# Too many to count...

## Brain injury in the context of domestic abuse

Brainkind

# Acknowledgements

We would like to thank all the women who participated in this research.

Their insights and experiences have made an invaluable contribution to understanding the relationship between domestic abuse and brain injury in the UK.

We would also like to thank the host sites and their practitioners for making time for our project and joining us on the journey to understand how we can adapt practice for the better.

Aurora New Dawn

I Choose Freedom

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# Abbreviations

| | |
|---|---|
| ABI | Acquired brain injury |
| BI | Brain injury |
| CJS | Criminal Justice System<br>(courts, police, prison and probation) |
| CFS | Children and Family Services |
| DA | Domestic abuse |
| HNF | Head, neck and face injuries |
| GP | General Practitioner |
| IPV | Intimate partner violence |
| TBI | Traumatic brain injury |

# Foreword

As the Chief Executive of Brainkind I am incredibly proud to share our latest research into the intersection of brain injuries and domestic abuse. For the past 18 months our team has spoken with people who have experienced domestic abuse and practitioners across England and Wales. We have worked hard to understand the specific experiences and complex issues faced by people who have experienced domestic abuse in the UK.

Too Many to Count is our fourth report developing recognition of the importance of brain injury awareness in the broader domestic abuse debate. Our findings are groundbreaking and reveal that 1 in 2 people who have experienced domestic abuse may be living with a mild to moderate brain injury. Our report recommendations focus on how we can work together to close the gaps in knowledge and practice around brain injuries.

As experts in brain injury, we are grateful to the professionals and people who have experienced domestic abuse who have already begun to work with us, through contributing and attending our most recent roundtable events, sharing their expertise and assisting us in identifying the key complexities and gaps in current provisions.

We are dedicated to continuing this work, collaborating with professionals in domestic abuse and frontline services, as well as with people who have experienced domestic abuse. We know tackling these issues requires a multidisciplinary approach and long-term commitment. We welcome working with anyone who wants to join us on this journey.

Irene

**Irene Sobowale**

*Chief Executive Officer*

# Executive summary

Too Many to Count is the first study in the United Kingdom to explore the prevalence of brain injury in people who have experienced domestic abuse, who access community-based services.

Our key findings were:

**55%** of participants screened positive for history indicative of brain injury.

**80%** had experienced a serious blow to the head.

**46%** reported being strangled.

**75%** had been held in a way they felt they couldn’t breathe.

We found that the women who screened positive for a history indicative of brain injury were more likely to experience moderate to severe post-concussion symptoms, low mood and post-traumatic stress. They also consistently reported a range of cognitive, emotional and physical symptoms of brain injury. Further exploration revealed significant overlap between brain injury and mental health symptoms, highlighting not only the risk of misattribution, but also to the complexity of accurate identification of brain injury in this population.

The participant focus groups and professional roundtables identified a widespread lack of awareness of the risks and consequences of brain injury in the domestic abuse (DA) context. Those with lived experience of domestic abuse called for easily accessible information on brain injury that would allow them to advocate for themselves. Professionals identified the need for awareness raising and training in identification of brain injury across all services working in the DA sector.

Significant health and social inequalities were also identified. The participants spoke of difficulty navigating complex health and social care systems, resulting in barriers to accessing the correct support. Professionals acknowledged not always being sure where to refer people presenting with brain injury symptoms. People with brain injury often struggle to access and/engage with standard mental health services without support. Therefore appropriate identification of brain injury and the correct signposting is likely to be key to improving all outcomes.

Many of the women we spoke with expressed concerns that the identification of brain injury might have a negative effect on them and their children. They raised concerns that having a diagnosis of brain injury might be used to discredit their recollection of events or question their capacity to parent. Such fears are likely to have a significant impact on an individual's ability and willingness to seek support. Equally, without accurate identification of brain injury, women may be left navigating complex court systems without the appropriate support, also putting them and their families at risk.

Brainkind recommends:

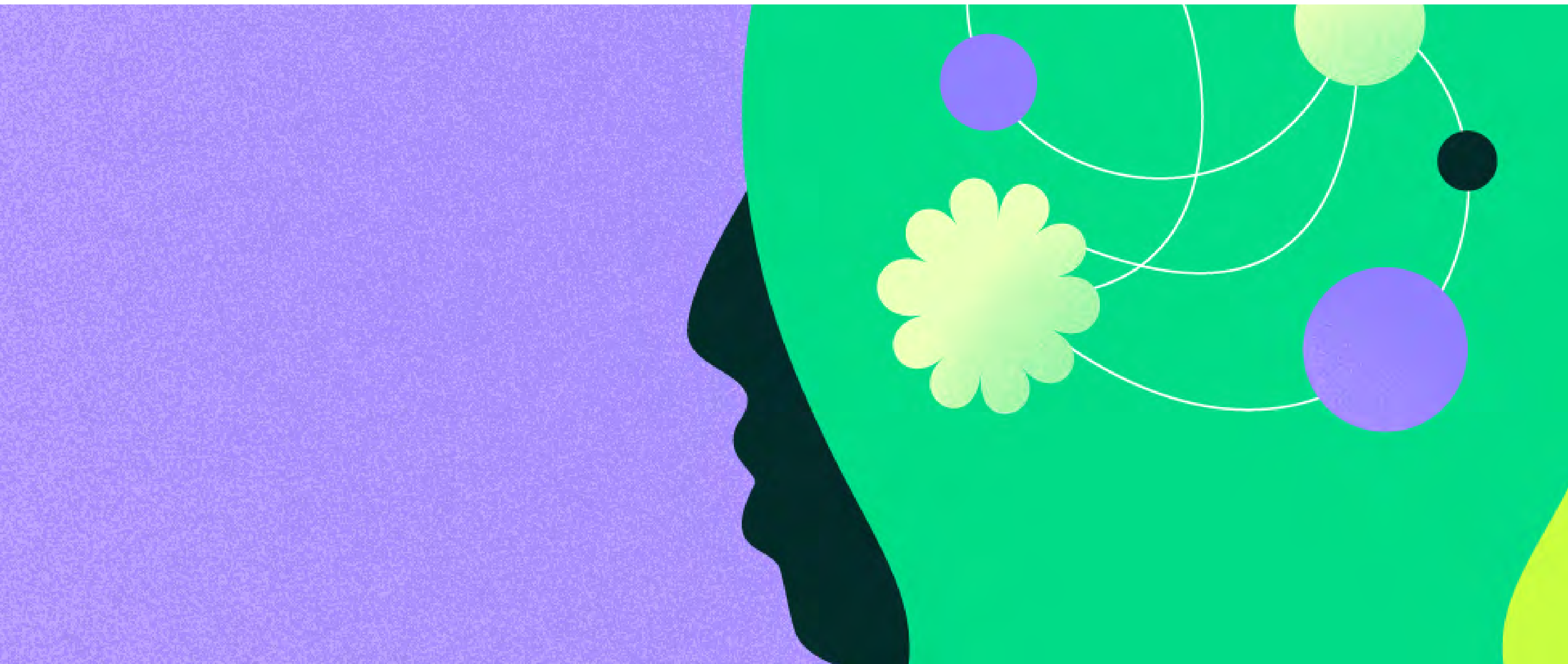
- Research to further our understanding of brain injury as a consequence of domestic abuse.
- Co-production of brain injury awareness resources with people who have experienced domestic abuse.
- Training in identification of brain injury, and the development of a toolkit for all staff working in domestic abuse services.
- Inclusion and recognition of brain injury and its impact on people experiencing domestic abuse in future policy and legislation.

# Introduction

Domestic abuse is a critical global public health issue. The World Health Organisation - WHO (2021) states that as many as one in three women worldwide will experience domestic abuse or intimate partner violence in their lifetime and cites domestic abuse against women and children as an "urgent public health priority" (WHO, p. 1).

The UK government defines domestic abuse as any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence, or abuse between those aged 16 or over who are "personally connected" or have been, and this includes intimate partners or family members, regardless of gender or sexuality. (Domestic Abuse Act, 2021). This abuse includes physical violence, sexual violence, economic abuse, psychological and emotional abuse, violent or threatening behaviour and controlling or coercive behaviour.

Recent UK data from the Office for National Statistics estimates that as many as 1 in 4 women and 1 in 6 men are affected by domestic abuse each year. The Crime Survey for England and Wales estimated that, in the year ending March 2022, 2.4 million adults experienced domestic violence and abuse. In the same year, police across England and Wales recorded 1,500,369 domestic abuse-related crimes (Office for National Statistics, 2022). This equates to a call to the police about domestic abuse every 30 seconds, making it one of the high-volume priority crimes in the UK (Crimestoppers UK, nd). Domestic abuse is often referred to as a hidden crime, one that is not always reported to the police or frontline services. Therefore, data can only provide a partial picture of the actual levels and types of domestic abuse experienced.



# Domestic abuse and brain injuries: background

Brainkind started to explore the intersection of domestic abuse and brain injury following the publication of Making the Link (2018). This report identified that 64% of female offenders at HMP Drake Hall had a history indicative of brain injury. Of those women, 62% reported they had sustained their traumatic brain injury (TBI) due to domestic abuse.

Following these findings, in November 2019, Brainkind hosted an expert roundtable to discuss brain injury in the context of domestic abuse. The roundtable explored the gaps in awareness, research, practice and policy. The discussions in Invisible Impact (Brainkind, 2021) indicated that practitioners perceived their own awareness and knowledge of brain injury as limited, they identified that brain injury often presents in ways that are not always easy to recognise, and they recognised that appropriate training is not readily available. The findings were mirrored by the responses to a national audit conducted by Brainkind and SafeLives in the same year, thus providing a clear rationale for research to establish the prevalence of brain injury in people who have experienced domestic abuse accessing services in the UK, and also to gain a better understanding of challenges faced by those with lived experience (A Practitioners Perception, Brainkind, 2021).

Internationally, a scoping review of prevalence studies conducted between 1990 and 2020 found the estimated prevalence of brain injury (in people who have experienced domestic abuse) to range from 42 to 89% (Campbell, Joseph, Rothman & Valera, 2022). Despite these stark findings, to our knowledge, there have been no UK-based prevalence studies.

Furthermore, despite one third of people affected by acquired brain injury (ABI) being women, very little of the ABI literature focuses on sex or gender differences (Haag et al., 2019; Costello and Greenwald, 2022). It has been observed that, when compared with men, women often present with different symptoms and are more likely to endorse emotional, cognitive and somatic difficulties (Schopp et al., 2001; Slewa-Younan et al., 2008; Mollayeva et al., 2018). Women's brain injury symptoms frequently overlap with post-traumatic stress (PTS) and depression symptoms, making it easy to misattribute these to mental health issues. Differences in presentation are likely to have significant implications for how women access services and the long-term consequences of their ABI. This is particularly pertinent in the context of domestic abuse where frontline practitioners may have very limited awareness of acquired brain injury (Manoranjan et al., 2022).

Head, neck, and face (HNF) injuries are common in the context of domestic abuse (Sheridan and Nash, 2007; George et al. 2019; Esopenko et al., 2021). Research indicates that the number of incidents of domestic abuse involving hits to the head ranges between 40% to 92%, with nearly half of the people who have experienced domestic abuse also reporting experiences of strangulation (Cimino et al., 2019; St. Ivany and Schminkey, 2016; Kwako et al., 2011). These findings demonstrate that people who have experienced domestic abuse are at an increased risk of experiencing both traumatic (following a serious head injury) and hypoxic (anoxia following non-fatal strangulation) brain injuries (Dams O'Connor et al., 2014; Monahan, 2019; Murray et al., 2016; Karakurt, 2021; Meyer et al., 2022).

People who have experienced domestic abuse are most likely to experience brain injury which presents as a "hidden disability". There is increasing awareness that even those brain injuries classified as mild can have long-term cognitive, social, and emotional consequences, requiring support across the lifespan and not just the acute phase of the injury (Valera et al., 2021; Centers for Disease Control and Prevention, 2023;). The symptoms commonly reported by women (e.g., difficulties with emotions and cognition) mean that they frequently struggle to access the long-term support they require. A Canadian study (Toor et al., 2016) found that although women with TBI accessing community-based healthcare services matched women without TBI for age education and geographic location, they reported significant financial and structural barriers to receiving care; with a lack of support for emotional and mental health issues most commonly cited. A vicious cycle is therefore being created with the cognitive, emotional, and social consequences of ABI placing women at risk of becoming socially isolated and losing financial security, both of which are risk factors for domestic abuse.

