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# The Information Gap for Children and Young People with Acquired Brain Injury

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## ABSTRACT

**Statement of Purpose:** This study explored the information requirements of children/youth with an acquired brain injury.

**Methods:** An online survey (n = 16), focus group (n = 5) and in-depth semi-structured interviews (n = 3) elicited the views of 24 children/youth with ABI. A priori thematic coding was used to analyze the data.

**Results:** Five themes emerged: stage and age, school, friendship and peers, delivery methods and information content. The desired information changes over time depending on age and time since the injury. Children/youth want their friends and teachers to access information on brain injury. Children/youth want information delivered through a range of channels, including videos (featuring genuine case studies), apps and board games. Children/youth wanted information specific to their injury, information on brain injury more generally, and practical strategies for overcoming problems.

**Conclusions:** Children/youth with ABI were able to express views about their information needs, which change over time and include a range of channels.

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## KEYWORDS

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## Introduction

Acquired brain injury (ABI) is the most common cause of death and disability in the United Kingdom (UK) and encompasses a range of etiologies: Trauma (e.g., road traffic accident, falls, and blows to the head), strokes, non-traumatic comas (e.g., following a brain infection) and brain tumors.<sup>1</sup> ABI is a newly-acquired condition that can occur suddenly following a period of typical development. However, many children and young people experience an ABI as a lifelong condition, with chronic deficits that persist into adulthood. The incidence of pediatric ABI is approximately 40,000 annually in the UK; with 6,000–7,000 likely to be in the severe category.<sup>1</sup>

Research has shown that children/youth with ABI are not well served by existing services in many countries.<sup>2</sup> Education and health services often lack the appropriate knowledge and fail to appreciate the unique set of needs of childhood ABI, which differs from the wider population with congenital neurodevelopmental diagnoses.<sup>3,4</sup> Furthermore, children and young people with acquired brain injuries and their families have been shown to have ongoing needs years after the original injury.<sup>5</sup> One approach to improving service delivery is by addressing the information needs of children/youth themselves which are likely to be as diverse as the sequelae they experience.

The diversity of these needs may offer some explanation as to the relative scarcity of information resources for children/youth with ABI when contrasted with the volume of material available for adults with ABI, professionals, and carers. It is therefore essential to consult children/youth with ABI when considering information resources. The British Society of Rehabilitation Medicine (BSRM) standards

state that specialist centers should conduct “Research to understand the needs of people with long-term neurological conditions and those who care for them, to determine how those needs may best be met”.

A historic paucity of research with children with ABI has been recognized, but there is an appetite within the research community to redress this balance.<sup>6,7</sup> The impact of cognitive impairment resulting from brain injury must be considered when designing research of this nature. Children/youth may experience difficulties with information processing, attention, or fatigue among others, but some authors identify strategies to minimize their influence on the research process and so allowing children/youth to participate in these studies.<sup>8,9</sup>

We know children/youth are capable of expressing their views and have a right to do so in matters affecting them.<sup>10,11</sup> Implicit in this right is that a child/youth is provided with the necessary level of age-appropriate information to allow them to express the most informed view possible. Shenton and Dixon (2004) define information in this context as

*“...the intellectual material needed by a person to ease, resolve or otherwise address a situation arising in his or her life” (p26)<sup>12</sup>*

Comprehensively meeting the health information needs of children and youth of varying ages and intellectual maturity may be challenging. Shenton and Dixon's study of 188 pupils from 14-year groups found young children are often dependent on adults to provide them with information, and that a parent/guardian may omit detail they feel would threaten the emotional well-being of the child.<sup>12</sup> They state that

*“Some youngsters require information to prepare them for increasingly demanding future tasks as they seek to learn more about what lies ahead of them” (p30)*

Shenton and Dixon also found that parental channel becomes less relevant in middle childhood as children begin to make more decisions about their everyday lives, based on the information available to them.<sup>12</sup> The study also found older children (aged 9–14) can become anxious about situations in which they perceive themselves to have little control whereas younger children tend to be more concerned about minor ailments.

