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Exploring participation after paediatric acquired brain injury

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Keyword:	Children and Young People, Acquired Brain Injury, Participation
Abstract:	<p>This study aimed to explore the levels of participation in a UK sample of children and young people (CYP) with an acquired brain injury (ABI) at home, school and in the community. The purpose of this study was to assess the feasibility of undertaking research with this population with a cross-sectional study using the Child and Family Follow-Up Survey (CFFS). The CFFS was distributed to parents/carers of 134 CYP with ABI (CYP-ABI) who received neuro-rehabilitation from 2014 to 2016. Access and recruitment was problematic resulting in a low response rate (4%). Widespread restrictions in participation were reported by 4 out of the 5 respondents with community structured events/activities and educational activities being the most restricted. Factors impacting on participation were cognitive-based and movement skills, family stress and lack of support/encouragement in the community. Study results provide information pertaining to the feasibility of undertaking research with this population whilst also highlighting the restrictions to participation experienced by CYP-ABI more than two years after injury.</p>

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Exploring participation after paediatric acquired brain injury

Abstract

This study aimed to explore the levels of participation in a UK sample of children and young people (CYP) with an acquired brain injury (ABI) at home, school and in the community through a cross-sectional study. The Child and Family Follow-Up Survey (CFFS) was distributed to parents/carers of 134 CYP with ABI (CYP-ABI) who received neuro-rehabilitation from 2014 to 2016. Access and recruitment was problematic resulting in a low response rate (4%). Widespread restrictions in participation were reported by 4 out of the 5 respondents with community structured events/activities and educational activities being the most restricted. Factors impacting on participation were cognitive-based and movement skills, family stress and lack of support/encouragement in the community. Study results provide information pertaining to the feasibility of undertaking research with this population whilst also highlighting the restrictions to participation experienced by CYP-ABI more than two years after injury.

Keywords

Children and young people, acquired brain injury, participation

Introduction

Whilst global prevalence is unclear, annually in the UK an estimated 40,000 children and young people (CYP) sustain an acquired brain injury (ABI) (NHS England, 2013). A childhood ABI can lead to a complex array of physical, cognitive, social, emotional and behavioural impairments which can result in lifelong disability (Andersson et al., 2016; Gordon and Di Maggio, 2012; Popernack et al, 2015). The long-term impact of these impairments on a CYPs physical and psychological development, quality of life (QoL), educational achievement and social inclusion can be significant, but often difficult to predict and monitor (Anderson et al., 2006; Anderson et al., 2012; Bedell and Dumas, 2004; Galvin et al., 2010; Kirk et al., 2015; Limond et al., 2009; Manning et al., 2017). Many factors influence recovery including site/size of the lesion, age at injury, premorbid abilities, family functioning, personal and environmental factors and variability in rehabilitation service provision (Galvin et al., 2010; Gordon and Di Maggio, 2012). The consequences of an ABI may continue to become evident months or years after the event as developmental, education and social demands increase and are often under-recognised and misunderstood (Feary and McKinlay, 2018; Gordon and Di Maggio, 2012).

Evaluating the effectiveness of rehabilitation is essential to expand the evidence base to inform commissioning and service development decisions in today's healthcare economic climate (Datta and Petticrew, 2013). Although researchers and clinicians agree that a multi-faceted approach is required, to date, there is no standardised formula or consensus on how to measure CYP-ABI outcomes effectively. The Royal College of Paediatrics and Child Health (RCPCH) childhood stroke guidelines recommend multi-disciplinary assessment of CYP and family needs using the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) domains and QoL measures, however no specific outcome measures are recommended (RCPCH, 2017; WHO, 2002). Consequently, identification of influential factors for recovery is limited, impacting development of the

