

Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children

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Abstract

Background

Children's burn injuries can have a significant psychosocial impact on parents. However, the stress involved in caring for a child following a burn can often go unrecognized and does not necessarily prompt help seeking by parents.

Objective

It is common for adults to seek health-related support and information via the Internet. Many benefit from immediate and easy access to online psychological interventions. A prototype burn-specific, parent-focused, peer-informed, supportive website, designed to provide easy access to information and psychoeducation, was created and tested for acceptability.

Patient Involvement

Using a partnership-based method of website development, parents and professionals (clinical, academic and support organizations) were recruited and their particular expertise was acknowledged and valued. A participatory action approach was adopted to determine the acceptability of the website for parents/carers.

Methods

31 participants (9 parents, 22 professionals) tested a prototype version of the website. Data was collected using the eHealth Impact Questionnaire and the concurrent think-aloud protocol.

Results

Parents and professionals had favorable opinions of the website. Parents' ratings tended to be more favorable than professionals', which was significant for the information and presentation. Participants' thoughts were categorized into seven topics: need, structure/navigation, trust/relevance, language/comprehension, therapeutic content, mode of delivery, and suggested improvements.

Discussion

Many practical and psychological barriers can prevent parents of burn-injured children accessing psychosocial support and contribute to a feeling of isolation. Participants felt that the website would be a valuable addition to UK pediatric burn care. The existence of an accessible resource could help

to normalize parents' experience of their child's injury and reduce their perceived isolation, although peer interaction is not provided by the website.

Practical Value

This online resource, hosting information and peers' personal experiences, offers promising and exciting opportunities to empower parents whilst providing accessible supportive advice to encourage self-care and formal/informal support seeking when necessary.

1. Introduction

Burns are the fifth most common cause of non-fatal childhood injuries[1]. These injuries can have a significant psychosocial impact on parents, affecting their health and mental well-being[2 3]. Parents experience reactive distress including anger, anxiety, guilt, and often doubled responsibilities during the acute phase of treatment[3 4].

Following the trauma of a burn, parents have a unique and integral role in their child's medical care and psychosocial recovery, most notably emotional containment. However, the stress involved in caring for a child undergoing unpleasant/painful procedures can go unrecognized by staff[5] and does not necessarily prompt help-seeking by parents[4]. Failure to appreciate and address this issue may contribute to parents' experience of post-traumatic stress disorder [6].

Throughout the family's post-injury experience, the occurrence of strong parental emotions concerning the burn-event and their long-term impact calls for care initiatives[2]. This is crucial as parents perceive emotional and practical barriers to accessing the currently available psychosocial support[4]. The necessity of support groups, peer-support opportunities, charities, websites and events is supported by the British Burn Association National Standards for Burn Care[7]. **While the standards state that a range of specific support resources should be available and highlighted to patients at all stages of their treatment[4 7], the provision of peer support for parents/carers within the UK is limited[8].**

Development of the intervention described built upon earlier investigations by the authors of the experiences and support needs of parents, as highlighted by 13 participants via semi-structured interview[4] and a further 57 participants via mixed-method questionnaire. Parents recognised the potential value of peer support; however, factors such as guilt, the pain of recollection, perceived stigma, time pressures, distance to the hospital, and financial concerns, could make accessing support difficult[4]. Therefore, online delivery of supportive information could be particularly appealing to parents[4]. With wide-spread internet access and growing dependence on computers and mobile devices, it is common for adults in the UK to seek health-related support and information on the internet[9], thereby benefitting from immediate and easy access to online psychological interventions[10].

It has been advised that self-help interventions should be based on cognitive behavioural therapy (CBT) principles rather than being purely educational[11]. To confirm the appropriateness of the CBT approach, NICE guidelines were consulted[10 12-15]. CBT was also found to be the most frequently reported theoretical orientation used by UK burns psychologists[16]. Therefore, it was logical to

provide information that could complement that which may be provided during professionally-led interventions.