One team of academics identifies the key information needs of disabled young people and state that the information which young people are provided with must go beyond medical information to include information to help them to manage daily living.<sup>13</sup> Beresford also highlights the importance of information being delivered in different ways by different people (e.g., health professionals, parents, others with the condition) and states that age alone cannot be used to predict what information a young person needs and when. The primary objective of this study was to explore the information requirements of children/youth with an acquired brain injury (ABI) at different ages. Specifically, we are interested in their views on the thematic content of information and the most appropriate channel to meet their needs.

The null hypothesis is that children/youth want the same information, via the same channels, as adults.

## Methods

This is a qualitative, exploratory, descriptive, cohort study aiming to gather rich, in-depth data about the information needs of children/youth with ABI. The data were collected in three stages over a 6-month period. Methods used were: Postal and online questionnaire, focus group and semi-structured interviews.

This three-tiered approach provided initial themes, which were explored at increasing levels of detail over the subsequent stages.

**Stage 1: Postal and online questionnaire.** A question format was developed with the project team. The questions focused primarily on what type of information the children/young people felt they would like and 'how' they may want information to be delivered.

The questions were reviewed by the rehabilitation facility's research committee and the local ethics committee.

**Stage 2: Focus group.** Children and young people from the survey were invited to take part in a focus group, staged at an accessible central London location. The structure of the questions for the focus group was derived from the results of the online survey.

**Stage 3: Semi-structured interviews.** The interviews were arranged at a time and place of convenience. Two interviews took place in the young person's home and one at the residential rehabilitation facility.

One participant wanted to provide additional information but lived some distance from the research center. He initially agreed to be interviewed by Skype but eventually provided his views by email correspondence at his convenience instead. This participant was younger and lacked confidence so felt more comfortable providing answers by email.

The initial questions in the interviews were derived from the content of the focus groups, and participants were given a summary of the topics to be covered. When new topics were introduced, young people were encouraged to develop these new ideas with additional open questions from the researcher.

## Participants

A total of 16 children and youth aged 6–18 years with an acquired brain injury were recruited via a range of methods.

The questionnaire was posted to all children in who had received residential and community-based rehabilitation from the United Kingdom brain injury rehabilitation facility 2009–2014. Our inclusion criteria were that children/youth should be between six and 18 years to ensure multiple age groups were represented.

All of the children/young people worked with health professionals who were able to confirm the child/young person's ability to understand written and spoken questions and their ability to formulate their responses using verbal or non-verbal methods.

Participants for the focus group and interviews were identified from the discharge records by the research team and by members of the Brain Injury Community Team. Additionally, a call for volunteers was placed on Brain Injury Rehabilitation's online information resource and social media platforms which are available internationally.

Following completion of the questionnaire, the participants were asked if they would like to join a focus group. Six children/young people attended a focus group that was hosted in a central London venue during school holidays.

Participants and their parents were paid travel expenses and most took advantage of spending some time in London (going on to see a show or visit a tourist attraction).

At the conclusion of the focus group, participants were asked if they would like to meet on an individual basis to develop their thoughts and ideas further. Four children/young people participated in individual semi-structured interviews.

## Data Analysis

The survey data were analyzed using simple descriptive statistics. The frequency of responses was calculated, and individual comments were noted.

The interviews and focus groups were recorded and transcribed verbatim. One member of the research team read and reread the focus group transcript and suggested a coding structure that reflected both the themes of the transcript and those that had emerged from the survey data.

This coding structure was applied to the focus group transcript by three members of the team to check the reliability of the coding. The interview data were also transcribed verbatim and the same coding structure was applied to the transcripts.

NVivo 10 software was used to code the data. The frequency of coding themes was also carried out using the capabilities of the software.

If there were differing codes assigned, the discussion would take place until consensus was reached. If this was not possible

a third team member would be asked to adjudicate. However, this was not required as all codes agreed.

This study received ethical approval from the National Research Ethics Service (London/Fulham) reference 13/LO/0294.

## Results

The online survey recruited 16 children/young people (see Table 1). This broke down to 11 under 16 years and five over 16 years. When participants were asked, “do you have as much information about what brain injury is as you would like?” Six young people said yes and 10 said no (see Figure 1).

The key information children and young people identified as wanting to know more about were: The brain’s structure and what happens in a brain injury, their own brain injury and how feelings and behaviors are affected by brain injury (see Figure 2).

