

PEER-INFORMED SUPPORT FOR PARENTS OF BURN-INJURED CHILDREN

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## Abstract

Burns are the fifth most common cause of non-fatal childhood injuries. In addition to the trauma of suffering a burn, the painful and intrusive medical procedures required to treat them can impact on the developing child cognitively, emotionally, psychologically, and socially. A child's burn injuries and their treatment can also have a significant psychosocial impact on parents<sup>1</sup>, affecting their health and mental well-being. Parents can experience a reactive distress including elevated stress, anger, anxiety, depression, post-traumatic stress, guilt, marital and financial problems, and increased responsibility and load, during the acute phase of treatment. Many must also divide their time to meet the needs of any uninjured siblings, and between work, the hospital, and home. This PhD used mixed methods to explore the experiences, access to support, opinions of peer support, and support needs amongst parents and carers of burn-injured children. Thirteen interviews were conducted with parents, followed by a survey of a further 57 parents.

The majority of parents reported that they were offered support, particularly during the acute phase of treatment. Most often, this was from nursing staff. Despite this, many parents also reported to feel isolated. Access to peer support has been recommended in the British Burn Care Standards (2013, 2018), and parents recognised the potential value of this. However, factors such as guilt, the pain of recollection, perceived stigma, time pressures, and distance to the hospital can make accessing such support difficult. The results of this research suggested that online delivery of supportive peer-informed information could be particularly appealing to parents, particularly that which retained the peer voice.

With widespread access to the internet 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. Many parents involved in this research had searched online for burn-related information following their child's injury but found this to be lacking. Therefore, using a partnership-based method of website development, [www.SupportingChildrenWithBurns.co.uk](http://www.SupportingChildrenWithBurns.co.uk) was developed and tested with nine parents and 22 professionals before being publicly released and accessed worldwide. An initial evaluation of the performance of this new resource over the first 6 months is provided.

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<sup>1</sup> 'Parent' will be used throughout this thesis but it is acknowledged that the same or similar issues are likely to be present for primary caregivers and guardians of children affected by burn injuries.

## Acknowledgements

This research was undertaken at the Centre for Appearance Research (CAR) within the University of the West of England, Bristol. CAR aims to “make a real difference to the lives of the many millions of people with appearance-related concerns both in the United Kingdom and across the world” (Centre for Appearance Research, 2005). I received fantastic support and supervision throughout this work from Professor Diana Harcourt and Dr Heidi Williamson from CAR, and Dr Lisa Williams from Chelsea and Westminster Hospital Burns Unit. I cannot thank them enough.

I also need to express my gratitude to all of the parents who were willing to share their experiences and stories with me as well as the participating healthcare professionals within UK burn services who were involved in the research and website development. Big thank yous are also owed to the Children’s Burns Trust, British Burn Association, Changing Faces, the Association of Child and Adolescent Mental Health, and Katie Piper Foundation who helped to promote the research, and to YellowRoad Designs who built the website and worked hard to have it ready for Burn Awareness Day 2018. Finally, thanks must also go to the UWE Bristol for funding this work. Without all of them, [www.SupportingChildrenWithBurns.co.uk](http://www.SupportingChildrenWithBurns.co.uk) would simply not exist. Thank you!

I feel incredibly proud of what has been achieved so far and eternally thankful to everyone who has helped to make this resource a possibility. I hope that through increasing knowledge, understanding, and awareness of the psychosocial impact of a child’s burn injury on parents, and developing a resource that is now being utilised around the world, I have assisted CAR in striving towards their aim.

## Publications resulting from this research<sup>2</sup>

- Heath, J., Williamson, H., Williams, L. & Harcourt, D. (2020). [www.SupportingChildrenWithBurns.co.uk](http://www.SupportingChildrenWithBurns.co.uk): A website developed with parents and professionals for the psychosocial support of parents of burn-injured children. *Burns*, [in press].
- Heath, J., Williamson, H., Williams, L. & Harcourt, D. (2019). Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children. *Patient Education & Counseling*, 102(9), 1730-1735.
- Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). 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*, 4, 1-12.
- Heath, J., Williamson, H., Williams, L. & Harcourt, D. (2018). "It's just more personal": Using multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects. *Applied Nursing Research*, 43, 30–35.
- Heath, J. (2018). Reflections on researcher positionality when using multiple techniques of qualitative data collection to facilitate participation in research focusing on a sensitive subject. In B. Clift, J. Hatchard & J. Gore (Eds), *How Do We Belong? Researcher Positionality Within Qualitative Inquiry: Proceedings of 4th Annual Qualitative Research Symposium* (pp.71-82). Bath, UK: University of Bath.
- Heath, J. (2016). Depression: An antecedent and consequence of burn-injuries to children. *Austin Journal of Emergency and Critical Care Medicine*, 3(1), 1046-1050.

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<sup>2</sup> Copies of these papers are included in the secure pocket at the end of this thesis.

## Conference presentations of this research

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2019, October).

[www.SupportingChildrenWithBurns.com](http://www.SupportingChildrenWithBurns.com): A peer-informed website for the psychosocial support of parents of burn-injured children. Award winning oral presentation at the Australia and New Zealand Burn Association Conference, Hobart, Tasmania.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2019, May). The development and performance of [www.SupportingChildrenWithBurns.co.uk](http://www.SupportingChildrenWithBurns.co.uk). Oral presentation at the 52<sup>nd</sup> Annual Scientific Meeting of the British Burns Association, Leeds, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018, June). Would the development of a supportive online resource be of value to parents of burn-injured children? Oral presentation at the Centre for Appearance Research Appearance Matters 8 Conference, Bath, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018, June). "It's big, and its red and it's obvious": The psychosocial impact on parents of a child's burn injury. Poster presentation at the Centre for Appearance Research Appearance Matters 8 Conference, Bath, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018, April). Development of an online resource for parents of burn-injured children. Oral presentation at the 51<sup>st</sup> Annual Scientific Meeting of the British Burns Association, Swansea, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018, January). Considering Methodological Relations: Researcher positionality when using multiple techniques of qualitative data collection to facilitate participation in research focusing on sensitive subjects. Oral presentation at the 2018 Qualitative Research Symposium (QRS), Bath, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2017, November). Developing accessible support for parents of burn-injured children. Oral Presentation at the Children's Burns Research Network meeting, Birmingham, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2017, September). Developing support services for parents of burn-injured children: Novel ideas based on parents' experiences and opinions about peer support. Oral presentation at the 17<sup>th</sup> European Burns Association Congress, Barcelona, Spain.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2017, June). Developing support services for parents of burn-injured children: Novel ideas based on parents' experiences and opinions about peer support. Oral presentation at the 8<sup>th</sup> World Congress on Paediatric Burns, Birmingham, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2017, May). Developing support services for parents of burn-injured children: Novel ideas based on parents' experiences and opinions about peer support. Award winning oral presentation at the 50<sup>th</sup> Annual Scientific Meeting of the British Burns Association, London, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2017, April). Developing peer support services for parents of burn-injured children. Poster presentation at the European Cooperation in Science and Technology Action IS1210, Ljubljana, Slovenia.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2016, July). Peer support for parents of people with burn injuries. Poster presentation at the Children's Burns Research Network Showcase, Bristol, UK.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2016, June). Peer support for parents of people with burn injuries. Poster presentation at the Centre for Appearance Research Appearance Matters 7 Conference, London, UK.

Heath, J. (2016, May). Managing the psychological impact of burn injuries. Oral presentation at the Primary Care and Public Health 2016 event, Birmingham, UK.

Presentations have also been made at the Centre for Appearance Research, the Psychology Department, and the Faculty of Health and Applied Science postgraduate events (in 2016, 2017, and 2018) at the University of the West of England (UWE Bristol), and at the British Burns Association Psychosocial Special Interest Group Meetings (2016, 2018). The research was featured on BBC Bristol News (2018), Heart FM West News (2018), Appearance Matters: The Podcast (2017, 2018), and BBC Radio Bristol (2016). In addition to this, I incorporated the findings into teaching I provided on the Burn Care and Rehabilitation 40 credit M level module delivered at Southmead Hospital in partnership with the University of the West of England (2018) and the Appearance Collective Workshop 'Supporting Families of People Affected by a Visible Difference' (2019). The findings and output of the work were also discussed during a parents' peer support group and a volunteer training event at a local paediatric burns club (2019).

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## Chapter 1: Introduction

This introductory chapter outlines the aims of the research and the approach to the program of work conducted throughout this PhD. The thesis structure and chapter outlines are presented, followed by information regarding the incidence of paediatric burn injury, the different types and depths of burn injuries, how burn injuries are treated within the UK's National Health Service (NHS), and the importance of psychosocial support, for all those affected, throughout this process.

### 1.1 Language

First, it is important to provide definitions for specific terms used in this thesis. The term 'parent' will be used throughout this thesis, but it is acknowledged that the same or similar issues are likely to be present for carers and guardians of children affected by burn injuries. Therefore, in addition to biological mothers and fathers, under the term parent, it is important to include carers, legal guardians and anyone else who has a significant role in parenting a child who has experienced such an injury, for example, grandparents, aunts and uncles.

The term 'child' will also be used. Child/children refers to any person under the age of 18 at the time of their injury. As this research was retrospective, it may be the case that, at the time a parent participated in the research, their child was an adult themselves.

The term 'burn' will be used to describe injuries sustained by contact with hot liquid or steam (scald), or hot surfaces, as well as flame and flash injuries, or those caused by chemicals. Burns can also be caused by electricity or radiation, but these injuries were not known to be represented in the experiences of any of the parents participating in this research. A major risk for burn injuries is improper adult supervision, although a number of burn injuries in children result from child maltreatment (Mullen, Begley, Roberts, & Kemp, 2019; Toon et al., 2011; World Health Organisation, 2016).<sup>3</sup> The work presented throughout this thesis is in the context of accidental burn injuries.

The term 'peer support' will also be used throughout this thesis. When this term is used, the definition below, cited by National Voices & Nesta (2015)<sup>4</sup>, should be applied:

"...people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial.

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<sup>3</sup> Mullen et al. (2019) cite that, in the UK, estimates of the proportion of paediatric burns resulting from maltreatment are 1%–16%, with burn injuries resulting from neglect or physical abuse occurring at a ratio of 9:1.

<sup>4</sup> National Voices is a coalition of charities that stands for people being in control of their health and care, and Nesta is an innovation foundation with an interest in personalised healthcare and public services.

Peer support is different from other types of support because the source of support is a similar person with relevant experience” (p.3).

## **1.2 Overall aim**

The aims of this program of work were to: (1) provide an in-depth exploration of the experiences and support needs of parents of children who have experienced a burn injury before the age of 18, from the perspective of parents themselves, before (2) developing an intervention that would be accessible and meet the needs identified.

The research investigated the impact of a child’s burn injury and associated treatment, and the challenges these impose on parents. Parents’ experiences of support and their opinions regarding their preferred mode of support was assessed. Parents reported that they preferred professionally-led support to be in a face-to-face format but they would prefer peer support to be online. Therefore, there was consideration of how an online peer support resource could effectively address parents’ needs before a prototype website was created and tested, then modified, prior to its public release.

## **1.3 Approach to the research**

In 2015, the Centre for Appearance Research (UWE Bristol) advertised a PhD Studentship with the title, ‘Peer Support for People Affected by Burn Injuries.’ The PhD would be supported by links with the South West Children’s Burns Research Centre. The opportunity to develop peer support within burn care, whilst being part of a unique, multi-disciplinary research collaboration, was attractive to me as a Clinical Psychologist who was, at that time, working in an adult’s Burns Unit in the UK. I had previously enjoyed developing therapeutic groups in older adult, learning disability, community weight-management, and bariatric surgery services (Saradjian, Heath, & McGregor, 2015). I had witnessed how beneficial groups could be for participants, with the peer support element facilitating participants’ realisation that they were not alone in their experience, aiding learning, and even acceptance, often motivating participants collectively to make helpful changes.

Within burn care, I recognised the lasting impact of the injury on patients and their families. Even when wounds healed physically, sometimes without permanent scarring, patients and families could continue to struggle with psychosocial difficulties relating to the traumatic injury and its psychosocial consequences. As a professional without lived experience of a burn injury, I noticed that patients could be sceptical of, or challenge, advice from professionals. Whilst professionals had medical knowledge, they lacked the experiential knowledge that is only held by peers. Patients and families rarely met others who had shared a similar experience, which could hinder learning from peers that, in time, they could also learn to cope with the physical, psychological

and/or social consequences of the injury. This is an issue exacerbated by the modern burn care ward that often accommodates patients in private rooms.

When this PhD began, within UK burn care, it was recommended that screening for psychosocial difficulties be part of routine care, with referrals being made, when necessary, to the psychology service for further assessment and intervention (National Network for Burn Care, 2013). The 2013 Burn Care Standards also stated that, for both child and adult services within burns centres, units and facilities<sup>5</sup>, “a support group should be available whereby patients, their families and/or carers have access to peer support from others who have experienced burn injuries (pg.10)” (National Network for Burn Care, 2013). In order to comply with the standard, it should be the case that, all patients, their families and/or carers have information and the opportunity to access an age appropriate burn support group (National Network for Burn Care, 2013).

Those statements within the Burn Care Standards demonstrated healthcare professionals’ awareness that self-help and support groups could be valuable elements of burn care rehabilitation, and that their existence should be encouraged. Despite this, in practice, few burn services within the UK provided self-help and/or support groups for patients (Batchelor & Williams, 2013), and no support groups specifically for parents of people with burn injuries were identified via an online search conducted by me in 2016. However, three services were found to be offering a group, befriending service, or club that enabled families to meet and interact. Often, support and resources, social programs and information for patients within the UK were provided by charitable organisations, such as Dan’s Fund for Burns, The Katie Piper Foundation and Changing Faces.

Dan’s Fund for Burns had previously commissioned a survey and analysis of adult group-based burns support (Batchelor & Williams, 2013) and, as a result of this, employed a project manager to develop service provision within this area. What also became clear, from a scoping review of the literature and of available resources, and from conversations with those involved in burn care (professionals and patients), was the consistent conclusion that the wider family of both adults and children who had experienced burn injuries also suffered, and that these people were in need of support too (Blakeney & Creson, 2008; Young, 2004). As a member of the British Burns Association (BBA) Psychosocial Special Interest Group (SIG), I was aware that this conclusion highlighted a disparity between identified patient and family need and current service provision.

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<sup>5</sup> Following the recommendations of the National Burn Care Review (2001), specialised burn services were stratified into three levels of service (National Network for Burn Care (NNBC), 2012): Burn Centres – This level of in-patient burn care is for the highest level of injury complexity and offers a separately staffed, geographically discrete ward. The service is skilled to the highest level of critical care and has immediate operating theatre access. Burn Units – This level of in-patient care is for the moderate level of injury complexity and offers a separately staffed, discrete ward. Burn Facilities – This level of in-patient care equates to a standard plastic surgical ward for the care of noncomplex burn injuries.

This dearth in peer support opportunities for families also existed despite qualitative studies of parents of children with disabilities and special needs, including dyslexia, chronic lung disease and diabetes, strongly suggesting that parents perceive benefits such as, shared social identity, learning from others' experiences, personal growth, and mutual support from peer support programs (Shilling, Bailey, Logan, & Morris, 2015a, 2015b; Shilling et al., 2013).

The argument that the whole family should be considered as the 'patient' during the post-burn period is compelling (Blakeney & Creson, 2008; Young, 2004). The literature demonstrates that the wellbeing of the patient can be significantly influenced by the wellbeing of their family (Blakeney, Robert, & Meyer, 1998), with patients of all ages often relying heavily on family members for support during recovery and rehabilitation following a burn injury. Factors such as parental adjustment, emotional availability, family functioning/environment, and support from family members were consistently identified as influencing positive psychosocial adjustment, post-burn outcomes, rehabilitation and quality of life in children who have experienced burns (Blakeney, Portman, & Rutan, 1990; Landolt, Grubenmann, & Meuli, 2002; LeDoux, Meyer, Blakeney, & Herndon, 1998; Liber, List, Van Loey, & Kef, 2006; Ødegård, 2005; Tarnowski, Rasnake, Gavaghan-Jones, & Smith, 1991). However, recovery and rehabilitation can be time-consuming and result in persistent distress for all involved, with research identifying that parents, especially mothers, suffer psychologically and emotionally when their child is burn-injured (Bakker, Van der Heijden, Van Son, & Van Loey, 2013; Bakker, Van Loey, Van Son, & Van der Heijden, 2009; Cahners, 1988; Phillips, Fussell, & Rumsey, 2007; Phillips & Rumsey, 2008; Rizzone, Stoddard, Murphy, & Kruger, 1994).

The influence of parental and familial factors supports the need for burn services to determine the level of psychosocial support required by each family affected by a burn injury, ensuring that family members surrounding the patient are included in the patient's treatment plan (Blakeney et al., 1998) and adequately supported themselves. In order to provide family-centred psychological interventions (Phillips & Rumsey, 2008), screening of the psychosocial impact of the event on family members is recommended (National Network for Burn Care, 2013). However, there is limited research on appropriate screening methods (Griffiths, Armstrong-James, et al., 2015; Griffiths et al., 2017) and the effectiveness of available support for family members of burn-injured children. This is discussed in more detail in Chapter 2, the conclusion of which points to the need for further exploration of the parental experience of the injury event, treatment and rehabilitation, as well as the support needs of parents during this time. This could then inform further work which would attempt to bridge the gap between literature recommendations and current service provision.

This program of PhD research provided an opportunity to involve parents of burn-injured children in research for patient and family benefit, with the potential to make a significant contribution to future service provision within burn care. By involving those affected in the design of the research, as well as focusing on the parental experience of the event, access to support, and opinions of peer support, participants were viewed as equal partners in planning and developing future support initiatives. Their contribution to this work helped to ensure that post-burn support for parents is better able to meet their needs.

#### **1.4 Thesis structure and chapter outlines**

The thesis begins with a review of what is known about the impact on parents of having a child experience a burn injury (Chapter 2). Following this, there is a discussion of the theoretical underpinnings, appropriate methodology, and the challenges of conducting research in this area (Chapter 3). The program of work that followed took a qualitatively driven mixed methods approach to investigating the experiences and support needs of parents. Chapter 4 presents the findings of qualitative interviews with parents about their experiences, support needs and access to support. The aim of this study was to increase understanding of their experience and whether parents, from their own perspective, felt able to access support, and whether the provision of support was able to adequately meet their needs. Chapter 4 also includes a preliminary discussion of whether peer support was perceived as a valuable or viable way of accessing support by the interviewed parents.

The information gleaned from the interviews was used to develop a focused, study-specific survey that quantitatively explored the areas of interest identified (Chapter 5). This data was also used to validate the interpretation of the interview data. The results from those two studies using different research methods were then mixed to provide a detailed picture of parents' experiences and support needs, and how an online peer-informed support website may address these (Chapter 6). Next, a prototype website was developed and a mixed method feasibility study was carried out with parents, burn care professionals, and members of national charitable support organisations (Chapter 7). The website was then amended according to the results of the feasibility study. Following its public release, an acceptability study was carried out with data collected via Google Analytics and an online survey of its value and appropriateness for parents (Chapter 8). The thesis concludes with a discussion of the implications of the research findings in relation to the latest literature, recommendations for future research, and a reflection on the research process (Chapter 9). The final section of the thesis provides the references and appendices.

## 1.5 The incidence of paediatric burn injury

Burn injuries are one of the most devastating conditions encountered in medicine, with the injury causing traumatic assault to all aspects of the patient, from the physical to the psychological (Gupta & Kumar, 2015). The most severe burn injuries are thought to be the most severe form of trauma that is survivable (Dunn, Reade, Dudley-Southern, Hollingsworth, & Foster, 2015).

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 accident and emergency departments for treatment after experiencing a burn. While hospital admission is not necessary for many children, around 3,750 children aged under 15 are admitted to hospital with burn injuries each year and around 500 children under 16 with severe burns are admitted to hospital for specialist care requiring fluid resuscitation (British Burns Association, 2015; National Burn Care Review, 2001).

Higher rates of burn-injuries are seen in children under the age of five (British Burns Association, 2015; National Burn Care Review, 2001), and subsequently make up the majority (62%) of paediatric burn injury admissions (Stockton, Harvey, & Kimble, 2015); most burns happen to children under the age of three (Pope, Solomons, Done, Cohn, & Possamai, 2007) due to their rapid motor development, limited knowledge of danger, and increasing exploration of their environment. Benson, Dickson, and Boyce (2006) reported the aetiology of paediatric burn injuries, stating that scalds were most common (60%), followed by flame burns (25%), contact burns (10%), electrical burns (2%), chemical burns (2%), and then sunburn (1%). Scalds are most often seen in children under the age of five where 24% of injuries in the UK are caused by hot drinks. Whilst scalds are more common in young children who can pull hot drinks or pans towards themselves, in older children and young people (5-19 years old), flame burns are more prevalent from accidents involving barbecues, campfires and experimenting with fire (Egberts, 2019). The risk of burn injury is also related to certain demographic characteristics. Burns are more common in households with a lower socioeconomic status (SES) (Park, Do Shin, Kim, Song, & Peck, 2009). A significant minority of paediatric burn-injuries are non-accidental, caused by child abuse and neglect (Mullen et al., 2019; Toon et al., 2011), although this classification of injury is not represented in this work.

Approximately 300 deaths occur per year from burn injuries. Deaths are more likely after larger burns, in people aged over 60, when other conditions affect the person's ability to respond to trauma (for example, cardiac disease, diabetes, or a compromised immune system), and when there has also been an inhalational injury (British Burns Association, 2015; Hettiaratchy & Dziwulski, 2004; National Burn Care Review, 2001).



## **1.6 The skin and burn injuries**

Knowledge of the structure of the skin and burn depth is of relevance when planning treatment and predicting healing (Benson et al., 2006). The skin is the largest organ of the body, acting as a protective barrier against injury and hazardous substances, preventing moisture loss, reducing the harmful effects of UV radiation, detecting touch, temperature changes and infections, regulating temperature, and producing vitamin D. The skin has three main layers: the epidermis, the dermis, and the subcutaneous layer. The epidermis is an elastic layer on the outside that is continually regenerated. The dermis is an inner layer, which includes the sweat glands and hair follicles for temperature regulation. The subcutaneous layer is beneath this, made up of connective tissue and fat for insulation.

Superficial epidermal burns (e.g. sunburn) affect the epidermis but the dermis is intact. The skin will be red and painful, but not blistered. Most superficial epidermal burns typically heal with conservative management within seven days and do not result in scarring. When a burn is partial thickness (superficial dermal) it will be pale pink with blistering. In these burns the epidermis and upper layers of dermis are involved. Superficial burns heal in around 14 days, leaving minimal scarring. Deep dermal (partial thickness) burns involve the epidermis, upper and deeper layers of dermis, but not the underlying subcutaneous tissues. When a person suffers a deep dermal burn their skin will appear dry, blotchy or mottled, and red, and is typically painful due to exposed superficial nerves. There may also be blisters. Full thickness burns extend throughout all layers of the skin to subcutaneous tissues. If they are severe, they will also extend into muscle and bone. These burns appear dry, leathery, or waxy and are white, brown, or black in colour, with no blisters and no pain (National Institute for Health and Care Excellence, 2017). Deeper burns are more likely to need excision and grafting (Benson et al., 2006).

The experience of a burn injury, regardless of its size or depth, can be very traumatic and may result in depression, acute stress disorder, post-traumatic stress disorder, sleep disorders (such as insomnia, hypersomnia, and nightmares), and an exacerbation of any previous psychological problems (Dunn et al., 2015). Most people will have some experience of a minor burn injury making burns unlike most forms of trauma. A consequence of this is that people possess at least a partial understanding of the pain, suffering and unpleasantness of such injuries (Dunn et al., 2015).

## **1.7 Treatment of burn injuries**

Advances in the medical treatment of burn injuries means that the mortality rate has decreased resulting in more people coping with complex issues throughout recovery (Andreasen & Norris, 1972; Blakeney, Herndon, Desai, Beard, & Wales-Scale, 1988; Esselman, Thombs, Magyar-Russell, & Fauerbach, 2006). In addition to the trauma of suffering a burn, the painful and intrusive

medical procedures required to treat them can also be profoundly traumatising, resulting in fear and helplessness (Bronson, 2004). When these experiences occur in childhood, they can affect the developing child cognitively, emotionally, psychologically, and socially (Bakker, Maertens, Van Son, & Van Loey, 2013).

A number of different professions work within a multidisciplinary burn team in order to provide the full range of medical and psychosocial care to patients. In the UK, patients with burn injuries should have access to surgeons, anaesthetists, nurses, therapists (e.g. psychosocial specialists, physiotherapists and occupational therapists), as well as specialist clinical support professionals (National Network for Burn Care, 2013).

The medical treatment of burns progresses across two phases from acute care (initial management of the burn wound) to reconstruction (improvement of the functional or visual effect of scarring) over a prolonged period (Dunn et al., 2015; National Institute for Health and Care Excellence, 2014). As well as treatment being painful, it is often time-consuming, and the uncertainty of the outcome can result in persistent distress for the patient and family (Rimmer et al., 2015). According to Hettiaratchy and Dziewulski (2004), there are seven stages of treatment, these are the: (1) initial rescue, (2) resuscitation, (3) retrieval, (4) resurfacing, (5) rehabilitation, (6) reconstruction, and (7) review. Each of these phases are described briefly in Table 1.

### **1.8 The importance of psychosocial support**

When a burn-injured child is hospitalized, they suffer enormous pain, fear, and anxiety in response to the burn event and the treatment procedures (Smith, Murray, McBride, & McBride-Henry, 2011), and each stage of treatment has an impact upon their parents. Children may also regress and therefore require a medical team and family that are supportive of positive adjustment in order to recover/develop the skills needed to become autonomous and confident individuals (Willemen et al., 2011). The reliance of patients and their family members on professionals, other family members, and friends for support can vary greatly due to differing premorbid psychosocial needs (Esselman et al., 2006).

Muangman et al. (2005) found two factors relating to burn survival were the size of the burn and the presence of social support. Social support can have a significant impact on health outcomes (Uchino, 2006), adjustment to injury and disability (Lawrence & Fauerbach, 2003; Li & Moore, 1998) and effective coping (Wallis, et al., 2006; Wilcox, 1981). The support of loved ones can also be associated with compliance with medical care and, therefore, impacts on patients' psychosocial and physical recovery (Cella, Perry, Kulchysky, & Goodwin, 1988).

Stage of treatment	Description
Rescue	Immediately following the injury event, friends, relatives, or emergency services may be those who initially rescue the patient. The decisions made and treatment provided at the scene, particularly the quality of any first aid, can have a profound effect on mortality and morbidity. Later, this experience can adversely affect the rescuer, particularly if they question whether their actions were appropriate.
Resuscitation	When an injury is small and uncomplicated, the patient will require very little systemic support. For larger injuries, in emergency departments and later in hospital wards, care can involve the most complex forms of intensive care, involving fluid infusions (for injuries of 10 per cent Total Burn Surface Area [TBSA] or over in children), support for the cardio-respiratory and renal systems, and intensive nursing care for the skin. High quality pain therapy is always required.
Retrieval	Patients may require retrieval from the primary emergency department assessment site to a facility where more complex and specialist burns treatment can be delivered. This may mean that they receive their treatment far away from home and their family and friends.
Resurfacing	All injuries to skin must be repaired. Following a burn, this can be done using dressings alone, which have to be changed frequently, or by replacing the skin via grafting (where healthy skin is removed from an unaffected area of the body and used to cover lost or damaged skin) if it is so damaged it would be unable to heal spontaneously. When skin grafting is required, surgery may involve removing dead skin, which is a form of secondary trauma or insult to the body. In some cases, admission into an intensive care environment is necessary for extended periods, far beyond the typical length of stay for other forms of trauma needing similar support. This also has psychosocial consequences for the patient and their family.
Rehabilitation	The goal of treatment is to enable the survival and recovery of the individual to their pre-injury state with “unaltered potential.” This usually involves physiotherapy, occupational therapy, and psychological support for both the individual and their family. However, the nature of burn injuries can make this idealistic goal unattainable.
Reconstruction	Post-burn scarring often requires reconstructive surgical intervention. This surgery aims to improve the functional or visual effect of scarring, removing unstable areas of skin and contracting scar tissue, and restoring the aesthetic characteristics of the injured area. This may be done months or years after the initial injury (National Institute for Health and Care Excellence, 2014). The goal is to recover the ability to perform activities relating to home-life, work and leisure, restore feeling, and to facilitate psychological recovery. However, the decision to have further treatment is often complex, requiring surgical opinion and consideration of the psychological impact. Although scars can be improved by surgery, they do not disappear and leave a permanent reminder that a person has been injured (Bradbury, 1996).
Review	Following a burn-injury and reconstruction, there is a lengthy follow-up period where progress is reviewed periodically. This enables professionals to ensure that the reconstructive and therapeutic efforts have a beneficial impact. For children with complex injuries, this review period can continue into adulthood and they may be seen intermittently by the burn service for many years.

Table 1: Seven stages of burn treatment (Hettiaratchy & Dziewulski, 2004)

As well as having the potential to affect the psychosocial development of the child (Grice, Barnes, & Vogel, 2015; Meyer, Blakeney, LeDoux, & Herndon, 1995; Tyack, Ziviani, & Pegg, 1999), burn injuries to children can also have a significant psychosocial impact on parents, affecting their health and mental well-being (Bakker, Van der Heijden, et al., 2013; Mason, 1993; Phillips et al., 2007; Phillips & Rumsey, 2008; Rizzone et al., 1994). A qualitative study by Öster, Hensing, Löjdström, Sjöberg and Willebrand (2014) into parents' perceptions of adaptation and family life after burn injuries in their children revealed a prevailing theme of “feeling quite alone in striving to regain family wellbeing”, connecting parental concerns regarding difficulties with remaining physical problems, affected family relations, alterations in everyday life, and need for parental and family support.

Research with parents of children with physical disabilities and chronic conditions has found that parental coping can be associated with social support, the maintenance of normality, interpersonal resources such as stress management, and understanding of information regarding the medical situation (Cavallo, Feldman, Swaine, & Meshefedjian, 2009; Hummelinck & Pollock, 2006). Horridge, Cohen, and Gaskell (2010) corroborated this, finding that parents who were better supported by their friends, families and communities were better able to cope with adapting their roles and learning new skills. Nevertheless, parents often experienced personal sacrifice to benefit their child's psychological and physical wellbeing. When families are involved with burns treatment, the child does often cope much better long-term, yet how family members provide care and support amid their own, their injured child's, and any siblings' reactions to the injury has rarely been studied (Ravindran, Rempel, & Ogilvie, 2013).

## **1.9 Conclusion**

This chapter has introduced the aims of this program of work, the approach to the research, and the structure of the thesis that follows. It has provided relevant information to set the scene, such as the incidence of burn injuries to children within the UK, terminology used to describe different burns, and how they are treated by medical professionals. The importance of psychological and social support for children and their family when recovering from a burn-injury has also been introduced. More detail regarding the biopsychosocial impact of a child's burn injury on parents is provided in the next chapter (Chapter 2).

