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# BMJ Open

## A qualitative study of the needs of injured children and their families after a child's traumatic injury

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2  
3 **Title:** A qualitative study of the needs of injured children and their families after a child's traumatic  
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5 injury.  
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**ABSTRACT**

**Objective:** To explore the needs of children and their families after a child's traumatic injury.

**Design:** Qualitative interview study.

**Participants:** 32 participants; 13 children living at home after a traumatic injury, their parents/guardians (n=14) and five parents whose injured child did not participate.

**Setting:** Two Children's Major Trauma Centres in England.

**Results:** Interviews were conducted a median 8.5 months (IQR 9.3) post injury. Injuries affected the limbs, head, chest, abdomen, spine or multiple body parts. Education and training were needed to help children and families understand the injury, how best to look after it and prepare for discharge. Information delivery needed to be timely, clear, consistent and complete, include the injured child, but take into account individuals' capacity to absorb detail. Quick and easy access to information was key, irrespective of the method of delivery. Similarly, services needed to be timely and easily accessible with flexible protocols and eligibility criteria to include injured children. Treatment (particularly therapy) needed to be structured, goal directed and of sufficient frequency to return injured children to their full function. A central point of contact is required after hospital discharge for advice, reassurance and to co-ordinate on-going care. Positive partnerships with professionals helped injured children and their families maintain a sense of hope and participate in joint decision-making about their care.

**Conclusion:**

Injured children and their families' needs focussed on education and training, effective information and communication, access to flexible specialist services, support to co-ordinate care, and positive relationships with professionals to provide flexible, patient centred care.

## ARTICLE SUMMARY

### Strengths and Limitations

- To improve the generalisability of the results we used a purposeful sampling for maximum variation, rather than a sample of convenience and we believe the participants in this study are broadly representative of children with severe trauma injuries and their families. [1]
- To our knowledge this is a first study to examine post-discharge needs for a broad range of injuries and ages from the perspectives of both the injured children and their parents.
- Age specific needs have previously been identified for adolescents. [2] Our initial intention was to explore age specific needs, but the data analysis showed that the identified needs were generic across all ages.
- However, more age-related needs may have been identified if there were greater numbers of participants across the different age ranges and interview probes placed more emphasis on issues relevant to age.

## INTRODUCTION

Injury is a leading cause of death and disability in children and young people, [3] which can affect quality of life and result in a significant burden of care over the child's life span. [4]

Centralised major trauma systems in England have successfully improved survival, [5] but rehabilitation has not matched the improvements in acute care. [6] Under the UK's major trauma system, an assessment of patients' need for rehabilitation should be completed in hospital and when appropriate at the point of discharge. [7] However, recovery and rehabilitation continue beyond the acute hospital admission and it is equally important to identify needs during the remainder of recovery. Furthermore, health and education services are generally aimed at children with development disabilities or long-term conditions rather than those acquired from an injury. [8] Children with newly acquired injuries are unlikely to have access to standardised pathways of care or long-term therapists who are well versed in their needs. In order to develop such services, it is critical to understand injured children's rehabilitation needs.

The literature on injured children's needs has focussed on specific types of injuries, primarily traumatic brain injuries; [2,9–15] the needs of parents or family members rather than the injured child, [11,13,15,16] or the specific needs of adolescents. [2,10] The aim of this study was therefore to explore the needs of injured children and their families for children of all ages and a broad range of injuries to obtain information to inform the delivery of patient-centred services.

## METHODS

### Study design and setting

1  
2  
3 This was a qualitative interview study conducted at two Children's Major Trauma Centres in  
4  
5  
6 England between March 2018 and August 2019. The study was approved by the National  
7  
8 Health Service, North West - Greater Manchester South Research Ethics Committee (REC  
9  
10 reference 17/NW/0615) and the Health Research Authority. The University of Manchester  
11  
12 was the study sponsor.  
13  
14

### 15 16 **Participants**

17  
18 Admission records were screened for 1) children aged 6-15 years admitted to a specialist  
19  
20 Major Trauma Centre with moderate to severe traumatic injury (Injury Severity Score>8) who  
21  
22 were discharged from the Centre within the previous 12 months. 2) Parents or guardians of  
23  
24 injured children who fulfilled the criteria. Parents of younger children aged two to 5 years at  
25  
26 the time of injury were also included. Participants were not included if they had been  
27  
28 discharged within the previous two weeks (as it was felt that they would have insufficient  
29  
30 experience of being home to fully contribute: Babies/infants (less than two years old),  
31  
32 children with isolated burn injuries (as they were managed in separate care pathway), non-  
33  
34 accidental injuries, or those for whom there were significant safeguarding concerns. A  
35  
36 purposeful approach to sampling was used to account for perspectives from a range of  
37  
38 injuries (in terms of severity and the types of injury), genders, ages and times since injury.  
39  
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### 46 **Data collection**

47  
48  
49 Potential participants were invited to take part by post or face-to-face contact with trauma  
50  
51 co-ordinator using age appropriate study information packs. Consent was obtained from the  
52  
53 parents and assent from the children before the interview started. All interviews were  
54  
55 conducted by SJ who is a clinical researcher/major trauma co-ordinator and has completed  
56  
57 training in interviewing children. A flexible interview format was used and participants were  
58  
59  
60



1  
2  
3 given the choice of conducting interviews; jointly (child and their parent/guardian together)  
4  
5 or separately, on the telephone or in person. A semi-structured topic guide was used to  
6  
7 explore the child's and when appropriate, parent's or family's needs. Interview questions  
8  
9 related to participants perceptions of the care and support they received after hospital  
10  
11 discharge. The semi-structured nature of the interviews allowed participants to explore other  
12  
13 topics which they considered relevant such as inpatient care. Interviews were digitally  
14  
15 recorded and transcribed verbatim. Data collection ceased once data saturation and  
16  
17 sufficient variation in the sample were attained.  
18  
19  
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### 23 **Analysis**

24  
25 The interviews were audio-recorded and the anonymised transcriptions were thematically  
26  
27 analysed using Excel and NVivo 11. [17] SJ became familiar with the data by re-reading  
28  
29 transcripts to identify and develop potential themes. Initial themes and sub-themes were  
30  
31 based on their relevance to the research question [18] and were refined through discussions  
32  
33 with the research team (SJ, ST, JY). SJ reviewed the full transcripts to identify quotes which  
34  
35 represented the existing themes and could be coded as such. A theoretical thematic analysis  
36  
37 was used in which the researcher used her knowledge and interest in the area to guide the  
38  
39 coding. This was most suitable approach because a specific research question had been  
40  
41 defined. [18] However, some quotes resulted in the development of emergent themes which  
42  
43 came solely from the data. An example of which was 'partnerships between professionals and  
44  
45 patients. The research team met regularly to discuss the interpretations, alternative  
46  
47 explanations for emergent findings and agree on the themes. Data within emergent findings  
48  
49 was reviewed to check the relevance to the research question and that there was sufficient  
50  
51 data to justify new themes.  
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## Patient and public involvement

The Women and Children's Patient and Public Involvement Team from Manchester Academic Health Science Centre provided feedback on the study documents (Patient information sheets, consent and assent forms).

## RESULTS

Twenty-six interviews were conducted involving 32 participants; 13 children and their parents/guardians (n=14) and five parents whose injured child did not participate. Interview duration ranged 11 to 76 minutes. The format for the interviews is summarised in Table 1 and the characteristics of injured children in Table 1.

Table 1 Interview structure

Interview format	Participants	Method	Number of participants
5 Parents only	5 mothers	3 Telephone 2 In person	5
5 Dyads (joint interviews with child & their parent/guardian)	5 children & their parents (4 mothers & 1 guardian)	All in person	10
7 Dyads (child & their parent interviewed separately)	7 children & their parents (7 mothers)	All in person	14
1 Triad (child interviewed separately, mother and father together)	1 child & their parents (1 mother & 1 father)	All in person	3
<b>Total number of participants</b>			<b>32</b>

Table 2 Characteristics of injured children (13 participants, 5 who did not participate but whose parents were interviewed)

<b>Characteristics</b>	
Gender	Male 11
	Female 7
Age at time of interview (years)	Range 5 to 15 (Median 12.0, IQR 2.8)
Injury mechanisms	4 Road traffic accidents
	3 Sport
	1 Fall >2 metres
	5 Fall <2 metres
	5 Other mechanism
Type of injury	1 Isolated head injury
	1 Isolated spinal injury
	3 Isolated abdominal injuries
	1 abdomen & chest
	6 Injuries to limb(s)
	6 Multiple injuries
Time since injury (months)	Range 1 to 12.5 (Median 8.5, IQR 9.3)

1  
2  
3 Most participants, particularly the children were unfamiliar with the concept of 'needs' as this  
4  
5 is an abstract concept coined by healthcare professionals, thus they seldom talked specifically  
6  
7 about their needs. However, needs were implicit in all participants' narratives about how their  
8  
9 healthcare was delivered, regardless of whether they were satisfied with their care or  
10  
11 whether their needs had been met. Each participant described their own unique experiences  
12  
13 and although these varied, they often pointed towards the same types of needs. The focus of  
14  
15 the interviews was after hospital discharge, but the researcher gave participants the flexibility  
16  
17 to discuss matters which were important to them including hospital care.  
18  
19  
20  
21

22 Four overarching themes emerged; Education and training needs, Information needs, Service  
23  
24 needs, and Positive partnerships between children, families and professionals.  
25  
26  
27

## 28 **1. Education and training needs**

### 29 **Education needs**

30  
31 Both injured children and their parents had to assimilate a large amount of information about  
32  
33 the accident and injury(ies). For most this was a completely unfamiliar situation and they  
34  
35 recognised that they had a lot to learn. Professionals needed to help by educating them about  
36  
37 their injury and how to manage it. Parents highlighted the need to be warned or advised about  
38  
39 the prognosis and forewarned about symptoms (such as pain, seizures, hallucinations,  
40  
41 difficulty concentrating, fatigue) which sometimes occurred unexpectedly. It was also  
42  
43 important to understand the reason why they occurred (Box 1: quote 1a, 1b, 1c).  
44  
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### 52 **Training needs**

53  
54 Participants identified that they needed training, particularly in preparation for hospital  
55  
56 discharge. This included issues such as how to look after wounds and scars; mobilise; and  
57  
58 return to activities and school. They needed opportunities to develop coping strategies and  
59  
60

to practice on-going care and treatments while in hospital to develop competence. This gave them confidence to execute these tasks at home. For more severely injured children this need went beyond merely practicing in the hospital environment. The opportunity to practice at home during weekend leave made the eventual return home more manageable (Box 1: quote 1d).

Box 1: Quotes regarding education and training needs

Sub-theme	Quote and participant
Education needs	<p>1a) <i>"...They did say to us that they would be... ..a miracle if they managed to save his eye. That was our worst-case scenario."</i> (Parent 11)</p> <p>1b) <i>"These sudden pains didn't start for a while after. I didn't know they were coming.....and then.....I felt like, "what's this? .....why is she getting these and is it.... fine that she should be exercising?"</i> (Parent 16)</p> <p>1c) <i>"if there would have been any side effects, or things, to look out for, you know?....like I suppose like you get on any medicine"</i> (Parent 26)</p>
Training needs	<p>1d) <i>"That really did help.....I just felt prepared then. It was like "right, we can do it at the hospital, we can do it at home."</i> (Parent 12)</p>

## 2. Information needs

### Information needs

Participants needed timely information to be provided in sufficient detail to understand *"what was going on"*. Delays in receiving information predominately related to administration (particularly referrals and transfer of health records), meetings and short notice of operation

1  
2  
3 cancellations. Several found the systems in place outdated (Box 2: quote 2a). The desired level  
4  
5 of detail varied, but all participants needed information to be clear and consistent. They often  
6  
7 explained how helpful they found well-executed explanations from professionals (Box 2:  
8  
9 quote 2b).

10  
11  
12  
13 Consistency of information was essential, but it was often conflicting. Participants attributed  
14  
15 this to the use of medical jargon in written and verbal reports, the number of professionals  
16  
17 involved in care and the different approaches between health professionals/hospitals (Box 2:  
18  
19 quote 2c). This conflicting information and advice caused “*tension*” and “*confusion*.”  
20  
21  
22 Participants reported that they were sometimes left not knowing what to expect or the best  
23  
24 way of managing the injuries. They recommended closer liaison between health  
25  
26 professionals.  
27  
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29

30  
31 Related to consistency of information, was participants’ need for up-to-date information.  
32  
33 They needed to be informed clearly and consistently about any changes in diagnosis,  
34  
35 prognosis, management plan or expected symptoms throughout all stages of their care.  
36  
37 Information was often considered insufficient. Gaps in information delivery were attributed  
38  
39 to health professionals not spending enough time with participants, not knowing specific facts  
40  
41 or presenting the information which they considered the most important. For example, one  
42  
43 family only became aware of the full details of their child’s head injury when they reviewed  
44  
45 the consent form for a procedure (Box 2: quote 2d).  
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### 51 **Effective communication and information sharing**

52  
53 Participants were asked about how information was provided for them, and what they  
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55 wanted and needed. Irrespective of the format, participants identified that information  
56  
57 needed to be available quickly and easily. Most parents considered written information to be  
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3 useful, particularly copies of clinic and referral letters and other relevant correspondence.  
4  
5 This enabled them to monitor progress of care and to play an active role in their child's care.  
6  
7 Written information was frequently needed to share information with other health  
8  
9 professionals and external agencies (such as schools) who often required "*a written letter*  
10  
11 *from doctor.*" Several found it difficult to absorb written information (such as leaflets and  
12  
13 booklets) given their emotional state, although several acknowledged these were valuable  
14  
15 "*to refer back to*". However, many parents preferred to liaise directly with health care  
16  
17 professionals in person or via texts, phone-calls and emails as their primary source of  
18  
19 communication and information (Box 2: quote 2e). Similarly, injured children preferred to ask  
20  
21 their parents questions rather than professionals. However open conversations with  
22  
23 professionals which included, and were directed towards the injured child were valued (Box  
24  
25 2: quote 2f). The use of visual aids, such as x-rays and scans also helped participants  
26  
27 understand the injury, particularly when there were no visible physical signs. One child used  
28  
29 his abdominal scan to help his peers understand the severity of his injury.  
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38 Dissatisfaction with information and communication arose when participants were  
39  
40 repeatedly asked the same questions by health professionals; when information was not  
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42 shared between health professionals, and when participants were not advised of the  
43  
44 outcomes of investigations or test results, or changes to care plans.  
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48

49 Box 2: Information needs  
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Sub-theme	Quote and participant
Information needs	2a) " <i>I don't understand why a hospital can't just get in the modern world and email people.....or phone them up and do a referral. Why they have to type and dictate a letter and it takes two weeks for it to get to the person they need it to get to.</i> " (Parent 7)

	<p>2b) <i>"they [the injuries] seemed quite complicated at first.....because there was a lot..... They listed them,....., so they laid it out clearly....., They just kind of explained each one to me.....And ...showed me some x-rays."</i> (Child 10).</p> <p>2c) <i>"I think the difficulty is in the hospital, there's loads of registrars doing ward rounds and stuff that don't have a consistent approach. So they... would come to you and tell you different things."</i> (Parent 8)</p> <p>2d) <i>"It said ... "fractured skull". We were like,..., "it's the first we've heard of it"..... So, that was kind of disappointing really, that we hadn't heard that."</i> (Parent 18)</p>
<p>Effective communication and information sharing</p>	<p>2e) <i>"We can just email at any stage if we've got any questions, which is fantastic. Anything I'm worried about, just email and they'll...respond straightaway."</i> (Parent 9)</p> <p>2f) <i>"I thought that was really good actually. A lot of the time they speak to [Injured child] rather than to me? Because he's the injured one and worrying."</i> (Parent 23)</p>

### 3. Service needs

Participants were clear about what they needed from services. They needed services to be accessible, timely, sufficient, structured and co-ordinated. Although many positive experiences and satisfaction were expressed, this was not universal. The types of difficulties outlined were not limited to one type of service: unmet needs for accessible services were described for most types of service.