When asked “where would you prefer to find out about these things?” The participants identified a variety of channels including in a book, on a website, on a tablet computer, and from a medical person.

They identified a range of desired delivery methods: Via parents (younger children), via health professionals (youths over 16), books and a tablet computer (see Figure 3).

The focus group included five children/youth and the interviews included three children/youth plus one email conversation. In all cases, the young people requested that a member of the research team read and reread the transcript of the focus group. Discussion in the focus group covered all five themes with the most discussion being around education (18%) followed by means of delivery (13.5%) and content (11%). The interviews varied in content but all three of the four interviews covered all five themes, two focused more on means of delivery (just under 24% and 27%) while the other two focused more on

Table 1. Participant demographics.

		Gender	Age	Injury type	Time since injury	Ethnicity	Main challenges
Stage 2 – focus group and interview	Participant 1	Female	17	Intraventricular haemorrhage	5 years	White British	<ul style="list-style-type: none"> <li>● Higher executive functional issues</li> <li>● Expressive language difficulties</li> </ul>
	Participant 2	Female	17	Posterior fossa tumour	4 years	White British	<ul style="list-style-type: none"> <li>● Headaches</li> <li>● Fatigue</li> <li>● Speech clarity</li> </ul>
	Participant 3	Female	13	Traumatic brain injury in utero	13 years	Mixed race	<ul style="list-style-type: none"> <li>● Difficulties in planning and organizing</li> <li>● Fatigue</li> </ul>
	Participant 4	Male	11	Meningitis	11 years	White British	<ul style="list-style-type: none"> <li>● Concentration</li> <li>● Fatigue</li> <li>● Memory</li> </ul>
	Participant 5	Female	9	Meningitis	9 years	White British	<ul style="list-style-type: none"> <li>● Memory</li> <li>● Concentration</li> <li>● Difficulties in planning and organizing</li> </ul>

