

**SupportingChildrenWithBurns.co.uk: Reporting on 3 years of use of a website developed for the psychosocial support of parents of burn-injured children**

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## **SupportingChildrenWithBurns.co.uk: Reporting on 3 years of use of a website developed for the psychosocial support of parents of burn-injured children**

### **Abstract**

SupportingChildrenWithBurns.co.uk was developed and tested with UK-based parents, burn-care professionals, and members of support organisations. The aim being to create an innovative patient-centred resource, tailored to meet the specific needs of parents/carers of children with burn-injuries, that would be a valuable addition to paediatric burn-care (Heath, 2020).

Whilst websites can never replace the services offered by the NHS, or address the challenges they face, it was hoped that the resource could support services and charities in providing the best care to patients/families in line with models of stepped-care. Having a trusted resource that parents can access any time/place, providing advice for self-care, whilst also normalising access to support, and directing parents to different forms of formal/informal support, may mean that more parents find their needs are, or can be, met.

Evaluation of the website is important to ensure that it is being accessed and to drive future development. Data regarding public access to, and use of, the website over three years (17.10.2018 to 13.10.2021) has been collated using Google Analytics and analysed using descriptive statistics.

Data demonstrates that the website is currently visited an average of 192-times-per-month from users around the world. Information regarding which pages are visited, most often and for longest, suggests that parents' primary focus is their injured child, not their own psychosocial needs; however, accessing information/advice, and seeking shared experiences from peers, is also sought and valued. Further evaluation of the website's impact on the emotional wellbeing of parents/carers following a child's burn-injury would be welcomed.

**Key words:** Co-design, online psychosocial support, burn care

## **Introduction**

Children are particularly vulnerable to burns; they are the fifth most common cause of non-fatal childhood injuries (World Health Organisation, 2016). Every year in the UK, approximately 58,000 children attend hospital for treatment after experiencing a burn. While hospital admission is not necessary for most, around 3,750 children aged under 15 are admitted to hospital with burn injuries, and around 500 children under 16 have severe burns requiring specialist hospital care (British Burns Association, 2015).

It is well known within the burns community that parents suffer psychologically and emotionally when their child is injured (Bakker, Van der Heijden, Van Son, & Van Loey, 2013). However, not all parents want, or feel able, to access support following their child's injury (Heath, Williamson, Williams, & Harcourt, 2018) and, for many worldwide, it may not be available. Nowadays, it is common for people to search for health information online (Office for National Statistics, 2018). Indeed, following a child's burn-injury, Heath (2020) found that many parents do look online for information about how to help their child but, due to a blinkered focus on their child's needs, parents often do not seek support that could be beneficial to themselves and their own adjustment post-injury (Bakker, Van Loey, Van der Heijden & Van Son, 2012; Heath et al., 2018).

For parents' individual needs to be adequately addressed following a child's burn injury, parents should be offered a range of information and support options following a stepped care model (Bessell, Dures, Semple, & Jackson, 2012; Rumsey & Harcourt, 2012). To this end, SupportingChildrenWithBurns.co.uk was developed during a programme of PhD research (Heath, 2020) using a participatory action approach (Greenwood, Whyte, & Harkavy, 1993) with UK-based parents, burn care professionals, and members of support organisations to ensure that the information presented was trustworthy, appropriate, and could meet the identified needs of parents for practical and emotion-focused information and support following the burn event (Heath, Williamson, Williams, & Harcourt, 2019; Lernevall et al., 2020).

Heath et al. (2019) describe the development of the website, and a link to a summary of this is included on the website home page. It was hoped that hosting information and peers' individual experiences online could help to normalise parents' experience of their child's injury, reducing perceived isolation. It could also offer an opportunity to empower parents/carers, whilst providing advice to encourage self-care and formal or informal support seeking when necessary. Additionally,

professionals could use parents' accounts, quotes, and videos to illustrate issues during pedagogic training (Heath et al., 2020).

Following development, there was active promotion of the resource leading to a feature in *The Psychologist* (British Psychological Society, 2018). Feedback and evaluation to date suggests that [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is an accessible online resource, allowing staff to signpost parents/carers to information and support, which can be accessed in their own time, when they feel ready (Heath, Williamson, Williams & Harcourt, 2020). However, if the website is to be an effective psychosocial support resource, it is important to know that it remains a useful tool, without active promotion by the development team. Therefore, this evaluation aimed to review data on the number of users, channels by which the website was accessed, the number of sessions and page views, and basic estimated user demographic information to ascertain whether the website continues to be accessed by the public and, if so, which areas of the website are most visited, in order to inform future development.