#### Accessible and timely services



1  
2  
3 After hospital discharge, services needed to be provided locally or at the participants' homes,  
4 often 'out of hours' or with 'open appointments' to enable participants to obtain care or  
5 assessments when needed (Box 3: quote 3a). However, many factors made services difficult  
6 to access. Participants described lengthy or difficult journeys to their healthcare provider; a  
7 lack of 7-day services and strict eligibility criteria which excluded children (but with no  
8 specialist children's services were available), or children's services which excluded those with  
9 acquired problems in favour of children with chronic conditions (Box 3: quote 3b).  
10 Additionally, rigid protocols prevented access to services such as school transport and  
11 equipment. For example, one injured child could only receive one set of equipment although  
12 they lived in two homes as their parents were separated. Services could not accommodate  
13 this commonplace living arrangement and would only supply one set of equipment.  
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31 The timing of services was very important; participants often experienced long waiting lists  
32 for services to start (particularly therapy) and cancelled operations. They were concerned  
33 about the negative impacts this had on the injured child's physical and psychological recovery  
34 and well-being (Box 3: quote 3c). A couple of participants proposed that appointments could  
35 be quicker if telephone consultations were available, or if primary and secondary care services  
36 worked more closely together to prioritise injured children more appropriately (Child 21 and  
37 Parent 22).  
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### 49 **Dose and structure of treatment**

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51 Participants also needed services to provide sufficient treatment. Many described unmet  
52 needs relating to low staffing levels (particularly hospital nurses), lack of children's mental  
53 health services and insufficient doses of therapy, mostly physiotherapy (Box 3: quote 3d).  
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2  
3 have a greater scope of ambition for the injured child's recovery. Rehabilitation goals whether  
4 set with therapists or autonomously were considered essential to gauge improvement,  
5  
6 inspire motivation and provide a focus for the future (Box 3: quote 3e). However several  
7  
8 participants reported that therapy finished before the injured child had reached their goals  
9  
10 to return to physical education, competitive sport or other activities (i.e. they had not reached  
11  
12 their rehabilitation potential). In order to deal with these unmet rehabilitation needs,  
13  
14 participants devised their own exercise and rehabilitation regimes; requested physiotherapy  
15  
16 reviews or funded therapy privately. Participants needed rehabilitation to be clearly  
17  
18 structured because the injury(ies) disrupted their usual routines.  
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### 26 **Co-ordination of care**

27  
28 Care and rehabilitation of children with severe traumatic injuries often involves input from  
29  
30 multiple professionals and services over an extended period to manage complex, sometimes  
31  
32 sensitive problems. Participants very clearly articulated the need for this complex, multi-  
33  
34 agency, multi-faceted, often long-term care to be co-ordinated by a health care professional.  
35  
36 They highlighted the need for help to co-ordinate timely provision of appropriate equipment,  
37  
38 appointments (such as out-patient clinics), care packages and return to education (whether  
39  
40 school or home schooling) and other activities (Box 3: quote 3f).  
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46  
47 Co-ordinating on-going care after discharge, such as clinic appointments and referrals was a  
48  
49 particular issue for most participants, regardless of the severity of injury or the number of  
50  
51 specialist services involved. They valued help to ensure referrals and appointments were  
52  
53 made; attempts to streamline appointments to minimise the number of trips and disruption  
54  
55 to schooling and employment; prompt notification of appointments; timely reminders and  
56  
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1  
2  
3 help to re-arrange appointments if necessary. When this co-ordination was not available,  
4  
5 participants described unsatisfactory experiences (Box 3: quote 3g).  
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7

8  
9 Most participants acknowledged that they needed a named contact to be involved  
10  
11 throughout their hospital stay, through discharge and for on-going care. They needed to  
12  
13 provide the co-ordination described above, plus information, advice, on-going monitoring of  
14  
15 recovery and needs, reassurance and emotional support (Box 3: quotes 3h and 3i). This named  
16  
17 contact was often a trauma coordinator, but participants also found their GP a helpful point  
18  
19 of reference and a means of accessing other services. Part of the co-ordinators role also  
20  
21 needed to 'signpost' children (and their families) to access appropriate on-going care.  
22  
23 Participants reported how problems and symptoms, particularly post-traumatic distress and  
24  
25 mental health problems often only became apparent after hospital discharge. To address such  
26  
27 problems, participants needed to know what sources of help were available and how to  
28  
29 access them. They described how they needed *"to be put in touch with the right people"*.  
30  
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36  
37 This signposting role extended beyond health care services. There was a particular need to  
38  
39 co-ordinate multi-agency care (usually for the more severely injured children) as participants  
40  
41 did not have the knowledge, skills or experience to negotiate the highly complex and variable  
42  
43 systems, particularly when community or education services were involved. Many met and  
44  
45 unmet needs were highlighted regarding return to education (whether at school or at home)  
46  
47 after a traumatic injury and these are addressed in a separate publication.  
48  
49

50  
51 Box 3: Service needs, partnerships between patients and professionals  
52

Sub-theme	Quote and participant: Service needs
Accessible and timely services	3a) <i>"We had an open appointment arrangement with the physio, where we could ring up if there was a problem."</i> (Parent 6)

	<p>3b) <i>"They [district nurses]... told me that they don't deal with anybody under the age of eighteen."</i> (Parent 8)</p> <p>3c) <i>"We were thrown into two weeks of, is he having brain surgery, is he not? And it happened, you know, twice, two cancellations. And that is such a huge thing for your heart to cope with."</i> (Parent 18)</p>
Dose and structure of treatment	<p>3d) <i>"We could just see that it [physiotherapy] wasn't gonna be what [injured child] needed. She needed more..... she wasn't even gonna start for at least a couple of weeks"</i> (Parent 9).</p> <p>3e) <i>"That really helped. We set some [goals] in hospital, didn't we? Something to do in the future like....., what do you want to do for your birthday? So I was like, I'd always wanted to go, like, Harry Potter World or something."</i> (Child 21).</p>
Co-ordination of care	<p>3f) <i>"I don't think I could have coped, if I'd had to ring up all them people and sort all her [injured child's] care package out, I couldn't have coped."</i> (Parent 2)</p> <p>3g) <i>"well we've got his appointment through. As I say, we were expecting it. They said it would be within six weeks, but it's actually 13...it'll be 13 weeks since the accident."</i> (Parent 26)</p> <p>3h) <i>"When I rang the nurse though, they were really reassuring, and they sort of said "I don't think it's anything too much to worry about, but mention it to the neurosurgeons". So, it did allay my fears a bit."</i> (Parent 19)</p> <p>3i) <i>"he just reassured me a lot and answered a lot of questions that I had about going ...back to school and sorting things out"</i> (Child 21)</p>
<b>Main Theme</b>	<b>Quote and participant</b>

<p><b>Partnerships between patients and professionals</b></p>	<p>4a) <i>"They [hospital staff] kept us positive and...yeah, didn't make us feel that, God, this was, you know, absolutely disastrous, but she was gonna get better."</i> (Parent 9)</p> <p>4b) <i>"I think the fact it was a children's hospital and they knew exactly what they were doing... You feel confident."</i> (Parent 26)</p> <p>4c) <i>"Originally I couldn't even get [injured child] there [Psychology Department]. But the therapist from CAMHS built up such a good relationship."</i> (Parent 12)</p> <p>4d) <i>"we just discussed it as a whole family and [trauma co-ordinator] ...everything that was worrying [Injured Child]... . And then she just literally said "right. I can fix that, that, that, that and that, but I can't do this... but I know somebody who might be able to, so let me look into it, leave it with me."</i> (Parent 21)</p> <p>4e) <i>"They [the council] were supposed to provide some equipment for the bath. And it never materialised. They came out, they brought the wrong bath board. And then they said they'd come out again. But they didn't."</i> (Parent 12)</p>
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#### 4. Partnerships between patients and professionals

Participants explained how they needed positive, supportive, trusting partnerships with the professionals involved in their care. A positive outlook from professionals helped to boost morale and gave a sense of hope and helped the injured children and their families feel emotionally supported (Box 3: quote 4a). This also related to the need to be able trust the skills, competence and reliability of the professionals and organisations involved in the injured child's care, which gave them confidence and reassurance (Box 3: quote 4b). This trust was

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3 also needed to persuade the injured children to adhere to aspects of treatment which they  
4 disliked and enabled professionals and participants to work effectively together (Box 3: quote  
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6 4c). Several children disliked certain aspects of their treatment (e.g. wearing an eye patch or  
7  
8 orthotic devices) and were reluctant to adhere to them. To minimise this problem, children  
9  
10 and their families needed to “*feel heard*”, be involved in discussions and decisions about their  
11  
12 care, to jointly solve problems by exploring alternative treatment options and finding  
13  
14 mutually agreeable solutions or compromises (where possible) (Box 3 quote 4d). However not  
15  
16 all relationships between services and participants were positive. There were several reports  
17  
18 of inadequate, possibly incompetent care. Examples included incorrect application of  
19  
20 orthotics, medical errors, failure to adhere to major trauma pathways, referrals which were  
21  
22 not made, delayed appointments etc. In these cases, participants felt they had not been  
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24 listened to by health professionals, nor involved in discussions/decisions about their care.  
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26 Consequently, they could not rely on some aspects of service provision (Box 3 quote 4e).  
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## 35 **DISCUSSION**

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38 The results of this study showed that injured children and their families’ needs focus on  
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40 education and training; effective communication; access to services; support to co-ordinate  
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42 care; and positive partnerships with professionals.  
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47 Participants’ unmet need for clear, consistent and complete information across the full  
48  
49 recovery continuum echoes findings from previous studies. [11,12,19] However, participants  
50  
51 needs and preferences varied, so consideration was needed to individualise the information  
52  
53 and ensure it is available in a range of different formats, as well as ensuring the injured child  
54  
55 and other family members are included in honest and open discussions. Additionally, clearer  
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57 information to manage expectations may be required when details are unknown or subject  
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3 to change, particularly care plans.  
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5 Although written information was often useful, this needed to be conveyed quickly (by email  
6 or text for example) and act as a supplement to verbal communication.  
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11 Access to services was a frequent unmet need. Most participants described a “*post code*  
12 *lottery*” when it came to rehabilitation. This is a common problem, [11,14,20,21] particularly  
13 for services relating to cognitive or mental health difficulties. [9,14,21] The haphazard and  
14 inadequate nature of trauma rehabilitation services has been recognised previously, [6,22]  
15 particularly as most services focus on children with chronic conditions. Moreover services for  
16 adults and children are often inequitable, for example adult hip fracture care is provided  
17 according to national guidance and linked to the payment of a best practice tariff, but the  
18 equivalent systems are not in place for children’s femoral fractures. [23]  
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32 There is a clear need to develop comprehensive, streamlined rehabilitation services for  
33 children with acquired injuries, whose needs may (or may not) be temporary or change over  
34 time. This could be achieved by expanding the UK’s major trauma networks to include  
35 specialist community-based paediatric trauma rehabilitation, but this would require  
36 sustained funding and training. [24,25] Work is currently underway to address these issues.  
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44 In agreement with previous studies, there was an overwhelming need for a single-point of  
45 contact during and after hospital discharge. [2,11,21,26,27] This was needed to help patients’  
46 access professional support and to co-ordinate the multiple professions, specialities, agencies  
47 and organisations involved in their care. A single point of contact is required over the long-  
48 term because on-going problems are highly prevalent for several years after severe injury,  
49 [27,28] but may not become apparent until after the child has been discharged from hospital,  
50 and attempts to return to their normal life. [9,14] Current clinical guidelines state that every  
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3 patient with a moderate to severe injury should have their rehabilitation needs assessed [29]  
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5 within 48 to 72 hours of hospital admission, and at discharge from hospital (for those  
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7 previously recognised to have rehabilitation needs). [7] This is achieved through the  
8  
9 completion of a 'rehabilitation prescription'. Although this is a good starting point, the  
10  
11 rehabilitation prescription has limitations, not least because it does not detect or address  
12  
13 problems which develop after hospital discharge. A system is required which continues to  
14  
15 screen for (and then treat and monitor) problems after hospital discharge. This may be most  
16  
17 pragmatically addressed by a comprehensive needs assessment tool which can be completed  
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19 by the patient/family at regular intervals throughout the full trajectory of recovery. Work to  
20  
21 develop such a tool which is suitable for all ages of children, types of injury and stages of care  
22  
23 is underway. Furthermore, a named co-ordinator/key worker is needed to provide long-term  
24  
25 support and to co-ordinate care. This could contribute to the trusting positive partnerships  
26  
27 that participants emphatically needed for more patient-centred care and enabling joint  
28  
29 decision making. [30] A sense of hope was maintained through such partnerships and this is  
30  
31 recognised as important aspect of trauma care to support the emotional recovery. [12,31]  
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33 Although, some major trauma services provide this service, many only provided a specialist  
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35 co-ordinator for hospital-based care. [21] Further work to develop and evaluate such services  
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37 is clearly needed.  
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## 48 **CONCLUSION**

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50 Severely injured children and their families require services that provide education and  
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52 training; effective information and communication; access to timely, specialist services at  
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54 sufficient dose; co-ordination of support and on-going care, and positive relationships  
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56 between staff and patients.  
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2  
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27 Research or the Department of Health.  
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29

30  
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32  
33 additionally contributed to collecting and analysing the data, and is the guarantor of the  
34  
35 study. All authors contributed to initiating the study, monitoring progress, the interpretation  
36  
37 of data, substantially to drafting the article or revising it critically.  
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# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
<b>Title</b>		
	<a href="#">#1</a> Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	Title page

## Abstract

[#2](#) Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions

Abstract

## Introduction

Problem formulation [#3](#) Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

Page 4

Purpose or research question [#4](#) Purpose of the study and specific objectives or questions

Page 4

## Methods

Qualitative approach and research paradigm [#5](#) Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and

Page 5,6

1 transferability. As appropriate the rationale for several  
 2  
 3 items might be discussed together.  
 4

5			
6	Researcher	<a href="#">#6</a>	Researchers' characteristics that may influence the
7			
8	characteristics and		research, including personal attributes, qualifications /
9			
10	reflexivity		experience, relationship with participants, assumptions
11			
12			and / or presuppositions; potential or actual interaction
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14			between researchers' characteristics and the research
15			
16			questions, approach, methods, results and / or
17			
18			transferability
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21			
22	Context	<a href="#">#7</a>	Setting / site and salient contextual factors; rationale
23			
24			
25	Sampling strategy	<a href="#">#8</a>	How and why research participants, documents, or
26			
27			events were selected; criteria for deciding when no
28			
29			further sampling was necessary (e.g. sampling
30			
31			saturation); rationale
32			
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34			
35	Ethical issues pertaining	<a href="#">#9</a>	Documentation of approval by an appropriate ethics
36			
37	to human subjects		review board and participant consent, or explanation
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39			for lack thereof; other confidentiality and data security
40			
41			issues
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45	Data collection methods	<a href="#">#10</a>	Types of data collected; details of data collection
46			
47			procedures including (as appropriate) start and stop
48			
49			dates of data collection and analysis, iterative process,
50			
51			triangulation of sources / methods, and modification of
52			
53			procedures in response to evolving study findings;
54			
55			rationale
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1	Data collection	<a href="#">#11</a>	Description of instruments (e.g. interview guides,	Page 5,6
2			questionnaires) and devices (e.g. audio recorders)	
3	instruments and		used for data collection; if / how the instruments(s)	
4			changed over the course of the study	
5	technologies			
6				
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11	Units of study	<a href="#">#12</a>	Number and relevant characteristics of participants,	Page 7,8
12			documents, or events included in the study; level of	
13			participation (could be reported in results)	
14				
15				
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18				
19	Data processing	<a href="#">#13</a>	Methods for processing data prior to and during	Page 5,6
20			analysis, including transcription, data entry, data	
21			management and security, verification of data integrity,	
22			data coding, and anonymisation / deidentification of	
23			excerpts	
24				
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30				
31	Data analysis	<a href="#">#14</a>	Process by which inferences, themes, etc. were	Page 5,6
32			identified and developed, including the researchers	
33			involved in data analysis; usually references a specific	
34			paradigm or approach; rationale	
35				
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41	Techniques to enhance	<a href="#">#15</a>	Techniques to enhance trustworthiness and credibility	Page 5,6
42			of data analysis (e.g. member checking, audit trail,	
43	trustworthiness		triangulation); rationale	
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48	<b>Results/findings</b>			
49				
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51	Syntheses and	<a href="#">#16</a>	Main findings (e.g. interpretations, inferences, and	Pages 9
52			themes); might include development of a theory or	to 21
53	interpretation		model, or integration with prior research or theory	
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1	Links to empirical data	<a href="#">#17</a>	Evidence (e.g. quotes, field notes, text excerpts,	19,20,21
2			photographs) to substantiate analytic findings	
3				
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6	<b>Discussion</b>			
7				
8				
9				
10	Intergration with prior	<a href="#">#18</a>	Short summary of main findings; explanation of how	19,20,21
11	work, implications,		findings and conclusions connect to, support,	
12			elaborate on, or challenge conclusions of earlier	
13	transferability and		scholarship; discussion of scope of application /	
14			generalizability; identification of unique contributions(s)	
15	contribution(s) to the field		to scholarship in a discipline or field	
16				
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24	Limitations	<a href="#">#19</a>	Trustworthiness and limitations of findings	3
25				
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27	<b>Other</b>			
28				
29				
30	Conflicts of interest	<a href="#">#20</a>	Potential sources of influence of perceived influence	22
31			on study conduct and conclusions; how these were	
32			managed	
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38	Funding	<a href="#">#21</a>	Sources of funding and other support; role of funders	22
39			in data collection, interpretation and reporting	
40				
41				
42				

None The SRQR checklist is distributed with permission of Wolters Kluwer © 2014 by the Association of American Medical Colleges. This checklist can be completed online using <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)

# BMJ Open

## A qualitative study of the needs of injured children and their families after a child's traumatic injury

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<b>Primary Subject Heading</b>:	Rehabilitation medicine
Secondary Subject Heading:	Paediatrics
Keywords:	TRAUMA MANAGEMENT, REHABILITATION MEDICINE, PAEDIATRICS, QUALITATIVE RESEARCH

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1  
2  
3 **Title:** A qualitative study of the needs of injured children and their families after a child's  
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5  
6 traumatic injury.

