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**Accepting what we do not know: A need to improve professional understanding of Brain Injury in the UK**

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**Accepting what we do not know: A need to improve professional understanding of Brain Injury in the UK**

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## Accepting what we do not know about acquired brain injury

### **Abstract**

Acquired brain injury (ABI) can lead to life-long changes and disability. The complex and extensive nature of behavioural, cognitive, executive, physical and psychological difficulties mean ABI survivors and their families may come into contact with a range of health and social care services as part of their long-term care. This study aimed to understand the ABI knowledge base of professionals across a range of organisations within the UK, and to identify areas for improvement. This was achieved through a mixed methods approach using a mixed methods questionnaire (117 participants) and qualitative semi-structured interviews about service experiences (31 participants) of professionals and service users (families and individuals with ABI). Participants included UK health and social care professionals, ABI specialists, ABI survivors, and family members. Data was collected from February 2017 to April 2018. The results of the study identified a lack of knowledge and understanding of ABI among health and social care professionals in the UK, from those involved in acute care through to long-term community services. Poor knowledge was associated with a lack of understanding of “hidden” disabilities associated with ABI, a lack of empathy, and a lack of knowledge regarding specific safeguarding. Health and social care professionals across a range of services could benefit in ABI-specific training to improve their knowledge and improve the service currently being provided to individuals with ABI and their families.

**Key Words:** adult social care, health care professionals, brain injury, community rehabilitation, social integration, professional training, long-term conditions

## Accepting what we do not know about acquired brain injury

### **What is known about the topic:**

- Previous research has identified that people with brain injuries and their families experience long-term rehabilitation and integration issues following discharge from hospital.
- Community services are often focused on short-term care for survivors and their families

### **What this paper adds:**

- This study found that the knowledge of both health and social care professionals in the UK about the long-term rehabilitation and integration difficulties experienced by survivors was poor.
- This study identified that health and social care professionals did not provide appropriate information to survivors and families about community-based health and social care services.

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### Introduction

Acquired Brain Injury (ABI) is a collective term referring to any alteration to brain function that occurs as a result of a wide range of illness and injuries which occur after birth. These may be from ~~a-traumatic-cause~~ (traumatic brain injury; TBI) such as road traffic accidents, falls and other external forces such as assaults, or non-traumatic causes (such as strokes, tumours or infections; Headway, 2015). The most common forms of ABI are strokes (132,199 hospital admissions in the UK in 2016-2017) and TBIs (155,919 UK hospital admissions; Headway, 2018). Estimates suggest there are over 1.3 million people in the UK with ABI, with men being 1.6 times more likely to experience an injury (Barnes, Bennet & Etherington, 2018). Understanding ABI and its effects has become increasingly important as more people are affected by it, particularly when considering the impact on working-age adults – the primary focus of this study.

The symptoms of ABI vary in severity and may include physical disabilities, such as difficulties in speech, movement, seizures, sensory difficulties, headaches and fatigue (Mass et al, 2017; Haywood, 2010; ~~Marshall, Teasell, Bayona & Bayley, 2007~~). However, those who recover physically may continue to experience longstanding non-physical, often invisible, symptoms. For instance, cognitive effects may result in deficits of attention/memory and, visuospatial skills ~~and executive functions~~ (Konrad et al, 2011; ~~King & Tyerman, 2003~~). Some cognitive difficulties are specifically associated with impairments in executive functioning impacting on planning, organisation, problem solving, ~~and~~ decision-making, ~~inhibiting inappropriate behaviour and initiating appropriate behaviour, and compounded by~~ impaired insight into level of disability. Furthermore, psychological and behavioural effects of ABI include

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3 depression, increased aggression, impulsivity and emotional instability (Arciniegas &  
4 Wortzel, 2014; ~~Kelly, Brown, Todd & Kremer, 2009~~).

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10 These effects of ABI can be detrimental to interpersonal relationships, housing (e.g.  
11 paying mortgages and, ~~maintaining tenancies and security of accommodation~~),  
12 employment and education, and increase the likelihood of anti-social behaviours by  
13 those with ABI (Materne, Lundqvist & Strandberg, 2017; Olson-Madden, Brenner,  
14 Corrigan, Emrick & Britton, 2012; ~~Braine, 2011; Hawley, Ward, Magnay & Mychalkiw,~~  
15 ~~2004~~). The difficulties that ABI survivors face means that integration back into the  
16 community can be challenging and the need for long-term community rehabilitation  
17 and support is essential ~~for some~~ (Clark-Wilson, Giles, Seymour, Tasker, Baxter &  
18 Holloway, 2016; Clark-Wilson & Holloway, 2015; ~~Salter, Foley, Jutai, Bayley & Teasell,~~  
19 ~~2008~~). Following discharge from hospital, rehabilitation and support services may be  
20 focused on improving the physical and functional abilities of individuals and,  
21 addressing any psychosocial difficulties faced by ABI survivors. ~~Some s~~Services may  
22 also focus upon areas such as return to work and/or education, renewing social  
23 relationships and reducing risks associated with impairments to functioning (Clark-  
24 Wilson, Giles & Baxter, 2014). However, ~~studies~~ studies have shown that substantial numbers  
25 of survivors have unmet needs following hospital discharge (Stalder-Luthy et al, 2013;  
26 Bay, Sikorskii & Gao, 2009; ~~Cierone, Mott, Azulay & Friel, 2004~~).

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51 The consequences of ABI ~~are not exclusive to the individual, but~~ also have an impact  
52 on family members and. ~~A substantial body of work has addressed the effects that~~  
53 ~~ABI has on~~ caregivers (the majority of whom are family members) ~~and on family~~  
54 ~~members more generally~~. Such effects include; difficulties in coping and adapting,  
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concerns for the future, increased loneliness and a higher risk of depression (Townshend & Norman, 2018; Braine, 2011; ~~Godfrey et al, 2003; Cannuscio et al, 2002~~). The breakdown of interpersonal relationships and family difficulties following ABI can cause social isolation and feelings of loneliness, increasing the vulnerability of those with ABI (Townshend & Norman, 2018; Wood, Lioffi & Wood, 2005). It is important to note that the majority of the literature in this area has been conducted with families from predominantly white, western societies and often with those with higher incomes. This is an important bias as it suggests that the picture for those less privileged may be even more problematic.