## **Chapter 2: The biopsychosocial impact of children's burn-injuries on parents**

The previous introductory chapter introduced the aims of the research and provided relevant information to contextualise the work that follows. This chapter provides an overview of the literature on the biopsychosocial impact of a child's burn injury on parents. The literature review was initially carried out at the beginning of the program of work in 2016 and a subsection specifically relating to depression was published in 2016 (Heath, 2016). The review was then updated in 2019. Without an understanding of the impact of paediatric burn injuries on parents, and what interventions have already been implemented and evaluated, it would not be possible to consider how the development of existing work, or a new intervention, might help parents.

### **2.1 Family demographics**

The most common location for a burn injury to occur is in the home: 78 per cent of children's burn injuries occurred in the home during 2014-15 (Dunn et al., 2015). Although burns are one of the most common household injuries, the physical and psychological devastation they can cause mean that they are a significant cause of mortality and morbidity (De-Souza & Aitken, 1998). Studies suggest that burn injuries occur more often in families that are already more stressed than the general population, or where emotional disturbance is present in parents, or in families in which the child has emotional or behavioural difficulties (Blakeney et al., 1993; Padalko, Cristall, Gawaziuk, & Logsetty, 2019). It has been suggested that high levels of disorganisation and emotional disturbance could contribute directly to these accidents (Cahners & Bernstein, 1979).

Kendall-Grove, Ehde, Patterson, and Johnson (1998) found that 36% of parents whose child experienced a burn injury exhibited at least one of: a history of substance abuse (18%), parental incarceration (18%), involvement of child protection services (17%), a history of psychological disorder (15%), and almost half the sample had low socioeconomic status with limited financial resources. Long and Cope (1961) also found a heightened incidence of psychopathology in the family unit prior to a child's injury. In addition to this, it has been suggested that burns are more likely to occur in single-parent families (Edelman, 2007). Although, the percentage of children who experience a burn injury living with married parents ranges from 60.4% to 68% (Kendall-Grove et al., 1998; Libber & Stayton, 1984; Rimmer et al., 2015). Most recently, Padalko et al. (2019) reported that the literature supports the influence of lower income, lower parental education, behavioural disorders in children, and living rurally with an increased incidence of a child experiencing a burn injury.

### **2.2 The psychological impact**

Information about studies included in this section is presented in Table 2.

Author(s)	Year	Location	Method	Sample Size	Measures
Bakker, Van Loey, Maarten, Van Son, & Van der Heijden	2010	The Netherlands	Quantitative Longitudinal	48 mothers	Impact of Event Scale (IES)
Bakker, Van Loey, Van der Heijden, & Van Son	2012	The Netherlands & Belgium	Quantitative Cross-sectional	182 mothers, 154 fathers	Impact of Event Scale (IES)
Bakker, Van der Heijden, Van Son, & Van Loey	2013	The Netherlands	Prospective Quantitative	182 mothers, 159 fathers	Impact of Event Scale (IES)
Blakeney, Moore, Broemeling, Hunt, Herndon, & Robson	1993	Texas, USA	Quantitative Cross-sectional	89 parents of children with acute burns 31 parents of recovering children	Parenting Stress Index (PSI)
Cella, Perry, Kulchycky, & Goodwin	1988	Chicago, USA	Mixed-method Longitudinal	48 close relatives (42 parents & 6 spouses): 36 females, 12 males	Impact of Event Scale (IES) Spielberger State Anxiety Inventory (SSAI) Beck Depression Inventory (BDI) Beck Hopelessness Scale (BHS) Perceived Stress Scale (PSS) Semi-structured interview
Cella, Perry, Poag, Amand, & Goodwin	1988	Chicago, USA	Quantitative Cross-sectional	36 parents of burn-injured children 22 parents of children hospitalised for other medical procedures	Impact of Event Scale (IES) Beck Depression Inventory (BDI) Profile of Mood States (POMS) Spielberger State Anxiety Inventory (SSAI) Interpersonal Support Evaluation List (ISEL) Beck Hopelessness Scale (BHS) (modified)
De Young, Hendrikz, Kenardy, Cobham, & Kimble	2014	Queensland, Australia	Quantitative Longitudinal	120 parents (111 mothers, 9 fathers)	Diagnostic Infant Preschool Assessment (DIPA) Child Behaviour Checklist for ages 1.5-5 (CBCL) Posttraumatic Stress Diagnostic Scale (PDS) Depression Anxiety Stress Scale-21 (DASS-21) Brief COPE

Dorn, Yzermans, Guijt, & van der Zee	2006	Volendam, Netherlands	Prospective population-based cohort study	418 parents of children involved in the fire 1462 parents of children not involved in the fire	GP and pharmacy records
El Hamaoui, Yaalaoui et al.	2006	Casablanca, Morocco	Cross-sectional	28 mothers	Mini International Neuropsychiatric Interview Hamilton Depression Rating Scale Hamilton Anxiety Rating Scale Global Assessment of Functioning Scale (GAF)
Enns, Gawaziuk, Khan, Chateau, Bolton, Sareen, Stone, Doupe, & Logsetty	2016	Manitoba, Canada	Population-based study	1026 parents, 4858 controls	Health records
Fukunishi	1998	Tokyo, Japan	Quantitative Longitudinal	16 mothers	Hamilton Depression Scale Structured Clinical Interview for DSM-III-R (SCID)
Hall et al.	2005	Massachusetts, USA	Quantitative Longitudinal prospective	62 parents (54 mothers, 8 fathers)	PTSD Checklist (PCL-C) Stanford Acute Stress Reaction Questionnaire Brief Symptom Inventory (BSI) Family Strains Index (FSI)
Hawkins, Centifanti, Holman, & Taylor	2019	Liverpool, UK	Quantitative Cross-sectional	91 parents (63 mothers, 25 fathers, 2 grandparents, 1 stepmother)	Impact of Events Scale-Revised (IES-R) Depression, Anxiety and Stress Scale 21 Trauma-Related Guilt Inventory (TRGI) Trauma-Related Shame Inventory (TRSI) Self-Compassion Scale-Short Form (SCS-SF)
Horridge, Cohen, & Gaskell	2010	Manchester, UK	Qualitative	12 parents (8 mothers, 4 fathers)	Semi-structured Interview
LeDoux, Meyer, Blakeney, & Herndon	1998	Texas, USA	Quantitative Cross-sectional	35 parents (32 mothers)	Child Behaviour Checklist (CBCL) Family Environment Scale (FES) Impact of Events Scale (IES) Beck Depression Inventory (BDI)
Mason	1993	Manchester, UK	Mixed method Longitudinal	57 mothers	General Health Questionnaire Semi-structured interview

McGarry, Elliott, McDonald, Valentine, Wood, Girdler	2015	Perth, Australia	Quantitative Cross-sectional	63 parents (46 mothers, 17 fathers)	Connor Davidson Resilience Scale (CD-RISC) Impact of Events Scale Revised (IES-R) Depression Anxiety Stress Scale
McGarry, Elliott, McDonald, Valentine, Wood, Girdler	2014	Perth, Australia	Qualitative	21 parents (14 mothers, 7 fathers)	Unstructured, face-to-face interviews
Meyer, Blakeney, Moore, Murphy, Robson, & Herndon	1994	Texas, USA	Quantitative Cross-sectional	38 mothers of burn injured children	Parental Stress Index (PSI) Eight State Questionnaire (8SQ) Child Behaviour Checklist (CBCL)
Odar, Brown Kirschman, Pelley, Butz, Besner, & Fabia	2013	Ohio, USA	Quantitative Cross-sectional	45 parents (37 mothers, 8 fathers)	PTSD Checklist Stressor-Specific Version (PCL-S) Child Stress Disorders Checklist (CSDC) Psychosocial Adjustment to Burn Questionnaire
Öster, Hensing, Löjdström, Sjöberg, & Willebrand	2014	Sweden	Qualitative	6 parents (5 mothers, 1 father)	Semi-structured interview
Phillips & Rumsey	2008	UK	Quantitative Cross-sectional	72 parents	Hospital Anxiety and Depression Scale (HADS) Mini Marker Personality Inventory McMaster Family Assessment Device (FAD) Strengths & Difficulties Questionnaire Toronto Childhood Experience Questionnaire Burn Specific Health Scale (BSHS) (extracts)
Ravindran, Rempel, & Ogilvie	2013	India	Qualitative	22 parents/caregivers (9 mothers, 9 fathers, 3 grandmothers, 1 aunt)	Semi-structured interview
Rimmer, Bay, Alam, Sadler, Richey, Foster, Caruso, & Rosenberg	2015	Arizona, USA	Quantitative Cross-sectional	69 parents/caregivers (51 mothers, 11 fathers, 3 grandmothers, 1 grandfather, 3 guardians)	11 item Likert scale survey of common parental problems reported in the burn literature, created by staff
Rivlin & Faragher	2007	UK	Matched cohort study	44 mothers of thermally injured children, 24 mothers of 'fracture' children, 24 mothers of healthy 'controls'	Present State Examination (PSE, 9 <sup>th</sup> Edition) General Health Questionnaire (GHQ) Eysenck Personality Questionnaire (EPQ) AECOM DP Scale (measure of depression) Manifest Anxiety Scale (MAS) Death Anxiety Questionnaire (DAQ) Social Interview Schedule (SIS) (extracts)



Rizzone, Stoddard, Murphy, & Kruger	1994	Massachusetts, USA	Cross-sectional	25 parents (24 mothers, 1 father)	PTSD section of the Structured Clinical Interview for DSM-III-R (SCID)
Rose, Holzer, Tuden, Rosenberg, Herndon, & Blakeney	2005	Texas, USA	Quantitative	148 English parents 142 Spanish parents	Parenting Stress Index (PSI) (English and Spanish versions)
Suurmond, Bakker, & Van Loey	2019	The Netherlands	Prospective Study 1: Quantitative Study 2: Qualitative	Study 1: 120 mothers, 106 fathers Study 2: 33 mothers, 5 fathers, 8 couples	Hospital Anxiety and Depression Scale (HADS) Impact of Events Scale (IES) Semi-structured interview
Thompson, Boyle, Teel, Wambach & Cramer	1999	Kansas, USA	Qualitative	27 family members of paediatric patients with burns	Open-ended interview

Table 2: Study information

### Measures References

- Anxiety Stress Scale (Connor & Davidson, 2003)  
AECOM DP Scale (Conte, Bakur-Weiner, Plutchnik, & Bennett, 1975)  
Beck Depression Inventory (BDI) (Beck, Steer, & Brown, 1987)  
Beck Hopelessness Scale (BHS) (Beck, Steer, & Pompili, 1988)  
Brief COPE (Carver, 1997)  
Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1993)  
Burn Specific Health Scale (BSHS) (Kildal, Andersson, Fugl-Meyer, Lannerstam, & Gerdin, 2001)  
Child Behaviour Checklist (CBCL) (Achenbach & Edelbrock, 1983)  
Child Stress Disorders Checklist (CSDC) (Saxe et al., 2003)  
Connor Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003)  
Death Anxiety Questionnaire (DAQ) (Templer, 1970)  
Depression Anxiety Stress Scale (Crawford & Henry, 2003)  
Diagnostic Infant Preschool Assessment (DIPA) (Scheeringa & Haslett, 2010)  
Eight State Questionnaire (8SQ) (Curran & Cattell, 1974)  
Eysenck Personality Questionnaire (EPQ) (Eysenck & Eysenck, 1975)  
Family Environment Scale (FES) (Moos & Moos, 1994)  
Family Strains Index (FSI) McCubbin & Patterson, 1982)  
General Health Questionnaire (GHQ) (Goldberg, 1978)  
Global Assessment of Functioning Scale (GAF) (Jones, Thornicroft, Coffey, & Dunn, 1995)  
Hamilton Anxiety Rating Scale (Shear et al., 2001)  
Hamilton Depression Rating Scale (Williams, 1988)  
Hospital Anxiety and Depression Scale (HADS) (Snaith, 2003)  
Impact of Event Scale (IES) (Sundin & Horowitz, 2002)  
Impact of Events Scale Revised (IES-R) (Weiss, 2007)  
Interpersonal Support Evaluation List (ISEL) (Cohen & Hoberman, 1983)  
Manifest Anxiety Scale (MAS) (Bendig, 1956)  
McMaster Family Assessment Device (FAD) (Epstein, Baldwin, & Bishop, 1983)  
Mini International Neuropsychiatric Interview (Sheehan et al., 1998)  
Mini Marker Personality Inventory (Saucier, 1994)  
Parenting Stress Index (PSI) (Abidin, 1986)  
Perceived Stress Scale (PSS) (Cohen, Kamarck, & Mermelstein, 1994)  
Posttraumatic Stress Diagnostic Scale (PDS) (Foa, 1995)  
Present State Examination (PSE, 9<sup>th</sup> Edition) (Wing, Cooper, & Sartorius, 2012)  
Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1989)  
Psychosocial Adjustment to Burn Questionnaire (Pelley et al., 2013)  
PTSD Checklist (PCL-C) (Weathers, Litz, Herman, Huska, & Keane, 1993)  
PTSD Checklist Stressor-Specific Version (PCL-S) (Weathers, Litz, Huska, & Keane, 1994)  
Self-Compassion Scale-Short Form (SCS-SF) (Raes, Pommier, Neff, & Van Gucht, 2011)  
Social Interview Schedule (SIS) (Clare & Cairns, 1978)  
Spielberger State Anxiety Inventory (SSAI) (Marteau & Bekker, 1992)  
Stanford Acute Stress Reaction Questionnaire (Cardena, Koopman, Classen, Waelde & Spiegel, 2000)  
Strengths & Difficulties Questionnaire (Goodman, 2001)  
Structured Clinical Interview for DSM-III-R (SCID) (Spitzer, 1985)  
Toronto Childhood Experience Questionnaire (Pertschuk & Whitaker, 1982)  
Trauma-Related Guilt Inventory (TRGI) (Kubany et al., 1996)  
Trauma-Related Shame Inventory (TRSI) (Øktedalen, Hagtvat, Hoffart, Langkaas, & Smucker, 2014)

### ***2.2.1 The immediate response to, and rationalisation of, the injury event***

A burn injury to a child can be one of the most stressful experiences for parents (Hall et al., 2005) and studies have found that parents, especially mothers, suffer psychologically and emotionally when their child is injured (Bakker, Van der Heijden, et al., 2013; Cahners, 1988; Phillips et al., 2007; Phillips & Rumsey, 2008; Rizzone et al., 1994). Horridge et al. (2010) reported parental descriptions of how they were engaged in everyday activities when their child's burn occurred and, in this context of normality, parents were neither expecting nor prepared for the injury. This led to descriptions of the occurrence of the injury as a complete shock and beyond the realms of imagination.

In a mixed-methods study of the implications of a child's burn injury on 57 mothers, Mason (1993) describes the immediate post-injury response as being one of 'shock, horror and disbelief' at one's failure to protect the child from pain and/or injury. Panic could then ensue if there was uncertainty about how to help the injured child during the rescue phase. Horridge et al. (2010) found that, in response to the injury, parents reacted either with panic and hysteria and were therefore unable to help their children, or calmly and thoughtfully and perceived themselves to be more useful in the crisis situation. In a symposium on burns, Francis (1990) reflected on a period of denial where parents felt numb and devoid of emotion about the burn. This was usually brief but could last longer if the accident happened whilst the child was in the care of others.

This initial reaction could be closely followed by attempts to rationalise the incident and its cause (Mason, 1993). Although the event was unintentional (in the population included in this research), an admission was usually produced that ultimate blame was with the parent, and excuses for the incident were made when parents were unable to acknowledge blame. To ease guilt, it has been reported that parents can look for a logical explanation for the event, and those around them can aid the suppression of feelings of culpability by talking about how nothing could have been done differently (Cahners & Bernstein, 1979).

### ***2.2.2 Blame, guilt and shame***

Table 2 demonstrates that most participants in studies regarding the impact of a child's burn on parents are in fact mothers. Fukunishi (1998) found that mothers placed the blame for the injury on their inattentiveness and wished they could have prevented the injury through having chosen a different course of action. Francis (1990) reported that, frequently, the carer said that they were tired or busy at the time of injury. Rizzone et al. (1994) found that guilt and self-blame were very common parental reactions. Fathers may feel guilty about their absence and mothers about their level of supervision (Cahners & Bernstein, 1979).

Mason (1993) reported that when there was denial of guilt, this was usually temporary. The alternative rationalisation suggested by Mason (1993) was that others were to blame for the accident as the mother's own safety precautions were justified. In relation to this, Cahners and Bernstein (1979) suggested that some parents need to blame each other in order to minimise their own guilt.

Guilt and shame are self-conscious emotions, arising from self-awareness of how one is perceived by others or measures up to personal standards (Hawkins, Centifanti, Holman, & Taylor, 2019). Although, the terms guilt and shame are frequently used interchangeably, it has been argued that these two emotions represent distinct constructs, with guilt being a negative evaluation of one's actions (which may be an adaptive response acting to motivate reparative actions) and shame being directed toward the self with a sense of being inferior or deficient (Lewis, 1971; Tangney, 1996). As a burn injury is associated with actual and perceived parental neglect, this makes blame and guilt more likely (Cella, Perry, Poag, Amand, & Goodwin, 1988; Francis, 1990), particularly when it is considered that 90% of burns are preventable (National Burn Care Review, 2001).

There may be gender and cultural differences in the magnitude that guilt and blame are experienced by parents. For example, Rivlin and Faragher (2007) found that mothers of burn-injured girls reported more guilt than boys' mothers. However, Suurmond, Bakker and Van Loey (2019) found that ethnic minority fathers, but not mothers, reported more guilt feelings than Dutch fathers of burn-injured children. Ravindran, Rempel and Ogilvie (2013) found that blame was a core issue experienced by Indian parents and this was described as a secondary trauma. Ravindran et al. (2013) found that Indian parents were criticized throughout the injury trajectory by family members, health professionals and strangers, for not protecting their child from the injury event, and their competence as parents was questioned.

Cahners and Bernstein (1979) wrote that people do not easily accept the appearance of a burned child, therefore they can be a constant source of hurt and unresolved guilt for parents. Mason (1993) also found that scars reinforced feelings of parental guilt and suggested that protective denial of guilt can be supported by covering scars and pressure garments with clothing in the short term, and over the longer term working to decrease the abnormality through mastering aftercare techniques, building knowledge of the scaring and healing process, and adapting to the increased workload of the daily routine. One would hope that today, greater visibility and acceptance of more diverse appearances means that parents struggle less with hurt and guilt due to an altered appearance. However, for parents of children without visible injuries, guilt can be maintained if community support and stress-reducing interventions are less available as they may appear to others to be more fortunate than those with visible injuries (Dorn, Yzermans, Guijt, & van der Zee, 2006).

Guilt may also be exacerbated if children regress developmentally because of the experience and Meyer et al. (1994) reported significantly more guilt for parents of children experiencing greater behavioural problems. Increased feelings of guilt are also associated with poorer adjustment in parents following paediatric burn injuries (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). In a study in which a large proportion of children's burns were small (65% of burns less than 2% TBSA), guilt and shame were found to independently predict measures of adjustment (depression, anxiety, and posttraumatic stress symptoms [PTSS]) in parents/primary caregivers of children who had experienced burn injuries (Hawkins et al., 2019). This supports earlier findings from Cella et al. (1988) and De Young et al. (2014) who found that guilt expressed early after the child's injury had a significant direct effect on acute parent distress, and posttraumatic stress symptoms six months later.

Interestingly, the experience of guilt and shame differed according to the age of the child, with parents of younger children expressing more feelings of guilt but not shame (Hawkins et al., 2019). A possible explanation for this is that guilt is more closely linked to parental responsibility (their parenting behaviour is seen as wrong rather than them feeling inferior/bad as a person) and that a parent's sense of this is related to their child's age (Hawkins et al., 2019). Pugh, Taylor, and Berry (2015) have highlighted that psychologists should be mindful of the impact of guilt and shame in their assessment and formulation of psychological distress as these emotions may constitute barriers to treatment if they are not addressed.

Mason (1993) reported that, for 81% of mothers, perceived failure to protect their child resulted in guilt and a desire to protect the child from further harm. Anxiety regarding future harm, and projection of guilt, can lead to over-protection (Cahners & Bernstein, 1979; Rizzone et al., 1994). Although, overprotection may be unhelpful for the child's recovery (Williamson et al., 2017). Opposed to over-protectiveness, Francis (1990) noted that some parents could ignore the child, withdraw from their care, or fail to visit if they believe the accident was their fault, because they could not bear to see their wounds.

### **2.2.3 Stress**

It is reasonable to assume that stress might increase in parents after a burn injury is experienced by their child as it is a sudden, unexpected, traumatic event, leaving parents little time to prepare for hospital admission and to manage other responsibilities (Blakeney et al., 1993; Francis, 1990). Self-blame has also been found to be a significant predictor of stress (Cella et al., 1988).

The hospitalisation of a child can impose stress on a family as parents need to attend the hospital whilst also caring for other children, managing work commitments, housekeeping, cooking, and worrying about the threat of death or disfigurement to their child (Blakeney et al., 1993; Francis,

1990). Cella et al. (1988) found evidence of this strain when 29% of parents approached to participate in their study declined; 20% reported that this was because they lacked time and were feeling under too much pressure.

Cella et al. (1988) found that, within 72 hours of their child's injury, parental levels of distress were high; 52% of their participants appeared to be suffering from an acute stress response and difficulties with coping tasks were extensive for all of their participants. De Young et al. (2014) found a lower rate of stress in their sample during the acute post-burn period, with 23% of parents experiencing moderate to extremely severe levels of stress. Rizzone et al. (1994) suggested that maternal stress symptoms were related to TBSA, with more stress being reported for larger burns. However, Meyer et al. (1994) found no association between stress with burn size in their sample of parents.

Cella et al. (1988) reported that parents of burned children suffer significantly more specific reactive distress (emotional reactions triggered by reminders of the traumatic event and attitudes towards it) than parents of children hospitalised for other reasons. Mason (1993) also found that parents reported being preoccupied with thoughts of the accident and experienced extremely high levels of intrusive and avoidant stress responses in an attempt to block such thoughts, resulting in an inability to concentrate, and exhaustion.

Following discharge from hospital, during recovery, immediate adjustment must take place to find time required for skin care and scar management (Cahners & Bernstein, 1979). During this time, demands continue to be high and so does parents' chronic stress. The usual family roles and responsibilities remain but in addition to these, attending hospital is replaced by responsibility for time-consuming and sometimes painful procedures for the child. De Young et al. (2014) found that after one month, 15% of parents still experienced moderate to extremely severe levels of stress. Cella et al. (1988) found that stress remained moderately high after two months, and specific stress response symptoms persisted despite improvement in ratings of anxiety and depression. They proposed that a stress response identified after six months was a chronic rather than a delayed response. However, at six months, 92% of parents in the study by De Young et al. (2014) were in the normal to mild range for stress.

Blakeney et al. (1993) found no significant differences between overall stress scores for parents of children with burns, either in the acute stage, during recovery or when compared to the normative sample of scores for the Parenting Stress Index (PSI) (Abidin, 1986). This study refutes the idea that stress is an etiological factor as high perceived stress would be expected. However, one would also expect the trauma of a burn injury to cause increased stress for the reasons mentioned above and so perhaps the measure used by Blakeney et al. (1993) - the PSI (Abidin,

1986) - was an inappropriate measure of stress in this population as it assesses a multitude of stressors rather than immediate reactions to trauma. For example, Cella et al. (1988) found that relatives of children with burns were more likely to respond with anxiety and stress responses specific to the traumatic event than would be reflected in the more general factors assessed by the PSI.

Although no significant differences were found between overall or total stress scores for parents of children with burns, Blakeney et al. (1993) did find that the pattern of stress scores differed significantly for parents of recovering children, compared to parents of newly injured children and the normative sample of scores. Parents of recovering children more frequently attributed the source of their stress to the child with burns; whereas parents of children without burns, or those with recent burns, attributed stress to be more evenly distributed between personal characteristics and their children, rather than with the burn-injured child. Meyer et al. (1994) also found that the mothers of children an average 3.6 years post-injury rated situational/ demographic life stress as only one third of the stresses of the normative population for the PSI, although these parents were reported to be more inwardly focused and reported higher levels of guilt and depression. However, there was a strong correlation between scores on the Child Behaviour Checklist (CBCL) (Achenbach & Edelbrock, 1983) and PSI, demonstrating that mothers of children with greater problems generally scored higher in total stress.

Blakeney et al. (1993) reported that parents described their children to be demanding, dependent, and unhappy during recovery, and perceived them to be overly active and restless. Blakeney et al. (1993) also suggested that these parents may experience disappointment in the child and do not find them to be a source of positive reinforcement, which will ultimately weaken the parent-child bond. They proposed that these parents were unlikely to be able to recognise, and therefore deal with, actual sources of stress because the burn-injured child is blamed/scapegoated for difficulties. In addition to changes in parent-child relationships, parents of burn-injured children may also experience changes in their marital relationships (Cahners & Bernstein, 1979). New pressures and responsibilities brought on by the injury, the guilt and the blame, can trigger separations. However, sometimes the strain can bring couples closer together (Cahners & Bernstein, 1979).

Research has also considered cultural differences in terms of parent-reported stress and coping in parents of burn-injured children. Rose et al. (2005) evaluated differences in Spanish-speaking and English-speaking families, finding significant differences between the two language versions of the of PSI suggesting cultural differences in how coping and stress are manifested. Spanish-speaking parents noted significantly higher overall levels of parenting stress than those who were English-speaking, and this was deemed to be due to a true difference in stressors and coping resources as

opposed to translation of the PSI. This difference could be related to family structure and engagement in supportive relationships with medical staff.

#### **2.2.4 Worry**

A greater degree of worry has been found in mothers of burn-injured children than in mothers of children with fractures and healthy controls (Rivlin & Faragher, 2007). Immediately following injury, parents can worry about whether their child will live, regardless of burn size (Verity, 1995). Thompson, Boyle, Teel, Wambach and Cramer (1999) reported that parents worried about pain, skin graft surgery, scarring and infection. More recently, Rimmer et al. (2015) reported that the physical pain experienced by the child was rated by all parents participating in their study as the most difficult element of their child's burn injury. In the early stages of aftercare, dressing changes frequently caused parents concern since they involved further pain for the child (Francis, 1990) – parents worried about hurting their child, which could then add to the emotional pain and distress caused by their perceived protection failure (Mason, 1993). When the child protested against the often painful care regime, this fed back into guilt and the mother's stress and anxiety (Francis, 1990; Mason, 1993).

An earlier study by Rivlin, Forshaw, Polowyj, and Woodruff (1986) reported that parents worried most about the effects of scarring followed by skin grafts. Rivlin et al. (1986), and more recently Verity (1995), described parental fears associated with aftercare and psychological after-effects. Concerns were multiple and included: mobility, physical condition, coping at home, other people's attitudes towards the injury and scarring, length of hospital admission, school activities, behaviour, surgery, accidents, pressure garments, sun exposure, physical sensitivity, future physical growth, home conditions, pain, explaining the burn to other children, feeding, itching, and the child's ability to live a normal life post-injury. Worry about issues such as the child's physical problems and affected family relations can lead to parents feeling alone (Öster et al., 2014). However, when parents see their child improve and retain optimism and hope about their situation, this can assist parents' coping (Thompson et al., 1999) .

#### **2.2.5 Anxiety**

Mason (1993) and Rivlin and Faragher (2007) found that anxiety was a somatic symptom frequently reported by parents following a child's burn injury. Parents with a history of a diagnosed mental illness have been found to experience significantly more anxiety than parents who did not have a mental illness (McGarry et al., 2013). Horridge et al. (2010) described that the lack of certainty regarding how and when their child's physical injuries would heal, along with the lack of control experienced in an inpatient setting when under the care of professionals, increased parental anxiety. Additionally, parents reported that seeing their children respond to their injury

with a stress reaction (such as disturbed sleep, heightened anxiety, and depression) were factors that heightened their own anxiety.

Phillips and Rumsey (2008) also found that, during the inpatient phase, parents of burned children, without previously identified mental health issues, exhibited high levels of clinically significant anxiety. Although McGarry et al. (2013) did not find significantly elevated levels of anxiety in a sample of 63 Australian parents of children injured within one week (compared to normative data from the US general population), De Young et al. (2014) found that during the acute post-burn period, 18% of parents experienced moderate to extremely severe levels of anxiety and, after one month, this fell to 12%. Cella et al. (1988) also found that anxiety dropped between 72 hours post injury and six to eight weeks, and continued to decline in subsequent months to a normal level. Hawkins et al. (2019) found a slightly higher prevalence of anxiety in the first eight weeks post burn, reporting that a quarter of mothers and fathers reported symptoms indicative of moderate to severe anxiety. They also found that younger child age predicted symptoms of parental anxiety. These findings closely resemble rates of anxiety reported by parents in other recent burns literature (Egberts, van de Schoot, Geenen, & Van Loey, 2018; Rodríguez-Rey, Alonso-Tapia, & Colville, 2018). De Young et al. (2014) and Cella et al. (1988) found that generalised anxiety appeared to remit spontaneously six to eight months post burn-injury, with De Young et al. (2014) demonstrating, at six months, that 92% of parents were in the normal to mild range for anxiety which is comparable to the normal population in Australia.

However, fluctuating levels of anxiety and depression at different time points following discharge from hospital have been noted (Phillips & Rumsey, 2008; Rossi, da SC Vila, Zago, & Ferreira, 2005). Phillips and Rumsey (2008) found that, early in the outpatient phase, parents reported higher levels of general anxiety and moderate depression; parents at the mid-term stage (6–24 months) reported general anxiety and the highest level of depression, and for the sample that were more than two years post-burn, it appeared that parents again reported general anxiety as the dominant adjustment issue. Increased anxiety two years post-burn is also supported by a Canadian population study. Enns et al. (2016) found that there were increased rates of anxiety, as well as depression and substance abuse, in parents of burn-injured children compared with control parents from the general population. These relative rates remained significant even after adjusting for sex, geography, and income with control parents in the two years after the burn injury date (Enns et al., 2016).

### **2.2.6 Depression**

The high levels of clinically significant anxiety exhibited during the inpatient phase found by Phillips and Rumsey (2008) were strongly associated with depression, which is suggestive of a



global impact of the burn event on parental well-being. Cella, Perry, Poag, et al. (1988) and Rivlin and Faragher (2007) found that depression was more pronounced in parents of burn-injured children than in parents of children hospitalised for other reasons. Mason (1993) also found that depression rose significantly at the time of hospital interview compared with retrospective pre-injury ratings and, within 72 hours of injury, 30% of participants were in the clinically depressed range on the BDI.

Although McGarry et al. (2013) did not find significantly elevated levels of depression in a sample of 63 Australian parents of children injured within one week (compared to normative data from the US general population), De Young et al. (2014) found that during the acute post-burn period, 22% of parents experienced moderate to extremely severe levels of depression. After one month, this fell to 14%, and similarly, Cella et al. (1988) also noted that depression dropped between 72 hours post-injury and the six to eight week follow-up. Again, Hawkins et al. (2019) found that a quarter of mothers and fathers in their sample reported symptoms indicative of moderate to severe depression. They also found that younger child age predicted symptoms of depression, resembling the findings for depression reported in other recent literature (Egberts et al., 2018; Rodríguez-Rey et al., 2018).