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8  
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40 **WORD COUNT: 4647**

## ABSTRACT

**Objective:** To explore the needs of children and their families after a child's traumatic injury.

**Design:** Semi-structured qualitative interviews with purposeful sampling for different types of injuries and a theoretical thematic analysis.

**Participants:** 32 participants; 13 children living at home after a traumatic injury, their parents/guardians (n=14) and five parents whose injured child did not participate.

**Setting:** Two Children's Major Trauma Centres (hospitals) in England.

**Results:** Interviews were conducted a median 8.5 months (IQR 9.3) post injury. Injuries affected the limbs, head, chest, abdomen, spine or multiple body parts. Participants highlighted that throughout their recovery (during and after inpatient stay). Education and training were needed to help children and families understand and manage the injury, and prepare for discharge. Information delivery needed to be timely, clear, consistent and complete, include the injured child, but take into account individuals' capacity to absorb detail. Similarly, throughout recovery, services needed to be timely and easily accessible, with flexible protocols and eligibility criteria to include injured children. Treatment (particularly therapy) needed to be structured, goal-directed and of sufficient frequency to return injured children to their full function. A central point of contact is required after hospital discharge for advice, reassurance and to co-ordinate on-going care. Positive partnerships with professionals helped injured children and their families maintain a sense of hope and participate in joint decision-making about their care.

**Conclusion:** Throughout the full trajectory of recovery injured children and their families need patient-centred, accessible, flexible co-ordinated health services, with more effective

1  
2  
3 harmonious communication between professionals, the child and their family. There is a  
4  
5 requirement for support from a single point of contact and a system that monitors the needs  
6  
7 of the injured child and their family after hospital discharge.  
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9

## 10 11 **ARTICLE SUMMARY**

### 12 13 **Strengths and Limitations**

- 14  
15  
16 • To improve the generalisability of the results we used a purposeful sampling for  
17  
18 maximum variation, rather than a sample of convenience and we believe the  
19  
20 participants in this study are broadly representative of children with trauma injuries  
21  
22 and their families.  
23  
24
- 25  
26 • To our knowledge this is a first study to examine needs throughout recovery for a  
27  
28 range of different injuries and ages from the perspectives of both the injured children  
29  
30 and their parents.  
31  
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- 33  
34 • Different needs may have been identified if the interviews had involved more fathers  
35  
36 and/or greater numbers of participants across the different age ranges.  
37  
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- 39  
40 • Joint interview formats may have influenced or limited the scope of the topics  
41  
42 discussed by either the child or the parent, but a positive aspect of this format was  
43  
44 that parents were able to provide insightful prompts, beyond the scope of the  
45  
46 researcher.  
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- 49  
50 • Self-reported needs are subjective and have not been quantified with any objective  
51  
52 measurements.  
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## INTRODUCTION

Injury is a leading cause of death and disability in children and young people, [1] which can affect quality of life and result in a significant burden of care over the child's life span. [2]

Centralised major trauma systems have demonstrated improvements in survival from severe injury. [3] Despite the improvements in acute care, the rehabilitation which follows is an emerging priority for improvement. [4] There is a need to strengthen rehabilitation for trauma, as unmet rehabilitation needs represent a worldwide problem. [5]

It is important to improve children's care beyond the acute hospital admission to enable children to reach their full emotional, social, physical and vocational potential. [6] However, health and education services are generally aimed at children with development disabilities or long-term conditions rather than those acquired from an injury. [7] Children with newly acquired injuries are unlikely to have access to standardised pathways of care or long-term therapists who are well versed in their needs. The unique nature of each child's injury, situation and difficulties means that rehabilitation ought to be tailored to their specific needs. Thus, an effective starting point for rehabilitation is to understand the needs of the injured child and their family to enable an individualised approach to their care.

Previous research, including our work to review needs following childhood injury, [8] highlighted a range of needs; particularly support with psychosocial problems for injured child and their other family members, [8–16] as well as physical and practical problems, [13,17,18] support to facilitate the child's transitions from hospital to home, [19] and return to school. [20,21] The need for information about the injury and its management are reoccurring themes in trauma related research. [9,19,22–25] However, the current evidence base focusses on the needs of children with traumatic head injuries. [8,13,16,26] Children and

1  
2  
3 families with other types of injury have received little attention. Furthermore the research on  
4  
5 the needs of injured children after traumatic brain injury mainly considers the needs of  
6  
7 parents or family members rather than the injured child, [9,14,27,28] or the specific needs of  
8  
9 adolescents. [24,29] This study aims to address this gap in the evidence by exploring the needs  
10  
11 of injured children and their parents, including children of all ages (aged to 2 to 15 years),  
12  
13 with a range of different injuries affecting different body parts. This will help to inform the  
14  
15 delivery of patient-centred services.  
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## 20 21 **METHODS**

### 22 23 **Study design and setting**

24  
25 This was a qualitative interview study conducted at two Children's Major Trauma Centres in  
26  
27 England between March 2018 and August 2019. The study was approved by the National  
28  
29 Health Service, North West - Greater Manchester South Research Ethics Committee (REC  
30  
31 reference 17/NW/0615) and the Health Research Authority.  
32  
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35

### 36 37 **Participants**

38  
39 Major trauma co-ordinators in the participating centres screened admission records to  
40  
41 identify potential participants to take part in the study. To be included participants needed to  
42  
43 be:  
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- 46  
47 1) children aged six to 15 years admitted to a specialist Major Trauma Centre with  
48  
49 moderate to severe traumatic injury (Injury Severity Score>8) who were discharged  
50  
51 from the Centre within the previous 12 months.  
52  
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- 54  
55 2) Parents or guardians of injured children who fulfilled the criteria.  
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2  
3 3) Parents of younger children aged two to five years at the time of injury were also  
4  
5 included.  
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7

8  
9 The following exclusion criteria were applied:  
10

11  
12 1) Participants who had been discharged within the previous two weeks (as it was felt  
13  
14 that they would have insufficient experience of being home to fully contribute).  
15  
16

17  
18 2) Babies/infants (less than two years old).  
19

20  
21 3) Children with isolated burn injuries (as they were managed in separate care  
22  
23 pathway).  
24  
25

26  
27 4) Non-accidental injuries, or those for whom there were significant safeguarding  
28  
29 concerns.  
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31

32  
33 A purposeful approach to sampling was used to account for perspectives from a range of  
34  
35 injuries, genders, ages and times since injury.  
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37

### 38 **Data collection**

39  
40 Potential participants were invited to take part by using age appropriate study information  
41  
42 packs which were either posted or provided in person by a trauma co-ordinator. Consent was  
43  
44 obtained from the parents and assent from the children before the interview started. All  
45  
46 interviews were conducted by SJ who is a clinical researcher/major trauma co-ordinator and  
47  
48 has completed training in interviewing children. A flexible interview format was used and  
49  
50 participants could choose: who participated (joint child and parent, or solely the child or  
51  
52 parent), where the interview took place (home, hospital, neutral location) and how the  
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3 interview was conducted (telephone, face-to-face). However, for interviews involving  
4  
5 children a face-to-face format was recommended.  
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9 A semi-structured topic guide was used to explore the child's and when appropriate, parent's  
10  
11 or family's needs (Appendix 1). Questions were simplified to suit children of younger ages.  
12  
13 Interview questions related to participants' perceptions of the care and support they received  
14  
15 throughout recovery (during inpatient care and after hospital discharge), but the semi-  
16  
17 structured nature of the interviews allowed participants to explore other topics which they  
18  
19 considered relevant. Interviews were digitally recorded and transcribed verbatim.  
20  
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22

### 23 **Analysis**

24  
25 Anonymised transcriptions were thematically analysed using Excel and NVivo 11. A  
26  
27 theoretical thematic analysis was used to analyse the data, which was considered to be the  
28  
29 most suitable method of analysis as a specific research question had already been identified.  
30  
31 [30] When using a theoretical thematic approach, the analysis is driven by the researchers'  
32  
33 knowledge and experience in the field. The researcher had insights into the needs of injured  
34  
35 children and their families because of her clinical and research experience with this group and  
36  
37 topic. [8] This knowledge was used to develop a coding framework of some main themes.  
38  
39 Firstly, SJ became familiar with the data by re-reading the transcripts. She then coded the  
40  
41 data to categorise it within the existing coding framework or determine whether codes  
42  
43 pointed towards a new theme. The research team (SJ, ST, JY) met regularly to review the  
44  
45 coded data, verify its relevance to main themes and discuss the interpretations, alternative  
46  
47 explanations for emergent findings and agree on any new theme headings which were  
48  
49 required. Data were coded as interviews were conducted. Data collection ceased once data  
50  
51 saturation and sufficient variation in the sample were attained. Data saturation was deemed  
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3 as the point at which coded data from new interviews only added to existing themes and no  
4  
5 new themes were developed. Field notes were maintained for the interviews to contextualise  
6  
7 and reflect on the data, such as how forthcoming children were in the interviews. Any actions  
8  
9 required from the interviews were documented in the field notes.  
10  
11

### 12 **Patient and public involvement**

13  
14  
15 The Women and Children's Patient and Public Involvement Team from Manchester Academic  
16  
17 Health Science Centre provided feedback on the study documents (Patient information  
18  
19 sheets, consent and assent forms).  
20  
21

### 22 **RESULTS**

23  
24  
25 Twenty-six interviews were conducted involving 32 participants; 13 children and their  
26  
27 parents/guardians (n=14) and five parents whose injured child did not participate. One child  
28  
29 was too young to participate according to the study criteria, two children were not considered  
30  
31 to be at an appropriate point in their psychological recovery, one child did not wish to take  
32  
33 part and for one child it was logistically too difficult to arrange a face to face interview.  
34  
35

36  
37 Interview duration ranged 11 to 76 minutes. The format for the interviews is summarised in  
38  
39 Table 1 and the characteristics of injured children in Table 2. All the interviews conducted in  
40  
41 person took place in participants' homes, with the exception of two interviews which were  
42  
43 conducted at the hospital (one parent interview and one parent-child dyad interview).  
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Table 1 Interview structure

Interview format	Participants	Method	Number of participants
5 Parents only	5 mothers	3 Telephone 2 In person	5
5 Dyads (joint interviews with child & their parent/guardian)	5 children & their parents (4 mothers & 1 guardian)	All in person	10
7 Dyads (child & their parent interviewed separately)	7 children & their parents (7 mothers)	All in person	14
1 Triad (child interviewed separately, mother and father together)	1 child & their parents (1 mother & 1 father)	All in person	3
<b>Total number of participants</b>			<b>32</b>

Table 2 Characteristics of injured children (13 participants, 5 who did not participate but whose parents were interviewed)

Characteristics	
Gender	Male 11 Female 7
Age at time of interview (years)	Range 5 to 15 (Median 12.0, IQR 2.8)
Injury mechanisms	4 Road traffic accidents 3 Sport 1 Fall >2 metres 5 Fall <2 metres 5 Other mechanisms
Type of injury	1 Isolated head injury 1 Isolated spinal injury 3 Isolated abdominal injuries 1 abdomen & chest injuries 6 Injuries to limb(s) 6 Multiple injuries
Time since injury (months)	Range 1 to 12.5 (Median 8.5, IQR 9.3)

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2  
3 Most participants, particularly the children were unfamiliar with the concept of 'needs' as this  
4  
5 is an abstract concept coined by healthcare professionals, thus they seldom talked specifically  
6  
7 about their needs. However, needs were implicit in all participants' narratives about how their  
8  
9 healthcare was delivered, regardless of whether they were satisfied with their care or  
10  
11 whether their needs had been met. Participants described their own unique experiences and  
12  
13 although these varied, they often pointed towards the same types of needs. The focus of the  
14  
15 interviews was after hospital discharge, but the researcher gave participants the flexibility to  
16  
17 discuss matters which were important to them including hospital care. School-based service  
18  
19 needs were identified in the analysis, but have been addressed in a separate paper due to the  
20  
21 range and depth of information obtained relating to these needs. Parents and older children  
22  
23 were able to give the most information about their needs.  
24  
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28

29  
30 Four overarching themes emerged; Education and training needs, information needs, service  
31  
32 needs, and positive partnerships between children, families and professionals.  
33  
34

### 35 36 **Education and training needs**

#### 37 38 ***Education needs***

39  
40 Both injured children and their parents had to assimilate a large amount of information about  
41  
42 the accident and injury(ies). For most this was a completely unfamiliar situation and they  
43  
44 recognised that they had a lot to learn. Professionals needed to help by educating them about  
45  
46 their injury and how to manage it. Parents highlighted the need to be warned or advised about  
47  
48 the prognosis and forewarned about symptoms (such as pain, seizures, hallucinations,  
49  
50 difficulty concentrating, fatigue) which sometimes occurred unexpectedly. It was also  
51  
52 important to understand the reason why they occurred (Box 1: quote 1a, 1b, 1c).  
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#### 57 58 ***Training needs***

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3 Participants identified that they needed training, particularly in preparation for hospital  
4 discharge. This included issues such as how to look after wounds and scars, mobilise, and  
5  
6 return to activities and school. They needed opportunities to develop coping strategies and  
7  
8 to practice on-going care and treatments while in hospital to develop competence. This then  
9  
10 gave them confidence to execute these tasks at home. For more severely injured children this  
11  
12 need went beyond merely practicing in the hospital environment. The opportunity to practice  
13  
14 at home during weekend leave made the eventual return home more manageable (Box 1:  
15  
16 quote 1d).

### 22 **Information needs**

#### 23 ***Information needs***

24  
25 Participants needed timely information to be provided in sufficient detail to understand  
26  
27 *“what was going on”*. Delays in receiving information predominately related to administration  
28  
29 (particularly referrals and transfer of health records), meetings and short notice of operation  
30  
31 cancellations. Several found the systems in place outdated (Box 1: quote 1e). The desired level  
32  
33 of detail varied, but all participants needed information to be clear and consistent. They often  
34  
35 explained how helpful they found well-executed explanations from professionals (Box 1:  
36  
37 quote 1f).