Much research has addressed the difficulties that ABI survivors have concerning the ~~long-term effects in cognitive, behavioural, psychological, and emotional outcome, and the subsequent effects~~ on their lives (Materne et al, 2017; Olson-Madden et al, 2012; Braine 2011; ~~Hawley et al, 2004~~). However, there is limited research investigating the interactions between people with ABI and community health and social care services. Furthermore, there is limited research on the level of knowledge and understanding that both healthcare professionals (HCPs) and social care professionals (SCPs) have about the long-term needs of ABI survivors and their families. Studies of educational professionals and nurses have identified poor understanding of the difficulties associated with ABI and people's long term needs (Linden, Braiden & Miller, 2013; Linden & McClure, 2012). This has also been highlighted by researchers working in the field of adult social care (Holloway & Fyson, 2016).

Traditionally resources for those with ABI have been focused on the acute care setting (Barnes et al, 2018). Within the UK healthcare expenditure has increased dramatically

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in this acute care, ~~most recently with the introduction of major trauma centres to improve acute care provision for those with ABI~~ (Kehoe, Smith, Edwards, Yates & Lecky, 2015) ~~but. While this is an important development~~, less focus has been given to the long-term complications associated with ABI, with post-discharge services receiving very limited funding (Barnes et al, 2018). This picture is reflected in other countries too, such as the US and Australia (Chard, 2006). This further highlights the importance in understanding the experiences of individuals with both health and social care services, particularly post-discharge.

This current study used a mixed methods approach to understand the knowledge base of HCPs and SCPs about ABI needs in acute care and following discharge from hospital. By exploring professional's experiences and the experiences of community rehabilitation and integration for those families and survivors, this study aims to identify 1) the knowledge base professionals have about the long-term needs of ABI survivors and their families and 2) to understand where improvements in knowledge and understanding are needed.

## Method

### Study Design

The project employed a predominantly qualitative research employing a thematic approach with some minimal quantitative data being collected. The free text sections of the questionnaires were analysed using a summative approach to qualitative content analysis, in order to quantify the textual content presented, as well as to interpret the underlying meanings behind its use (Hsieh & Shannon, 2005). This approach to content analysis is appropriate as the study contained a relatively large sample for analysis. The themes identified from this process were then used to create a framework for coding the follow-up interviews. This coding framework consisted of



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the overall themes and codes that had been identified during analysis that could be picked up within the interviews. Interview data were analysed using a mixed inductive and deductive approach to thematic analysis (Hsieh & Shannon, 2005). In stage one the themes identified from the qualitative questionnaire were used to devise a framework for deductive analysis of the interview transcripts to identify similar coding.

### **Participants**

Participants were recruited through social media and local UK branches of the charitable organisation that supports individuals with brain injury, Headway, as well as independent case management organisations. Headway is an international charity that supports individuals with brain injuries and their families within the community. Headway in the UK provides social clubs, respite day care centres and outreach support for clients and their families in their own homes. In some places Headway also provides a hospital and discharge service for those early on in the recovery process. Ethical approval was gained through the University faculty ethics committee. One hundred and seventeen participants (aged 18 to 76, 61 females) took part in the online questionnaire. Participants consisted of ABI survivors (30; 21 male; reflecting the male to female ratio in the general population), family members (26), ABI specialist professionals (31) and professionals working across a range of generic health and social care settings (30). These included police, mental health practitioners, social workers and care workers (see Table 1 for full list of participant details).

*Insert Table 1 here*

Thirty one participants (12 female, aged 31-79 years) also took part in an interview (12 ABI survivors, five family members, four professionals working with ABI, and 10 community service professionals; GPs (seven), nurse, police officer, social worker).

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These participants completed an additional consent form after receiving a copy of the extended information sheet about the nature of the interviews.

### **Procedure**

Participants were asked to complete a short online self-designed survey using “Survey Monkey” consisting of 12 - 15 questions about their experiences of interacting with services (Appendix A). Questions were tailored so that specific questions were asked of those with ABI, their families and professionals. Questions were tailored so that specific questions were asked of those with ABI, their families and professionals. Data from the survey did not collect IP addresses or other identifiable information that is often available through Survey Monkey and the survey was created using a private account only accessible by the research team. On completion of the study all data **were** downloaded on to a password protected laptop and deleted from the survey monkey server. Any identifiable information (e.g. email addresses for taking part in the interview study) were stored separately to the online survey data to ensure confidentiality was maintained during analysis.

The survey consisted of questions about age, participant type (e.g. ABI survivor, family etc.), length and type of injury, and questions about participants’ experiences of interacting with community health and social care organisations. Professionals were asked about their experiences of interacting with ABI survivors and their families within these settings. At the end of the questionnaire participants were given the option to self-select to take part in follow-up interviews.