Consequently, a prototype parent-focused peer-informed website was designed by the authors and created by a professional website designer. The design was influenced by five themes applicable to the impact of using health-related websites: 1) information, 2) feeling supported, 3) relationships with others, 4) experiencing health services, **and** 5) affecting behaviour[17]. The website provided information about the common experiences of parents in their own words, CBT-based psychoeducation and stress management advice, information about supporting the injured child and sibling(s), and links to other resources and sources of support.

This article describes a participatory action approach[18], taken with parents and professionals from academic and charity sectors, to determine the acceptability of a website for parents/carers of burn-injured children. The approach emphasises co-learning, participation, and transformation, with the involvement of those with lived experience helping to ensure that the resource was parent-centred, attractive, trustworthy, appropriate, and intuitive for users with varying levels of traditional and computer literacy, and sociodemographic characteristics[18]. This was critical as intervention acceptability is necessary to ensure its implementation, effectiveness, and users' motivation to maintain use of it[19].

2. Methods

This study obtained ethical approval from the Research Ethics Committee of the authors' academic institution. Convenience sampling resulted in 31 participants (9 parents, 22 professionals) from nine UK locations, providing feedback on the prototype website within groups or individual sessions with the first author. Feedback from parents and professionals was gathered separately. After providing informed consent, participants were instructed to complete part 1 of the eHealth Impact Questionnaire (eHIQ), which asked about their general attitudes towards health-related websites[20]. Participants were then presented with the home page of the website on a personal or laptop computer, or using a projector in the group sessions. When more than one person was viewing the website, one person was nominated to be in control of navigation.

Using an approach based on the concurrent think-aloud (CTA) method[21] and informed by reflections from others who have used CTA[22], participants were asked to 'think out loud' as they reviewed the prototype site and to identify aspects that could be modified to improve its usability or relevance to parents/carers. Professionals were also asked to comment on the appropriateness of the psycho-educational content and evidence-based information/advice provided. Initially, there

was a general request that participants ‘think-aloud’ but a range of other prompts were used to assist data collection and emphasise that participants should try to use the website as they would outside the research setting[22]. When participants finished viewing the website, they were asked to complete the eHIQ-Part 2, which asked for their views on the prototype site[20]. For professionals, this was modified to ask how they perceived parents/carers would be impacted by the website. All participants were also asked whether they would recommend the website and to propose a name for it.

All verbalised data was audio-recorded for verbatim transcription and analysis by the research team, using a mix of inductive and deductive content analysis based on established guidelines[23 24]. A categorisation coding matrix was developed that reflected the information sought regarding the content and design of the website but also permitted inclusion of new categories based on issues raised by participants. Analysis was conducted at a manifest level, describing the visible/obvious components of the text rather than interpreting underlying meaning[25].

3. Results

Participant information is presented in Table 1. Overall, participants viewed the website for a mean of 65.5 minutes, with parents viewing the website longer than professionals (mean viewing times were 90.6 minutes and 55.3 minutes, respectively). Some participants viewed every page and others viewed those relevant to themselves.

[Table-1]

Mann-Whitney U tests indicated that, prior to viewing the prototype website, professionals and parents had similar opinions in relation to both online health information and sharing health experiences online, as measured by the eHIQ-Part 1 (Table 2). After viewing the prototype website, the results of the eHIQ-Part 2 demonstrated that parents rated the information and presentation of the website significantly more positively than professionals did. All participants reported that they would recommend the website to others (Table 2).

[Table-2]

The qualitative data produced by participants ‘thinking aloud’ formed seven topic areas (need, structure/navigation, trust/relevance, language/comprehension, therapeutic content, mode of delivery, and suggested improvements) and informed the website’s name. These areas are illustrated in Table 3 using anonymised quotes as examples of the positive and negative feedback. The proportions of responses categorised into each topic area are also provided.

[Table-3]

Feedback was that the website could have a positive impact on parents' emotional wellbeing and transform the delivery of parent-focused psychosocial information following a child's burn injury. Professionals also felt that it was a good pedagogic resource. Additionally, the website received constructive criticism and this, in addition to the researcher's observations of where information was overlooked, informed changes required (in the context of limited time and budget, detailed in Table 3) before its public launch.