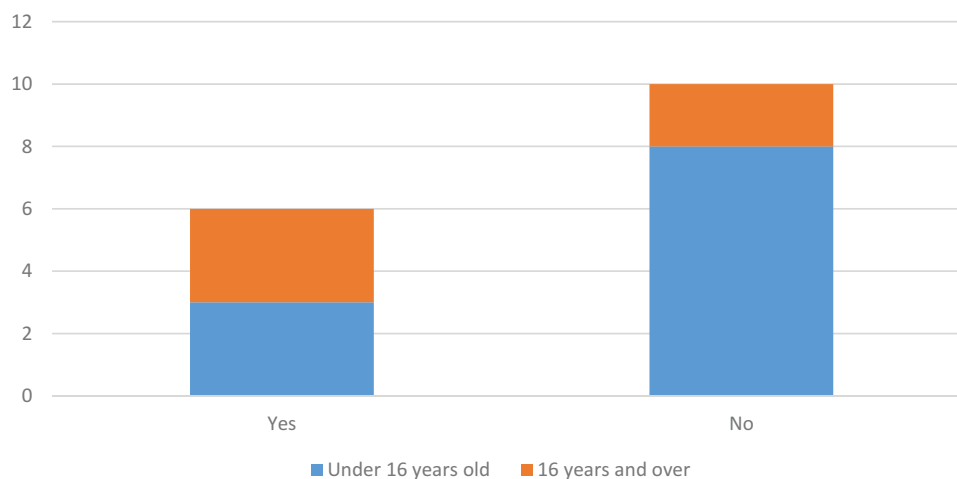
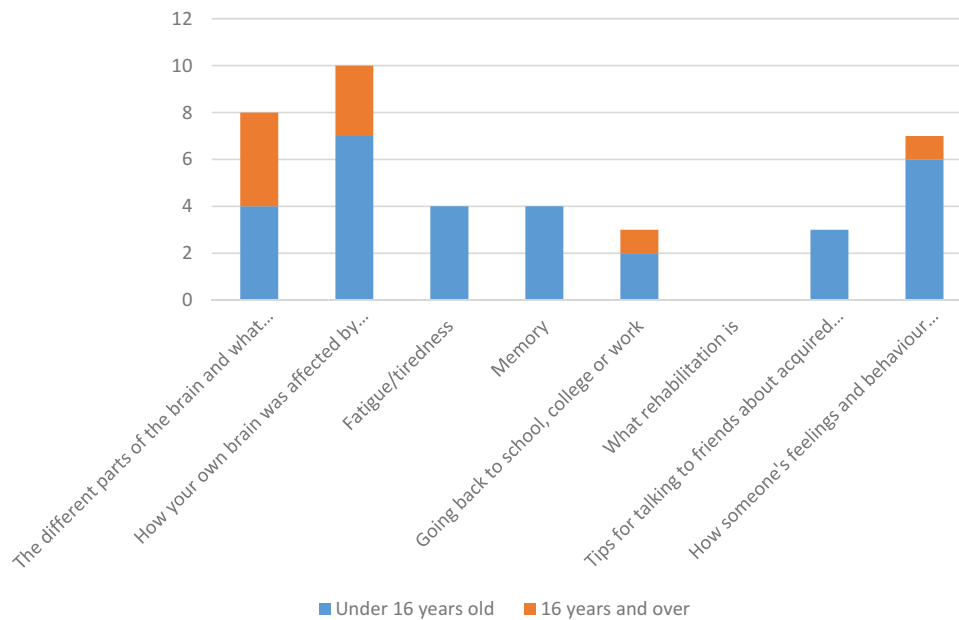
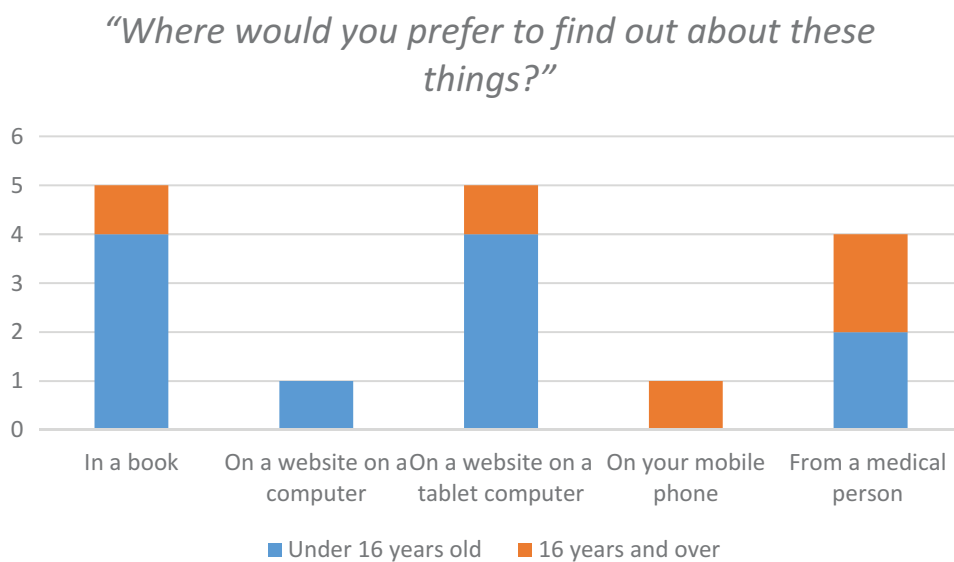


Figure 1. Frequency of survey responses to question “Do you have as much information about what brain injury is as you would like?”



**Figure 2.** Frequency of survey responses to question “If you had to pick two of these things you are most interested in knowing about what would they be?”



**Figure 3.** Frequency of survey responses to question “Where would you prefer to find out about these things?”

content (27% and 34%). Education was covered the least in the interviews varying between 0% and 7%.

Themes emerged through the process of immersion in the interview transcripts and were informed by the topics covered in the focus groups. These themes were used as an apriori coding structure to assign codes to the transcripts. All five themes were coded in excess of 17 references, thus endorsing the coding structure. The themes that emerged were stage and age, school, friendship and peers, delivery methods and information content.

### **Stage and Age**

Unlike adults, the participants spoke not only of how their age may influence their information needs but also about how their

information needs may differ at different stages of the recovery journey. Therefore, the null hypothesis is disproved.