38  
39 Consistency of information was essential, but it was often conflicting. Participants attributed  
40  
41 this to the use of medical jargon in written and verbal reports, the number of professionals  
42  
43 involved in care and the different approaches between health professionals/hospitals (Box 1:  
44  
45 quote 1g). This conflicting information and advice caused *“tension”* and *“confusion.”*  
46  
47  
48 Participants reported that they were sometimes left not knowing what to expect or the best  
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3 way of managing the injuries. They recommended closer liaison between health  
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5 professionals.  
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9 Related to consistency of information, was participants' need for up-to-date information.  
10  
11 They needed to be informed clearly and consistently about any changes in diagnosis,  
12  
13 prognosis, management plan or expected symptoms throughout all stages of their care.  
14  
15 Information was often considered insufficient. Gaps in information delivery were attributed  
16  
17 to health professionals not spending enough time with participants, not knowing specific facts  
18  
19 or presenting the information which they considered the most important. For example, one  
20  
21 family only became aware of the full details of their child's head injury when they reviewed  
22  
23 the consent form for a procedure (Box 1: quote 1h).  
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### 29 ***Effective communication and information sharing***

30  
31 Participants were asked about how information was provided and what they wanted and  
32  
33 needed. Irrespective of the format, participants identified that information needed to be  
34  
35 available quickly and easily. Most parents considered written information to be useful,  
36  
37 particularly copies of clinic and referral letters and other relevant correspondence. This  
38  
39 enabled them to monitor progress of care and to play an active role in their child's care.  
40  
41 Written information was frequently needed to share information with other health  
42  
43 professionals and external agencies (such as schools) who often required "*a written letter*  
44  
45 *from a doctor.*" Several found it difficult to absorb written information (such as leaflets and  
46  
47 booklets) given their emotional state, although several acknowledged these were valuable  
48  
49 "*to refer back to*". However, many parents preferred to liaise directly with health care  
50  
51 professionals in person or via texts, phone-calls and emails as their primary source of  
52  
53 communication and information (Box 1: quote 1i). Similarly, injured children preferred to ask  
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3 their parents questions rather than professionals. However, open conversations with  
4  
5 professionals which included and were directed towards the injured child were valued (Box  
6  
7 1: quote 1j). The use of visual aids, such as x-rays and scans also helped participants  
8  
9 understand the injury, particularly when there were no visible physical signs. One child used  
10  
11 his abdominal scan to help his peers understand the severity of his injury.  
12  
13

14  
15  
16 Dissatisfaction with information and communication arose when participants were  
17  
18 repeatedly asked the same questions by health professionals; when information was not  
19  
20 shared between health professionals, and when participants were not advised of the  
21  
22 outcomes of investigations or test results, or changes to care plans.  
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## Box 1: Education, training and information needs

Themes	Quote and participant
Education and training needs	<p>1a) <i>"...They did say to us that they would be... ..a miracle if they managed to save his eye. That was our worst-case scenario."</i> (Parent 11)</p> <p>1b) <i>"These sudden pains didn't start for a while after. I didn't know they were coming.....and then.....I felt like, "what's this? .....why is she getting these and is it.... fine that she should be exercising?"</i> (Parent 16)</p> <p>1c) <i>"if there would have been any side effects, or things, to look out for, you know?....like I suppose like you get on any medicine"</i> (Parent 26)</p> <p>1d) <i>"That really did help.....I just felt prepared then. It was like "right, we can do it at the hospital, we can do it at home."</i> (Parent 12)</p>
Information needs	<p>1e) <i>"I don't understand why a hospital can't just get in the modern world and email people.....or phone them up and do a referral. Why they have to type and dictate a letter and it takes two weeks for it to get to the person they need it to get to."</i> (Parent 7)</p> <p>1f) <i>"they [the injuries] seemed quite complicated at first.....because there was a lot..... They listed them,....., so they laid it out clearly....., They just kind of explained each one to me.....And ...showed me some x-rays."</i> (Child 10).</p> <p>1g) <i>"I think the difficulty is in the hospital, there's loads of registrars doing ward rounds and stuff that don't have a consistent approach. So they... would come to you and tell you different things."</i> (Parent 8)</p> <p>1h) <i>"It said ... "fractured skull". We were like,..., "it's the first we've heard of it"..... So, that was kind of disappointing really, that we hadn't heard that."</i> (Parent 18)</p>
Information needs: effective communication and information sharing	<p>1i) <i>"We can just email at any stage if we've got any questions, which is fantastic. Anything I'm worried about, just email and they'll...respond straightaway."</i> (Parent 9)</p> <p>1j) <i>"I thought that was really good actually. A lot of the time they speak to [Injured child] rather than to me? Because he's the injured one and worrying."</i> (Parent 23)</p>

### **Service needs**

Participants were clear about what they needed from services throughout their recovery. Whether inpatient or community based, they needed services to be accessible, timely, sufficient, structured and co-ordinated. Although many participants expressed positive experiences and satisfaction, this was not universal. The types of difficulties outlined were not limited to one type of service: unmet needs for accessible services were described for most types of community-based services.

### ***Accessible and timely services***

After hospital discharge, services needed to be provided locally or at the participants' homes, often 'out of hours' or with 'open appointments' to enable participants to obtain care or assessments when needed (Box 2: quote 2a). However, many factors made services difficult to access after hospital discharge. Participants described lengthy or difficult journeys to their healthcare provider and strict eligibility criteria which excluded children. (Box 2: quote 2b). Additionally, rigid protocols prevented access to services such as school transport and equipment. For example, one injured child lived in two homes as their parents were separated, but services could not accommodate this commonplace living arrangement and would only supply one set of equipment.

In order to be accessible, some services needed to be made available to family members as well as the injured child. Post-traumatic stress type symptoms and/or mental health issues were often experienced in injured child and their family members, including parents, grandparents and siblings (participants' experiences are reported in detail elsewhere). Although the hospital offered psychological support to the whole family, this holistic approach was more difficult to access in the community after hospital discharge (Box 2: quote

1  
2  
3 2c). However, several participants did not take up psychological support during inpatient stay,  
4  
5 as difficulties often only became apparent after discharge when participants tried to return  
6  
7 to 'normal 'life'.  
8  
9

10  
11 The timing of services was very important; participants often experienced long delays for  
12  
13 services to start (particularly community therapy) and cancelled operations. Such delays were  
14  
15 difficult for families (Box 2: quote 2d). A couple of participants proposed that appointments  
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17 could be quicker if telephone consultations were available after discharge, or if primary and  
18  
19 secondary care services worked more closely together to prioritise injured children more  
20  
21 appropriately (Child 21 and Parent 22).  
22  
23  
24

### 25 26 27 ***Dose and structure of treatment***

28  
29 Whether during inpatient or community-based care, participants needed services to provide  
30  
31 sufficient treatment throughout the continuum of recovery. In the hospital, a lack of nursing  
32  
33 staff was highlighted as a key issue. However, there was a notable discrepancy between  
34  
35 satisfaction with mental health and therapy services in the hospital and community setting,  
36  
37 with such services generally regarded as comprehensive in the hospital, but lacking in the  
38  
39 community. After discharge from hospital, participants described a lack of children's mental  
40  
41 health services or professionals who deliver specific psychotherapy treatments for children.  
42  
43 Similarly, in contrast to the hospital, community-based therapy was often regarded as  
44  
45 insufficient (Box 2: quote 2e). Another issue was that treatment in the community (often  
46  
47 physiotherapy or occupational therapy) needed to have a greater scope of ambition for the  
48  
49 injured child's recovery. Rehabilitation goals, whether set with therapists or autonomously  
50  
51 were considered essential to gauge improvement, inspire motivation and provide a focus for  
52  
53 the future (Box 2: quote 2f). Several participants reported that community therapy finished  
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3 before the injured child had reached their goals to return to physical education, competitive  
4 sport or other activities (i.e. they had not reached their rehabilitation potential). In order to  
5  
6 deal with these unmet rehabilitation needs, participants devised their own exercise and  
7  
8 rehabilitation regimes; requested physiotherapy reviews or funded therapy privately.  
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10  
11 Participants also needed rehabilitation to be clearly structured because the injury(ies)  
12  
13 disrupted their usual routines.  
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### 17 18 ***Co-ordination of care and ongoing support*** 19

20  
21 Care and rehabilitation of children with traumatic injuries often involved input from multiple  
22  
23 professionals and services over an extended period to manage complex, sometimes sensitive  
24  
25 problems. Participants very clearly articulated the need for this complex, multi-agency, multi-  
26  
27 faceted, often long-term care to be co-ordinated by a health care professional. They  
28  
29 highlighted the need for help to co-ordinate timely provision of appropriate equipment,  
30  
31 appointments, care packages and return to education (whether this be school or home  
32  
33 schooling) and other activities (Box 2: quote 2g).  
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38  
39 Co-ordinating on-going care after discharge, such as clinic appointments and referrals were a  
40  
41 particular issue for most participants, regardless of the severity or complexity of the injury or  
42  
43 the number of specialist services involved. They valued: help to ensure referrals and  
44  
45 appointments were made, attempts to streamline appointments to minimise the number of  
46  
47 trips and disruption to schooling and employment, prompt notification of appointments,  
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49 timely reminders and help to re-arrange appointments if necessary. When this co-ordination  
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51 was not available, participants described unsatisfactory experiences (Box 2: quote 2h).  
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57 Most participants acknowledged that they needed a named contact to be involved  
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59 throughout their hospital stay, through discharge and for on-going care. This professional  
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3 needed to provide the co-ordination described above, plus on-going monitoring of recovery  
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5 and needs, reassurance, emotional support and continued advice especially about new  
6  
7 symptoms. (Box 2: quotes 2i and 2j). Where available this named contact was often a trauma  
8  
9 co-ordinator, but participants also found their general practitioner a helpful point of  
10  
11 reference and a means of accessing other services. Part of the co-ordinator's role also needed  
12  
13 to 'signpost' children (and their families) to access appropriate on-going care. Participants  
14  
15 reported how problems and symptoms, particularly post-traumatic distress and mental  
16  
17 health problems often only became apparent after hospital discharge. To address such new  
18  
19 problems, participants needed to know what sources of help were available and how to  
20  
21 access them. They described how they needed "*to be put in touch with the right people*". This  
22  
23 signposting role extended beyond health care services.  
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30  
31 There was a particular need to co-ordinate multi-agency care (usually for the more severely  
32  
33 injured children) as participants did not have the knowledge, skills or experience to negotiate  
34  
35 the highly complex and variable systems, particularly when community or education services  
36  
37 were involved. Many met and unmet needs were highlighted regarding return to education  
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39 (whether at school or at home) after a traumatic injury and these are addressed in a separate  
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41 publication.  
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## Box 2: Service needs

Themes	Quote and participant: Service needs
Service needs: Accessible and timely services	<p>2a) <i>"We had an open appointment arrangement with the physio, where we could ring up if there was a problem."</i> (Parent 6)</p> <p>2b) <i>"They [district nurses]... told me that they don't deal with anybody under the age of eighteen."</i> (Parent 8)</p> <p>2c) <i>"I think we were offered everything we.... could have been. I think getting counselling for me mum [child's grandparent] was a bit harder...." [referring to experience after hospital]</i></p> <p>2d) <i>"We were thrown into two weeks of, is he having brain surgery, is he not? And it happened, you know, twice, two cancellations. And that is such a huge thing for your heart to cope with."</i> (Parent 18)</p>
Service needs: Dose and structure of treatment	<p>2e) <i>"We could just see that it [physiotherapy] wasn't gonna be what [injured child] needed. She needed more..... she wasn't even gonna start for at least a couple of weeks"</i> (Parent 9).</p> <p>2f) <i>"That really helped. We set some [goals] in hospital, didn't we? Something to do in the future like....., what do you want to do for your birthday? So I was like, I'd always wanted to go, like, Harry Potter World or something."</i> (Child 21).</p>
Service needs: Co-ordination of care	<p>2g) <i>"I don't think I could have coped, if I'd had to ring up all them people and sort all her [injured child's] care package out, I couldn't have coped."</i> (Parent 2)</p> <p>2h) <i>"well we've got his appointment through. As I say, we were expecting it. They said it would be within six weeks, but it's actually 13...it'll be 13 weeks since the accident."</i> (Parent 26)</p> <p>2i) <i>"When I rang the nurse though, they were really reassuring, and they sort of said "I don't think it's anything too much to worry about, but mention it to the neurosurgeons". So, it did allay my fears a bit."</i> (Parent 19)</p> <p>2j) <i>"he just reassured me a lot and answered a lot of questions that I had about going ...back to school and sorting things out"</i> (Child 21)</p>

### Partnerships between patients and professionals

Participants explained how they needed positive, supportive, trusting partnerships with the professionals involved in their care. A positive outlook from professionals helped to boost morale and gave a sense of hope and helped the injured children and their families feel emotionally supported (Box 3: quote 3a). This also related to the need to be able trust the skills, competence and reliability of the professionals and organisations involved in the injured child's care, which gave them confidence and reassurance (Box 3: quote 3b and 3c). This trust was also needed to persuade the injured children to adhere to aspects of treatment which they disliked and enabled professionals and participants to work effectively together (Box 3: quote 3d). Several children disliked certain aspects of their treatment (e.g. wearing an eye patch or orthotic devices) and were reluctant to adhere to them. To minimise this problem, children and their families needed to "feel heard", be involved in discussions and decisions about their care, to jointly solve problems by exploring alternative treatment options and finding mutually agreeable solutions or compromises (where possible) (Box 3 quote 3e). However, not all relationships between services and participants were positive. There were several reports of perceived problems with care. Examples included the incorrect application of orthotics, medication error, issues with adherence to major trauma pathways, referrals which were not made, delayed appointments, etc. In these cases, participants felt they had not been listened to by health professionals, nor involved in discussions/decisions about their care. Consequently, they could not rely on some aspects of service provision (Box 3 quote 3f).

## Box 3: partnerships between patients and professionals

Themes	Quote and participant
Partnerships between patients and professionals	<p>3a) <i>"They [hospital staff] kept us positive and...yeah, didn't make us feel that, God, this was, you know, absolutely disastrous, but she was gonna get better."</i> (Parent 9)</p> <p>3b) <i>"I think the fact it was a children's hospital and they knew exactly what they were doing... You feel confident."</i> (Parent 26)</p> <p>3c) <i>"you know, the people who do these types of operations, they're good at their job"</i> (Child 17)</p> <p>3d) <i>"Originally I couldn't even get [injured child] there [Psychology Department]. But the therapist from CAMHS built up such a good relationship."</i> (Parent 12)</p> <p>3e) <i>"we just discussed it as a whole family and [trauma co-ordinator] ...everything that was worrying [Injured Child]... . And then she just literally said "right. I can fix that, that, that, that and that, but I can't do this... but I know somebody who might be able to, so let me look into it, leave it with me."</i> (Parent 21)</p> <p>3f) <i>"They [the council] were supposed to provide some equipment for the bath. And it never materialised. They came out, they brought the wrong bath board. And then they said they'd come out again. But they didn't."</i> (Parent 12)</p>



## DISCUSSION

The results of this study showed that injured children and their families' needs focus on education and training to help understand the injury and how to manage it, effective communication, access to sufficient services, support to co-ordinate care and positive partnerships with professionals.

Participants' unmet need for clear, consistent and complete information across the full recovery continuum echoes findings from previous studies [9,13,23] and is attributed to the range of professionals often involved in trauma care. [23] However, participants' needs and preferences varied, so consideration should be given to individualising the information and ensuring it is available in a range of different formats, as well as ensuring the injured child and other family members are included in honest and open discussions. Additionally, clearer information to manage expectations may be required when details are unknown or subject to change, [9] particularly care plans. Although written information was often useful, this needed to be conveyed quickly (by email or text for example) and act as a supplement to verbal communication. Electronic patient held records or portals have been shown to enhance information and communication exchange, [31,32] and may help to fulfil children's and family's needs for more immediate, accessible and consistent information.