A lack of awareness of brain injury amongst frontline practitioners working in the domestic abuse field is a clear barrier to accurate diagnosis and treatment (Nemeth, Ramirez, Debowski, et al., 2023). Other issues, such as the individual remaining within the abusive relationship, a lack of awareness of the potential seriousness of head injury or non-fatal strangulation (NFS), previous bad experiences of statutory services, and a fear of stigmatisation, may also result in a reluctance to disclose symptoms to professionals. Frequently cited reasons for non-disclosure include concerns that children will be taken into care or that the diagnosis of a brain injury will be used against the individual in legal proceedings. The Women's Aid report Two Years, Too Long (2022) documents the lack of progress in transforming family courts in the UK, highlighting that the justice system continues to fail people who have experienced domestic abuse and their families.

A Canadian study (Boyle et al., 2023) looked at the ethico-legal considerations of screening for brain injury (BI) in women who have experienced domestic abuse. The study interviewed 12 lawyers, who identified that a diagnosis of brain injury could be used to argue that the person has diminished capacity to parent, to raise concerns about the capacity to litigate and may present challenges in a context where there is limited case law to inform judges. This is consistent with womens' concerns that a diagnosis of brain injury may leave them legally vulnerable. However, without the identification of ABI, women are also vulnerable to being failed by the court system due to the incorrect support (e.g., not being given enough time to process questions or review information). These findings highlight the importance of setting up informed responsible ABI screening with support and advocacy for those that screen positive for brain injury.

In this study, we aimed to explore the prevalence of acquired brain injury amongst people who have experienced domestic abuse in community-based services, across the United Kingdom. We examined how brain injuries may present in this population, the difficulties women are experiencing and the support they have received during their experiences. Through exploring these issues we hope to gain greater understanding of ABI in this population, how it can be effectively identified and how women can be better supported to access the services they need.

# Methodology

This study was approved by Brainkind's Research Group, the institutional review board overseeing research governance and ethics within the organisation.

The research questions relating to experiences of services and support were co-produced with members of the SafeLives Pioneers Survivor group. Our research questions were:

- What is the prevalence of brain injury amongst people who have experienced domestic abuse, and are accessing community-based domestic abuse support services in the UK?
- What are the challenges faced by people with lived experience when accessing appropriate support services?

All 60 participants were recruited and supported by nine different host sites - domestic abuse support services across England and Wales, comprising of both safe accommodation refuges and outreach and community-based services. Where possible, host sites from different regions were engaged to ensure representation from different communities across the UK.

Research interviews were conducted between July 2022 and July 2023. They took place either in person or remotely.

The study followed a quasi-experimental design, where the results of participants who screened positive for brain injury were compared to those who screened negative.

## Outcome measures

The research interview included a range of questions on basic demographic information and the participants' experiences of seeking support. Three questionnaires on brain injury and related symptoms and four questionnaires relating to mental health were also administered to all participants (Table 1).

*Table 1. Outcome measures*

1 The Brain Injury Screening Index - BISI (O'Sullivan et al., 2019; Ramos et al., 2018) was used to assess the lifetime prevalence of brain injury.

2 The Rivermead Post-Concussion Symptoms Questionnaire (King et al., 1995) was used to assess ABI symptomology. Each item in this tool is scored on a scale from zero to four, where lower scores represent no or mild symptoms.

3 The CHATS (Ramirez, Nemeth & Ohio Domestic Violence Network, 2018) is a structured questionnaire designed to support practitioners to identify and provide information on head injury to people who have experienced domestic abuse. It was used to screen for symptoms experienced by participants.

4 The Patient Health Questionnaire - 9 (PHQ-9, Kroenke, Spitzer, & Williams, 2001, Kroenke & Spitzer, 2002) was used to measure symptoms of depression. It is the depression portion of the Patient Health Questionnaire and used to aid in the identification and diagnosis of depression. It scores each of the nine DSM-IV criteria for depression over a 14-day timeframe as "0" (not at all) to "3" (nearly every day).

5 The Generalised Anxiety Disorder assessment (GAD-7, Spitzer, Kroenke, Williams and Löwe, 2006) was used to measure symptoms of anxiety. This tool assesses the frequency of symptoms in the past 14 days. It is scored on a scale from zero to three, where "0" indicates "not at all" to "3" "nearly every day".

6 The five-item Dimension of Anger Reactions (DAR-5, Forbes et al., 2014) was used to assess problems with anger.

7 The Revised Impact of Events Scale (IES-R, Weiss, & Marmar, 1997) was used to measure symptoms of PTSD.

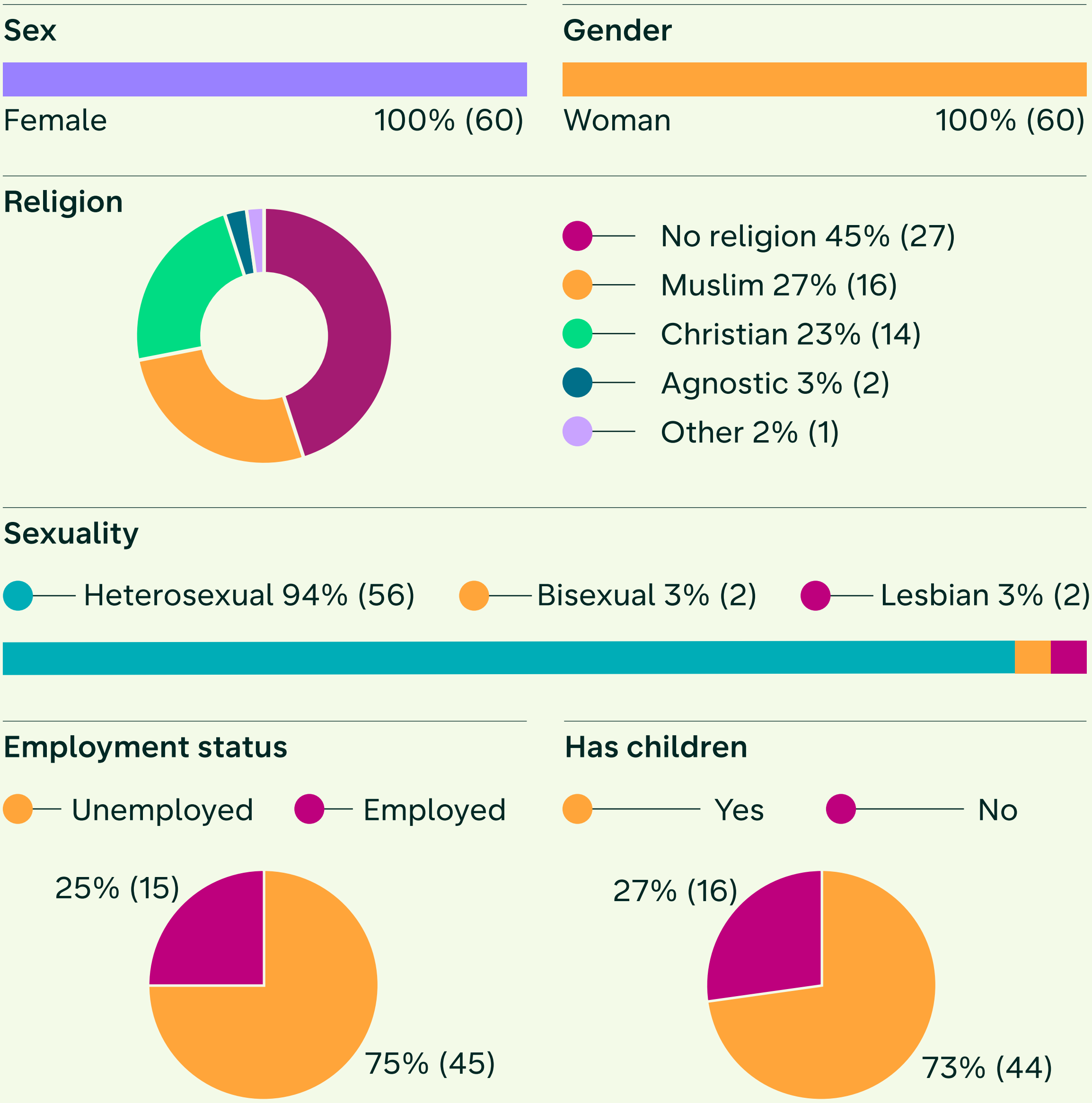
# Our findings

## Demographics

We interviewed 60 people who have experienced domestic abuse, all of whom stated they were female and identified as women. Our participants were aged between 18 and 72, with a mean average age of 36. The participants were recruited from sites across England and Wales and reflected a wide range of ethnicities (Appendix; Table A1).

All participants reported experiencing more than one type of abuse (Appendix; Table A2), with emotional (93%), physical (88%) and verbal (75%) abuse most commonly endorsed.

*Table 2. Demographic characteristics of participants*



## Research findings

Over half of all participants in this study (n = 33, 55%) screened positive for history indicative of a brain injury on the BISI. Eighty percent of participants (n = 48) reported having experienced a significant blow to the head at least once, and of those participants, 85% (n = 41) disclosed that they had experienced this more than once.

To explore potential hypoxic brain injuries, we included in the BISI the question, “Have you ever been held in a way that you felt you could not breathe?”. Seventy-five percent of participants reported that they had experienced this. Where participants felt comfortable to do so, they were asked to describe the act. Forty-five percent of participants disclosed being “strangled” at least once; capturing those that had experienced non-fatal strangulation (NFS). The women in this study identified a range of mechanisms of a potential hypoxic brain injury, including the use of water to drown or waterboard them, being choked, being suffocated or smothered with an object.

> *Our findings indicate that not all people who have experienced domestic abuse identify strangulation as the mechanism of injury or a description of their experience. By simply asking about non-fatal strangulation there is potential to miss identifying hypoxic injuries that have resulted from other experiences of having breathing restricted.*

The above findings were mirrored by the participants responses on the CHATS. Eighty-three percent of participants stated they had been hit or hurt in the head, neck, or face, consistent with the answers on the BISI; in which 80% of participants said they had experienced a serious blow to the head. Furthermore, 70% of the women stated: “that someone had put their hands around their neck, put something over their mouth, done something that made them feel choked, suffocated, or strangled”.

## Nature of injury

We wanted to understand how many participants who had screened positive on the BISI (i.e., had a history indicative of brain injury) had also experienced non-fatal strangulation. We coded responses on the BISI by the nature of their injury (Table 3), which allowed us to explore possible differences between the symptoms associated with different mechanisms of brain injury.

The four groups resulting from this categorisation were:

- Group 1 participants who did not screen positive on the BISI and did not disclose any experience of non-fatal strangulation.
- Group 2 participants who screened positive on the BISI but did not disclose any experience of non-fatal strangulation.
- Group 3 participants who screened negative on the BISI but disclosed non-fatal strangulation.
- Group 4 participants who had screened positive on the BISI and had also disclosed non-fatal strangulation.