They spoke of specific requirements for younger children, notably that younger children may not require as much detail. This idea is continued in section three where participants discussed means of delivery in relation to age. Participants also showed some understanding of how difficult it is to absorb information, and how it may need to be repeated several times, especially as you get older.

One of the participants who was first told about their brain injury at five-years-old said,

*I think when I was actually told I might have been a bit too young to like understand.*

They then went on to say,

*Maybe I think when I was about like 10 maybe was about the right age.*

Participants also said,

*When I was a bit older because I think when I was actually told I might have been a bit too young to like understand it.*

*I didn't really find anything out for myself, and I decided to live with it rather than trying to find stuff out. But now I am older I'm trying to like solve the problems I have and trying to find things out for myself.*

Participants spoke of their individual experiences at the early stages of recovery, with one young person wishing she had known more, while another was glad that she did not.

*I think as I was recovering I would have liked to have more information to know what was happening and what operations I would have to help me. I didn't know that much because my brain was a little bit muddled.*

*When I was in hospital nothing would have helped me because I wouldn't have understood. When I was at [rehabilitation] I think more information would have helped. It was quite nice not knowing cos then I didn't worry about it.*

They spoke of wishing to know more when they returned home from a health-care setting, and also a few months later which they linked to going back to school. When they talked about the return to education, there was a shift in focus in the discussion, away from their own information needs and towards the importance of teachers and peers needing access to information about ABI.

One participant reflected on the information needs of parents before children

*I think parents need to know first. But then children need to help themselves, by I don't know, doing some different things, like if it's tiredness maybe going to bed a bit earlier.*

Participants also spoke of the importance of the pace of information sharing

*Difficult to ask questions early and so books might help.*

*Gradually – little bits of information and then more later.*

*Too much at the beginning might make me worry more.*

## Content

The participants provided long lists of ideas for the content of the information they required. The collective list of ideas was the brain; 'symptoms' and understanding that brain injury affects these things; management strategies; the future; how to explain to others; other people need to know; sleep; memory; help in school; driving; jobs and working; fatigue; emotions; University and higher education; relationships.

Although the participants expressed a desire for a high volume of information, with significant detail on occasion, they also expressed a need for information to be placed in context. They were particularly interested in the experience of other children/youth with ABI if their circumstances were similar to their own.

For me I find that my brain injury to me is more important but it is interesting to hear about other people's brain injuries and what they've been through compared to me.

But also like to know like what parts of my brain had been damaged.

They were particularly interested in the everyday experiences of other young people and their strategies for managing school, daily life, and relationships.

*Don't go that route, that won't help. Go through this ...*

*What would like happen to me because of the brain injury, like what things I wouldn't be able to do as well like other children and that it made me more tired.*

*Give us ideas of what helps us easiest, like when we have depressed moment or something what we should do.*

*I think things like driving and like getting a job and things.*

*How you can improve it in little ways you can try.*

*How can we manage daily life, how can we deal with that?*

They were also concerned about whether or not there was any truth in some of their assumptions.

I won't get help at work

We won't go to uni

Might not be able to drive

Might not be able to live on their own

## Means of Delivery (or Channel)

The participants were highly creative in developing ideas for sharing information with children and young people of all ages. They did not dismiss the possibility of a health professional sitting with them to share information.

Although they may at times prefer someone who has shared a similar experience, they nevertheless stressed the importance of 'real people' and 'to be told in person'.

*People who've had that situation because they know how it feels.*

*Someone who's been through it who you can talk to.*

*Other people's stories, and how they cope with things so you can do the same.*

*I think it is also good hearing about different people's experiences as well.*

Participants spoke positively about books and comics that have previously been produced. They liked biographies (such as the book written by the rower James Cracknell, who himself sustained a brain injury).

A comic is fun because they've got pictures and it's brightly coloured and it's just layed (sic) out more clearly, more interesting for children to read.

Like quite funny stories so it's not too depressing.

When I read the MediKidz book it helped me just know more about what I had gone through.

Books I think really helped me, have been very helpful.

A comic is fun because they've got pictures and they are brightly coloured.