Access to services was a frequent unmet need, which was most pronounced in the community setting. It is unsurprising that most participants described a "post code lottery" when it came to rehabilitation in the community setting. All the participants included in this study had been managed in specialist children's Major Trauma Centres. The resources, standards and clinical governance processes present in these centres only cover hospital-based care [4] and do not extend to the community setting, where there are few services specifically for injured

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2  
3 children. Similarly, disparities in access to post-discharge rehabilitation for childhood  
4 traumatic injury have been reported in the United States. [6] Further research is required to  
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6 better understand how injured children's community-based rehabilitation can be provided  
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8 efficiently and effectively.  
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13 Inadequate service provision has been reported previously, [7,9,16,33] particularly for  
14 services relating to cognitive or mental health difficulties. [12,16,33,34] The current study  
15  
16 reinforces this by highlighting that although psychological support during the inpatient stay  
17  
18 was comprehensive, it was lacking after discharge, which is when difficulties often emerged.  
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20 Psychological support services needed to extend throughout the full recovery trajectory and  
21  
22 cater for the needs of the whole family unit. To achieve this, the capacity of children's  
23  
24 community mental health services needs to expand by training more professionals, [35] and  
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26 educating both parents [36] and professionals [10] about how to detect signs of post-  
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28 traumatic stress, particularly as symptoms can present late in recovery. [15,37] In contrast to  
29  
30 previous research, our participants placed more importance on the need for physical and  
31  
32 practical support. This may reflect the variety of injuries included in our sample, rather than  
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34 being limited to head injuries.  
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44 There is a clear need to develop comprehensive, streamlined rehabilitation services for  
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46 children with acquired injuries, whose needs may be temporary or change over time.  
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48 Expansion of the Major Trauma Networks to include all facets of rehabilitation for all ages  
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50 could provide this support, but this would require sustained funding and training. Like  
51  
52 previous studies, we found an overwhelming need for a single-point of contact during and  
53  
54 after hospital discharge [9,29,33,38,39] to help patients access professional support and to  
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56 co-ordinate the multiple professions, specialities, agencies and organisations involved in their  
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3 care. Co-ordinators could work in conjunction with rehabilitation medicine consultants, [40]  
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5 who would lead clinical decision making. This approach may achieve more streamlined  
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7 rehabilitation and consistent communication. Some major trauma services provide a  
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9 specialist co-ordinator, but this is often limited to hospital-based care. [33] However, support  
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11 may be required over the long-term as on-going problems are highly prevalent for several  
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13 years after severe injury, [39,41] but may not become apparent until after the child has been  
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15 discharged from hospital and attempts to return to their normal life. [12,16] Ongoing support  
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17 may contribute to trusting, positive partnerships that participants emphatically needed for  
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19 more patient-centred care and to enable joint decision making. [42] In this study and previous  
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21 research an important role of a known contact is to provide reassurance and maintain a sense  
22  
23 of hope. [13–15,19,36,43] An important aspect of trauma care is to support the emotional  
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25 recovery [43] of the child and their parents. [36]

26  
27 A system is required that continues to screen for (and then treat and monitor) problems after  
28  
29 hospital discharge. This may be most pragmatically addressed by a comprehensive needs  
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31 assessment tool which can be completed by the child/family at regular intervals throughout  
32  
33 the full recovery. Work is underway to develop such a tool that is suitable for all ages of  
34  
35 children, types of injury and stages of care.

### 36 37 38 39 40 41 42 43 44 **Strengths and Limitations**

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46 A common criticism of qualitative research is the limited generalisability of the results. [44]  
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48 To address this, we used a purposeful sampling for maximum variation, rather than a sample  
49  
50 of convenience and we believe the participants in this study are broadly representative of  
51  
52 children with a range of traumatic injuries. [45] To our knowledge this is a first study to  
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54 examine needs throughout recovery for a broad range of injuries and ages from the  
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56 perspectives of both the injured children and their parents. However, the purposeful  
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3 approach to sampling did not encompass attaining equal numbers of mothers and fathers.  
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5 The majority of mothers who took part was an unexpected finding, which may have  
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7 influenced the range of needs and experiences reported. Previous qualitative studies have  
8  
9 shown a difference in themes identified for males and females. [46]  
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12  
13 Due to involvement of children and sensitive nature of the interview topic (childhood injury)  
14  
15 it was important to give participants the opportunity to take part in the interviews in the way  
16  
17 that they felt most comfortable. We acknowledge that joint interview formats may have  
18  
19 influenced or limited the scope of the topics discussed by either the child or the parent. [47]  
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21  
22 One positive aspect of joint interviews was that parents were able to provide insightful  
23  
24 prompts, beyond the scope of the researcher.  
25  
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28 Age specific needs have previously been identified for adolescents. [29] Our initial intention  
29  
30 was to explore age specific needs, but the data analysis showed that the identified needs were  
31  
32 generic across the ages investigated. More age-related needs may have been identified if  
33  
34 there were greater numbers of participants across the different age ranges and interview  
35  
36 probes placed more emphasis on issues relevant to age.  
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40 We acknowledge that self-reported needs are subjective and have not been quantified with  
41  
42 any objective measurements. Self-reported, subjective data can be influenced by different  
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44 forms of bias, [48,49] including social desirability bias. [49] For example, social desirability  
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46 bias may have occurred because participants wanted to appear to be coping and thus may  
47  
48 have under reported their level of need.  
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## 51 52 **CONCLUSION**

53  
54 This research has helped to identify unmet healthcare needs of a new target population.  
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56 Children with a range of injuries and their families need patient-centred, accessible, flexible  
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58 co-ordinated health services throughout the full trajectory of recovery, with more effective  
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3 harmonious communication between professionals, the child and their family. Trauma  
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5 rehabilitation should be provided as a continuum of care, part of which should involve the  
6  
7 ongoing monitoring of the injured child's and family's needs. Services between hospital and  
8  
9 community setting need to be more seamless and equitable. This may be achieved by  
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11 attaining evidence such as that presented here, about needs through the full trajectory of  
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13 recovery, which can then be used to inform policy and commissioning.  
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38 the interpretation of the data.  
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#### 48 **Data Sharing statement**

49  
50 All data relevant to the study are included in the article or uploaded as supplementary  
51 material.  
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## APPENDIX 1

	<b>Guide to Questions</b>
<b>Generic needs</b>	<p>Tell me about what was different for <b>you/ you and your child</b> following your injury?</p> <p>What help did <b>you/your child</b> need after your injury?</p>
<b>Discharge specific needs</b>	<p>What was it like for <b>you/ you and your child</b> when you went home from the hospital?</p> <p>When <b>you/your child</b> went home from the hospital how did you feel?</p> <p>Did you feel <b>you/you and your child</b> prepared to go home?</p> <p>Was there anything that worried <b>you/ you and your child</b> about going home?</p> <p>Did <b>you/you and your child</b> need any support/help from hospital staff/health professionals when you went home from the hospital?</p> <p>Did you feel that you got the help <b>you/you and your child</b> needed?</p> <p>Did <b>you/your child</b> have any difficulties when you went home from the hospital?</p> <p>Was there anything that really helped or made things easier when <b>you/your child</b> went home?</p> <p><b>Probes:</b> Equipment, modifications to home, home visits, advice leaflets, meetings before discharge, follow up appointments, phone calls from the hospital.</p>
<b>Key Worker</b>	<p>Did <b>you/your child</b> have a key worker (a health professional/nurse/physio/occupational-therapist/carer/doctor) who provided help or advice when you went home from the hospital?</p> <p><b>If answers yes:</b> Did you find this helpful? Why was this helpful? What did the key worker do for you?</p> <p><b>If answers no:</b> Do you think that a key worker would have been helpful?</p> <p>What help/support could have they provided?</p>
<b>Information needs</b>	<p>Was <b>your/your child's</b> injury explained to you in the hospital?</p> <p>Did you understand the explanation of <b>your/your child's injury</b>?</p> <p>Did you understand how the injury would affect <b>you/your child</b>?</p>

	<p>Were you provided with advice about <b>what you/your child</b> was allowed and not allowed to do following <b>your/your child's injury</b>? Was this easy to understand?</p> <p>Did you receive any advice or information when you were discharged from the hospital? Probe: information booklet, helplines, follow up appointments/ follow up phone calls.</p> <p><b>If answers yes:</b> Was the information helpful/how? Were you given enough information? Was it easy to understand? Who gave you the information?</p> <p><b>If answers no:</b> Was there you wanted to know when you went home from the hospital, which you were not told? Was there anything you had to find out for yourself?</p>
<p><b>Educational needs</b></p>	<p>How did <b>you/your child</b> deal with returning to school after their injury?</p> <p>Did <b>you/your child</b> have any difficulties returning to school?</p> <p>Did <b>your/your child's teachers</b> know that you/your child had suffered from an injury?</p> <p><b>Probes:</b> Did they understand the injury/do anything differently?</p> <p>Was there anything that really helped <b>you/your child</b> when you returned to school?</p> <p>Were there any changes made or advice which made <b>your/your child's</b> return to school easier?</p>
<p><b>Social needs</b></p>	<p>Did <b>your</b> friends/family know about <b>your/your child's</b> injury?</p> <p>Do you think they understood what had happened to <b>you/your child</b>?</p> <p>Were <b>your friendships</b> different in any way following <b>your/your child's</b> injury?</p> <p>Did your friends and family help <b>you/your child after your child's injury</b>?</p> <p>Did <b>your/your child's</b> hobbies/play/sporting activities change following your injury?</p>
<p><b>Physical</b></p>	<p>Did <b>you/your child</b> have any physical problems following the injury? (Probes: will depend on the age of child: difficulties walking, talking, crawling, eating, speaking hearing, toileting, returning to their usual activities)</p>

	<p>Did <b>you/your child</b> need crutches/walking frame/wheel chair after your injury?</p> <p>Did <b>you/your child</b> have any treatment from therapists /health professionals to help with the physical problems after the injury? Therapists and Health Professionals are: physiotherapists/occupational therapists/dieticians/speech therapists/nurses/doctors.</p> <p>Did you need additional care/help at home? Probe: adaptations to the home, downstairs living.</p> <p>Was there any change to <b>your/your child's</b> appearance after their injury? <b>Probes:</b> scars, cuts &amp; bruises, weight gain or loss, items your child had to wear: supports, casts, brace, breathing pipe.</p>
<b>Psychological</b>	<p>Were <b>you or your child</b> scared or worried after <b>your/your child's injury</b>?</p> <p>Did <b>you or your child</b> have any problems sleeping following their injury?</p> <p>Did <b>your child's/your behaviour</b> change following the injury?</p>
<b>Emotional needs</b>	<p>How did you feel after <b>your/your child's injury</b>?</p> <p>Did <b>your/your child's</b> injury affect you emotionally?</p> <p>Did you receive any emotional support from staff at the hospital or people in your local community?</p> <p><b>Probes:</b> worried, concerns for the future, upset, scared.</p>
<b>Family/work needs?</b>	<p>Did <b>your/your child's</b> injury affect the family or family life? <b>Probes:</b></p> <ul style="list-style-type: none"> <li>• Was there any change to the daily routine?</li> <li>• Was there any change to roles/responsibilities within the family?</li> <li>• Do you have other children? Was it difficult to look after them at the time of your child's injury?</li> <li>• Were you working at the time of your child's injury? Did their injury affect work in any way?</li> <li>• Was your place of employment supportive after your child's injury?</li> <li>• Did you need any support to look after your child ?</li> </ul>
<b>Current situation</b>	<p>What are things like for <b>you/your child now</b>?</p> <p>Are you receiving help from either the hospital or your community services?</p>

	<p>Have you/ your child regained their previous level of activities at home? And at school?</p>
<b>Unmet needs/met needs</b>	<p>Looking back over the time since the injury, is there anything that could have been done differently to help <b>your/your child's</b> recovery?</p> <p>With hindsight were there any services which you did not receive which you think would have helped you and your child/you?</p> <p>What really helped you after your injury/ you and your child after your child's injury. Probes: Advice/information/people (health professionals/family, friends/people in the community), equipment, support groups, follow ups.</p>
<b>Closing</b>	<p>Thank you for much for talking to me today. Do you have any questions or is there anything else you would like to tell me which we haven't covered?</p>

# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

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The page numbers refer to the unmarked copy.

	Reporting Item	Page Number
<b>Title</b>	<a href="#">#1</a> Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or	Title page

1 data collection methods (e.g. interview, focus group) is  
 2 recommended  
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## 5 Abstract

6  
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 9 [#2](#) Summary of the key elements of the study using the Abstract  
 10 abstract format of the intended publication; typically  
 11 includes background, purpose, methods, results and  
 12 conclusions  
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## 18 Introduction

19  
 20  
 21  
 22 Problem formulation [#3](#) Description and significance of the problem / Page 4  
 23 phenomenon studied: review of relevant theory and  
 24 empirical work; problem statement  
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29 Purpose or research [#4](#) Purpose of the study and specific objectives or Page 4  
 30 question questions  
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## 35 Methods

36  
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 38 Qualitative approach and [#5](#) Qualitative approach (e.g. ethnography, grounded Page 7  
 39 research paradigm theory, case study, phenomenology, narrative research)  
 40 and guiding theory if appropriate; identifying the  
 41 research paradigm (e.g. postpositivist, constructivist /  
 42 interpretivist) is also recommended; rationale. The  
 43 rationale should briefly discuss the justification for  
 44 choosing that theory, approach, method or technique  
 45 rather than other options available; the assumptions  
 46 and limitations implicit in those choices and how those  
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1 choices influence study conclusions and

2 transferability. As appropriate the rationale for several

3 items might be discussed together.

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8	Researcher	<a href="#">#6</a>	Researchers' characteristics that may influence the
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10	characteristics and		research, including personal attributes, qualifications /
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12	reflexivity		experience, relationship with participants, assumptions
13			and / or presuppositions; potential or actual interaction
14			between researchers' characteristics and the research
15			questions, approach, methods, results and / or
16			transferability
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24	Context	<a href="#">#7</a>	Setting / site and salient contextual factors; rationale
25			
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28	Sampling strategy	<a href="#">#8</a>	How and why research participants, documents, or
29			
30			events were selected; criteria for deciding when no
31			further sampling was necessary (e.g. sampling
32			saturation); rationale
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38	Ethical issues pertaining	<a href="#">#9</a>	Documentation of approval by an appropriate ethics
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40	to human subjects		review board and participant consent, or explanation
41			for lack thereof; other confidentiality and data security
42			issues
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47	Data collection methods	<a href="#">#10</a>	Types of data collected; details of data collection
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50			procedures including (as appropriate) start and stop
51			dates of data collection and analysis, iterative process,
52			triangulation of sources / methods, and modification of
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1		procedures in response to evolving study findings;	
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3		rationale	
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6	Data collection	<a href="#">#11</a> Description of instruments (e.g. interview guides,	Page 6,
7			
8	instruments and	questionnaires) and devices (e.g. audio recorders)	7 & 32
9			
10	technologies	used for data collection; if / how the instruments(s)	
11		changed over the course of the study	
12			
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15	Units of study	<a href="#">#12</a> Number and relevant characteristics of participants,	Page 9
16			
17		documents, or events included in the study; level of	
18		participation (could be reported in results)	
19			
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22			
23	Data processing	<a href="#">#13</a> Methods for processing data prior to and during	Page 7
24			
25		analysis, including transcription, data entry, data	
26		management and security, verification of data integrity,	
27		data coding, and anonymisation / deidentification of	
28		excerpts	
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35	Data analysis	<a href="#">#14</a> Process by which inferences, themes, etc. were	Page 7
36			
37		identified and developed, including the researchers	
38		involved in data analysis; usually references a specific	
39		paradigm or approach; rationale	
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45	Techniques to enhance	<a href="#">#15</a> Techniques to enhance trustworthiness and credibility	Page 7
46			
47	trustworthiness	of data analysis (e.g. member checking, audit trail,	
48		triangulation); rationale	
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53	<b>Results/findings</b>		
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1	Syntheses and	<a href="#">#16</a>	Main findings (e.g. interpretations, inferences, and	Pages 8
2			themes); might include development of a theory or	
3	interpretation		model, or integration with prior research or theory	to 21
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9	Links to empirical data	<a href="#">#17</a>	Evidence (e.g. quotes, field notes, text excerpts,	14,19, 21
10			photographs) to substantiate analytic findings	
11				
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14	<b>Discussion</b>			
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17	Intergration with prior	<a href="#">#18</a>	Short summary of main findings; explanation of how	22, 23,
18			findings and conclusions connect to, support,	
19	work, implications,		elaborate on, or challenge conclusions of earlier	24, 25,
20			scholarship; discussion of scope of application /	
21	transferability and		generalizability; identification of unique contributions(s)	26
22			to scholarship in a discipline or field	
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32	Limitations	<a href="#">#19</a>	Trustworthiness and limitations of findings	24, 25
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35	<b>Other</b>			
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38	Conflicts of interest	<a href="#">#20</a>	Potential sources of influence of perceived influence	27
39			on study conduct and conclusions; how these were	
40			managed	
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46	Funding	<a href="#">#21</a>	Sources of funding and other support; role of funders	27
47			in data collection, interpretation and reporting	
48				
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# BMJ Open

## A qualitative study of the needs of injured children and their families after a child's traumatic injury

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2  
3 **Title:** A qualitative study of the needs of injured children and their families after a child's  
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6 traumatic injury.