Parents and professionals recommended that sub-headings be added to help users find personally relevant information, sections be reorganized to avoid pathologising normal emotional responses, and sub-sections be created to allow users to drill-down to more specific information as needed. Whilst the website was commended for appearing inclusive, it was felt that neglecting to highlight the impact of cultural and social pressures could be perceived as dismissive, therefore such information was added.

The informal language used was praised but feedback suggested that certain clinical/scientific terms should be simplified. Often, parents and professionals had differing opinions about the website's name, emphasising the value of consulting different stakeholders. Parents favoured the insertion of the word 'child' and professionals favoured 'parents' or 'family'.

4. Discussion and Conclusion

4.1. Discussion

This partnership-based method of website development promoted the formation of non-hierarchical collaborative relationships that acknowledged the expertise of relevant stakeholders (parents/carers, health professionals and the research team)[26]. The research team contributed knowledge of evidence-based intervention development and evaluation, parents contributed their experiences and insights, and healthcare professionals contributed their expertise from working with those affected by burn-injuries. Although the observational nature of the CTA method may have caused participants to navigate the website unnaturally, it did provide valuable information on real-time use of the resource by participants with varying levels of website-navigation experience[22].

The website was designed to provide trustworthy burn-specific information to parents/carers, as well as relevant quotes from parents who had shared a similar experience. Feelings of guilt and shame are known to maintain difficulties (e.g. PTSD and depression), and are associated with poorer adjustment in parents[27]. It has been suggested that parents may benefit from psychosocial interventions that normalise their experience, promote self-management skills to tackle blame and

shame (e.g. self-compassion)[27]. It was hoped that such content would decrease users' sense of isolation, whilst providing psychoeducation and direction to other sources of psychosocial support. Providing patient-centered information online would mean that it was accessible if and when parents needed it, without any need to travel or talk about what happened, which would be particularly helpful to those not accessing support due to such barriers[4]. It is evident from the feedback from all stakeholders that these aims were achieved.

Most people can benefit from general population campaigns (e.g. information booklets), with far fewer requiring intensive and expensive higher-level face-to-face interventions[28]. Participants felt that the website would have been a valuable resource in place of information booklets that would enable all parents/carers to access the same information at the same time even when the family was separated. Therefore, this website should be regarded as a targeted campaign: a self-administered, easily accessible intervention that also directs users to higher-level sources of support should they want to access more formal interventions. Revision of the language and reduced use of clinical terms resulted in the modified website obtaining a Flesch–Kincaid grade-level of 8.0 and a Flesch Reading Ease score of 68.1, from previous scores of 8.5 and 65.4. These changes brought the readability of the website more in line with NHS Patient Information Leaflets[29], with the scores indicating that 'plain English' was used and 13 to 14-year-old (8th grade) students would easily understand it.

To help ensure that parents accessed the website when searching for burn-related information, it was important that the name mentioned 'child' as this is where parents' attention was focused. However, a name that suggested its suitability for anyone surrounding the injured child was also thought necessary to avoid exclusion and promote the fact that all those around the child are affected. Therefore, the website was named supportingchildrenwithburns.co.uk.

To promote the existence of the website, it was released on UK National Burn Awareness Day 2018, with promotion from the authors' academic institution, Children's Burns Trust, and social media advertisement. The first author had been building a social media audience through awareness, engagement, connection and loyalty[30]. Fliers and cards were also posted to paediatric burn units for dissemination to families accessing services. In addition to this, users were invited to submit tips and stories to be added to the website (following screening) to provide ongoing search engine optimisation benefits[31].

A strength of this research is the participatory action approach[18]. All participants were encouraged to be constructively critical, empowering them to assist in the development of an acceptable resource that would integrate theoretical and current evidence within the content, whilst

acknowledging the beliefs, motivations, language, culture and practices of potential users and healthcare providers. However, study limitations also warrant discussion. Participants were self-selected and potentially motivated to address perceived deficits in support that they considered important. The sample had little ethnic diversity (93.5% White-British, 6.5% Asian-British) and was not representative of patients and families seen within UK paediatric burns services[32]. While a lack of participant representativeness could be considered a limitation of any participatory research[33], these findings in particular may also reflect a degree of social desirability (attempts to please the first author/website creator), as the research design did not permit anonymous feedback.