At six months post-injury, De Young et al. (2014) found that 93% of parents were in the normal to mild range for depression which, like anxiety, was comparable to the normal population in Australia and supports Cella et al. (1988) who found that depression continued to decline in the subsequent months to a normal level. It seems from these studies that, typically, depression remits spontaneously six to eight months post burn-injury.

The findings of Mason (1993) demonstrated a similar decrease in depression as measured by the General Health Questionnaire (GHQ) up to six months, although 17.5% of mothers in that sample reported that, at some stage during the initial six months post-injury, they had contemplated suicide or felt their life was not worth living. The difference between Mason's results and those of the other studies is that scores on the GHQ at six months were still twice that rated for pre-injury. It is possible that the retrospective pre-injury data was not accurate but, should it be accurate, it demonstrates persistent symptoms of depression. Compared to a randomly-selected community sample of women, the pre-injury depression scores of mothers of burn-injured children refuted the suggestion that parental psychiatric morbidity, particularly maternal depression, was a contributing factor to children's burn-injuries (Mason, 1993).

Blakeney et al. (1993) explored depression over a longer follow-up period and found that the depression score of the parent domain of the PSI changed significantly from year to year for parents of children recovering from a burn injury. Regardless of burn size, Meyer et al. (1994)

found that parents reporting greater problems on the CBCL (Achenbach & Edelbrock, 1983) also reported statistically more depression than those reporting less problems with their children. Blakeney et al. (1993) found that parents assessed at two years post-burn were significantly more depressed than all of the other parents. Those assessed at year three appeared to 'normalise' and those assessed at years four and five reported significantly less depression than either the normative sample or the group of parents with newly burnt children. Higher parental depression at two years post-burn suggests that the time when the child's treatment regime is most involved for parents is the time when parents may struggle most to adhere to such a demanding regime; this could result in a positive feedback loop which could lead to more depression and guilt (Blakeney et al., 1993).

Few studies have examined cultural differences in parents' responses to their child's injury. Suurmond et al. (2019) examined psychological distress following a child's burn-injury in ethnic minority parents and native Dutch parents. Their quantitative findings confirmed that ethnic minority parents experienced more symptoms of depression following their child's burn event when compared with native Dutch parents and it was suggested that this may be explained by impaired social support, hampered medical communication, maladaptive aspects of religious coping, and barriers to psychosocial support.

### ***2.2.7 Grief and sadness***

Cahners (1979) described the painful process of mourning which is endured by families of burn-injured children for months or even years after the traumatic loss of function, self-image, what was 'normal' and, for some, even life. On top of the stress of surgery, hospital admission, scar management, the emotional, financial and practical stress on the child and family, unresolved past losses or grief experiences can be triggered and provoke difficult emotions for parents to manage (Verity, 1995).

In a descriptive article illustrating the impact of facial scars on the family, Adriaenssens et al. (1987) described their experience of providing therapeutic sessions to over 20 families, where parents reflected on feeling glad their child had survived but that occasionally their looks could make them miserable. The realisation of the consequences of the accident caused parents to mourn the loss of their 'perfect' child and a self-perception of themselves as a good parent (Mason, 1993).

### ***2.2.8 Hopelessness and helplessness***

Cella et al. (1988) found that, in general, parents of hospitalised children were highly distressed; however, hopelessness was more pronounced in parents of burn-injured children than in parents of children hospitalised for other reasons. Horridge et al. (2010) reported parental helplessness at

their inability to fulfil their parental role of protecting their child. This could negatively impact on parents' confidence, leading to them questioning their ability to be 'good enough' parents, and to worry about whether their child would fully recover, physically and psychologically, from their experience. In addition to this, Francis (1990) found that when parents were not able to cuddle their child, this increased their feelings of inadequacy.

Despite finding normal perceived stress levels in the years post-burn, Blakeney et al. (1993) found that parents appeared to respond with increased sadness and feelings of hopelessness which could peak at around two years after the burn event. In contrast to this, within the first 72 hours post-burn, Cella et al. (1988) did not detect any significant magnitude of hopelessness amongst relatives of children with a mean TBSA of 21%, despite their distress. It was suggested that denial of the injury and its potential consequences, and remaining active (at work or by visiting the hospital) could reduce hopelessness and potentially aid adequate coping (Cella et al., 1988).

During the outpatient phase, parents receive regular advice from professionals with instructions of what they need to do to promote their child's recovery, further preventing them from making independent decisions and potentially further diminishing their confidence in their roles as parents. Horridge et al. (2010) wrote that parents described how they doubted their abilities to make what would usually be minor decisions. This could stem from the impact of their perception that they have already failed to protect their child (Mason, 1993), from a learnt dependence on staff, or also because, with a heightened level of stress, it is naturally difficult to make such decisions. One way of helping a parent to deal with helplessness (and guilt) is through their active involvement in decision making about practical aspects of their child's care. As this is also an important and necessary aspect in the provision of quality care (Foertsch, O'Hara, Stoddard, & Kealey, 1996; Garland & Kenny, 2006), members of a medical team typically expect the presence and participation of a parent/caregiver during medical procedures, assisting in their child's recovery, rehabilitation, and resocialisation (Stolbova & Broz, 1999). However, professionals should be mindful that parents do not become overinvolved, resulting in overprotectiveness and depriving other siblings of attention (Cahners & Bernstein, 1979).

### ***2.2.9 Posttraumatic stress syndrome and posttraumatic stress disorder***

Studies have investigated post-traumatic stress in parents of burn-injured children, but studies differ in the use of terminology. Whilst some studies present symptoms of post-traumatic stress disorder (PTSD), others acknowledge a lack of information from structured diagnostic interviews, which limits their generalizations beyond questionnaire scores to clinical diagnosis of PTSD, and therefore refer to post-traumatic stress syndrome (PTSS) during the acute phase of paediatric burn injuries.

Egberts et al. (2018) reported that, in the immediate aftermath of a burn event, between 24% and 50% of parents in the Netherlands were found to meet clinical criteria for PTSS. In an Australian sample of 63 participants 21.3% were reported as meeting the threshold for clinical concern within one week of the burn occurring (McGarry et al., 2013). Hawkins et al. (2019) found that 32.8% of mothers and 40% of fathers in the UK met clinical criteria for PTSS during the first 8 weeks following their child's injury. In a larger Australian study of 120 parents, De Young et al. (2014) found lower rates of PTSD. They reported that 22% of parents had probable PTSD one month after their child's injury. However, there was a significant reduction in both PTSD prevalence rates and PTSS from one to six months. Five per cent of parents continued to have a probable PTSD diagnosis at six months, and 11% were experiencing PTSS in the moderate to moderate-severe range. For 13% of parents, their symptoms were also causing a moderate impairment in functioning. In the USA, Odar et al. (2013) reported that, overall, 29% of parents reported clinically significant symptoms on at least one PTSD symptom cluster, and 13% reported symptoms on at least two. Of the parents in their study, 4% met diagnostic criteria for PTSD within one year of the burn injury. A reduction in PTSS overtime was also supported by Egberts, Van de Schoot, Geenen, and Van Loey (2017) in a sample of 111 mothers and 91 fathers, finding that within the first month post-burn, 48% of the mothers and 26% of the fathers reported clinically significant PTSS, which decreased to 19% and 4% respectively at 18 months. Egberts et al. (2017) found that symptoms of intrusion were mainly individually experienced, whereas parents within a couple were more similar in terms of their avoidance symptoms. The perceived threat to life, and feelings of guilt and anger linked to the burn event, were significantly related to parental PTSS, especially in mothers (Egberts et al., 2017).

According to Rizzone et al. (1994), 28% of parents reported no symptoms of PTSD at any time after the child's burn injury, leaving 72% of parents reporting that they had experienced symptoms, 56% reported that their symptoms had persisted and they were, at the time of the study (mean = 7.3 years post-injury), experiencing symptoms of PTSD. Of the sample of 25 parents (24 mothers), 52% met diagnostic criteria for acute PTSD with symptoms beginning within six months of the burn trauma and continuing for years for four of those 13 parents. No parents in that sample had delayed onset PTSD.

When looking at predictors of PTSS, De Young et al. (2014) found that acute parent distress and concurrent child PTSS emerged as the best predictors of parent PTSS at one month. At six months, predictors for parents' PTSS were the number of invasive procedures the child had undergone, acute parent distress, parent PTSS at one month and concurrent child PTSS. Path analyses showed that a greater number of invasive procedures predicted higher parent PTSS at one and six months, and prior trauma history was associated with more PTSS at one month (De Young et al., 2014).

Many studies of the impact of a child's burn injury on parents included a larger proportion of mothers than fathers, but Hawkins et al. (2019) were able to establish that whilst more fathers reported clinically significant symptoms of PTSS than mothers (who were present during the child's hospitalization or burn dressing appointment), overall mothers and fathers did not differ statistically in severity of PTSS symptomatology. Greater number of family mental health diagnoses and familial stress prior to the burn event have also been related to total parent PTSS, and greater PTSS was associated with greater levels of stress (Odar et al., 2013).

Some parents show symptoms of posttraumatic stress disorder (PTSD) many years after the injury (Bakker et al., 2009). Using hierarchical multiple regression, Rizzone et al. (1994) showed that TBSA and proximity to the trauma predicted past and present PTSD in the first step, and perceived stress and social support at the second step. In that study, TBSA was the strongest predictor of PTSD symptoms which conflicts with the results of Cella, Perry, Kulchysky, et al. (1988) who found that burn severity was not a predictor but blaming oneself for the injury was a significant predictor.

Hawkins et al. (2019) found that longer stays in hospital and younger child age were associated with higher levels of PTSS in parents. However, factors not found to be associated with parent PTSS by Odar et al. (2013) were: parent age, gender, ethnicity, income, parental education, or marital status, level of support received by friends and family, the number of days a child spent as an inpatient, time since injury, and parental presence at the time of injury. This highlights inconsistencies in findings between studies. Hawkins et al. (2019) also highlighted another confounding factor; whilst length of hospitalization did predict symptoms of PTSS, it was also possible that hospitalization may be related to variables not measured in their study, such as pain or smoke inhalation, which in turn may be associated with PTSS. Supporting Odar et al. (2013), Suurmond et al. (2019) also found more symptoms of posttraumatic stress in ethnic minority parents compared to native Dutch parents.

### **2.2.10 Anger**

Parents of children who suffer burns can also experience feelings of anger as a result of the burn event. They love their child but feel angry that they played with fire (Adriaenssens et al., 1987). When there is death of a partner in the injury-event, the remaining parent can feel anger at having to be the one left to face the problems and challenges (Cahners, 1979). Verity (1995) also wrote about anger being expressed by the parent absent at the time of the accident, directed at the parent who was the caretaker. This reaction can further fuel the distress felt by the parent who had responsibility for the child's safety.

### **2.3 The social impact**

Due to inherent expectations and a societal focus on aesthetics, anyone who has an altered appearance can experience staring and mocking (Rumsey & Harcourt, 2012b), and Adriaenssens et al. (1987) wrote that parents must side with their child because society will not. Social dysfunction and isolation can be perpetuated by the reactions of others (Mason, 1993) and mothers of burn-injured children can experience more (but not significantly so) social unease because of a lack of self-confidence with other people than mothers of children with fractures and healthy controls (Rivlin & Faragher, 2007).

In attempting to manage their stress and anxiety, parents may develop coping strategies including heightened safety-consciousness (Verity, 1995) and overprotectiveness (El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006; Horridge et al., 2010; Rizzone et al., 1994), controlling (LeDoux et al., 1998) and restricting their child's activities in the hope that this will minimise the chance of further injury (Hall et al., 2005; Horridge et al., 2010). Such reactions can impact negatively upon relationships and family dynamics and affect the capacity of a family to adapt to different situations (Rossi et al., 2005).

Roles and routines within the family have been found to change noticeably to enable parents to deal with the various issues arising from the burn and the treatment regime, in order to promote the physical recovery of the child (Horridge et al., 2010; Mancuso, Bishop, Blakeney, Robert, & Gaa, 2003). Post-injury, parents are required to learn a variety of new skills needed to care for their child, to promote their physical recovery, which (as discussed) often involves making large adjustments to family life. This means that, during the acute phase of treatment, parental responsibilities are increased (Cella, Perry, Kulchycky, et al., 1988).

All of this change and new learning must occur within the context of "normal" life, which usually involves a job, other children and other commitments. This results in greatly increased parental responsibilities and load (Cella et al., 1988; Phillips & Rumsey, 2008). Therefore, parents must develop the flexibility that allows them to attempt to find a balance between these elements. This is a difficult task if lifestyles are inflexible because of full-time work or a family lacks access to support networks (Horridge et al., 2010). Within the context of low self-confidence and self-doubt, these demands can further test parents (Horridge et al., 2010).

### **2.4 The physiological impact**

In addition to the emotional and social consequences of burn injuries, such traumatic experiences can also trigger intense physiological reactions in those affected (Norris et al., 2002; Yzermans et al., 2005). Following the 2001 New Year's Eve fire at a pub in Volendam, the parents of those involved were subjected to a number of stressful experiences, such as learning that their child had

been injured or killed. Long-term, the parents of survivors had to cope with their child's chronic physical disabilities and emotional scars (Barnes, 1998). As has been described, there are many psychosocial consequences of parenting a burn-injured child and studies have linked negative affect (which may manifest itself as depression, anxiety, anger, or hostility) with hypertension (Pickering, 2001).

Dorn et al. (2006) demonstrated that traumatic experiences affect not only those who are directly exposed, but also those who are close to the victims. They examined whether the parents of those with burn-injuries were more at risk of developing hypertension than a control group of parents from the community. After adjusting for covariates (age, gender, health insurance type, history of chronic disease, number of contacts with the family practitioner during follow-up, family practice, and single parenthood) they found that the risk of becoming hypertensive during the four year post-fire follow-up period was 1.48 times higher in parents of the injured than in the control group. When compared with the control group of parents from the community, bereaved parents had the highest risk of becoming hypertensive, followed by parents of survivors with burns, and then parents of survivors without burns (Dorn et al., 2006).

More recently, Enns et al., (2016) compared the physical health outcomes of parents of burn-injured children with general population control parents in the two years after the child's injury. As with the mental health outcomes, Enns et al., (2016) found increased rates of conditions such as coronary artery disease, diabetes, fractures, and hypertension, among parents of burn-injured children compared with control parents. Again, these relative rates remained significant even after adjusting for sex, geography, and income.

The findings of Dorn et al. (2006) and Enns et al. (2016) are in agreement with literature on secondary traumatic stress or compassion fatigue - the adverse effects on people who are psychologically close to survivors of trauma (Figley, 1998). It should be noted that the parents in the study by Barnes (1998) had children who were of adult age at the time of their injury, and the research by Dorn et al. (2006) concluded that parents of adolescents involved in disasters were more at risk of developing hypertension than parents from the same community whose children had not been involved in the fire. This further emphasises the impact that traumatic burn injuries can have on parents' health.

## **2.5 Interventions for families**

Simons, Ziviani, and Copley (2010) concluded that parental features at hospital admission more consistently predicted the outcome for children with burn injuries at six months after their injury than injury, child or familial factors did. Given the impact on parents and the significance of this for the child's recovery, pre-burn disturbance, grief over losses and parental depression

experienced during at least the first two years following a child's injury should be planned for within the treatment plan of the child (Blakeney et al., 1993). Such a plan would include assistance for caregivers in managing their own emotions and coping with the stressful demands of parenting a recovering child, without destroying the parent-child bond (Blakeney et al., 1993). This calls for the whole family to be considered as the 'patient' during the post-burn period (Blakeney & Creson, 2008; Young, 2004).

It has been suggested that structured sessions for parents and group therapy may be useful in facilitating coping skills and reducing stress (Rizzone et al., 1994). Peer support may also be valuable (Badger & Royse, 2010). In a description of group meetings for families of burned children, Cahners and Bernstein (1979) described the apparent comfort gained from retelling tragic experiences to those who have been there, "They bring to the meetings their guilt, their depression, fears, rage, resentment, helplessness and feelings of isolation. They also share their defences against being overwhelmed by these emotions." (P.170). Barnett, Mulenga, Kiser and Charles (2017) also found that a support group in Malawi for burn survivors and families provided a setting for participants to discuss their subjective experience, emotions and struggles, helping them to find mutual support from others and coping strategies.

Sveen et al. (2015) and Sveen, Andersson, Buhrman, Sjöberg, and Willebrand (2017) developed an internet-based information and self-help program with therapist contact for parents of children and adolescents with burns. Content development was based on the findings of Phillips and Rumsey (2008) and Frenkel (2008), therefore the resource covered the core themes: blame and guilt (linked to isolation and stigma), fear that the child would die, gratitude that the child survived, concern about scarring, religion as an anchor and a way of making sense of the event, description of behaviour change in the child (more clingy or frightened), and family problems. It also included the following advice, information and support: 1) family members' acceptance of the child's altered appearance, 2) scars and appearance, 3) understanding changes in the child after the burn, and in coping with altered family dynamics, and 4) how to deal with uncomfortable social encounters.

Sveen et al. (2017) found that their six-week psychoeducational program with therapist feedback had a beneficial effect on posttraumatic stress in the short term but did not affect levels of general stress or parental stress. Whilst the parents rated the program as being informative and meaningful, some of them thought it was time-consuming. Nevertheless, it was concluded that the program had the potential to support parents of burn-injured children and was deemed by Sveen et al. (2017) to be easily accessible, cost-effective, with the potential to be implemented in rehabilitation. At the time the Sveen et al. (2017) study was published, no internet-based psychoeducational or support program had been evaluated for parents of burn-injured children.



Considering the findings of this review, a clinical recommendation is that, regardless of burn size or severity, all parents should be screened for psychological distress following paediatric burn injuries, including assessment of subjective appraisals of the burn event. The importance of screening has also been highlighted in recent publications (Egberts et al., 2018; Griffiths, 2016; Hawkins et al., 2019). When support needs are identified, it is important to then consider the increased demands on parents. Services should offer support via the least burdensome method. For example, co-ordinated appointments can be important, particularly as chronic distress from continuing demands on the patient and their family can make adherence to recommended treatment regimens and appointment attendance difficult. When families are supported with their involvement with burns treatment, they are likely to cope much better in the long-term.

## **2.6 Limitations**

Several methodological limitations exist in this area of research, such as the reliance on self-reported retrospective data collected at different time points, use of different psychometric measures, and varying sample sizes with different participant characteristics. It is apparent from Table 2 that a variety of psychometric tools are used to assess the psychological impact of burn-injuries to children on their parents and this makes comparison between studies difficult and reduces the strength of conclusions that can be drawn. It is also important to acknowledge that parents may have a qualitatively different experience of trauma in the acute phase (first 30 days) compared with later time points. To better explore this, future research should consider focusing on one adjustment period only at a time within a longitudinal study (Hawkins et al., 2019).

More research needs to be done, particularly across cultures, as highlighted by Rose et al. (2005). Table 2 shows that the majority of studies come from North America and from particular groups of researchers/authors. This could also mean that participant populations lack diversity across studies. One way in which studies lack diversity is the fact that the participants recruited are largely, if not entirely, mothers. Research has tended to focus on the response of mothers to a child's burn injury as they are most likely to be the main carer for the child and therefore accompany them to the hospital (Mason, 1993).

It would also be valuable to explore the adaptive response of those who cope well compared to those who do not. As there is limited qualitative data about the impact of paediatric burns on parents, particularly those based in the UK (only four of the 28 studies presented in Table 2 were conducted in the UK), it is important that such studies are carried out in order to better understand their experiences and the how problems and difficulties they experience can be best addressed by services. This could enable focused interventions to be developed, implemented and evaluated. Ensuring that emotions and feelings (such as worry and anxiety) are well defined

within studies, and then appropriately assessed is also necessary to improve the quality of the literature.

Due to the use of multiple measures, it would be beneficial to create a set of core screening and outcome measures to assess the psychosocial impact of a child's burn injury on parents. This would help researchers and NHS staff better understand the needs and progress of patients and their family members and ensure that they are directed to appropriate support/care. UK parent PROMs (patient reported outcome measures) have been created and have been found to meet various psychometric standards, including construct reliability, internal consistency and validity, but these have not yet been tested to ensure that they can detect change over time (Griffiths, Guest, & Harcourt, 2017). It would also be important to combine these with psychometric measures and the use of clinical interviews for diagnosis of problems such as depression, anxiety and PTSD.

Finally, it would be valuable for more qualitative studies of parents' experiences to be conducted. Such data could provide more insight into factors that contribute to parents' biopsychosocial outcomes following their child's burn injury. Whilst the studies to date provide useful information regarding the impact on parents and highlights the necessity of support for them, the voice of the parent is largely unheard. Exploring their experiences and thoughts surrounding psychosocial support would be particularly valuable when considering interventions that may help to alleviate the impact of a child's burn injury on parents.

## **2.7 Conclusion**

Children's burn injuries can have a significant psychosocial impact on parents, affecting their health and mental well-being (Bakker, Van der Heijden, et al., 2013; Phillips & Rumsey, 2008). Parents experience a reactive distress including anger, anxiety, guilt, and often increased responsibilities (e.g. caring for an acutely unwell child and dividing their time between the hospital, work, and any uninjured siblings) during the acute phase of treatment (Phillips & Rumsey, 2008).

Sometimes the burn event exacerbates previous difficulties or highlights current difficulties. It is crucial that the trauma to both child and parents is minimized (Smith et al., 2011), as parental adjustment, emotional availability, family functioning/environment, and support from family members have been consistently identified as factors influencing positive psychosocial adjustment, burn outcomes, rehabilitation and quality of life in children who have experienced burns (Blakeney et al., 1990; Landolt et al., 2002; LeDoux et al., 1998; Liber et al., 2006; Tarnowski et al., 1991). In order to identify and appropriately support vulnerable patients and their

caregivers, early psychosocial input is needed from the burns service to screen parents and offer intervention beginning at the inpatient stage (Hawkins et al., 2019; Phillips & Rumsey, 2008).

This review has provided an overview of the research investigating the impact on parents when their child suffers a burn injury. It is clear that there is a biopsychosocial impact of these events on parents. Chapter 4 will describe a qualitative study that provided a detailed exploration of parents' experiences of the injury event, access to support, and opinions on peer support. Before this, Chapter 3 will provide an overview of the methodology and methods employed in the research that follows.

## **Chapter 3: Methods**

This chapter introduces the methodology and methods employed in this thesis. The research aims are outlined for each study and the justification for using different methods to achieve these aims is described. This chapter also considers the challenges, ethical considerations, and personal reflections of researching such an emotive and sensitive topic. More detailed descriptions of the methods used in each study can be found in the relevant chapters.

### **3.1 Research overview**

The research aims to explore parents' experiences and support needs before developing an intervention were achieved in four stages/studies and the research employed a mixed methods approach. The first study used qualitative methodology, with a semi-structured interview schedule, designed to explore parents' experiences. The findings of this study then informed the development of a quantitative survey which was used in Study 2. The findings from studies one and two were mixed to provide an understanding of parents' experiences, their access to support and opinions on peer support. These findings then informed the development of an intervention to support parents. Study 3 followed a Plan-Do-Study-Act (PDSA) cycle in which an intervention was designed, tested, amended and then released to the public, to be further studied in Study 4 that followed the live release of the intervention and consisted of a naturalistic evaluation of the intervention's acceptability.

The PDSA cycle is a Quality Improvement (QI) method, used in NHS QI projects, that focuses on the translation of realistic and achievable ideas and intentions into action. QI is defined as, "the combined and unceasing efforts of everyone – healthcare professionals, patients and their families, researchers, payers, planners and educators – to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning)" (Batalden et al., 2015). QI methods have been used in healthcare to support the delivery of safe, timely, effective, efficient, equitable, and cost-effective care. The methodology behind QI 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. QI utilises the subject matter expertise of people closest to the identified issue - staff and service users (in this case, parents) - in order to systematically identify potential solutions to the issue and test them. Therefore, it is important that, during this process, that 'improvement' is measurable from the perspectives of all key stakeholders.

PDSA is a valuable tool within healthcare improvement, with the purpose of the PDSA method being to learn as quickly as possible whether an intervention works in a particular setting. The

PDSA cycle and the concept of iterative tests of change are central to many QI approaches, providing a structured experimental learning approach to testing changes (Reed & Card, 2016). Examples of PDSA in action in healthcare include improving access to services (Gowling et al., 2016; Pavlidou, 2015) and investigation of the role of peer support workers in improving patient experience (Kulik & Shah, 2016).

In contrast to controlled trials, PDSAs allow new learning to be built into the experimental process. If problems are identified then revisions can be made that build on the learning, with a subsequent study to see if the changes have resolved the problem and to identify if any further problems need to be addressed. The intended output of the cycle is learning and informed action (Reed & Card, 2016). Within this PhD, studies one and two provided the idea and studies three and four put that idea into action. Beyond the PhD, these features of PDSA will enable the continuous development, testing and evolution of the intervention created.

### **3.2 Design and epistemology**

In view of the focus of this PhD being peer support, an area in which there is limited research (particularly for parents of burn-injured children), an exploratory mixed-methods approach was adopted. Consideration of the rationale and purpose of mixing data was an important and primary ethical concern in the design of this research. This is because the mixed method must add value, such as improving validity over that which could be achieved using a single method (Elliott, Fischer, & Rennie, 1999).

A qualitatively-driven mixed-method design emphasises the value of the qualitative perspective and aims to represent and understand the lived experiences and actions of people in particular situations (Elliott et al., 1999) with the goal of also working toward change (Hesse-Biber, Rodriguez, & Frost, 2015). As qualitatively-driven approaches tend to be better suited to exploratory research than quantitatively-driven approaches, the initial exploratory qualitative study formed the core of the overall project and was used to direct the quantitative research that followed (Hesse-Biber et al., 2015). The process followed was akin to the study by Fuentes (2008) whose sequential exploratory mixed methods design was described by Hesse-Biber (2010), as it provided richer detail than either method could generate alone, with the quantitative phase being employed to generalize the results of the qualitative study.

The literature review in Chapter 2 highlighted a number of challenges that could be experienced by parents but the success of a project such as this, which aims to develop an intervention, is often linked to meaningful patient participation (Kulik & Shah, 2016). Therefore, in the development of a UK based intervention, it was essential to involve parents throughout the work as the 'service user's' perspectives and priorities can be very different to those of professionals

(McInerney & Cooke, 2015). It was important that these parents were based in the UK as much of the research to date has focused on families in the USA where access to healthcare is very different.

Within a qualitatively-driven mixed methods approach, whether or not the secondary quantitative component can form a separate study by itself is contested. There is a continuum of thought from those researchers who posit that to engage in a qualitatively-driven design means that the secondary component cannot stand on its own as a separate study as it is supplementary, to those who view it as making a contribution to the core qualitative component and also complete in itself (Hesse-Biber et al., 2015; Morse, 2016). Within this PhD, the secondary quantitative study was dependant on the first qualitative study. Whilst the data could be interpreted separately, it would not have been generated had it not been for Study 1. Therefore, the first two studies of this PhD employed a sequential mixed methods design. Sequential mixed methods typology has three designs: (a) sequential exploratory, (b) sequential explanatory, and (c) sequential transformative (Creswell, Plano Clark, Gutmann, & Hanson, 2003), where one type of data provides a basis for the collection of another type of data.

A sequential exploratory design was appropriate for this research, in that the qualitative method was dominant and the aim was to enhance the data and clarify the results with the quantitative method (Caracelli & Greene, 1997). When using qualitative methods as the main data collection method, followed by quantitative methods, it is important to consider the point at which qualitative and quantitative data will be related to each other (Morse, 2016). In this case, integration was at the results stage as described below and illustrated in Figure 1.

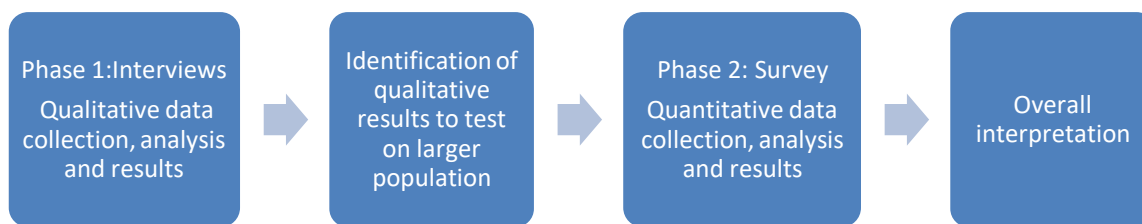


Figure 1. The sequential exploratory mixed methods design (as used by Fuentes (2008) and described by Hesse-Biber (2010))

Following the initial qualitative study, the quantitative approach and method took on a secondary role in the mixed-methods design. The role of the secondary (or auxiliary) method was to ask sub-questions, generated following analysis of the qualitative data, that assisted in the elaboration and clarification of the core research questions (Hesse-Biber et al., 2015). Within this PhD, this helped to validate the qualitative findings and ascertain whether experiences and ideas that emerged could be generalised to a larger population of parents (Hesse-Biber et al., 2015). This

was a necessary step before considering the development of an intervention as these studies had the potential to produce different results. It could have been the case that some parents would suggest a need for an intervention whilst other parents might have held the opinion that this was not necessary. It was therefore also important to be mindful of my own perceptions of the value of a peer support intervention and ensure that I did not interpret the results through a lens which focused only on evidence to support intervention development. The data from Study 1 and Study 2 were analysed separately with Study 1 presented in Chapter 4 and the findings of Study 2 mixed with those of Study 1 in Chapter 5.

Another important early consideration was that, whilst the two data sets may support one another, there was the possibility that the findings could be inconsistent. Inferences made from the findings of the two studies were therefore compared to those made from the combined data in the discussion of Study 2. Inconsistencies could then be integrated, generating important insights and helping to develop a more complex understanding of parents' experiences of parenting a child with a burn-injury, accessing support, and the perceived value of peer support (Yardley & Bishop, 2015). Similarities and inconsistencies are described in Chapter 6 alongside relevant theory. Therefore, the process of knowledge building within this PhD was iterative, testing out ideas and collecting more data in a process known as analytical induction (Hesse-Biber et al., 2015)

After gaining a better understanding of parents' experiences and how they felt their needs might be best met, it was important that the intervention developed was piloted and evaluated for feasibility and acceptability. Following the creation of the prototype intervention, Study 3 was a multi-method study that collected both qualitative and quantitative data from parents and professionals to enable the results to be triangulated. The qualitatively driven process promoted deeper listening between the researcher and participants in order to obtain "more genuine expressions of beliefs and values that emerge through dialogue [and] foster a more accurate description of views held" (p. 54) (Howe, 2004). In this study, the qualitative data was used to provide evidence of changes that needed to be made, or not, and these were verified by the quantitative data. Study 4 then aimed to provide evidence that the changes made to the prototype had been beneficial using a survey, which was available to all of those who accessed the intervention (parents, health care professionals, and any other users), again collecting quantitative and qualitative data.