Questions consisted of a mixture of qualitative and quantitative approaches, using Likert scales and free text responses. Data from the Likert scales were analysed using

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3 descriptive statistics. Qualitative data were analysed using direct content analysis  
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5 where the surface level meaning of quotations are coded with the purpose of  
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7 answering a specific series of pre-determined questions (in this case about the ABI  
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9 knowledge base of professionals). The coding was achieved through an inductive  
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11 process of reading and identifying codes from within the participant responses. The  
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13 surveys were read through thoroughly to identify initial codes. These codes were then  
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15 grouped into similar topics of meaningful data and were assigned themes and sub-  
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17 themes. Next the data were reviewed to define clear distinctions between categories  
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19 and a set of quotes from the interviews were collated to support each theme identified.  
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21 The data were analysed by the investigator and then validity checked by another  
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23 member of the research team. Further member checking took place within the follow-  
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25 up interviews to ensure the validity of the content analysis (Guest, MacQueen &  
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27 Namey, 2012). These codes were used to generate a coding framework for analysing  
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29 the subsequent interviews.  
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38 Participants in the interview part of the study were asked to provide further informed  
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40 consent to take part. All consent forms were kept separately from the data and stored  
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42 on a password protected computer. Questions were developed prior to commencing  
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44 the survey study and then modified based on findings from the survey. Interviews were  
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46 semi-structured in nature using a series of prompts and limited questions to elicit  
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48 information about access to services and interactions with organisations. The  
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50 questions used covered areas of; social services, employment and education, crime  
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52 and probation, family dynamics, effectiveness of treatment, relationships between  
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54 professionals and people with ABI, life changes after ABI and positive versus negative  
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56 experiences. Interviews with professionals and family members took place over the  
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3 phone, with most interviews with ABI survivors taking place face-to-face. Individuals  
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5 with ABI often find telephone communication difficult as picking up on non-verbal cues  
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7 is more difficult (Togher, Hand & Code, 1997). These face-to-face interviews took  
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9 place in a quiet interview room at the University or were arranged through the charity  
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11 Headway and took part at one of their day care centres in a private room. Where  
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13 necessary the individuals with ABI were interviewed with a family member or a support  
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15 worker present to support them with the interview process. ~~Therefore, it was decided~~  
16  
17 ~~to do these interviews face-to-face.~~ Interviews lasted between 25 minutes and an hour.  
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21 Interviews were transcribed verbatim and then analysed using thematic analysis  
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23 (Braun & Clarke, 2006).  
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29 Each interview transcript was read multiple times to ensure all codes that cross-  
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31 referenced with the framework created within the survey were identified. This coding  
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33 process took place after the survey coding had been completed. Once this process  
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35 was completed the interview transcripts were then re-read to identify any new codes  
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37 not already identified from the framework using an inductive approach. This mixed  
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39 thematic approach using a model of framework analysis was used to validity-check  
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41 the data analysis from the content analysis, and to capture any new data not already  
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43 identified (Fereday & Muir-Cochrane, 2006).  
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50 Triangulation of the data across both stages of analysis took place and superordinate  
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52 themes and clusters were grouped with similar superordinate themes across all the  
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54 interview transcripts, and were developed into master themes and superordinate  
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56 themes as outlined below. After the analysis a second member of the research team  
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58 undertook a validity check of the analysis and this was then member checked by  
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3 participants (seven responded but all were invited to comment) to ensure  
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5 methodological rigour (Smith & Osborn, 2008).  
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## 10 **Results**

11 ~~Participants in the online questionnaire were asked to identify all services they had~~  
12 ~~come in contact with since they or their relative/client had experienced their ABI. If~~  
13 ~~they were a professional responding to the survey, they were asked to consider what~~  
14 ~~services they felt individuals with an ABI may come in contact with.~~ A range of  
15 different services were identified that relatives or clients with ABI had come in  
16 contact with including GP services, general hospital services (associated with  
17 rehabilitation following ABI), social services, solicitors, home care services,  
18 educational establishments, mental health services and disability and employment  
19 services. Participants were asked to select three organisations with whom they had  
20 been in contact, or had experience of interacting with on behalf of a client, that had a  
21 good understanding of the needs of those with ABI. Participants were then asked to  
22 produce a similar list of three organisations that had the poorest understanding of the  
23 needs of those with ABI. These data are reported below within the sub-themes.  
24 Participants were then encouraged to provide qualitative feedback about their  
25 experiences of interacting with different community health and social care  
26 organisations. These data were combined with the interview data to provide rich and  
27 detailed accounts of participants.  
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53 The analyses identified three main themes with associated sub-themes 1)  
54 knowledge and understanding of HCPs with associated sub-themes of service  
55 provision and signposting, 2) knowledge and understanding of SCPs, and 3) training  
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needs with associated sub-themes of empathy, hidden disability and safeguarding (Table 2). The data represent a broad range of difficulties with interactions from the acute setting through to discharge and across long-term social care access. While this is a difficult narrative to summarise in one paper, the authors have included each aspect to provide an overview of the comprehensive difficulties patients and family members experience at each stage.

***Insert table 2 here***

### **Theme 1: Knowledge and Understanding of Healthcare Professionals**

Despite the growing number of people diagnosed with ABI, participants with an ABI, their families and ABI-specific professionals revealed their concerns about the insufficient knowledge and understanding that the professionals within hospital services associated with acute care an inpatient neurorehabilitation had about the long-term needs of those with ABI and their families. This led to individuals being discharged from hospitals without follow up, appropriate signposting and/or information about their condition. This was associated with 1) a lack of service provision and 2) a lack of signposting to services post-discharge. As well as collecting the qualitative data, participants with an ABI, their families and ABI-specific professionals were asked to pick the top three services with respect to their knowledge and understanding of ABI (Figure 1). These data suggest that these participants found solicitors, GPs and general hospital services to be the best at understanding the needs of ABI survivors. These participants were also asked to pick the worst three services with respect to their knowledge and understanding of ABI (Figure 2). Social services were rated as the worst service, with general hospital

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3 services and GPs also ranked poorly. This suggests a discrepancy among  
4 participants in terms of their experiences of GPs and hospital services which may be  
5 associated with the specific GP or hospital service ABI survivors have had contact  
6 with.  
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14 ***Insert Figure 1 here***

15 ***Insert Figure 2 here***

### 16 17 18 19 20 21 22 **Sub-theme: Service Provision**

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24 This sub-theme characterised a lack of service provision during hospital admission  
25 or stay which led to longer-term problems with managing the consequences of ABI.

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27 Within this study there were a large number of ABI survivors with a TBI. This aspect  
28 of this sub-theme of service provision seemed unique to this population compared to  
29 the other identified themes that were more generally observed across injury-type.