*Table 3. Reported nature of injury*

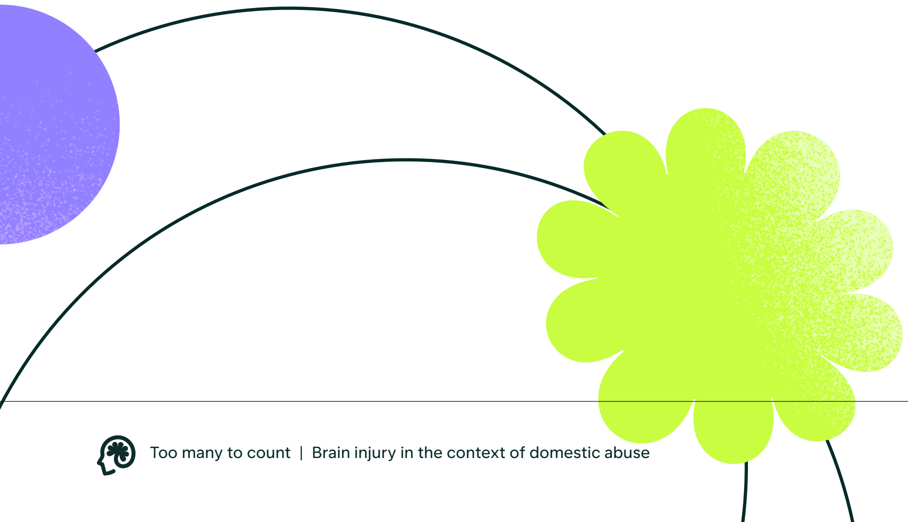
| Group | Nature of Injury | Number of participants |
|---|---|---:|
| 1 | None | 9 |
| 2 | ABI only | 6 |
| 3 | Non-fatal strangulation (NFS) only | 18 |
| 4 | ABI & NFS | 27 |

## ABI symptoms

We used the BISI, CHATS and Rivermead Post-concussion Symptom Questionnaire (RPQ) to explore post-head injury symptoms. We found that the majority of participants fell in the moderate to severe range on the RPQ (Table 4).

*Table 4. Post concussion symptoms as measured by RPQ*

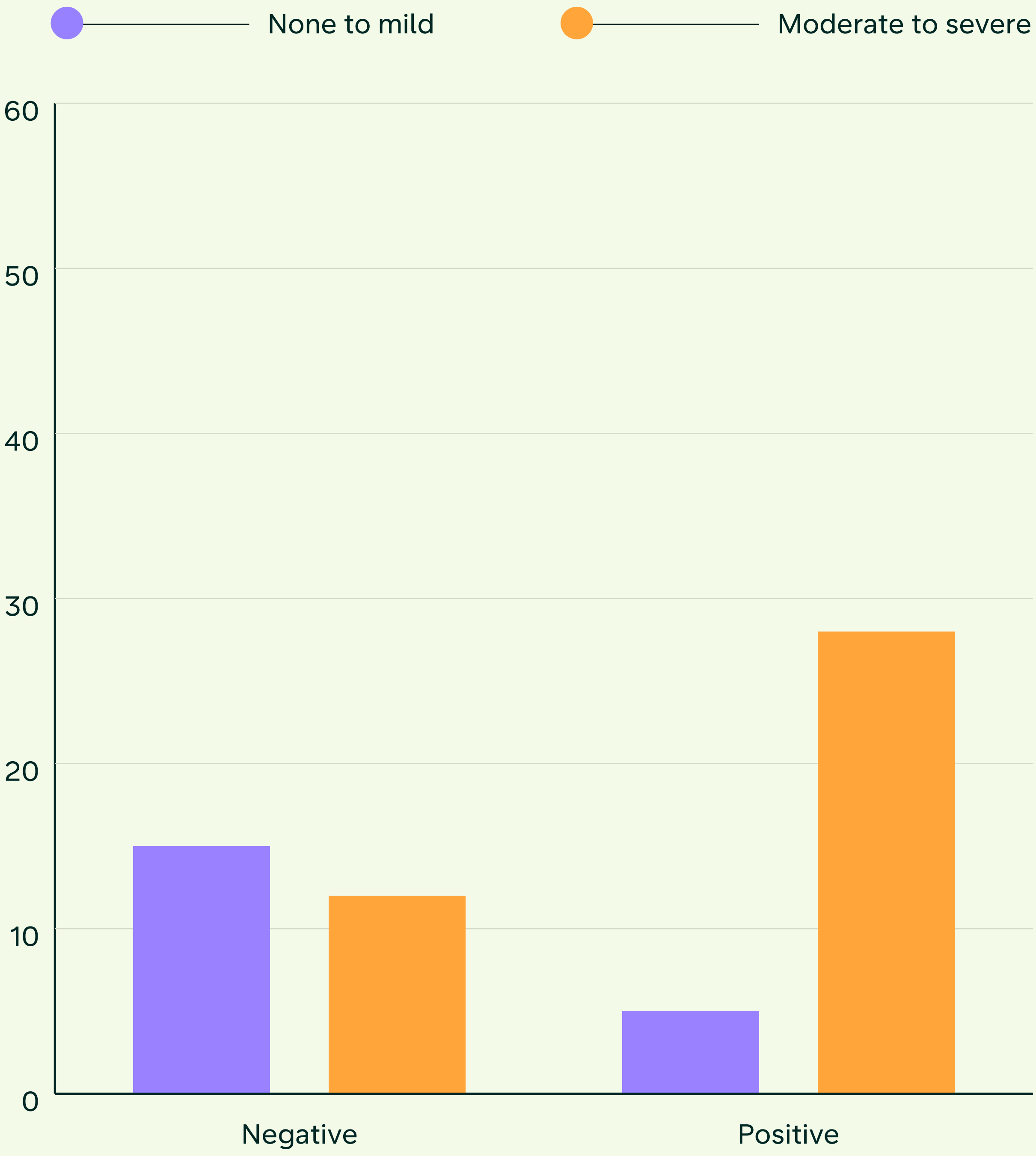
| RPQ Classification | Number of participants | Percentage of participants |
|---|---:|---:|
| Mild | 9 | 15% |
| Minimal | 11 | 18% |
| Moderate | 11 | 18% |
| Severe | 29 | 48% |
| Total | 60 | 100% |



We also compared the severity of ABI symptoms between participants who screened positive or negative on the BISI. This revealed that the proportion of participants who experienced moderate to severe ABI symptoms was significantly greater among those who had a history indicative of brain injury (i.e., screened positive on the BISI) than those who did not (Figure 1).

## Comparison of the severity of post-concussion symptoms between participants who screened positive, or negative for a history indicative of brain injury on the BISI

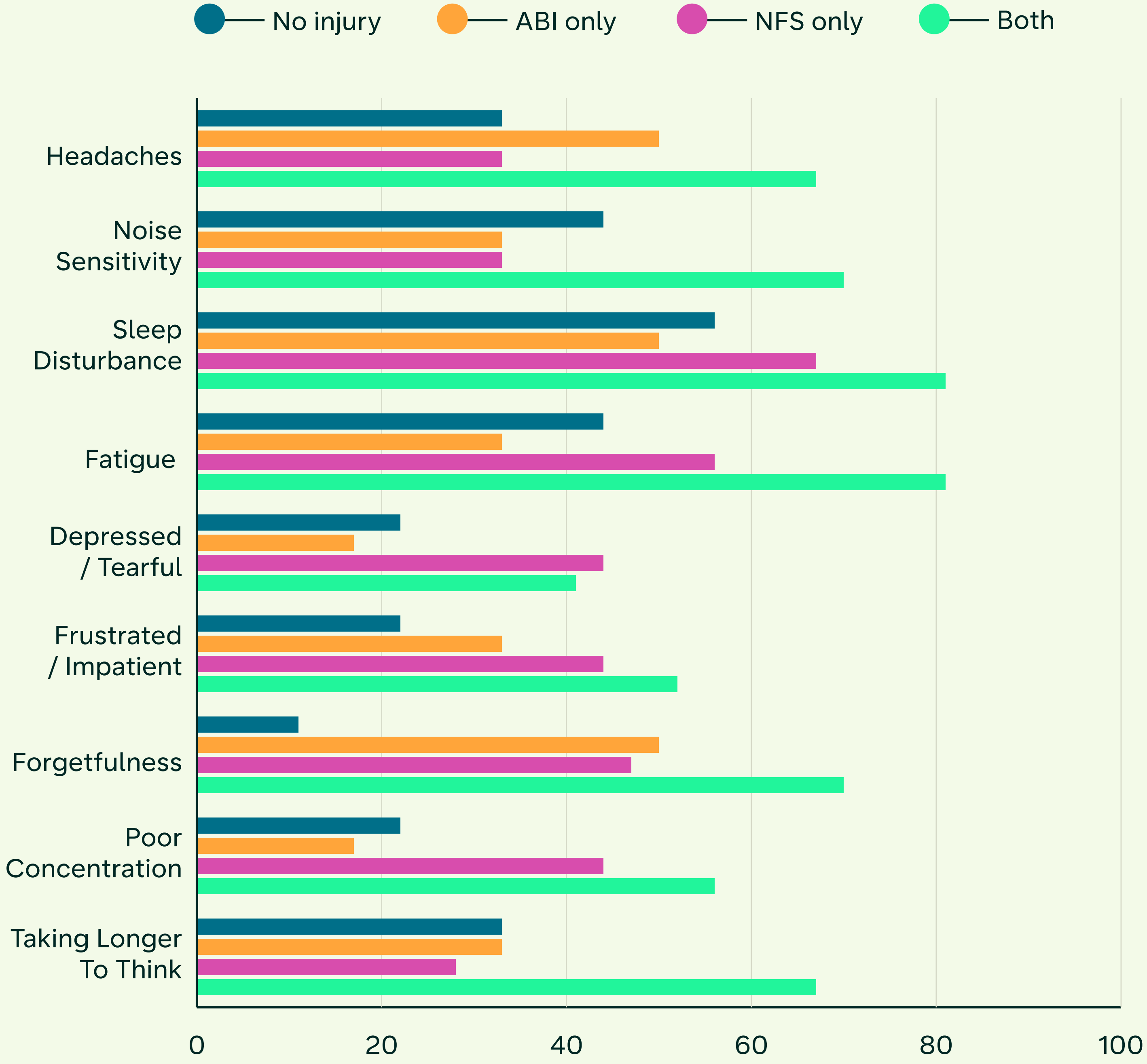
*Figure 1.*



We then looked more specifically at symptoms reported most frequently on the RPQ by nature of injury (Figure 2). We found that sleep disturbance, noise sensitivity and fatigue were frequently reported as severe across all four groups, even those who had not experienced an ABI. This highlights the overlap in symptoms between brain injury and mental health issues (e.g., trauma).

