**Experiences of Headway’s Brain Injury Identity Card**

A report into the experiences of Headway’s Brain Injury Identity Card holders



This report explores the results of the survey *Experiences of Headway’s Brain Injury Identity Card,* which sought to gather card holders’ experiences of a newly launched identity card. The card was designed and launched to raise awareness and understanding of acquired brain injury among the general public and the criminal justice system.

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**Executive summary**

The survey *Experiences of Headway’s Brain Injury Identity Card* collected responses from almost 600 brain injury survivors who are holders of Headway’s Brain Injury Identity Card.

The survey results show that the card has been very well received, with holders finding the application process easy to navigate and the card itself helpful in a variety of settings.

The most common setting in which the card was used was everyday social scenarios, for instance while in a shop, pub, bank, restaurant or supermarket.

Card holders also frequently used it during a GP, hospital or other medical appointment, and while using public transport.

A small minority of card holders had used the criminal legal assistance number. The few who had used this service were happy with it.

Card holders felt that the card made them feel more confident and reassured, and made it easier for them to explain their brain injury.

This report was produced as part of Headway’s Justice Project*.* For more information on the project, visit [www.headway.org.uk/idcard](http://www.headway.org.uk/idcard).

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# Key findings

of respondents that used the online application form thought it was excellent or good

**97%**

of respondents that used the paper application form thought the form was excellent or good

**92% **

of respondents thought their ID card was excellent or good

**97% **

**80%**

of respondents who had used the criminal legal assistance number were happy with the service provided.

of respondents felt that when they used their ID card, it was very helpful or helpful

of respondents had used their ID card. Of these, 72% had used their card in a social scenario setting

**97% **

**58% **

# Introduction

In August 2015, Headway – the brain injury association launched its Justice Project. The Justice Project aims to:

* raise awareness of brain injury throughout UK criminal justice systems
* improve brain injury identification
* ensure people with brain injuries in contact with the criminal justice system are treated appropriately and provided with the support they need
* provide brain injury survivors with access to specialist legal advice and representation
* divert people with brain injuries away from the criminal justice system where appropriate

The project was developed in response to research demonstrating a high prevalence of brain injury (up to 60%) in some offending institutions in the UK[[1]](#footnote-1) [[2]](#footnote-2). Despite high prevalence of brain injury, anecdotal evidence from brain injury survivors indicates a lack of understanding about brain injury within the criminal justice system.

Headway’s Brain Injury Identity Card has been developed as part of the Justice Project to improve identification of brain injury and to provide brain injury survivors with access to criminal legal advice and representation.

A pilot study of the Brain Injury Identity Card was carried out from April to June 2016 within the internal Headway network. In this time 259 survivors associated with a Headway group or branch were issued with an ID card and, as part of the pilot evaluation, asked what they thought of the ID card and the application process.

The results were overwhelmingly positive, with the vast majority of respondents feeling that the application process and card itself were excellent.

Feedback received resulted in a number of changes being made to the card; this included featuring the Headway helpline number on the card, allowing the brain injury survivor to personalise the card by choosing four listed effects rather than using four generic statements about common effects, and shortening the application to make it more user-friendly.

The Justice Project was publicly launched by HRH Prince Harry in July 2017 in England, with subsequent launch events taking place in October 2017 in Scotland, and June 2018 in Northern Ireland. Plans are in place to launch the card in Wales. Following the public launches, the number of ID card applications increased significantly and in excess of 4,000 cards have now been issued.

In May 2018, a second survey was conducted to gather further feedback on the card. The survey was sent to brain injury survivors who had successfully received a card and had given their consent to be contacted for evaluation purposes.

The survey was hosted on the Survey Monkey website ([www.surveymonkey.com](http://www.surveymonkey.com)) and promoted via email to all Headway groups and branches.

595 people responded to the survey. Headway would like to take this opportunity to thank everyone who took the time to participate.

If you would like to discuss any aspect of the survey, the ID card or the Justice Project, please contact Liz Partridge, Justice Project Manager, on justiceproject@headway.org.uk

Media requests should be directed to James Coxon on press.manager@headway.org.uk or 0115 947 1901.

