unit on the AQ was associated with an increase of 0.224 in self-efficacy ($SE=0.046$), $p<0.001$.

The modelling assumption of a common residual variance was met, and a histogram of residuals and Kolmogorov-Smirnov test of normality similarly demonstrated that the modelling assumption concerning the residuals being normally distributed was met ($p>0.2$).

Discussion

Overview of findings

Perceived stigma

The current study aimed to explore whether survivors perceive stigma and as hypothesised, participants believed that they were stigmatised because of their brain injury. However, contrary to the hypothesis, survivors did not perceive an equal amount of stigma as those with mental illness²⁸.

This sample was compared to a mental health group as it is widely recognised that they are similarly a stigmatized group^{13,28,36}. However, the nature and onset of the difficulties caused by mental health problems and ABIs differ, which may account for the different levels of stigma perceived. Firstly, ABIs, such as traumatic brain injuries

are typically sudden in onset and caused by a tangible event that causes damage to the brain. This event can cause an immediate and marked difference in the survivor's abilities after the event, as compared to before³⁷. A survivor's ability to attribute their difficulties to a sudden and tangible event when explaining their difficulties may allow survivors to perceive their difficulties as more legitimate and therefore perceive less stigma. Whereas, the onset of mental health problems, such as depression, are typically more gradual in nature and not necessarily caused by a single tangible event that can be identified. This may cause individuals to perceive their mental health problems as less legitimate and therefore perceive more stigma. This is supported by themes that emerged from interviews with survivors. Nochi³⁸ highlighted that survivors were keen to emphasise that their difficulties were caused by an 'injury' and hence, 'a physical force from the outside' when explaining their difficulties to others.

Secondly, societal beliefs regarding the cause of mental illness and ABI differ which, in line with both the social-cognitive model of public stigma and MLT, is likely to influence the degree of discrimination displayed by society in addition to the degree of discrimination that is anticipated by the individual^{5,9}. Research cross-culturally reports that the public understand mental health problems to be caused by personal weaknesses^{39,40}. In contrast the public have demonstrated their awareness that ABIs are often caused by uncontrollable and tangible events, such as strokes and road traffic accidents⁷. Therefore, it is not surprising that those with mental illness perceive more stigma than survivors of ABI, given the cause of their diagnosis is associated with more negative stereotypes. Consistent with this proposed explanation is the finding that levels of perceived stigma increased as levels of emotional distress increased.

Perceived stigma and employment

The study further aimed to investigate whether perceived stigma was related to post-injury employment status and the ‘change’ in employment status from pre- to post-injury. In contrast to previous research, the hypothesis that unemployed survivors would perceive significantly more stigma was not supported^{12,16}. Similarly, the hypothesis concerning the ‘change’ in employment status from pre- to post-injury was not supported. These findings may be understood in a number of ways. Firstly, the current study employed a different measure of perceived stigma to that used by Alonso et al.¹². On closer inspection, the two-item measure employed by Alonso et al.¹² appeared to measure ‘experienced stigma’, which is considered distinct from ‘perceived stigma’, and therefore may explain this inconsistency^{41,42}.

Alternatively, the finding that unemployed survivors did not perceive significantly more stigma than employed survivors, may lead us to speculate that survivors perceived their injury as a legitimate reason for their unemployment. Therefore, unemployed survivors did not anticipate more discrimination from society.

Moreover, qualitative research highlights that survivors come to reappraise the meaning and importance of employment following their injury^{43,44}. Survivors described prioritising their simple enjoyment of life, causing employment to become ‘less important’ and ‘less central’ to their lives post-injury⁴³. Therefore, being a respected and successful member of a work organisation appeared to be of much less significance post-injury, and as result may not contribute to a survivor’s understanding of how society values and perceives them. Hence, unemployed survivors did not anticipate society to be less accepting of them because of their employment status and therefore did not perceive more stigma than employed survivors.

There was no significant difference in the number of difficulties reported by survivors in supported and unsupported employment, which may lead us to speculate that the support currently being provided to survivors is well-targeted. However, the number of difficulties survivors in supported employment would have experienced had support not have been provided is unknown. As hypothesised, there was a significant positive correlation between perceived work-difficulty and perceived stigma amongst those in unsupported employment. Although there was no evidence of this association amongst those in supported employment. It is important to acknowledge that the supported employment group comprised of a small sample, which limits the reliability. However, the lack of evidence for such an association in this study may reflect the valuable and protective role of formal support in reducing survivors' perceptions of stigma when faced with difficulties in the workplace. Hence, if survivors experience difficulties in the workplace and have a relationship with a specific individual in a supportive capacity, the survivor may feel better understood and therefore less likely to perceive stigma.

Further alluding to the importance of support, was the finding that survivors recruited online reported significantly higher levels of emotional distress than those completing paper forms. Survivors who completed paper forms were either members of a local Headway group or patients under the care of community brain injury services; hence all had a relationship and contact with a supportive other (e.g. health professional or support group facilitator). This finding may demonstrate the potential benefit of support provided by an individual outside of the survivor's family, in reducing the level of emotional distress experienced by survivors. The value of support groups in addition to support provided by their families was highlighted by survivors attending Headway, UK support groups ⁴⁵.

Perceived stigma, self-efficacy and employment-related self-efficacy

In line with previous research and the study's hypotheses, a significant negative correlation was found between perceived stigma and self-efficacy^{15,17}: survivors who perceived more stigma reported lower levels of self-efficacy. The current study is unable to comment on the issue of causality, however, it seems plausible to consider this relationship as bidirectional: firstly, survivors who concur with society's negative attitudes towards ABI and perceive stigma, may experience a lowering of self-efficacy, but in addition, lower self-efficacy may cause survivors to be more susceptible to perceiving stigma.

A significant negative correlation was similarly found between perceived stigma and employment-related self-efficacy: survivors who perceived more stigma, reported lower levels of employment-related self-efficacy. Given employment-related self-efficacy has been found to be significantly associated with current employment status²³, it was interesting that the above correlation was found yet an association between perceived stigma and post-injury employment status was not. Amongst those who continue to value employment post-injury, it may be their belief in their own employability (employment-related self-efficacy) which is of more significance in determining whether they perceive stigma, as opposed to their actual employment status. This is consistent with research exploring the role of support systems in enhancing health, which concludes that it is an individual's perceived social support that is influential over and above the actual support that they receive⁴⁶.

Survivors in supported employment reported significantly higher levels of employment-related self-efficacy than any other group, indicating that they had the greatest confidence in their ability to find employment and conduct work-related tasks.

Interestingly, those in supported employment perceived themselves to be more employable than those in unsupported employment, despite the two groups reporting an equal number of difficulties in the workplace, as measured by the TBI-WIS. The definition of employment-related self-efficacy encompasses the individual's belief in their ability to complete work-related tasks, which may have led us to expect this to be related to the number of actual difficulties that the individual experiences. However, this was not supported, and therefore leads us to speculate that it is the support that is provided which is effective in increasing a survivor's confidence in their employability as opposed to the actual number of difficulties that they encounter. This is of importance given that an individual's employment-related self-efficacy has previously been found to be associated with actual employment status after controlling for covariates ²³.

It is concerning that survivors in supported employment reported lower levels of self-efficacy, although this result was only approaching significance ($p=0.074$). This may suggest that in the presence of support, survivors are less likely to attribute the success of a task to their own abilities, and may instead attribute this to the support. This is consistent with the findings that survivors in unsupported employment reported higher levels of self-efficacy, which was similarly approaching significance. It is necessary that supported employment placements address this finding to ensure that survivors attribute the success of a task to their own abilities even in the presence of support, in order to enhance their self-efficacy.

Limitations

The findings of this study are subject to a number of limitations. Firstly, although the recruitment method was deemed appropriate for a study of this type, the possibility that

survivors who opted into the research differed in their perceptions of stigma than those who did not, must be acknowledged. It could be hypothesised that survivors perceiving particularly high levels of stigma chose not to participate, given their drive to avoid situations which may result in negative evaluation. Therefore this study may underestimate the prevalence of perceived stigma amongst survivors of ABI.

Secondly, this study required employed participants to declare their employment as unsupported or supported. Definitions of supported employment can vary greatly and this was not accounted for within the analysis. Moreover, the study limited the number of pre- and post-injury employment categories that participants could select. The number of participants that were to be recruited was unknown at the design stage of the study therefore the number of employment categories was limited to prevent having some employment groups with very few participants and therefore reducing power. However, it could be postulated that limiting the number of employment categories failed to capture some of the categories of work undertaken post-injury. For example, the employment categories employed by the questionnaire failed to accommodate for participants who engage in voluntary work or define their employment status as 'home-makers'. Moreover, the number of hours and days that survivors work post-injury can vary greatly given that survivors often return to work in a graded fashion, which may be associated with the degree of stigma perceived. Therefore it may be beneficial for future studies to firstly, increase the number of employment categories available to be selected and secondly, measure the duration of the work undertaken by participants. For example, future studies could separate part-time and full-time employment or alternatively require participants to declare the exact number of hours or days worked each week; this would enable any association between the duration of the work undertaken and the participant's level of perceived stigma to be explored.