## Post concussion symptoms as measured by the RPQ and nature of injury

*Figure 2.*



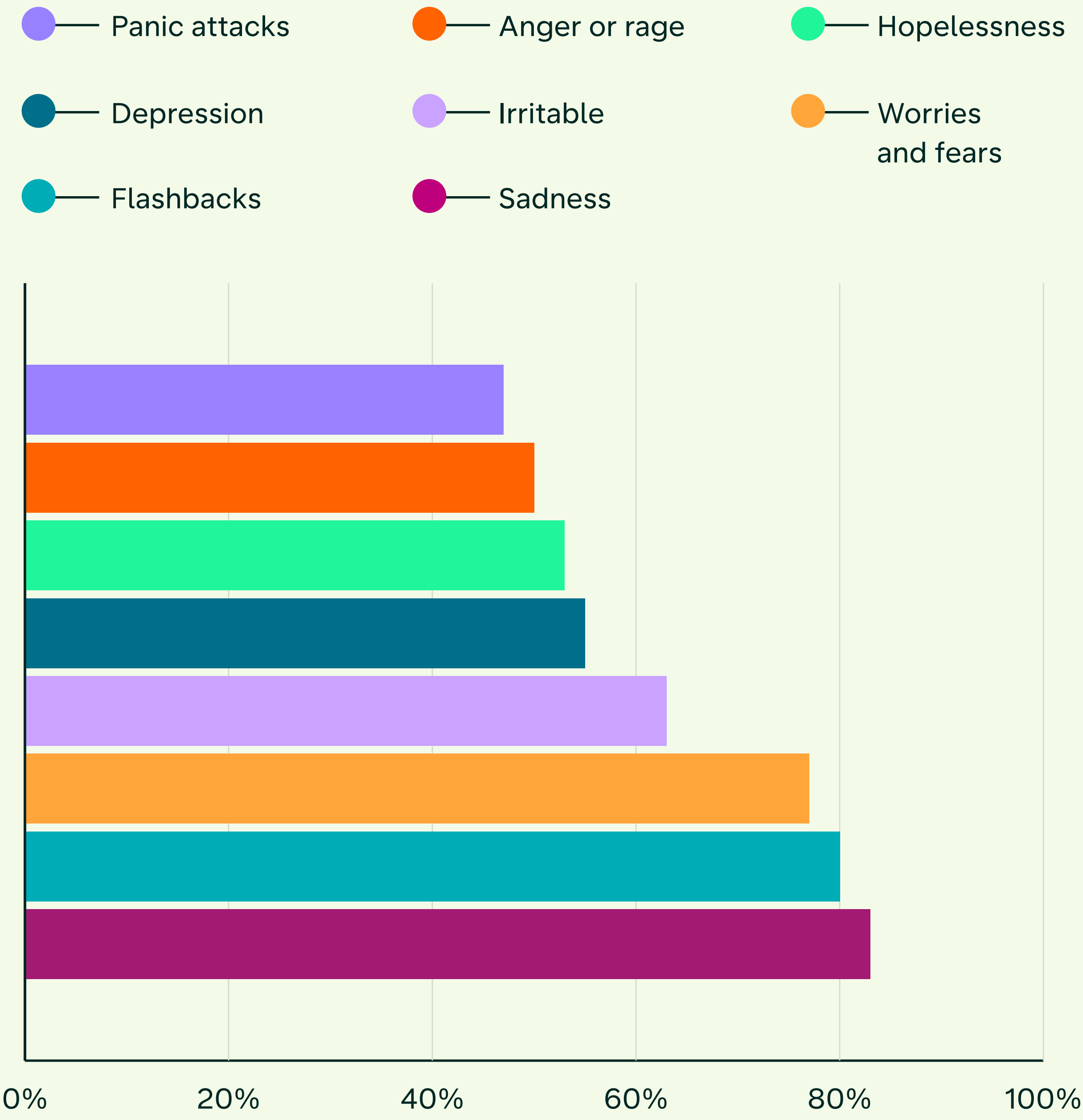
There was some indication that cognitive symptoms such as “taking longer to think”, “forgetfulness” and “poor concentration” (as measured by the RPQ) were more frequent in those with both types of brain injury (i.e., ABI and NFS) than any of the other groups. It may be that this group of participants have experienced more significant injuries, or a greater number of injuries, placing them at higher risk of experiencing more post-concussion symptoms. However, the cognitive symptoms also occur in the context of these participants experiencing greater sleep disturbance, fatigue, noise sensitivity and headaches - all of which are likely to have an impact on cognition. These physical symptoms are commonly experienced in the context of trauma as well as ABI, once again highlighting the complex relationship between trauma and brain injury symptoms.

The CHATS also asks about physical, cognitive and emotional symptoms post-head injury. Our participants, consistent with their responses on the RPQ, endorsed a wide range of physical symptoms. Most frequently reported were “sleeping problems” (73%), “headaches” (68%), “fatigue” (65%) and “sensitivity to light and noise” (60%).

All the emotional symptoms listed in the CHATS were endorsed by participants (Figure 3). Frequently endorsed (75% of participants or more) were “sadness”, “flashbacks”, “worries, and fears”. This is understandable in the context of domestic abuse and the associated trauma people experience. Furthermore, we know that having a brain injury also puts an individual at greater risk of experiencing difficult emotions. Once again, the intersection between brain injury and mental health difficulties is illustrated.

## Emotional symptoms as measured by the CHATS

*Figure 3.*



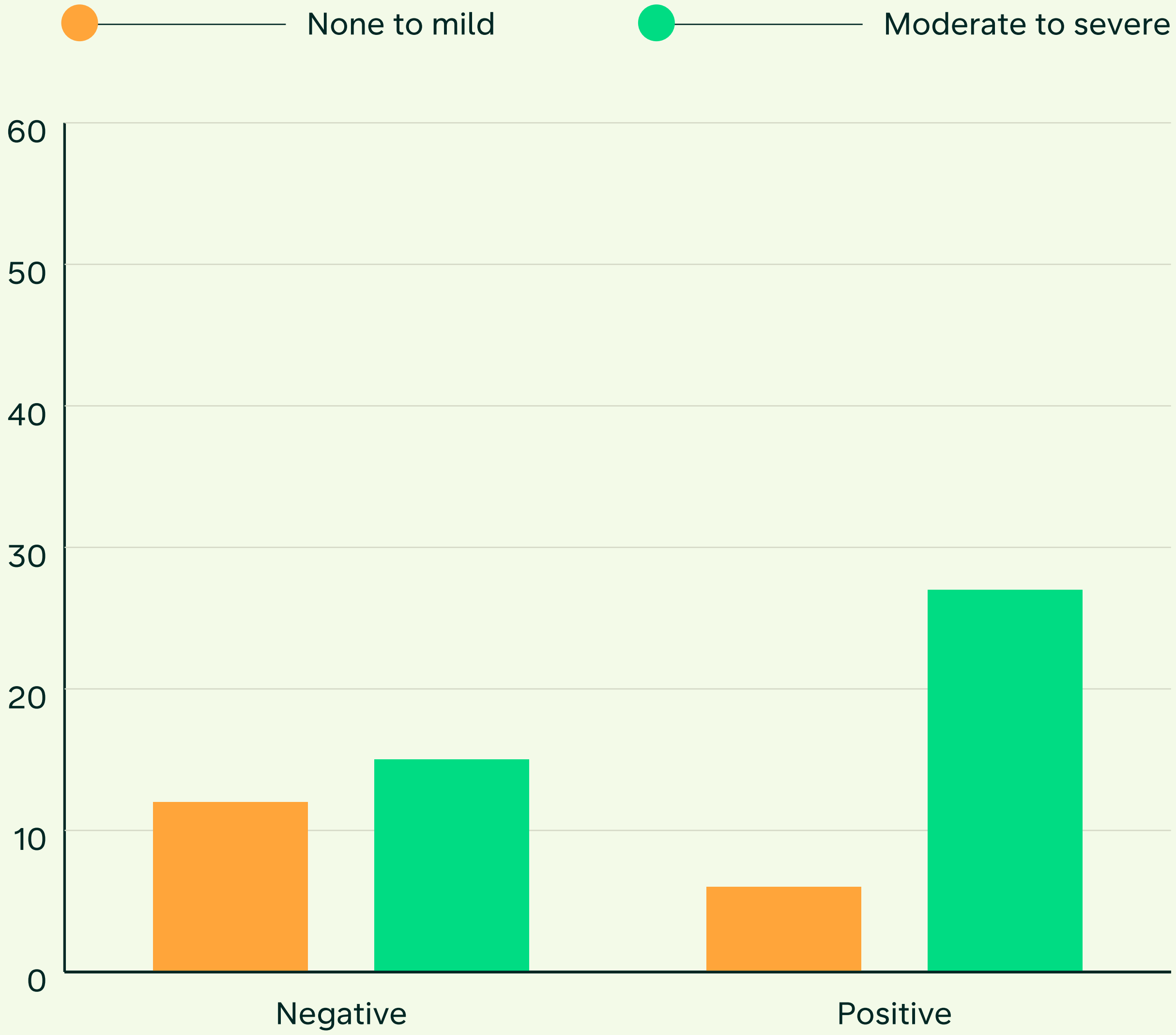
## Low mood and depression

Forty-two (70%) participants in our study scored within the moderate to severe range on the PHQ-9, indicating that they were experiencing high levels of symptoms associated with low mood.

We then compared results on the PHQ-9 between participants who screened positive or negative on the BISI. The results suggested that participants who screened positive (i.e., had a history indicative of brain injury) on the BISI were significantly more likely to score in the moderate to severe range on the PHQ-9 (Figure 4).

**Comparison of the severity of low mood symptoms between participants who screened positive, or negative for a history indicative of brain injury on the BISI**

*Figure 4.*

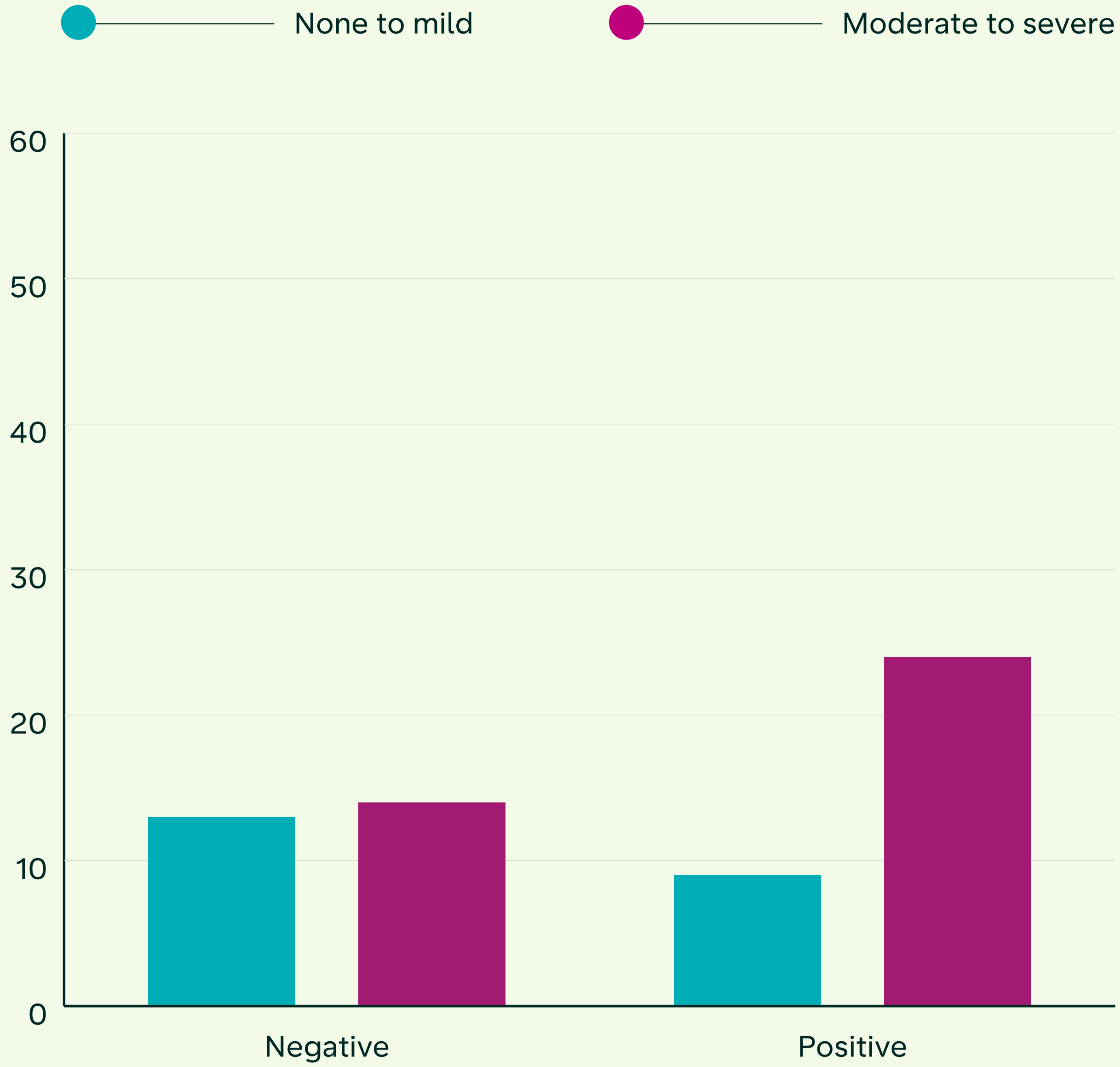


## Anxiety symptoms

Thirty-eight participants (64%) scored in the moderate to severe range on the GAD-7. We further found that the prevalence of moderate to severe anxiety symptoms was comparable between those who had a history indicative of brain injury (positive on the BISI) and those who did not (negative on the BISI) (Figure 5). These findings highlight that participants, regardless of whether or not they had history indicative of brain injury, were experiencing anxiety symptoms.