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9 Samantha Jones<sup>1,2,3</sup>, Sarah Tyson<sup>1,3</sup>, Naomi Davis<sup>2,3</sup>, Janelle Yorke<sup>1,3,4</sup>

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40 **WORD COUNT: 4910**

## ABSTRACT

**Objective:** To explore the needs of children and their families after a child's traumatic injury.

**Design:** Semi-structured qualitative interviews with purposeful sampling for different types of injuries and a theoretical thematic analysis.

**Participants:** 32 participants; 13 children living at home after a traumatic injury, their parents/guardians (n=14) and five parents whose injured child did not participate.

**Setting:** Two Children's Major Trauma Centres (hospitals) in England.

**Results:** Interviews were conducted a median 8.5 months (IQR 9.3) post injury. Injuries affected the limbs, head, chest, abdomen, spine or multiple body parts. Participants highlighted needs throughout their recovery (during and after the hospital stay). Education and training were needed to help children and families understand and manage the injury, and prepare for discharge. Information delivery needed to be timely, clear, consistent and complete, include the injured child, but take into account individuals' capacity to absorb detail. Similarly, throughout recovery, services needed to be timely and easily accessible, with flexible protocols and eligibility criteria to include injured children. Treatment (particularly therapy) needed to be structured, goal-directed and of sufficient frequency to return injured children to their full function. A central point of contact is required after hospital discharge for advice, reassurance and to co-ordinate on-going care. Positive partnerships with professionals helped injured children and their families maintain a sense of hope and participate in joint decision-making about their care.

**Conclusion:** Throughout the full trajectory of recovery injured children and their families need family-centred, accessible, flexible, co-ordinated health services, with more effective

1  
2  
3 harmonious communication between professionals, the child and their family. There is a  
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5 requirement for support from a single point of contact and a system that monitors the needs  
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8 of the injured child and their family after hospital discharge.  
9

## 10 11 **ARTICLE SUMMARY**

### 12 13 **Strengths and Limitations**

- 14  
15  
16 • To improve the generalisability of the results we used purposeful sampling for  
17  
18 maximum variation, rather than a sample of convenience and we believe the  
19  
20 participants in this study are broadly representative of children with trauma injuries  
21  
22 and their families.  
23  
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- 25  
26 • To our knowledge this is a first study to examine needs throughout recovery for a  
27  
28 range of different injuries and ages from the perspectives of both the injured children  
29  
30 and their parents.  
31  
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- 33  
34 • Different needs may have been identified if the interviews had involved more fathers  
35  
36 and/or greater numbers of participants across the different age ranges.  
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- 39  
40 • Joint interview formats may have influenced or limited the scope of the topics  
41  
42 discussed by either the child or the parent, but a positive aspect of this format was  
43  
44 that parents were able to provide insightful prompts, beyond the scope of the  
45  
46 researcher.  
47  
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- 49  
50 • Self-reported needs are subjective and have not been quantified with any objective  
51  
52 measurements.  
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- 55  
56 • No data is available relating to the ethnicity of the study participants. Therefore, we  
57  
58 do not know if the sample reflects population diversity.  
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## INTRODUCTION

Injury is a leading cause of death and disability in children and young people, [1] which can affect quality of life and result in a significant burden of care over the child's life span. [2]

Centralised major trauma systems have demonstrated improvements in survival from severe injury. [3] Despite the improvements in acute care, the rehabilitation which follows is an emerging priority for improvement. [4] The imperative to strengthen children's trauma rehabilitation reflects the global issue of unmet rehabilitation needs. [5]

It is important to improve children's care beyond the acute hospital admission to enable children to reach their full emotional, social, physical and vocational potential. [6] However, health and education services are generally aimed at children with development disabilities or long-term conditions rather than those acquired from an injury. [7] Children with newly acquired injuries are unlikely to have access to standardised pathways of care or long-term therapists who are well versed in their needs. The unique nature of each child's injury, situation and difficulties means that rehabilitation ought to be tailored to their specific needs. Thus, an effective starting point for rehabilitation is to understand the needs of the injured child and their family to enable an individualised approach to their care.

Previous research, including our work to review needs following childhood injury, [8] highlighted a range of needs; particularly support with psychosocial problems for the injured child and their other family members, [8–16] as well as for physical and practical problems. [13,17,18] Support is required to facilitate the child's transitions from hospital to home, [19] and return to school. [20,21] The provision of information has been shown to reduce parents' anxiety [19] and increase participation in the care of their child. [22] In trauma related research the need for information about the injury and its management are reoccurring

1  
2  
3 themes. [9,23,24] However, the current evidence base focusses predominately on the needs  
4  
5 of children with traumatic head injuries, [8,13,16,25] and mainly considers the needs of  
6  
7 parents or family members rather than the injured child, [9,14,26,27] or the specific needs of  
8  
9 adolescents. [28,29] As trauma involves the whole-body system it is important for clinicians  
10  
11 to understand needs for different types of injuries. In addition to head injuries, children suffer  
12  
13 from injuries to the limbs/pelvis, spine, abdomen and thorax, which occur in a variety of  
14  
15 combinations. [30] Childhood head injuries often result in cognitive, behavioural and  
16  
17 functional impairments. [11,25,31,32], whilst other types of injuries (orthopaedic, abdominal  
18  
19 and thoracic injuries) cause mainly physical problems, such as pain, loss of mobility and  
20  
21 breathing difficulties. Head injuries are often thought of as invisible injuries [9], which could  
22  
23 also be the case for internal organ injuries, but orthopaedic injuries are often associated with  
24  
25 visible physical signs, such as a cast or the use of mobility aids. All types of injuries have the  
26  
27 potential to affect psychological health and/or to be life changing. [15]  
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36 This study aims to address this gap in the evidence by exploring the needs of injured children  
37  
38 and their parents, including children with a wider range of ages and injuries affecting different  
39  
40 body parts. This will help to inform the delivery of family-centred services.  
41  
42  
43

## 44 **METHODS**

### 45 **Study design and setting**

46  
47 This was a qualitative interview study conducted at two Children's Major Trauma Centres in  
48  
49 England between March 2018 and August 2019. The study was approved by the National  
50  
51 Health Service, North West - Greater Manchester South Research Ethics Committee (REC  
52  
53 reference 17/NW/0615) and the Health Research Authority.  
54  
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### 60 **Participants**

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2  
3 Major trauma co-ordinators in the participating centres screened admission records to  
4 identify potential participants to take part in the study. To be included participants needed to  
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6  
7  
8 be:

- 9  
10  
11 1) children aged six to 15 years at the time of injury admitted to a specialist Major  
12 Trauma Centre with moderate to severe traumatic injury (Injury Severity Score >8)  
13 who were discharged from the Centre within the previous 12 months.  
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19 2) Parents or guardians of injured children who fulfilled the criteria.  
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23 3) Parents of younger children aged two to five years at the time of injury were also  
24 included.  
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28 The following exclusion criteria were applied:

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31 1) Participants who had been discharged within the previous two weeks (as it was felt  
32 that they would have insufficient experience of being home to fully contribute).  
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37 2) Babies/infants (less than two years old).  
38  
39  
40  
41 3) Children with isolated burn injuries (as they were managed by separate care  
42 pathway).  
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45  
46 4) Non-accidental injuries, or those for whom there were significant safeguarding  
47 concerns.  
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52 A purposeful approach to sampling was used to account for perspectives from a range of  
53 injuries, genders, ages and times since injury.  
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### 57 **Data collection**

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3 Potential participants were invited to take part by using age appropriate study information  
4 packs which were either posted or provided in person by a trauma co-ordinator. Consent was  
5  
6 obtained from the parents and assent from the children before the interview started. All  
7  
8 interviews were conducted by SJ who is a clinical researcher/major trauma co-ordinator and  
9  
10 has completed training in interviewing children. A flexible interview format was used and  
11  
12 participants could choose: who participated (joint child and parent, or solely the child or  
13  
14 parent), where the interview took place (home, hospital, neutral location) and how the  
15  
16 interview was conducted (telephone, face-to-face). However, for interviews involving  
17  
18 children a face-to-face format was recommended.  
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26 A semi-structured topic guide was used to explore the child's and when appropriate, parent's  
27  
28 or family's needs (Appendix 1). Some of the questions in the topic guide are dealt with in  
29  
30 companion papers addressing children's and family's experiences and educational needs  
31  
32 which are in preparation and will be published in due course. Questions were simplified to  
33  
34 suit children of younger ages. Interview questions related to participants' perceptions of the  
35  
36 care and support they received throughout recovery (during inpatient care and after hospital  
37  
38 discharge), but the semi-structured nature of the interviews allowed participants to explore  
39  
40 other topics which they considered relevant. Interviews were digitally recorded and  
41  
42 transcribed verbatim.  
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### 48 **Analysis**

49  
50 Anonymised transcriptions were thematically analysed using Excel and NVivo 11. A  
51  
52 theoretical thematic analysis was used to analyse the data, which was considered to be the  
53  
54 most suitable method of analysis as a specific research question had already been identified.  
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57 [33] When using a theoretical thematic approach, the analysis is driven by the researchers'  
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3 knowledge and experience in the field. The researcher had insights into the needs of injured  
4 children and their families because of her clinical and research experience with this group and  
5 topic. [8] The results of the scoping review relating to the needs of injured children and their  
6 families were used to produce a preliminary framework of key themes. [8] Firstly, SJ became  
7 familiar with the data by re-reading the transcripts. She then coded the data to categorise it  
8 within the existing coding framework or determine whether codes pointed towards a new  
9 theme. The research team (SJ, ST, JY) met regularly to review the coded data, verify its  
10 relevance to main themes and discuss the interpretations, alternative explanations for  
11 emergent findings and agree on any new theme headings which were required. Data were  
12 coded as interviews were conducted. Data collection ceased once data saturation and  
13 sufficient variation in the sample were attained. Data saturation was deemed as the point at  
14 which coded data from new interviews only added to existing themes and no new themes  
15 were developed. Field notes were maintained for the interviews to contextualise and reflect  
16 on the data, such as how forthcoming children were in the interviews.

### 37 **Patient and public involvement**

38 The Women and Children's Patient and Public Involvement Team from Manchester Academic  
39 Health Science Centre provided feedback on the study documents (patient information  
40 sheets, consent and assent forms).

### 47 **RESULTS**

48 Twenty-six interviews were conducted involving 32 participants; 13 children and their  
49 parents/guardians (n=14) and five parents whose injured child did not participate. One child  
50 was too young to participate according to the study criteria, one child did not wish to take  
51 part, for one child it was logistically too difficult to arrange a face to face interview and two  
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3 children were receiving psychological support and they and/or their parents did not feel they  
4 could manage the potential psychological impacts of an interview.  
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8 Interview duration ranged 11 to 76 minutes. The format for the interviews is summarised in  
9  
10 Table 1 and the characteristics of injured children in Table 2. All the interviews conducted in  
11 person took place in participants' homes, with the exception of two interviews which were  
12  
13 conducted at the hospital (one parent interview and one parent-child dyad interview).  
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For peer review only

Table 1 Interview structure

Interview format	Participants	Method	Number of participants
5 Parents only	5 mothers	3 Telephone 2 In person	5
5 Dyads (joint interviews with child & their parent/guardian)	5 children & their parents (4 mothers & 1 guardian)	All in person	10
7 Dyads (child & their parent interviewed separately)	7 children & their parents (7 mothers)	All in person	14
1 Triad (child interviewed separately, mother and father together)	1 child & their parents (1 mother & 1 father)	All in person	3
<b>Total number of participants</b>			<b>32</b>

Table 2 Characteristics of injured children (13 participants and 5 who did not participate but whose parents were interviewed)

Characteristics	
Gender	Male 11 Female 7
Age at time of interview (years)	Range 5 to 16 (Median 13.0, IQR 3.5)
Injury mechanisms	4 Road traffic accidents 3 Sport 1 Fall >2 metres 5 Fall <2 metres 5 Other mechanisms
Type of injury	1 Isolated head injury 1 Isolated spinal injury 3 Isolated abdominal injuries 1 abdomen & chest injuries 6 Injuries to limb(s) 6 Multiple injuries
Time since injury (months)	Range 1 to 12.5 (Median 8.5, IQR 9.3)

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2  
3 Most participants, particularly the children were unfamiliar with the concept of 'needs' as this  
4 is an abstract concept coined by healthcare professionals, thus they seldom talked specifically  
5  
6 about their needs. However, needs were implicit in all participants' narratives about how their  
7  
8 healthcare was delivered, regardless of whether they were satisfied with their care or  
9  
10 whether their needs had been met. Participants described their own unique experiences and  
11  
12 although these varied, they often pointed towards the same types of needs. The interviews  
13  
14 focussed on care after hospital discharge, but the researcher gave participants the flexibility  
15  
16 to discuss matters which were important to them including hospital care. School-based  
17  
18 service needs were identified in the analysis, but have been addressed in a separate paper  
19  
20 due to the range and depth of information obtained relating to these needs. This paper is in  
21  
22 preparation. Parents and older children were able to give the most information about their  
23  
24 needs.  
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32 Four overarching themes emerged; Education and training needs, information needs, service  
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34 needs, and positive partnerships between children, families and professionals. Education and  
35  
36 information needs are interrelated. Education/training needs focus on what children and  
37  
38 families need to help them look after the injury, whilst information needs relate to how advice  
39  
40 is delivered.  
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44

## 45 **Education and training needs**

### 46 ***Education needs***

47  
48 Both injured children and their parents had to assimilate a large amount of information about  
49  
50 the accident and injury(ies). For most this was a completely unfamiliar situation and they  
51  
52 recognised that they had a lot to learn. Professionals needed to help by educating them about  
53  
54 their injury and how to manage it. Parents highlighted the need to be warned or advised about  
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3 the prognosis and forewarned about symptoms (such as pain, seizures, hallucinations,  
4 difficulty concentrating, fatigue) which sometimes occurred unexpectedly. It was also  
5  
6 important to understand the reasons why they occurred (Box 1: quote 1a, 1b, 1c).  
7  
8  
9

### 10 ***Training needs***

11  
12 Participants identified that they needed training, particularly in preparation for hospital  
13 discharge. This included issues such as how to look after wounds and scars, mobilise, and  
14  
15 return to activities and school. They needed opportunities to develop coping strategies and  
16  
17 to practice on-going care and treatments while in hospital to develop competence. This then  
18  
19 gave them confidence to execute these tasks at home. For more severely injured children this  
20  
21 need went beyond merely practicing in the hospital environment. The opportunity to practice  
22  
23 at home during weekend leave made the eventual return home more manageable (Box 1:  
24  
25 quote 1d).  
26  
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### 32 **Information needs**

#### 33 ***Information needs***

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35 Participants needed timely information to be provided in sufficient detail to understand  
36  
37 “*what was going on*”. Delays in receiving information predominately related to administration  
38  
39 (particularly referrals and transfer of health records), meetings and short notice of operation  
40  
41 cancellations. Several found the systems in place outdated (Box 1: quote 1e). The desired level  
42  
43 of detail varied, but all participants needed information to be clear and consistent. They often  
44  
45 explained how helpful they found well-executed explanations from professionals (Box 1:  
46  
47 quote 1f).  
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55 Consistency of information was essential, but it was often conflicting. Participants attributed  
56  
57 this to the use of medical jargon in written and verbal reports, the number of professionals  
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3 involved in care and the different approaches between health professionals/hospitals (Box 1:  
4 quote 1g). This conflicting information and advice caused “*tension*” and “*confusion*.”  
5  
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7  
8 Participants reported that they were sometimes left not knowing what to expect or the best  
9  
10 way of managing the injuries. They recommended closer liaison between health  
11  
12 professionals.  
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16 Related to consistency of information, was participants’ need for up-to-date information.  
17  
18 They needed to be informed clearly and consistently about any changes in diagnosis,  
19  
20 prognosis, management plan or expected symptoms throughout all stages of their care.  
21  
22 Information was often considered insufficient. Gaps in information delivery were attributed  
23  
24 to health professionals not spending enough time with participants, not knowing specific facts  
25  
26 or presenting the information which they considered the most important. For example, one  
27  
28 family only became aware of the full details of their child’s head injury when they reviewed  
29  
30 the consent form for a procedure (Box 1: quote 1h).  
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### 36 ***Effective communication and information sharing***