Lastly, there are limitations associated with the study's use of a cross-sectional design. It aimed to explore whether survivors perceived stigma because of their ABI, however, this design was unable to account for individual differences in the amount of stigma survivors perceive as a result of other difficulties or anxieties. Similarly, this study was unable to draw any causal conclusions with regard to perceived stigma, self-efficacy and employment-related self-efficacy.

Clinical Implications

This study concludes that individuals with ABI perceive stigma as a result of their injury, which is associated with reduced self-efficacy and reduced employment-related self-efficacy. As proposed by MLT, previous research demonstrates that those who perceive stigma withdraw and avoid a wide range of social, employment and treatment opportunities in an attempt to protect themselves from the anticipated discrimination, which results in further negative consequences¹¹⁻¹³. This may have specific negative consequences for this population as engagement in these activities are consistently found to improve recovery outcomes and quality of life post-injury^{25,37,47}. In addition, these findings further point to the increased risk of perceiving stigma for survivors with mental health difficulties; this demands attention given survivors are at heightened risk of developing mental health difficulties post-injury⁴⁸.

It is vital that the general public, healthcare providers and policy makers are aware that survivors of ABI perceive stigma because of their injury and understand the negative consequences that result from this. This study emphasises that educating society about ABI, reducing prejudices and promoting the inclusion of survivors should be a public health priority, as is reducing prejudices about mental illness.

This study further supports the need for survivors to be supported on reintegrating in to society, in order to reduce the negative effects of any prejudice or discrimination they may perceive or experience. However, unfortunately support groups of this nature have been found to be sparse⁴⁹. Specific to the workplace, this study proposes the role of support in protecting survivors from perceiving stigma in the presence of work-related difficulties and enhancing survivors' beliefs in their own employability. Therefore this study suggests that employed survivors considered likely to experience difficulties in the workplace would benefit from on-going support.

Future research

A longitudinal design is required to explore how survivors come to perceive stigma, whilst controlling for initial levels of perceived stigma. Although, this study highlighted the associations between perceived stigma, self-efficacy and employment-related self-efficacy, a longitudinal design would enable causal conclusions to be drawn. This would enable more effective clinical interventions to be developed which aim to limit the negative effects of stigma.

In addition, research demonstrates that the public have different prejudices towards different types of brain injuries, dependent on the situations in which they were acquired; survivors considered responsible for their injury have been found to be perceived more negatively^{50,51}. It might be interesting to explore whether the way in which an ABI was acquired influences the amount of stigma that is perceived. Moreover, it may be valuable to determine whether the visibility of the injury influences perceptions of stigma, given some survivors have physical impairments which provide an outward indication of their injury. This would enable survivors at increased risk of

perceiving stigma to be identified and enable more anti-stigma interventions to be developed that are injury-specific.

References

1. Royal College of Physicians. *Rehabilitation following acquired brain injury: National clinical guidelines*. London, UK: Royal College of Physicians & British Society of Rehabilitation Medicine; 2003.
2. Zasler N, Martelli M. Mild traumatic brain injury: Impairment and disability assessment caveats. *Neuropsychol Rehabil*. 2003;13:31-42.
3. Jones JM, Jetten J, Haslam SA, Williams WH. Deciding to disclose: The importance of maintaining social relationships for well-being after acquired brain injury. In: Jetten J, Haslam C, Haslam A, eds. *The social cure: Identity, health and well-being*. Hove: Psychology Press; 2012.
4. Goffman E. *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice Hall; 1963.
5. Corrigan PW, Watson AC. The paradox of self-stigma and mental illness. *Clinical psychology: Science and Practice*. 2002;9:35-53.
6. Hamilton D, Sherman J. Stereotypes. In: Wyer R, Srull T, eds. *Handbook of social cognition, vol. 1: Basic processes*. 2nd ed. Hillsdale, NJ: Erlbaum; 1994.
7. Linden MA, Boylan A. 'To be accepted as normal': Public understanding and misconceptions concerning survivors of brain injury. *Brain Inj*. 2010;24:642-650.
8. Simpson G, Mohr R, Redman A. Cultural variations in the understanding of traumatic brain injury and brain injury rehabilitation. *Brain Inj*. 2000;14:125-140.
9. Link BG, Cullen FT, Struening EL, Shrout PE. A modified labeling theory approach to mental disorders: An empirical assessment. *Am Sociol Rev*. 1989;54:400-423.
10. Burgener SC, Berger B. Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and parkinson's disease. *Dementia*. 2008;7:31-53.

11. Link B. Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *Am Sociol Rev.* 1987;52:96-112.
12. Alonso J, Buron A, Rojas-Farreras S, et al. Perceived stigma among individuals with common mental disorders. *J Affect Disord.* 2009;118:180-186.
13. Markowitz FE. The effects of stigma on the psychological well-being and life satisfaction of persons with mental illness. *J Health Soc Behav.* 1998;39:335-347.
14. Hayward P, Wong G, Bright JA, Lam D. Stigma and self-esteem in manic depression: An exploratory study. *J Affect Disord.* 2002;69:61-67.
15. Kleim B, Vauth R, Adam G, Stieglitz R, Hayward P, Corrigan P. Perceived stigma predicts low self-efficacy and poor coping in schizophrenia. *J Ment Health.* 2008;17:482-491.
16. Alonso J, Buron A, Bruffaerts R, et al. Association of perceived stigma and mood and anxiety disorders: Results from the world mental health surveys. *Acta Psychiatr Scand.* 2008;118:305-314.
17. Bos AER, Kanner D, Muris P, Janssen B, Mayer B. Mental illness stigma and disclosure: Consequences of coming out of the closet. *Issues Ment Health Nurs.* 2009;30:509-513.
18. Snook EM, Motl RW. Physical activity behaviors in individuals with multiple sclerosis: Roles of overall and specific symptoms, and self-efficacy. *J Pain Symptom Manage.* 2008;36:46-53.
19. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. *Psychol Rev.* 1977;84:191-215.
20. Steadman-Pare D, Colantonio A, Ratcliff G, Chase S, Vernich L. Factors associated with perceived quality of life many years after traumatic brain injury. *J Head Trauma Rehabil.* 2001;16:330-342.

21. Shames J, Treger I, Ring H, Giaquinto S. Return to work following traumatic brain injury: Trends and challenges. *Disabil Rehabil.* 2007;29:1387-1395.
22. Tsaousides T, Warshowsky A, Ashman TA, Cantor JB, Spielman L, Gordon WA. The relationship between employment-related self-efficacy and quality of life following traumatic brain injury. *Rehabil Psychol.* 2009;54:299-305.
23. Waghorn GR, Chant DC, King R. Work-related subjective experiences, work-related self-efficacy, and career learning among people with psychiatric disabilities. *Am J Psychiatr Rehabil.* 2007;10:275-300.
24. Gilworth G, Carey A, Eyres S, et al. Screening for job loss: Development of a work instability scale for traumatic brain injury. *Brain Inj.* 2006;20:835-843.
25. Cullen N, Chundamala J, Bayley M, Jutai J. The efficacy of acquired brain injury rehabilitation. *Brain Inj.* 2007;21:113-132.
26. Wehman P, Targett P, West M, Kregel J. Productive work and employment for persons with traumatic brain injury: What have we learned after 20 years? *J Head Trauma Rehabil.* 2005;20:115-127.
27. Gamble D, Moore CL. Supported employment: Disparities in vocational rehabilitation outcomes, expenditures and service time for persons with traumatic brain injury. *J Vocat Rehabil.* 2003;19:47-57.
28. Link BG, Struening EL, Neese-Todd S, Asmussen S, Phelan JC. The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatr Serv.* 2001;52:1621-1626.
29. Facebook advertising. www.facebook.com. Accessed May to March, 2011 to 2012.
30. Link BG, Mirotznik J, Cullen FT. The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? *J Health Soc Behav.* 1991;32:302-320.

31. Bigelow D, Gareau M, Young D. *Quality of life questionnaire-respondent self-report version (interview schedule)*. Oregon: Oregon Health Sciences University; 1991.
32. Zigmond A, Snaith R. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand*. 1983;67:361-370.
33. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the hospital anxiety and depression scale: An updated literature review. *J Psychosom Res*. 2002;52:69-77.
34. The awareness questionnaire. <http://www.tbims.org/combi/aq>. Updated 2004. Accessed 10/09, 2010.
35. Sherer M, Bergloff P, Boake C, High W, Jr., Levin E. The awareness questionnaire: Factor structure and internal consistency. *Brain Inj*. 1998;12:63-68.
36. Rüsçh N, Angermeyer MC, Corrigan PW. Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *Eur Psychiatry*. 2005;20:529-539.
37. Douglas JM. Social linkage, self-concept, and well-being after severe traumatic brain injury. In: Jetten J, Haslam C, Haslam SA, Jetten J, Haslam C, Haslam SA, eds. *The social cure: Identity, health and well-being*. New York, NY US: Psychology Press; 2012:237-254.
38. Nochi M. "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Soc Sci Med*. 1998;46:869-878.
39. Link BG, Phelan JC, Bresnahan M, Stueve A, Pescosolido BA. Public conceptions of mental illness: Labels, causes, dangerousness, and social distance. *Am J Public Health*. 1999;89:1328-1333.
40. Nakane Y, Jorm AF, Yoshioka K, Christensen H, Nakane H, Griffiths KM. Public beliefs about causes and risk factors for mental disorders: A comparison of Japan and Australia. *BMC Psychiatry*. 2005;5.

