



the brain injury association

A survey into the Experiences of Headway Brain Injury Identity Card holders



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Introduction

In 2015, Headway – the brain injury association launched its Justice Project with the aim of improving awareness and identification of brain injury within the UK criminal justice systems. This was in response to research indicating an over-representation of brain injury in offending populations in the UK (see [here](#)).

The Brain Injury Identity Card, publicly launched by Prince Harry in 2017, forms an integral part of the Justice Project. The card is designed to help criminal justice professionals and other staff more easily identify survivors of brain injury and ensure they receive an appropriate response and support.

The scheme has the support of the National Police Chiefs' Council, Police Scotland and the Police Service of Northern Ireland.

The personalised and clinically verified ID Card details the cardholder's name, photograph and four effects of their brain injury which they choose during the application process.

The ID Card provides brain injury survivors access to free criminal legal advice and representation from solicitors trained in understanding brain injury.

Since the launch of the scheme, the card has proved very popular both among survivors who have come into contact with the criminal justice system and those who have not. Many cardholders have found their ID Card to be helpful in a range of everyday scenarios and social situations.

There are now more than 9,000 Brain Injury Identity Cards in circulation across the UK with more applications being processed and received on a daily basis.

In November 2020, Headway conducted a survey of ID cardholders to gather additional feedback on the scheme.

The survey was designed to be completed by existing Brain Injury Identity Card holders or families and carers on their behalf. It was promoted via email to all cardholders who had consented to receive updates by email, as well as on social media channels.

901 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 Holly Warner, Justice Project Manager, on justiceproject@headway.org.uk



Key findings

94%

of respondents thought the application process was 'Excellent' or 'Good'

97%

of respondents rated the Brain Injury Identity Card as 'Excellent' or 'Good'

88%

of respondents had used their Brain Injury Identity Card

57%

used their Brain Injury Identity Card at least once a month

58%

of respondents said they had used their ID card in social scenarios

85%

of respondents said when they used their card it had been 'very helpful' or 'helpful'

Executive summary

The survey collected responses from 901 Brain Injury Identity Card holders.

The results of the survey indicate that cardholders' views on the scheme remain overwhelmingly positive.

The application process has been rated favourably, with cardholders finding the process of applying quick and simple.

Our findings show the Brain Injury Identity Card continues to provide survivors with help explaining the effects of their injury and provides many with greater confidence and reassurance as they go about their everyday lives.

The majority of cardholders use the Brain Injury Identity Card in everyday social scenarios, such as in a shop, pub, bank, restaurant or supermarket.

The card has also proved useful in a range of other settings, including on public transport, during medical appointments and as part of the process of applying for welfare benefits.

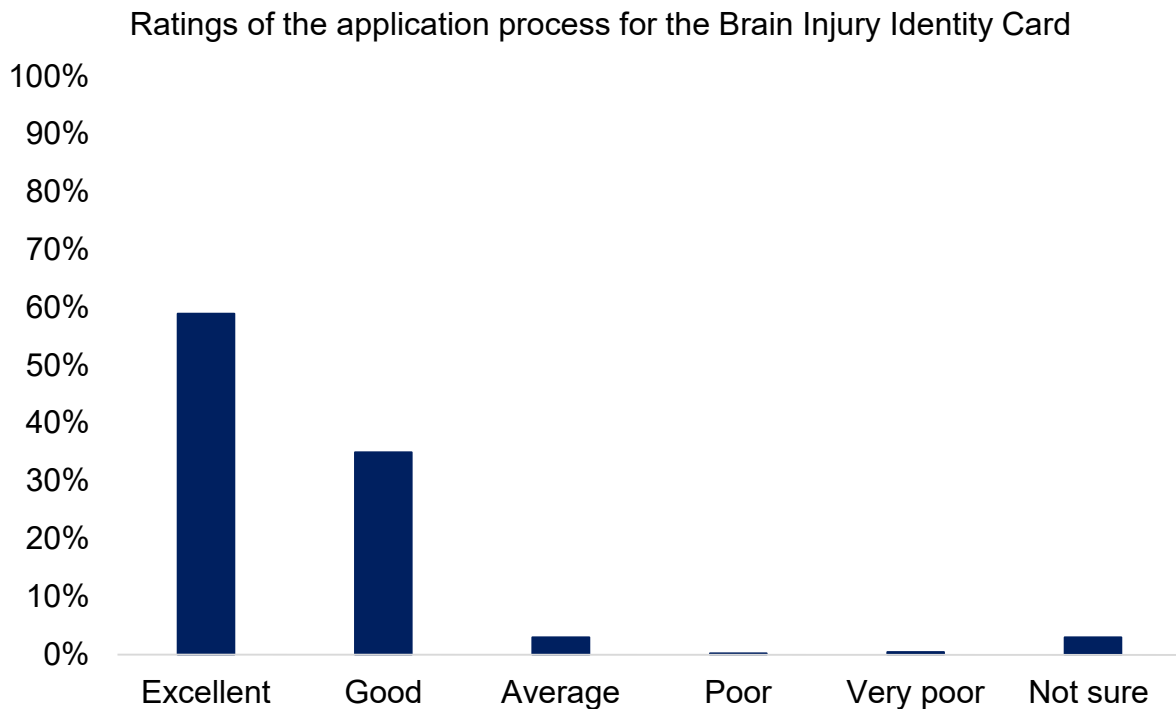
A small proportion of respondents to this survey reported that they had used the criminal legal assistance number. Out of those that had, the majority were pleased with the support provided.