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31 For example, participant 16 had experienced a fall and had other injuries which were  
32 perceived by staff as more important at the time than her ABI, and this led the  
33 participant to feel that their ABI had been ignored, or was not perceived as being as  
34 important by health professionals.  
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48 *“My nose was the biggest concern at the time...I was bleeding out my mouth ...*  
49 *having a head injury wasn't at that point a major concern... But even though I got*  
50 *transported due to a head injury in A&E they were very very much focused on*  
51 *the...blood gushing out my face...” Interview participant (P)16 (individual with*  
52 *ABI).*  
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58 The participants with TBI **specifically**, their families and the ABI-specific  
59 professionals highlighted that often there was a lack of understanding of the impact  
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of ABI and the significance of clinical symptoms, and that appropriate checks were often not forthcoming. This was associated with staff shortages and time constraints as well as poor knowledge and understanding of ABI. This issue was also raised by some health professionals working in more general neurorehabilitation settings.

*"...they hadn't carried out a brain scan... hadn't checked me...so I went back in two days after that...at no point did they keep me in, they kept putting me back into the care of my wife". P20 (individual with an ABI).*

*"...My daughter and son in law knew I had concussion...they didn't pick that up...even though my eyes were apparently darting all over the place...so they're not very aware. P15 (Individual with an ABI).*

*"...it would have been a good idea for me...not to have had to have actually seek out the neurologist in the first place; It would have been nice if they'd actually thought "well hang on a minute we put this woman in HDU thinking that she wouldn't survive because she'd bashed her head so hard, perhaps we should have called her [the neurologist]" [laughs]" P18 (Individual with an ABI).*

All those with ABI (**not just those with TBI specifically**), their families and ABI-specific experts identified the need for follow-up appointments following mild ABIs that did not require hospital stays. They felt that this would provide more opportunities for HCPs to identify longer-term difficulties. This was linked to the signposting sub-theme below which outlined a lack of signposting to longer-term support post-discharge.

*"You'd be a bit more in the system...you'd have a follow up appointment...they would know...have you on file" P16 (Individual with ABI).*

While most ABI survivors (both ABI and TBI) and their family members were happy with the hospital treatment they received, it was in the weeks and months that followed where they experienced greater lack of knowledge and understanding



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among HCPs, particularly in community healthcare settings. This was supported by the data from professionals (both ABI-specific experts and other health professionals). This often led to poor service provision or inappropriate access to services.

*“Now my GP who I started to see regularly ... he said “I don’t know anything about brains.” ... “I can’t tell you what’s happening to you. I don’t understand what’s happening to you because it’s not my field”.” P14 (Individual with ABI).*

*“I got given migraine meds and (...) I felt like I was going to die on these meds and it was just horrible.” P13 (Individual with ABI).*

### Sub-theme: Signposting

Most of the participants with ABI reflected on their experience of being discharged from hospital, without being signposted to resources that could increase their own knowledge about ABI, as did family members. The participants described being unprepared, confused and not being able to appreciate what it means to have ABI. These participants found that it was the period following discharge from hospital when they found that they needed the most support and received the least, leading them to have to seek out help themselves often without any knowledge of what was happening to them.

*“They [the health professionals] just instructed me to lie in a dark room...I was confused like I had a fog, I’m a single mum of a, urm he was seven at the time, and I couldn’t hear, I couldn’t see, I was falling when I walked” P8 (individual with ABI).*

*“Going to see the neurologist was quite a big deal. But I had to do that myself like nothing was really offered.” P15 (individual with ABI).*

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The data also revealed a failure among HCPs to take responsibility for signposting and proactive support of ABI survivor and family members. Participants with ABIs and their families suggested that each medical department did not consider support or signposting to be something that they should provide or within their field of expertise. For example, in the case of participant 15, the neurologist could tell her she had an ABI but could not offer anything in terms of signposting to support services or even information provision. This created a gap within the service provision available to patients following ABI.

*“the ophthalmologist didn’t know, they were interested in my eyes...The fracture clinic was interested in my shoulder... And the maxillofacial people wanted to know whether the bones were healing around my skull...But no-one really knew or cared about what [laughs] what was going on inside my brain you know” P14 (Individual with an ABI).*

Participants in the initial survey, including professionals themselves, acknowledged that services do not provide enough information to ABI survivors and their families about the long-term difficulties. This lack of information from HCPs led to a lack of knowledge and understanding of ABI among survivors and their families. Without having the means to learn more about ABI, families will naturally lack awareness about the ABI caused impairments that may lead to changes in functional abilities, behaviour and personality. The findings from the current study suggest that there is a need to make the provision of information about the prognosis of ABI an essential part of the discharge process to reduce uncertainty and psychological distress.

*“it didn’t start until ten days after... I had no idea, I, my family had no idea, I just started acting very bizarre. If they’d been some kind of explanation of what could happen, like psychologically, what can change in case you did have a brain injury” P8 (individual with ABI).*

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The responses from GPs suggest that GPs assumed that it was not their responsibility to signpost. This was due to a belief that their patients had received signposting already from specialist services. However, this was often not the case with many ABI survivors being discharged without a rehabilitation package or even any information on ABI, as highlighted above. Some of the GP's simply had poor knowledge of local services and therefore were unable to signpost. Only one respondent mentioned the charitable organisation Headway (an ABI specific service) despite all working within the vicinity of a local group. This highlights a poor knowledge of local services. This is reflected in the responses of survivors and families who noted that it was anywhere from six months to four years post-injury before they were referred to Headway.