41. Van Brakel WH, Anderson AM, Mutatkar RK, et al. The participation scale: Measuring a key concept in public health. *Disabil Rehabil.* 2006;28:193-203.
42. Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: A review of measures. *BMC Health Serv Res.* 2010;10:80-91.
43. Johansson U, Tham K. The meaning of work after acquired brain injury. *Am J Occup Ther.* 2006;60:60-69.
44. Gilworth G, Eyres S, Carey A, Bhakta BB, Tennant A. Working with a brain injury: Personal experiences of returning to work following a mild or moderate brain injury. *J Rehabil Med.* 2008;40:334-339.
45. Glover A. An exploration of the extent to which attending headway enhances quality of life after traumatic brain injury. *Disabil Rehabil.* 2003;25:750-760.
46. Haber MG, Cohen JL, Lucas T, Baltes BB. The relationship between self-reported received and perceived social support: A meta-analytic review. *Am J Community Psychol.* 2007;39:133-144.
47. Dunn EC, Wewiorski NJ, Rogers ES. The meaning and importance of employment to people in recovery from serious mental illness: Results of a qualitative study. *Psychiatr Rehabil J.* 2008;32:59-62.
48. Williams WH, Evans JJ. Brain injury and emotion: An overview to a special issue on biopsychosocial approaches in neurorehabilitation. *Neuropsychol Rehabil.* 2003;13:1-11.
49. Lefebvre H, Pelchat D, Swaine B, Ge'linas I, Levert M. The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Inj.* 2005;19:585-597.

50. Redpath SJ, Linden MA. Attitudes towards behavioural versus organic acquisition of brain injury. *Brain Inj.* 2004;18:861-869.
51. Linden MA, Hanna D, Redpath SJ. The influence of aetiology and blame on prejudice towards survivors of brain injury. *Arch Clin Neuropsychol.* 2007;22:665-673.
52. Gonzalez BD, Jacobsen PB. Depression in lung cancer patients: The role of perceived stigma. *Psychooncology.* 2012;21:239-246.
53. McBrinn J, Wilson FC, Caldwell S, et al. Emotional distress and awareness following acquired brain injury: An exploratory analysis. *Brain Inj.* 2008;22:765-772.
54. Brown AW, Moessner AM, Mandrekar J, Diehl NN, Leibson CL, Malec JF. A survey of very-long-term outcomes after traumatic brain injury among members of a population-based incident cohort. *J Neurotrauma.* 2011;28:167-176.

Part Three: Appendices

Appendix 1: Reflective statement

This reflective account aims to document my journey through the research process, focussing on the initial design stages of the project, obtaining ethical approval, experiences of data collection and report-writing, with reference to the specific areas of personal learning throughout.

Designing the research

The prospect of designing and undertaking an innovative research project within a department that has a substantial publication history was very exciting and motivating! However, my growing awareness of the degree of decision-making that this project would demand added a little anxiety in to the mix; ‘decision-making’ being a recurrent theme that featured greatly in my reflective diary and personal learning.

I was immediately drawn to my area of specific interest, brain injury and began conducting initial and broad literature searches in this area. However it was the Research Fair, in which potential Research Supervisors proposed initial ideas that brought me to explore and consider the issue of stigma in relation to brain injury. Having had little contact with survivors of brain injury at this stage, it was the experiences of my supervisor from her Neuropsychology role and the reading of survivors’ personal accounts that made me aware of the prejudices experienced by survivors daily. Finding journal articles, Government policies and media campaigns recognising and fighting the stigma of mental illness appeared relatively easy, however, in relation to survivors of brain injury, this was very difficult. At this point, it became clear that research of this kind was extremely sparse. This inspired me to focus my research project on survivor’s perceptions of stigma and aim to raise awareness of this

issue. In retrospect, choosing a topic that I was passionate about was wise, given its ability to motivate me through times of stress and challenge.

From this point forwards, my ideas and research questions were developing, expanding and multiplying, which led me to question whether the research project was becoming too ambitious. On reflection, I feel that my reluctance to assert limits to this research project at this point was associated with my struggle to make decisions with confidence. It was helpful to discuss this with my research supervisor and additional colleagues, with front-line experience of the challenges of the research process. It became clear that a common theme in their advice pertained to the simplicity and the size of the research project, with an emphasis on being 'realistic'! Following this, it was felt necessary to accept and negotiate limits that needed to be applied to this project, and after much deliberating, two research questions were dropped.

With regards to the research methodology, I was passionate to hear from as many survivors as possible, as I anticipated survivors' perceptions and experiences of stigma to vary. Following my recent learning, I was mindful to apply the same approach to recruitment: restrain over-ambition and apply realistic limits. Quantitative methodology allowed for specific concepts, such as perceived stigma to be reliably measured and compared, and allowed a large sample to be recruited. In addition, the growing use of online recruitment and participation led me to question whether this methodology could be used for this project. I was mindful of the pros and cons associated with online recruitment and aware that some survivors may be prohibited from participating given their need to access the internet. However, online recruitment was to be used as an adjunct to face-to-face recruitment from local brain injury services and support groups, which was thought to provide additional survivors with opportunities to participate. It was at this point, that communicating with colleagues

that had previously used online methodology and making contact with potential facilitators, who were in a position to advertise the online study that was of extreme value, in order to ascertain whether this methodology was a viable option. I was excited by the positivity and enthusiasm that this received, particularly amongst those with close contact with survivors. I was also encouraged to learn that online recruitment and participation had been previously used within the field of brain injury research, and therefore decided to make use of online methodology.

Obtaining ethical approval

It was necessary to obtain ethical and research governance approval from two NHS sites, which felt a very lengthy and slow process. Initially, I was very enthusiastic to hear that my project proposal satisfied the requirements for the Proportionate Review Sub-Committee, which was designed for studies with few ethical considerations and aimed to accelerate proposals through the ethical approval process. Although I was grateful for the immediacy of the committee's opinion, this meant that my excitement was short-lived, as the committee felt unable to grant approval due to the issue of participants' capacity to consent to online studies. I felt frustrated at this point, given survivors of brain injury were being considered differently to participants with other clinical conditions or diagnoses. Recruiting survivors using this methodology had been undertaken previously with huge success, therefore the committee's reluctance to grant approval at this stage and potentially putting additional obstacles in the way, seemed to only serve to deny survivors the opportunity to participate, and further reinforce the stigma they experience. In addition, there was no Committee available to review the proposal again for at least one month, which further added to my frustration. At this time, I perceived a delay of one month as a huge set-back, however in hindsight I was

still ahead with regards to having the project completed on time. Following minor amendments, the project was granted ethical and research governance approval.

Data collection

After uploading the approved questionnaire on to surveymonkey.com, it was very exciting to finally click the tab named 'open collector' to open the online questionnaire to participants! My task was then to motivate and develop working-relationships with facilitators who were in a position to display and advertise the web-link amongst survivors of brain injury. On reflection, it was the initial ground-work in forming these relationships and regular contact with key facilitators which was most effective in raising survivors' awareness of the study and providing them with the opportunity to participate. I learnt the value of forming relationships and liaising with other professionals in order to conduct research on a big scale. It was extremely exciting to observe the number of participants starting the questionnaire online increase and I was surprised by the rate at which this increased! Participants wrote additional comments below the web-link following their completion, which were very moving and reflected their positivity about the project.

In addition, I attended brain injury services and support groups, which enabled me to meet with survivors directly. I was privileged to hear the stories shared by survivors and developed an understanding of their need and desire to do this. At times I felt uncomfortable listening as it felt alien to be in the presence of survivors without focussing on therapeutic goals and formulation, and in some ways left me with a feeling of uselessness. It was necessary to reflect, seek supervision and discuss with colleagues in order to make sense of this; on reflection this discomfort appeared to stem from the unfamiliarity of meeting survivors in a sole research capacity, given I was more

comfortable adopting the more familiar clinical role. However, I was able to become more aware of the therapeutic benefits of simply listening, which reminded me not to lose sight of this in my clinical work.

In contrast to my colleagues, it became clear that I was going to achieve my target number of participants easily. I was struck by how eager I was to analyse the findings given I had anticipated being quite avoidant of the analysis stage due to the complexity of statistical analysis and SPSS. There was something about analysing data that I had collated, which was extremely motivating and caused a positive shift in my initial thoughts towards data analysis. It was essential that I controlled this eagerness in order to provide as many survivors with the opportunity to participate and share their personal experiences as possible.