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3 evidence base for interventions (Badge et al., 2009; Gordon, 2014). Badge et al. (2009) through
4 literature review and extensive Australian clinical consultation identified three main
5 rehabilitation outcome priorities: family functioning, school performance and participation.
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10 The ICF, a holistic biopsychosocial model for describing and understanding the impact of a
11 health condition on a person, defines participation as 'involvement in a life situation' (WHO,
12 2002). Participation is an essential part of child development, associated with increased QoL,
13 social competence and educational success of CYP with and without disabilities (Bedell et al.,
14 2011; Galvin et al., 2010; WHO, 2002). Whilst there is some development of the literature
15 field regarding participation of children with disabilities such as cerebral palsy, the field of
16 literature for CYP-ABI is as yet under-developed. Participation has been found to be restricted
17 in CYP-ABI in several studies in the USA, Canada and Australia (De Kloet et al., 2015;
18 Fougeyrollas et al., 2014; Law et al., 2011; Thompson et al., 2016). However, no such studies
19 researching participation in UK CYP-ABI were identified. Further research is required to
20 explore measurement tools, data collection methods and this population's response to
21 participation in research. Such work may contribute to conceptualising participation after
22 paediatric ABI and inform larger scale studies.
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44 Aim:

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46 This study aimed to explore the levels of participation in a UK sample of CYP-ABI at home,
47 school and in the community after discharge from inpatient rehabilitation using a cross-
48 sectional study.
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56 **Method**

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58 Participants and procedures:
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3 A cross-sectional survey was identified as an appropriate method, to access information from
4 a larger target population (Bowling, 2014). The methodological and procedural components;
5 the recruitment processes and procedures and appropriateness of the selected outcome measure
6 (CFFS) were also evaluated (Arain et al., 2010).
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11 A purposive sampling strategy was used to recruit participants from four centres in England.
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13 Local collaborators identified eligible participants from existing service user databases using
14 pre-determined eligibility criteria (stated below). Postal invitation letters and participant
15 information sheets, specific for parents/carers and for CYP, were sent, inviting participants to
16 access and complete the online survey. Further telephone reminders were completed by the
17 local collaborators four weeks after the postal invitations were sent.
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30 Inclusion criteria:

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32 • Parents/carers of CYP-ABI aged 5-18 who received inpatient neurorehabilitation at one
33 of the identified four centres between October 2014 and October 2016
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35 • Sufficient command of the English language to understand the study literature, consent
36 and complete the survey
- 37
38 • CYP aged 11-18 associated to the participating parent/carer who consented to complete
39 the CYP section of the survey.
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50 Exclusion criteria:

- 51
52 • Parents/carers of CYP under 5 or over 18 (outcome measure requirements)
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54 • Insufficient command of English language to complete the survey
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56 • Parents/carers and CYP unable to provide assent or consent to participation.
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58 • CYP under age of 11 years (outcome measure requirement)
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6 Ethics:

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9 Ethical and governance approvals were gained from National Research Ethics Committee and
10 four participating National Health Service sites (REF: 17/WM/0163). Vital to any clinical
11 ethical approval is that all principles of ethical research have been met (Emanuel, Wendler and
12 Grady, 2000). In this research study practical examples include compliance with the General
13 Data Protection Regulations 2018, data confidentiality and protection and risk benefit
14 equipoise. The research team carefully considered the online survey approach's potential to
15 allow frank and honest responses whilst recognising the need for parental guidance where a
16 child completed their sections, given the potential sensitive nature of the issues being explored.
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18 Participants were provided with contact details for the research team and their local clinicians
19 should any concerns arise.
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35 Survey:

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38 Bristol Online Survey (BOS) was used to create an online survey using demographic questions,
39 consent and the CFFS. Permission was given by the CFFS's author (Professor Gary Bedell,
40 PhD) for this and some minor alterations to the wording (American to English) for local context
41 and UK spelling. Content and face validity were reviewed by the research team.
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47 A review of the literature and the participation outcomes used in previous studies (Chien et al.,
48 2014; De Kloet et al., 2015) identified the CFFS as an appropriate outcome measure for this
49 feasibility work. Originally developed to monitor outcomes and needs of CYP-ABI, the CFFS
50 was developed from the ICF and quantitative and qualitative research regarding participation
51 of CYP with a range of disabilities (Bedell, 2011). The CFFS is a parent-reported standardised
52 measure, validated in North America and Australia, with good test-retest reliability (0.67-0.94),
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3 internal consistency (0.91-0.98) and evidence of criterion-validity (Galvin et al., 2010).
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5 Normative data is not currently available, but results can be descriptively interpreted to
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7 understand patterns of participation (Galvin et al., 2010; McDougall et al., 2013). Included
8
9 within the CFFS are three quantitative scales; the Child and Adolescent Scale of Participation
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11 (CASP), Child and Adolescent Factors Inventory (CAFI) and Child and Adolescent Scale of
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13 Environment (CASE), and open-ended questions giving opportunity for further information to
14
15 be shared.
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19 **CASP:** Participation levels of CYP-ABI in activities at home, school and the community are
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21 scored for 20 items using a Likert scale (1-4) or not applicable. Item scores are added together
22
23 and divided by the maximum score for each applicable item giving a total score ranging from
24
25 0-100. Higher scores indicate CYP are participating at age expected levels. Parent and CYP
26
27 aged 11+ versions are available and important to ensure both perspectives are captured
28
29 (McDougall et al., 2013). The CASP-Youth version (CASP-Y), has been validated in Canadian
30
31 English speaking 11-17 year olds (McDougall et al., 2013). It is considered a reliable and valid
32
33 measure as strong internal structure validity and internal consistency (Cronbach's $\alpha=0.87$
34
35 (youth) and 0.95 (parent)) is reported for both versions and intra-class correlation moderate
36
37 agreement (ICC=0.63, 95% confidence interval=0.41-0.75) between the two versions
38
39 (Adolfsson et al., 2011; Bedell and Coster, 2008; Chien et al., 2014; McConachie et al., 2006).
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45 **CAFI:** Parent-reported scale that measures the impact of child-related impairment factors on
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47 participation across 15 items.
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50 **CASE:** Parent-reported scale that assesses environmental factors as facilitating or hindering
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52 participation across 18 items.
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54 Both the CAFI and CASE are scored on a scale of 1-3 or not applicable, total scores can be
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56 calculated for each measure, higher scores indicating significant impairment or environmental
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58 problems impacting on participation.
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3 The survey also included 12 open ended questions which provided the respondent opportunity
4 to offer free text responses and provide more detail. These questions included the impact of
5 their health condition on participation, equipment or strategies used to support participation,
6 current service provision for their CYP and family; satisfaction with provision and suggestions
7 for improving services.
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18 Data Analysis:

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20 Completed survey results were downloaded from BOS and reviewed in Microsoft Excel
21 format. Participants completed the survey anonymously, however, where names were
22 mentioned in the free text boxes these were anonymised. STATA (Version 15, 2015) was used
23 to analyse quantitative data. Descriptive analysis was conducted for the demographic
24 information, CASP, CASP-Y, CAFI and CASE data.
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32 The responses to open-ended question were analysed using the thematic analytical approach
33 by Braun and Clarke (2006). This data driven approach allowed for emergent themes to be
34 identified through a process of (1) reading for familiarity; (2) line-by-line coding; and (3)
35 reading, connecting and aggregating the code into themes (emergent) (Maguire & Delahunt
36 2017).
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47 **Results**

48 Respondents:

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50 In total 134 (centre 1 n=60; centre 2 n=17; centre 3 n=17; centre 4=40) invitations were sent.
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52 Only five responses were received giving a response rate of 4%. All five parent respondents
53 were mothers. Three of the participants were over 11 years old and all three consented to
54 complete the CASP-Y. The characteristics of the participants are displayed in Table 1.
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11 Participation (CASP/CASP-Y):