This report was produced as part of Headway's Justice Project. For more information on the project, visit www.headway.org.uk/idcard.

The Brain Injury Identity Card application process

Respondents were asked what they thought of the ID Card application process. Applications can be completed both online and by requesting a paper application form.

94% of applicants thought the application process was 'Excellent' or 'Good'.



Applicants commented on the following aspects when prompted to tell us more about their thoughts of the application process

Ease of the application process and the support from Headway staff:

“The application information I was given by Headway, the support & encouragement to apply were all excellent. That made the whole process very easy & the speed at which my card arrived was remarkable.”

“It was quick and easy for me to complete. I did not experience any hitches.”

“The process is very easy to do and the staff were very understanding.”

“Was very friendly and professional. Reassuring and lovely people who kept me updated.”

“Easy and transparent. Very helpful staff and fast dispatch of the card.”

“It was easy and straightforward and that’s high praise coming from me as I suffer with sensory overload when confronted with too much information now”

Some applicants encountered challenges but were able to complete the form with additional support:

“I think I remember getting very confused trying to apply (I get very stumped when faced with forms, info etc.) - I definitely made full use of the telephone and the lass at your end who was coordinating it; pretty sure she sorted me out and in due course the card arrived.”

“I had a few minor issues but was helped through the process.”

“My OT helped me to complete mine. I wasn’t sure what things should be highlighted about me on my card and who I should ask to verify my injury”.

A number appreciated the value of the brain injury verification:

“I like the fact you have to show proof you have a brain injury so people can’t take advantage of the card.”

“Very good, done through local branch and simple to follow. I also like the fact that medical evidence is required. This should prevent misuse of the card.”

“I understood and appreciated the need to provide clinical evidence of a brain injury. It gave me the confidence to own my brain injury and consider my specific needs.”

“It was good you verified the person had a brain injury. With some other cards anyone can get them which devalues their meaning.”

However, a few respondents found getting this information themselves difficult or were frustrated by the delay it caused:

“Supplying information at the time was not easy for me as I had problems understanding the requirements due to my injury.”

“It’s a certain amount of hassle because you have to get references.”

“Long process as I had to wait for a letter before I could apply.”

A few respondents commented on other delays they experienced to the application:

“It took a long time because of COVID and it would have been great to have at the start of all the craziness, but it is what it is and it’s peace of mind having it.”

“Took some time due to COVID lockdown but was advised to send evidence and received card shortly afterwards.”

“It takes too long to receive the card after applying, something should be done about the wait.”

Some respondents commented on how simple it was to request a replacement card:

“I was assisted to re-apply when I lost mine. I had to do very little and was guided to reply and received my new card very quickly, thank you.”

“Really quick and easy. Especially the replacement!”

“I had to change my symptoms and the new card was dispatched in a day, wonderful service.”