*"I don't think that would be my first thoughts [offering patients with ABI information about brain injury services], and perhaps that should be...I don't think I'd immediately...or whether we should be doing that and sort of pre-empting that a little bit". P26 (GP).*

*"I think I'd probably assume, and maybe that's a very wrong assumption, that in their rehab you know just initially in hospital or...perhaps physio or something afterwards that in those sort of services...other health professionals... tell them about stroke association or you know..." I'm assuming that that's all there for that sort of rehab stuff rather than us." P24 (GP).*

*Head injury instruction sheet...I don't know any services, um Headway is a good charity isn't it? But that's about it really...I don't really know round here what provisions we have for people..." P25 (GP).*

## Theme 2: Knowledge and Understanding among Social Care Professionals

This theme highlighted specific deficits in the knowledge of SCPs working in long-term community settings. All participants (including professionals without a specialism in ABI) acknowledged that not all services are equipped with the knowledge to understand the impact of ABI, particularly in relation to cognitive and behavioural changes, which often take the form of an "invisible disability". Due to this

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lack of understanding, such services were unable to provide appropriate services to ABI survivors and their families.

*“Mental health services [...] told a brain injured client that they have capacity to deal with their own finances despite the client telling them 'I will spend all my money if I was to have a large sum of money. MHS proceeded to tell the client that they could help the client have capacity to manage their money’’. Survey Participant (S)14 (ABI-specific expert).*

*“Poor understanding of implications of cognitive and behavioural changes, so poor capacity assessments/care needs assessments’’. S21 (ABI-specific expert)*

As well as an absence of knowledge surrounding the cognitive and behavioural difficulties associated with ABI, organisations also seemed to have a lack of understanding of the long-term psychosocial impact of ABI on survivors and their families. These difficulties were highlighted in areas such as return-to-work with poor understanding from benefits assessors, employment service employees and employers.

*“On one occasion I was told that if I got too tired at work I could walk, take a train and bus to get home’’. S32 (Individual with ABI)*

*“I'm employed as a police officer. They were sympathetic at the start but soon lost patience when it became clear I would not be returning "as before" the accident.’’ S41 (individual with ABI & police officer).*

A similar picture was portrayed in the return to education with schools often failing to take account of a child's ABI when providing support or intervention. This is highlighted by participant five who provides an account of her grandson's lack of attendance at school due to his fatigue and anxiety following an ABI.

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*“School hopeless – no support, they just wanted him out when he returned to education 2 months after the fall/head injury and his behaviour changed”. S82 (family member)*

The education department’s role in the mother’s prosecution potentially demonstrates the poor knowledge they have about the complications and effects ABI can have on a child. Such comments can support the notion that particular services need more training on aspects of ABI in order to improve their understanding of the impact that an ABI can have on long-term functioning.

*“the education department are probably going to take her to court again for...lack of attendance...and she probably will have to do a few days in prison...it [evidence of the ABI] was presented at court but it wasn’t deemed sufficient reason for his... terrible record of school attendance.” P5 (family member).*

### Theme 3: Need for training

The general lack of knowledge and understanding amongst both HCPs and SCPs within community services suggests a need for improved training of staff within such organisations. This was an area specifically addressed by participants with ABI and their families and was associated with 1) a lack of empathy, 2) training on the hidden disabilities associated with ABI and 3) improved training on the impact of ABI on families.

#### Sub-theme: **Eempathy**

The thematic analysis revealed that a lack of knowledge among HCPs and SCPs led

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to ABI survivors and their families feeling unheard, and unsupported. Many participants described this as a lack of empathy shown by a diverse range of professionals. Participants with ABI knowledge reported that ABI survivors and their families wanted to feel that professionals cared about their recovery, and they wanted to feel supported. For example, some of the participants experienced being labelled as difficult and accused of malingering from the professionals.

*“The way people in various organisations look and treat you .....just because you look ok.” S42 (individual with an ABI).*

Participant four described a situation where a HCP told her that she was “*wasting their time*” and she “*needed to move on with her life*”. Participant five reflected on her grandson’s poor attendance in school and felt that the school did “*little to acknowledge*” his ABI and “*lacked empathy*” when they decided to prosecute his mother. This lack of empathy was often associated with professionals’ lack of understanding of the consequences of ABI, particularly cognitive and behavioural ones. Family participants and those with ABI did provide some positive experiences of empathy and found these useful to supporting them long-term.

*“NHS CHC have been a nightmare to work with! [...] Total lack of any common sense or compassion.” S35 (ABI-specific expert).*

*“they [police] didn’t...take into account I may be disabled or give me a chance to get my crutch out the car, they kind of treated me like I’m a criminal [assumed to be drunk-driving due to slurred speech]...it was quite interesting because...as soon as...I told them, they acted differently towards me...” P6 (individual with ABI).*

*“GP listened to me rather than thinking he knew all the answers!” S3 (individual with ABI).*

*“Headway supported me when the NHS stopped doing anything by offering counselling. [...] I felt listened to and got a better understanding of what had happened to me”. S55 (individual with ABI).*

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**Sub-theme: Hidden disability**

A number of respondents had used the term 'hidden' or 'invisible disability' to describe the predominantly cognitive difficulties associated with ABI that are not physically visible or immediately apparent. It was identified that these "hidden disabilities" were not understood by professionals without a specialism in ABI.

*"My clients have invisible disabilities and these are not responded to by social workers in particular. The response by social services is embarrassingly bad and is killing people with an ABI."* S69 (ABI-specific expert).

*"Where do you want to start? There is a terrible lack of underpinning knowledge amongst non-specialist professionals – insight and executive impairments are virtually always missed".* S69 (ABI-specific expert).

This sub-theme illustrates the difficulties experienced by ABI survivors as a consequence of the non-physical invisible side of ABI. The ABI-specific expert participants explained how the hidden disabilities of ABI acted as a barrier in providing appropriate support due to difficulties in identifying and knowing the severity of ABI. The family members and individuals with ABI revealed the frustration they had towards the professionals and the public who stereotyped their disability. In the following extract, participant four describes the extent to which her husband "hid" his symptoms of ABI from HCPs.

*"If you met him now you wouldn't think there was a problem...this is where the so-called professionals have...not kind of seen...I've seen it urm my friends have seen it, my family have seen it..."* P4 (family member).