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14 Parent-reported total scores ranged from 70-100 (median=82.50). Age appropriate
15 participation in all items was reported for one CYP, however restrictions in 19/20 items were
16 reported for four CYP (Table 3). Structured events/activities and educational activities were
17 the most restricted (n=4 somewhat or very restricted). Further restrictions were reported in
18 communication, social, play, and leisure activities with friends, moving around
19 neighbourhood, household activities and using transport.
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28 Three CYP completed the CASP-Y, with one CYP reporting no participation restrictions. Two
29 CYP participants reported restrictions in 18/20 items (Table 2). Whilst there was general
30 agreement in the restricted items between parents and CYP, there were differences in terms of
31 degree of restriction. One CYP's total score being higher than the parent's score (83.82 v
32 71.05), and the other CYP's score lower (66.25 v 70.00).
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42 [Insert Table 2]
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46 Child-related difficulties (CAFI):

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48 One CYP had no parent-reported problems in any areas. Significant impairments were reported
49 by four parents with total scores ranging from 44.44–71.11. Cognitive based skills, behaviour
50 management, movement, strength and energy levels, speech and sensory problems were the
51 highest reported impairments with only hearing reported as unaffected by all.
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3 Environmental difficulties (CASE):
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5 Environmental barriers were reported for four out of five participants. Family stress, lack of
6 support/encouragement and services in the community were reported as barriers to
7 participation.
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15 Open-ended questions findings:
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17 Four out of five participants responded to the open-ended questions with 14 different codes
18 being identified. Two main themes emerged: cognition and communication difficulties and
19 environmental factors. The later included barriers and facilitators to participation and CYP,
20 parental and school responsiveness to adaptation.
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26 Participation restrictions due to communication difficulties were reported in the measurable
27 and open-ended questions by the CYP respondents and their parents, indicating a significant
28 problem for both. One CYP stated *'My speech gets in the way a bit but I try and talk to my
29 friends and they always listen and now I've started talking again me and my friends are getting
30 along much better'* whilst another stated *'Seizures as they make me tired, fatigue,
31 concentration. I sometimes struggle to communicate what I want to say, no word finding'*.
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40 Parents and CYP reported strategies used to support and improve participation, particularly at
41 school. Open-ended responses demonstrated families' reliance upon school responsiveness to
42 adapt for the child's altered needs post ABI and implement support strategies. These included
43 teaching assistant support, altered timetables and working environments. One parent reported
44 *'We try to keep [her] in a more quiet environment at school, she works in small groups rather
45 than a full class, she has regular 'brain breaks', she has a chill out area to go when feeling
46 frustrated'*.
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55 Parents were also asked about other services, assistance and information they felt they needed
56 to support participation. Parents identified a lack of emotional and peer support for the CYP-
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3 ABI, siblings and parents as a barrier, three providing detailed responses about how they felt
4 they, their CYP and family needed help to learn to accept, develop coping strategies and discuss
5 problems that arise. One parent stated '*support and coping strategies, support groups. Offer*
6 *support to families to help them learn to accept and cope including siblings once discharged*
7 *[home]. We were offered nothing and have struggled daily with the stresses'*.
8
9

15 **Discussion:**

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18 Participation is vital in all spheres of development for CYP and is an important rehabilitation
19 outcome (Bedell and Coster, 2008; Chien et al., 2014; Galvin et al., 2010). The introduction of
20 the ICF has led to increased focus on participation as an outcome and the development of
21 several outcome measures (Chien et al., 2014). This study aimed to explore the levels of
22 participation in a sample of UK CYP-ABI at home, school and in the community after
23 discharge from inpatient rehabilitation using a multi-centre cross-sectional survey. Whilst
24 recruitment to this study via postal invitation was low, the online data collection method and
25 survey was effective for those participants that completed it. Important knowledge has been
26 gained with participants' voices being enabled to be heard and similar factors impacting
27 participation identified, consistent with previous studies (Bedell and Dumas, 2004; Galvin et
28 al., 2010; Wells et al., 2009). Participation in structured community activities and social, play
29 and leisure activities rely on a high degree of skill socially, cognitively and physically and the
30 ability to adapt quickly to changing situations and responses from others (Galvin et al, 2010).
31 Social interaction is fundamental to child development and disruption at any stage of the
32 lifespan can have implications for mental health, QoL, academic and career achievement
33 (Anderson et al., 2013). Although relatively invisible, the impact of cognitive and
34 communication impairments are common after ABI, impact heavily on participation and are a
35 major source of stress and burden for CYP and families, as demonstrated in this small sample
36 (Turkstra et al. 2015). Increased awareness of ongoing cognitive and communication
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3 difficulties is vital to ensure effective support and assistance for CYP and their families (Galvin
4 et al., 2010; Turkstra et al., 2015).