## Methods

### Design

[SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) was designed, evaluated, amended, and then released to the public in line with a Plan-Do-Study-Act (PDSA) cycle<sup>1</sup> (Batalden et al., 2015), allowing for a naturalistic evaluation of the intervention's acceptability (Heath et al., 2020). PDSA methodology is applied when tackling complex adaptive problems, where the problem is not completely understood and where the answer is not known. For example, how to facilitate parents' access to peer support and psychosocial support more generally.

PDSAs allow new learning to be built into the experimental process. If problems are identified then revisions can be made, building on learning from the expertise of those closest to the issue (parents of burn-injured children and burn care professionals), with subsequent study to see if changes resolve the problem, and to identify if further problems need addressing; the intended output of the cycle is learning and informed action.

**Plan:** Mixed-method research investigating peer-informed support for parents of burn-injured children concluded that an online resource disseminating parent stories, burn-focused

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<sup>1</sup> The PDSA cycle is a Quality Improvement (QI) method, used in NHS QI projects, focusing on the translation of realistic and achievable ideas and intentions into action, to support the delivery of safe, timely, effective, efficient, equitable, and cost-effective care (Batalden et al., 2015).

information, and psychoeducation may be beneficial for a much wider audience than traditional face-to-face support for those affected by a child's burn-injuries (Heath et al., 2018; Heath, 2020).

**Do:** An initial prototype website was developed and evaluated, using a partnership-based method of website development, with parents and professionals (clinical, academic and support organizations) whose particular expertise was acknowledged and valued to inform amendments.

**Study:** Described in Heath et al. (2019), parents and professionals had favourable opinions of the prototype website. Feedback was categorized into seven topics: need, structure/navigation, trust/relevance, language/comprehension, therapeutic content, mode of delivery, and suggested improvements. The results of that study informed the development of the current version of the website, which was released to the general public.

**Act:** SupportingChildrenWithBurns.co.uk has been publicly available (worldwide) since UK National Burn Awareness Day 2018 (17.10.2018). Heath et al. (2020) describe the positive evaluation of the acceptability and accessibility of the website, as well as the use of it during the first six-months post-release. Google Analytics was used to track the activity of users visiting the website between the release date and National Burn Awareness Day 2021 (13.10.2021) allowing for a naturalistic evaluation of the intervention's continued use.

### **Analysis**

Descriptive statistics of data collected via Google Analytics over a three-year period provides insights including the number of users (new and returning), channels by which the website was accessed, the number of sessions and page views, and the geographical location of users, as well as their age and gender. It should be noted that the largest potential threat to the accuracy of this data comes from users deleting or blocking Google Analytics cookies<sup>2</sup>. For this reason, the data presented should be considered incomplete and interpreted with caution.

### **Results**

Three years of Google Analytics data (17.10.2018-13.10.2021) is collated and described below.

#### **Sessions**

'Sessions' represents the number of times a user was active on the website; users can have multiple sessions if they visit the website multiple times. During the period of evaluation, Google Analytics logged 6905 sessions from 5428 users, equating to 192 sessions of activity on the website per month

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<sup>2</sup> Any individual web user can block or delete cookies resulting in the loss of data for those visits. Website developers can encourage users not to disable cookies, for example, by making visitors more comfortable using the website by posting a privacy policy. A privacy policy explaining the reason for the data collection is included on the website.

from an average of 151 visitors. Over the last three years, 1477 users (21.4%) were return visitors and, on average, the number of sessions per user was 1.3.

### Pages/Session

'Pages/session' represents the average number of pages on the website that users viewed per session. For SupportingChildrenWithBurns.co.uk, this figure is 2.5. New visitors view an average of 2.5 pages per session, and return visitors view an average of 2.7. The top 10 pages on which users spent most time are presented in Table 1.

10 longest viewed website pages	Length of visit (mins)
/impact-on-parents/parent-stories/	4.38
/where-can-i-find-support/books-apps-and-websites/	2.30
/stress-management/avoidance/	2.28
/supporting-your-child/your-child-their-scars-and-the-future/	2.27
/top-tips/	2.23
/supporting-your-child/supporting-siblings/	2.13
/impact-on-parents/adjusting-and-adapting/	2.11
/impact-on-parents/dealing-with-the-reaction-of-others/	2.10
/impact-on-parents/the-impact-on-your-relationship-with-your-spouse-partner/	2.08
/stress-management/relaxation/	2.05

Table 1: Longest visited pages

Following, the home page (5344 visits), the 10 most frequently viewed pages are presented in Table 2.