Amongst other ideas, they considered a board game, an online game, a cartoon video and a quiz.

people who have been through it make a quiz ... if they get the answer wrong it could say no you should do this instead

you say a word like haemorrhage or brain tumour and have a sort of a simple definition ... you could maybe make like a jigsaw and put them together

They also considered that it was important to take into account age when creating information resources.

For younger children you make an easy word.

But like older children like teenagers ... children from 13 onwards are easy to use computer. Young children might not find it as easy ... I know I wouldn't go on the computer as much when I was young ... I think for younger ones maybe just a book or game ... or maybe someone to talk to them.

I think little children of like five would like fun books more and as you get older then you might like an app because most little children don't really use the computer.

I think at ten you could probably do it on your own but when you're five you'd have to do it with someone.

## School

Participants' experiences at school had not been entirely positive and some felt their experiences could be improved by the provision of information, both to themselves and to others.

For themselves, they expressed a need for information about special schools, alternative routes to university and specific information about subject choice and exams.

Can we opt out of compulsory subjects?

There's nowhere that says, 'a brain-injured kid can have this, this and this' for exams.

Different information for different exam boards.

It would be good to have talks about doing, um, BETECs and courses in one year

Having information about special schools and things would just make you feel more comfortable about school.

They spoke about how difficult the condition is to explain to others, and that peers at school often do not understand.

About brain injury but also particulars about the person – why they need to sit out of PE, hospital appointments, why they have help, why they're off so much.

Might not be able to catch up when schooling missed, eg appointments. Need to be given the information missed instead.

They need slightly different information, like how to help someone deal with it, and how to like include them in conversation and stuff.

They also spoke about teachers and other school staff needing to know more about brain injury and the specific challenges they are facing.

I think that like TAs and teachers and any member of staff at school need to know what people have been through, and just, like, bring them a book or something just to show them what they've been through and tell them.

They just need to know about brain injury, erm, how to deal with a child if they are tired, if they are upset. Just be nice to them.

Participants were able to reflect on methods of information sharing that had worked for them and spoke positively about brain injury books and videos.

*The acquired brain injury book has helped teachers and TAs at my school*

They also reflected that information needed to be repeated over the years and sometimes needed a professional to come to speak to peers and teachers at the school before support was forthcoming.

## Friendship and Peers

Participants spoke of the importance of information for friends and peers. They were concerned that friends should have an insight into their situation, including why they have help, why they get tired, why they feel sick, why they are often last to finish or 'why everything's hard'.

No one really knows I'm injured, because they all think I'm the same and then they wonder why I'm off school so much.

They might look down on you, or ... avoid you.

You're not ... thick ... as your mates may call you.

I think it would help their friend understand what they've been through and then friends might be nicer and understand and not ignore them.

Again, they spoke about a range of resources that could support information sharing with friends, including a professional speaker addressing peers and teachers.

For people to come and speak to them because if you gave them a book to read they might say I can't be bothered to read that

*Maybe like a ... a comic or a cartoon video thing.*

Participants made it clear that they found interactions with peers challenging, and would like support in passing information on to friends, including information on how to broach the conversation and how much information to share.

Maybe learned what to say to friends to make them come to me. Because I had to wait at least half a year maybe a year to actually get a proper friend.

They need slightly different information, like how to help someone deal with it, and how to like include them in conversation.

## Discussion

Children/youth with ABI were able to express views about their information needs and were engaged in the process. This supports the finding by Boylan (2009) who found that by using methods to overcome the cognitive, behavioral, emotional and physical challenges faced by children and youth with ABI this children/youth can participate in research.<sup>8</sup> Their needs include

information specific to their own injury, as well as more general information on ABI. They are particularly interested in strategies for overcoming problems.

Children/youth want different amounts of information at different times, depending on both their age and the stage they are at in the post-injury process of recovery. They want friends and teachers to have more information to help them to understand the challenges the child/youth with ABI is facing and how they can support them. Children/youth also want information delivered across a range of channels, including books, apps, and board games. They want to hear the experience of others with brain injury, preferably through videos, and how these individuals coped with everyday challenges.

Results echo the findings of previous research that children and young people with an ABI need both medical and psycho-social information.<sup>12</sup> Although these authors had a lesser emphasis on the age of the child, our findings suggest that age at injury has greater importance in this group. This is significant, as the number of years of typical development before injury will not necessarily be a factor in each individual's understanding of their illness and resulting disability. This suggests that an older child may have a better understanding of their illness and the resulting disability than a younger child.