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8 The environmental factors component of the ICF represents external influences on function,
9 physical, social and attitudinal (Ciccia and Threats, 2015). Family stress, lack of
10 support/encouragement and services in the community were reported by parents as
11 environmental factors impacting on participation. Parental stress and burden are known to be
12 directly related to functional outcome after youth traumatic brain injury with sibling
13 reaction/stress also playing an important role (Aitken et al., 2009; Ciccia and Threats, 2015).
14
15 Whilst there are positive developments within wider society to address participation of people
16 with disabilities, there are still many barriers to achieving full societal participation following
17 childhood ABI (Brittain and Beacom, 2016). A family-centred ethos to long-term CYP-ABI
18 rehabilitation is critical in recognising and addressing the impact on the whole family and the
19 influence of family stress on the CYPs recovery (Aitken et al., 2009; Cole et al., 2009).
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36 **Limitations:**

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38 This study has provided novel insights pertaining to participation of CYP-ABI. Whilst we
39 recognise that the findings are not generalizable, they do indicate that there may be outstanding
40 needs and issues for CYP-ABI and their parents that require further exploration, support and
41 intervention. However, this study does have a number of limitations that must be recognised
42 relating to access to participants, and recruitment/survey responses.
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50 Firstly, the CYP-ABI population were difficult to identify and access. Currently in the UK,
51 there is no established CYP-ABI registry or national patient and public involvement (PPI)
52 forum. Therefore, this study accessed potential participants via the CYP-ABI's local hospital
53 through the clinical ABI services database. However, this approach was limited as it was
54 dependent upon local hospitals maintaining the quality and completeness of these databases
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3 (such as up to date contact details). As such some potential participants may not have been
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5 invited due to changes in contact details.
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8 Secondly, the postal invitation recruitment method proved unsuccessful as it yielded a very
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10 low response rate. Therefore, it must be recognised that the views/experiences identified in
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12 the findings of this study, may not transferable to the national heterogeneous cohort. Despite
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14 attempts to improve responses, with a protocol amendment for telephone prompts, this did not
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16 result in an increase in recruitment. Whilst other recruitment methods were explored when
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18 designing this study, such as telephone invitations or recruitment in clinics, postal invitations
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20 were deemed the least intrusive for families and feasible in light of the time and resources
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22 available.
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26 Collectively, the design of the study was considered at length and a parent and child were
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28 involved in this process alongside feedback from other local service users. However, in relation
29
30 to addressing these limitations in future research, more extensive and geographically wider PPI
31
32 is required to establish effective approaches to recruit participants (Hunt et al., 2015), as well
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34 as strategies for optimising responses to surveys. The reality of typical 21st century family life
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36 is busy balancing multiple demands, with this population having the added complexity of
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38 supporting a CYP-ABI; this may have affected the response rate (Aitken et al., 2009; Bailey et
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40 al., 2014; Thompson et al., 2015; Wharton, 2012). Therefore, a range of methods for reporting
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42 should also be offered (such as postal, telephone, face to face, or online) as this may
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44 accommodate the potentially diverse and changing demands that families have and enhance
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46 opportunities for research participation (Pulham et al, 2019).
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54 **Conclusion**