The Brain Injury Identity Card

Ratings of the Brain Injury Identity Card

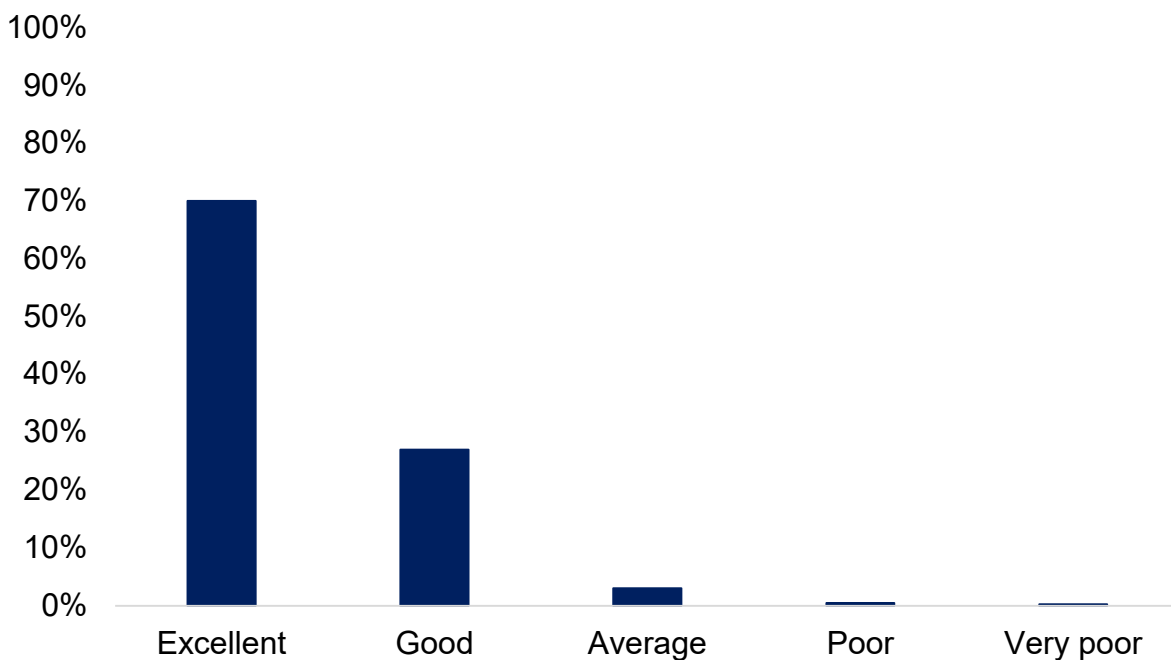
Respondents were asked how they would rate their Brain Injury Identity Card on a scale from ‘Excellent’ to ‘Very Poor’.

97% of respondents rated their Brain injury Identity Card as ‘Excellent’ or ‘Good’.

70% of respondents rated their ID Card as ‘Excellent’.

Fewer than 1% of respondents rated their ID Card as ‘Poor’ or ‘Very Poor’.

Ratings of the Brain Injury Identity Card



Respondents were asked how often they used their Brain Injury Identity Card

57% of respondents told us they used their Brain Injury Identity Card at least once a month, with **one-quarter (26%)** using it at least once a week.

28% of respondents said they used their card less than once a month, while **15%** said they had never used their card.

Situations in which the Brain Injury Identity Card has been used

Respondents were asked in what types of situations they had used their Brain Injury Identity Card.

The majority (58%) of respondents told us they use their Brain Injury Identity Card in everyday social scenarios, such as in a shop, pub, bank, restaurant or supermarket.

“In the Barbican I got lost. I could not get a phone signal and had a total meltdown. I showed him the card and he was amazing!”

“Have used my card at pharmacy when [I] found it difficult to get my point across and it offered me more compassion and help from staff.”

“I use it when I get irritable in public social situations, particularly shops and cafes. It does not take much for me to 'lose it', and when I do I tend to raise my voice when angry. People are more understanding when they see the card, e.g. supermarket management/security.”

Other situations in which the card has been used include:

34% during a GP, hospital or other medical appointment

“My GP surgery threatened to remove me due to missed or being late for appointments - my ID card helped to explain my time management issues.”

“I had a consultant’s appointment at hospital last week. The reception staff asked my husband to wait in the car due to Covid, however showing my card meant that he was able to come in with me & remember all that was said.”