10 most frequently viewed website pages	Number of visits	% of total visits
/where-can-i-find-support/	773	4.48
/impact-on-parents/common-feelings-after-the-injury/	765	4.43
/supporting-your-child/managing-itchy-scars/	743	4.30
/top-tips/	704	4.08
/impact-on-parents/parent-stories/	660	3.82
/impact-on-parents/	632	3.66
/supporting-your-child/	588	3.41
/supporting-your-child/your-child-their-scars-and-the-future/	538	3.12
/supporting-your-child/managing-itchy-scars/what-can-reduce-the-itch/	391	2.27
/supporting-your-child/scar-management/	379	2.20

Table 2: Most frequently visited pages

### Acquisition Behaviour

The mechanisms by which users find the website are known as channels. Google Analytics revealed four channels through which the users found the website: 1) direct - visits from typing the exact URL

or visits from places that Google cannot determine (43.03%); 2) organic - visits from organic search results from search engines (40.42%); 3) referral - visits from links clicked on other websites (9.02%); and 4) social - visits from social networking platforms e.g., Facebook, Twitter, and Instagram (7.53%).

This data suggests that, as most people typed in the exact URL, they find the website after being informed of the name, perhaps from promotional flyers/cards that were distributed by burn services. High traffic from the organic channel also suggests that people are searching for information or support online, and the website is being found using key words typed into search engines. The fact that some users are finding the website via the referral channel shows that other websites sharing the URL to SupportingChildrenWithBurns.co.uk is helping people to find the website. Finally, whilst social media was initially used to promote the site, and early data suggested that this was beneficial, this channel now directs the least traffic to the website.

### Estimated User Demographics

Based on the users' browser language<sup>3</sup>, most users are from the UK (50.6%), however 50% appear to access the website from other countries (Table 3). This is not completely unexpected given that the website has previously been presented and commended at international burn care conferences.

Google Analytics was able to provide data regarding the sex of 20.34% of the total users, with 28.7% of those being male and 71.3% being female. Data was also provided on 19.83% of users regarding age. From the data available, it appears that the highest proportion of users were aged between 25 and 34.

		%
<b>Sex</b>	Male	28.7
	Female	71.3
<b>Geographic location</b>	UK	50.6
	USA	13.3
	Australia	5.4
	France	3.3
	Canada	2.6
<b>Age range (years)</b>	18-24	14.0
	25-34	34.0
	35-44	22.5
	45-54	14.5
	55-64	7.5
	65+	7.5

Table 3: Estimated user demographics

<sup>3</sup> If website users were using a VPN (Virtual Private Network) which placed their IP address (Internet Protocol address) in a different country, then the geolocation would be inaccurate. However, if these users still accepted cookies, then they would be tracked normally, and their location could be judged by their browser setting for language.

## Discussion

This evaluation aimed to ascertain whether the website [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) continues to be accessed and used, three years after its public release in 2018, in order to drive further development. Such information is important to ascertain as it was found by Schoenebeck and Bruckman (2013) that new websites can experience momentary peaks of interest followed by an abrupt decline in use. Whilst it could be argued that [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) did experience an early peak in interest, owed to widespread promotion on UK National Burn Awareness Day 2018, the data for monthly visits has since been consistent, suggesting that use has stabilised at an average of 151 visitors per month. Using Google Analytics, it has been possible to identify the channels by which users find the website and provide both user and session characteristics; all of which are important considerations to assist future dissemination, development, and promotion of the resource.

Within a stepped care model, the website should be considered a targeted population-based intervention, allowing individuals to search for information that is personally relevant to them. Following its development in the UK, as anticipated, the website is predominately accessed from UK-based users, although it does receive international visitors, with Google Analytics reporting users from 21 different countries during the first 6 months of its existence (Heath, 2020). The newly analysed data from Google Analytics regarding the age and sex of website users suggests that the majority could be mothers of young children. This demographic was expected given that higher rates of burn-injuries are seen in children under the age of five (British Burns Association, 2015; Stockton, Harvey, & Kimble, 2015) due to their rapid motor development, limited knowledge of danger, and increasing exploration of their environment, and that studies have found that mothers in particular suffer psychologically and emotionally when their child is injured (Bakker et al., 2013; Phillips et al., 2007). Although the potential for almost 29% of users to be male requires confirmation through further research, it does relate to the findings of Bragadóttir (2008) who reported that fathers read messages in online parent discussions but rarely write messages themselves.

Data regarding the mechanisms of website acquisition is important to seek as barriers to accessing support come in various forms; people may not be aware of the available support whilst others may be reluctant to access it (Heath et al., 2018). In the case of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), it appears that most users find the website by typing the exact URL into their search engine. Such information is valuable when considering the best ways to promote the resource. During the first 12 months of its existence, flyers and business cards containing the website URL were sent to burn



services to be disseminated to parents; from the data, it seems that this was an effective method of promotion. Following this, it was reported by clinicians that some services also incorporated the website URL into their standard service-specific material.