Participant 4, alongside other participants interviewed, revealed how apparent



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3 the effects of ABI were to themselves, but were not accepted by society. It  
4 wasn't until participant 4's husband displayed "actual symptoms" [physical  
5 symptoms] of ABI that the professionals were willing to do a full assessment.  
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7 The description of "actual symptoms" further shows that unless the symptoms  
8 conform to the norms and validates the public and professionals' preconceived  
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10 idea of ABI, the symptoms are often ignored.  
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### 19 **Sub-theme: Safeguarding**

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21 A lack of knowledge and understanding of these often hidden disabilities was  
22 associated with professionals' lack of understanding of the safeguarding issues  
23 surrounding ABI survivors and how vulnerable they can be.  
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28 *"Police not understanding how vulnerable a person is when they can't see the*  
29 *disability."* S11 (ABI-specific expert).  
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33 Such comments stress the need for specific training and understanding when  
34 working with ABI clients, particularly with regards to invisible cognitive disabilities  
35 such as executive dysfunction, memory deficits or speed of processing difficulties.  
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43 A number of family member and ABI-specific expert participants also described  
44 experiences with services in which provision of safeguarding had not been properly  
45 implemented due to a lack of understanding of the nuances of ABI.  
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52 *"he started smoking weed...we tried to talk to him about it he said it's the only*  
53 *thing that makes him feel better...he sees it as his only support."* P5 (Family  
54 member).  
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56 *"they tend to urm, be isolated in the community...more likely to attract people who*  
57 *may have other motives by befriending them, urm, around sort of...using their*  
58 *house...as somewhere to stay if they may be homeless or... exploiting them*  
59 *financially...urm some form of exploitation"* P7 (ABI-specific expert).  
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3 *“it would take a while for that information to...sink in and then what we get is the,*  
4 *the after effect of that conversation understood or been taken literally...so on the*  
5 *face of it, it makes it seem quite, they respond quite normally or, or seem whatever*  
6 *is normal and respond appropriately and what we see afterwards is something*  
7 *completely different” P3 (ABI-specific expert).*

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9 *“Inexperienced social worker assessed my client as having no needs and no risk*  
10 *[...] Following complaint and re-assessment, he was identified as high risk and*  
11 *needing a significant support package”. S25 (ABI-specific expert).*

## Discussion

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18 The purpose of this study was to gain an in-depth understanding of the knowledge  
19 base of professionals working in health and social community services across the UK.

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23 The main findings of the study revealed that ABI survivors and their families come into  
24 contact with a range of health and social care professionals post-injury and that while  
25 some services are performing well in understanding needs, other organisations are  
26 not. The study identified that ABI survivors experience difficulties receiving the  
27 appropriate medical care, both during hospital admission and on discharge, and are  
28 often not appropriately referred or signposted to services that can provide care or  
29 support long-term needs. This was found to be due to a lack of understanding of the  
30 long-term consequences of ABI and the symptoms, particularly cognitive and  
31 behavioural difficulties. Social care organisations also failed to take these difficulties  
32 into account and at times this led to safeguarding issues. This study is original its  
33 attempt to capture the views and experiences of a wide range of participants, including  
34 professionals themselves across a range of different health and social care settings.  
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The study identifies the need for appropriate ABI training for health and social care  
professionals.

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The findings illustrate a lack of training when identifying and responding to people with  
ABI in the acute setting (*“we put this woman in HDU...because she’d bashed her head*

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3 *so hard, perhaps we should have called her [the neurologist]*". This resulted in poor  
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5 treatment management of individuals with ABI and labelling of survivors by  
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7 professionals who lacked empathy (*The way people in various organisations look and*  
8  
9 *treat you...just because you look ok*"). The lack of training is further supported by  
10  
11 previous research which has found substantial misconceptions about the implications  
12  
13 of ABI among nurses (Linden & Redpath, 2011) and trainee nurses (Linden & McClure,  
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15 2012). There is a tendency among professionals to overlook, or fail to acknowledge,  
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17 the invisible symptoms of ABI (Langlois, Rutland-Brown and Wald, 2006), leading to  
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19 frustration amongst family and survivors. This harmed the relationship between  
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21 patients, families and professionals.  
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27 Both ABI survivors and their families failed to receive the subsequent support required  
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29 for ongoing symptoms. The implications of a lack of support include difficulties with  
30  
31 community reintegration (Linden & Boylan, 2010), often associated with the lack of  
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33 information provision given to families and survivors at the time of injury. This can lead  
34  
35 to individuals, and family members, leaving hospital with a lack of awareness about  
36  
37 post-injury symptoms (Barlow, 2016). This can lead to longer-term difficulties through  
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39 individuals with ABI pushing themselves too hard (Matser, Boon, & Mertens, 2017),  
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41 and can make it difficult to plan realistic long-term goals in rehabilitation (Flashman &  
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43 McAllister, 2002; Fleming & Strong, 1995). In many cases this can lead to a delay in  
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45 receiving any form of community rehabilitation which is an important part of improving  
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47 prognosis and preventing social isolation and deprivation (Hoffmann, Düwecke & von  
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49 Wild, 2002). This is further exacerbated by the lack of knowledge and understanding  
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51 of professionals within community health and social care settings who also fail to  
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53 provide, or signpost to, appropriate services (Norman, 2016; Holloway & Fyson, 2016;  
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55 Linden et al, 2013).  
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## Accepting what we do not know about acquired brain injury