**Comparison of the severity of anxiety symptoms between participants who screened positive, or negative for a history indicative of brain injury on the BISI**

*Figure 5.*



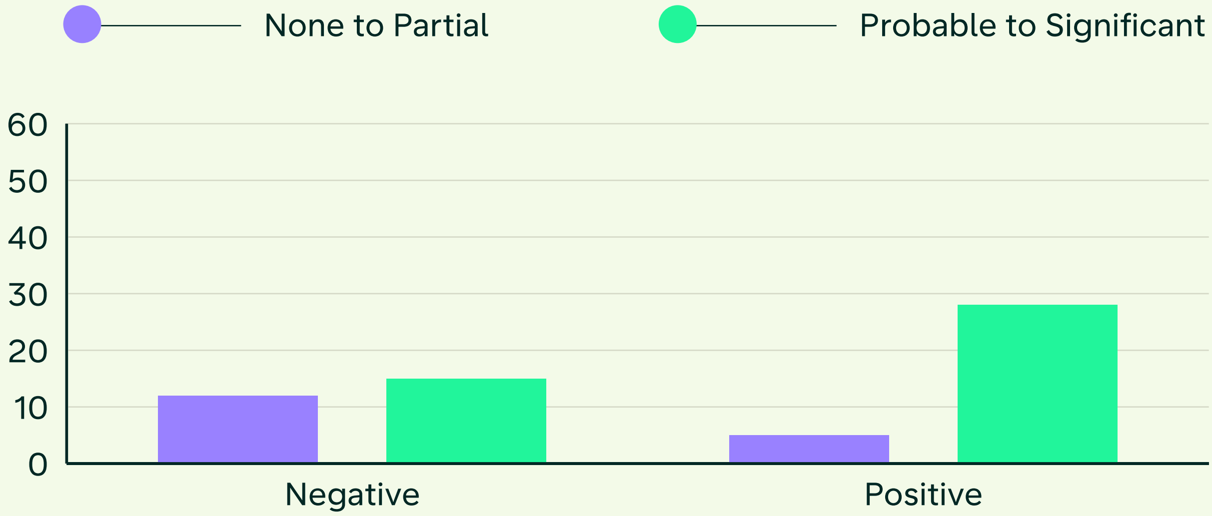
## Post-traumatic stress symptoms

We used the Impact of Event Scale (IES) to measure post-traumatic stress symptoms. Our results indicated that 72% (n = 43) of participants met the criteria for a diagnosis of post-traumatic stress disorder (PTSD) according to the IES criteria, with 85% of participants experiencing some post-traumatic symptoms.

We then explored participant scores on the IES and compared those who scored positive on the BISI with those who scored negative on the BISI (Figure 6). We found a significant association between scoring positive on the BISI and post-traumatic stress symptoms, with participants who screened positive being 4.5 times more likely to have moderate to severe post-traumatic stress symptoms.

**Comparison of the likelihood of post-traumatic stress symptoms between participants who screened positive, or negative for a history indicative of brain injury on the BISI**

*Figure 6.*

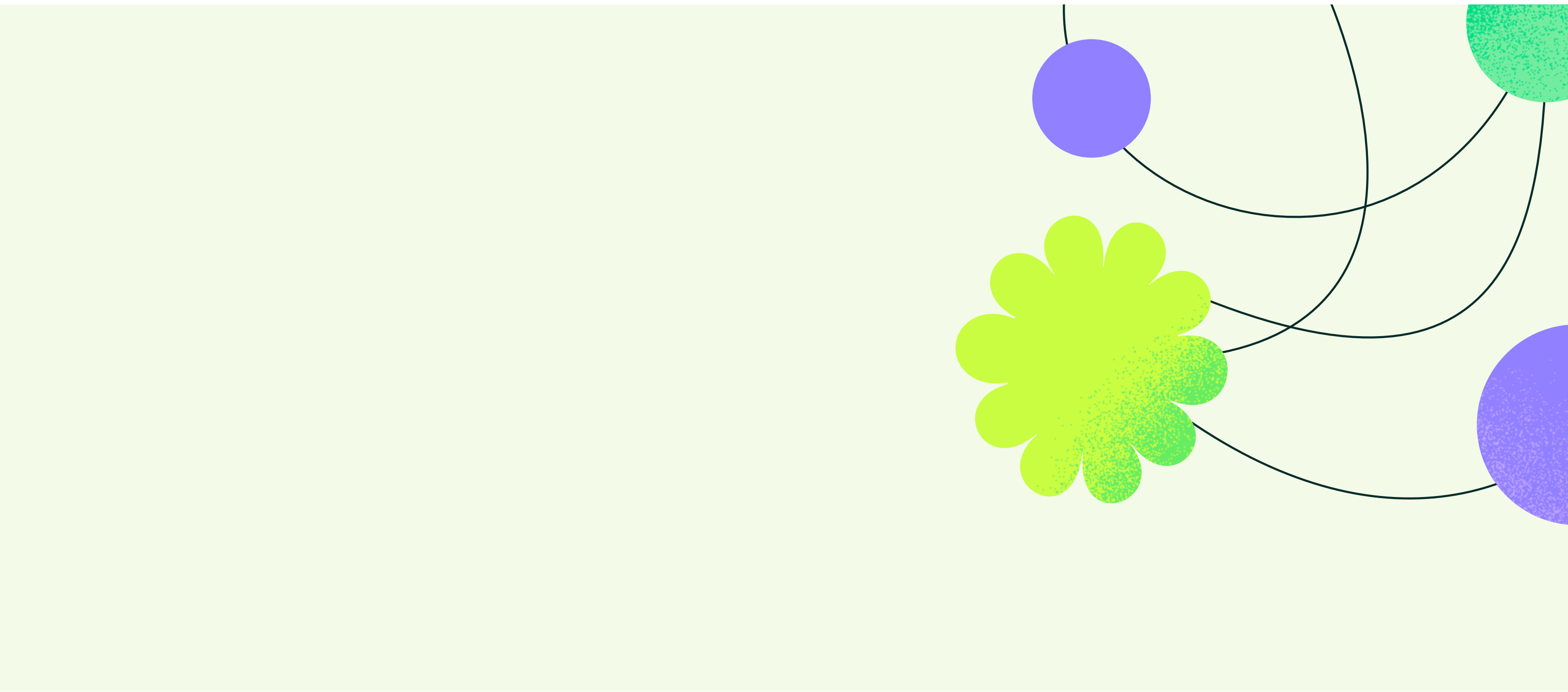


In addition, we found that 93% of the participants who had experienced ABI and NFS (Group 4) fell into the probable or likely PTSD range, indicating that these women were more likely to have severe symptoms of PTSD (93%, n = 27), than those who had experienced ABI due to a single cause (58%, n = 24). This could be because those who screened positive for both types of injury may have endured more abuse, or for a longer period, hence more physical trauma; but it could also be due to the cumulative effect of ABIs. There is, therefore, an indication that a person's injury history may have an influence on the severity of PTSD symptoms experienced.

## Experience of anger

We used the DAR-5 to explore our participants' experience of anger. This allowed us to understand their experience of anger (frequency, intensity, and duration), aggression and its impact on their social functioning. Interestingly, experiences of anger were not as commonly endorsed as we expected. There was no significant difference in anger scores when looking at those who screened positive or negative on the BISI.

A further comparison of the DAR results across the four nature of injury groups revealed that the majority of participants were not experiencing significant anger symptoms, including those with a history of brain injury. However, those who had potentially experienced brain injury due to multiple causes (i.e., ABI and NFS: Group 4), appeared more likely to present with anger problems. However, due to the unbalanced numbers across groups, these results should be considered tentative and a potential area for further exploration.



## Memory, speech, and concentration

Our participants reported a range of cognitive difficulties including: memory (n = 42, 70%), speech (n = 20, 33%) and concentration (n = 38, 63%) as measured by the BISI. On the CHATS most frequently rated were: “remembering things” (65%), “controlling emotions or reactions” (62%) and “figuring out what to do next” (60%).

## Participants who reported cognitive difficulties

(as measured by the BISI)

**Memory**

**Speech**

**Concentration**

On the CHATS

**Remember things**

**Controlling emotions or reactions**

**Figuring out what to do next**

> “I think I need to go to the doctors to see regarding memory because I can forget what happened an hour ago sometimes. I notice this a lot, that I keep forgetting things. I need to write things down to make sure I don’t forget things.”
>
> Research participant

> “I have significant problems with my memory. Sometimes I forget when a friend calls me, and I cannot recollect their name from hearing their voice. I sometimes forget what I ate for dinner the night before and things like that.”
>
> Research participant

Half of all of participants reported difficulties with “organisation”, “problems solving” and “figuring out what to do next” on the CHATS. These difficulties are associated with impaired executive functioning and are common following ABI.

Qualitatively, participants reported being unable to recall specific words, struggling in conversations and finding it difficult to remember to attend appointments or to engage with support services. The women spoke about how they had difficulty accurately recalling information and how this affected their ability to give statements to the police and recall events in court.

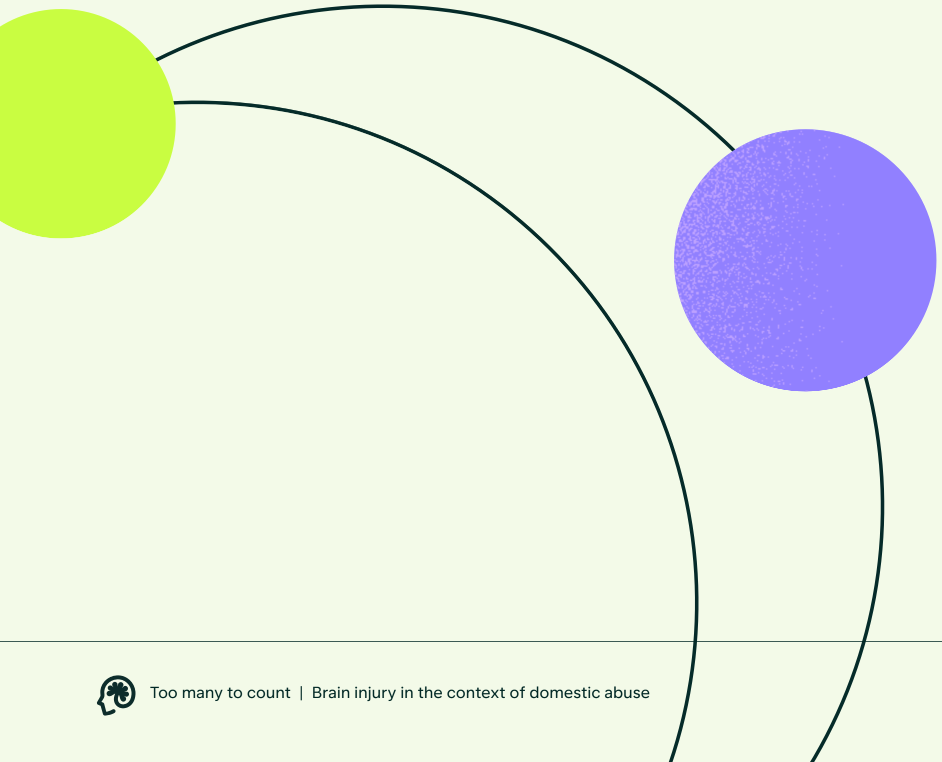
> “I have issues with my memory and need constant reminders about appointments. At work I have to count numbers two or three times because I can’t remember whilst I am counting.”
>
> Research participant

## Summary

We found a 55% prevalence rate of brain injury in the women in our study, with findings consistent between the different measures used (BISI and CHATS). Our participants also reported a range of cognitive, emotional and physical symptoms commonly associated with brain injury, indicating the importance of asking about these issues.

In terms of mental health, responses indicated that many participants were experiencing moderate to severe levels of low mood and anxiety. Post-traumatic stress symptoms were also common, with 72% of participants reaching the threshold for a probable diagnosis of PTSD.  An overlap in the symptoms of brain injury and mental health issues was observed.

Finally, there were indications that experiencing ABI via multiple mechanisms placed people at risk of experiencing more severe post-concussion, low mood and anger difficulties.



# Theme 1: Identification of acquired brain injury

Fifty-five percent of women in our sample reported a history indicative of brain injury, with 80% having experienced a serious blow to the head. The finding that 45% of women reported that they had been strangled, whilst 75% endorsed having been held in a way they couldn't breathe, highlights the importance of language. Our findings show that despite the recent increase in awareness around the potential consequences of non-fatal strangulation, not all people who have experienced domestic abuse identify the term as a mechanism of injury or a description of their experience. The freedom to describe something in one's own terms seems particularly important in this context.