# Survey results – Experiences of Headway’s Brain Injury Identity Card

This questionnaire was intended for brain injury survivors who were successful in their application to receive a Headway Brain Injury Identity Card.

# Section one: Application form

# Respondents were first asked what they thought of the ID card application form. The application form was available in both an electronic and paper form.

# Of the respondents who had completed the electronic form, 97% felt that it was ‘excellent’ or ‘good’, with almost 60% of these feeling that it was ‘excellent’. Less than 1% of respondents felt that it was ‘poor’, and no respondents felt that it was ‘very poor’.

*Figure 1.* Ratings of Brain Injury Identity Card online application form

# Similarly, 92% of respondents who had completed the paper form felt that it was ‘excellent’ or ‘good’, with almost 50% of these feeling that it was ‘excellent’. No respondents felt that the paper form was ‘poor’ or ‘very poor’.

*Figure 2.* Ratings of Brain Injury Identity Card paper application form

# Respondents rated the form favourably for the following reasons:

# Simple to use

# “*A simple and well structured form which was easy to fill in and complete.”*

# *“It was quick, simple and straight forward – exactly all the things it should be given the market/audience it is designed to accommodate/cater for, namely the brain injured.”*

# *“I’m dyslexic and the form was easy to understand and fill in.”*

# *“Pretty straight forward to do, to my surprise. Ever since my brain injury any kind of forms I have avoided as I find them overwhelming.”*

# Comprehensive

# *“Covered all the vital information.”*

# *“Professional with inspiring questions that didn’t overstep the mark.”*

# *“The paper application form listed so many different daily challenges that someone with a brain injury can encounter, so many of them were relevant.”*

# Choice between electronic and paper version

# *“Easier than using actual pen and paper. Easy to correct my mistakes before submitting!”*

# *“Being able to complete the form online sped up receipt of the card.”*

# *“I applied online but did print copies off to send to other people like myself.”*

# *“I found the form confusing and had difficulty completing all the tasks on the computer. I became flustered and frustrated and eventually just emailed Headway to request a paper version of the form, knowing that I would be more comfortable with it that way. They responded favourably and posted the form out to me!”*

# Several respondents commented on the fact that they had required support from a family member, carer or professional with filling out the form. However, with this extra support the form was found to be simple to complete.

# *“Was a little complicated but with some extra help I managed.”*

# *“It was easy enough to complete with assistance available if I got stick at all.”*

# *“Simple form to fill in. I had guidance from a member of staff.”*

# *“My wife filled it in, [she] said [it was] excellent, easy to fill in.”*

# Section two: Brain Injury Identity Card

# Ratings of the card

# Respondents were asked how they would rate the Brain Injury Identity Card itself.

# The vast majority of respondents rated their card as being ‘excellent’ or ‘good’ (97%), with over three quarters of respondents rating it as ‘excellent’ (77%). Less than 1% thought that the card was ‘poor’ or ‘very poor’.

*Figure 3.* Ratings of Brain Injury Identity Card

# Respondents rated the card favourably for a number of reasons. Over 20% of respondents (22%) specifically mentioned the word ‘understanding’ within the context of the card helping them to make others understand their brain injury.

# *“If people don’t understand why I don’t understand a situation, I show them the*

# *card and they get where I am coming from.”*

# *“I’ve used it at the initial point of contact in some shops etc in order to get a bit of understanding.”*

# *“I get confused easily and then don’t know what to respond to an unexpected question, then I show my ID card and the staff understand and help me.”“Always treated with respect and understanding when I have shown card.”*

# For some respondents, the effects of their injury can prevent them from being able to explain their support needs to others, which the card also helped with.