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3 A lack of signposting and support within a community setting was a particular difficulty  
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5 in areas such as TBI where there is no formalised care pathway and shortages of  
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7 provision within the UK (Holloway, 2014). In areas such as stroke, there are clearer  
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9 care pathways which leads to better forms of support particularly after discharge from  
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11 hospital. However, these services tend to be focused on older adults which can lead  
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13 to a lack of tailored provision for younger adults who have experienced strokes (Walsh,  
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15 Galvin, Loughnane, Macey & Horgan, 2015).  
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20 The importance of safeguarding those who may be vulnerable was identified in the  
21  
22 current study (*There is a terrible lack of underpinning knowledge amongst non-*  
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24 *specialist professionals – insight and executive impairments are virtually always*  
25  
26 *missed*). This is supported by many researchers who have identified a link between  
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28 ABI and homelessness (Hwang et al, 2008), substance abuse (Parry-Jones, Vaughan,  
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30 & Cox, 2004), mental health difficulties (Owen, Freyenhagen, Martin & David, 2017)  
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32 and suicide (Madsen, Erlangsen & Orlovskaja, 2018). A recent safeguarding review  
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34 highlighted the need for greater “professional curiosity” of the impact of ABI on long  
35  
36 term functioning (Morgan, 2017; Flynn, 2016). Therefore, appropriate safeguarding  
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38 measures should be put in place for those likely to fall in this category through means  
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40 such as regularly reviewing the vulnerability and capabilities of those with ABI in the  
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42 community.  
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50 The study included a mixed range of participant perspectives which was important for  
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52 capturing a broader sense of the experiences of ABI survivors and their families across  
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54 different health and social care settings. However, the authors acknowledge that there  
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56 were a limited number of professionals from public sector health and social care  
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58 organisations (e.g. NHS and social care departments) without ABI-specific expert  
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3 knowledge included within the study. It is the voice of these professionals that would  
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5 not only elucidate a greater understanding of the knowledge base of professionals, but  
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7 would also aid our understanding of how best to support training needs. As each  
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9 organisation is different, a greater selection of professionals from across different  
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11 services would have enhanced the study and should be a focus for future research.  
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15 Another potential issue was the use of an online survey and recruiting through  
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17 predominantly online sources (e.g. social media). The research team were mindful of  
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19 the potential for this bias meaning that the participant group, particularly those with  
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21 ABI, would not necessarily been representative of the population as a whole.  
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23 Therefore, it is important to note that the local headway groups helped to facilitate  
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25 clients completing the online survey and the follow-up interviews by working with them  
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27 to complete the survey in the day centres and advocating for them during interviews  
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29 where necessary. This also enabled those participants with ABI from less fortunate  
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31 social-economic backgrounds to engage in the study.  
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## Conclusions

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42 The study has identified several key recommendations for policy and practice. Key  
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44 recommendations for practice include improvements to training provided to staff in  
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46 health and social care settings, improvements in information provision to families and  
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48 patients on discharge and access to community rehabilitation services. The study  
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50 has highlighted that many professionals working outside of ABI-specific services do  
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52 not possess the knowledge and understanding of the long-term effects of ABI on  
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54 individuals and their families. This is especially true of symptoms that may be  
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56 invisible to the observer, particularly those associated with executive dysfunction.  
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## Accepting what we do not know about acquired brain injury

The authors recommend that training in ABI symptoms, and the needs of individuals and their families, should be a staple part of all health and social care professionals' "continuing professional development". Such training should be provided by experts in the field of ABI and should include specific training on the issues around safeguarding issues with individuals with ABI (Moore, Wotus, Norman, Holloway & Dean, 2019). This training is important for all professionals from those in acute settings through to those working in community organisations. Future research is important to understand how to engage with health and social care professionals and structures within organisations to improve the training possibilities for staff.

Training packages for professionals should also include useful resources that can allow professionals to easily signpost ABI survivors and their families to relevant ABI-specific services. This should include provision of information resources such as leaflets provided by Headway UK that improve an individual's knowledge and understanding of their own condition, and that of their family members. This form of written information provision helps to reduce psychological distress (Morris, 2001). Further research would be useful; to identify the exact gaps in knowledge of staff in different health and social care settings to ensure signposting information and training is tailored to their needs and the needs of families and service users at this stage.

It would appear that at least some professionals would benefit from basic training to improve their interpersonal skills. Basic listening and empathy skills are important in building relationships with service users and their families more generally, and have been known to have health benefits over and above specific interventions for long term conditions (Fleming & Ownsworth, 2006; Medley & Powell, 2010). Health and social care professionals could considerably improve their interactions with ABI

1 Accepting what we do not know about acquired brain injury

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3 survivors and their families, and build their trust, by simply providing a more  
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5 empathetic ear to service users.  
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10 Finally, the findings from this study suggest the need for improved access to services  
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12 within the community setting. The study has highlighted the need for improved  
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14 access to community neurorehabilitation, community integration, including social  
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16 support and increased access to follow-up appointments to check basic healthcare  
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18 needs associated with their injury.  
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24 In conclusion, this study has supported the findings of existing studies that have  
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26 highlighted a lack of knowledge and understanding of ABI amongst various health  
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28 and social care professionals. This study has shown a general lack of understanding  
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30 that starts with health professionals working in acute settings and spans the range of  
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32 services right through to health and social care professionals working in longer-term  
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34 settings. In order to provide satisfactory and appropriate care for people with ABI and  
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36 their families long-term, it is essential to improve the knowledge-base of health and  
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38 social care professionals' regarding ABI and its long-term consequences.  
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**Table 1: Participant characteristics**

<b>Respondent characteristics</b>	<b>N</b>
<b>Gender</b>	
<b>Total sample</b>	
Females	61
Males	46
<b>ABI survivors</b>	
Females	9
Males	21
<b>Family members</b>	
Females	20
Males	6
<b>Professionals</b>	
Females	32
Males	19
<b>Age (total sample)</b>	
18-25 years	12
26-35 years	11
36-45 years	24
46-55 years	26
56-65 years	14
66-75 years	8
76 years	1
<b>Geographic location (total sample)</b>	
South west	40
South east	3
South	29
Midlands	4
North east	18
North west	11
<b>Characteristics of those with ABI*</b>	
<b>Gender</b>	
Males	31
Females	25
<b>Age</b>	
18-25	13
26-35	7
36-45	12
46-55	13
56-65	4
66-75	6
76	1