“Many consultants have recognised the card and it makes it easier to continue with the appointment, speaking more with my wife/ daughter regarding my situation.”

31% using public transport

“I needed assistance to purchase a train ticket as [I] was getting in a muddle. The ticket person was getting annoyed but, once I showed them my card, they became more helpful.”

“I got very confused on a train that was the wrong train. The conductor was fantastic and once I showed her the card, she could not have done more for me.”

“I was in a train station and the train was delayed. The hall became cramped and very noisy and I couldn't process information on the board. I took my card to a member of staff, who asked for my ticket, stayed with me until my train came in and walked me onto it, into a quiet carriage, I was so grateful as I was so close to curling up in a ball on the concourse floor before that.”

21% to assist in applying for welfare benefits

“Included a photocopy of my card when applying for ESA / PIP - it’s classed as an aid.”

“It came in handy when I was being assessed for PIP.”

19% with colleagues, employers or education providers

“Being able to produce it has given me confidence to speak up about my disability when I have needed to during my firm’s recent redundancy consultation.”

“I just wear it at work just in case, as I tend to get anxious and a bit flustered.”

“I can’t cope with a lot of noise/several things going at once. It helps to show work colleagues my card as they are more tolerant then.”

14% during work-related assessments / appointments with Jobcentre Plus

“Used it when I was meeting with a person in the Jobcentre and when I had a medical appointment in the hospital.”

“I went for a Work Capability Assessment for Universal Credit. Showing the card gave me confidence, as I was given more time to answer questions.”

12% with the police

“Police was when I was a victim, shaken. [I] showed my card for understanding and then explained the incident. I was shown care and quick action was taken.”

“It is handy as ID and in difficult situations, say police station.”

11% with other emergency services (e.g. ambulance service)

“Made it easier to interact with GP and ambulance staff.”

“I’ve had episodes in public areas where I have had an episode/seizure and needed help. The card has saved time, and I’ve not had to be rushed to hospital or wasted the ambulance. Carrying the card makes me more secure and confident.”

When asked how helpful the card had been, the vast majority (**85%**) found it ‘very helpful’ or ‘helpful’.

Fewer than 3% of respondents did not find the card helpful.

Respondents commented on the difference the Brain Injury Identity Card has made in these kinds of situations, with people being more understanding and patient once they are presented with the card:

“People were more understanding. It’s peace of mind for me as I don’t have confidence to speak up so I have [the card] ready so if people ask I can show [the card] - job done, move on.”

“[I] became confused which led to me becoming agitated and made my stutter worse. I was given time to compose myself.”

“They see my condition and try to help as much as they can. It’s amazing how much they change, and they think it is an excellent card to have.”

“It has given me time to think and has given other people a visual summary of what I need help with particularly as I have difficulty speaking when I get stressed.”

“People speak slower, offer more assistance, check I understand, realise I am not drunk.”

Some respondents also commented on how the card has removed the difficulty of having to explain the effects of their brain injury:

“When I show my card, it saves me the stress of trying to explain my issues, it’s a quick fix in our sometimes hectic world.”

“Having my card means that I don’t have to try and find the words to explain how difficult things are for me.”

“It has helped in easing situations that I have found difficult to explain to people.”

“It has really helped as it took away the stress of explaining about my condition as when I am stressed it is difficult to get my words out. Also when I am very tired and need to rest it helps explain why I am tired but look ‘well’.”

Unfortunately, a small number of respondents indicated they had not had positive experiences when they have used their Brain Injury Identity Card in public:

“Nothing happened, they didn’t recognise it at all and said ‘so what you’ve got a card that anyone can get.’”

“Some people changed and had a much better approach but others didn’t really change or understand.”

“It has been ignored and people don’t think it’s real.”

“The person didn’t even look at it but the fact I could produce it made me feel very secure and validated.”

Criminal legal advice / representation

Respondents were asked if they had made use of the 24-hour criminal legal assistance line detailed on the front of the Brain Injury Identity Card.

5% of survey respondents had made use of this service. 18 told us they had used it, while 17 were unsure.

Of the 18 cardholders that had called the number to request criminal legal assistance, 10 were happy with the service they were provided. 8 told us they were not happy or unsure.