As participants may have over-emphasised positive aspects of the website and the anticipated benefits for other parents, and been reluctant to criticise it, further research is necessary. The live website has analytics enabled to monitor visit frequency and duration. Users are also invited to provide ongoing feedback and for evaluation and further development.

4.2. Conclusion

Using a partnership-based method of website development, parents and professionals contributed to an innovative patient-centered resource - the first of its kind in the UK. The website was considered to be a highly acceptable and accessible psychosocial intervention, tailored to meet the specific needs of parents or carers of children with a burn injury. Feedback reflected on the need for such a resource, the structure and navigation, trust and relevance, language and comprehension, therapeutic content, mode of delivery, and improvements that could be made, whilst also assisting in the naming of the resource. It was felt that the website would be a valuable addition to UK pediatric burn care, helping to normalize parents' experience of their child's injury and encourage support seeking when they are struggling.

4.3 Practice Implications

Supportingchildrenwithburns.co.uk hosts information about the common experiences of parents when their child is injured, peers' personal experiences, as well as self-care and stress management information and advice. It contains information and tips on how to support a child through different aspects of burn care and treatment, and information on supporting uninjured siblings. Parents involved in the development of the website also shared their 'top tips' and coping strategies, and quotes from them are included throughout. Staff working within pediatric burns services can direct parents to this resource and it can be viewed in their own time, when they feel ready. Parents highlighted that this may be less overwhelming than being presented with an information pack containing multiple leaflets and allows parents/carers not present at the hospital to concurrently read the same information.

Participants reiterated previous research findings regarding the many barriers to accessing psychosocial support following a child's burn injury[4]. The easily accessible information and psychoeducation within this resource has the potential to help parents/carers overcome some of the emotional barriers that limit access to professionally-led care. The website was described by one parent as "*a one stop shop*" for information and advice on how parents/carers can care for themselves and support their children through what is often a very stressful time. It is hoped that sharing this information will help to normalise parents' experiences, empowering and encouraging them to seek support from family or friends as well as help from professionals if/when they need it. It can also be used by professionals to educate other specialists about parents' post-burn experiences. All visitors to the website have the opportunity to feed into its future development.

References

1. World Health Organisation. Burns Fact Sheet: Media Centre, 2016.
2. Bakker A, Van der Heijden PG, Van Son MJ, Van Loey NE. Course of traumatic stress reactions in couples after a burn event to their young child. *Health Psychology* 2013;**32**(10):1076
3. Phillips C, Rumsey N. Considerations for the provision of psychosocial services for families following paediatric burn injury—a quantitative study. *Burns* 2008;**34**(1):56-62
4. Heath J, Williamson H, Williams L, Harcourt D. Parent-perceived isolation and barriers to psychosocial support: A qualitative study to investigate how peer support might help parents of burn-injured children. *Scars, Burns & Healing* 2018;**4**:2059513118763801
5. Smith AL, Murray DA, McBride CJ, McBride-Henry K. A comparison of nurses' and parents' or caregivers' perceptions during pediatric burn dressing changes: an exploratory study. *Journal of Burn Care & Research* 2011;**32**(2):185-99
6. Callery P. Caring for parents of hospitalized children: a hidden area of nursing work. *Journal of advanced nursing* 1997;**26**(5):992-98
7. British Burn Association. National Standards for Provision and Outcomes in Adult and Paediatric Burn Care, 2018.
8. Batchelor C, Williams L. Survey and Analysis of Adult Group-based Burns Support. 2013. <http://www.dansfundforburns.org/documents/surveyGroupBasedBurnsSupport.pdf>.
9. Office for National Statistics. Statistical bulletin: Internet access – households and individuals, Great Britain, 2018.
10. National Institute for Health and Clinical Excellence. Final Appraisal Determination – Computerised cognitive behaviour therapy for depression and anxiety (review), 2005:1-36.
11. Gellatly J, Bower P, Hennessy S, Richards D, Gilbody S, Lovell K. What makes self-help interventions effective in the management of depressive symptoms? Meta-analysis and meta-regression. *Psychological medicine* 2007;**37**(9):1217-28
12. National Institute for Health and Care Excellence. Depression in adults: recognition and management, 2009.
13. National Institute for Health and Care Excellence. Generalised anxiety disorder and panic disorder in adults: management 2011.
14. National Institute for Health and Care Excellence. Social anxiety disorder: recognition, assessment and treatment, 2013.
15. National Institute for Health and Care Excellence. Post-traumatic stress disorder: management, 2005.
16. Lawrence JW, Qadri A, Cadogan J, Harcourt D. A survey of burn professionals regarding the mental health services available to burn survivors in the United States and United Kingdom. *Burns* 2016;**42**(4):745-53
17. Kelly L, Ziebland S, Jenkinson C. Measuring the effects of online health information: scale validation for the e-health impact questionnaire. *Patient education and counseling* 2015;**98**(11):1418-24
18. Greenwood DJ, Whyte WF, Harkavy I. Participatory action research as a process and as a goal. *Human relations* 1993;**46**(2):175-92
19. Nastasi BK, Varjas K, Schensul SL, Silva KT, Schensul JJ, Ratnayake P. The Participatory Intervention Model: A framework for conceptualizing and promoting intervention acceptability. *School Psychology Quarterly* 2000;**15**(2):207
20. Kelly L, Jenkinson C, Ziebland S. Measuring the effects of online health information for patients: Item generation for an e-health impact questionnaire. *Patient Education & Counseling* 2013;**93**(3):433-38 doi: <https://doi.org/10.1016/j.pec.2013.03.012>[published Online First: Epub Date].
21. Ericsson K, Simon H. Protocol Analysis: Verbal Aspects as Data, revised ed: Cambridge, MA: MIT Press, 1993.