### **3.3 Methodological considerations**

This PhD topic, and the research questions posed, benefitted from the mixed-method design and mixing the data at various stages, such as exploration in Study 1, explanation and expansion in Study 2, and development and triangulation in Studies 3 and 4 (Preissle, Glover-Kudon, Rohan,

Boehm, & DeGross, 2015). The use of mixed-methods of data collection is supported by pragmatism as a research paradigm. Pragmatism also allows for mixed-methods of analysis and abductive reasoning that is guided by the researcher's desire to produce socially useful knowledge (Feilzer, 2010). Pragmatism argues that the methods used in research should be those that best suit the research questions. As information regarding parents' access to, experience of, and demand for peer support was limited, and qualitative methods are well suited to exploratory research (Hesse-Biber et al., 2015), the decision to select this qualitatively-driven mixed-methods design was pragmatic.

As explained in Chapter 1, I approached this PhD with experience working clinically within burn services and it is well known that personal experience of a topic can influence engagement with the research area (Finlay, 2002). Prior experience and perspectives would inevitably influence the choices that I would make within the research design, data collection, analysis and interpretation (Mauthner & Doucet, 2003). For this reason, it is good practice within qualitative research for the researcher to acknowledge their theoretical orientations and personal anticipations in an attempt to recognise their interests and assumptions, and how these may colour their understanding of the data and relationships with participants (Elliott et al., 1999).

I approached this PhD believing that peer support could be beneficial to people affected by burn injuries. Having developed and facilitated various psychoeducational and therapeutic groups with adult service users, I was aware that peer support groups within burn care struggled to engage people who had experienced burns (Batchelor & Williams, 2013) and I envisaged that this might be the focus of my PhD – How do we engage parents of burn-injured children in peer support groups? My previous research experience had also been largely quantitative (Heath et al., 2011; Heath, Mitchell, & Fletcher, 2019; Heath, Norman, Christian, & Watson, 2017; Saradjian et al., 2015) and so embarking on a qualitatively driven journey was initially quite daunting.

Disclosure of one's position in relation to the topic under investigation acts to reduce or balance the impact of personal influence, biases, and values on the research agenda (Braun & Clarke, 2006; Elliott et al., 1999; Greenbank, 2003). Within inductive approaches to research, positionality is used to explore researcher reflections and place them within the work, considering the context, power dynamics, identities, and the researcher's point of view (England, 1994; Lave & Wenger, 1991). This process of reflexivity can then inform the research rather than to invalidate it as biased or contaminated by personal perspectives.

The term 'positionality' describes an individual's world view and their chosen position in relation to a specific research task (Savin-Baden & Major, 2013). Deutsch (1981) suggested that a researcher's position is not simply ascribed to them but is a process of ongoing evaluation as we



are all multiple 'insiders' and 'outsiders.' This can result in a researcher's position shifting with experience and across different research contexts. The 'outsider' is a non-member of the group under investigation (for example, myself as I was neither a parent nor a carer for a child with a burn-injury) with the 'insider' being a member of the group being researched (for example, the participating parents and their peers – other parents/carers of children who have experienced a burn). However, Herod (1999) wrote that the researcher may not be an insider or an outsider. I perceived the 'other' to be someone who perhaps, like me, had a dual identity as a practitioner and a researcher in the field. Whilst I had worked within burn care and had supported people affected by burn-injuries, I did not share the same experiential knowledge as a parent/carers of a child.

Although I was an outsider to the group studied, throughout the task of conducting this research, I moved through various 'other' positions which I have reflected on in more detail in the paper Heath (2018) included in the secure pocket. I was aware that, as someone who has already contributed to the provision of burn care, I would need to employ critical reflection throughout this work to continually monitor my role and the impact of my views on the research process. Discussion of this during supervision would help me to ensure that prior assumptions regarding different approaches to providing psychosocial care did not divert the development of parental support away from that suggested by the data collected. It was also important to acknowledge, and make explicit, how intersubjective elements (for example, what I thought participants thought, or did not think) might influence data collection and analysis. Careful consideration of these issues helped me to ensure that the participant experience was transformed into trustworthy, public, accountable knowledge, via transparent methodology. Further discussion of this process and my subsequent contribution to the literature is provided in Chapter 9.

### **3.4 Challenges of conducting research in this area**

The ontological position of qualitatively-driven mixed-methods approaches are that there are multiple social realities rather than a concrete social world. As social realities are constructed and subjective meaning is a critical component of knowledge building (Hesse-Biber et al., 2015), learning more about the parent/carers experience, the meaning attached, the support experiences, needs and demand for additional support would contribute to a better understanding of this population. In turn, this could then inform the development of an appropriate intervention, as indicated by the findings.

Interventions can be targeted to meet individual needs or have a broader focus to meet the needs of many (Harcourt & Rumsey, 2012; Jenkinson, 2012). With peer support being the focus of this PhD, it was important that a broad understanding of the needs of many parents was gained in

order to examine whether peer support could be appropriate for parents of burn-injured children. However, this process required me to recruit a sufficient number of participants in order to understand enough of the different realities experienced by parents.

Burns research in general can be sensitive because, as described, it focuses on an event that is often very stressful for the participant. When parents are the focus of the research following an injury to their child, participation might be perceived as threatening due to feelings of guilt and the upset caused by recalling distressing events (Mason, 1993). Other particularly pertinent issues in this population are the fear of judgment or stigmatisation from the researcher, and/or concerns about anonymity within the data (Braun & Clarke, 2013; Pyer & Campbell, 2012). These concerns can exist even when injuries are accidental as parents may have experienced a child protection interview due to the significant minority of paediatric burn-injuries that are non-accidental (Mullen et al., 2019; Toon et al., 2011).

In order to facilitate the participation of parents within this research, the establishment of rapport was vital (Dickson-Swift, James, Kippen, & Liamputtong, 2009). To establish rapport, I needed to take steps to make participants feel relaxed and comfortable enough to share their experiences (Liamputtong, 2007). Personal data is more likely to be disclosed when assurances of privacy, confidentiality and a non-condemnatory attitude are provided (Wellings, Branigan, & Mitchell, 2000). Lee (1993) suggested that when research focuses on a sensitive topic – one that potentially poses a threat [psychologically or otherwise] to those who are, or have been, involved - the method through which information is collected can be particularly important to participants. Other factors found to facilitate research engagement are subjective interest, curiosity, or enjoyment (Clark, 2010).

In terms of data collection method, qualitative research has typically relied upon one interview method in isolation, with the face-to-face interview being viewed as the 'gold standard' (Deakin & Wakefield, 2014). However, there are growing numbers of options available for researchers wishing to conduct interviews, and it is increasingly likely that more than one type of interview will be employed within a single study, for example using Skype and face-to-face interviews (Deakin & Wakefield, 2014), or a combination of face-to-face, telephone, and email interviews (Dures, Morris, Gleeson, & Rumsey, 2011). During this PhD, I hoped that flexibility in data collection method may improve participants' access to the research and help them to feel more comfortable or safer when it came to self-disclosure. For this reason, Study 1 invited participation via multiple methods of interview: face-to-face, telephone, Skype and email.

Recruitment into Study 1 was challenging but yielded a sample of 13 parents. This was considered a sufficient number of participants as it has previously been recommended that qualitative

studies require a minimum sample size of at least 12 to reach data saturation (Clarke & Braun, 2013; Guest, Bunce, & Johnson, 2006; Vasileiou, Barnett, Thorpe, & Young, 2018). However, when conducting research with hard-to-reach groups it is important to consider different ways to maximise participant access and facilitate participation. One strategy is to utilise online, or web-based, methods of data collection. Web-based research can improve access to hard-to-reach groups, particularly when potential participants are in geographically diverse locations (Wilkerson, Iantaffi, Grey, Bockting, & Rosser, 2014), and it has also been found to improve participation from ethnic minorities (Joseph et al., 2013). To facilitate the recruitment of a larger sample of parents into a quantitative study, Study 2 collected data via Qualtrics, a secure online survey website. Use of this software permitted anonymous participation and so any participants that might be concerned about confidentiality or judgement did not have to supply identifying information.

In addition to the data collection method, the sampling method chosen can also increase participation in research with hard-to-reach groups. Methods found to be effective are snowball, chain referral, and respondent-driven sampling. In snowball sampling, already recruited participants identify further participants through their social network, who, in turn, identify further participants (Atkinson & Flint, 2001). Study 3 benefitted from this with mothers recruiting husbands, and professionals recruiting their colleagues. Studies 3 and 4 also benefitted from a shift in the focus of the research in that, in those studies, I was giving an intervention and, although participation in Study 3 required a face-to-face meeting with me, studies 3 and 4 did not require parents to talk about personal experiences, only to provide feedback on the intervention created. The dynamic had shifted from one where I, the researcher, took (data from them about their experience), to one where I provided (a new intervention for them/their peers).

Another potentially fruitful sampling technique is chain referral sampling. This method was not employed during this PhD but may have been useful, particularly now that the work has some presence on social media and the internet more widely. This technique builds on the snowball sampling technique by simultaneously focusing on multiple social networks (Penrod, Preston, Cain, & Starks, 2003). Respondent-driven sampling also involves participants actively recruiting others to the study but uses a coupon management system. Participants are provided with coupons to recruit others which are tracked by the research team. Recruiting participants are paid for each new recruit, who is then provided with their own coupons to recruit others (Marpsat & Razafindratsima, 2010). With limited peer to peer meetings and evidence of parent-perceived isolation in the literature, I felt that it was unlikely that these would be effective methods for recruiting parents to participate in this program of research. However, towards the end of the research it was noted that parents of burn-injured children, whether they had participated in the

research or not, helped to promote the intervention created to other parents by 'snowballing' the links and advertisements on their own social media.

When trying to recruit a sample who meet pre-specified inclusion criteria, the sampling method of time-location sampling can assist with the recruitment of hard-to-reach populations and also with the generalisation of findings to the relevant population (Marpsat & Razafindratsima, 2010; Semaan, 2010). This technique makes use of locations that are often used by the target population, in this case paediatric burn services, family burns camps, or charitable organisations. Without NHS ethical approval, I could not recruit directly from NHS paediatric burn units but, as the research was promoted to clinicians within NHS services via the BBA and to families via burn camps and charities, the time-location sampling method still led to the recruitment of some participants involved in the work included in this PhD. Utilisation of relationships with key organizations related to the population under investigation has also been highlighted as a way to improve participants' perceptions of the research as credible and acceptable (Altpeter, Houenou, Martin, Schoster, & Callahan, 2011).

Whilst time-location sampling could be useful in recruiting some participants, it was also important to note that this method may have limited the sample to parents who were already engaging in, or seeking, psychosocial support from burn services, camps and charities. As this research sought the perspectives of a range of parents in order to identify any unmet support needs, it was important to recruit parents who were less engaged in these spheres. Therefore, recruitment via other avenues, such as through unfocused social media and through healthcare professionals providing the medical care to the child, was necessary.

As none of these sampling methods are random, there are several other issues that should be considered, such as gatekeeper bias and disclosure of participant identity. Gatekeepers are those people who can control or limit a researcher's access to potential participants. In burns research, gatekeepers may be hospital staff or those involved with burns patients and their families in other ways, such as through camps or clubs. Gatekeepers are valuable as they can pass on research information to those who may be interested in participation. However, another role of the gatekeeper is to ensure that participants are not subjected to any potentially harmful research (Coyne, 2010). Gatekeeper bias occurs when a gatekeeper chooses not to facilitate contact between the researcher and a potential participant (Groger, Mayberry, & Straker, 1999). Another ethical issue of non-random sampling techniques, such as those using gatekeepers or snowball-related sampling methods, is that asking participants to identify other potential participants introduces issues of participants' personal information being disclosed to others (Sadler, Lee, Lim, & Fullerton, 2010).

Concerns about harm and confidentiality could have been significant in this research as it was focusing on a subject that would likely be upsetting for parents to recall. Clark (2008) suggested that a lack of understanding about particular research methods may promote indifference or resistance in participants. Therefore, clarity of information and transparency was also important to ensure that participants understand the true purpose of the research and why it is being conducted using the methods chosen.

It is important to bear in mind, particularly in research regarding sensitive subjects, that participants may be suspicious of the purposes of the research or the researcher's intentions (Sukarieh & Tannock, 2013). This is particularly relevant to this population as McQuaid, Barton, and Campbell (2003) found that some parents of burn-injured children could be wary of research of their or their child's experiences, sometimes suspecting that there may be an alliance between researchers and social services. However, this could also be the case for gatekeepers. This issue meant that clear study information was imperative in order to give accurate information as to the focus of the research, the limits of confidentiality, and also about different sources of support for any parents that might want to seek help for on-going distress, or for distress that could have been fuelled by their participation in the research. Copies of all of the information sheets used throughout this PhD are provided in the Appendix (A.iv, B.iii, C.iv, & D.iv).

Another issue in research using hard-to-reach participants is that, once participants are recruited, subject to the necessary ethical approval, they can be asked for their consent to be contacted about any future studies that they may be eligible to participate in. Previous burns research in CAR had already created a 'participant pool' and this was utilised in this research, and other ongoing burns research within CAR, until the introduction of the General Data Protection Regulation in 2018 (Information Commissioner's Office, 2018).

A danger of using a participant pool for recruitment is 'research fatigue'. This is when individuals are 'over-researched' and become unwilling to take part in further studies (Clark, 2008). Research fatigue can be particularly problematic in that which focuses on hard-to-reach groups or small target populations as they are approached for participation more often than other groups (Pagano-Therrien, 2013). This was very relevant to the research in this PhD as there were several burns research projects recruiting parents of burn-injured children (Griffiths et al., 2017) and burn survivors (Griffiths et al., 2019) concurrently within CAR. It is also likely that they were being asked to consent to concurrent psychosocial and medical research at other centres such as that by Bennett et al. (2019), Green, Cadogan, and Harcourt (2018) and Hawkins et al. (2019). This may partly explain the limited recruitment into Study 1, although it has been found that subjective interest in the research topic can overcome research fatigue and facilitate continued participation (Way, 2013) and those willing to share their emotive experiences in this research were clearly

motivated to do so. Throughout the research, when using the participant pool and recruiting from other sources, it was also important to track which participants had taken part in Study 1 to ensure that they were not approached again in Study 2 as the aim was to build upon the data from the first study.

### **3.5 Analysis**

As this PhD employed mixed methods (qualitative and quantitative) and also multiple methods of qualitative data collection, different methods of data analysis were utilised. Study 1 collected qualitative data via face-to-face, Skype, telephone and email interviews and employed thematic analysis (Braun & Clarke, 2006). Study 2 collected quantitative and qualitative data via an online survey. Quantitative data in Study 2 was analysed using simple frequencies and percentages and content analysis was used to summarise the qualitative data. Study 3 collected qualitative and quantitative data. Again, content analysis was used for the qualitative data and non-parametric statistical tests were conducted on the quantitative data due to the small sample sizes. Study 4 collected quantitative data which was again analysed using non-parametric statistical tests and the limited qualitative data collected is presented. The qualitative and quantitative analysis methods utilised are described below.

#### **3.5.1 Thematic analysis**

Thematic analysis (TA) (Braun & Clarke, 2006) was used to analyse the interview data from Study 1 (see Appendix A.vii for an example of how the data was coded). Thematic analysis was chosen as it is an appropriate method to qualitatively investigate individual experiences (e.g. what's it like to have a child suffer a burn injury?), views and opinions (e.g. whether support is needed for parents), practices (e.g. whether they have sought or accessed support), the reasons why people think or feel or do particular things (e.g. why they accessed support), and the factors or processes that underpin and shape particular experiences or decisions (e.g. whether the support is helpful or not), how particular social objects are represented in particular contexts (e.g. what support is currently available to parents and where?) and how social objects are constructed/the discourses surrounding a particular social object (e.g. how support for parents is perceived and who accesses it?) (Braun & Clarke, 2006).

TA focuses mainly on the patterning of meaning across participants (Braun & Clarke, 2006). In terms of the analytical procedures, TA involves coding and theme development according to the steps outlined in Table 3. After a process of data familiarisation, coding begins across the entire dataset, followed by the development of themes from those codes. The themes produced then provide an organising framework for the analysis and reporting of the results (Braun & Clarke, 2006).

Stage	Process	Description of the process
1	Familiarisation with the data	Transcribing data (where necessary), reading and rereading the data, noting down initial ideas.
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4	Reviewing themes	Checking that themes work in relation to the coded extracts and the entire data set, generating a thematic "map" of the analysis.
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6	Producing the report	Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature.

Table 3. The six phases of thematic analysis (Braun & Clarke, 2006)

### **3.5.2 Content analysis**

Qualitative data in studies two and three were analysed using content analysis. Content analysis classifies text responses into categories that can be quantified with the aim of identifying meaning across text (Elo & Kyngäs, 2008). Content analysis goes beyond a simple word count to form categories that are well defined and mutually exclusive (Stemler, 2001). To do this, responses to questions were listed, read, and initial codes were generated. The data was then coded within the list and quantified by counting the frequency of each code. Key advantages of content analysis are that it is systematic and replicable and can deal with large volumes of data (Stemler, 2001). The process of analysis involved reviewing the qualitative data and looking for common response categories, with these categories being generated inductively.

### **3.5.3 Non-parametric statistical tests**

The statistical tests used in studies 3 and 4 were the Mann-Whitney U test and the Kruskal-Wallis H test. The Mann-Whitney U test is a non-parametric test, used as an alternative to the independent samples t-test when the assumptions of the t-test are not met, to test whether or not two sample means are equal. Assumptions of the Mann-Whitney U test are that: 1) the sample drawn from the population is random, 2) there is independence within the samples and mutual independence, and 3) an ordinal measurement scale is used.

The Kruskal-Wallis H test is another non-parametric test, used as an alternative to the one-way ANOVA. It is an extension of the Mann-Whitney U test to allow the comparison of more than two independent groups. Assumptions of the Kruskal-Wallis H test are that: 1) the dependent variable is ordinal, 2) the independent variable consists of three or more categorical, independent groups

(e.g., parent, professional and other); and 3) the distribution of scores for each group of the independent variable have the same variability.

### **3.6 Summary**

The research process, study design, methodological considerations, reflexivity, and challenges involved in this research have been introduced and discussed. Recruitment methods and methodological issues are discussed in more detail for each study in the relevant chapters. At this stage, it is important to acknowledge that factors which influence participation in the different studies may also reflect factors that influence parents' decisions to seek or engage in different forms of support. The following chapter will present the first study, a qualitative exploration of parents' experiences and support needs following their child's burn injury. Parents' opinions regarding peer support specifically will also be gleaned which will be a new contribution to the literature in this area.



## **Chapter 4: Interviews to explore the experiences and support needs of parents of children who have had a burn injury**

This chapter presents Study 1, which used semi-structured interviews, conducted with parents of burn-injured children to explore their individual experiences. The chapter provides a brief introduction to the research, the study design, interview process, data analysis and results, and a discussion of the findings. The results will be split into two sections according to the focus of the questions asked. The first section will present parents' experiences of the injury event and beyond, and the second section will present experiences of support and opinions on peer support specifically. This study resulted in three published papers: a reflective paper about researcher positionality (Heath, 2018), a paper about the use of multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects (Heath, Williamson, Williams, & Harcourt, 2018a), and a paper that described some of the findings of the interviews with parents (Heath, Williamson, Williams, & Harcourt, 2018b).

### **4.1 Introduction**

Accidents are inevitable, especially during childhood but, in addition to the trauma for the child, children's burn injuries can also have a significant psychosocial impact on parents, affecting their health and mental well-being (Bakker, Van der Heijden, et al., 2013; Mason, 1993; Phillips et al., 2007; Phillips & Rumsey, 2008; Rizzone et al., 1994). In terms of support for families of people with burn-injuries, the literature is descriptive, demonstrating awareness of the issues and concerns affecting family members (Lawrence, Qadri, Cadogan, & Harcourt, 2016; Sundara, 2011), and the influence of familial values on long-term psychological adjustment of burn-injured children (Bakker et al., 2013; Blakeney et al., 1990). Research has also tended to focus on the response of mothers (Mason, 1993) as they are traditionally most likely to accompany the child to hospital.

This research explores parents' experiences of the injury event and access to support following their child's injury, and their thoughts on peer support specifically. To date, the under-representation of parents of children with burn injuries in the peer support literature has hindered the development of such evidence-based support interventions for this group. Support services that are not based on evidence can suffer from a lack of insight into what support is needed, how it is best provided, when, and to whom (Onyett, 2007). Public involvement is important when planning, developing and monitoring care, with service users/parents/patients viewed as equal partners in order to ensure that their needs are met.

In a review of the effectiveness of different types of peer support, National Voices & Nesta (2015) highlighted that although peer support has been shown to be beneficial to carers in terms of their

experience and the emotional impact of their role, there is little published evidence of its benefit in these domains for parents specifically and none of the studies included in their review were conducted within burn care. Despite peer support being recommended in burn care guidelines, and the UK National Network for Burn Care Standards (National Network for Burn Care, 2013) stating that support groups should be available to patients, their families and/or carers, the provision of such support within the UK, particularly for parents/carers, is limited (Batchelor & Williams, 2013). Therefore, an important question to address is whether parents themselves think that they could benefit from peer support.

## **4.2 Aims**

This study had three broad aims, to:

- 1) Explore parents' experiences of having a child suffer a burn injury
- 2) Examine parents' experiences of accessing support for themselves following their child's injury
- 3) Establish parent's opinions of peer support and whether they would value this following their child's burn injury.

## **4.3 Method**

### **4.3.1 Design**

Pragmatism argues that the methods used in research should be those that best suit the research questions (Denscombe, 2014) and current information regarding parents' access to, experience of, and demand for peer support is limited. As described in Chapter 3, qualitative approaches are appropriate for the exploration of novel areas (Morse, 2016). Therefore, this research employed semi-structured interviews delivered via different interviewing methods (e.g. face-to-face, telephone, Skype, and email) in order to aid participation. Interview data was analysed using thematic analysis (TA) (Braun & Clarke, 2006) as the primary goal was to investigate the experiences of a group of individuals, to inform future research and the provision of support.

### **4.3.2 Ethical approval**

This study obtained ethics approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (REC Ref. HAS/16/06/151; Appendix A.i).

### **4.3.3 Public involvement**

During the design stage of this study, four parents of burn-injured children participating in other ongoing burns-related studies at CAR were invited to review and provide feedback on the study information, consent form, and semi-structured interview schedule. The aim of this public involvement was to check whether the study information and research questions were worded

appropriately, and that the research questions would allow parents to fully discuss their opinions and experiences of support following their child's injury. Two parents accepted this invitation (Appendix A.ii) and provided feedback via email. Following this review, minor changes in wording and the use of abbreviations were made, as recommended by the parents. One of these parents went on to participate in the study. Another participating parent also provided feedback on the interpretation of the interview data at the end of the study.

#### **4.3.4 Recruitment**

Written information was disseminated to potential participants during September 2016 via a university press release, a local radio interview, advertisements on social media, and via appropriate charity/support organisation websites ([Children's Burns Trust](#), [Changing Faces](#), [Katie Piper Foundation](#)). These channels enabled parents who were not in contact with burns charities/support services to be recruited. As previously stated, when recruiting hard-to-reach groups, the internet can facilitate participants' access to research, particularly when participants are from geographically diverse locations and/or from ethnic minorities (Joseph et al., 2013; Wilkerson et al., 2014). Parents from around the UK who had previously been recruited from NHS sites and consented to being contacted about burn care research opportunities at CAR were also recruited from the CAR participant pool (Appendix A.iii). The study advertisements directed parents to a secure online survey website, Qualtrics. This hosted the study information (Appendix A.iv), consent form (Appendix A.v) and space for parents to add their contact details should they wish to participate. The contact details provided were then used to arrange an interview with consenting parents. Upon initial contact, participants were encouraged to ask any questions that they might have before consenting to take part and given the opportunity to view the semi-structured interview schedule.

#### **4.3.5 Participants**

For inclusion in the study parents had to be English speaking, at least 18 years of age, with a child who had experienced and survived a burn injury before the age of 18 years, that required hospital treatment as either an inpatient or an outpatient in a specialist burns service. The injury should have occurred at least six months prior to participation (to allow acute stress reactions to have subsided and adaptation to the situation to have begun) as there is some evidence that encouraging recollection of the traumatic event, accompanied by normalisation of emotional reaction, within the first month post-injury may increase the risk of PTSD and depression (Rose, Bisson, Churchill, & Wessely, 2002). Although a minimum time since injury was recommended for participation, no maximum time was set in order capture experiences of parents at different stages of treatment and beyond. Exclusion criteria were non-accidental injury, and when the child had since died because of their injury or subsequent complications. Participants were not asked

to provide evidence that they met the inclusion/exclusion criteria, it was left to them to judge their eligibility to participate in the research.

#### **4.3.6 Semi-structured Interviews**

A semi-structured interview schedule was created to capture the unique experiences of the participants whilst simultaneously ensuring that the core areas of interest were covered: the experience of having a child suffer a burn injury, access to support, and perceptions of peer support (Appendix A.vi). The interview schedule was guided by questions included in the study by Phillips et al. (2007) in their research considering psychosocial support needs for families following burn injury, and Sproul, Malloy, and Abriam-Yago (2009) who looked at perceived sources of social support in adult burn survivors. To meet the study aims, additional questions were generated with the supervisory team regarding the perceived value of peer support, whether such support would be valuable to parents of burn-injured children, and when, following the injury, it might be appropriate to offer such support.

#### **4.3.7 Procedure**

Participating parents were offered a choice of interview method: face-to-face, Skype, telephone or email interview. Informed consent was obtained from all participants included in the study and, prior to the interview commencing, participants were again given a further opportunity to ask questions or to view the semi-structured interview schedule. Those participating via Skype, telephone or face-to-face also provided verbal consent for the audio recording of their interview for later verbatim transcription. Participants requesting to participate via email had the interview questions emailed to them and could respond in their own time. Follow-up emails were exchanged to clarify meaning and to seek more information where necessary and appropriate. Email interviews were saved as text files for analysis. All demographic information was self-reported by interviewees. It was possible for more than one parent of the same child to participate in the research, although only one parent from each affected family took part. After the interview, participants were reminded of the support options listed in the initial study information should they decide that they could benefit from accessing it. All participants received a £10 Amazon voucher as a thank you for their time and contributions to the study.

### **4.4 Analysis**

#### **4.4.1 Descriptive analysis**

Descriptive analyses of demographic information and participant characteristics (relationship to child, child age at injury, burn type, time since injury, TBSA, marital/relationship status, ethnicity, geographical location, and employment status) were performed.

#### **4.4.2 Qualitative Analysis**

TA (Braun & Clarke, 2006) was used to analyse the qualitative data generated by the interviews. As described in Chapter 3, TA was chosen because it is a theoretically flexible method of analysis (Braun & Clarke, 2013), maintaining the depth of the data whilst enabling areas of commonality between participants to be analysed. This allowed the study to focus on the identification of broad themes in the participants' experience. The six phases of conducting thematic analysis are described in Chapter 3, and were adhered to as described by Braun and Clarke (2006). An example of coding, and how the six phases were adhered to, is presented in Appendix A.vii. NVivo software was used to organise the data during this process.

Mixing techniques of qualitative data collection resulted in differing depths of participant responses to questions depending on the method used, with face-to-face, Skype and telephone interviews providing much more in depth and rich data than the email interviews. This meant that the data generated by the eight spoken interviews was supplemented by the five email responses to ensure that the data, at least for the group studied, was relatively complete (Elliott et al., 1999); the goal being to produce knowledge about parents' experiences of having a child suffer a burn injury, accessing support, and their opinions of peer support. I conducted the data analysis with input from the supervisory team during the latter three stages of the TA: (4) reviewing the themes, (5) defining and naming the themes, and (6) producing a report.

All themes were supported with examples from across the transcripts. Following analysis, a summary of the key themes was sent to the 10 participants who requested this information (Appendix A.viii). These participants were invited to provide feedback on the interpretation. Only one participant responded to this request for member checking of the data interpretation stating, "It's a great report! Nicely put together and interesting how many challenges were shared across parents." [Mother]

There are a range of approaches to judging the quality of a qualitative analysis (Morrow, 2005; Vasileiou et al., 2018; Yardley, 2008). These include examination of the sampling procedures and quality, length, and depth of interview data. Morrow (2005) suggests that these aspects within qualitative research are of far greater importance than aspects such as sample size.

As discussed in Chapter 3, there are a number of different sampling procedures. Marshall (1996) highlights differences between convenience sampling (recruitment of the most easily accessible participants) and judgement sampling (actively recruiting the most appropriate sample to answer the research question). Whilst convenience sampling can save researchers time and effort, it is the least rigorous sampling technique and can result in poorer quality data. However, judgement sampling is criterion-based (recruiting participants who meet specific criteria/have experienced a

particular phenomenon) (Morrow, 2005). For this reason, it was important that the dissemination of information about the research was far reaching but also that inclusion criteria were employed to ensure that the participants were appropriate for the research question. Although a purposive sampling procedure can be believed to generate a non-representative sample of the population that is ungeneralizable, Morse (1999) has argued that, in contrast to quantitative research which focuses on demographic characteristics, qualitative research should select participants specifically for the contribution they can potentially make to the emerging theory. Crouch and McKenzie (2006) stated that this sampling procedure is the way that analytic, inductive, exploratory studies should be conducted.

In terms of the quality, length, and depth of interview data, Morrow (2005) highlighted the importance of articulating the interview strategy, suggesting that fewer, open-ended questions, which involve clarification of responses throughout the interview, are the most effective ways of ensuring that data is rich and spontaneous. Whilst the semi-structured interview was short, containing 15 open-ended questions (Appendix A.vi), it was also important to consider how the questions seeking clarification were constructed. The process of reflexivity, “owning one’s perspective” (Elliott et al., 1999), is another key quality criteria that I engaged in as described in Chapter 3. As previously mentioned, an in-depth reflection on data collection in this study has been published (Heath, 2018) as feelings and attitudes towards psychological support within burn care, peer support, the interview, and the participant could affect the questions asked within the interview and then the interpretation of the data afterwards.

#### **4.5 Results**

Over a nine-week period, 14 parents and one grandparent expressed an interest in taking part in a semi-structured interview, but two parents later opted out by ceasing communication once the interview was arranged. This left a final sample of 12 parents (11 mothers) and one grandfather who had a significant role in the upbringing and care of his grandchild, particularly since the injury. One parent chose a face-to-face interview, two chose Skype, five chose telephone, and five chose to take part via email.

One parent took part in the interview only 11 weeks after the injury event. Despite reading the study information, this participant had volunteered to participate earlier than had been requested. However, as participants were not asked to provide evidence that they met the inclusion/exclusion criteria prior to participation, the time since injury data was only gathered during the interview. As this participant had provided informed consent, their data was also included in the analysis following discussion with the supervisory team. Although this participant was upset that the accident had happened there were no obvious or disclosed signs, during the

interview, that suggested they were suffering from an acute stress reaction, such as avoidance of reminders, intrusions, or physical symptoms of stress. They had also previously seen a psychologist to address feelings of guilt following the accident.

Participants were recruited from a diverse range of locations around the UK with their children receiving treatment from different burn services. A response rate cannot be calculated as recruitment through radio, charity and social media advertisement cannot be known. Participant characteristics are presented in Table 4.

#### **4.5.1 Demographics**

Participants from different locations around the UK were recruited. Most participants were mothers (11), with only one father and one grandfather taking part, with a mean age of 41.96 years (SD = 9.53; range = 28.96-63.04). The mean time since injury was 2.87 years (SD = 4.00; range = 0.22-15.33 years), with the mean age of the child at injury being 3.62 years (SD = 4.16; range = 0.60-13.00 years). The majority of participating parents were married (10), white British (12) and employed (8).