Report writing

Despite approaching this final phase of the research process in a timely fashion, I was unable to escape the overwhelming feelings associated with the sheer size of the portfolio that needed to be written. Although the experience of writing a portfolio shared similarities with previous assignments I had written, I had rarely experienced the need to focus on two papers simultaneously, which although were strongly linked, were very distinct pieces of work that I aimed to submit for publication in isolation. This required extensive time-management skills and clear boundary setting, in order for the impending deadline to be met. The write-up process was aided by setting clear self-imposed deadlines that were shared with my supervisor. I was struck by how similar the conclusions and clinical implications of both the systematic literature review and empirical paper were, which on a personal level reinforced the extent to which brain

injury warrants the attention of policy-makers, and government and media campaigning to raise awareness and promote the inclusion of survivors.

Concluding reflections

On approaching the end of this research journey, I continue to be very passionate about this research area. I am indebted to the survivors that shared their experiences by participating in this research and believe that it is essential that these are shared with a wider audience. I have therefore chosen to submit the systematic literature review to the multi-disciplinary journal, *Brain Injury*. The majority of journal articles evaluated by this review were published in this journal, which therefore provides continuity for readers. For the empirical paper, the *Journal of Head Trauma Rehabilitation* was chosen due to it being very highly ranked in the field of rehabilitation. This journal provides empirical evidence for the clinical management and rehabilitation of survivors and therefore was hoped to bring the issue of stigma to the forefront of the minds of a range of professionals working directly with survivors.

It is clear that this research journey has been a positive one. It has provided me with the opportunity to identify and work through personal challenges, in addition to developing practical skills and a working knowledge of the research process. But in particular, this experience has led me to truly understand the importance of research and appreciate the efforts of Researchers in striving to undertake high quality projects. It is easy to spot some of the limitations when reading empirical papers and overlook these as a simple critique of previous work. However, research limitations are much more than this, and this process has enabled me to fully appreciate their role and potential; limitations are quite possibly the most vital aspect of the process, in allowing us to identify future research questions and possibilities, in order to further our understanding and knowledge. I am excited by the endless opportunities that research poses and have

realised through the means of this process that research is undoubtedly part of what I aim to achieve in the future.

Appendix 2: Author guidelines for submission to journals

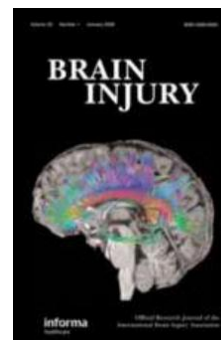
Appendix 2.1: Brain Injury guidelines.

Appendix 2.2: Journal of Head Trauma Rehabilitation guidelines.

Brain Injury

Instructions for Authors

Brain Injury publishes critical information relating to research and clinical practice, adult and pediatric populations. The Journal covers a full range of relevant topics relating to clinical, translational, and basic science research. Manuscripts address emergency and acute medical care, acute and post-acute rehabilitation, family and vocational issues, and long-term supports. Coverage includes assessment and interventions for functional, communication, neurological, and psychological disorders.



Manuscript Preparation

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author(s) should be removed from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

Brain Injury considers all manuscripts at the Editors' discretion; the Editors' decision is final.

Brain Injury considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to ***Brain Injury***, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which ***Brain Injury*** incurs, and their papers will not be published. Copyright will be transferred to the journal ***Brain Injury*** and Informa UK Ltd., if the paper is accepted.

General Guidelines

Please write clearly and concisely, stating your objectives clearly and defining your terms. Your arguments should be substantiated with well reasoned supporting evidence.

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal, and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

For all manuscripts, gender-, race-, and creed-inclusive language is mandatory.

Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons).

Ethics of Experimentation: Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human subjects. The Code of Ethics of the World Medical Association ([Declaration of Helsinki](#)) represents a minimal requirement.

Abstracts are required for all papers submitted, they should not exceed 200 words and should precede the text of a paper. [See below](#) for further information.

Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see [References](#) section for examples).

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (on separate pages); figures; figure captions (as a list).

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing your article. The title page should be uploaded separately to the main manuscript and designated as “title page – not for review” on ScholarOneManuscripts.

Abstract

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title and author's name and address, preceding the main text.

For papers reporting original research, state the primary objective and any hypothesis tested; describe the research design and your reasons for adopting that methodology; state the methods and procedures employed, including where appropriate tools, hardware, software, the selection and number of study areas/subjects, and the central experimental interventions; state the main outcomes and results, including relevant data; and state the conclusions that might be drawn from these data and results, including their implications for further research or application/practice.

For review essays, state the primary objective of the review; the reasoning behind your literature selection; and the way you critically analyse the literature; state the main outcomes and results of your review; and state the conclusions that might be drawn, including their implications for further research or application/practice.

The abstract should not exceed 200 words.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written $10.0 \text{ SD } 2.65$. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years $4 \pm$ and a group all precisely 4.0 years, 4.0.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here

Each table and/or figure must have a title that explains its purpose without reference to the text. Tables and/or figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should

contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher.

Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

Letters to the Editor

Letters to the Editor will be considered for publication subject to editor approval and provided that they either relate to content previously published in the Journal or address any item that is felt to be of interest to the readership. Letters relating to articles previously published in the Journal should be received no more than three months after publication of the original work. Pending editor approval, letters may be submitted to the author of the original paper in order that a reply be published simultaneously. Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via ScholarOne Manuscripts and should contain a Declaration of Interest statement.

Notes on Style

All authors are asked to take account of the diverse audience of *Brain Injury*. Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience.

Some specific points of style for the text of original papers, reviews, and case studies follow:

- *Brain Injury* prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.
- *Brain Injury* uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.
- Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.
- Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
- Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.
- Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).
- ***Brain Injury*** is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.
- Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.

- All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).
- Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally. Some suggested editorial emendations to a typical text are indicated in the following with square brackets: 'From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been a shift from heurism to constructivism in the design of [British] science courses'.
- The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.
- Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly.
- n (not N), % (not per cent) should be used in typescripts.
- Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading "Declaration of interest". If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: The authors report no declarations of interest. When submitting a paper via ScholarOne Manuscripts, the "Declaration of interest" field is compulsory (authors must either state

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References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

Examples are provided as follows:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. *Science* 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. *The pharmacological basis of therapeutics*. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. *Advances in the control of Theileriosis*. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. *Brain Injury* 23(11):853-865. <http://www.informaworld.com/10.1080/02699050903283221>. Accessed 2009 Oct 06

Webpage: [6] British Medical Journal [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: <http://bmj.bmjournals.com>

Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: <http://www.cdcnpin.org/>

SCOPE

The *Journal of Head Trauma Rehabilitation (JHTR)* is a bimonthly journal devoted to clinical management and rehabilitation of persons with brain injury. It is interdisciplinary, and designed to provide the most current and relevant information for the practicing professional. Four issues each year are devoted to single topics, solicited by the editors, and two consist primarily of unsolicited, empirical research reports.

Authors are encouraged to submit to *JHTR* original manuscripts based on observations or experimentation that add new knowledge to the field of brain injury and rehabilitation. Analytical reviews that codify existing knowledge or illuminate the present and future roles of practitioners in the field are welcomed. In addition to topical articles, *JHTR* seeks manuscripts dealing with a variety of subjects that have current or future importance to all areas of brain injury rehabilitation, from acute medical management and rehabilitation therapies to problems with reintegration into the community. Acceptance or rejection of an article is determined through masked peer review.

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Authors must state all possible conflicts of interest in the **Title Page of the manuscript**, including financial, consultant, institutional and other relationships that might lead to bias or a conflict of interest. If there is no conflict of interest, this should also be explicitly stated as none declared. All sources of funding should be acknowledged in the **Title Page of the manuscript**. All relevant conflicts of interest and sources of funding should be included on the title page of the manuscript with the heading "Conflicts of

Interest and Source of Funding:”.

For example:

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- Manuscripts should be ordered as follows: title page, abstracts, text, references, appendixes, tables, and any illustrations.
- Manuscripts should be line numbered in their original format (e.g. Microsoft Word line numbering).
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- Manuscripts should generally not exceed 25 double-spaced, typed pages, inclusive of references, tables, figures and text. Longer papers may be submitted when clarity of content substantially depends on length.
- Title page including (1) title of the article; (2) author names (with highest academic degrees) and affiliations (including titles, departments, and name and location of institutions of primary employment); (3) all possible conflicts of

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- A structured abstract of no more than 200 words should be prepared and include up to 10 key words that describe the contents of the article like those that appear in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) or the National Library of Medicine's Medical Subject Headings (MeSH).
- There should be a clear indication of the placement of all tables and figures in text.
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- References must be cited in text and styled in the reference list according to the *American Medical Association Manual of Style*, ed. 9, copyright 1998, AMA. They must be numbered consecutively in the order they are cited; reference numbers may be used more than once throughout an article. Page numbers should appear with the text citation following a specific quote. References should be double spaced and placed at the end of the text.
- References should not be created using Microsoft Word's automatic footnote/endnote feature.
- References should be included on a separate page at the end of the article and should be double-spaced.
- Examples of correctly styled reference list entries:

Journals: Author, article title, journal, year, volume, inclusive pages. Doe J. Drug therapy in brain injury. *J Clin Psychopharmacol*. 1975;23:170–184.