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56 This study aimed to explore levels of participation in CYP-ABI. Whilst the response rate was
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58 low, these findings, though not generalizable, are important and informative. Particularly the
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3 qualitative responses, have provided rich and novel insights into the phenomena. Participation
4 is an important goal of long-term rehabilitation/support for CYP-ABI and clinicians should
5 seek to address factors that affect it. In order to optimise participation for CYP-ABI throughout
6 their lifespan, awareness needs to be raised. The challenges for researchers of engaging with,
7 accessing and recruiting CYP and their parents for research should not be a prohibitive barrier
8 to work in this field. As researchers we need to seek appropriate funding, increase preparatory
9 dialogue with CYP-ABI and their parents to delimit such potential barriers in order to increase
10 their involvement in research. Establishing a national network for CYP-ABI and their families
11 should be considered to provide family peer support and support future research through PPI
12 engagement. Further research aimed at comprehensively understanding acceptable and feasible
13 research methods with this population is essential to ensure future research is effective in
14 reaching and engaging CYP-ABI and their families. Additionally, international comparison is
15 required to establish the generalisability/transferability of the phenomena. Whilst it is
16 necessary to investigate participation levels with a larger population, it is apparent that
17 engagement of CYP-ABI and their families in research itself must also be addressed.
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Acknowledgments:

Declaration of interest:

The authors report no conflict of interest.

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For Peer Review

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Demographics of the CYP participants

Demographic Information	n (%)	Min.	Max.	Median	Standard Deviation
Age (years)		6	15	12	4.09
Gender					
Male	1(20)	--	--	--	--
Female	3(60)	--	--	--	--
Unspecified	1(20)	--	--	--	--
Diagnosis					
Trauma	4(80)	--	--	--	--
Infection	1(20)	--	--	--	--
Time since injury (months)	--	19	38	24.93	8.3
Time since discharge (months)	--	17	34	24.77	7.61
Length of Stay (days)	--	5	118	52	55.4
Admitting Hospital					
Centre 1	3(60)	--	--	--	--
Centre 2	0	--	--	--	--
Centre 3	1(20)	--	--	--	--
Centre 4	1(20)	--	--	--	--
Mainstream School	5(100)				
Primary	2(40)	--	--	--	--
Secondary	3(60)	--	--	--	--

CASP (parents) and CASP-Y (CYP) Scores

	CASP Score- parent reported (n)						CASP-Y Score - CYP reported (n)					
	Age expected	Somewhat limited	Very limited	Unable	N/A	Total affected	Age expected	Somewhat limited	Very limited	Unable	N/A	Total affected
Home Participation												
Social, play, leisure with family	3	2	--	--	--	2	2	--	1	--	--	1
Social, play, leisure with friends	2	3	--	--	--	3	1	1	1	--	--	2
Family chores at home	3	2	--	--	--	2	1	2	--	--	--	2
Self-care activities	3	2	--	--	--	2	2	1	--	--	--	1
Moving in and around home	4	1	--	--	--	1	3	--	--	--	--	0
Communication	3	1	1	--	--	2	2	1	--	--	--	1
Community Participation												
Social, play, leisure with friends	2	1	1	1	--	3	1	1	1	--	--	2
Structured events/activities	1	2	2	--	--	4	1	--	1	--	1	1
Moving around neighbourhood	2	1	2	--	--	3	2	--	1	--	--	1
Communication	3	--	2	--	--	2	1	--	2	--	--	2
School Participation												
Educational activities	1	4	--	--	--	4	2	--	1	--	--	1
Social, play, recreation with peers	2	3	--	--	--	3	1	1	1	--	--	2
Moving around	3	2	--	--	--	2	2	1	--	--	--	1
Using educational materials	5	--	--	--	--	0	3	--	--	--	--	0
Communication	2	2	1	--	--	3	2	--	1	--	--	1
Home and community living activities												
Household activities	1	3	--	--	1	3	2	--	1	--	--	1
Shopping and managing money	2	2	--	--	1	2	2	--	1	--	--	1
Managing daily schedule	2	2	--	--	1	2	2	--	1	--	--	1
Using transport	1	1	1	1	1	3	1	--	1	--	1	1
Work activities/responsibilities	1	2	--	--	2	2	1	--	1	--	1	1

For Peer Review

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