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38  
39 Participants were asked about how information was provided and what they wanted and  
40  
41 needed. Irrespective of the format, participants identified that information needed to be  
42  
43 available quickly and easily. Most parents considered written information to be useful,  
44  
45 particularly copies of clinic and referral letters and other relevant correspondence. This  
46  
47 enabled them to monitor progress of care and to play an active role in their child’s care.  
48  
49  
50 Written information was frequently needed to share information with other health  
51  
52 professionals and external agencies (such as schools) who often required “*a written letter*  
53  
54 *from a doctor*.” Several found it difficult to absorb written information (such as leaflets and  
55  
56 booklets) given their emotional state, although participants acknowledged these were  
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1  
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3 valuable “to refer back to”. However, many parents preferred to liaise directly with health  
4  
5 care professionals in person or via texts, phone-calls and emails as their primary source of  
6  
7 communication and information (Box 1: quote 1i). Similarly, injured children preferred to ask  
8  
9 their parents questions rather than professionals. However, open conversations with  
10  
11 professionals which included and were directed towards the injured child were valued (Box  
12  
13 1: quote 1j). The use of visual aids, such as x-rays and scans also helped participants  
14  
15 understand the injury, particularly when there were no visible physical signs. One child used  
16  
17 his abdominal scan to help his peers understand the severity of his injury.  
18  
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22

23 Dissatisfaction with information and communication arose when health care professionals  
24  
25 repeatedly asked the same questions, did not share information and/or did not advise  
26  
27 participants of the outcomes of investigations, test results, or changes to care plans.  
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## Box 1: Education, training and information needs

Themes	Quote and participant
Education and training needs	<p>1a) <i>"...They did say to us that [it] would be... ..a miracle if they managed to save his eye. That was our worst-case scenario."</i> (Parent 11)</p> <p>1b) <i>"These sudden pains didn't start for a while after. I didn't know they were coming.....and then.....I felt like, "what's this? .....why is she getting these and is it.... fine that she should be exercising?"</i> (Parent 16)</p> <p>1c) <i>"if there would have been any side effects, or things, to look out for, you know?....like I suppose like you get on any medicine"</i> (Parent 26)</p> <p>1d) <i>"That really did help.....I just felt prepared then. It was like "right, we can do it at the hospital, we can do it at home."</i> (Parent 12)</p>
Information needs	<p>1e) <i>"I don't understand why a hospital can't just get in the modern world and email people.....or phone them up and do a referral. Why they have to type and dictate a letter and it takes two weeks for it to get to the person they need it to get to."</i> (Parent 8)</p> <p>1f) <i>"they [the injuries] seemed quite complicated at first.....because there was a lot.... They listed them....., so they laid it out clearly....., They just kind of explained each one to me.....And ...showed me some x-rays."</i> (Child 10).</p> <p>1g) <i>"Some people were saying he needs to wake up, he's going to turn day into night and it's not good for them... and some people were saying why are you waking him up.....he needs to sleep, he needs to recover, and we were a bit like ... what do we do? Are we going to wake him up or let him sleep?"</i> (Parent 6)</p> <p>1h) <i>"It said ... "fractured skull". We were like,..., "it's the first we've heard of it"..... So, that was kind of disappointing really, that we hadn't heard that."</i> (Parent 18)</p>
Information needs: effective communication and information sharing	<p>1i) <i>"We can just email at any stage if we've got any questions, which is fantastic. Anything I'm worried about, just email and they'll...respond straightaway."</i> (Parent 9)</p> <p>1j) <i>"I thought that was really good actually. A lot of the time they speak to [Injured child] rather than to me? Because he's the injured one and worrying."</i> (Parent 23)</p>

## **Service needs**

Participants were clear about what they needed from services throughout their recovery. Whether inpatient or community based, they needed services to be accessible, timely, sufficient, structured and co-ordinated. Although many participants expressed positive experiences and satisfaction, this was not universal. The types of difficulties outlined were not limited to one type of service: unmet needs for accessible services were described for most types of community-based services.

### ***Accessible and timely services***

After hospital discharge, services needed to be provided locally or at the participants' homes, often 'out of hours' or with 'open appointments' to enable participants to obtain care or assessments when needed (Box 2: quote 2a). However, many factors made services difficult to access after hospital discharge. Participants described lengthy or difficult journeys to their healthcare provider and strict eligibility criteria which excluded children. (Box 2: quote 2b). Additionally, rigid protocols prevented access to services, such as school transport and equipment. For example, one injured child lived in two homes as their parents were separated, but services could not accommodate this commonplace living arrangement and would only supply one set of equipment.

In order to be accessible, some services needed to be made available to family members as well as the injured child. Post-traumatic stress type symptoms and/or mental health issues were often experienced by an injured child and their family members, including parents, grandparents and siblings (participants' experiences will be reported in detail in a pending publication). Although the hospital offered psychological support to the whole family, this

1  
2  
3 holistic approach was more difficult to access in the community after hospital discharge (Box  
4  
5 2: quote 2c). However, several participants did not take up psychological support during  
6  
7 inpatient stay, as difficulties often only became apparent after discharge when participants  
8  
9 tried to return to 'normal life'.  
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14 The timing of services was very important; participants often experienced long delays for  
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16 services to start (particularly community therapy) and cancelled operations. Such delays were  
17  
18 difficult for families to cope with (Box 2: quote 2d). A couple of participants proposed that  
19  
20 appointments could be quicker if telephone consultations were available after discharge, or  
21  
22 if primary and secondary care services worked more closely together to prioritise injured  
23  
24 children more appropriately (Child 21 and Parent 22).  
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### 28 29 ***Dose and structure of treatment***

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31 Whether during inpatient or community-based care, participants needed services to provide  
32  
33 sufficient treatment throughout the continuum of recovery. In the hospital, a lack of nursing  
34  
35 staff was highlighted as a key issue. However, there was a notable discrepancy between  
36  
37 satisfaction with mental health and therapy services in the hospital and community setting,  
38  
39 with such services generally regarded as comprehensive in the hospital, but lacking in the  
40  
41 community. After discharge from hospital, participants described a lack of children's mental  
42  
43 health services or professionals who deliver specific psychotherapy treatments for children.  
44  
45 Similarly, in contrast to the hospital, community-based therapy was often regarded as  
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47 insufficient (Box 2: quote 2e). Another issue was that treatment in the community (often  
48  
49 physiotherapy or occupational therapy) needed to have a greater scope of ambition for the  
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51 injured child's recovery. Rehabilitation goals, whether set with therapists or autonomously  
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53 were considered essential to gauge improvement, inspire motivation and provide a focus for  
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3 the future (Box 2: quote 2f). Several participants reported that community therapy finished  
4 before the injured child had reached their goals to return to physical education, competitive  
5 sport or other activities (i.e. they had not reached their rehabilitation potential). In order to  
6 deal with these unmet rehabilitation needs, participants devised their own exercise and  
7 rehabilitation regimes; requested physiotherapy reviews or funded therapy privately.  
8 Participants also needed rehabilitation to be clearly structured because the injury(ies)  
9 disrupted their usual routines.  
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### 21 ***Co-ordination of care and ongoing support***

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23 Care and rehabilitation of children with traumatic injuries often involved input from multiple  
24 professionals and services over an extended period to manage complex, sometimes sensitive  
25 problems. Participants very clearly articulated the need for this complex, multi-agency, multi-  
26 faceted, often long-term care to be co-ordinated by a health care professional. They  
27 highlighted the need for help to co-ordinate timely provision of appropriate equipment,  
28 appointments, care packages and return to education (whether this be school or home  
29 schooling) and other activities (Box 2: quote 2g).  
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41 Co-ordinating on-going care after discharge, such as clinic appointments and referrals were a  
42 particular issue for most participants, regardless of the severity or complexity of the injury or  
43 the number of specialist services involved. They valued help to ensure referrals and  
44 appointments were made, attempts to streamline appointments to minimise the number of  
45 trips and disruption to schooling and employment, prompt notification of appointments,  
46 timely reminders and help to re-arrange appointments if necessary. When this co-ordination  
47 was not available, participants described unsatisfactory experiences (Box 2: quote 2h).  
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3 Most participants acknowledged that they needed a named contact to be involved  
4 throughout their hospital stay, through discharge and for on-going care. This professional  
5  
6 needed to provide the co-ordination described above, plus on-going monitoring of recovery  
7  
8 and needs, reassurance, emotional support and continued advice especially about new  
9  
10 symptoms. (Box 2: quotes 2i and 2j). Where available this named contact was often a trauma  
11  
12 co-ordinator, but participants also found their general practitioner a helpful point of  
13  
14 reference and a means of accessing other services. Part of the co-ordinator's role also needed  
15  
16 to 'signpost' children (and their families) to access appropriate on-going care. Participants  
17  
18 reported how problems and symptoms, particularly post-traumatic distress and mental  
19  
20 health problems often only became apparent after hospital discharge. To address such new  
21  
22 problems, participants needed to know what sources of help were available and how to  
23  
24 access them. They described how they needed "*to be put in touch with the right people*". This  
25  
26 signposting role extended beyond health care services.  
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35  
36 There was a particular need to co-ordinate multi-agency care (usually for the more severely  
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38 injured children) as participants did not have the knowledge, skills or experience to negotiate  
39  
40 the highly complex and variable systems, particularly when community or education services  
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42 were involved. Many met and unmet needs were highlighted regarding return to education  
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44 (whether at school or at home) after a traumatic injury and these are addressed in a separate  
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46 manuscript, which is in preparation.  
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## Box 2: Service needs

Themes	Quote and participant: Service needs
Service needs: Accessible and timely services	<p>2a) <i>"We had an open appointment arrangement with the physio, where we could ring up if there was a problem."</i> (Parent 6)</p> <p>2b) <i>"They [district nurses]... told me that they don't deal with anybody under the age of eighteen."</i> (Parent 8)</p> <p>2c) <i>"I think we were offered everything we.... could have been. I think getting counselling for me mum [child's grandparent] was a bit harder...." [referring to experience after hospital]</i> (Parent 11)</p> <p>2d) <i>"We were thrown into two weeks of, is he having brain surgery, is he not? And it happened, you know, twice, two cancellations. And that is such a huge thing for your heart to cope with."</i> (Parent 18)</p>
Service needs: Dose and structure of treatment	<p>2e) <i>"We could just see that it [physiotherapy] wasn't gonna be what [injured child] needed. She needed more..... she wasn't even gonna start for at least a couple of weeks"</i> (Parent 9).</p> <p>2f) <i>"That really helped. We set some [goals] in hospital, didn't we? Something to do in the future like....., what do you want to do for your birthday? So I was like, I'd always wanted to go, like, Harry Potter World or something."</i> (Child 21).</p>
Service needs: Co-ordination of care	<p>2g) <i>"I don't think I could have coped, if I'd had to ring up all them people and sort all her [injured child's] care package out, I couldn't have coped."</i> (Parent 2)</p> <p>2h) <i>"well we've got his appointment through. As I say, we were expecting it. They said it would be within six weeks, but it's actually 13...it'll be 13 weeks since the accident."</i> (Parent 26)</p> <p>2i) <i>"When I rang the nurse though, they were really reassuring, and they sort of said "I don't think it's anything too much to worry about, but mention it to the neurosurgeons". So, it did allay my fears a bit."</i> (Parent 19)</p> <p>2j) <i>"he just reassured me a lot and answered a lot of questions that I had about going ...back to school and sorting things out"</i> (Child 21)</p>

### Partnerships between patients and professionals

Participants explained how they needed positive, supportive, trusting partnerships with the professionals involved in their care. A positive outlook from professionals helped to boost morale and gave a sense of hope and helped injured children and their families feel emotionally supported (Box 3: quote 3a). This also related to the need to be able trust the skills, competence and reliability of the professionals and organisations involved in the injured child's care, which gave them confidence and reassurance (Box 3: quotes 3b and 3c). This trust was also needed to persuade the injured children to adhere to aspects of treatment which they disliked and enabled professionals and participants to work effectively together (Box 3: quote 3d). Several children disliked certain aspects of their treatment (e.g. wearing an eye patch or orthotic devices) and were reluctant to adhere to them. To minimise this problem, children and their families needed to "feel heard", be involved in discussions and decisions about their care, to jointly solve problems by exploring alternative treatment options and finding mutually agreeable solutions or compromises (where possible) (Box 3 quote 3e). However, not all relationships between services and participants were positive. There were several reports of perceived problems with care. Examples included the incorrect application of orthotics, medication error, issues with adherence to major trauma pathways, referrals which were not made, delayed appointments, etc. In these cases, participants felt they had not been listened to by health professionals, nor involved in discussions/decisions about their care. Consequently, they could not rely on some aspects of service provision (Box 3 quote 3f).

## Box 3: partnerships between patients and professionals

Themes	Quote and participant
Partnerships between patients and professionals	<p>3a) <i>"They [hospital staff] kept us positive and...yeah, didn't make us feel that, God, this was, you know, absolutely disastrous, but she was gonna get better."</i> (Parent 9)</p> <p>3b) <i>"I think the fact it was a children's hospital and they knew exactly what they were doing... You feel confident."</i> (Parent 26)</p> <p>3c) <i>"you know, the people who do these types of operations, they're good at their job"</i> (Child 17)</p> <p>3d) <i>"Originally I couldn't even get [injured child] there [Psychology Department]. But the therapist from CAMHS built up such a good relationship."</i> (Parent 12)</p> <p>3e) <i>"we just discussed it as a whole family and [trauma co-ordinator] ...everything that was worrying [Injured Child]... . And then she just literally said "right. I can fix that, that, that, that and that, but I can't do this... but I know somebody who might be able to, so let me look into it, leave it with me."</i> (Parent 21)</p> <p>3f) <i>"They [the council] were supposed to provide some equipment for the bath. And it never materialised. They came out, they brought the wrong bath board. And then they said they'd come out again. But they didn't."</i> (Parent 12)</p>

## DISCUSSION

The results of this study showed that injured children and their families' needs focus on education and training to help understand the injury and how to manage it, effective communication, access to sufficient services, support to co-ordinate care and positive partnerships with professionals.

Participants' unmet need for clear, consistent and complete information across the full recovery continuum echoes findings from previous studies [9,13,23] and is attributed to the range of professionals often involved in trauma care. [23] However, participants' needs and preferences varied, so consideration should be given to individualising information and ensuring it is available in a range of different formats, as well as ensuring the injured child and other family members are included in honest and open discussions. Additionally, clearer information to manage expectations may be required when details are unknown or subject to change, [9] particularly care plans. Although written information was often useful, this needed to be conveyed quickly (by email or text for example) and act as a supplement to verbal communication. Electronic patient held records or portals have been shown to enhance information and communication exchange, [34,35] and may help to fulfil children's and family's needs for more immediate, accessible and consistent information.