Most burns were described as either deep dermal or full thickness and the mean total burn surface area reported was 20.00% (SD = 13.97; range = 5 - 50%; data missing for 3 participants). The most common cause of injury was scalding (10), caused by hot drinks (7) and hot bath water (1) (2 did not specify). The second most common injuries were flame burns (3), which were caused by flash flames (2) and falling into fire (1). Other causes of burn were not represented in this sample. In terms of medical interventions, 12 of the 13 children were treated as inpatients. To give context to participants' response, injury details are provided in Table 5. Pseudonyms have been used to protect the identity of participants.

#### **4.5.2 Thematic Analysis**

Spoken interviews lasted a mean of 60.13 minutes (range = 50 – 75 minutes). With respect to the actual injury event, a broad range of experiences were reported by participating parents. When the interview focused on their access to and experience of support, it became clear that there were similarities in the experiences described, their needs, and the types of support felt to be beneficial. Table 6 shows the four themes identified within the qualitative data to be discussed in the following section: losses experienced by parents, changes imposed upon them, perceptions of isolation, and access to psychosocial support.

The analysis is presented in two parts. Part one describes parents' experiences of the injury event and the aftermath, and part two looks specifically at experiences of support and parents' thoughts about peer support specifically. The results are reported within the general themes and

quotes have been selected that best illustrate each point, whilst attempting to represent as many interviewees as possible.

<b>Participant Characteristics</b>		<b>n</b>
Relationship to child	Mother	11
	Father	1
	Grandfather	1
Child gender	Female	7
	Male	6
Burn type	Superficial dermal	1
	Deep dermal	5
	Full thickness	6
Burn cause	Flame	3
	Scald	10
Treatment	Inpatient	12
	Outpatient	1
Marital status	Married	10
	Single	1
	Separated	1
	Data missing	1
Ethnicity	White British	10
	Indian British	1
	British	2
Geographical location	<i>North West</i>	
	Cheshire	1
	Cumbria	1
	Merseyside	1
	<i>North</i>	
	West Yorkshire	2
	<i>East</i>	
	Bedfordshire	1
	<i>South West</i>	
	Gloucestershire	1
	Wiltshire	1
	<i>South East</i>	
	Berkshire	1
	Surrey	1
	South England	1
Wales	1	
Carmarthenshire	1	
Participation method	Email	5
	Phone	5
	Skype	2
	Face-to-face	1
Employment status	Employed	8
	Carer for injured child	1
	Homemaker	2
	Student	1
	Retired	1

Table 4. Participant information for Study 1



Parent's pseudonym	Child gender	Child age at injury (yrs.)	Time since injury (yrs.)	Cause	TBSA
Beth	Female	3.00	15.33	Scald	33
Carol	Male	1.43	.79	Scald	12
Cathy	Female	1.27	.60	Scald	20
Colin	Male	4.87	1.73	Scald	10
Fran	Male	12.19	1.24	Flame burn	5
Jess	Female	13.00	1.21	Flash flame	15
Jim	Female	.81	1.70	Scald	-
Mary	Female	1.41	5.26	Flame burn	50
Sally	Male	1.36	3.19	Scald	7
Sarah	Male	2.31	.22	Scald	-
Sue	Male	1.43	.82	Scald	-
Theresa	Female	.60	3.45	Scald	30
Trish	Female	3.35	1.74	Scald	18

Table 5. Injury characteristics of the children of participants in Study 1

Themes	Subthemes
1. Losses experienced by parents	a. Fear of losing the child b. Loss of the perfect child c. Action to repair
2. Changes imposed upon parents	a. Scars remind me b. Impact on self-perception c. Engagement with others
3. Perceptions of isolation	a. Physical isolation b. Psychological isolation
4. Access to psychosocial support	a. Support from someone who has seen it before b. Barriers to accessing support c. Seeking support online

Table 6: Themes and subthemes emerging from interviews in Study 1

#### **4.5.2 Parents' experiences**

During the interviews, parents talked about the devastating impact the burn injury had on themselves and their child. This was discussed in relation to initial fears of loss, realisations of loss, and attempts to put this right. The event changed a lot of things for parents and their experience of the hospital and the treatment, the impact of the resultant scarring, and the perceived impact that this could have on the child's future could all affect parents in the long-term. Despite input from professionals, family members and/or friends the whole experience could be very isolating.

#### **Theme 1: Losses experienced by parents**

##### **Fear of losing the child**

Fear of losing the child refers to parents' fear of the death or loss of the child. Parents described their concerns that their child would die as a result of the accident, or from shock. Parents could

also be fearful that their child could be taken away from them by social services because, as the child's parents, they were deemed to have not provided adequate care to their child.

"I thought he was dead at first." [Fran]

"I was very scared that she was going to get, in some way, taken away from me, either because she was going to die of shock or injury, or someone was going to come along and say, 'You're an unfit mother'." [Theresa]

This fear could re-emerge if children became more unwell at later stages of their treatment.

"She also contracted toxic shock syndrome, probably a week after the period when the burn happened... she had to go onto life-support... nothing seemed to help." [Trish]

### **Loss of the perfect child**

Parents talked about their child's burn scarring and being saddened at the loss of their 'perfect' child. Many of them reported that they were bothered by their child's altered appearance and how their changed appearance illuminated implicit views held by society.

"You've got this child that's perfect and happy... and you're very lucky to have a perfect baby... we were all a bit sad really that all of a sudden she was different." [Jim]

"It's big, and its red and it's obvious. And it's a bit bumpy and it's going to look different forever. And it's never going to go away." [Sarah]

"This is part of her and we can't hide it. You can't... You also see people's prejudices about making children perfect." [Theresa]

### **Action to repair**

Several parents discussed their desire and efforts to repair the damage that had been done to their child's appearance.

"There's a lot of research that we do to see how we can, before she hits her teens... what we could do to at least help alleviate some of it or make it, whatever." [Trish]

"I just pray her beautiful skin goes back to how it was." [Cathy]

Some parents reported that the scars were still visible reminders that they could struggle with and want to avoid. Some parents reported to no longer see/notice their child's scars or referred to them as marks of bravery that had become part of them. Despite this positive interpretation, there remained a wish for them to be undone and a drive to search for information to improve

the cosmetic appearance of their child's skin. The desire to return their child to their previous form could lead to parents consenting to additional surgery for cosmetic procedures.

"She's an incredibly strong, brave girl and I don't look at them. They're just part of who she is. You know, I do everything I can to try and reduce them. Some of the surgery she has is purely cosmetic." [Mary]

Some parents described being anxious that a new treatment might be available that they were not aware of. This was driven by a desire to regain the perfect child that was lost, which may then help parents to relinquish feelings of guilt. The search for new treatments was also spurred on by a desire to reduce any anticipated negative impact on the child as they grow, and because of concern about the reactions of others to the scarring.

"It's that constant quest for knowledge and treatment... you're on such a micro-level each day or every week managing the burns so for you it becomes an obsession." [Trish]

Parents also spoke about ways in which they compensated their child for the injury experience and for scarring that could not be reversed. They "spoil" and were "soft" on their children to compensate them for the "horrific" experience of the accident and treatment. Such compensation can also be considered a form of reparation.

"I think my daughter was definitely spoiled growing up because of the... I thought that, you know, we might not have had her, you know? She might not have been here so... she was definitely spoiled." [Beth]

"I think overall I spoil her now... I probably spend far more money on her... than I might if this had never happened... I can justify to myself that yes I spend a lot of money on her and do a lot of stuff with her but look what she's been through." [Theresa]

## **Theme 2: Changes imposed upon parents**

The child's injury and the treatment required imposed unavoidable changes on parents, the child, and wider family. Parents lived with the constant reminder of the scarring and, in the early stages, the management of the intense treatment regime would also keep the event at the forefront of their mind. The fact that the event had occurred, and the resultant scarring, could change parents' perception of themselves as adequate parents who were effectively able to protect their child, and this shift in perception could also impact upon their interactions with others.

### **Scars remind me**

For parents, their child's scars were a constant reminder of different emotions and events that could be both positive and negative, such as their child's pain, their pride in their child's bravery,

and their own feelings of guilt. For some, the scars had become part of who the child was. One parent reported that the scarring no longer bothered them, but seeking help from a psychologist had helped them to come to terms with the accident and its consequences. Most parents experienced the scars as a reminder of the unfortunate event and how they had failed their child, which related to the second subtheme: the impact on their self-perception.

“It’s a memory of what we didn’t do right at the time.” [Trish]

“They [the scars] also remind me of the worse day of my life and all the feelings of guilt I hold.”  
[Sue]

“Every time I see it... it kind of brings back the whole, if I’d done something differently, this might not have happened.” [Sarah]

The scars did not just remind parents of their own pain but also that their child has been changed and that this may act to alter the course of their life. Regardless of how parents felt about their child’s scars, they had concerns about the detrimental impact they might have on their child’s future. This was in terms of the pain they might have to go through should further surgery be necessary, and how they might negatively impact on social interactions, the formation of relationships, and their impact on their child’s self-esteem. These issues seemed particularly anxiety provoking with regards to future transitional points, such as starting school and making new friends, and when they would become more self-aware, such as during adolescence.

“They just reminded me of the pain that she’s been through and the pain she will go through. You know, pain in terms of what she’s going to go through with... psychologically through people noticing, relationships, you know, her future.” [Trish]

“I worry about how he may feel about them in the future... My son has just started school and I worry about how he will cope if someone notices his scar.” [Sally]

### **Impact on self-perception**

The child’s scarring could also be a reminder of the guilt and self-blame, as illustrated in the quotes above. Some parents reported that the accident had occurred because they had failed in their parental duty to adequately protect their child. This changed, at least temporarily, parents’ perceptions of themselves as able protectors and, therefore, good enough parents.

“It’s a parent’s duty to protect their children and on this occasion, for a split second we had failed.” [Colin]

“Looking at the sight of the injury, just made me feel sick and shaky, and like the worst mum in the world... He was too little to have had any, kind of control. I’m supposed to protect him. I’m

supposed to, look after him. That's my job... It was completely my fault because I'm the parent and it's my responsibility even if I didn't do the injury causing." [Sarah]

This impact on self-perception and parenting ability also meant that parents were acutely aware of how others might perceive them, which could provoke further anxiety.

"When I used to go shopping and things, I could feel that... everyone knew what had happened and everyone thought I was a bad mother and 'how could she let somebody... her eighteen-month-old get a cup of coffee in his hand.'" [Carol]

Even when the parent was not present at the time of the accident, the perception of a failure to protect could also fuel anger towards those who had the duty of care at the time of the event, even if these feelings were never expressed in an attempt to protect the family unit from further distress.

"I'm a bit angry really that there's three adults in a room and none of them were watching her, it's hard not to be honest when there's three adults there and my daughter's making her bottle and they just, you know, were all on their mobile phones or laptops and that. I felt angry about that but I didn't say anything." [Jim]

The distress that the parents experienced led to many becoming hypervigilant to danger.

"You won't walk into a room and just 'walk into a room'. You walk into a room and see 50 things that could go wrong." [Carol]

Parents' desire to prevent an incident such as this from ever happening again, and their attempts to restore their confidence that they could protect their child, led to all of them adopting an over-protective parenting style, keeping their child out of the kitchen or away from campfires. Parents were not only attempting to prevent their child from experiencing further physical harm, but also from potential psychological harm that might result from difficulties due to their altered appearance.

"My view is that nothing like this would ever happen again. I am very conscious of safety in the home since it happened. I am actually paranoid about anything hot near her." [Cathy]

"I'm over-protective of her... I'm less carefree about... I'm constantly saying to her, 'be careful.' It's probably one of the reasons why we've paid for her to go into private school, to protect her from possibly more kids being bullies." [Theresa]

## Engagement with others

The injury to the child forced parents to engage with services that they “wouldn’t normally expect to” [Mary] or even knew existed previously. Parents could have experienced contact with many different professionals, including the air ambulance crew, psychologists, plastic and reconstructive surgeons, nurses, physiotherapists and play specialists, and often accompanied their injured child to many appointments. Engagement with others had the potential to increase or decrease parents’ feelings of anxiety related to guilt and self-blame.

“The air ambulance doctor and nurse came with us in the ambulance and they were saying ‘Oh we see this all the time’, so it kind of made it more normal I suppose, in a way... And that made me feel a bit better.... I already blamed myself, I didn’t want anyone else to blame me as well from an authoritarian point of view and saying my child was in danger.” [Theresa]

“It was nice to have someone tell me it wasn’t my fault.” [Sarah]

The quality or nature of contact with others might have also changed as a result of the burn. For example, strangers who might not normally exchange more than a glance or a brief acknowledgement might ask questions or make comments.

“People make comments – you know, ‘It’s a shame.’ Somebody noticed it and said to me ‘Has she damaged... has she burnt herself?’” [Jim]

When the prejudices of strangers were apparent, one parent was able to describe how she acted as an advocate for her child with a very powerful and worrying example.

“When she was 11 months old, they had photographs taken at nursery and she was wearing something where the top of her scar showed and when I got the photographs back the photographer had airbrushed the scar out. And I went apoplectic! “How dare you change the appearance of my child without asking me!” “Oh well we thought she’d look better.” I said, “What do you mean better? How on earth are people going to live with things if you airbrush them at the age of one? Put it back in, I’m not buying them.” Because what if she looked at it and went “Where’s my scar?” “Oh, we took it out because it looked ugly!” You know, you can’t.” [Theresa]

Participants described how, whilst the focus was on their child’s needs and efforts to support them, their engagement with their spouse, the rest of their family, other children, work colleagues and friends decreased. This could also have detrimental consequences, increasing parental anxiety. This could be particularly problematic when contact with uninjured siblings was reduced. Not only could it be upsetting for the child at home, but it also added additional stress to parents who could then feel that they were being neglectful. This could potentially reinforce parents’ perceptions of their inability to parent well.

“We neglected our oldest child who was 7 at the time. About 6 months after the accident he got very upset one night and when questioned, said that he felt ‘unloved.’” [Colin]

Unfortunately, the severity of the injury in some cases meant that parents had to leave work and become full-time carers for their children. However, less severe injuries could also reduce contact with friends and peers.

“We never had friends over, saw friends, went out for dinner, had people round for dinner. They just didn’t... it wasn’t a normal life anymore.” [Carol]

The accident and treatment also impact on parents’ relationships with their spouse. This could be in terms of communication, more specifically a lack of communication regarding feelings related to the accident (such as anger), and also when blame was attributed to one parent.

“My husband has had to deal with a lot of the guilt. I’ve never blamed him consciously, it was an accident, but of course it’s very hard to get rid of that underlying blame because he was the parent at fault, or accountable of the accident at the time.” [Mary]

“Me and my husband have never spoken about it since... You couldn’t show how upset you were because I didn’t know how my husband was feeling... I actually didn’t have a clue.” [Carol]

### **Theme 3: Perceptions of isolation**

Isolation, in the emotional and physical sense, emerged as a significant challenge that parents faced when their child was newly injured. This could be emphasised early on by the (at least temporary) restrictions on parents’ lives, their ability to work, and their interaction with friends and family members. Initially, the hospital could be perceived as a “bubble” or a “cocoon”, leaving parents “cut off from the outside world.” The sense of isolation changed over time, with parents perceiving more psychological than physical isolation later. This sense of isolation could be maintained by communication difficulties between spouses. Even when the family was reunited, a lack of communication could result in it seeming as though no one else had shared their experience; they are “the only one.”

#### **Physical isolation**

Parents found themselves suddenly in the “contained environment” of the hospital with their injured child, often in single rooms due to infection protocols, sometimes in high dependency or intensive care units where visitors were not permitted.

“The hospital is quite a contained environment... I’d spent the best part of six weeks in the Intensive Care room with my daughter and you’re in a kind of cocoon, that you’re in this bubble of a hospital it’s... you’re cut off from the outside world.” [Mary]

In a busy hospital environment, this issue may go unnoticed by professionals. Parents' focus on being there to support their child, particularly when they were the only parent present, meant they even neglected some of their own basic needs.

"I was basically stuck in a room for a week with [my son]; I had to leave him, at his most vulnerable, to get food. Which was hard as he didn't want me to leave, so some days I would eat little, if anything." [Sue]

### **Psychological isolation**

Although parents were surrounded by a multidisciplinary team, and sometimes other family members and friends, they still felt very much alone.

"Sort of trapped and almost alone, I suppose because you... I felt like I was the only person that felt like this... You feel like you're the only person it has ever happened to." [Carol]

"You feel like you are completely by yourself." [Fran]

Participants alluded to the fact that staff working in paediatric burn services encouraged parents to try to look after themselves and conserve their strength for when their child was discharged and they would be required to take over their care at home. However, the value of this advice and support could be difficult to accept as some parents felt that staff did not have the same experiential knowledge that they had.

"At the hospital they said frequently to me 'Save your strength.' When you get home, you're going to need it. This gets far worse when you're home.' And, of course, when you're in an Intensive Care [Unit] you can't imagine anything being worse... the hospital can tell you that but they probably don't really know what it means. They've heard it but they don't actually probably recognise what that means in your day to day life because you're then taking on a job that they've been doing as a team... it was just immense... the hospital probably know but they wouldn't know what that really means in reality." [Mary]

Parents reported that it would have helped if someone, potentially another parent who had already experienced what they were going through, could have met them "Just to feel less alone." [Jess]. Peers could then normalise the common/typical emotional and behavioural reactions of parents to a child's injury and provide them with ideas about how to cope with any difficulties, should they arise. Although parents were able to acknowledge that this normalising information was disseminated by staff members in the burn service, their advice does not seem to be heard in the same way by the parent as they perceive it would be if it came from a peer who had previously shared their experience.



"I think the people that were telling me that... how it was going to end up were all medical people and not parents, so they were all telling me very factual things about the scar and none of them said 'It will be like this.'" [Theresa]

"I think it's important at that time... that first few days, if [a peer] actually said to me, you know, it is going to be ok, that'd have meant a lot more to me than the nurses saying it would be... there is someone that's already gone through it." [Beth]

There was a sense that this information might be better heard from a peer who is not talking from a medical perspective, someone "a little bit ahead" who could talk with lived experience, about what the future might hold, and begin to offer support and optimism.

"The medical person is obviously always seeing it from a different side... maybe talking to other parents who were out the other side of a similar experience... that probably would have been quite useful." [Fran]

"I would have liked to have met someone a little bit ahead of me... someone that had been where I'd been and could explain to me the future because, yeah, other than the Burns Unit saying to that it gets harder when you get home, I didn't really have any idea of what I was up against and there was no way really... to be able to talk... for the heads up of what was coming, the support, the optimism." [Mary]

"I felt that other parents were very sympathetic as they had been through a similar situation and could empathise which made me feel that I wasn't alone." [Cathy]

#### **Theme 4: Access to psychosocial support**

Support was defined loosely for parents during the interview, and could include informal support from friends and family, peers, hospital staff, and higher-level formal face-to-face interventions, or any other resource that they found supportive. Most parents reported to have been offered support following their child's injury, however not all of them accepted it. Those who did access some form of support generally found it helpful. Parents' thoughts and experiences regarding support formed three subthemes covering the importance of accessing support from someone who has seen it before, barriers to accessing support, and seeking support online.

##### **Support from someone who has seen it before**

Someone who had seen 'it' before could be a professional or a peer; they were someone who might 'know what it feels like'. Most parents reported being offered one-to-one support with a psychosocial professional, such as a psychologist. For some, it was important that the person they spoke to about their feelings had experience working with families in similar situations and who

was not a family member. Access to a psychosocial specialist could help parents manage feelings of blame and let go of unanswerable questions about what might have been, assisting them in “accepting it and moving on rather than trying to turn the clock back and change anything.” [Theresa]. This was achieved in at least one case by offering alternative perspectives that did not place the parent in a role at fault.

“The blame and the ‘what if’s’ and... I think it was just generally accepting it and moving on rather than trying to turn the clock back and change anything... I think it was just helpful to talk to somebody that wasn’t a family member that had maybe seen it before.” [Tracey]

Other examples of helpful input were teaching coping strategies to parents, such as mindfulness for anxiety, or helping them to accept and move on from the traumatic event without attributing blame to themselves. This could be liberating for parents. One mother described how the psychologist helped her to see where she could help herself and conquer troubles. It is important to be aware that, although participants are using the term ‘psychologist’, they may well be referring to a counsellor, psychotherapist, or play specialist who has provided them with emotional support and containment, as some services do not employ clinical psychologists.

“Being with the psychologist and helping me see what was wrong. She really helped you see the light... she just helped you see where you could help yourself... she used a thing called Mindfulness that we practised in our sessions... I still do it now... it just relaxes the mind. It’s great!” [Carol]

As well as formal support offered by the psychologist, some parents found key members of staff to be supportive, offering advice, comfort and distraction for the child, which parents also described as beneficial.

“[Nursery Nurses] were just the best... they visit all the rooms and round the beds and just play with all the kids and... that’s what you wanted.” [Carol]

In most cases, psychological support was offered to parents during the inpatient phase. Once the child was discharged from hospital and the parent experienced more demands, uptake/continuation of formal support could be limited by the barriers described in the next section. At this time, special effort from staff or parents might be required to maintain supportive relationships.

“She’s been an absolute stand out support and she’s rung her at home as well... I think that’s a source of comfort that there’s a general interest in the child. ...when they speak about the person or they speak about my daughter in a caring way and I think that’s significant to (my daughter) and myself.” [Jim]

In addition to hospital-based support, other support available to parents was from peer-led face-to-face self-management programs, burns camps, and from chance meetings with other parents at the hospital. Access to support from peers was potentially more acceptable to those who held concerns regarding negative judgement from others.

“We found it helpful to have brief informal chats with other parents on the hospital ward who you knew were feeling the same guilt and shame about the accidents that had occurred, and they were not judging you.” [Sally]

Some parents reflected on the injury characteristics of their child and the potential impact (or not) that this could have on peer exchanges. Whilst some parents may find that they are ‘differently similar’, for others the difference could be a barrier to making effective use of peer support.

“It was useful to talk to other parents about their experiences which turned out to be very similar, although the injuries and nature of accidents varied.” [Colin]

“The one thing that I find a little bit hard... I suppose it’s around the peer to peer support – so most of the children I meet through the one day events that I go to, they don’t have anywhere near the level of injury that my daughter has... and whilst I appreciate that their injuries are every bit as significant to them and what they went through was equally traumatic, however I don’t feel quite the same level of... empathy or ability to talk given that the severity of her injuries, both in terms of the fact it was life-threatening and the time she spent in intensive care and also then... her level of disfigurement... I just can’t quite relate to them in the same way... I wouldn’t have felt that I had anything particularly to offer them or vice versa.” [Mary]

### **Barriers to accessing support**

One significant barrier to accessing support was a lack of knowledge of its availability. Although most parents reported to have been aware of the provision of professionally-led support for themselves, one was not.

“If there were some kind of easily accessible information around then that might have been useful but certainly a suggestion by the doctor, even if they weren’t saying ‘Would you like this?’ but even just saying, ‘think about it.’ That would have been helpful.” [Fran]

Those who were aware of the presence of support discussed practical and psychological barriers to them accessing or receiving it. Parents discussed the challenges imposed on their routine, including: complex scar management routines, devising ways to get a young child into tight-fitting pressure garments, scheduling time to get to hospital appointments, managing the financial costs,

performing increased levels of care on top of other commitments such as work, parenting other children and other aspects of family life, and co-ordinating any additional services (such as local financial support or care teams). Although attempts to attend to their own needs were discussed by some parents, these actions were of low priority with parents putting their “own needs last.” There was a sense that parents accepted this was an unavoidable consequence of the injury.

“From my perspective, my son was the one that needed the care. I, I hadn’t really thought about the fact that I was struggling. Or that I would struggle emotionally with it if that makes sense. But yeah, I wouldn’t have. It kind of felt self-indulgent to have support.” [Sarah]

As a result, most found ways to manage the challenges as many of the tasks would likely contribute to the recovery of the child and therefore were actions that would help to repair the damage done. As discussed above, perhaps acts of reparation could help parents to relinquish feelings of guilt and loss. Generally, caring for a child who has suffered a burn injury was immensely challenging on top of other parental demands and it affected the whole family. The presence of real-world and psychological barriers to support meant that parents focussed on their child’s needs at the expense of their own.

Real-world or practical barriers were when a lack of resources, time, or geographical factors caused difficulties for parents accessing support. These included the often long distance to the specialist burn service, the time commitment involved in attending the child’s multiple appointments, and the financial impact of travel and parking. Financial difficulties could also be exacerbated if parents had to decrease their working hours or cease work altogether to care for their child. Parents could find themselves split between attempting to continue with the reality of life versus being trapped in the hospital “bubble.”

“You’re in a specialist unit... for me living 90 miles away... it’s a two-hour drive away... It’s practically too difficult to access... It was there, easily accessible within the hospital environment, but then to get something locally to me... I didn’t feel that there was anyone checking in as to how we were doing as a family... and whether or not we were coping.” [Mary]

“Personally, we didn’t have any support... We’ve asked could they go anywhere more local; you know? To make it easier really.” [Jim]

Interviewees described how caring for a sick or injured child also had financial implications. For some, their hours in work were reduced and travel to the hospital could be expensive. Parents already felt the financial burden of supporting their child’s access to treatment and, when their own needs were already over shadowed, making additional trips to access support for themselves (when their focus was on their child) would create an additional burden.

“Just the financial hit of going back and forward to [the burns unit] is significant” [Mary]

“It’s not a short drive, it’s 35 mile each way... The parking’s a multi-storey and it’s finding a parking space is difficult. There’s an expense... you know I don’t have a State... I just live off a small private pension.” [Jim]

Parents could also find it difficult to access support when much of their spare time was taken with their child’s medical appointments.

“We just focused on my son getting his treatment and attending the many hospital appointments. During the time of treatment, I guess you are very focused on that, attending all the appointments etc. that you put your own needs last, and block out your feelings to hold it together for your child.” [Sally]

The demands of care, work, and siblings put pressure on parents leaving them with little time to access support for themselves.

“Trying to balance working full-time, looking after the family and her on-going medical needs as she gets older, concern about her psychological welfare... the intensity of the level of care she needed was pretty much a full-time job... The absolute hands-on care of a child coming out of a severe burns injury was just immense... I can’t travel up to [the hospital] to see a psychologist and, if I’m in [the hospital] I’ve got my daughter with me. It’s just practically a little bit difficult to access.” [Mary]

Whilst time is needed to access peer support, it also requires a time commitment from other parents who would facilitate it. This could also be a barrier to the development of peer support interventions.

“I would be happy to do it informally, but I don’t have the time to be able to go to [the hospital] to go through the training. I understand why they need to do that.” [Mary]

Other barriers preventing parents accessing support were psychological in nature and resulted in them being ‘blinkered’ to their own needs. Guilt was and, for many, continued to be felt following their child’s injury. This became evident as an area in which parents could benefit from support. However, the reinforcement of their guilt could be a psychological barrier preventing parents from seeking support from professionals, friends or family members if they perceived that they were “always explaining it and it always was because of something [they’d] done” [Theresa]. The child’s scars could also fuel guilt, and although the participating parents recognised this, addressing it was difficult when they did not want to talk about it.

“You still feel a lot of guilt and you don’t want to answer people’s questions.” [Carol]

Recalling and talking about the event, being in similar situations, and answering questions about their feelings, could cause parents to experience pain or upset. This was evident in one parent's report of experiencing "the noises associated with the accident" [Colin] as he responded to the email interview. There was also the concern that if their child were to see them upset, this would also have a detrimental impact on them. This desire to avoid pain and upset could act as a barrier to parents seeking or accessing support from their spouse or other family members.

"We've never gone through that day; we've never re-lived it in any way whatsoever... if you came crashing down he'd feel bad... you know it was just, yes, head up, stay strong, you've got to, there's no choice" [Carol]

Parents could put on a brave face and be perceived by others to be coping by avoiding thinking or talking about what had happened. One mother described the moment she was asked by a friend about the incident and how she and her son were coping: her façade crumbled, exposing the emotional impact the event had had on her.

"It's emotional having to go through it... it was initially so difficult to even get out what had happened without feeling very, very upset... as soon as you've got to tell somebody else what's happened, you know, you can be coping, or appearing to be coping fine, it's the articulation of it to somebody else that can then set you off, you know, it's the... don't ask me if I'm fine, kind of thing." [Fran]

Linking with the real-world barriers, parents described being "blinkered" to focus on a narrow set of priorities, accompanying and supporting their injured child through treatment, focusing completely on getting their child well again, and maintaining a sense of normality as far as possible. Rather than thinking about themselves, they might only consider "what do I do to keep going here?" [Mary] in order to cope and "hold it together" [Sally]. This narrow-focused approach may help parents mask what they perceive as weakness for needing support. Although it might also be the only option when parents are unaware of, or unable to access, that support available.

"I think you go into yourself a bit and just deal with it and get on with it and treat it... you kind of treat it in a way – no it's not really happened" [Jim]

"I was just completely blinkered in terms of... there was no "What about me?" within my mental framework at all. It was all about right, what do I do to keep going here? What do I do?" [Mary]

"The priority was to get our daughter healthy and well." [Jess]

“I just sort of dismissed it. Basically, my brain hadn’t configured what had actually gone on and my priority then was to get my son home and feeling better... When you’ve been the parent you don’t realise how much you need to talk to people about it... I didn’t want my family to think that I was weak.” [Carol]

Despite the provision of psychosocial support within burn services, due to the barriers described, parents may feel unsupported at a time of heightened distress. Some parents held negative connotations around accessing psychological support for themselves, particularly after their child’s accident. This could result in unmet needs that could potentially be addressed by peers - other parents who have shared a similar experience and know what it feels like.

Some parents had accessed peer support informally and found it helpful; it allowed them to feel “more normal rather than feeling singular”, and to appreciate that accidents do happen and, for some, even that they were fortunate that their child’s injury or the circumstances were not worse. Due to the experiential knowledge possessed by peers, parents were able to sympathise and empathise with each other in a way that professionals were not.

“I found it very reassuring to see that accidents do happen and talking to others hearing what they went through made me feel like I wasn’t alone. I felt a problem shared is a problem halved and felt it was good to talk to get things off my chest. Talking to other parents in similar situations made me feel stronger about the whole incident.” [Cathy]

Although most parents described how peers could be a valuable source of emotional and practical support, this was not always the case.

“I felt that she actually didn’t really want... it was a difficult situation for them... I felt that she was actually still in a very difficult place herself, so she wasn’t really... probably weren’t quite matched, at the time, to be able to offer each other support.” [Mary]

### **Seeking support online**

It could be difficult for parents to engage in the traditional model of face-to-face psychosocial support as overcoming the barriers described above requires substantial resources and effort. Some of the parents interviewed in this study had already turned to the internet as a medium for sharing and gleaning peer experiences, and many had searched for information online. This was a self-directed effort, rather than under the advice of others, however, the provision of appropriate resources and online support was noticeably lacking.