Books: Author, book title, place of publication, publisher, year.

Rosenthal M, Griffith ER, Kreutzer JS, et al, eds. *Rehabilitation of the Adult and Child with Traumatic Brain Injury*. 3rd ed. Philadelphia: FA Davis Co; 1999.

Chapters: Author, chapter title, book editor book title, place of publication, publisher, year.

McTavish IM. P Mild brain injury in the community. In: Rosenthal M, Griffith ER, Kreutzer JS, et al, eds. *Rehabilitation of the Adult and Child with Traumatic Brain Injury*. 3rd ed. Philadelphia: FA Davis Co; 1999.

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- Tables should be on a separate page at the end of the manuscript.
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- Include explanatory footnotes for all nonstandard abbreviations.
- Cite each table in the text in consecutive order.
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Thank you.

Appendix 3: Ethical and Research Governance Approval

Appendix 3.1: NHS Ethical approval correspondence

*Appendix 3.2: Research Governance approval for NHS Ashton, Leigh & Wigan
PCT*

*Appendix 3.3 Research Governance approval for NHS Leeds Community
Healthcare Trust*

Appendix 3.1: NHS Ethical approval correspondence

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Appendix 4: Supplementary information for the systematic literature review

Appendix 4.1: Data extraction form for quantitative studies

Appendix 4.2: Data extraction form for qualitative study

Appendix 4.3: Quality assessment tool for quantitative studies

Appendix 4.4: Quality assessment tool for qualitative study

Appendix 4.5: Kappa ratings for each criterion of the quality assessment tool

Appendix 4.6: Quality assessment ratings for quantitative studies (rater A and rater B)

Appendix 4.7: Quality assessment ratings for qualitative study (rater A and rater B)

Appendix 4.1: Data extraction form for quantitative studies

<p>Author(s):</p> <p>Title:</p> <p>Journal:</p>
<p>Study Characteristics</p> <p><i>Research questions/aims:</i></p> <p><i>Replication of previous study?</i></p> <p><i>Study location:</i></p> <p><i>Study design:</i></p> <p><i>Sub-groups compared?</i></p>
<p>Participant Characteristics</p> <p><i>Sample size:</i></p> <p><i>Participant demographics (Age; gender; ethnicity; education)</i></p>
<p>Participant Recruitment</p> <p><i>Recruitment method and location (e.g. shopping mall)</i></p> <p><i>Inclusion/exclusion criteria</i></p>
<p>Measures</p> <p><i>Target measure (knowledge or attitudes)</i></p> <p>Measures used to assess knowledge or attitudes</p> <p>Other factors explored (e.g. familiarity with ABI; aetiology of ABI)</p>

Results

Statistical tests used

Main findings (Differences between groups found?)

Findings comparable to previous studies?

Conclusions

Clinical Implications

Limitations:

Further comments

Appendix 4.2: Data extraction form for qualitative study

<p>Author(s):</p> <p>Title:</p> <p>Journal:</p>
<p>Study Characteristics</p> <p><i>Research questions/aims:</i></p> <p><i>Replication of previous study?</i></p> <p><i>Study location:</i></p> <p><i>Study design:</i></p> <p><i>Sub-groups compared?</i></p>
<p>Participant Characteristics</p> <p><i>Sample size:</i></p> <p><i>Participant demographics (Age; gender; ethnicity; education)</i></p>
<p>Participant Recruitment</p> <p><i>Recruitment method and location (e.g. shopping mall)</i></p> <p><i>Inclusion/exclusion criteria</i></p>
<p>Results</p> <p><i>Analysis</i></p> <p><i>Themes</i></p> <p><i>Main Findings</i></p>

*Findings comparable to
previous studies?*

Conclusions

Clinical Implications

Limitations:

Further comments

Appendix 4.3: Quality assessment tool for quantitative studies

<p style="text-align: center;">Quality criteria for quantitative studies</p>	<p style="text-align: center;">Quality rating: Yes (1) OR No (0) OR Not applicable (-)</p>
	<p style="text-align: center;">Study Author Study Title</p>
<p>Abstract adequately discusses:</p> <p>1 Objectives/Aims/Hypotheses</p> <p>2 Design</p> <p>3 Method</p> <p>4 Results</p> <p>5 Conclusions</p>	
<p>6 Appropriate and clearly focussed research question(s)/aim(s)</p> <p>7 Main outcomes to be measured clearly described in introduction or method? <i>(if the main outcomes are first mentioned in the Results section, the question should be answered no.)</i></p>	
<p>8 Design appropriate to study research question(s)?</p>	
<p>Sample</p> <p>9 Sample representative of the group from which it is drawn (i.e. public or students)</p> <p>10 Participant demographics adequately reported? (i.e. gender; age; education level)</p> <p>11 Response rate reported?</p>	
<p>Subgroups of participants (only relevant to those studies with comparison groups)</p> <p>12 If relevant, have differences between subgroups, which may influence results been acknowledged? (e.g. age; gender; familiarity with ABI) (If differences (age; gender etc) have been explored then answer yes)</p>	

<p>13 If relevant, were participants randomly allocated to groups? (If subgroups were distinguished on the basis of participant demographics (i.e. males and females) and hence could not be randomly allocated, mark as n/a)</p>	
<p>Method</p> <p>14 Sampling method reported and appropriate</p> <p>15 Data collection method reported and appropriate</p>	
<p>Measures</p> <p>16 Are the main outcome measures used accurate and reliable?</p>	
<p>Data analysis</p> <p>17 Data analysis strategy reported</p> <p>18 Data strategy analysis appropriate to research question(s)</p> <p>19 If relevant, have actual probability values been reported (<i>e.g. 0.035 rather than <0.05</i>) for the main outcomes except where the probability value is less than 0.001?</p>	
<p>Findings</p> <p>20 Main findings clearly described</p> <p>21 Findings and conclusions are relevant to initial research question(s)</p> <p>22 Limitations reported</p> <p>23 Implications reported</p>	
<p style="text-align: right;">Total Score</p> <p style="text-align: right;">% of relevant criteria met</p>	

Appendix 4.4: Quality assessment tool for qualitative study

Quality criteria for qualitative studies	Quality rating: Yes (1) OR No (0) OR Not applicable (-)
	Study Author Study Title
<p>Abstract</p> <p>1 Objectives/Aims/Hypotheses</p> <p>2 Design</p> <p>3 Method</p> <p>4 Results</p> <p>5 Conclusions</p>	
<p>6 Appropriate and clearly focussed research question(s)/aim(s)</p> <p>7 Main outcomes to be measured clearly described in introduction of method? <i>(if the main outcomes are first mentioned in the Results section, the question should be answered no.)</i></p>	
<p>8 Qualitative methodology most appropriate for study objectives</p> <p>9 Underpinning values and assumptions discussed</p>	
<p>Sample</p> <p>10 Sample representative of the group from which it is drawn</p> <p>11 Participant demographics adequately reported? (i.e. gender; age; education level)</p> <p>12 Response rate reported?</p>	
<p>Method</p> <p>13 Sampling method reported and appropriate</p> <p>14 Data collection method reported and appropriate</p>	
<p>Data analysis</p> <p>15 Data analysis strategy reported</p> <p>16 Data strategy analysis appropriate to research question(s)</p> <p>17 More than one rater</p>	

<p>Findings</p> <p>18 Main findings clearly described</p> <p>19 Findings and conclusions are relevant to initial research question(s)</p> <p>20 Limitations reported</p> <p>21 Implications reported</p>	

Total Score

% of relevant criteria met

Appendix 4.5: Kappa ratings for each criterion of the quality assessment tool

Table 1: Kappa ratings for each criterion of the quality assessment tool for quantitative studies

Criterion	Kappa value	p value
1	0.855	<0.001
2	0.89	<0.001
3	0.771	0.001
4	-	-
5	0.771	0.001
6	0.642	0.003
7	0.441	0.054
8	0.826	<0.001
9	-	-
10	0.612	0.004
11	1	<0.001
12	0.85	0.000
13	1	0.025
14	0.24	0.107
15	-	-
16	0.855	<0.001
17	0.275	0.226
18	-	-
19	0.767	0.001
20	-	-
21	-	-
22	0.872	<0.001
23	-	-
M= 0.729		-

*Kappa values unable to be calculated for criteria where at least one rater gave only one response for all papers reviewed

Table 2: Guidelines for the interpretation of Kappa (Landis & Koch, 1988)

Kappa value	Interpretation
< 0	Poor agreement
0.0 – 0.20	Slight agreement
0.21 – 0.40	Fair agreement
0.41 – 0.60	Moderate agreement
0.61 – 0.80	Substantial agreement
0.81 – 1.00	Almost perfect agreement

Landis J, Koch G. The measurement of observer agreement for categorical data. Biometrics 1988;33:159-74

