

## Consent Form

### Stigma following acquired brain injury (ABI)

Name of researcher: Andrea Ralph

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. *(please tick)*

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 I understand that once I have submitted the survey it is not possible for my answers to be withdrawn since all the data is anonymous.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

**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

The next section asks about how you feel. Please read each statement carefully and then circle the answer, which comes closest to how you have been feeling in the past week. Don't take too long over your replies, your immediate reaction to each statement will probably be more accurate than, a long, thought-out response.

1	I feel tense or wound up	<i>Most of the time</i>	<i>A lot of the time</i>	<i>From time to time, occasionally</i>	<i>Not at all</i>
2	I still enjoy the things I used to enjoy	<i>Definitely as much</i>	<i>Not quite so much</i>	<i>Only a little</i>	<i>Hardly at all</i>
3	I get a sort of frightened feeling as if something awful is about to happen	<i>Yes definitely and quite badly</i>	<i>Yes, but not too badly</i>	<i>A little, but it doesn't worry me</i>	<i>Not at all</i>
4	I can laugh and see the funny side of things	<i>As much as I always could</i>	<i>Not quite so much now</i>	<i>Definitely not so much now</i>	<i>Not at all</i>
5	Worrying thoughts go through my mind	<i>A great deal of the time</i>	<i>A lot of the time</i>	<i>Not too often</i>	<i>Very little</i>
6	I feel cheerful	<i>Never</i>	<i>Not often</i>	<i>Sometimes</i>	<i>Most of the time</i>
7	I can sit at ease and feel relaxed	<i>Definitely</i>	<i>Usually</i>	<i>Not often</i>	<i>Not at all</i>
8	I feel as if I am slowed down	<i>Nearly all the time</i>	<i>Very often</i>	<i>Sometimes</i>	<i>Not at all</i>
9	I get a sort of frightened feeling like 'butterflies' in the stomach	<i>Not at all</i>	<i>Occasionally</i>	<i>Quite often</i>	<i>Very often</i>
10	I have lost interest in my appearance	<i>Definitely</i>	<i>I don't take as much care as I should</i>	<i>I may not take quite as much care</i>	<i>I take just as much care as ever</i>
11	I feel restless as if I have to be on the move	<i>Very much indeed</i>	<i>Quite a lot</i>	<i>Not very much</i>	<i>Not at all</i>
12	I look forward with enjoyment to things	<i>As much as I ever did</i>	<i>Rather less than I used to</i>	<i>Definitely less than I used to</i>	<i>Hardly at all</i>
13	I get sudden feelings of panic	<i>Very often indeed</i>	<i>Quite often</i>	<i>Not very often</i>	<i>Not at all</i>
14	I can enjoy a good book or radio or television programme	<i>Often</i>	<i>Sometimes</i>	<i>Not often</i>	<i>Very seldom</i>

Please read the following statements carefully. Please rate your level of agreement with each statement by circling the answer which best applies to you, using the scale from “Strongly disagree” to “Strongly agree”.

1	Most people would accept a person who had a brain injury as a close friend.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
2	Most people believe that a person who has been on a rehabilitation unit is just as intelligent as the average person.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
3	Most people believe that a person who has been hospitalized with a brain injury is just as trustworthy as the average citizen.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
4	Most people would accept a person who has made a full recovery from a brain injury as a teacher of young children in a public school.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
5	Most people believe that entering a rehabilitation unit is a sign of personal failure.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
6	Most people will not hire a person who has been hospitalized with a brain injury to take care of their children, even if he or she had been well for some time.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
7	Most people think less of a person who has been on a rehabilitation unit.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
8	Most employers will hire a person who has been hospitalized with a brain injury if he or she is qualified for the job.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
9	Most employers will pass over the application of a person who has been hospitalized with a brain injury in favour of another applicant.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
10	Most people in my community would treat a person who has been hospitalized with a brain injury just as they would treat anyone.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
11	Most young women would be reluctant to date a man who has been hospitalized with a brain injury.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
12	Once they know a person was on a rehabilitation unit, most people will take his or her opinions less seriously.	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
13	Most people think that a person who has been hospitalized with a brain injury is dangerous and unpredictable	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>

These next questions ask about how you handle making decisions, dealing with conflict and communicating with others. Please read each question and circle the answer which best applies to you using the scale.

1	In the last week, how did you find shopping, paying bills, preparing meals, and generally looking after your basic necessities?	<i>Very easy</i>	<i>Fairly easy</i>	<i>Rather difficult</i>	<i>Very difficult</i>
2	...and how enjoyable was it?	<i>Very enjoyable</i>	<i>Fairly enjoyable</i>	<i>Fairly unpleasant</i>	<i>Very unpleasant</i>
3	In the last week, how often did you go out socially?	<i>More than 3 times</i>	<i>2 or 3 times</i>	<i>Once</i>	<i>Never</i>
4	When you receive broken merchandise, poor service or, are overcharged, how hard is it for you to complain to the store, dealer or company?	<i>Can't do it at all</i>	<i>Very hard</i>	<i>A little hard</i>	<i>Not hard at all</i>
5	When you want to join a conversation (e.g. at a party) how hesitant do you feel about doing so?	<i>Can't do it at all</i>	<i>Very hesitant</i>	<i>Slightly hesitant</i>	<i>Not at all hesitant</i>
6	When you are treated unfairly by someone you know well like a family member or close friend, how difficult is it for you to tell them so?	<i>Can't do it at all</i>	<i>Very difficult</i>	<i>Slightly difficult</i>	<i>Not difficult</i>
7	How confident are you in the decisions you make for yourself (eg., What to buy, where to live, what to do etc.)?	<i>Quite confident</i>	<i>Some confidence</i>	<i>Little confidence</i>	<i>No confidence</i>
8	How often do you put off making decisions until it is too late?	<i>Always</i>	<i>Often</i>	<i>Occasionally</i>	<i>Never</i>

These questions ask for your opinion on looking for a job. Even if you are not looking for a job, the questions ask about how you *would* feel if you were looking for a job. Please read each question and circle the answer which best applies to you.