22. Cotton D, Gresty K. Reflecting on the think-aloud method for evaluating e-learning. *British Journal of Educational Technology* 2006;**37**(1):45-54
23. Elo S, Kyngäs H. The qualitative content analysis process. *Journal of Advanced Nursing* 2008;**62**(1):107-15
24. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research* 2005;**15**(9):1277-88
25. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 2004;**24**(2):105-12
26. Power TJ, Blom-Hoffman J, Clarke AT, Riley-Tillman TC, Kelleher C, Manz PH. Reconceptualizing intervention integrity: a partnership-based framework for linking research with practice. *Psychology in the Schools* 2005;**42**(5):495-507
27. Hawkins L, Centifanti L, Holman N, Taylor P. Parental adjustment following pediatric burn injury: the role of guilt, shame, and self-compassion. *Journal of Pediatric Psychology* 2018
28. Rumsey N, Harcourt D. The psychology of appearance: The future. In: Rumsey N, Harcourt D, eds. *The Oxford Handbook of the Psychology of Appearance*. Oxford, UK: Oxford University Press, 2012:679-92.
29. Williamson JML, Martin A. Analysis of patient information leaflets provided by a district general hospital by the Flesch and Flesch–Kincaid method. *International Journal of Clinical Practice* 2010;**64**(13):1824-31
30. Schaefer M. *Known: The handbook for building and unleashing your personal brand in the digital age*. Louisville (KY): Mark W. Schaefer, 2017.
31. Hampson A. How to improve your organic search engine optimisation. *Journal of Aesthetic Nursing* 2018;**7**(1):48-49
32. Richards H, Kokocinska M, Lewis D. A five year review of paediatric burns and social deprivation: Is there a link? *Burns* 2017;**43**(6):1183-88
33. Entwistle VA, Renfrew MJ, Yearley S, Forrester J, Lamont T. Lay perspectives: advantages for health research. *BMJ: British medical journal* 1998;**316**(7129):463