“I remember coming home from the hospital and reading about other people’s recoveries and things like that but there wasn’t too much... It was adults that had been burnt and put their stories on.” [Carol]

Most parents discussed the benefits of having “something on the internet” that they could access if/when they needed it and in their own time. Rather than the internet being a substitute for face-to-face support and experience sharing, it could be a preference.

“We’re so more internet-based nowadays.” [Carol]

It was alluded that some might feel “more confident to type” about their experiences than they would be to talk in real-time. The internet can provide support at a distance, allowing parents the opportunity to be more in control of, and selective about, what information they access or even share (physically and emotionally), and when, than they would be in a face-to-face situation. As well as overcoming some of the real-world barriers to accessing psychosocial support, perhaps the provision of an online resource could help alleviate the sense of isolation felt by parents and overcome some of the psychological barriers to support, facilitating manageable empathic relationships from afar with interaction when parents feel ready and able to do so.

“I have sought out various discussion groups, I’ve looked online.” [Mary]

However, the vast amount of information available online could be difficult to manage.

“It’s really difficult to unite all that information around the world so that you can glean something from it in different stages of the burns process – you know, the recovery.” [Trish]

There were different views about the format that remote/online peer support could take, suggesting multiple methods of support delivery require consideration.

**An online group/forum.** This would allow parents to interact, share stories and obtain advice from other parents.

“Something on the internet – you know, like a forum? So people can go on and talk and you can read other people’s stories, and things like that. I probably wouldn’t pick up the phone to talk to somebody, I would go on the internet and look at a forum of some sort and talk to people on there. Because you feel a bit more confident to type away and talk to somebody than pick up the phone and talk to a stranger.” [Carol]

“Like Mumsnet – when you’ve got a crazy question you can just type it into Mumsnet and 500 people will come back with an idea... it would be quite good to have that ability to go on a group or something and ask a question and get some support.” [Theresa]

Another parent pointed out a downside to online peer support; it can be easy for relationships to become unbalanced.



“It can be fantastically useful and helpful but... you kind of get stuck in other people’s dramas when you’re talking to other parents about their stuff and I almost always spend my time trying to make other people feel better when in that sort of situation. So I tend to get less out of it because I’m doing the supporting.” [Sarah]

**Email.** When parents want to communicate with others at times that are convenient for themselves, and where distance might otherwise hinder interaction, email was felt by some participants to be a valuable mode of interaction.

“I do think that talking to another parent, maybe by email would have been useful, because you know they are not judging you and know exactly the feelings you are experiencing.” [Sally]

“I think, having almost like... when you’re having a new baby, where you get that NCT class? There should be that. I think that was the biggest bit of support I felt lacking – well here’s a group in the same phase as you, why don’t you all exchange emails?” [Trish]

**A website.** Parents did not necessarily want to interact with others, but still wanted to seek information regarding their experiences. This could be the case when anonymity is valued. In this case, some parents said that they would value websites that present information or accounts (such as blogs). A common topic that parents said they sought information on was appearance-based concerns.

“What would be quite nice as well, is to be able to upload like a timeline of photographs of the scar so that people can see, you know, this is how this has turned... I know every scar’s different, but it might help people understand the changes that might take place, how long they take, you know? That would probably be quite useful for other mothers to see that actually it looks kind of ok and then they do the surgery and it kind of looks awful... and then all of a sudden it just starts to fade. And I think just seeing a progression through treatment would be really helpful and I never saw anyone else’s. I haven’t been shown any pictures of scars.” [Theresa]

Most parents were in agreement that peer support would have been useful to them, but a formal support group was not needed. The anonymity offered by online/remote support was also valued by most, but not all, participants.

“Someone might not want to go on a forum and say what’s happened to their child but if they know someone’s had a very similar experience, especially if there’s like someone where they blame themselves, then that’s probably chatting to... one on one, face to face is easier and more useful perhaps than talking over internet.” [Theresa]

For some parents, face-to-face interaction was considered important when sharing personal experiences but the different methods of research participation (discussed later in this chapter) suggest that this is difficult to do.

“I think the more parents you can get together about it would have helped. Because I’d never met anyone who’d had a burnt child until I had a burnt child... you find out suddenly that there are all these people that have been through a similar experience so it would be nice to be, I suppose, put in touch with them... I think face to face is really important... a monthly get together would have been nice because I think then you could have said “Oh, how’s so and so getting on?” and we could have shared photographs... it is putting faces to names and actually just talking to people one on one.” [Theresa]

It became evident that one of the challenges of developing an online support service is that ‘one size does not fit all’, or all stages post-burn, but having an online resource that could be advertised to parents would allow them to make the decision as to whether or not to make use of it, when, and which parts they wanted to access.

“Once you get discharged from hospital if they had like a leaflet or something to tell you where to go and... so that you sort of could do it in your own time, but you had the information there.” [Carol]

Participants also justified why it is important to consider the timing of offers of support. When children are being treated as inpatients, parents focus on being there for their child.

“Prior to the wound actually healing, that is probably a bit early because at that stage where you don’t know what’s happening... I think it’s once you’re discharged from the hospital then that would be good to have some kind of support and help.” [Theresa]

However, it is at this time that professional support is most accessible for parents in the hospital. When asked when it would be most beneficial to offer peer support to parents, some parents felt that in the initial stages, whilst their child was in hospital or prior to wound healing, would be appropriate. However, the majority felt that this might be too early and advocated for peer support during rehabilitation, after wounds had healed but before scar maturation.

“I can imagine if your child is still in a life-threatening position it’s a difficult relationship to build up... I appreciate that when you’re in the throes of that that probably peer-to-peer support isn’t very helpful because the end isn’t guaranteed, but once that roller-coaster has finished, I think to just give them... a light that yes it’s not all plain sailing and it is going to be very, very difficult but look at mine now.” [Mary]

Following discharge, parents could be overwhelmed by the increased demands made upon them.

“The Burns Unit, they put into action a whole load of local services, so in my first week I was a little bit bombarded with phone calls from Occupational Health, Physiotherapy, my GP all offering their support. But you’re so, so confused and in and out of hospital and... on top of the fact you’re then having to do complex medical needs as well.” [Mary]

However, for some, this was a time that they would appreciate some easily accessible support with the time following wound healing, prior to scar maturation, also being identified as a time when parents might be more receptive to support.

“When you’ve come out of hospital and a little bit later when you’re dealing with rubbing in the cream, putting on the vest, being anxious initially about how it’s going to go... The stage of learning how to deal with it.” [Jim]

“I think it would be best later on rather than at the time, because I think at the time... all you really want to do is talk to medical people.” [Sarah]

It was also stated that peer support should be offered for as long as it is needed, and that staff should continue to advertise the availability of it, even if it is declined initially. This would remind parents that there is always support available to them. Participants described how, once their child’s wounds had healed and some sense of normality was regained, it was then easier to recognise the magnitude of the impact the event had had on them, and how support may have been, and could still be, beneficial.

“I can only look back now and realise how significantly I was affected... I can recognise now that I would have received a diagnosis of PTSD. I was not in a good place.” [Mary]

The importance of timing and of matching the amount of information that parents receive to their ability to comprehend the information was also highlighted and should not be underestimated. Telling parents either more or less than they want to know about what the future holds for their child, themselves and the impact on the family can make it more stressful (Miller, 1995).

“I suppose if someone had said to me at the time it happened, ‘These are all the things you’re going to have to go through in the next two years,’ I’d have fallen apart completely but because everything was new and novel and you went from one thing to another, it wasn’t so bad in that way.” [Theresa]

#### 4.6 Discussion

The aim of this initial study was to explore parents' experiences of having a child affected by a burn-injury. Emerging themes following the interviews with parents referred to loss, change, and isolation. This study also explored whether parents access support following their child's injury, both within the hospital and post-discharge, whether they find it beneficial, in addition to establishing their opinions of peer support, and whether they would have valued this following their child's injury.

As illustrated in Chapter 2, the experience of having a child suffer a burn injury can have a significant negative impact on parents. After the initial fear that they would lose their child as a result of the accident, the injury event could cause parents to experience the loss of their "perfect" child and lead to a parent-held perception that they had failed in their duty to protect their child. Any resulting scarring could also fuel parental guilt, reminding them of what they had or had not done at the time. As a result, parents commonly discussed being "less carefree", "very safety conscious", "over-cautions" and "over-protective" of their children since the injury. Similar consequences were found by Mason (1993) and this can also be recognised by children and young people (Egberts et al., 2018). Over protective parenting can result in children engaging less with their peers and in developmentally appropriate risk-taking activities (Brussoni, Olsen, Pike, & Sleet, 2012). However, burn injuries can also disrupt children's participation in daily activities such as schoolwork and sports, sleep, playing with other children, as well as less enjoyable activities (Tyack et al., 1999). As activity participation is important for enhancing children's abilities, skills, relationships with peers and adults, and overall physical, mental, and emotional well-being, children with burns may have more difficulties in these areas than children without burns (Grice et al., 2015).

Horrige et al. (2010) described parents' reports that their children had been cared for in the hospital with idealised perfect care. Although this may reflect the gratitude that parents felt for the substantial recoveries that their children made, when considered alongside parents' reported fears that they are a 'failed protector', this may further reinforce their fears that the care they are capable of providing is in some way inadequate. Those thoughts and feelings may contribute to over-protective behaviours and hypervigilance in response to the injury, finding new dangers in familiar environments (Horrige et al., 2010). However, these psychological difficulties can become less pronounced with time as parents and children come to terms with their experience. For parents to recover psychosocially, they must not only regain their confidence in their ability to protect their child, but also in their child's abilities to take care of themselves, particularly in situations or during activities that would be in some way dangerous (Horrige et al., 2010). Over time, as parents witness their children's physical and psychosocial recovery, their stress and

anxiety can also decrease (Horridge et al., 2010). However, there is the potential for this to be alleviated earlier through parents meeting other parents who are further ahead in their post-burn treatment journey than themselves.

Parents discussed a desire to repair the damage done, seeking out information about new treatments, praying that their scars would fade and their skin would return to normal, and following advice to improve scarring as far as possible. It should be noted here that, due to the effects of social desirability bias, it might be unlikely for parents to report doing anything other than following the advice of their child's health care professionals in order to improve the appearance of their child's scars, despite the challenges involved such as difficulties dressing children in pressure garments and ensuring that the scars are always protected from the sun.

In addition to active attempts to repair damage, parents also described compensatory actions such as "spoiling" their child or being "softer" on them to make up for what they had suffered or may suffer in the future. This impact on parenting could also affect siblings. The perception of un-injured siblings that their injured brother or sister were "spoilt" following a burn-injury can be problematic for those who notice this special attention (Phillips et al., 2007). In addition to this, parenting a burn-injured child could also affect parents' interactions with others. Parents were required to engage with healthcare professionals, sometimes social services, familial roles may have changed (at least temporarily), and they may even have taken on the role of advocate for their child when others showed prejudices.

In a study of adult adjustment to disfigurement, ambiguous stimuli (for example unexpectedly meeting the eye of a stranger) was found to be more likely to be interpreted as associated with the different appearance by those who are poorly adjusted and these views of the self are chronic and hard to shift (Moss & Carr, 2004). Moss and Carr (2004) found that a myriad of thoughts, feelings and memories were associated with the poor adjusters' view of themselves and their appearance. Perhaps this can be applied to parents who are very concerned about their child's changed appearance, how they might cope in the future, and also how this influences other people's perception of them. The consequences of a burn-injury are very visual and when a parent has less 'non-appearance' related information available to act as a buffer, their thoughts may become dominated by appearance.

Social skills training and cognitive behavioural therapy has been found to be successful for these clients, teaching them a new mental script for interacting with others and challenging negative thoughts about appearance to manage social encounters (Moss & Carr, 2004). As parents may not have to navigate challenging social situations as their child becomes more independent, it may be

that their concerns are alleviated by 'decompartmentalising' their thoughts about appearance. This would mean using techniques to integrate positive, non-appearance relevant information into their thoughts about their child and reducing the differential importance placed on appearance by re-valuing alternative aspects (Moss & Carr, 2004).

Although data were collected a mean of three years post injury, it was apparent that recalling the injury event, or being in similar situations to the event, could be troublesome for some parents. This was evident in Colin's report of experiencing "the noises associated with the accident" and the impact of the traumatic event influencing the change to a more overprotective parenting style. Parents' symptoms of general anxiety and injury-related fear avoidance are amongst some of the symptoms found to be associated with a perceived lack of support (Willebrand & Sveen, 2016). Therefore, the evidence presented here suggests that some parents would benefit from support to help them to adjust to their child's injury and the impact that this has on themselves, their parenting style, and interactions with others.

Lawrence et al. (2016) reported prevalent, although varied, post-burn injury psychosocial support within the UK. It is apparent that professionally-led psychological support was available to most parents who participated in this study, particularly during the inpatient phase. Most parents in this study stated that they had been offered, and generally accessed, such support, finding it helpful to speak to someone who has seen what they were going through before. However, real-world and psychological barriers to accessing support were experienced, mostly following the child's discharge from hospital.

When children were treated as outpatients, the time taken to attend appointments, lengthy scar management regimes, and the distance from the hospital where the support was located meant that parents often focused solely on their child's recovery rather than on their own needs. Being blinkered to their child's needs might mean that parents do not even recognise their own needs. Parents' geographical distance from the service has also been identified by staff as a barrier to providing psychosocial support within UK burn services (Guest, Griffiths, & Harcourt, 2018).

Similarly, Bakker, Van Loey, Van der Heijden, & Van Son (2012) noted that psychosocial support during hospitalisation was available for children and families, but support following discharge was predominantly centred around the physical recovery of the child, which was also the time when parents of more severely injured children experienced more stress symptoms.

Guest et al. (2018) explored reasons why patients might not always be signposted to psychosocial support services, such as lack of staff knowledge and a view that psychosocial support services are of less importance compared to those addressing the physical symptoms of injury. Such findings can also be applied to parents. It is possible that staff without adequate training in post-burn

psychosocial issues might find it difficult to detect certain problems or be aware when a referral for specialist support is necessary (Wisely, Hoyle, TARRIER, & Edwards, 2007). Other barriers to support, which were perceived by parents, were psychological in nature. These included feeling guilty and not wanting to talk about what they perceived they “didn’t do right at the time” [Trish]. Accessing support was considered by some to be self-indulgent when their child is suffering and, as a responsible parent, they feel they are in some way to blame for that. Pugh et al. (2015) have highlighted that guilt and shame may constitute barriers to treatment if they are not addressed.

Studies of burns support groups, have shown that people prefer to speak to others who have been through similar experiences and therefore have a better understanding (Chedekel & Tolia, 2001; Cooper & Burnside, 1996). Bakker et al. (2009) suggested that a group cognitive restructuring program to address guilt and self-blame, designed for parents of severely disabled children (Nixon & Singer, 1993), could help to reduce self-blame and guilt in parents of burn-injured children and reduce its influence on subsequent PTSS, particularly for mothers (Bakker, Van der Heijden, et al., 2013). Through the sharing of experiences and social comparison, the suggested intervention could enable parents to validate and normalise their feelings (Nixon & Singer, 1993). This was an important factor also highlighted by Frenkel (2008) who described how parents meeting and discussing their emotions concerning the burn event in a support group with other parents could be beneficial. More recently, following a recent integrative review of research focussing on the support needs of parents of children hospitalised with a burn injury, Lernevall, Moi, Cleary, Kornhaber and Dreye (2019) concluded that parental feelings of distress, guilt and blame, as well as their needs for information and support, calls for further research to facilitate the development of evidence-based support programs that address these needs.

The importance of normalising feelings was also highlighted in the current study. As was found by Phillips et al. (2007), parents in this study reported that it would have helped if someone had informed them of common emotional and behavioural reactions of other parents to a child’s injury, and how to cope with the difficulties should they arise. For this reason, including the findings of the literature review in the development of an intervention would be important to educate parents, normalise their own experience, and alert them to the support available for these difficulties, should they recognise them in themselves after reading about them. Additionally, encouraging couples to communicate with one another could reduce some of the psychological isolation as grief studies have shown that couples may attempt to protect each other by avoiding conversations about their loss and holding in their feelings, resulting in more grief for themselves and their partner (Stroebe et al., 2013).

Emotional difficulty connecting with others who are dealing with the same issues can result from identity tension – the feeling of ‘being differently the same’ - that needs to be negotiated in order for peers to be able to engage and benefit from experiential information sharing (Mazanderani, Locock, & Powell, 2012). An important way in which a person might manage their sense of identification with another is through being selective about the communication channel through which they connect with them (Mazanderani et al., 2012). The value of having multiple channels was supported during recruitment into this study with participants choosing to take part via the method they perceived to be most convenient whilst also allowing them to develop a rapport with me (the researcher), facilitate their openness, and also for the depth of their responses to be facilitated (Heath et al., 2018). However, as the provision of peer support is limited (Batchelor & Williams, 2013), particularly for parents in the UK, and with there being limited opportunities for experience sharing, selecting an appropriate channel can be difficult and may lead to parents feeling as though there is no one that they can talk to.

Some of the participants in this study expressed their willingness to offer support to others. This was also evident in the study by Badger and Royse (2010), which suggested that the value of this service was recognised by adult burn-survivors and mutual aid involves reaching out to others. Peer support has been defined as, “people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial” (p.3) (National Voices & Nesta, 2015). It has been found that caregivers and those who have experienced a medical crisis in the past year are particularly likely to use peer-to-peer resources (Fox, 2011). Studies have also assessed motivations for participating in online peer support, which range from self-interest to altruism (Kollock & Smith, 1996).

Peers possess unique specialised coping information, perspectives and experiential knowledge - ‘truth based on personal experience with a phenomenon’ (Borkman, 1976) (p.445) - that can make mutual aid effective (Borkman, 1999). The idea that experiential knowledge can be a valuable resource in healthcare appeared in the 1970’s driven by the self-help movement (Mazanderani et al., 2012). Peer support is based on the premise that sharing mutual experience provides a unique and valuable form of psychosocial support (Legg, Occhipinti, Youl, Dunn, & Chambers, 2017) and parents in this study discussed the anticipated value of such support.

It was apparent from the current study that many parents felt isolated as a result of their child’s injury. This might seem an unlikely outcome in a busy hospital environment, but parents are often a significant distance from their home, the rest of their family and support network, in an unusual environment, often with little understanding about the procedures taking place. Smith et al. (2011) speculated whether this issue could go unnoticed by professionals whose focus is on



treating the injuries of the child and other patients on the ward. It has been suggested that a failure to appreciate and address this issue may contribute to parents' experience of post-traumatic stress disorder (Callery, 1997).

In a description of group meetings for families of burned children, Cahners and Bernstein (1979) describe the apparent comfort gained from talking to those who had been through a similar experience themselves. More recently, Kornhaber, Wilson, Abu-Qamar, McLean, and Vandervord (2015) found that peer support had a significant impact on burn-survivors' psychosocial rehabilitation, providing encouragement, inspiration, hope and reassurance. In line with the helper therapy principle, helping others can result in a positive upward spiral for the helper since peers have reported personal growth as a positive outcome (Chambers et al., 2013). In addition to this, the helped can become helpers themselves, expanding the resources of the group, thereby building the social capital (Riessman, 1965).

Structured peer support networks for adults with burn-injuries have been created and report positive outcomes (Bennett, 2007) in North America and Australia, but the lack of burns-specific peer support in the UK appears to be due to difficulties with recruitment and maintenance of interest and enthusiasm (Batchelor & Williams, 2013). Most parents participating in the current study agreed that peer support would have been useful to them. However, the majority of participants felt that a formal support group was not needed – a finding also supported by Phillips et al. (2007). Thus, some consideration of how the provision of peer support could be developed for parents is required. In the research that follows, it was important to establish whether there was parental demand for peer support following their child's burn injury and, if so, when the demand was highest and for what form of peer support, as this too may change over time. Heisler (2006) describes seven models of peer support which vary in the level of professional involvement and the number of participants required for the model to be successful. Each one of these models will be described in turn in Table 6.

Model of Peer Support	Description
Professional-led groups with peer exchange	<p>These are organised, professional-led groups of eight to 20 participants, participating in groups which vary in length from 90 minutes to half-day, that are held monthly to quarterly in frequency. These groups have a planned focus with a targeted focus on improving necessary self-management skills through discussion and presentation of a chosen topic with time to address individual questions. There is scheduled, brief one-to-one contact with clinicians if required (for example primary care providers, registered nurses, nurse educators, physiotherapists, occupational therapists). Peer support occurs through the interaction with other patients facing similar challenges.</p> <p>The benefits of professional-led groups with peer exchange are that they are time and cost effective. Care providers can give information to a large group of patients at one time, leaving more time for processing and clarification of this information and patient education. The groups provide patients with additional contact with their health care team without increasing the workload of the healthcare providers and this longer exposure to a wider array of health professionals, and other patients, allows for interactive problem solving. Relatives and spouses of patients are also often welcome to attend these groups and may learn important ways to support their family member.</p>
Peer-led face-to-face self-management programs	<p>These programs are run by peer leaders, rather than professionally led, and can therefore be outside of normal working hours. The groups are for 10 to 15 patients, usually facilitated by two peer leaders who encourage interactive exercises to promote behavioural skills to enable patients to carry out the necessary tasks to live well (such as managing stress, managing and monitoring symptoms, navigating health systems, and working with healthcare professionals). Peer-led groups promote the value of working together to develop effective problem-solving techniques and strategies with the help of healthcare staff who aid the scheduling, delivering materials, location and other organisational tasks. These programs provide information to build self-efficacy but specific content is not planned. Training for facilitators and ongoing supervision and support is provided by a trainer.</p>
Peer coaches	<p>Peer coaches meet one-to-one with patients to listen, discuss concerns, and provide support. Meetings are not regularly scheduled but dictated by peer mentors' availability. These sessions can help to alleviate the fears of new patients and help them adapt to their condition. Peer coaches are volunteers who receive between eight and 32 hours of training. The training ensures that peer mentors understand their own condition to minimise misinformation and also focuses on empathic listening, helping patients clarify life goals and values, problem solving, grief and loss, sexuality and relationships, working with healthcare providers and assertiveness. This model of peer support is especially effective with patients from black and minority ethnic populations.</p>
Community health workers	<p>Community health workers are not peers in terms of the health condition being lived with but peers in other respects, such as language, culture and community. Community health workers care for and support patients, identifying resources, managing cases, reaching out by telephone, documenting care, providing information, educating patients about self-care and helping them learn self-care skills. All supportive care and</p>

	education is provided by health care professionals who help to coordinate care and acting as a point of liaison with the health care system. In this model, community health workers are providing a source of peer support by providing social support through their availability to listen and talk through problems that patients are experiencing.
Support groups	10 to 15 patients meet at least monthly. Meetings maybe initiated and structured by professionals but they are largely run by, and for, the group members. Professionals may participate in the self-help process at the request of the group, but meetings always include discussion, sharing information and experiences, and other activities that promote mutual support and empowerment. Support groups are open to anyone who has shared the experience in order for them to offer and receive emotional and practical support from their peers. Sometimes telephone and buddy systems of support may also develop out of groups, and group members often form friendships and build social networks with other participants.
Telephone-based peer support	This can be a stand-alone intervention or used to compliment another intervention such as a support group, self-management training, or group visits. Telephone-based peer support is sometimes preferable to a face-to-face intervention as it overcomes some barriers that participants face in accessing peer support – some patients prefer the relative anonymity and privacy of the telephone. Training for peer-supporters using this medium should include empathetic listening and open-ended questions. Some of the challenges of setting up a telephone-based peer support service are that there can be reluctance to share phone numbers or pay the costs of long-distance calls, and there also needs to be a commitment from participants to regular calls. Telephone-based peer support is also difficult to monitor by health care providers. However, an interactive voice response exchange platform (a system that can respond with pre-recorded or dynamically generated audio information or messages) can counter some of these disadvantages.
Web- and email-based peer support	This is similar to telephone support as it overcomes the problems experienced by some with managing face-to-face interactions. This mode of peer support is also low cost and easy to disseminate, providing supportive interactions alongside information and education outside of the clinic environment. Web- and email-based peer support can provide patients with condition-specific information and resources, along with decision making aids, via online access to self-management coaches and health experts. Social peer support resources, such as facilitated or professionally monitored online support groups, emails, chat rooms, and professionally moderated internet discussion groups can be hosted on the internet. These are convenient and anonymous, and the faceless quality allows participants to be valued for the strength of their contributions rather than their appearance or disability. Advantages of web-and email-based peer support are that it is not limited to a particular geographical area and can therefore reach more people. It can provide a public face to health care institutions and can enhance the public image, thereby encouraging others to receive interventions and other services.

Table 6: Heisler’s (2006) seven models of peer support

There are some important factors that need consideration before peer support is considered as an intervention for parents of burn-injured children. For example, there are multiple components of peer support programs that can contribute to their success as opposed to a single effective ingredient. These include: 1) the maintenance of frequent contact with participants in the long-term to provide ongoing support, 2) the development and maintenance of links with health systems and primary care providers, 3) encouragement of self-care behaviours, 4) assistance in developing problem-solving, decision-making, and coping skills, 5) sensitivity to individual, social and cultural characteristics of participants, and 6) consideration of the individual rights, privacy, and the limits on the role of peer supporters (Heisler, 2006).

A peer supporter's role is limited; they are not primary care providers and should not give medical advice or diagnoses. Rather, they are a person who has knowledge from their own experiences with a condition. If people have questions or issues that require clinical expertise to address, the peer supporter should encourage them to contact their regular source of care (such as their burn service or GP) and, if necessary, help them do so. Hence, it is also recommended within peer support that those providing the support receive adequate supervision (Tolley & Foroushani, 2014). Therefore, if parents are struggling to access professionally-led support for significant mental health concerns, peer support should not be considered a substitute, rather a link that can assist people in seeking such support through normalising the process of help seeking and accessing support (Barak, Boniel-Nissim, & Suler, 2008). Despite the many considerations and the limits of this source of support, there is a case for the continued development of psychosocial interventions beyond the immediate offer of one-to-one psychological intervention for parents and other affected family members in order to improve access to support and offer appropriate interventions in a stepped care model (Harcourt & Rumsey, 2012).

Stepped care is a tiered approach to treatment, commonly used within psychological therapy services, in which each tier/step up is a treatment with increased intensity (Bower & Gilbody, 2005; National Institute for Health and Care Excellence, 2011b). This allows individuals to access the level and type of intervention that is most suitable for them (Bessell, Dures, Semple, & Jackson, 2012). National Institute for Health and Care Excellence (2011b) guidelines suggested that an individual should start at the lowest step appropriate to their needs and progress through each step sequentially if they do not respond to treatment. The Centre for Appearance Research also created a model of stepped care for appearance-related interventions that aims to reflect the needs of those receiving the intervention (Rumsey & Harcourt, 2012a). Within the model (Figure 2), the number of people requiring the intervention reduces as the intensity of the intervention increases. It ranges from level 0 (general population and societal campaigns) to level 5 (complex,

specialist-led counselling/therapy for individuals/families). The CAR framework is similar to the NICE stepped care model, however, rather than suggesting that individuals begin at the lowest appropriate level and move sequentially through the steps above, the CAR framework proposes that people can begin at any level and move fluidly through the levels as required.



Figure 2. The CAR Framework of Interventions (Rumsey & Harcourt, 2012a)

Considering this model within the context of this work, it is important that parents' needs are adequately addressed via mechanisms that are accessible and appropriate to them. As parents are often experiencing continuous stress from increased demands, no support provision should inadvertently add to these stresses and decrease their capacity to provide support to their child and any other children. Parents in this study discussed how access to online support from peers might overcome some of the barriers to professionally-led support. Bakker (2013) commented that web-based information might be useful to reach many parents from multiple hospitals, providing information about potential reactions in children to help parents identify their child's symptoms. However, as discussed above, information regarding parent reactions and symptoms may also be beneficial for parents, normalising their experience and highlighting when they might benefit from support. Considering the stepped care model described above, web-based information would be considered as level 1 in the CAR framework. This is supported by Groen et al. (2015) who suggested that information technology could have a role in providing peer support to cancer survivors. Facilitation of supportive peer interactions online can overcome psychological

and real-world barriers to peer engagement and could enable the provision of easily accessible, up-to-date, information for parents of burn-injured children.

Traditionally, websites have presented scientific information about health issues (Ziebland & Wyke, 2012). However, patients are increasingly communicating their experiences online via social networking and blogs, and these experiences are often now included on health websites (Pulman, 2010). For some, this experiential information can be an important supplement to the medical information provided by healthcare professionals. Potential positive effects of identifying with peers online, reported in research of other health conditions, include creating a sense of communality and belonging (Sharf, 1997; Steffen, 1997; van Uden-Kraan et al., 2008), and comparing and validating knowledge and information (Armstrong & Powell, 2009; Locock & Brown, 2010), facilitating the exchange of practical tips and advice (Steffen, 1997; van Uden-Kraan et al., 2008), and enabling normalisation and expectation management (Lowe, Powell, Griffiths, Thorogood, & Locock, 2009; Nixon & Singer, 1993).

#### **4.7 Limitations**

The fact that most parents included in this sample were mothers is representative of other samples recruited in burns literature (Dunn, Jordan, Lacey, Shapley, & Jinks, 2004; Markanday, Brennan, Gould, & Pasco, 2013; Mason, 1993). Mason (1993) also found this and suggested that this is because the mother is the most likely person to supervise and look after the child generally, and most likely to feel responsible for the child's care. It may also be that women are more likely, in general, to participate in scientific research than men (Dunn et al., 2004; Markanday et al., 2013).

The largest proportion of referrals to burn services (38%) come from children aged 1-2 years (Richards, Kokocinska, & Lewis, 2017), however the children that parents referred to in this study were, on average, older at 3.6 years of age. Of these children, six were sons and seven were daughters, although the national data suggests that the proportion of male children experiencing burn injuries is slightly higher (57.2%) than that of females (42.8%) (Dunn et al., 2015). With only one participant identifying as Indian British, the ethnicity of the sample was also not typical of the families seen in burn services (Richards et al., 2017). Generally, a higher proportion of scalds are seen in young children (Richards et al., 2017), as found in this sample, but the mean TBSA reported is much larger than those typically seen in paediatric burn services (98% <10% TBSA, 0.6% >20% TBSA) (Dunn et al., 2015).

Although this study recruited an appropriate number of participants for qualitative research, and participating parents were treated by various services around the UK, with their responses indicating issues to consider in the development of parent-focused support within burn care,

there are limitations. It is important to note that the age of the child at the time of injury in this study ranged from 0 to 13 years and, consequently, the results may not be applicable to parents of teenagers, and the sample demographics are not necessarily representative of burn care referrals to UK paediatric burn services. It is also possible that the participating parents may represent those who are actively seeking or involved in peer support. It is also important to note that only one father and one grandfather participated in this study with all other participants being mothers. This is potentially problematic as there is evidence to suggest that mothers' and fathers' emotional responses to their child's injury can differ (Egberts et al., 2018).