> "Every time he hit me; he would hit my head he would always say it was the one place that wouldn't bruise… it was too many times to count…"
>
> Research participant

> **“…strangulation was probably the main one and he would do it to the point that I would pass out to the point I wet myself, which I later learned wasn’t because I was scared. It was because I was dying…”**
>
> Research participant

The women in our study reported a wide range of cognitive symptoms including difficulties with memory, problem-solving and concentration. These symptoms whilst commonly experienced following a brain injury can also be experienced in the context of mental health difficulties. Depression and anxiety, for example, are known to have an impact on memory and concentration. The same applies to physical symptoms following brain injury. Symptoms such as sleep disturbance and sensitivity to light and noise are often experienced by those with post-traumatic stress, as well as those with brain injury.

This overlap in symptoms highlights the complexity of accurate ABI diagnosis, particularly given that many women reported not being able to access timely healthcare support. In this context it is easy to see how a person’s difficulties with cognition or emotion have the potential to be misattributed and opportunities to access the right support missed. Our professional roundtable discussions suggested that ABI is rarely considered when women present to domestic abuse services with the sorts of difficulties described.

Furthermore, the physical, cognitive and emotional difficulties the women in our study described are likely to impact on their ability to access support. We know that not having access to support following a brain injury often leads to financial vulnerability (i.e., loss of job) and social isolation. Given these are both risk factors for domestic abuse it can be seen how not being able to access the right support is likely to make these women even more vulnerable, stuck in a cycle of domestic abuse and not feeling able to leave. Accurate identification and signposting to appropriate support is critical in breaking this cycle.

Together, these findings highlight the importance of considering brain injury in the context of domestic abuse and of creating clear pathways for accurate diagnosis and support.

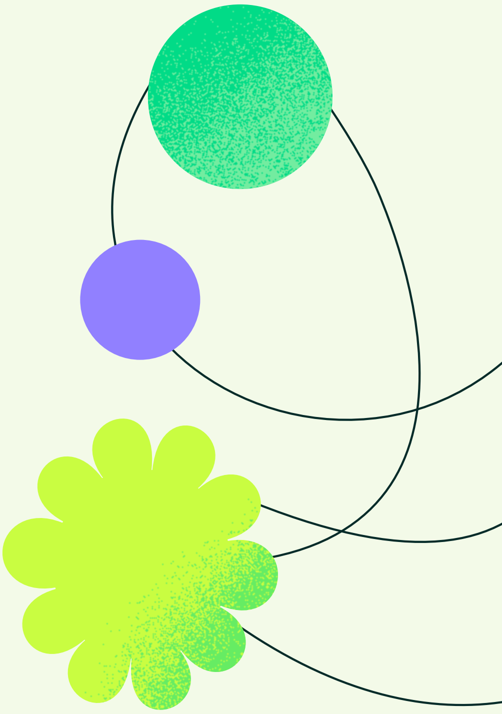
# Focus groups – 2023

## Participants’ focus group

In September 2023, Brainkind hosted two participant focus groups, drawn from the 60 research participants, one in-person and one online, to discuss the findings from this study. The groups considered the four key emerging themes, as well as our suggested recommendations for next steps.

When we asked about what is needed from services to best support people, and what positive changes this research could support, participants at the roundtable said:

- To have access to easy-to-understand and clear information about brain injury would enable people to self-advocate.
- There is a need for a consistency in support when people are accessing services and treatments, and as such, training for professionals is needed to better understand the connections between domestic abuse and brain injury.
- It is important for people to feel not only heard but understood and supported when disclosing and seeking help regarding domestic abuse and brain injury.



Participants spoke about the importance of raising awareness of brain injury amongst people experiencing domestic abuse. One of the women stated she thought she had dementia or was going through the menopause before it was identified that she had experienced a brain injury. All the women agreed that being provided with information that “allows you to advocate for yourself is key to regaining control over your life”. Women spoke about being able to access resources to understand more about brain injury and the symptoms they may be experiencing, alongside information about how to get support via a GP or other services. Women taking part in the focus groups talked about how important the timing of support was and how allowing the person ownership over when and how they sought support was essential. Several participants shared that for them, information, and moments of realisation around their abusive situations came from conversations with other women, as well as seeing posters on the back of toilet doors, or leaflets in GP surgeries. They wondered if a similar approach of awareness campaigns, through posters and stickers in everyday places, would work for raising awareness of brain injury in this context.

Women who participated in the focus groups recommended that any tools or screening methods developed would need to consider the significant concerns people may have regarding access and the potential for deliberate misuse of their personal details. Participants asked about how feasible it would be for professionals’ screening to be able to provide reassurances that any diagnosis and medical records would only be shared with their explicit consent. Participants told us they were worried about how a brain injury diagnosis if listed on medical records could be information that is requested and made known to family courts, as well as civil and criminal courts, and weaponised against them.

## Professional roundtable

Brainkind hosted a professionals’ roundtable in September 2023. The event was attended by representatives from leading domestic abuse charities, including several of the host sites from this study, professionals from brain injury organisations, housing and homelessness prevention staff, barristers and representatives from NHS England.

The roundtable breakout sessions identified the following as potential ways to integrate the results into practice and achieve next steps:

*Table 5. Feedback from the 2023 professional roundtable*

**Future research**

To explore how we can implement standardised systems for documenting brain injury and monitoring outcomes in this population.

To support and collaborate on inclusive research that includes minoritised groups and marginalised voices.

**Screening tools and methods**

Development of a brain injury screening and information toolbox, available to professionals and people experiencing domestic abuse.

Consider whether information could be provided online to help people identify if they may need further assessment.

Importance of providing support after the screening.

**Training and resources**

Training developed by those with brain injury expertise should be accessible and inclusive of all domestic abuse practitioners and those with lived experience.

Training should centre on voices of those with lived experience and knowledge of brain injury experts.

Training should be online and in-person, offering different levels and depth of learning.

Training resources to be trauma-informed with safeguarding as a priority.

**Policy and legislation**

At the local level, encourage the development of policies and procedures that recommend including ABI screening alongside existing routine domestic abuse screening processes.

Improve domestic abuse legislation as well as ABI legislation to make it easier to use and be less fragmented.

# Theme 2:
# Lack of awareness and knowledge of ABI in systems designed to support women

Brainkind's research and roundtable events have highlighted a limited awareness of ABI amongst professionals and people who have experienced domestic abuse. Women repeatedly told us that despite being seen by multiple services it was often many years before ABI was identified as a potential cause of their difficulties, if at all. Their stories indicate that this issue is widespread across multiple systems (e.g., domestic abuse services, health, social care, family courts).

Seventy-three percent of women in our study had children aged 18 or under, with nearly three-quarters of this group of women reporting they had taken part in at least one assessment with Children and Family Services. Eighty-four percent of this group of women who were assessed, screened positive for a history indicative of brain injury. Participants spoke about receiving positive support from Children and Family Services, where they had felt listened to. Those with social workers who demonstrated knowledge around domestic abuse and who were consistent in meeting with them, really valued the support.

> **"I've had support from my healthcare assistant, health care visitor and midwife and IDVA. They are all very supportive and particularly my IDVA, she sees this sort of thing every day."**
>
> Research participant

> **“They have changed and the social worker I’ve got now is good. She’s very good. Yeah. She comes to see me every month. She comes every month to ask me how I am and see the children. She didn’t just leave me, they didn’t just abandon me. They came back.”**
>
> Research participant

Although some participants identified positive experiences, there were also negative experiences, including:

- not being listened to
- domestic abuse not being understood by professionals
- not being informed or provided with full information as to why they were being assessed, or the reasons for the assessment

Participants spoke of being allocated multiple social workers, with some stating that often there was a change in social workers without explanation or warning, causing confusion and distress at having to explain and re-tell their stories; sometimes feeling like they had to “re-convince” a professional of the severity of their experiences. Furthermore, the implementation of any adjustments required to meet the individual’s needs had the potential to be lost due to fragmentation of the support process.

Participants also spoke of additional barriers that made it difficult for them to get the appropriate support, such as not having recourse to public funds or frequently moving and not having access to a GP or other health professional who knew them well.

> **“Until I had this social worker, they were absolutely appalling. They never asked the questions. They didn’t care. They didn’t communicate between local authorities.”**
>
> Research participant

> “I think they kind of did make it a hell of a lot more stressful. They sort of came in like a bit of a bulldozer, really… we were forced to move away.”
>
> Research participant

The lack of awareness of brain injury in the context of domestic abuse goes across multiple services and systems. At Brainkind, we have a well-established model of training, designed for frontline workers with no experience of working with people with ABI. Our Ask, Understand, Adapt training (predominantly used in the Criminal Justice System) has been successful in improving awareness and identification of ABI. The model provides the necessary information and tools for all professionals to be able to: ask questions to identify that ABI may be an issue, understand what the issues are for the individual, and adapt their practice to support the person with ABI. Given our findings, we believe a similar model may be helpful for improving awareness and knowledge amongst professionals working in domestic abuse settings.

Broader awareness raising of ABI in domestic abuse is also of critical importance. For people experiencing or having survived domestic abuse, understanding their risk of ABI following head, neck and face (HNF) injuries or non-fatal strangulation is central to them being able to advocate for themselves and access the correct care and support. The women in our study told us that access to this sort of information via posters in waiting rooms was often what prompted them to seek support. A joined-up approach between domestic abuse and ABI organisations will be key to any successful brain injury awareness raising campaign.

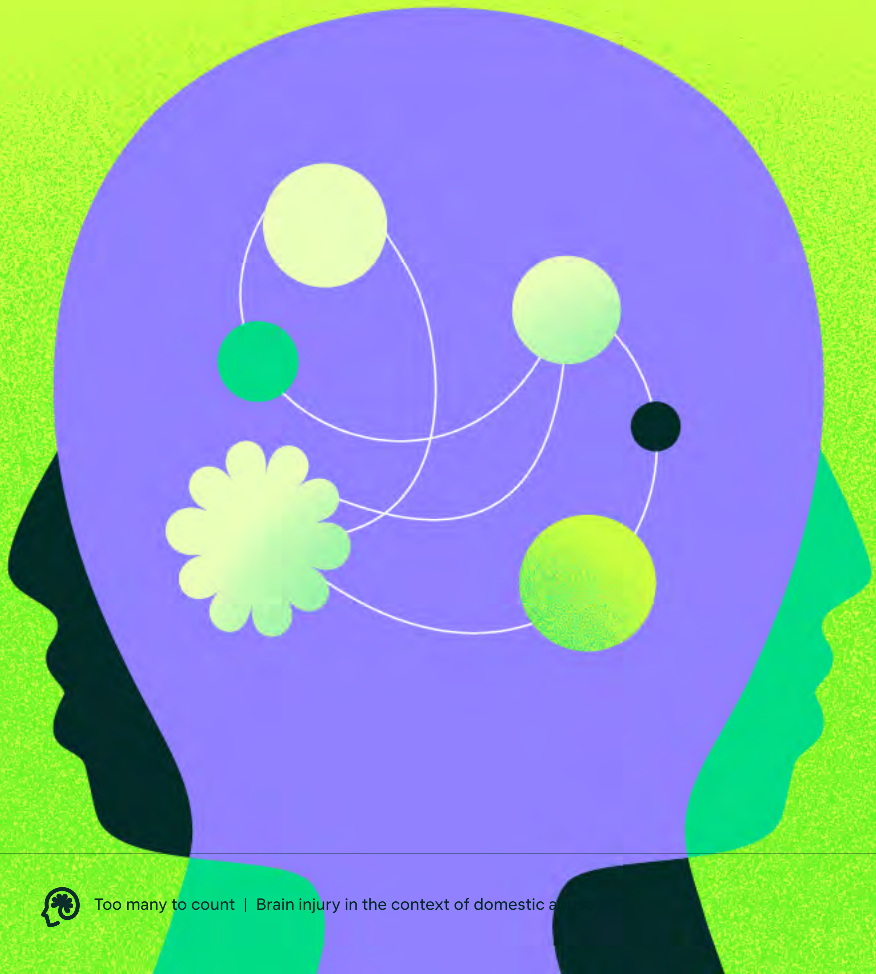
It is important that any raising of awareness is done in the context of education on the broader issues associated with identification of a potential ABI. Consideration needs to be given to issues like consent, information sharing and access to ongoing support. Our study and the subsequent roundtables and focus groups clearly identified a number of risks (further discussed in theme 4) associated with information about ABI being used against the people who have experienced domestic abuse.