Appendix 4.6: Quality assessment ratings for quantitative studies (Author and independent rater)

Criteria	Included studies									
	Gouvier et al. (1988)	Aubrey et al. (1989)	Mittenberg et al. (1992)	Willer et al. (1993)	Vaughn et al. (1994)	Lees-Hayley & Dunn (1994)	O'Jile et al. (1997)	Guilmette & Paglia (2004)	Redpath & Linden (2004)	Linden et al. (2005)
	Author (Independent rater)									
1	0 (0)	0 (0)	0 (0)	1 (1)	1 (0)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)
2	0 (1)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	1 (1)
3	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	0 (1)	0 (0)	1 (1)	1 (1)	1 (1)
4	1 (1)	1 (1)	1 (1)	1 (1)	0 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
5	1 (1)	0 (0)	1 (1)	0 (0)	1 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
6	1 (1)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
7	1 (0)	1 (1)	1 (1)	0 (0)	1 (1)	0 (1)	0 (0)	1 (1)	1 (1)	1 (1)
8	1 (1)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
9	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	0 (1)	1 (1)	1 (1)
10	1 (1)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (0)	1 (1)
11	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
12	- (-)	0 (0)	1 (0)	0 (0)	1 (1)	- (-)	1 (1)	1 (1)	0 (0)	1 (1)
13	- (-)	0 (0)	- (-)	- (-)	- (-)	- (-)	- (-)	- (-)	1 (1)	- (-)
14	1 (1)	0 (0)	1 (1)	0 (1)	1 (1)	0 (0)	0 (1)	0 (0)	0 (1)	0 (1)
15	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (0)	1 (1)
16	0 (0)	0 (0)	0 (0)	0 (0)	0 (1)	0 (0)	0 (0)	0 (0)	1 (1)	1 (1)
17	1 (0)	1 (1)	0 (0)	0 (1)	0 (1)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)
18	1 (1)	1 (1)	0 (1)	0 (1)	1 (1)	0 (1)	1 (1)	1 (1)	1 (1)	1 (1)
19	0 (0)	0 (0)	0 (1)	- (-)	1 (1)	- (-)	1 (1)	0 (0)	1 (1)	1 (1)
20	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	0 (1)	1 (1)	1 (1)	1 (1)	1 (1)
21	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
22	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	1 (0)
23	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
Total %	76.2% (71.4%)	47.8% (47.8%)	68.2% (72.7%)	52.4% (66.7%)	77.3% (81.8%)	50% (55%)	72.7% (77.3%)	72.7% (77.3%)	82.6% (78.3%)	90.9% (90.9%)

Criteria	Included studies								
	McKenzie & McMillan (2005)	Hux et al. (2006)	Linden & Crothers (2006)	Mulhern & McMillan (2006)	Crothers et al. (2007)	Linden et al. (2007)	Chapman & Hudson (2010)	McLellan et al. (2010)	McKinlay et al. (2011)
	Author (Independent rater)								
1	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
2	0 (0)	1 (1)	0 (0)	0 (0)	0 (0)	1 (1)	1 (1)	0 (0)	1 (1)
3	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
4	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
5	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
6	0 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
7	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
8	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	0 (1)	1 (1)
9	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
10	1 (1)	1 (1)	1 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)
11	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
12	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)
13	- (-)	- (-)	- (-)	- (-)	- (-)	1 (1)	- (-)	1 (1)	1 (1)
14	0 (1)	1 (1)	0 (1)	1 (1)	0 (1)	1 (1)	0 (1)	1 (1)	1 (1)
15	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
16	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	1 (1)	0 (0)	0 (0)	0 (0)
17	1 (0)	1 (1)	1 (1)	1 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
18	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
19	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	1 (1)	1 (1)	0 (0)	0 (1)
20	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
21	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
22	1 (1)	0 (0)	1 (1)	1 (1)	1 (1)	0 (0)	0 (0)	1 (1)	1 (1)
23	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
Total %	72.7% (77.3%)	85.7% (85.7%)	77.3% (81.8%)	81.8% (77.3%)	86.3% (90.9%)	91.3% (91.3%)	81.8% (86.3%)	73.9% (78.3%)	82.6% (87%)

Appendix 4.7: Quality assessment ratings for qualitative study (Author and independent rater)

Study	
Linden & Boylan (2010)	
Criteria	Author (Independent rater)
1	1 (1)
2	1 (1)
3	1 (1)
4	1 (1)
5	1 (1)
6	1 (1)
7	1 (1)
8	1 (1)
9	0 (0)
10	0 (1)
11	1 (1)
12	0 (0)
13	0 (0)
14	1 (1)
15	1 (1)
16	1 (1)
17	1 (1)
18	1 (1)
19	1 (1)
20	1 (1)
21	1 (1)
Total %	81% (85.7%)

Appendix 5: Supplementary information for the empirical paper

Appendix 5.1: Advertisement displayed on Headway, UK website and Headway page of social networking site, Facebook.

Appendix 5.2: Information sheet – online form

Appendix 5.3: Consent form – online and paper form


Appendix 5.4: Information sheet – paper form

Appendix 5.5: Flyer outlining details of online participation

Appendix 5.6: Questionnaire (including all measures) completed by all participants

Poster 25/02/11
Version 2.0

Be part of an important new Stigma Research Study...



This study is researching the views of people who have had a brain injury.

- Are you aged 18 or over?
- Have you had a brain injury in the past?


If you have answered YES to these questions, we invite you to take part and complete a questionnaire.

This will take you about 25minutes.

To find out more & to complete the questionnaire please go on the link below:
<https://www.surveymonkey.com/s/acquiredbraininjury>

OR Log on to the Headway website and find the link under the 'News' tab then the 'Research' tab

OR Contact Andrea Ralph on A.J.Ralph@2009.hull.ac.uk



Participant Information Sheet: Online form

Study title: Stigma following acquired brain injury (ABI)

We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read this information carefully. If there is anything you read that is not clear or you would like to ask any questions, please do not hesitate to contact me using the details given below before deciding whether to take part.

What is the purpose of the study?

Sometimes people who suffer from illness or injury worry that people hold negative views about them because of their illness or injury. We are looking at whether people who have a brain injury believe other people hold negative views about them because of their brain injury. We are also looking at whether these beliefs change depending on whether people are in work or not, and how this affects how they feel about themselves. This will help us better understand how such beliefs can affect people, and give us an idea of how to help people better.

The study is being undertaken for educational purposes and will be submitted as part of the researcher's clinical psychology doctoral training course.

Why have I been invited?

You have been invited to take part because you are over the age of 18 and you have had a brain injury in the past. The study aims to recruit 63 participants.

What do I need to do if I chose to take part?

You will be asked to complete a questionnaire online. It should take you approximately 25minutes to complete.

The questionnaire will ask you some general questions about you, how you feel at the moment and whether you experience any difficulties since your injury. It will also ask you to think about how others may think about somebody who has had a brain injury. If you have a job at the moment, you will be asked to complete some questions about how well you think you are coping at work. The questionnaire will not ask for any personally identifiable information.

Do I have to take part and what if I change my mind?

No, it is up to you to decide to take part and no-one will know if you decide to take part or not. If you decide to take part but then change your mind whilst you are completing it, that is okay, you can click on the 'discontinue' button, which is shown on every page. If you discontinue your responses will not be saved and will not be used in the study. But once you have 'submitted' the survey it cannot be withdrawn because the data is anonymous.

If you would like to read some general information about taking part in research take a look at <http://www.nhs.uk/Conditions/Clinical-trials/Pages/Introduction.aspx>.

Will my taking part in this study be confidential?

No personally identifiable information will be collected during this study and your computer's IP address will not be saved. Therefore, we cannot trace your responses back to you.

What are the possible risks of taking part?

Some people may become upset when completing this survey because it asks you to think about how you feel at the moment and how well you think you are coping. Some people also become tired after reading and answering questions, so you are reminded to take breaks if needed. If you do become upset or tired and you do not wish to finish the questionnaire you can click on the 'discontinue' button, which is shown on every page. You will then be presented with a screen, which lists helpful information on how to receive some support. This page will also be shown at the end of the questionnaire if you have 'submitted' your questionnaire. You are encouraged to contact the researcher if you feel that you would like to discuss options for support.

What are the possible benefits of taking part?

We cannot promise this study will help you but we hope that the information we gain from this study will help improve the support that people with a brain injury receive and raise awareness about some of the difficulties that people with brain injuries can face.

Taking part will give you a chance to think about how you are feeling at the moment and how well you are coping since your injury and some people can find that helpful.

Can I find out my results or what they mean?

All the data collected is anonymous and so we are not able to trace your responses back to you. Therefore we are not able to provide you with your results. A summary of the overall results will be available on the 'Headway, UK' website and the Headway Facebook page when the study is completed.

What will happen to the results of this study?

The results will be submitted as part of the researcher's training course. It is also hoped that the results will be published in international journals and presented at conferences.

Expenses and payments

You will not be paid for taking part in the study and you cannot claim any expenses.

Who has reviewed this study?