Table 1: Participant information

Factor	n	Descriptive Statistics	
Relationship to child	9	Mother	7
		Father	2
Child's sex	7	Male	4
		Female	3
Child's age at injury	7	Mean	1 year, 6 months
Time since injury	7	Mean	7 years, 4 months
Cause of injury	7	Scald	5
		Hot Surface	1
		Flame	1
Initial treatment	7	Inpatient	6
		Outpatient	1
Surgery required	7	Yes	5
		No	2
Total burn surface area	6	Mean	16.5% (range: 3-50)
Mean time viewing website	9	Parents	90.6 minutes (range: 61-108)
	22	Professionals	55.3 minutes (range: 24-81)
Professional roles	22	Clinical Psychologist	7
		Physiotherapist	3
		Research Psychologist	2
		Assistant Psychologist	2
		Support Organisation	2
		Management	2
		Nurse	1
		Occupational Therapist	1
		Play Specialist	1
		Administration	1

Table 2: Professional and parent scores on the eHIQ subscales and likeliness to recommend

		Professional (n = 22)	Parent (n = 9)	Significance
eHIQ-Part 1	Attitudes towards online health information (5 items)	65.00 (16.25)	70.00 (15.00)	U = 125.00, p = .273
	Attitudes towards sharing health experiences online (6 items)	75.00 (12.50)	75.00 (27.08)	U = 86.00, p = .593
eHIQ-Part 2	Confidence and identification (9 items)	75.00 (12.50)	80.56 (23.61)	U = 115.50, p = .480
	Information and presentation (8 items)	71.88 (15.63)	90.63 (20.31)	U = 149.00, p = .029
	Understanding and motivation (9 items)	77.78 (18.06)	77.78 (16.67)	U = 116.00, p = .480
How likely would you be to recommend this website to others? (5-point Likert scale)		Likely: n = 9 Extremely likely: n = 13	Likely: n = 1 Extremely likely: n = 8	

Median scores (and the interquartile range) are provided. Potential scores on each eHIQ subscale ranged from 0-100; higher scores indicate responses that are more positive. 5-point Likert scale responses ranged from "Extremely Unlikely" to "Extremely Likely".

Table 3: Quotes illustrating the seven topics and name suggestions emerging from the testing and the resultant changes

Topic Area (% = proportion of responses)	Examples	Changes
Need (5%)	<p><i>"It's such a gap with burns care, parent support and resources. Parents just seem to be left to work it out themselves."</i> [Clinical Psychologist, 1]</p> <p><i>"When I arrived at the hospital, I got handed like a wodge of leaflets, which I was like 'oof I can't even think about that now.' My husband wasn't given anything so for us both to have just been given a link to go straight to and then we could have both read the same things, and it always be there so you can find it easy, that would have been really good."</i> [Mother, 2]</p>	
Structure / Navigation (14%)	<p><i>"It's really sectioned out well and it's kind of done in a timeline because there's the initial impact, which would be the first thing you're going to look at, and there's the stress that comes later, then when you get your child home there's all of that."</i> [Mother, 2]</p> <p><i>"Impact on your child should come first. Then impact on family and impact on yourself for the three sort of areas."</i> [Mother, 1]</p> <p><i>"It's not difficult to navigate"</i> [Mother, 3].</p>	Additional section headings added to aid navigation
Trust / Relevance (16%)	<p><i>"It's always really nice to have something that explains who it is that is putting information forwards. Knowing where it's come from then allows you to make the decision whether or not you trust it."</i> [Mother, 4]</p> <p><i>"[The quotes] kind of back up all the things that you've got on the website. You're reading through it and thinking, you can see where that links to places."</i> [Mother, 3]</p> <p><i>"I don't know where it might be, about more cultural diversity. Because I know that, in terms of scarring and healing, different skin types respond differently, and different communities might have different responses to visual scars or stigma around that, so it feels like it needs to be in there. Although there's nothing that's excluding, accept for implicitly, because there's not something to reference that actually there might be something different for different communities."</i> [Assistant Psychologist, 1]</p> <p><i>"I like the live illustration by a parent talking about their kid"</i> [Clinical Psychologist, 2]</p>	<p>Additional information added about the team who developed the website</p> <p>Additional quotes added throughout</p> <p>Additional reference made to cultural differences</p> <p>Additional videos of parent talking about their experience added as well as additional quotes</p>
Language / Comprehension (15%)	<p><i>"I thought the language was very good throughout, it wasn't condescending and it wasn't preachy. It was just a really friendly voice. It's easily read. It's laid out well"</i> [Father, 2]</p> <p><i>"I think it's easy to understand but some of the terms are quite clinical and we understand them but maybe not everyone will."</i> [Clinical Psychologist, 3]</p>	Clinical terms explained in lay language and simplified where possible
Therapeutic content (25%)	<p><i>"You've got a good balance because you've got enough information but you're not trying to pretend to be an expert in scar management or something. And you can tell the content has come from parents' experiences especially because you've got all of the quotes. It's really driven by the parents which is really nice."</i> [Research Psychologist, 1]</p> <p><i>"I think it's pathologising feeling stressed. I think it's important to have the information about PTSD but I almost wonder if it goes into a separate tile called something else. It almost feels like that would fit more under impact on parents and it feels</i></p>	<p>Emphasised that parents with questions about scar management should direct them to their burns team</p> <p>Sections on stress and stress management</p>