# *“When I have a small/medium seizure, I can’t talk at all, so it is useful to show people to explain to them.”*

# *“I tend to stutter when I’m annoyed, tired or stressed, so it helps to explain things.”*

# *“I panic in crowds and it can make me collapse. I have memory issues as well and if I show my card people seem to try and help me more.”*

# For others, the card enabled them to access support or understanding that they might otherwise not have received.

# *“I was feeling dizzy in a shop and asked for a chair, the assistant looked at me like I was just tired… so I showed her my card and she got me a chair and water.”*

# *“It helps when I am confused in the supermarket; the shop assistants have been wonderful if I forget where things are, or how to use my debit card. In a restaurant they give me more time to pay my order and explain any discounts. On the bus it helped so that driver can call out when I get to my bus stop.”*

# *“I forgot to pay a bill, but the card explained why my memory was so bad and I did not incur any charges.”*

# *“I could not get a seat on a bus; people were being quite rude to me so I used my card then. I showed it to the bus driver; he kindly asked some younger people if they would kindly mind moving.”*

# *“In one situation I got very confused with my mobile and could not phone a taxi. I approached a group of women who at first thought I was begging for money or*

# *similar, but after showing my card they looked after me like mother hens. They organised a taxi and walked me to it and told the driver about my brain injury. The driver was very caring. It was such a nice experience for me.”*

# For some respondents, the card helped them in serious situations in which their safety was at risk by helping them to get necessary assistance.

# *“The help I received was crucial as I was lost and confused; my card use saw me home safely.”*

# *“I forgot my way back home and I have asked someone to guide me and showed my ID.”*

# *“I say stuff I shouldn’t say and was able to use the card when I apologised, and it helped diffuse the situation.”*

# The card’s primary purpose is to improve identification of brain injury, especially in situations potentially involving the criminal justice system. Some respondents shared their experience of using their card in situations that could potentially have involved, or did involve, the police.

# *“I presented my card to the police when a woman accused me of drink-driving because I was wobbly on my feet.”*

# *“The police found the card in the pocket and [I was] taken to a Mental Health Hospital rather than being arrested and brought to the police station.”*

# *“I was taking an item of clothing back to the shop...I was struggling with speech and auditory memory. The shop assistant didn’t understand what I was trying to do and started insinuating ‘I’d found the bag with the item and tried to return for the money’. I started crying as I couldn’t explain myself and the communication was getting lost. So… I showed the shop assistant the card and then he was more helpful finally. So the card really helped me in this situation.”*

# *“I had to give a statement regarding an incident I was involved in. I had a solicitor with me, but felt that showing my card would be helpful… It made the officer aware of the fact that I wasn’t being difficult, or evasive, when I asked for clarification of some questions.”*

# Others felt that just having the card with them gave them security and reassurance.

# *“Even though I do not present my card to the bus driver now, I know I can always take my card out of my purse to explain my difficulties in this or any other situation I find myself in - it’s like having a safety net when I do not have my carer or a family member or friend with me which means I can go out on my own to places.”*

# *“Having it to hand gave me confidence.”*

# *“I wear it whenever I leave the house. I feel more comfortable wearing it.”*

# Some respondents expressed a genuine sense of gratitude towards the general ID card scheme.

# *“Thank you for sending me the card. I feel more confident now I have it… A great idea for people like me. Thank you so much.”*

# Situations in which the card had been used

# Over half of the respondents had used their card (58%). 37% had not yet used the card, and 4% were not sure whether they had or had not used their card.

# Almost all of the respondents who had used the card found that it had been ‘very helpful’ or ‘helpful’ (97%), with three quarters finding it to be ‘very helpful’. Less than 1% of respondents did not find the card helpful.

*Figure 4.* Ratings of helpfulness of ID card

# Of the respondents who had used their card, the most common situation in which the card was used was everyday social scenarios, for instance in a shop, pub, bank, restaurant or supermarket; this comprised 72% of respondents, and was reflected in many of the comments offered above.

*Figure 5.* Situations in which the card had been used

# The second most common situation in which the card was used was during a medical appointment, such as during a GP or hospital appointment.

# *“In a doctor’s appointment, the doctor started talking too fast and was using abbreviations… I asked them to stop and showed my brain injury card. They got the message.”*

# *“With doctors it just helps to explain.”*

# *“I’ve used it to show various medical professions so they will give me the time I need to speak and listen rather than talk over the top of me all the time without listening to my needs.”*

# Patient reports have indicated that primary neurological care is generally poor, with issues such as delays in being referred to neurological specialists, lengthy waiting lists for referral appointments and dissatisfaction with information received about patient’s condition being reported[[3]](#footnote-3).