It should be noted that a significant minority of paediatric burn injuries are non-accidental (Toon et al., 2011) and this was a specified exclusion criteria as these parents may have different needs to those parents whose children experienced accidental injuries. This is an important, although challenging, area for future research as a non-accidental injury could be caused by a parent or someone else and in each instance the experiences and needs of the parent might be different. It was also apparent during interviews that factors such as other life circumstances and stressors aside from the burn-injury might also influence parents' experience of having a child suffer a burn. Nevertheless, a strength of the research is recruitment of parents who have lived with the burn and its consequences over a relatively long span of time. Whilst a representative sample in traditional positivistic terms was not sought, parents provided information to further the understanding of a range of parental experiences. This allows for consideration of different needs in the future development of a parent-focused intervention. Considering differences in needs and whether these change over time is important as there is evidence that initial stress symptoms tend to decline over time in most parents (Le Brocque, Hendrikz, & Kenardy, 2010) and these may give way to other concerns.

Finally, this study recruited a relatively small number of parents who took part in in-depth interviews ( $n = 8$ ). With the recruitment of only eight parents who provided in-depth data, it could be argued that data saturation may not have been achieved as it has been suggested that this is achieved with 12 or more interviews (Clarke & Braun, 2013). However, these in-depth interviews were supplemented by the five email interviews, and this data combined produced the themes. The exploratory findings gained from this study did require confirmation through subsequent research. Although, it is likely that the differing depths and qualities of information regarding parents' experiences gleaned from the interviews using different techniques sheds light on parents' challenges in terms of engagement in face-to-face and remote forms of interaction regarding the subject of their child's burn injury. This is discussed below.

#### 4.8 Parents' reflection of interview choice

As participating parents had the option of sharing their experiences in this study via telephone, Skype, email or face-to-face, they were asked why they chose to participate in the interviews in their particular way. Responses indicated that their participation method preferences were determined by, 1) their ability to get a "feel" for the researcher, 2) their belief in their ability to be open with the researcher despite potential upset caused by the topic, 3) concern about giving adequate depth in their responses, and 4) personal convenience. These themes are discussed below, and reported in (Heath et al., 2018).

The theme 'getting a "feel" for the researcher' reflects the establishment of rapport which required me to manage emotions expressed within the interaction and make participants feel comfortable (Hubbard, Backett-Milburn, & Kemmer, 2001; Liamputtong, 2007). Establishing rapport and putting the participant at ease is particularly important when researching a sensitive topic such as this (Baumrind, 1985), but the method of interviewing used in doing this is likely to influence participants' responses. This is because different interview techniques are likely to influence the extent to which participants feel comfortable enough to answer openly and honestly (Dures et al., 2011). As participants were able to choose their preferred interview method, it was hoped that this would create a more relaxed interview experience and would facilitate the disclosure of material that might be withheld in more formal settings (Hart & Crawford-Wright, 1999). Considering this in relation to how parents might choose to engage, or not, in psychosocial support is important. Those opting for remote methods of participation may not engage in a face-to-face intervention/setting, and those choosing email may not want any regular interaction, perhaps preferring to share information in an asynchronous way online. Therefore, it is important to highlight that only one participant took part in a face-to-face interview, with seven choosing online methods of responding (Skype and email).

Despite references to telephone interviews not being well suited to qualitative interviewing, due to the lack of face-to-face contact restricting the development of rapport (Irvine, 2011), telephone interviews were, jointly, the most frequently chosen option for participation in this study. According to participants, telephone interviews offered a convenient method of participation whilst also allowing them to get a "feel" for the researcher and, with that, a sense that the depth of their response was appropriate.

Skype offered face-to-face contact, and convenience and the ability to get a "feel" for the researcher also emerged as important aspects. Participants' decisions to use a method of participation that positions them remotely from the researcher, yet face-to-face, was perhaps a strategy to manage the emotional intensity of the situation, or perceived pressure to respond in a socially desirable way, at a safe distance (de Leeuw & Van Der Zouwen, 1988; Groves, 1979).



Reasons why telephone interviews might be preferable to participants, particularly when discussing sensitive topics, have been proposed previously. Comparatively, telephone encounters afford greater anonymity and reduced intensity (Chapple, 1999; Hershberger & Kavanaugh, 2017). Yet, these arguments were not consistently supported in this study. As one participant commented, not being face-to-face with the researcher might make participants present themselves as “braver”, which could make the communication “very contrived” (Heath et al., 2018). In this case, seeing the researcher, as opposed to being on the phone, was reassuring as facial expressions communicated a non-judgemental attitude that facilitated more candid communication. This finding supports Groves (1979) who reported that most respondents would have preferred to be interviewed face-to-face rather than by telephone regarding sensitive topics.

The third interview method also chosen for its convenience was email. Telephone calls could be made easily to participants at home or work; however, one could argue that email was even more convenient, potentially allowing responses to be composed intermittently, from any location, and with more privacy. Parents choosing to participate by email also commented that email allowed them to communicate their feelings and experiences despite the significant upset they experienced whilst recalling the events in question. All other methods would require the researcher to be witness to this, which is perhaps too exposing for some, particularly as it is recognised that participants can avoid revealing personally-perceived negative characteristics in the physical presence of another (de Leeuw & Van Der Zouwen, 1988).

Only one participant volunteered for a face-to-face interview. For convenience, the interview could be held at a location of the participant’s choice, but she chose to be interviewed at UWE Bristol after describing feeling drawn to the address as it shared the name with, and was geographically close to, the hospital in which her child was treated. Although she did not describe this as convenient, it was preferred due to its familiarity. Perceived familiarity may be another factor that influences participants’ openness regarding their experiences, enabling them to provide more depth in their responses, despite these being potentially upsetting. It is also the case that, for some participants, the opportunity to talk about their experiences can be a therapeutic process (Hart & Crawford-Wright, 1999). Returning to a location in close proximity to the hospital providing treatment appeared to be poignant for this participant and the importance of familiarity might also apply to accessing support; the more familiar and convenient a method is to access, the more likely a parent might be to engage in it. However, this might not be true for all parents in terms of research participation or access to support, as it has been found that the environment can be a barrier itself, particularly when this shares features that can function as reminders of the trauma (Gilmore et al., 2016), whether this be the sight of other children’s and/or families distress, members of staff, uniforms, particular rooms, or smells.

Due to the preventable nature of burn injuries in young children, and parents' feelings of guilt and self-blame because of the (albeit momentary) 'neglect', as described earlier, the experience can challenge parents'/carers' identity as a good parent/carer (Mason, 1993; Verity, 1995). This can make this population particularly sensitive to judgment from others. Therefore, although some participants may have benefitted from seeing or hearing a researcher who demonstrated a non-judgemental attitude, it might be preferable for others to use a remote method of participation to facilitate their openness during research so that fear of judgement does not hamper communication. These are also important considerations when considering parent preferences for different forms of support. Whilst some may value face-to-face intervention with a professional or peer, others may prefer a more remote format.

The theme of response depth also emerged from respondents who chose telephone interviews. The topics explored in these interviews were clearly important to the participants, and they may have felt they had a stake in providing all of the information they could in order to facilitate the development of parental support for others who faced similar circumstances. Studies have supported this idea showing that many people, particularly those who identify as vulnerable, are keen to participate in research altruistically where sharing their experiences may improve the lives of others (Alexander, 2010; Tatano Beck, 2005). This can also be a motivating factor for people participating in peer support (Bragadóttir, 2008). However, whilst participants might acknowledge the value of sharing their experiences, communicating them can be challenging due to concerns about how they might be perceived.

These findings suggest that, in order to maximise recruitment and the quality of interview data available for analysis, it is important for researchers to be flexible and offer a choice of how they take part. This conclusion should also be applied to the provision of support where flexibility and choice is also important. This is supported by the theory of optimal matching (Cutrona & Russell, 1990) which posits that it is important to match the characteristics of the specific stressful event confronting the individual and the type of social support that is most beneficial. Whilst the buffering hypothesis argues that social support is the most powerful factor in ameliorating stressful events (Cobb, 1976), a parent's support needs might not always be obvious, hence choice being important. With such limited uptake for face-to-face interview about this sensitive subject, this might be indicative of the difficulty that parents face when engaging in face-to-face support.

#### **4.9 Conclusion**

The study explored UK parents' experiences following their child's burn-injury and also their access to support and opinions regarding peer support. This was a novel perspective as most studies have focused on the psychosocial impact on parents, rather than on how this may or may

not be address by current service provision or new developments within paediatric burn care (such as peer support). This study was also able to provide valuable insights into parents preferred methods of research participation. These findings, alongside reflexivity and consideration of researcher positionality, were important outcomes with such information having the potential to influence future study designs to facilitate recruitment in research focusing on sensitive subjects.

Parents in this study discussed their losses and fears of loss, the imposed changes on their, and their child's life, and their attempts to put this right. The experience of the hospital and their child's treatment, the impact of the resultant scarring, and the perceived impact that this could have on the child's future could all affect parents in the long-term. Despite input from professionals, the whole experience could be incredibly physically and emotionally isolating.

It is clear that the provision of professionally-led psychosocial support is valued and helpful, and both parents and the literature suggest that interventions to help parents to cope with, and accept, the occurrence of the traumatic event, and its consequences, are important. However, parents also spoke of how psychosocial support could also be gleaned from chance, informal, meetings with peers in hospital corridors or kitchens. Most parents found these conversations to be supportive. Parents tended to feel that peers could offer practical support based on their experiential knowledge. Some participants had accessed support via charities such as burns camps and, despite attendance at such events being initially anxiety provoking, meeting others was beneficial. Parents had often searched for information online, finding this lacking. It is noteworthy that support offered by friends or family members did not feature during the interviews, despite parents being asked whether support was available and from whom, and support from family and/or friends being a prompt on the interview schedule.

Given that the findings of qualitative studies are often felt to have limited generalisability (Vasileiou et al., 2018), a quantitative study was conducted, in order to validate these findings in a larger sample of parents and investigate the most valuable way forward in the development of support for this population (Chapter 5). It was also important that the perspectives of both mothers and fathers were gleaned from future research and public involvement, in order to apply the findings to the development of interventions for parents rather than solely for mothers, and to ensure a range of needs are met. Whilst the research sought a representative sample of the range of lived experiences, it is interesting that parents of children with larger burns have volunteered to participate in this research. Perhaps the development of support services is particularly pertinent to these parents, particularly mothers.

## **Chapter 5: An online survey to further explore the experiences and support needs of parents of children who have had a burn injury**

This chapter details Study 2: an online survey of parents' experiences of their child's injury, their own access and experiences of support, and their opinions on peer support. This study was designed to assist in the validation of the qualitative findings regarding parents' experiences following their child's burn injury. A brief introduction to the research, the study design, data collection, analysis and results will be described, followed by a discussion of the implications of the results for the development of a parent-focused intervention.

### **5.1 Introduction**

After recruiting 13 participants from around the UK into the initial qualitative study, a larger sample of parents were required to validate the findings and assess their generalisability to other parents of burn-injured children. Previous studies have highlighted challenges in recruiting participants into qualitative research (Armstrong-James, 2017; Clark, 2008; McQuaid et al., 2003; Pagano-Therrien, 2013; Sukarieh & Tannock, 2013; Way, 2013) and Study 1 struggled to attract a representative sample of parents seen in UK burn services, with limited data being collected from fathers and parents from ethnic minorities.

The lack of representation of certain demographics is evident from a comparison with those reported in the literature. For example, Richards et al. (2017) reported an over-representation of patients from ethnic minorities, particularly Asian and African families, and an under-representation of Caucasian children in their burns referral data. This is opposed to the demographics of parents recruited into Study 1. In terms of the cause of injury, the participants recruited to date are representative. Generally, a higher proportion of scalds are seen in young children (Dunn et al., 2015; Richards et al., 2017) but the mean TBSA reported by the sample in Study 1 is larger than would normally be seen in burns services based on the national burn-injury data for paediatric burn injuries (Dunn et al., 2015). The fact that more mothers have been recruited than fathers is in line with other studies in the paediatric burn literature (Dunn et al., 2004; Markanday et al., 2013; Mason, 1993).

One method for improving research access for geographically diverse hard-to-reach groups in research is to utilise web-based methods of data collection (Wilkerson et al., 2014). Web-based research has also been found to improve participation in research from ethnic minorities (Joseph et al., 2013). In an effort to recruit a sample that was more representative of the UK paediatric burn patient population, this was an important consideration.

## **5.2 Aims**

This study had three broad aims, to:

- 1) Validate the experiences of parents described in Study 1, to ensure that the findings were representative of a larger sample of parents of burn-injured children
- 2) Collect data regarding parents' experiences of accessing support for themselves following their child's injury
- 3) Further investigate parents' opinions of peer support and whether they would value this following their child's burn injury and, if so, through what medium.

## **5.3 Design**

A cross-sectional survey, hosted online, was used to provide a standardised way of collecting data which could compliment that collected in Study 1.

## **5.4 Method**

### ***5.4.1 Ethical approval***

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (REC Ref. HAS.17.05.160; Appendix B.i).

### ***5.4.2 Survey***

The survey used in this study was created to validate the themes which emerged from the interview data described previously (Study 1, Chapter 4) and to ascertain figures regarding how many parents accessed support and who provided this support. Many of the questions presented to parents during this study linked directly to the themes and subthemes identified (as shown in Table 7). It was felt important to retain the voice of the parents who participated in Study 1, therefore some questions were generated from quotes from the interviews, others were influenced by existing questionnaires used to examine barriers to accessing mental health support (Clement et al., 2012) or the perceived value of online support (Kelly, Jenkinson, & Ziebland, 2013) and modified to suit the aims of this study. No whole measure was retained as the supervisory team was mindful of questionnaire length and the burden of the time taken to complete it for the participants. Questions seeking demographic information were also included.

### ***5.4.3 Public involvement***

One parent who had participated in the previous interview study (Chapter 4) reviewed and provided feedback on the study information, consent form, and survey questions. The aim of this review process was to establish whether the study information and research questions were worded appropriately. Following this, minor changes in wording were made to help to avoid

confusion on some negatively worded questions. This parent did not participate in the current study as their interview data had contributed to the development of the questions being asked.

#### **5.4.4 Recruitment**

Presentations of the results of the qualitative study, and the plans for the quantitative study, were made at the BBA Annual Meeting in London (May 2017) and at the Paediatric Burns Club World Congress (July 2017). At these events, flyers detailing the web address of the online survey were disseminated so that burn care professionals and charity members were aware of the study that would be taking place and could inform parents about its existence. Written information was disseminated to the general population between July and October 2017 via a university press release, advertisements on social media (Facebook, Instagram and Twitter), via charity websites (Children's Burns Trust, Changing Faces, Katie Piper Foundation) and also directly to 305 potential participants from around the country by emailing the CAR burns participant pool (as described in section 4.3.4). The parents in the participant pool had previously been recruited from NHS burn services into burn care research by researchers in CAR, and had consented to being contacted about future research that they may be eligible to participate in. The Chelmsford Burns Camp advertised the research to families attending their summer camp, the research was discussed on a podcast (Appearance Matters: The Podcast [August 2017]), and also listed on Mumsnet and the Children's Burns Research Network website. An article was also written for the Association of Child and Adolescent Mental Health Newsletter which advertised the program of research and the current study (Appendix E.ii). Wide and varied dissemination of information about the research facilitated the recruitment of parents not already in contact with burns charities/support services.

#### **5.4.5 Participants**

Participants were recruited from a diverse range of locations around the UK using the methods described above. For inclusion in the study parents had to be able to read in English, be at least 18 years of age, with a child who experienced but survived a burn injury before the age of 18 years, which required hospital treatment as either an inpatient or an outpatient in a specialist burns service. Exclusion criteria were non-accidental injury, and when the child had since died because of their injury or subsequent complications, and when the burn occurred less than six months prior to participation. Participants were not asked to provide evidence that they met the inclusion/exclusion criteria; it was left to them to judge their eligibility to participate in the research. All participants provided informed consent prior to accessing the online survey, without doing this they could not access the survey.

Themes		Main points for further investigation	Questions/Comments
Losses experienced by parents	Fear of losing the child	Fear of loss due to the injury or shock/complications (death), or social services (removal).	Modified quotes: Initially, I was scared my child would die. Initially, I was worried that social services might take my child away from me.
	Loss of the perfect child	Sadness regarding child becoming different/damaged.	Modified quote used: I was sad that, all of a sudden, my child was different.
	Action to repair	A wish that scars could be undone. A “constant quest” for new treatments to repair the damage done. Parenting style being affected by injury event leading to compensation - “spoiling” or being “soft” on injured children to compensate them for what they had been/were going through.	Relevant question on the Parenting Style Questionnaire (Robinson, Mandelco, Olsen, & Hart, 1995): ‘3. I spoil my child.’ Modified to retain focus on the impact of the injury: I spoil my child because of what they have been through. Modified quotes used: I hope that my child’s skin will go back to the way it was. I do everything I can to try to reduce my child’s scarring. I am concerned that there might be new treatments for scarring available that I haven’t heard about. I am softer on my child because of what they have been through.
Changes imposed upon parents	Scars remind me	The child’s scarring as reminder of the injury event, of “something that [parents] didn’t do right”, their guilt, and/or the “worst day of [their] life.” The child’s scars as marks of bravery and/or strength.	Relevant questions on the DAS-59 (Carr, Harris, & James, 2000) (General self-consciousness of appearance): 35. Concern when others make remarks; 34. Distress when others stare; 30. Made to feel embarrassed; 12. Hurt by others comments; 36. Distress when others ask about the feature; 15. Raising the feature in conversation Modified quotes used: My child’s scars remind me of what we/I didn’t do right at the time. My child’s scars remind me of the worst day of my life <del>and all the feelings of guilt I hold.</del> My child’s scars remind me of how guilty I feel My child’s scars remind me of all the pain they have been through and will go through in the future. My child’s scars remind me of how brave <del>they are</del> [my child is]. I worry about how my child will be affected by their scars in the future. <del>My child’s scars are just part of them.</del> I see my child’s scars as being part of them.
	Impact on self-perception	The accident impacted upon whether parents felt that they were good-enough parents.	Since the accident, I am no more conscious of safety than I used to be. [Reversed response item] Since the accident, I am overprotective. Since the accident, I am less care-free.

		<p>Their child's appearance influencing other people's thoughts/judgements about them.</p> <p>If the injury occurred because parents had, in some way, failed their child, or not adequately fulfilled their role of protecting them then the desire to prevent a future accident from occurring leads to hypervigilance and/or an over-protective parenting style.</p>	<p>Barriers to Accessing Care Evaluation (Clement et al., 2012): Concern that I might be seen as a bad parent – rephrased as 'I worry about whether others might think I am a bad parent' for consistency in statement phrasing.</p>
	<p>Engagement with others</p>	<p>The injury forces parents to engage with services that they had never anticipated or even knew existed. This reduces their contact with friends and peers, and impacts on their relationship with their spouse. There was also concern that whilst the injured child was unwell, siblings had been neglected.</p>	<p>Modified quotes used:</p> <p>I am hurt by other people's comments about my child's scars.</p> <p>I experience distress when others ask about my child's scar.</p> <p>Since the accident, life hasn't been normal.</p> <p>My child's injury has had a negative impact on my social life.</p> <p>My child's injury has had a negative impact on family life.</p> <p>I worry that I neglected my other children after the accident.</p> <p>My child's injury has had a negative impact on my work life.</p> <p>Because of the accident, I interact with services that I wouldn't normally expect to.</p> <p>The accident has had a negative impact on my marriage/relationship.</p>



Perceptions of isolation	<p>The hospital is experienced as being like a “cocoon” or a “bubble”, and parents feel “cut off from the outside world.”</p> <p>Following discharge from hospital, parents continue to feel alone and as though they are the only one who has ever been through this or felt this way.</p>	<p>Self, Thomas and Randall (2012) proposed domains and indicators for assessing relationships: Perception of loneliness; Time spent with family every day or most days; Time spent together with friends; Trust; Feeling of belonging; and Participation. The DAS-59 (Carr et al., 2000) also contains ‘feeling isolated’ as a measure of social self-consciousness of appearance.</p> <p>Modified quotes used:</p> <p>My partner and I have never spoken about how we feel regarding the accident.  I felt isolated when my child was in hospital.  I felt isolated following my child’s discharge from hospital.  I felt like I was the only person that felt like this.  I felt like I was the only person this had ever happened to.  I felt like I was completely by myself.  I think the professional staff recognise how devastating this type of injury is for parents.  The hospital staff warned me that life would be challenging when we were discharged from hospital.  I had a good idea of the challenges I would face when my child was discharged from hospital.  I felt prepared for caring for my child once they were discharged from hospital.</p>	
Access to psychological support	Support from someone who has seen it before	<p>Most parents reported that the psychosocial support offered was one-to-one support with a professional. Is this the case for all? How long is support offered/accessed for? Who provided this? When was it provided?</p>	<p>Modified quotes used:</p> <p>I had support whilst my child was an... inpatient/outpatient/both/I didn’t access support (If support was accessed) I received support from:...</p> <p>I am aware that I still have a lot of feelings about the accident and its impact, but I haven’t dealt with them.  I received enough support.  The support I received was helpful.  The support I received met my needs.  The support I received was accessible when I needed it.  Question included from the IES-R (Weiss, 2007) I <del>was</del> [am] aware that I still <del>had</del> a lot of feelings about it, but I <del>did</del> haven’t deal[t] with them</p>
	Barriers to accessing support	<p>There are ‘real world’ barriers to accessing support such as:</p> <p>Time  Financial issues  Distance</p>	<p>Barriers to Accessing Care Evaluation (Clement et al., 2012): Have any of these issues ever stopped, delayed or discouraged you from getting, or continuing with, professional care for a mental health problem?</p> <ol style="list-style-type: none"> <li>1. Being unsure where to go to get professional care support.</li> <li>2. <del>Wanting to solve the problem on my own</del></li> <li>3. Concern that I might be seen as weak for <del>having a mental health problem</del> needing support.</li> <li>4. <del>Difficulty taking time off work</del></li> </ol>

		<p>There are also psychological barriers to accessing support such as:</p> <p>Guilt/blame  'Blinkered'  Pain</p>	<ol style="list-style-type: none"> <li>5. <del>Fear of being put in hospital against my will</del></li> <li>6. <del>Concern that it might harm my chances when applying for jobs</del></li> <li>7. Problems with transport or travelling to appointments</li> <li>8. Thinking the problem would get better by itself</li> <li>9. Concern about what my family [other people] might think, say, [do or feel]</li> <li>10. <del>Being unhappy with the available services</del></li> <li>11. Feeling embarrassed or ashamed</li> <li>12. Preferring to get alternative forms of care (e.g. religious healing or alternative therapies)</li> <li>13. Not being able to afford the financial costs involved [in travelling/accessing support.]</li> <li>14. <del>Concern that I might be seen as 'crazy'</del></li> <li>15. Thinking that professional care probably would not help</li> <li>16. Concern that I might be seen as a bad parent (used above)</li> <li>17. Professionals from my own ethnic or cultural group not being available</li> <li>17. <del>Concern that people I know might find out</del></li> <li>18. <del>Being too unwell to ask for help</del></li> <li>19. <del>Concern that people I know might find out</del></li> <li>20. Dislike of talking about my feelings, emotions or thoughts</li> <li>21. <del>Concern that people might not take me seriously if they found out I was having professional care</del></li> <li>22. <del>Having no one who could come to appointments with me</del></li> <li>23. <del>Lack of trust in professionals who provide professional care for mental health problems</del></li> <li>24. <del>Concerns about the treatments available</del></li> <li>25. <del>Not wanting a mental health problem to be on my medical records</del></li> <li>26. <del>Concern that it might bring shame or disapproval on my family</del></li> <li>27. Having had previous bad experiences with professional care for [accessing support or] mental health [care].</li> <li>28. Preferring to get help from family or friends</li> <li>29. <del>Concern that my children may be taken into care or that I may lose access or custody</del></li> <li>30. Thinking I did not have a problem</li> <li>31. <del>Concern about what my friends might think, say or do (incorporated above)</del></li> <li>32. <del>Thinking appointments take too much time or are inconvenient</del></li> <li>33. <del>Concern that it might harm my career or chances of promotion</del></li> <li>34. Having problems with childcare while I receive professional care</li> <li>35. <del>Having no one who could help me get professional care</del></li> </ol>
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			<p><del>36. Concerns about the confidentiality of the information I share</del></p> <p>Questions with strikethrough not included to limit the burden of participation on parents and to maintain a focus on the findings of Study 1. Question from the IES-R (Weiss, 2007) modified: I tried not to talk about it - It was too painful to talk about what happened and how I felt</p> <p>Modified quotes used:</p> <p>Feeling guilty</p> <p>The distance to the hospital/medical centre</p> <p>Not having the time to access support for yourself</p> <p>My focus was on getting my child well, I didn't think about my own needs</p> <p>I would have accessed support if it was more local</p>
Peer support	Seeking online support	<p>Some parents had turned to the internet as a medium for sharing and gleaning peer experiences, however, the provision of appropriate resources and online support was noticeably lacking. Parents discussed email, telephone, online forums, and the internet in general, as well as face-to-face support. Whilst face-to-face interaction was important to some, other parents reported that they felt more confident to type to somebody than pick up the phone and talk to a stranger. The internet provided anonymity, allowed images to be accessed, it was accessible if/when needed and in their own time, and it also gave parents the opportunity to receive input from many.</p>	<p>The e - Health Impact Questionnaire (Kelly et al., 2013)</p> <ol style="list-style-type: none"> <li>1. The internet is a reliable resource to help me understand what a doctor tells me-[health professionals have told me about my child's injury and treatment].</li> <li><del>2. The internet can help people know what it is like to live with a health problem.</del></li> <li>3. The internet can be useful to help people [parents] decide if their symptoms are important enough to go to see a doctor [they themselves should seek support].</li> <li><del>4. I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).</del></li> <li><del>5. I would use the internet to check that the doctor is giving me appropriate advice.</del></li> <li>6. The internet is a good way of finding other people who are experiencing similar health problems.</li> <li>7. It [would] can be helpful to see[/hear about] other [parents] people's health-related experiences [of parenting a child following a burn injury] on the internet.</li> <li>8. The internet is useful if you don't want to tell people around you (for example, your family or people at work [professionals]) how you feel.</li> <li><del>9. It can be reassuring to know that I can access health-related websites at any time of the day or night.</del></li> <li><del>10. The internet is a good way of finding other people who are facing health-related decisions I may also face.</del></li> <li>11. Looking at health [a burn-specific] websites [would] reassures me that I am not alone with my health concerns.</li> </ol>

			<p>Questions with strikethrough not included to limit the burden of participation on parents and to maintain a focus on the findings of Study 1. Modified quotes used:</p> <p>I would have liked to have met someone a little bit ahead of me who could explain to me what the future would be like.</p> <p>I think it is important that parents can contact other parents whose child's injury was similar to their own child's injury</p> <p>I look for information and images regarding scar progression and management</p> <p>I use the internet to see how I can alleviate or improve my child's scarring</p> <p>When looking for information and support in relation to my child's burn-injury, I have used the internet to find other people who are experiencing similar challenges to me and to learn about their experiences.</p> <p>Engaging in face-to-face support would be too demanding/difficult for me.</p> <p>Accessing a group would be too difficult/demanding for me.</p> <p>I would be worried about who I might meet/come into contact with. Yes/No</p>
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Table 7: Semi-structured interview schedule and question justification

#### **5.4.6 Procedure**

Study advertisements (Appendix B.ii) directed parents to an online secure survey website: Qualtrics. Qualtrics hosted the study information (Appendix B.iii), consent form (Appendix B.iv) and the survey (Appendix B.v). Participants were provided with the contact details of the researcher and notified that they could ask questions before consenting to take part, or complete the survey via telephone, or on paper if they wished to.

Information regarding sources of support was presented to parents who selected the option to decline participation after reading the study information, and at the end of the survey to all those who completed it. Participants did not have to provide any identifying information during their participation and only provided their contact details if they wished to be: 1) entered into a prize draw as a thank you for their time and contributions, 2) notified of the results of the study, or 3) informed about further research that they may be eligible to participate in.

Responses to the survey questions were provided using a Likert scale and multiple-choice options were given for demographic questions. Three open text boxes were also provided. For most questions there was a five-option response format of: strongly disagree, somewhat disagree, neutral, somewhat agree, strongly agree. For some questions there was also a 'not applicable' option. Data collected using the online survey was downloaded to SPSS (version 21) for analysis.

### **5.5 Analysis**

#### **5.5.1 Descriptive analysis**

Descriptive analyses of demographic information and participant characteristics (relationship to child, parent age at participation, child age at injury, time since injury, TBSA, affected body part, treatment required, marital/relationship status, ethnicity, method of recruitment, and geographical location) were performed.

Frequencies and the percentage agreement (those responding somewhat agree or strongly agree) or disagreement (those responding somewhat disagree or strongly disagree) to questions was calculated and is presented below in sections which map onto the themes from which the questions were derived. Where percentages are stated, this is the percentage agreement with the statement, unless otherwise stated. Neutral responses did not contribute the percentage agreement or disagreement.

#### **5.5.2 Content analysis**

Qualitative data, collected by open text boxes, was analysed using content analysis. To do this, open ended responses to questions were listed, read, and initial codes were generated. The data

was then coded within the list and quantified by counting the frequency of each code. The main benefit of using this method was that it was systematic and replicable (Stemler, 2001).

Following analysis, a summary of the results was sent to the 34 participants who requested this information (Appendix B.vi). These participants were invited to provide feedback and one participant responded, stating, "I've just got round to reading your findings below and wanted to take the time to say thank you. I'm in tears as I type this, as reading your article brings it all back, and knowing other families are going through the same feelings is quite emotional. Two years on, and the rawness of my son's accident is still there. The impact it had on us as a family was enormous and on-going. To see the good work you are doing to ease this for future families is fantastic. Well done." [Mother]

## **5.6 Results**

### **5.6.1 Demographic information**

Over a four-month period, 57 parents completed the online survey. A response rate cannot be calculated as recruitment through word of mouth, charity and social media advertisement cannot be known. Participant demographics are presented in Table 8.

No participants requested a paper-based survey or to answer the questions by telephone. However, one person did contact with the researcher for advice about where support could be accessed. This person was sent an email directing them to sources of support as detailed in the study information sheet (Appendix B.iii) and did not make contact with the researcher again.

Forty participants (70.2%) were recruited following face-to-face contact with professionals from burn services; this includes the participants who were recruited through the CAR participant pool (7.2% response rate via email) which made up 38.6% of the sample. A mean of 3.12 years (range = 0.84-17.15; n = 46) had passed since the injury event.

As in the previous qualitative study, most of the sample were mothers (94.7%) identifying as White British (75.4%). The mean age of parents who disclosed this information at participation was 39.43 (range = 24.84 - 63.86; n = 44).

The participants' child's injury characteristics disclosed are shown in Table 9. The mean age of children at the time of injury was 4.60 (range = 0.43 – 16.63; n = 44). The most common burn injury was a scald (75.4%) and the most frequently affect area of the child's body was the neck (56.1% of cases). Most children had been treated as inpatients (77.2%), with 38.6% requiring surgical intervention. When reported/known, the parent-reported mean TBSA was 16.7% (range = 0.5 - 60; n = 26).