In summary, global research and the present findings reinforce the call for better understanding of ABI for both professionals and those with lived experience of domestic abuse. It is our responsibility to make sure that any approach to this is trauma-informed and sensitive to the wide-ranging issues associated with identifying brain injury in the domestic abuse context. Collaboration across the different sectors will be critical to improving outcomes for those experiencing ABI as a result of domestic abuse.

# Theme 3: Health and social inequalities

Twenty-eight percent of women in this study reported that they had a diagnosed mental health condition and were being prescribed anti-depressants. Sixty-five percent of this group of women screened positive on the BISI for a history indicative of brain injury. A lack of awareness of the prevalence of ABI and the potential impact on emotions may well lead to women being treated for a mental health condition without ABI being considered.

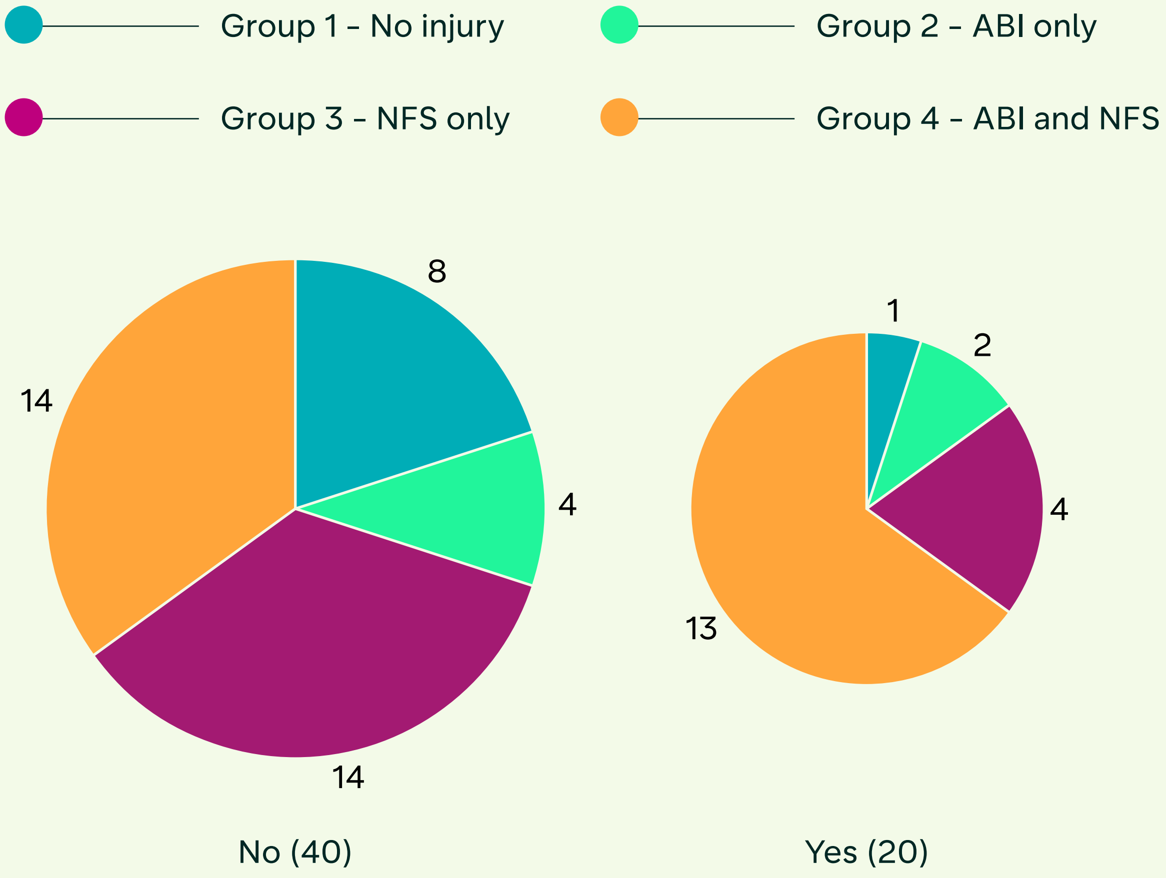
Brainkind believes that central to accurate diagnosis of ABI, is improving awareness of ABI amongst both professionals and people who have experienced domestic abuse. Educating professionals about ABI means that individuals are more likely to have their ABI identified in a timely manner. Raising awareness amongst people who have experienced domestic abuse allows them to make informed decisions about their care and advocate for themselves.



An ABI can affect emotions, behaviour and cognition with its hidden nature meaning behaviours relating to these conditions can be easily misunderstood or misattributed. Low mood and suicidal ideation are commonly experienced following brain injury but in the context of domestic abuse risk being only viewed in the context of trauma and mental health difficulties. Consistent with this, twenty participants in our study disclosed a history of self-harm. Fifteen of the twenty screened positive on the BISI for a history indicative of brain injury.

## How many participants reported self-harm by nature of injury?

*Table 6.*



The results further show that participants in Group 4 who had experienced both ABI and NFS injuries were more likely to self-harm.

Fifty-seven percent of participants stated they had thought about ending their life and 47% of those said they had made an attempt to take their life. Looking more closely at these disclosures revealed that more than half of all participants who reported suicidal ideation screened positive on the BISI (Table 7): further exploration is needed in this area.

## Participants who disclosed suicidal ideation screened positive for a history indicative of brain injury

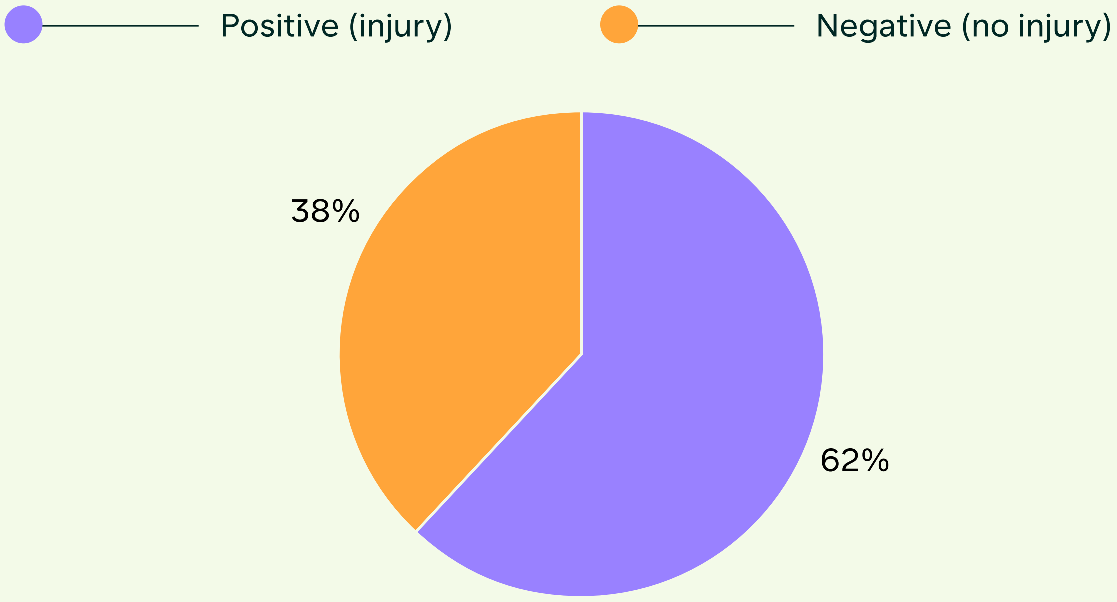


*Table 7. How many participants reported suicidal ideation by brain injury?*

| Nature of Injury | Number of participants who disclosed suicidal ideation | | | |
|---|---|---|---|---|
| | Yes | No | No answer | TOTAL |
| Group 1<br>No injury reported | 6 | 3 | 0 | 9 |
| Group 2<br>Only ABI reported | 3 | 3 | 0 | 6 |
| Group 3<br>NFS only | 7 | 11 | 0 | 18 |
| Group 4 - Both ABI and NFS reported | 18 | 8 | 1 | 27 |
| TOTAL | 34 | 25 | 1 | 60 |

Data from those who had made an attempt on their lives revealed that those with a history of brain injury due to both ABI and NFS were more likely to have attempted suicide (Table 8).

## Participants who disclosed a suicide attempt screened positive for a history indicative of brain injury

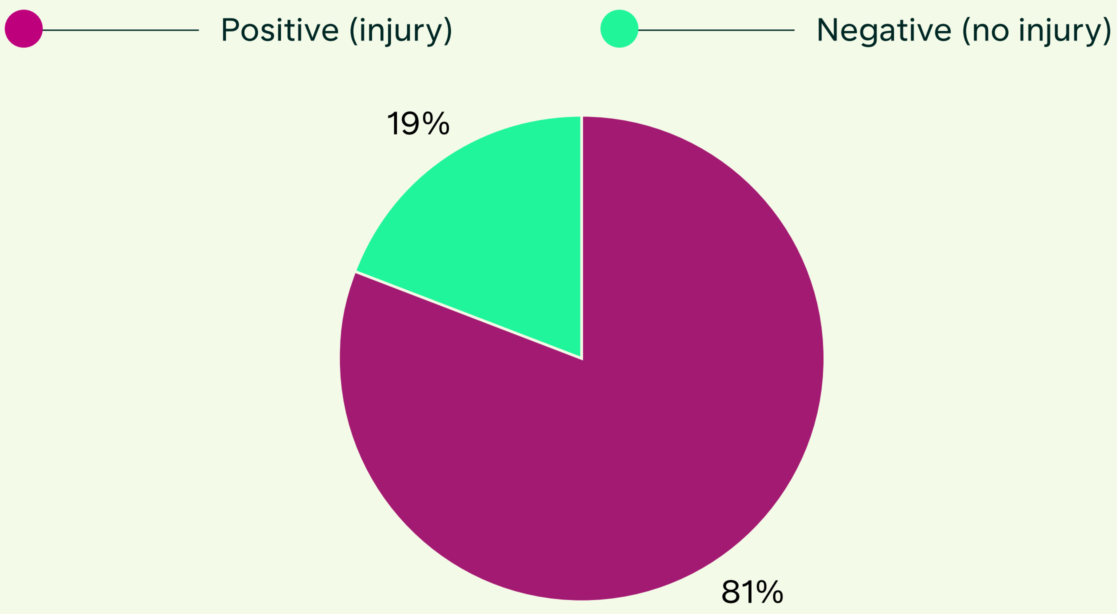


*Table 8. How many participants disclosed a suicide attempt by nature of injury?*

| **Nature of Injury** | **Number of participants disclosing a suicide attempt** | | | |
|---|---|---|---|---|
| | **Yes** | **No** | **No answer** | **TOTAL** |
| Group 1 - No injury reported | 2 | 7 | 0 | 9 |
| Group 2 – Only ABI reported | 1 | 5 | 0 | 6 |
| Group 3 – NFS only | 2 | 16 | 0 | 18 |
| Group 4 - Both ABI and NFS reported | 11 | 15 | 1 | 26 |
| TOTAL | 16 | 43 | 1 | 59 |

> **“Yeah. I’ve woken up most mornings and not wanted to be here. I wouldn’t do anything to risk leaving my kids though.”**
>
> Research participant

The experiences participants shared, highlighted the known variability in services across the UK. When accessing support from General Practitioners (GPs), women experienced different levels of awareness and understanding of domestic abuse, including different levels of confidence from practitioners when responding to their health needs in this context. Significantly, very few people (n = 2) were referred to neurology clinics, and/or had a neurological assessment in relation to problems they reported to their GP. Confirming the emerging indications that brain injury is rarely considered in the context of domestic abuse.