# These concerns are echoed by GPs themselves, with one study finding that 84% of GPs in England feel they could benefit from further training on identifying and managing people presenting with neurological conditions[[4]](#footnote-4). It is positive to find that the ID card is being used as a tool to help GPs with identifying and understanding the needs of brain injury survivors.

# 22% of respondents used the card when using public transport.

# A further 20% had used the card to assist them when applying for welfare benefits.

# *“I was able to show [the card] at a PIP tribunal which felt very reassuring.”*

# *“I’ve used it [the card] at Citizen’s Advice centre when they were helping me claim benefits.”*

# Previous research from Headway has found that welfare benefits assessors often have a lack of understanding about brain injury[[5]](#footnote-5), so it is positive to find that the ID card is being used as a tool to raise awareness and understanding of brain injury among welfare benefits assessors.

# Section three: Criminal legal advice/representation

# Respondents were asked whether they had used the telephone number on the front of the ID card to request criminal legal advice or representation. The majority of respondents had not used this number (97%), with only ten of the respondents having used it and eight unsure.

# Of the ten respondents who had used the number, eight were happy with the service provided. Feedback provided on this was as follows:

# *“Really good help and advice, got back to me with more information.”*

# *“I was treated with respect and dignity on the phone, and when I met with my solicitor he didn’t talk to me like I was three years old, which often happens when I state I have brain injuries.”*

# Section four: Impact on life

# Respondents were asked to explain the difference that their ID card makes to their life.

# The majority of responses to this question echo what has largely been discussed in this report already, namely that the card makes brain injury survivors feel more confident and reassured, and that it helps them with explaining the impact of their injury in a variety of settings.

# Indeed, almost a quarter of responses contained the word ‘confidence’ (24%). Other words commonly used were ‘explain’ (used by 75 respondents), ‘reassurance’ (used by 30 respondents) and ‘security’ (used by 28 respondents). The phrases ‘help

# people’ and ‘help others understand’ were used by 39 respondents.

# Even when card holders had not yet used the card, it was still having a positive impact on their life.

# *“Even though I have not used it yet I feel better in the knowledge that I have the card and if I am ever in a position where I need it I know it is there.”“Just to have it on me when I go out makes me feel safer.”*

# *“I haven’t used the card yet but if I show the card I will get help if I’m lost or if I can’t remember why I am somewhere.”*

# Some respondents felt pleased about the way in which the card was helping to raise awareness of brain injury, even within personal circles.

# *“It’s helped to raise awareness in public and with family and friends.”*

# *“Brain injury… is not well understood, having the card gives added confidence that something can be easily shown to evidence one’s issues/impairments.”*

# Other respondents appreciated having a physical form of evidence for their otherwise ‘hidden’ disability.

# *“It looks like official confirmation of my TBI.”*

# *“Validates what is wrong with me which is not always visible.”*

# *“It serves as a kind of reminder and validation for me in general. TBI is the ‘invisible disability’ as they say, and sometimes I look at it to remind me ‘you’re not stupid, you’re not going crazy – you have a brain injury.”*

# Conclusion

The feedback gathered from the ID card survey was overwhelmingly positive, with
the vast majority of respondents finding it to be an excellent resource that helped them in a variety of settings. Even when survivors had not yet used the card, it was a reassurance for them to be carrying it with them, should the situation arise in which the card would be needed.

To date, more than 4,000 cards have been distributed around the UK as part of the Justice Project. It is Headway’s hope that the card will serve to continue raising awareness of brain injury, among both the general public and the criminal justice

system.

For more information about the card, please visit [www.headway.org.uk/idcard](http://www.headway.org.uk/idcard), or contact Liz Partridge (Project Manager: The Justice Project – Headway - the brain
injury association) on justiceproject@headway.org.uk.

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3. Falling short – How has neurology patient experience changed since 2014? – The Neurological Alliance, 2017. [↑](#footnote-ref-3)
4. Neurology and primary care – Improving the transition from primary care for people with neurological conditions – The Neurological Alliance, 2016. [↑](#footnote-ref-4)
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