1	How good an impression do you feel you would make in a job interview?	<i>Very good</i>	<i>Good</i>	<i>Poor</i>	<i>very poor</i>
2	How serious are any emotional problems you may have which would make it hard for you to find work?	<i>Very serious</i>	<i>Pretty serious</i>	<i>Slightly serious</i>	<i>Not at all serious</i>
3	How comfortable do you feel going out to look for a job?	<i>Completely</i>	<i>Quite</i>	<i>Fairly</i>	<i>Not at all</i>
4	How hard is it for you to stick to a job when it becomes unpleasant or boring or stressful?	<i>Can't do it at all</i>	<i>Very hard</i>	<i>A little hard</i>	<i>Not hard at all</i>
5	If you had a chance to get more job training how willing would you be to get it?	<i>Not interested</i>	<i>Slightly willing</i>	<i>Fairly willing</i>	<i>Very willing</i>
6	How comfortable do you feel working with co-workers?	<i>Not at all comfortable</i>	<i>Fairly</i>	<i>Quite</i>	<i>Completely</i>

The next two questions are a bit different. I'm going to ask you to list some things.

7 Please name some of your hobbies and special interests.

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8 Please name some of the ways you know for finding a job.

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The next section is about how you see yourself now. Please read the following questions carefully. Please answer each question circling the answer that best applies to you, using the scale ranging from “Much worse” to “Much better”.

1	How good is your ability to live independently now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
2	How good is your ability to manage your money now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
3	How well do you get along with people now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
4	How well can you do on tests that measure thinking and memory skills now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
5	How well can you do the things you want to do in life now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
6	How well are you able to see now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
7	How well can you hear now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
8	How well can you move your arms and legs now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
9	How good is your coordination now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
10	How good are you at keeping up with the time and date and where you are now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
11	How well can you concentrate now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
12	How well can you express your thoughts to others now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
13	How good is your memory for recent events now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
14	How good are you at planning things now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
15	How well organized are you now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
16	How well can you keep your feelings in control now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>
17	How well adjusted emotionally are you now as compared to before your injury?	<i>Much worse</i>	<i>A little worse</i>	<i>About the same</i>	<i>A little better</i>	<i>Much better</i>

**This next section must ONLY be completed by those who are employed.**

**Please skip to the end of the survey if you are unemployed.**

If you are employed, please complete the following section. In this section you will find some statements, which have been made by people who have had a brain injury. Please read each statement carefully and then circle *True* if the statement applies to you and *Not true* if it does not apply to you at the moment.

1	I can't remember how to do some things at work	<i>True</i>	<i>Not true</i>
2	It's harder to control my feelings	<i>True</i>	<i>Not true</i>
3	I make more mistakes now	<i>True</i>	<i>Not true</i>
4	I feel I am a burden to others at work	<i>True</i>	<i>Not true</i>
5	I just don't feel right	<i>True</i>	<i>Not true</i>
6	I am having to learn how to do my job again	<i>True</i>	<i>Not true</i>
7	I have to double check things more often	<i>True</i>	<i>Not true</i>
8	I get wound up more easily	<i>True</i>	<i>Not true</i>
9	I have to do one thing at a time now	<i>True</i>	<i>Not true</i>
10	My concentration span is shorter	<i>True</i>	<i>Not true</i>
11	My memory isn't back to normal	<i>True</i>	<i>Not true</i>
12	I am worried about embarrassing myself	<i>True</i>	<i>Not true</i>
13	I feel like a hurdle has been put in my way	<i>True</i>	<i>Not true</i>
14	I am concerned about my memory	<i>True</i>	<i>Not true</i>
15	I can't remember important numbers like phone numbers	<i>True</i>	<i>Not true</i>
16	I really have to concentrate on what I'm doing	<i>True</i>	<i>Not true</i>
17	I don't feel like I'm back to normal	<i>True</i>	<i>Not true</i>
18	I am very worried about my ability to keep working	<i>True</i>	<i>Not true</i>
19	I lose my train of thought more often	<i>True</i>	<i>Not true</i>
20	My self confidence has gone	<i>True</i>	<i>Not true</i>
21	My skill level has dropped	<i>True</i>	<i>Not true</i>
22	I find going to work daunting now	<i>True</i>	<i>Not true</i>
23	Things are really getting to me	<i>True</i>	<i>Not true</i>
24	My colleagues have to make allowances for me	<i>True</i>	<i>Not true</i>
25	I can't remember people's names	<i>True</i>	<i>Not true</i>
26	I feel I'm performing as well at work	<i>True</i>	<i>Not true</i>
27	I feel like I'm in the wrong job	<i>True</i>	<i>Not true</i>
28	My words don't come out as I want them to	<i>True</i>	<i>Not true</i>

29	I don't feel a part of things at work	True	Not true
30	My colleagues don't understand	True	Not true
31	I don't know how I manage to get through the week	True	Not true
32	I can't do everything I need to at work	True	Not true
33	I don't have the stamina at work, like I used to	True	Not true
34	I worry about everything now	True	Not true
35	I find things get me down more easily	True	Not true
36	I am embarrassed by how I am now	True	Not true

### END OF THE SURVEY

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

***Please return this questionnaire and the consent form 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](http://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](http://www.headway.org.uk) **OR** email: [helpline@headway.org.uk](mailto: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

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