As with other researcher findings, children/youth with ABI respond to genuine stories, relayed by individuals who have shared their experience.<sup>9</sup> What is more, they are interested in stories of older children/youth who have successfully navigated the 'next stage' and can share experiences of driving, school or university.<sup>8,9</sup>

Linden and Boylan (2010) highlighted that people fail to see brain injury as a hidden condition and expect to see some outward sign.<sup>3</sup> Participants of our study reinforced this by asking for more information for the people around them to understand more of the challenges they are facing. However, children/youth with ABI also expressed a need for their parents to receive the information first possibly due to their age or injury limiting their understanding. This supports Linden and Boylan's finding that the voice of the child should be heard alongside the voice of the parent to gain a better understanding of both the child/youth's information needs, as well as the parents.<sup>3</sup>

Also, significant is the participants' expression of their information needs as fluid and subject to change. This does not relate purely to their age and level and comprehension, but to another significant dimension – the time that has elapsed since their injury. The experience of brain injury itself is not a single event with a clear trajectory of recovery; we know many children experience chronic deficits that persist into adulthood. The information needs of children and youth reflect this often complex narrative in that participants expressed a clear need for different information at different times.

Some participants demonstrated a high degree of self-awareness in acknowledging that too much information would have troubled them during the early stages of their recovery. This supports the growing evidence that information needs to be tailored to the individual and that each child/youth is different and will require different amounts of information delivered at different times and in different ways.<sup>8</sup>

A limitation of this study is that it is a small sample of children/youth with brain injury and so future studies could aim to look at

the information needs of a greater number of children/youth after brain injury. A potential limitation of the study could be the use of focus groups and interviews to collect responses as participants may choose to give an answer which is socially desirable. However, throughout the study participants were reassured answers would remain anonymous and the interviewer was non-judgmental of the responses given.

Participants wanted a wide range of areas covered, including information about the brain, information about their own brain injury and psycho-social information such as coping strategies for common challenges following brain injury and advice on key life transitions such as going to university and finding a job. This finding supports Beresford and Sloper's findings that information for young people with chronic conditions must extend beyond medical information.<sup>12</sup>

The participants of our study came up with lots of ideas both in terms of content and delivery of information after brain injury. Their ideas went far beyond what we expected and included information for both themselves and those around them, especially teachers and friends.

## Conclusion

This study has added to and complemented previous studies which have found that children/youth require information that extends beyond medical information to more psychosocial issues. This study also reinforces that children/youth can participate in research to help us better understand their needs. The study shows that children/youth's information needs are very complex, different from adults, and will vary both in terms of age, the severity of injury and time post-injury. They also want information to extend beyond themselves to others such as friends and teachers but feel the information needs of these groups are different to their own.

So perhaps it is not surprising that there is a lack of resources for this population when their needs are so complex. What this study does highlight is that children/youth after brain injury have a real need for information delivered in different ways. And so this is an important area for the international community to develop information resources in order to improve children/youth's experiences after brain injury.

Following this study, we are developing a handbook for young people following brain injury which includes real stories and advice from other young people. We are looking into the possibility of a video-based internet resource where young people could watch videos of other young people sharing their experiences after brain injury.

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## Appendix 1

### Questions for online survey

Do you have as much information about what brain injury is as you would like?

Yes

No

Do you have as much information about your own brain injury as you would like?

Yes

No

Would you like the information given to you:

Through a parent

Through someone your own age

Directly to you

Through another adult who helps you, like a doctor or therapist

If you had to pick two of these things you are most interested in knowing about, what would they be?

The different parts of the brain

How your own brain was affected by your injury/illness

Fatigue/tiredness

Memory

Going back to school, college, or work

What rehabilitation is

Tips for talking to friends about brain injury

How someone’s feelings and behavior might change after a brain injury

Where would you prefer to find out about these things?

In a book

On a website on a computer

On a website on a tablet computer (like an iPad or Galaxy)

On your mobile phone

From a medical person like a doctor or therapist

Is there anything else you would like to tell us about information about acquired brain injury?