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4	<b>Types of ABI</b>	
5	Traumatic Brain injuries	43
6	restricted/disrupted blood flow	7
7	hypoxic injury	5
8	brain infection	1
9		
10	<b>Causes of ABI</b>	
11	Road traffic accidents	23
12	Falls	9
13	Sports or work injuries	4
14	Assaults	7
15	Stroke	6
16	Cardiac arrest	2
17	Oxygen deprivation	2
18	Aneurysm	1
19	Surgery	1
20	Brain infection	1
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22		
23	<b>Severity**</b>	
24	Mild	21
25	Moderate	17
26	Severe	18
27		
28	<b>Years since injury</b>	
29	less than one year	7
30	1-3 years	12
31	4-5 years	4
32	6-10 years	8
33	11-20 years	10
34	21-30 years	12
35	31-40 years	2
36	41-50 years	1
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40	<b>Characteristics of professionals</b>	
41	<b>Job type</b>	
42	Non-specialist	
43	GP	9
44	Social worker	6
45	Police	4
46	Nurse	2
47	Mental health practitioners/psychiatry	4
48	Care workers/managers	5
49		
50	Specialist	
51	Brain Injury case managers	13
52	Solicitors (personal injury)	2
53	Speech therapist	2
54	Occupational therapists	6
55	Brain injury support workers/Headway staff	6
56	Neurorehabilitation manager	1
57	Neuropsychologist	1
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<b>Number of Clients seen with ABI (expert respondents only)</b>	
0-1	1
2-5	2
6-10	6
11-15	8
16-20	4
20+	10

\*respondents or family member responses

\*\*self-reported

For Peer Review

**Table 2. Emergent themes and sub-themes**

Themes and Sub-Themes	Number of times mentioned (in questionnaire)
<b>Theme 1: Knowledge and Understanding of Healthcare Professionals</b>	
Lack of service provision	53
Lack of signposting	42
<b>Theme 2: Knowledge and understanding of social care professionals</b>	35
<b>Theme 3: Training needs</b>	
a. Empathy	24
b. Hidden Disability	26
C. Safeguarding	13

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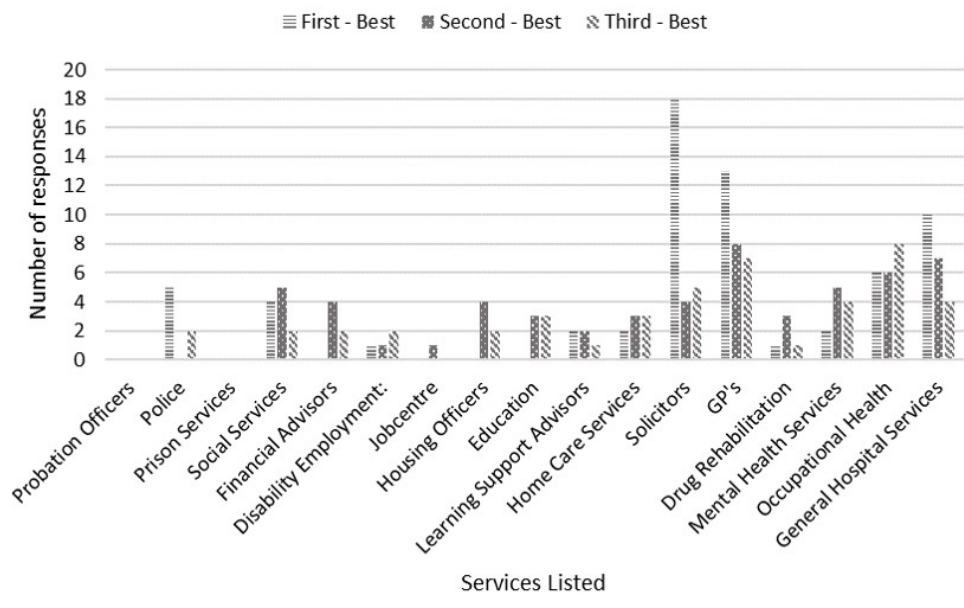


Figure 1: Online survey results showing services identified as best meeting the needs of ABI survivors

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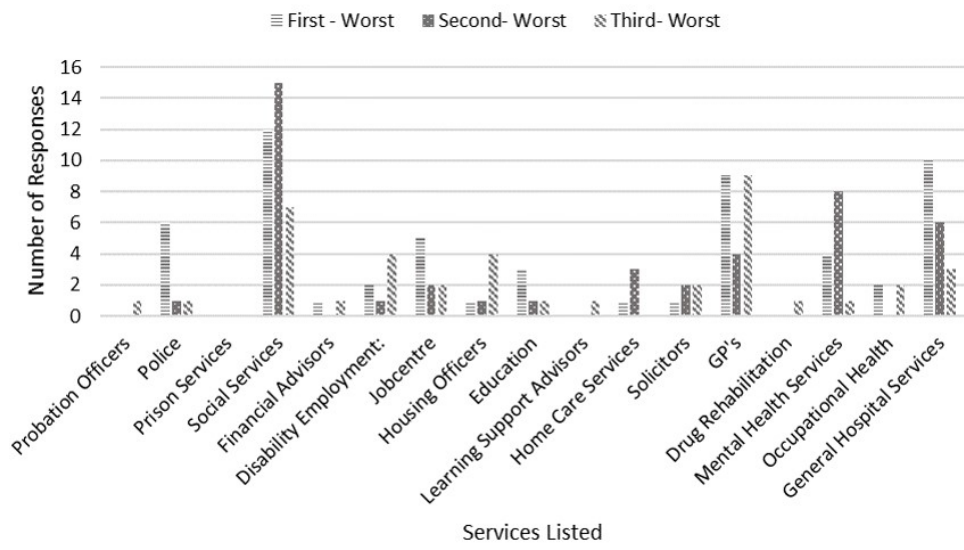


Figure 2: Online survey results identified as least able to meet the needs of ABI survivors

227x133mm (98 x 98 DPI)