“The solicitor really went the extra mile and persuaded the prosecution to drop the charges. Without his assistance, the outcome might have been a custodial sentence.”

“Advice was good and helpful.”

“Would highly recommend the Solicitors. They were professional, efficient, sympathetic, understanding and helpful at a very difficult time”.

“Got valuable advice.”

Headway’s figures indicate that 461 calls were made to the criminal legal helpline on the front of the ID Card in 2020. 41% (184) of these were referred to the criminal legal team managed by a firm of solicitors trained in understanding brain injury.

Brain Injury Identity Card holders’ experiences with Jobcentre Plus

Any respondent who indicated they had experienced difficulty explaining the effects of their brain injury or had used their Brain Injury Identity Card with Jobcentre Plus was asked further questions about their experience:

30% (48) of these respondents stated they had missed scheduled appointments / assessments with Jobcentre Plus due to the effects of their brain injury.

33% (54) of these respondents told us they had been subjected to benefit sanctions due to difficulty explaining the effects of their brain injury.

Headway has been working closely with the Department for Work and Pensions (DWP) to improve staff understanding and awareness of brain injury. As part of this collaborative work, the DWP has agreed to recognise the Brain Injury identity Card.

Jobcentre Plus staff across the country have been provided with information on the Brain Injury Identity Card and instructions on how to “pin” this information to a customer’s record. This important development will help ensure everyone involved in a customer’s support is aware of their condition and the support they receive can be tailored appropriately.

The impact of the Brain Injury Identity Card on survivors' lives

Respondents were asked what difference the Brain Injury Identity Card has made to their lives.



The majority of responses to this question indicated that survivors feel more confident, reassured and feel the card helps them explain the effects of their injury.

'Confidence' was mentioned more than 100 times by respondents to this question, 'explain' over 70 times and 'reassurance' 60 times.

"Just having it with me gives me the confidence to go out on my own. For the first time in 8 years I went on a flight on my own with the card."

"Gives me confidence. It takes the pressure off having to take my time when communicating or speaking too fast that I'm embarrassed."

"It makes me feel able to socialise as previously people thought I was drunk, so I was too anxious to go out. Also, it explains I have speech problems, so people now realise I'm not just being rude or uncooperative."

Other key themes that arose included survivors feeling their lives were made easier, they felt safer and more secure.

"It has been a 'safety net' which I can produce from my wallet and show to people if I am ever overwhelmed by information in a conversation."

"Carrying the card makes me feel safer. I know that if I can't explain why I can't immediately deal with a situation I can flash the card. It will explain to others without me having to struggle to find the words at a moment when I really can't."

“It makes my life a lot easier.”

Some others also mentioned they felt the card was helpful as it validated their disability, especially for those living with the hidden effects of brain injury.

“It helps to explain quickly to people who don't understand brain damage or hidden disabilities. It helps to provide proof as I don't 'look disabled.’”

“Confidence just from having it in my wallet. It's kind of a validation of something so invisible but so all consuming.”

“It is a crutch that makes me feel protected and validates that I am still me, but the new version has a card which outlines things I struggle with.”

Although not all respondents use their Brain Injury Identity Card regularly, the simple fact of knowing it is there if they need it is reassuring.

“Even though I don't use it often it is always with me so I know I can use it if need be and that reduces the anxiety I struggle with.”

“I have not used my card, but I carry it everywhere with me just in case. Carrying my card gives me confidence.”

“Hugely reassuring to have. Even if it's not used very often.”

Conclusion

The vast majority of responses to this survey indicate cardholders' views of the Brain Injury Identity Card scheme are extremely positive. The results show that the ID Card has become a highly respected and valuable tool for survivors of brain injury.

The ID Card continues to provide many survivors of brain injury with greater confidence and reassurance as they go about their lives in various settings such as visiting shops, pubs, restaurants, banks, attending medical appointments and while using public transport.

To date, more than 9,000 Brain Injury Identity Cards have been issued to survivors across the UK. With the number of cardholders increasing by almost 20% last year, it is clear that the scheme will provide benefit to many more survivors in the future.

For more information about the card, please visit www.headway.org.uk/idcard. You can also contact Holly Warner, Justice Project Manager on justiceproject@headway.org.uk.