This study has been reviewed by the Nothern and Yorkshire Research Ethics Committee. It has also been peer reviewed by the research team at the Department of Clinical Psychology and Psychological Therapies at the University of Hull and is being sponsored by Humber Foundation NHS Trust.

Further information and contact details.

The research is organised by Andrea Ralph, a Trainee Clinical Psychologist employed by Humber NHS Foundation Trust and training at the University of Hull. If you have any questions about this study please do not hesitate to contact her on:

A.J.Ralph@2009.hull.ac.uk

Consent Form
Stigma following acquired brain injury (ABI)

Name of researcher: Andrea Ralph

(please tick)

1. I confirm that I have read and understand the information sheet dated 25/03/11 (version 2.0) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that once I have submitted the survey it is not possible for my answers to be withdrawn since all the data is anonymous.

4. I understand that relevant sections of my medical notes and data collection during the study may be looked at by individuals from the regulatory authorities or NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

*If you are participating via the Headway website this point is NOT applicable to you- please tick here

5. I am aware of the potential risks and benefits of taking part.

6. I agree to take part in the above study.

Participant Information Sheet: Paper form

Study title: Stigma following acquired brain injury (ABI)

We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read this information carefully. If there is anything you read that is not clear or you would like to ask any questions, please do not hesitate to contact me using the details given below before deciding whether to take part.

What is the purpose of the study?

Sometimes people who suffer from illness or injury worry that people hold negative views about them because of their illness or injury. We are looking at whether people who have a brain injury believe other people hold negative views about them because of their brain injury. We are also looking at whether these beliefs change depending on whether people are in work or not, and how this affects how they feel about themselves. This will help us better understand how such beliefs can affect people, and give us an idea of how to help people better.

The study is being undertaken for educational purposes and will be submitted as part of the researcher's clinical psychology doctoral training course.

Why have I been invited?

You have been invited to take part because you are over the age of 18 and you have had a brain injury in the past. The study aims to recruit 63 participants.

What do I need to do if I chose to take part?

You will be asked to complete a questionnaire. It should take you approximately 25 minutes to complete.

The questionnaire will ask you some general questions about you, how you feel at the moment and whether you experience any difficulties relating to your injury. It will also ask you to think about how others may think about somebody who has had a brain injury. If you have a job at the moment, you will be asked to complete some questions about how well you think you are coping at work. The questionnaire will not ask for any personally identifiable information.

Do I have to take part and what if I change my mind?

No, it is up to you to decide to take part and no-one will know if you decide to take part or not. If you decide to take part but then change your mind whilst you are completing it, that is okay, you don't need to return the questionnaire. But once you have returned the questionnaire, it cannot be withdrawn because all the questionnaires are anonymous.

If you would like to read some general information about taking part in research take a look at <http://www.nhs.uk/Conditions/Clinical-trials/Pages/Introduction.aspx>.

Will my taking part in this study be confidential?

Since no personally identifiable information will be collected during this study, your responses cannot be traced back to you. Therefore, the researcher will not know which responses you gave.

What are the possible risks of taking part?

Some people may become upset when completing this survey because it asks you to think about how you feel at the moment and how well you think you are coping. Some people also become tired after reading and answering questions, so you are reminded to take breaks if needed. If you do become upset or tired and you do not wish to finish the questionnaire you do not have to finish and return it. You will find some helpful information and contact details on the back page of the questionnaire, which tells you how you can receive some support. You are encouraged to contact the researcher if you feel that you would like to discuss options for support.

What are the possible benefits of taking part?

We cannot promise this study will help you but we hope that the information we gain from this study will help improve the support that people with a brain injury receive and raise awareness about some of the difficulties that people with brain injuries can face. Taking part will give you a chance to think about how you are feeling at the moment and how well you are coping since your injury and some people can find that helpful.

Can I find out my results or what they mean?

All the data collected is anonymous and so we are not able to trace your responses back to you. Therefore we are not able to provide you with your results. A summary of the overall results will be available at the place where you were given the questionnaire when the study is completed.

What will happen to the results of this study?

The results will be submitted as part of the researcher's training course. It is also hoped that the results will be published in international journals and presented at conferences.

Expenses and payments

You will not be paid for taking part in the study and you cannot claim any expenses.

Who has reviewed this study?

This study has been reviewed by the Northern and Yorkshire Research Ethics Committee. It has also been peer reviewed by the research team at the Department of Clinical Psychology and Psychological Therapies at the University of Hull and is being sponsored by Humber Foundation NHS Trust.

Further information and contact details.

The research is organised by Andrea Ralph, a Trainee Clinical Psychologist employed by Humber NHS Foundation Trust and training at the University of Hull. If you have any questions about this study please do not hesitate to contact her on:

A.J.Ralph@2009.hull.ac.uk

Flyer
23/12/10
Version 1.0

You have been invited to take part in a new research study...

This study is researching the views
of people who have had a brain injury.



We want to know how you think other
people would view somebody who had

We invite you to complete a questionnaire that
will take about 25 minutes.



**To find out more & to
complete the questionnaire
please log on to:**

Or contact Andrea Ralph on
A.J.Ralph@2009.hull.ac.uk

Stigma following acquired brain injury (ABI)

Thank you for agreeing to complete this survey. Your taking part is greatly appreciated. It should take you approximately 25 minutes to complete this survey.

The following questions are about you. Please tick an answer by clicking a box or type an answer for each question.

- Please indicate your gender:

Male
Female

- What is your age? ____ years

- Which of the following best described your education level?

High school or less
College/Sixth form
University level

- How long a go did you have you brain injury?

0-2 years a go
3-5 years a go
More than 6 years a go

- What was your employment status *before* your brain injury?

Student
No employment
Part-time or full-time employment

- What is your employment status *now*?

Student
No employment
Unsupported employment
Supported employment

[Hospital Anxiety and Depression Scale (HADS)]

REMOVED FOR HARD BINDING

[Perceived Devaluation and Discrimination Scale (PDD)]

REMOVED FOR HARD BINDING

[Independence subscale (IND) of the Bigelow Quality of Life Questionnaire (BQQ)]

REMOVED FOR HARD BINDING

[Perceived Employability subscale (PEM) of the Bigelow Quality of Life Questionnaire (BQQ)]

REMOVED FOR HARD BINDING

[Awareness Questionnaire (AQ)]

REMOVED FOR HARD BINDING

[Traumatic Brain Injury: Work Instability Scale (TBI-WIS)]

REMOVED FOR HARD BINDING

END OF THE SURVEY

Thank you for completing this survey, your taking part is greatly appreciated.

Please return this questionnaire in the Freepost envelope provided.

If you feel you need some support or further information it may be helpful to speak to your key-worker or GP in the first instance.

You may also find the following resources useful:

Samaritans:

Confidential support for people experiencing feelings of distress or needing support.
08457 90 90 90 (24-hour helpline) **OR** www.samaritans.org.uk

Headway:

Is a charity that provides help and support to people affected by a brain injury.
0808 800 2244 (Free helpline) **OR** www.headway.org.uk **OR** email:
helpline@headway.org.uk

If you would like any further information, or if you have a concern about any part of the study, you can contact the researcher on the details below.

Researcher: Andrea Ralph

Contact *by email on:* A.J.Ralph@2009.hull.ac.uk

by post at: Department of Psychology and Psychological Therapies,
The University of Hull, Cottingham, Hull. HU6 7RX

Appendix 6: Data analyses for empirical paper

Research question 2 (i): Perceived stigma ANCOVA, with post-injury employment status as independent variable.

Tests of Between-Subjects Effects

Dependent Variable: Perceived stigma

Source	Type III Sum of Squares	df	Mean Square	F value	Significance (p value)
Corrected Model	10.733 ^a	6	1.789	13.011	.000
Intercept	11.510	1	11.510	83.721	.000
AQ	1.690	1	1.690	12.291	.001
Emotional distress	1.166	1	1.166	8.478	.004
Time since injury	.885	1	.885	6.436	.012
Age	.102	1	.102	.745	.389
Post-injury empl. status	.329	2	.164	1.195	.306
Error	19.660	143	.137		
Total	1032.003	150			
Corrected Total	30.393	149			

a. R Squared = .353 (Adjusted R Squared = .326)

Research question 2 (ii): Perceived stigma ANCOVA, with 'change' in employment status from pre- to post-injury as independent variable.