Access to services was a frequent unmet need, which was most pronounced in the community setting. It is unsurprising that most participants described a "*post code lottery*" when it came to rehabilitation in the community setting. All the participants included in this study had been managed in specialist children's Major Trauma Centres. The resources, standards and clinical governance processes present in these centres only cover hospital-based care [4] and do not extend to the community setting, where there are few services specifically for injured

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2  
3 children. Similarly, disparities in access to post-discharge rehabilitation for childhood  
4 traumatic injury have been reported in the United States. [6] Further research is required to  
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6 better understand how injured children's community-based rehabilitation can be provided  
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8 efficiently and effectively.  
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13 Inadequate service provision has been reported previously, [7,9,16,36] particularly for  
14 services relating to cognitive or mental health difficulties. [12,16,36,37] The current study  
15  
16 reinforces this by highlighting that although psychological support during the inpatient stay  
17  
18 was comprehensive, it was lacking after discharge, which is when difficulties often emerged.  
19  
20 Psychological support services needed to extend throughout the full recovery trajectory and  
21  
22 cater for the needs of the whole family unit. To achieve this, the capacity of children's  
23  
24 community mental health services needs to expand by training more professionals, [38] and  
25  
26 educating both parents [39] and professionals [10] about how to detect signs of post-  
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28 traumatic stress, particularly as symptoms can present late in recovery. [15,40] In contrast to  
29  
30 previous research, our participants placed more importance on the need for physical and  
31  
32 practical support. This may reflect the variety of injuries included in our sample, rather than  
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34 being limited to head injuries.  
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44 There is a clear need to develop comprehensive, streamlined rehabilitation services for  
45  
46 children with traumatic injuries, whose needs may be temporary or change over time.  
47  
48 Expansion of the Major Trauma Networks to include all facets of rehabilitation for all ages  
49  
50 could provide this support, but this would require sustained funding and training. Like  
51  
52 previous studies, we found an overwhelming need for a single-point of contact during and  
53  
54 after hospital discharge [9,28,36,41,42] to help patients access professional support and to  
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56 co-ordinate the multiple professions, specialities, agencies and organisations involved in their  
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3 care. Co-ordinators could work in conjunction with rehabilitation medicine consultants, [43]  
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5 who would lead clinical decision making. This approach may achieve more streamlined  
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7 rehabilitation and consistent communication. Some major trauma services provide a  
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9 specialist co-ordinator, but this is often limited to hospital-based care. [33] However, support  
10  
11 may be required over the long-term as on-going problems are highly prevalent for several  
12  
13 years after severe injury, [42,44] but may not become apparent until after the child has been  
14  
15 discharged from hospital and attempts to return to their normal life. [12,16] Ongoing support  
16  
17 may contribute to trusting, positive partnerships that participants emphatically needed for  
18  
19 more family-centred care and to enable joint decision making. [45] In this study and previous  
20  
21 research an important role of a known contact is to provide reassurance and maintain a sense  
22  
23 of hope. [13–15,19,39,46] An important aspect of trauma care is to support the emotional  
24  
25 recovery [46] of the child and their parents. [39]

26  
27 A system is required that continues to screen for (and then treat and monitor) problems after  
28  
29 hospital discharge. This may be most pragmatically addressed by a comprehensive needs  
30  
31 assessment tool which can be completed by the child/family at regular intervals throughout  
32  
33 the full recovery. Work is underway to develop such a tool that is suitable for all ages of  
34  
35 children, types of injury and stages of care.

### 36 37 38 39 40 41 42 43 44 45 **Strengths and Limitations**

46  
47 A common criticism of qualitative research is the limited generalisability of the results. [47]  
48  
49 To address this, we used purposeful sampling for maximum variation, rather than a sample  
50  
51 of convenience and we believe the participants in this study are broadly representative of  
52  
53 children with a range of traumatic injuries. [30] To our knowledge this is a first study to  
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55 examine needs throughout recovery for a broad range of injuries and ages from the  
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57 perspectives of both the injured children and their parents. However, the purposeful  
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3 approach to sampling did not encompass attaining equal numbers of mothers and fathers.  
4  
5 The majority of mothers who took part was an unexpected finding, which may have  
6  
7 influenced the range of needs and experiences reported. Previous qualitative studies have  
8  
9 shown a difference in themes identified for males and females. [48]  
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12  
13 Due to involvement of children and sensitive nature of the interview topic (childhood injury)  
14  
15 it was important to give participants the opportunity to take part in the interviews in the way  
16  
17 that they felt most comfortable. We acknowledge that joint interview formats may have  
18  
19 influenced or limited the scope of the topics discussed by either the child or the parent. [49]  
20  
21 One positive aspect of joint interviews was that parents were able to provide insightful  
22  
23 prompts, beyond the scope of the researcher.  
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26  
27 Age specific needs have previously been identified for adolescents. [28] Our initial intention  
28  
29 was to explore age specific needs, but the data analysis showed that the identified needs were  
30  
31 generic across the ages investigated. More age-related needs may have been identified if  
32  
33 there were greater numbers of participants across the different age ranges and interview  
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35 probes placed more emphasis on issues relevant to age.  
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39 We acknowledge that self-reported needs are subjective and have not been quantified with  
40  
41 any objective measurements. Self-reported, subjective data can be influenced by different  
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43 forms of bias, [50,51] including social desirability bias. [51] For example, social desirability  
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45 bias may have occurred because participants wanted to appear to be coping and thus may  
46  
47 have under reported their level of need. Finally, we do have data about the ethnicity of the  
48  
49 study participants. Therefore, we do not know if the sample reflects population diversity.  
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## 52 53 54 **CONCLUSION**

55  
56 This research has helped to identify unmet healthcare needs of a new target population.  
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58 Children with a range of injuries and their families need family-centred, accessible, flexible  
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3 co-ordinated health services throughout the full trajectory of recovery, with more effective  
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5 harmonious communication between professionals, the child and their family. Trauma  
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7 rehabilitation should be provided as a continuum of care, part of which should involve the  
8  
9 ongoing monitoring of the injured child's and family's needs. Services between hospital and  
10  
11 community settings need to be more seamless and equitable. This may be achieved by  
12  
13 attaining evidence such as that presented here, about needs through the full trajectory of  
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15 recovery, which can then be used to inform policy and commissioning.  
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35 collection, data analysis, interpretation of the data and produced the manuscript drafts. Sarah  
36 Tyson and Janelle York contributed to the design of the work, data analysis and interpretation  
37 of the data. Sarah Tyson contributed to drafting the manuscripts. Naomi Davis contributed to  
38 the interpretation of the data.  
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#### 49 **Data Sharing statement**

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51 All data relevant to the study are included in the article or uploaded as supplementary  
52 material.  
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## APPENDIX 1

	<b>Guide to Questions</b>
<b>Generic needs</b>	<p>Tell me about what was different for <b>you/ you and your child</b> following your injury?</p> <p>What help did <b>you/your child</b> need after your injury?</p>
<b>Discharge specific needs</b>	<p>What was it like for <b>you/ you and your child</b> when you went home from the hospital?</p> <p>When <b>you/your child</b> went home from the hospital how did you feel?</p> <p>Did you feel <b>you/you and your child</b> prepared to go home?</p> <p>Was there anything that worried <b>you/ you and your child</b> about going home?</p> <p>Did <b>you/you and your child</b> need any support/help from hospital staff/health professionals when you went home from the hospital?</p> <p>Did you feel that you got the help <b>you/you and your child</b> needed?</p> <p>Did <b>you/your child</b> have any difficulties when you went home from the hospital?</p> <p>Was there anything that really helped or made things easier when <b>you/your child</b> went home?</p>

	<p><b>Probes:</b> Equipment, modifications to home, home visits, advice leaflets, meetings before discharge, follow up appointments, phone calls from the hospital.</p>
<p><b>Key Worker</b></p>	<p>Did <b>you/your child</b> have a key worker (a health professional/nurse/physio/occupational-therapist/carer/doctor) who provided help or advice when you went home from the hospital?</p> <p><b>If answers yes:</b> Did you find this helpful? Why was this helpful?</p> <p>What did the key worker do for you?</p> <p><b>If answers no:</b> Do you think that a key worker would have been helpful?</p> <p>What help/support could have they provided?</p>
<p><b>Information needs</b></p>	<p>Was <b>your/your child's</b> injury explained to you in the hospital?</p> <p>Did you understand the explanation of <b>your/your child's injury</b>?</p> <p>Did you understand how the injury would affect <b>you/your child</b>?</p> <p>Were you provided with advice about <b>what you/your child</b> was allowed and not allowed to do following <b>your/your child's injury</b>? Was this easy to understand?</p> <p>Did you receive any advice or information when you were discharged from the hospital? Probe: information booklet, helplines, follow up appointments/ follow up phone calls.</p>



	<p><b>If answers yes:</b> Was the information helpful/how? Were you given enough information? Was it easy to understand? Who gave you the information?</p> <p><b>If answers no:</b> Was there you wanted to know when you went home from the hospital, which you were not told? Was there anything you had to find out for yourself?</p>
<p><b>Educational needs</b></p>	<p>How did <b>you/your child</b> deal with returning to school after their injury?</p> <p>Did <b>you/your child</b> have any difficulties returning to school?</p> <p>Did <b>your/your child's teachers</b> know that you/your child had suffered from an injury?</p> <p><b>Probes:</b> Did they understand the injury/do anything differently?</p> <p>Was there anything that really helped <b>you/your child</b> when you returned to school?</p> <p>Were there any changes made or advice which made <b>your/your child's</b> return to school easier?</p>
<p><b>Social needs</b></p>	<p>Did <b>your</b> friends/family know about <b>your/your child's</b> injury?</p> <p>Do you think they understood what had happened to <b>you/your child</b>?</p> <p>Were <b>your friendships</b> different in any way following <b>your/your child's</b> injury?</p> <p>Did your friends and family help <b>you/your child after your child's injury</b>?</p> <p>Did <b>your/your child's</b> hobbies/play/sporting activities change following your injury?</p>



<p><b>Physical</b></p>	<p>Did <b>you/your child</b> have any physical problems following the injury?</p> <p>(Probes: will depend on the age of child: difficulties walking, talking, crawling, eating, speaking hearing, toileting, returning to their usual activities)</p> <p>Did <b>you/your child</b> need crutches/walking frame/wheel chair after your injury?</p> <p>Did <b>you/your child</b> have any treatment from therapists /health professionals to help with the physical problems after the injury?</p> <p>Therapists and Health Professionals are: physiotherapists/occupational therapists/dieticians/speech therapists/nurses/doctors.</p> <p>Did you need additional care/help at home? Probe: adaptations to the home, downstairs living.</p> <p>Was there any change to <b>your/your child's</b> appearance after their injury?</p> <p><b>Probes:</b> scars, cuts &amp; bruises, weight gain or loss, items your child had to wear: supports, casts, brace, breathing pipe.</p>
<p><b>Psychological</b></p>	<p>Were <b>you or your child</b> scared or worried after <b>your/your child's injury</b>?</p> <p>Did <b>you or your child</b> have any problems sleeping following their injury?</p> <p>Did <b>your child's/your behaviour</b> change following the injury?</p>
<p><b>Emotional needs</b></p>	<p>How did you feel after <b>your/your child's injury</b>?</p>

	<p>Did <b><i>your/your child's</i></b> injury affect you emotionally?</p> <p>Did you receive any emotional support from staff at the hospital or people in your local community?</p> <p><b>Probes:</b> worried, concerns for the future, upset, scared.</p>
<p><b>Family/work needs?</b></p>	<p>Did <b><i>your/your child's</i></b> injury affect the family or family life?</p> <p><b>Probes:</b></p> <ul style="list-style-type: none"> <li>• Was there any change to the daily routine?</li> <li>• Was there any change to roles/responsibilities within the family?</li> <li>• Do you have other children? Was it difficult to look after them at the time of your child's injury?</li> <li>• Were you working at the time of your child's injury? Did their injury affect work in any way?</li> <li>• Was your place of employment supportive after your child's injury?</li> <li>• Did you need any support to look after your child ?</li> </ul>
<p><b>Current situation</b></p>	<p>What are things like for <b><i>you/your child now?</i></b></p> <p>Are you receiving help from either the hospital or your community services?</p> <p>Have you/ your child regained their previous level of activities at home?</p> <p>And at school?</p>
<p><b>Unmet needs/met needs</b></p>	<p>Looking back over the time since the injury, is there anything that could have been done differently to help <b><i>your/your child's</i></b> recovery?</p> <p>With hindsight were there any services which you did not receive which you think would have helped you and your child/you?</p> <p>What really helped you after your injury/ you and your child after your child's injury. Probes: Advice/information/people (health</p>

	professionals/family, friends/people in the community), equipment, support groups, follow ups.
<b>Closing</b>	Thank you for much for talking to me today. Do you have any questions or is there anything else you would like to tell me which we haven't covered?

For peer review only

# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

The page numbers refer to the unmarked copy.

	Reporting Item	Page Number
<b>Title</b>	<a href="#">#1</a> Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data	Title page

collection methods (e.g. interview, focus group) is recommended

## Abstract

[#2](#) Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions

Abstract

## Introduction

[#3](#) Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

Page

4&5

[#4](#) Purpose of the study and specific objectives or question

Page 5

## Methods

[#5](#) Qualitative approach and research paradigm

Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those

Page

7&8

choices influence study conclusions and transferability.

As appropriate the rationale for several items might be discussed together.

1			
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7			
8	Researcher	<a href="#">#6</a>	Researchers' characteristics that may influence the
9			
10	characteristics and		research, including personal attributes, qualifications /
11			
12	reflexivity		experience, relationship with participants, assumptions
13			and / or presuppositions; potential or actual interaction
14			between researchers' characteristics and the research
15			questions, approach, methods, results and / or
16			transferability
17			
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24	Context	<a href="#">#7</a>	Setting / site and salient contextual factors; rationale
25			
26			
27			
28	Sampling strategy	<a href="#">#8</a>	How and why research participants, documents, or
29			
30			events were selected; criteria for deciding when no
31			6&8
32			further sampling was necessary (e.g. sampling
33			
34			saturation); rationale
35			
36			
37	Ethical issues pertaining	<a href="#">#9</a>	Documentation of approval by an appropriate ethics
38			
39	to human subjects		review board and participant consent, or explanation
40			
41			5&7
42			for lack thereof; other confidentiality and data security
43			
44			issues
45			
46			
47	Data collection methods	<a href="#">#10</a>	Types of data collected; details of data collection
48			
49			
50			procedures including (as appropriate) start and stop
51			
52			dates of data collection and analysis, iterative process,
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54			triangulation of sources / methods, and modification of
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1		procedures in response to evolving study findings;	
2			
3		rationale	
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5			
6	Data collection	<a href="#">#11</a> Description of instruments (e.g. interview guides,	Page 7,
7			
8	instruments and	questionnaires) and devices (e.g. audio recorders)	33-36
9			
10	technologies	used for data collection; if / how the instruments(s)	
11		changed over the course of the study	
12			
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15			
16	Units of study	<a href="#">#12</a> Number and relevant characteristics of participants,	Page 8,
17			
18		documents, or events included in the study; level of	9&10
19			
20		participation (could be reported in results)	
21			
22			
23	Data processing	<a href="#">#13</a> Methods for processing data prior to and during	Page
24			
25		analysis, including transcription, data entry, data	7&8
26			
27		management and security, verification of data integrity,	
28			
29		data coding, and anonymisation / deidentification of	
30			
31		excerpts	
32			
33			
34			
35	Data analysis	<a href="#">#14</a> Process by which inferences, themes, etc. were	Page 8
36			
37		identified and developed, including the researchers	
38			
39		involved in data analysis; usually references a specific	
40			
41		paradigm or approach; rationale	
42			
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44			
45	Techniques to enhance	<a href="#">#15</a> Techniques to enhance trustworthiness and credibility	Page 8
46			
47	trustworthiness	of data analysis (e.g. member checking, audit trail,	
48			
49		triangulation); rationale	
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51			
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53	<b>Results/findings</b>		
54			
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1	Syntheses and	<a href="#">#16</a>	Main findings (e.g. interpretations, inferences, and	Pages 8
2			themes); might include development of a theory or	
3	interpretation		model, or integration with prior research or theory	to 22
4				
5				
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8				
9	Links to empirical data	<a href="#">#17</a>	Evidence (e.g. quotes, field notes, text excerpts,	15,20,
10			photographs) to substantiate analytic findings	22
11				
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13				
14	<b>Discussion</b>			
15				
16				
17	Intergration with prior	<a href="#">#18</a>	Short summary of main findings; explanation of how	23-27
18			findings and conclusions connect to, support, elaborate	
19	work, implications,		on, or challenge conclusions of earlier scholarship;	
20			discussion of scope of application / generalizability;	
21	transferability and		identification of unique contributions(s) to scholarship	
22			in a discipline or field	
23	contribution(s) to the field			
24				
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32	Limitations	<a href="#">#19</a>	Trustworthiness and limitations of findings	3, 25-26
33				
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35	<b>Other</b>			
36				
37				
38	Conflicts of interest	<a href="#">#20</a>	Potential sources of influence of perceived influence	28
39			on study conduct and conclusions; how these were	
40			managed	
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46	Funding	<a href="#">#21</a>	Sources of funding and other support; role of funders	28
47			in data collection, interpretation and reporting	
48				
49				
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