It is apparent that links embedded in other websites, such as charities, are also referring/taking users to the website. To support dissemination with limited resources, a QR code was also generated and added to waiting room/clinic posters. It was hoped that this could go some way in continuing the advertisement of the website without the need for the re-printing of multiple cards and flyers. Posters containing a QR code can be scanned by parents using their mobile phones or tablets and, with internet access, this links them directly to the website from the hospital without them needing to type in the website address.

Evidence of parents independently seeking support and resources comes from data regarding the second most popular acquisition channel: results of internet search engines. This suggests that people type in key words that bring the website to their attention. The finding that the website is accessed more than once by some parents is encouraging and suggests that it is perceived to be a helpful resource. It is hoped that the website is felt to be trustworthy by virtue of the fact it is promoted via burn care professionals and because the research that led to the development of the website is explained to users who choose to read that section.

There is evidence that 21.4% of users return to the website, with users viewing 2-3 pages per session. The average time that users spend on each page is 2 minutes, which is perhaps not enough time to read all information in any detail. However, with sections having headings and subheadings, the content can be scanned by the user for relevance to them. In line with the findings of studies contributing to this resource (Heath, 2020), data regarding page views suggests that accessing information and advice, and seeking shared experiences from peers, is sought and valued, however often the primary focus of parents is the injured child (Heath et al., 2018). The two most frequently viewed pages are about where support can be found and common feelings of parents after a child's burn injury, indicating that burn services should pay special attention to ensuring that parents are aware that they can access support via them should they want or need it.

### **Limitations**

Participants involved in the development of SupportingChildrenWithBurns.co.uk (both parents and health professionals) were self-selected and potentially motivated to address perceived deficits in

support that they considered important. The sample had little ethnic diversity and therefore was not representative of families seen within UK paediatric burn services (Richards, Kokocinska & Lewis, 2017). It would also be remiss to not consider that the largely positive feedback received regarding the website could be indicative of a lack of representation from the target population, with those involved in development also providing feedback on the resource.

### **Practice Implications**

It is always important to consider the timing of a recommendation or referral to support to ensure that signposting is appropriately matched to identified needs. From the acquisition data, it can be inferred that users are likely to be parents who are seeing or receiving information in hospital or from a charity; they are parents who have either a recently injured child or a child who is still undergoing treatment or follow-up. These parents appear to be actively seeking supportive resources and information regarding peers' shared experiences, therefore may benefit from explicit offers of support from services, as well as peer support, as recommended in the burn care guidelines (British Burn Association, 2018). It is also important to be aware that parents may be unaware of their own needs, particularly if they are not supported to discover them and miss out on opportunities for peer support through the usual contact with services due to COVID-19 restrictions. When considering the impact of COVID-19 on services, a factor which did not impact on access to support when this research was conducted, it is helpful to consider the familiarisation of people with online resources. Hosting information online, which has been informed by the experiences of other parents (peers) and professionals, allows parents to access relevant information, at a time that is convenient, without having to travel or arrange childcare, or find the courage to ask others, especially when feelings of guilt or a focus on the child are acting as barriers to other forms of support (Heath et al., 2018); this is also true when other events (e.g., a pandemic) impact on service access.

### **Future Work**

With evidence to suggest that mothers' and fathers' emotional responses to their child's injury can differ (Egberts et al., 2018), and with more mothers contributing to the development of the website than fathers (Heath, 2020), further research into the value of this resource for fathers could be beneficial to inform further development. Further work to address cross-cultural differences would also be valuable, with Suurmond, Bakker and Van Loey (2020) reporting that limited access to psychosocial care plays a role in heightened distress in ethnic minority parents of children with burns.

Evaluation of the impact of SupportingChildrenWithBurns.co.uk by paediatric burn services would be welcomed, in order to ascertain whether the easily accessible information and psychoeducation within this resource has the potential to influence help seeking behaviour and/or coping, and assist parents/carers in overcoming some of the emotional barriers that limit access to professionally-led care (Heath et al., 2020). It would also be interesting to explore whether parents whose children have been discharged from burns services find the peer voice beneficial and if so, how peer support could be implemented given the barriers to engagement identified (Heath et al., 2018) and potentially exacerbated by the pandemic.

### **Conclusion**

SupportingChildrenWithBurns.co.uk is an innovative patient-centred resource - the first of its kind in the UK – developed with parents and professionals and tailored to meet the specific (sometimes unmet) needs of parents/carers of children with a burn injury. During the first three years, it has received visitors from around the world at a rate of over 150 per month.

As previously reported (Heath et al., 2020), the data collected suggests that the website is considered to be a highly acceptable and accessible psychosocial intervention that is a valuable addition to UK paediatric burn care. It is hoped that the universal sharing of 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.

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