	<p><i>more like it would be the impact on them, and then the stress management is the things like the mindfulness and relaxation.” [Clinical Psychologist, 4]</i></p> <p><i>“This is well designed. I think it would be very useful to someone who’s just kind of, ‘I don’t know what I’m doing, my child’s now got a burn, where do I go? What do I do?’ I think that’s quite useful. And I think it would have been useful to use when we were in the earlier stages.” [Mother, 3]</i></p> <p><i>“We get a lot of people avoiding for a long time. So, the stories are all useful, especially someone saying we actually got support. Or I tried mindfulness and this this this this. So that they can see, not only are they being directed to it but then the outcome for someone else when they’re reading that.” [Clinical Psychologist, 5].</i></p>	<p>reorganised and new PTSD section formed</p> <p>Additional parent story added</p>
Mode of delivery (8%)	<p><i>“There is a lot to read and the parents who go on this really want to read it. They don’t want pictures, although it’s nice to have pictures, they’re going on it because they’re doing their homework.” [Support Organisation Employee, 1]</i></p> <p><i>“You don’t really want images, do you? You don’t really want to portray anything, you just want to break up the text.” [Mother, 4].</i></p>	
Suggested improvements (17%)	<p><i>“I think a lot of the pages are quite text heavy. And it’s not necessary to remove any of the text but if you could, for example the explain reassure distract you could make it a bit more colourful or a feature or graphic to break up the text like three little speech bubbles or something.” [Clinical Psychologist, 4]</i></p> <p><i>“Headings are good because I think that means that people get to the information that they need, but it’s not good if you want them to read every single word because it will help them to skip. But if the aim is just to get them to the information that they want, then I don’t think that they ever hurt.” [Mother, 4]</i></p> <p><i>“I think you need more pictures or sketches and I’d also have to say more quotes because I think more quotes are really valuable.” [Mother, 5]</i></p> <p><i>“In terms of scarring and healing different skin types respond differently, and different communities might have different responses to visual scars or stigma around that so it feels like it needs to be referenced, that actually there might be something different for different communities.” [Assistant Psychologist, 1]</i></p> <p><i>“You’ve covered a hell of a lot on this website. I think there should be a bit more of the bloke’s perspective” [Father, 1].</i></p>	<p>Subheadings, logos, quotes, and images used, where possible, to break up text</p> <p>Additional reference made regarding the responses of different communities to visible difference</p> <p>More quotes from fathers added where possible</p>
Name	<p><i>“I think probably support for burn injured children, something like that. Because that’s whoever you are when you’re with that child.” [Mother, 5]</i></p> <p><i>“I said child burn support in the search terms because I wouldn’t be looking for support for myself.” [Mother, 4]</i></p> <p><i>“Parent burns support.” [Clinical Psychologist, 3]</i></p> <p><i>“Family burn support – does what it says.” [Clinical Psychologist, 1]</i></p> <p><i>“Support for parents of a child with a burn... but is it wider than just parents though? Because extended families suffer as much as the parents suffer in the whole experience. Maybe it’s for families, support for families.” [Nurse]</i></p>	<p>Action-based name/URL chosen rather than one which specified a particular target audience</p>