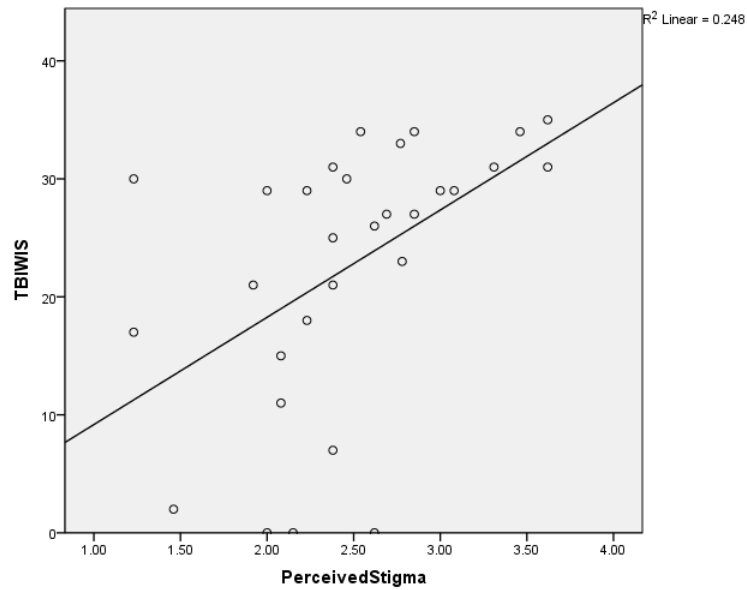
Tests of Between-Subjects Effects

Dependent Variable: Perceived stigma

Source	Type III Sum of Squares	df	Mean Square	F value	Significance (p value)
Corrected Model	10.709 ^a	6	1.785	12.966	.000
Intercept	11.495	1	11.495	83.508	.000
AQ	1.750	1	1.750	12.715	.000
Emotional distress	1.141	1	1.141	8.289	.005
Time since injury	.859	1	.859	6.239	.014
Age	.094	1	.094	.686	.409
'Change' in empl. status	.304	2	.152	1.106	.334
Error	19.685	143	.138		
Total	1032.003	150			
Corrected Total	30.393	149			

a. R Squared = .352 (Adjusted R Squared = .325)

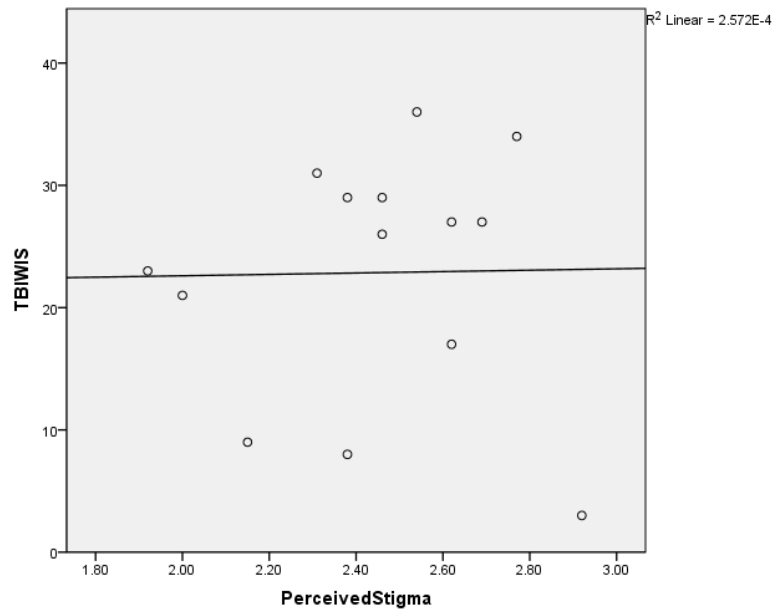
Research question 2 (iii): Correlation between perceived stigma and perceived work-difficulty for unsupported employment group.



		TBI-WIS	Perceived stigma
TBI-WIS	Pearson Correlation	1	.498**
	Significance. (2-tailed)		.005
	N	30	30
Perceived stigma	Pearson Correlation	.498**	1
	Significance. (2-tailed)	.005	
	N	30	30

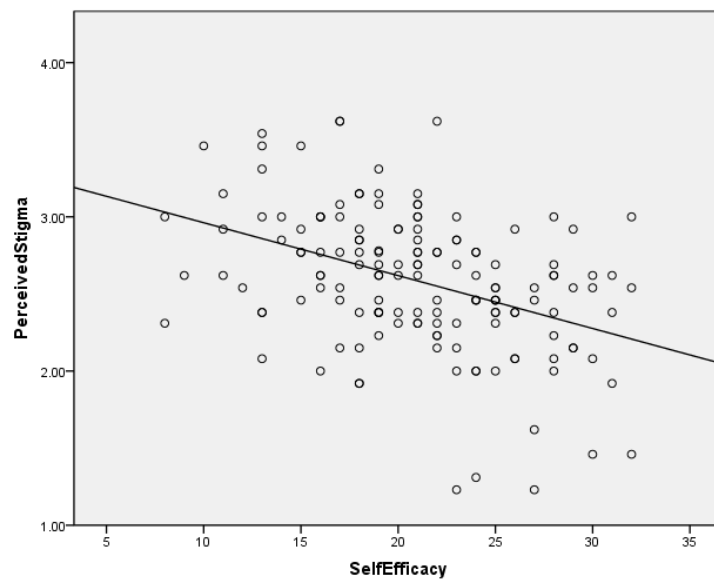
** . Correlation is significant at the 0.01 level (2-tailed).

Research question 2 (iii): Correlation between perceived stigma and perceived work-difficulty for supported employment group.



		TBI-WIS	Perceived stigma
TBI-WIS	Pearson Correlation	1	.016
	Significance (2-tailed)		.957
	N	14	14
Perceived stigma	Pearson Correlation	.016	1
	Significance (2-tailed)	.957	
	N	14	14

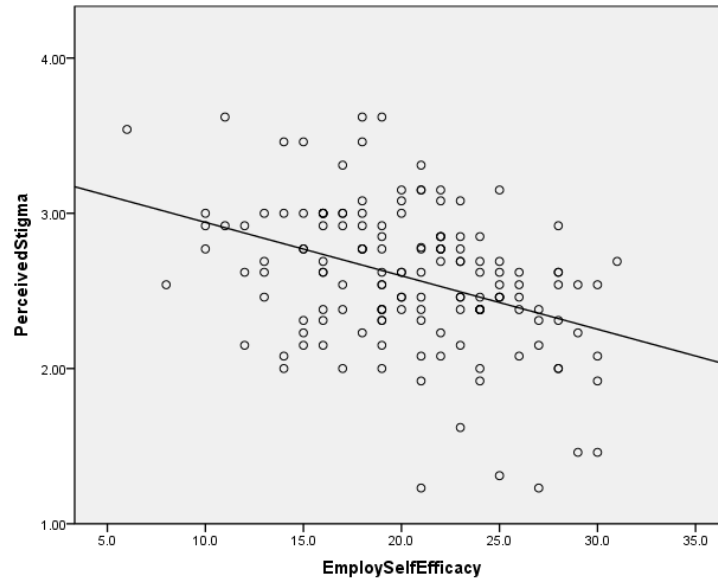
Research question 3 (i): Correlation between perceived stigma and self-efficacy.



		Self-efficacy	Perceived stigma
Self-efficacy	Pearson Correlation	1	-.412**
	Significance (2-tailed)		.000
	N	150	150
Perceived stigma	Pearson Correlation	-.412**	1
	Significance (2-tailed)	.000	
	N	150	150

** . Correlation is significant at the 0.01 level (2-tailed).

Research question 3 (ii): Correlation between perceived stigma and employment-related self-efficacy.



		Employment-related self-efficacy	Perceived stigma
Employment-related self-efficacy	Pearson Correlation	1	-.389**
	Significance (2-tailed)		.000
	N	150	150
Perceived stigma	Pearson Correlation	-.389**	1
	Significance (2-tailed)	.000	
	N	150	150

** . Correlation is significant at the 0.01 level (2-tailed).

Post-hoc analysis Self-efficacy ANCOVA, with post-injury employment status as independent variable.

Tests of Between-Subjects Effects

Dependent Variable: Self efficacy

Source	Type III Sum of Squares	df	Mean Square	F value	Significance (p value)
Corrected Model	2523.638 ^a	6	420.606	32.384	.000
Intercept	453.245	1	453.245	34.897	.000
Age	1.319	1	1.319	.102	.750
AQ	457.827	1	457.827	35.250	.000
Emotional distress	324.490	1	324.490	24.984	.000
Time since injury	6.172	1	6.172	.475	.492
Post-injury empl. status	69.008	2	34.504	2.657	.074
Error	1857.302	143	12.988		
Total	70657.000	150			
Corrected Total	4380.940	149			

a. R Squared = .576 (Adjusted R Squared = .558)

Post-hoc analysis: Employment-related self-efficacy ANCOVA, with post-injury employment status as independent variable.

Tests of Between-Subjects Effects

Dependent Variable: Employment-related self-efficacy

Source	Type III Sum of Squares	df	Mean Square	F value	Significance (p value)
Corrected Model	1687.895 ^a	6	281.316	18.305	.000
Intercept	442.069	1	442.069	28.765	.000
AQ	365.261	1	365.261	23.767	.000
Emotional distress	139.406	1	139.406	9.071	.003
Time since injury	19.161	1	19.161	1.247	.266
Age	.247	1	.247	.016	.899
Post-injury empl. status	101.283	2	50.642	3.295	.040
Error	2197.678	143	15.368		
Total	66228.000	150			
Corrected Total	3885.573	149			

a. R Squared = .434 (Adjusted R Squared = .411)