Brainkind believes improving the accessibility of health services for people who have experienced domestic abuse is key. The presence of a brain injury is likely to place individuals at even greater risk of mental health issues and make it harder for them to navigate complex health and social care systems. Furthermore, they may struggle to access standard mental health interventions without adaptation or specialist support. We believe integrating brain injury understanding and awareness with mental health and trauma informed support will be key to improving the short, and long-term health outcomes for people who have experienced domestic abuse.

> **“I have [attempted to take my own life] … it felt like the only escape at one point … I literally felt like I couldn’t escape.”**
>
> Research participant

# Theme 4: Protection and prevention - Criminal Justice System and the Family Courts

The participants described mixed experiences of their contact with the Criminal Justice System (CJS). There were examples of excellent support, with professionals demonstrating an understanding of domestic abuse, interpreters provided for non-English speakers, participants being asked about physical injury and being assisted to access appropriate and timely medical care after physical assaults. Several participants spoke about the importance of having female officers in attendance when being interviewed in their homes for statements.

> “In my eyes, they have done everything. They have arrested him and kept him in.”
>
> Research participant

> **“The police were very supportive. They had an interpreter and there was a female officer present too.”**
>
> Research participant

Participants also reported that navigating the CJS was challenging and resulted in some very difficult experiences. Common themes shared were:

- information about processes not explained clearly
- lack of support to help people navigate the system
- little or no explanation provided when cases were not being actively investigated
- not being believed by professionals

> **“You know the first call I made I’d gone through a hell of a lot before that first call that took up a lot of guts and courage and bravery to actually ring and then I was dismissed.”**
>
> Research participant

> **“He was let out and nothing else happened. The police called me to let me know he was coming out after 24 hours because there was no evidence, and he didn’t agree with my statement. No one spoke to me about domestic abuse. I think the police should be better trained on this.”**
>
> Research participant

Of the 60 participants, 53 (88%) stated that they had been involved with the CJS on at least one occasion. Interestingly, two thirds (67%) of participants with no history of brain injury had experienced contact with the CJS, in contrast with 93% of participants who screened positive for a history indicative of brain injury reporting contact with the CJS (Table 9).

*Table 9. How many participants were in contact with the Criminal Justice System by nature of injury?*

| **Nature of Injury** | **Have you ever been in contact with the criminal justice system?** | | |
|---|---|---|---|
| | **No** | **Yes** | **Total** |
| Group 1 - No injury reported | 3 | 6 | 9 |
| Group 2 – Only ABI reported | 0 | 6 | 6 |
| Group 3 – NFS only | 0 | 18 | 18 |
| Group 4 - Both ABI and NFS reported | 4 | 23 | 27 |
| Total | 7 | 53 | 60 |

Participants reported different levels of belief in the effectiveness of the police, with some women choosing not to report domestic abuse as they believed it would not make a difference. Other women said they had lost count of the number of times they had reported domestic abuse to the police. Participants described a variety of responses and processes used by different police and court systems, however there was a coherent narrative around the demands of repeated statements, and the understanding of the process and support available.

Difficulties with memory, concentration and understanding of complex information were frequently reported by the women in our study. These difficulties are likely to affect an individual’s ability to effectively navigate the complexity of police and court systems. It is therefore crucial that when brain injury is identified, practice is adapted and accessible and trauma informed support is provided.

### The Family Court system

As previously stated, 73% of participants who took part in this study had children, with nearly 75% of this group of women having taken part in assessments related to their children by social services. During conversations with SafeLives’ Pioneers Survivor group as part of the development of this study, together with the participants focus groups, the women we spoke with highlighted the possibility that screening and identification of history indicative of brain injury could put them and their children at risk. The concerns raised regarding the impact of a positive screening for a history indicative of brain injury were mainly expressed in two areas:

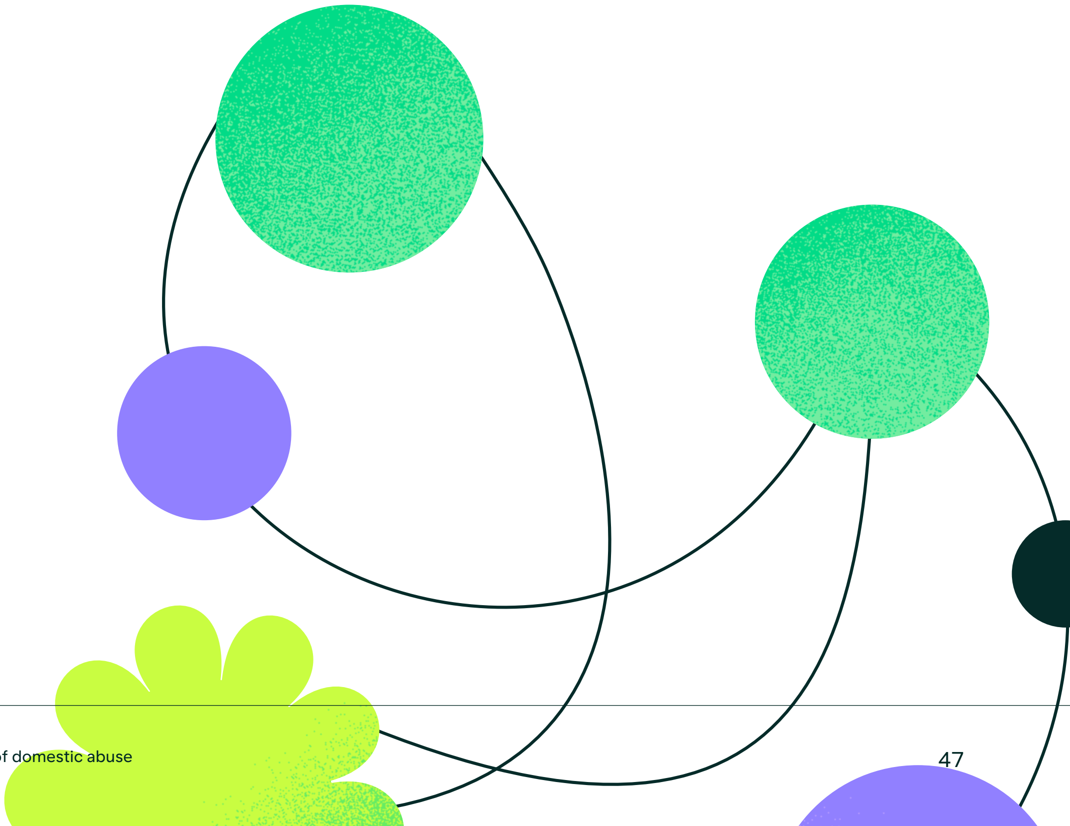
- the potential to discredit a person’s recollection of events
- the ability for professionals to suggest individuals have a diminished capacity to parent

Some participants described not being able to understand the Family Court system, coupled with an overwhelming fear of making a mistake which could lead to the placement of children into care. The women’s understanding of the support offered to them appeared to have a significant impact on their ability and willingness to seek help and support for their own health and wellbeing.

> **“It is better you accept the child arrangement … because if you go down that route [of saying it is domestic abuse] they’re going to press that section where the child needs to be taken for weeks, months, maybe putting into adoption…”**
>
> Research participant

> **“Yes, I did have a social worker who told me if I didn’t leave him, they would take the children off me.”**
>
> Research participant

Due to the coercive and controlling nature of domestic abuse, more needs to be done to understand the loss of autonomy and decision-making ability experienced by those living in the context of domestic abuse. Our findings demonstrate that an ABI is likely to contribute to these complex issues. Further research should consider the cumulative impact of trauma, mental health conditions, and ABI on complex decision making and what support is needed to enable people who have experienced domestic abuse to negotiate a safer future for them and their families.



# Limitations

Whilst contributing to the knowledge base on the prevalence of brain injury amongst individuals who have experienced domestic abuse in the UK and are currently supported in community-based settings this study has several limitations that may affect the generalisability of our findings.

The study used self-report questionnaires and screening tools, alongside an interview about access to services and other experiences. The limitation of this is that respondents may not have been able to accurately recall events or did not wish to disclose certain details. We were not able to corroborate their self-report of brain injury by exploring medical records or cognitive difficulties through performance-based cognitive tests.

Our study was open to anyone who had experienced domestic abuse and was actively receiving support from a domestic abuse service. We contacted over 30 domestic abuse services across the United Kingdom, including LGBTQIA+ specialist services. However, the services that participated were predominantly single-sex services. Because of this, only female participants participated in the study.

We were only able to conduct one interview with each participant and were not able to repeat the interviews across multiple visits to assess the reliability of our measures. The interviews ranged between 35 minutes and 2.5 hours, and the duration of each interview depended on the level of detail provided by each participant.

Despite these limitations, four clear themes have been explored and avenues for further research identified.

# Conclusion and recommendations

Domestic abuse can lead to traumatic and hypoxic brain injury, often resulting from blows to the head or non-fatal strangulation. This abuse can have lasting cognitive, emotional, and physical effects. Additionally, the long-term consequences of brain injury, such as impaired decision-making and emotional regulation, can further perpetuate cycles of abuse.

This is the first study in the United Kingdom to explore the prevalence of brain injury in people that have experienced domestic abuse and are accessing community-based services. Our research findings, underpinned by global research, clearly show the critical need for change to best meet the needs of people experiencing domestic abuse that are living with brain injury.

Recognising and addressing the intersection of brain injury and domestic abuse is central to providing effective support, as well as holding perpetrators accountable for the full extent of harm they inflict. It is imperative that, when a person seeks help regarding domestic abuse, frontline staff (across all sectors and services) understand not only the impact of trauma and abuse, but also the potential for brain injury.

Brainkind has four key recommendations:

**Research**

- Call for further studies to continue to contribute with data on the prevalence of brain injury among people who have experienced domestic abuse.
- Develop further research to understand the links between brain injury and health inequalities for people who have experienced domestic abuse.
- To capture lived experience of a wide range of people in the context of domestic abuse who have a history indicative of brain injury, including people who are LGBTQIA+, from Black, Asian and minoritised ethnicities, people with a disability, as well as older people.

### Tools and resources

- Work with people who have experienced domestic abuse to develop tools and resources that will enable individuals to advocate for themselves and communicate their needs clearly.
- Develop a brain injury and domestic abuse toolkit for domestic abuse practitioners / staff, including a quick guide to support.

### Training

- Train domestic abuse services staff to raise awareness and increase identification of brain injury, including understanding individual needs, and ways to adapt practice.
- Incorporate domestic abuse into Brainkind's wider training offer available for health professionals.

### Policy

- Increase societal awareness of domestic abuse as a possible cause of brain injury.
- Run an awareness campaign about brain injury in the context of domestic abuse, targeting people who have experienced domestic abuse, and the systems and services that support them.
- Inclusion and recognition of brain injury and its impact on people experiencing domestic abuse in future policy, as well as any potential revisions made to the Domestic Abuse Act 2021.

## Brainkind's next steps

Brainkind is committed to understanding more about brain injury in the context of domestic abuse. We hope to use our research to drive change in policy and practice, improve access to and provision of the appropriate services and to bring brain injury and domestic abuse to the forefront of national discussion and action.

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# Appendix

*Table A1. Ethnicities of participants*

| Ethnicity (self-described by participants) | % of participants |
|---|---|
| White – English / Welsh / Scottish / Northern Irish | 48 |
| Pakistani | 18 |
| Other ethnic group | 13 |
| Black African | 5 |
| Other white ethnic background | 3 |
| Asian/British Asian | 2 |
| Black British | 2 |
| Black Caribbean | 2 |
| Indian | 2 |
| Mixed Caribbean | 2 |
| White and Black African | 2 |

*Table A2. Types of abuse reported by participants.*

| Types of abuse cited | $N = 60$ | % |
|---|---|---|
| Emotional | 56 | 93 |
| Physical | 53 | 88 |
| Verbal | 45 | 75 |
| Financial | 38 | 63 |
| Psychological | 38 | 63 |
| Coercive control | 37 | 62 |
| Sexual | 33 | 55 |
| Forced servitude | 12 | 20 |
| Stalking | 10 | 17 |

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