<b>Participant characteristics</b>		<b>n</b>	<b>%</b>
Relationship to Child	Mother	54	94.7
	Father	1	1.8
	Grandfather	2	3.5
Ethnicity	White British	43	75.4
	Asian or Asian British	11	19.3
	Black or Black British	1	1.8
	Chinese	1	1.8
	Other Ethnic Group	1	1.8
Marital Status	Single	4	7.0
	Married/Civil Partner	42	73.7
	Divorced/Civil Partnership dissolved	2	3.5
	Separated	6	10.5
	Not disclosed	3	5.3
Recruited via	CAR Participant Pool	22	38.6
	Informed by a burn care professional	18	31.6
	Children's Burns Trust website	9	15.8
	Burn Camp	1	1.8
	Facebook advertisement	3	5.3
	Other	4	7.0
Geographical location	England	15	26.3
	<i>North West</i>		
	Cheshire	7	12.3
	Merseyside	3	5.3
	<i>North</i>		
	Yorkshire	1	1.8
	<i>Midlands</i>		
	Derbyshire	1	1.8
	Warwickshire	1	1.8
	<i>East</i>		
	Cambridgeshire	2	3.5
	Essex	1	1.8
	<i>South West</i>		
	Avon	2	3.5
	Dorset	1	1.8
	Gloucestershire	5	8.8
	Somerset	2	3.5
	Wiltshire	3	5.3
	<i>South East</i>		
	Kent	2	3.5
	London	1	1.8
	Surrey	2	3.5
	Wales	1	1.8
Cardiff	1	1.8	
Mid Glamorgan	1	1.8	
Scotland	1	1.8	
United Kingdom	4	7.0	

Table 8: Information regarding participants in Study 2

Injury characteristics		n	%
Cause of Injury	Scald – Hot fluid	43	75.4
	Hot surface	6	10.5
	*One child was reported to have both a chemical and flame burn	7	12.3
	Friction	1	1.8
	Chemical	1	1.8
Affected Body Part	Head/face	28	49.1
	Neck	32	56.1
	Chest	14	24.6
	Back	22	38.6
	Abdomen/stomach	18	31.6
	Arms	16	28.1
	Hands	15	26.3
	Legs	9	15.8
	Feet	4	7.0
	*Range of affected body parts = 1-9	Buttocks	1
	Genitals	25	43.9
Treatment	Inpatient	44	77.2
	Outpatient	13	22.8
Required surgery	Yes	22	38.6
	No	35	61.4

Table 9: Injury characteristics of the children of participants in Study 2

### 5.6.2 Survey Responses

The survey questions with the percentage responses will be described below in line with the themes that emerged from Study 1 (presented in Chapter 4).

#### Theme 1: Losses experienced by parents.

This theme has three subthemes: Fear of losing the child, loss of the perfect child, and action to repair. **Fear of losing the child** describes parents' fears that they would lose their child either due to the injury itself, because their child would go into shock, or because social services may deem the accident to be evidence of unfit parenting and take their child away from them. Such fears might also return for parents if there were medical complications. Overall, 23/57 (40.4%) of parents feared that their child would die (a larger proportion than the number of children with burns so serious that they required surgery [38.6%]) and 30/57 (52.6%) worried, initially, that social services may take their child away from them. **Loss of the perfect child** describes the sadness surrounding the realisation that their child's injury would lead to lifelong scarring. The majority were in strong agreement that they were sad that, all of a sudden, their child was different (40/57, 70.2%).

**Action to repair** describes the response of parents to the scarring. Most parents (40/57, 70.2%) hoped that their child's skin would return to the way it was and the majority reported to do everything they could to try to reduce the scarring (53/57, 93.0%). More than half of parents (33/57, 57.9%) were also in agreement that they were concerned there might be new treatments



available that they had not heard about. In addition to this, many parents reported that they were softer on their child because of what they had been through (31/57, 54.4%) and that they also “spoiled” their child (29/57, 50.9%). These figures are illustrated graphically in Figure 3.

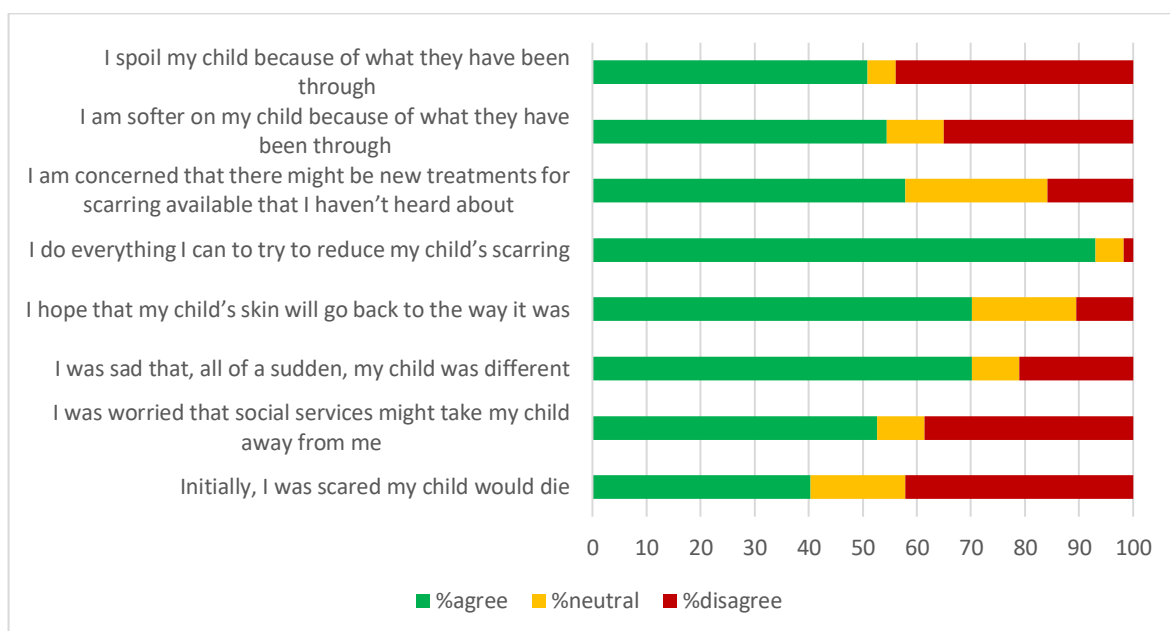


Figure 3. A breakdown of responses to statements related to the theme of losses experienced by parents

## Theme 2: Changes imposed upon parents

This theme also had three subthemes: Scars remind me, the impact on parents' self-perception, and their engagement with others. **Scars remind me** refers to the constant reminder that parents had from their child's scars of different emotions and events that could be both positive and negative, such as their child's pain, their pride in their child's bravery, and their own feelings of guilt. The scarring reminded most parents about the worst day of their life (45/57, 78.9%), about what they had not done right at the time (41/57, 71.9%), and how guilty they felt (44/57, 77.2%). Although most parents reported that they saw their child's scars as part of them (40/57, 70.2%), the majority reported to worry about how they would be affected by them in the future (41/57, 71.9%). Whilst, for most, the scars were a reminder of all the pain their child had been through and would continue to go through in the future (46/57, 80.7%), they also reminded parents of how brave and strong their child was (53/57, 93.0%).

**Impact on self-perception** refers to the fact that some parents felt that their child's accident occurred because they had not adequately fulfilled their parental role. They had failed their child, for a split second, by not adequately protecting them. Concern was expressed that other people might think that they were a bad parent (27/57, 47.4%). The desire to prevent a future accident led many parents to become wary of danger, which could lead to many parents becoming over-protective (37/57, 64.9%). Since the accident, parents felt that they were more safety conscious

than they used to be (40/57, 70.2%) and less carefree (33/57, 58.9%). These figures are illustrated graphically in Figure 4.

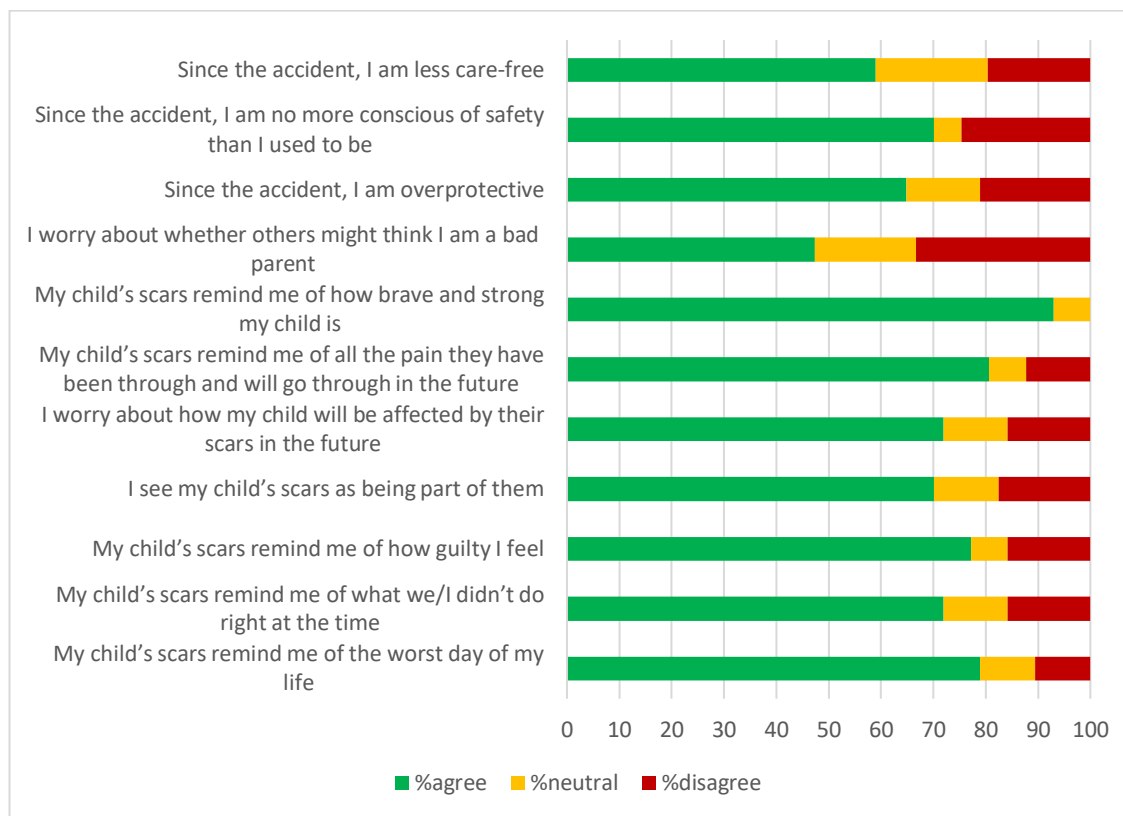


Figure 4. A breakdown of responses to statements related to the theme of changes imposed upon parents in relation to scarring and the impact on their self-perception

**Engagement with others** refers to the experience of many parents of utilising services that they had never thought about or even knew existed before (such as social services, physiotherapy and occupational therapy, psychology services and burns camps). Most parents reported that they now interact with services they would not normally expect to (37/57, 64.9%). Despite this, almost half of the sample agreed that life had been “normal” since the accident” (27/57, 47.4%), without having a negative impact on their social life (29/57, 50.9%) or family life (26/57, 45.6%). However, some parents did report a negative impact of the accident on their relationship/marriage (24/54, 44.4%), and their work life (22/50, 44.0%), and many parents with other children worried that they neglected uninjured siblings after the accident (27/45, 60.0%). Engagement with friends and strangers could also be affected. Overall, more parents agreed that they were hurt by people’s comments about their child’s scars (27/57, 47.4%), than not (13/57, 22.8%), and half of parents reported that they experienced distress when asked questions about their child’s injury (29/57, 50.9%). These figures are illustrated graphically in Figure 5.

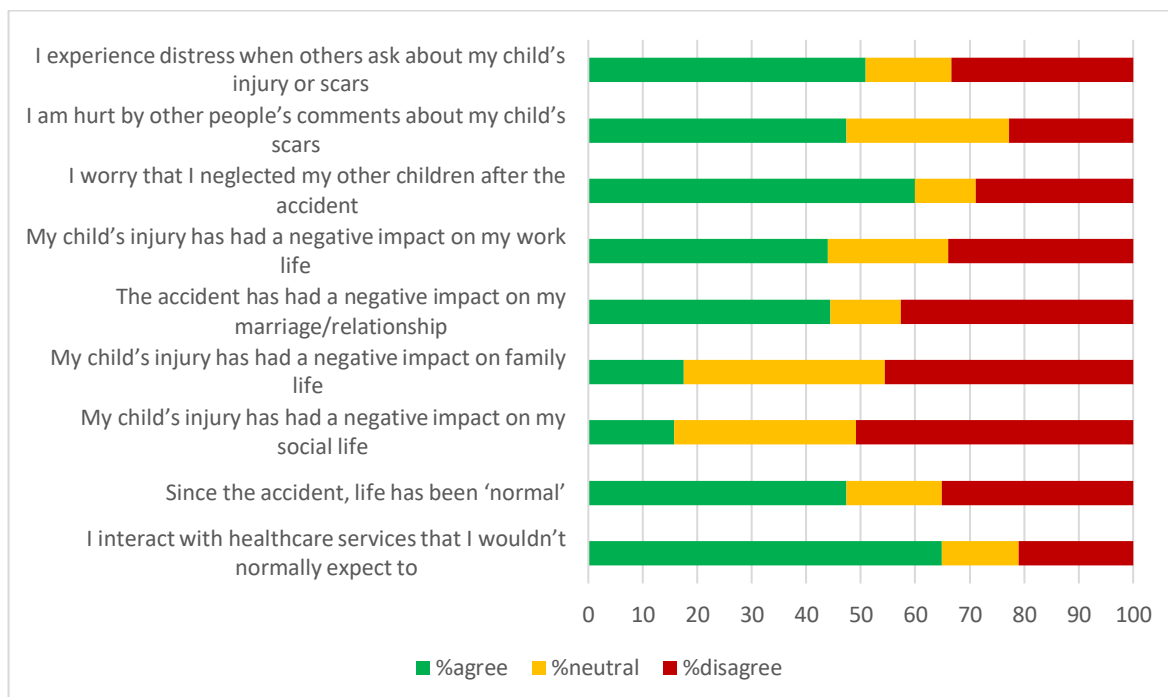


Figure 5. A breakdown of responses to statements related to the theme of changes imposed upon parents in relation to their engagement with others

### Theme 3: Perceptions of isolation

This theme referred to the physical and psychological isolation that could be perceived by parents, despite them being surrounded by teams of health professionals, and often other family members and friends. Over half of parents reported to feel isolated when their child was in hospital (31/57, 54.4%), and many parents continued to feel this way following their discharge from hospital (28/57, 49.1%). Parents tended to disagree with the statement, "I felt like I was the only person this had ever happened to" (25/57, 40.4% disagreed), However, more parents agreed with the statement "I felt like I was the only person that felt like this" (29/57, 50.9%), and "I felt completely by myself" (27/57, 47.4%). In fact, 28/56 (50.0%) of participants reported that they and their partner had never spoken about how they felt regarding the accident.

Most parents felt that professional staff do recognise how devastating a child's burn injury is for parents (25/57, 61.4%). Yet, less than half of respondents reported that hospital staff warned them that life would be challenging once they were discharged from hospital (25/57, 43.9%). Despite this, many agreed that they had a good idea of the challenges they would face when their child was discharged (28/57, 49.1%), and the majority felt prepared for caring for their child following their discharge from hospital (45/57, 79.0%). These figures are illustrated graphically in Figure 6.

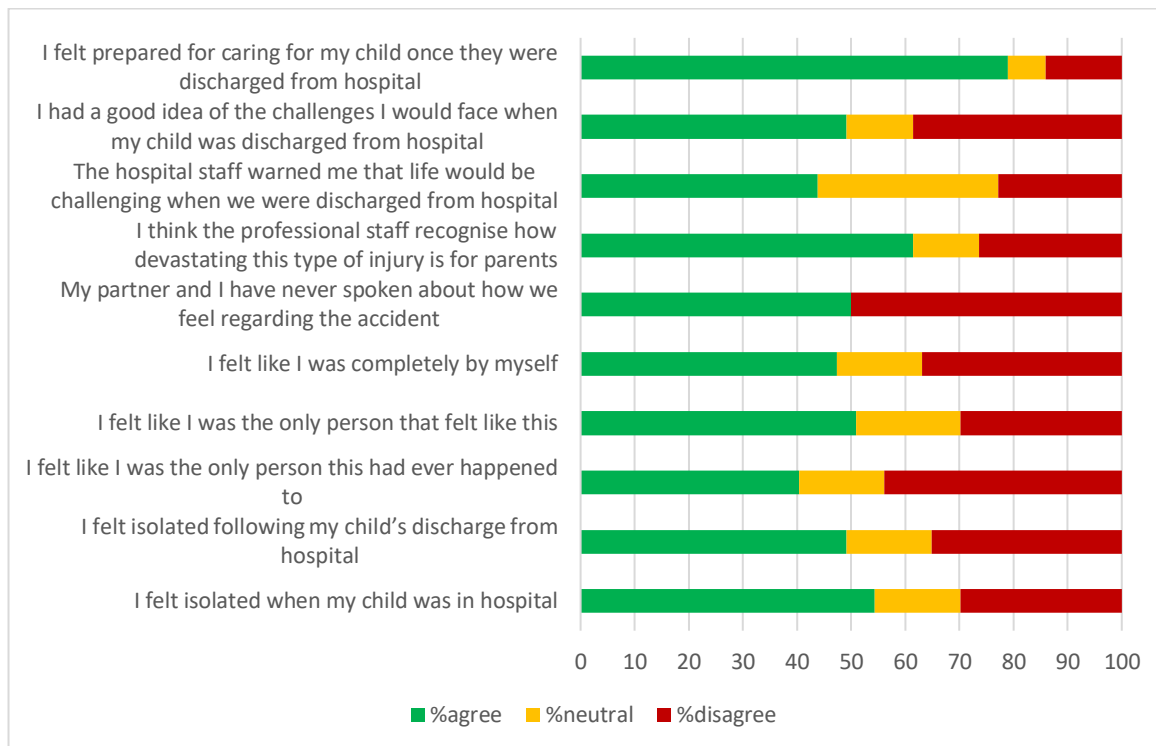


Figure 6. A breakdown of responses to statements related to the theme of perceived isolation and the expected challenges following discharge

#### Theme 4: Access to psychosocial support

This theme referred to parents' desire to access support from a professional who is familiar with this type of injury or a peer who knows what it feels like to a parent of child who has had a burn injury; 'someone who has seen it before'. Study 1 also identified barriers to accessing support, as well as the potential use of the internet when seeking support. Most parents accessed support (50/57, 87.7%); seven parents (12.3%) reported that they did not have support and had not known where to get it from.

In terms of professionally-led support, some parents (17/57, 29.8%) reported that they received support whilst their child was being treated as an inpatient, 3/57 (5.3%) reported to receive support whilst their child was an outpatient, and 30/57 (52.6%) received support throughout both the in- and outpatient phases of care. Most frequently, support received was provided by nursing staff (43/50, 86.0%). Other sources of support reported were the family (28/50, 56.0%), psychosocial professionals (psychologist/counsellor/ psychotherapist) (25/50, 50.0%), friends (21/50, 42.0%), play specialists (17/50, 34.0%), peers (5/50, 10.0%), a peer support group (2/50, 4.0%), a social worker (1/50, 2.0%), a burns nurse at home (1/50, 2.0%), neighbours (1/50, 2.0%), the sibling's school (1/50, 2.0%) and researchers (1/50, 2.0%). Whilst the majority agreed that the support they received was helpful (44/50, 88.0%), there was less agreement from parents that they received enough support (28/50, 56.0%) and that this support met their needs (32/50, 64.0%). Generally, however, parents agreed that support was accessible when they needed it (31/50, 62.0%). These figures are illustrated graphically in Figure 7.

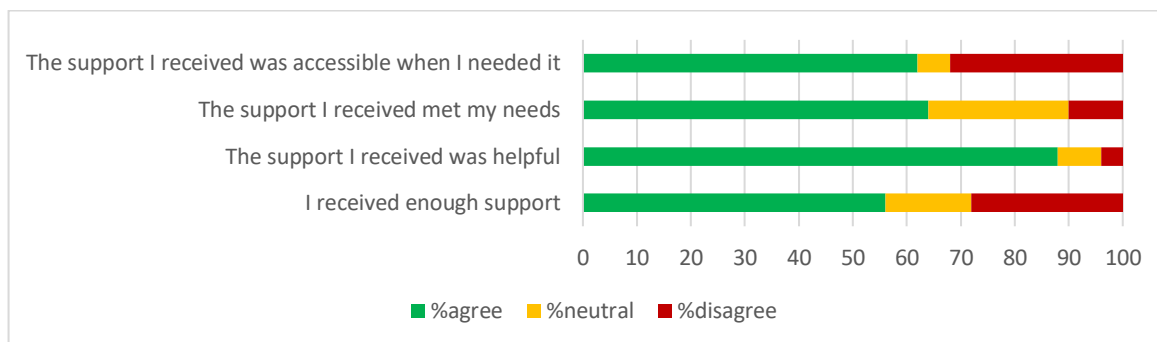


Figure 7. Responses to statements referring to support received (from any source) following their child's injury

When accessing professional support, most people would rather access it in a face-to-face context (54/57, 94.7%). Other options ranked by parents were via telephone (21/57, 36.8%), email (20/57, 35.1%), and Skype (7/57, 12.3%). Two parents (3.5%) reported that they were not interested in accessing professional support.

Parents also looked for supportive resources in a variety of places and, when parents sought support, nearly two-thirds (36/57, 63.2%) said that they were able to find it somewhere. Participants were provided with a free text box to report where they found support or information; it tended to be found in a variety of places: at the hospital (n=4), from the staff (n=3) [which included an outpatient nurse (n=1), specialist nurses (n=2) and outreach team (n=1)], in burns unit information (n=1), on NHS websites (n=1), and in leaflets from the hospital that could be accessed online (n=1), and other online sources (n=4) [although these were not named]. Burns clubs provided support (n=3), as well as peers and their children who had shared a similar experience (n=2). Family members could also be supportive (n=4) as well as friends (n=1), GPs (n=1), and counsellors (n=1). In addition, information accessed through the library (n=1), burns collective newsletters (n=1) and from burns research groups (n=1) could also be perceived as supportive. One participant (1.8%) commented that they sought out research groups in order to help others, and eight parents (14.0%) reported that they did not look for any supportive resources or information. Table 10 presents an overview of where parents looked for support.

Support sought from...	n	%
Internet	33	57.9
Hospital staff	30	52.6
Family/friends	24	42.1
Peers	14	24.6
Charities	13	22.8
Burns camps	4	7.0
Support groups	2	3.5
Requested referral	1	1.8

Table 10. Where participants in Study 2 looked for support

In total, 121 avenues of support were reported to have been explored by participants in this study. On average, participants who reported to find support explored 2.4 different avenues (range = 0-5). Those who reported to not find support explored 1.6 avenues (range = 0-4). Those participants who reported that they had found support had most frequently turned to hospital staff (24/36, 66.7%). However, participants who did not find support most frequently turned to the internet (11/21, 52.4%). This demonstrates that, although participants most frequently turn to the internet (33/57, 59.7%), this search is less likely to be fruitful than approaching a professional in a face-to-face capacity. This may be harder to do once the child is discharged from hospital and where there are psychological and practical barriers to accessing support.

Real world and psychological barriers could prevent some parents from accessing support, or accessing adequate support. More than half of participants agreed that a barrier to accessing support was not knowing where to go to get it (31/57, 54.4%). Other real-world barriers were not having the time to access support (30/57, 52.6%), and problems with childcare (27/57, 47.4%), the distance to the hospital/medical centre (27/57, 47.4%), and problems with transport or travelling to appointments (26/57, 45.6%). Most parents reported that they were focussing on getting their child well and not thinking about their own needs (51/57, 89.5%). More than half of parents agreed that they would have accessed support if it was more local (32/57, 56.1%). Despite the financial impact of injury being a reason provided in the previous qualitative study for not accessing support, the largest proportion of people disagreed that the financial costs involved in travelling and accessing support were prohibitive (25/57, 43.9% disagreed). These figures are illustrated graphically in Figure 8.

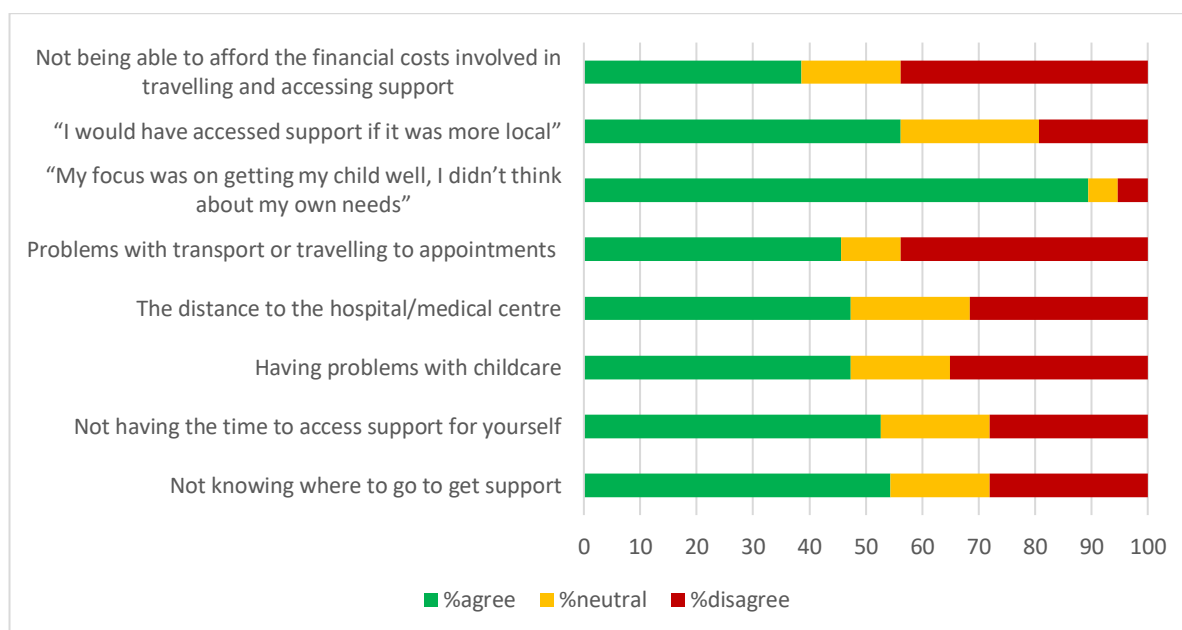


Figure 8. Participants' responses to statements regarding real world barriers to accessing support

In terms of psychological barriers, feeling embarrassed or ashamed (32/57, 56.1%) and/or feeling guilty (42/56, 75.0%) were emotions identified most frequently as making it difficult to access support. Parents also reported that it could be too painful for them to talk about what happened and how they felt (34/57, 59.7%). Within this sample, some parents also reported the following as barriers to accessing support: concern that they might be seen as weak for needing support (25/57, 43.9%), worry about what other people might think, say, do or feel (23/57, 40.4%), preferring to get alternative forms of care (e.g. religious healing) (5/57, 8.8%) or help from family or friends (13/57, 22.8%), thinking that support probably would not help (12/57, 21.1%), that they did not have a problem (8/57, 14.0%), or that things would get better by themselves (22/57, 38.6%). Some participants also reported a previous bad experience accessing support or mental health care as a barrier to support following their child's injury (9/57, 15.8%). Despite the pain of recounting what had happened being a significant barrier to many, parents tended to report that a dislike of talking about their feelings, emotions or thoughts was not the reason that they did not access support (25/57, 43.9%). These figures are illustrated graphically in Figure 9.

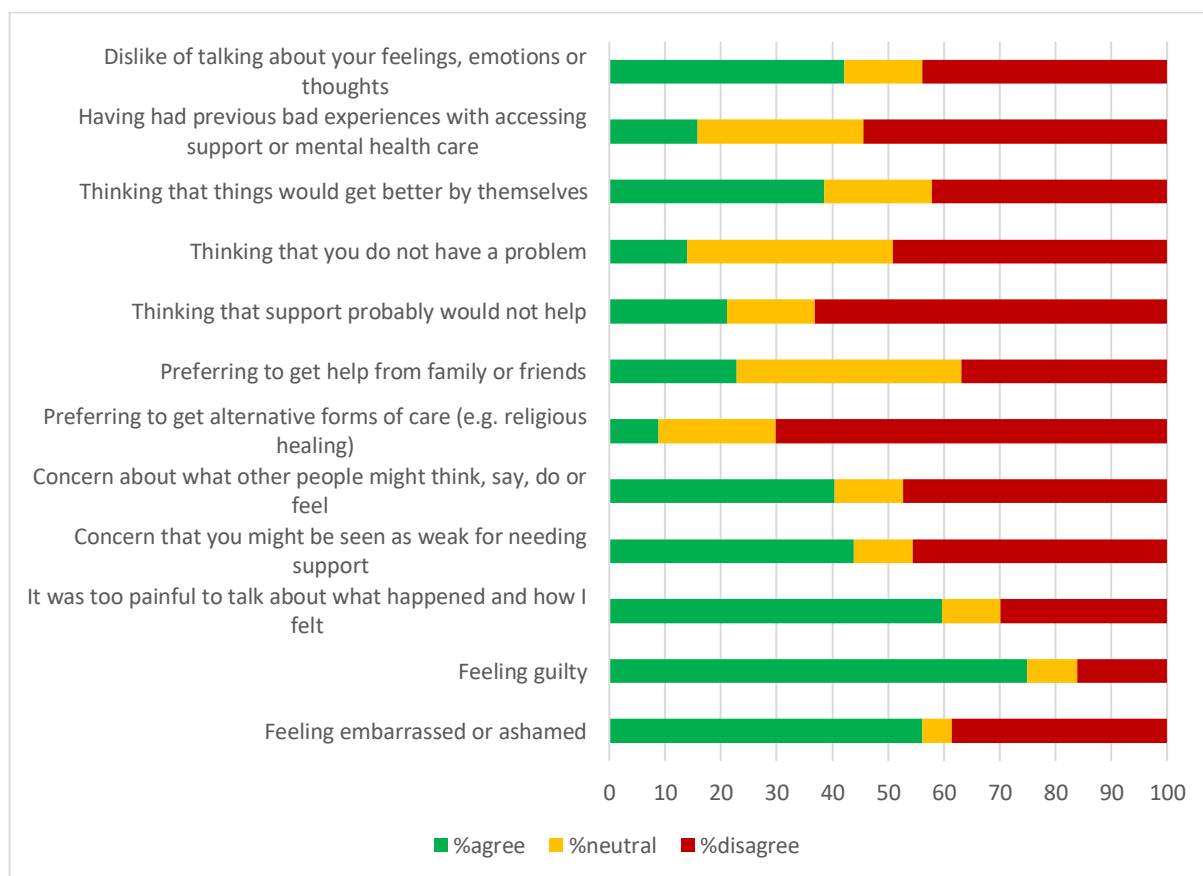


Figure 9. Participants' responses to statements regarding psychological barriers to accessing support

If parents do not want to tell people around them (family or professionals) about how they feel, there was agreement that, in this case, the internet is a useful source of support (42/57, 73.7%). In terms of online support, many parents had looked to the internet for supportive resources

(33/57, 57.9%), and almost half had used the internet to find other people who were experiencing similar challenges to themselves (28/57, 49.1%). Parents tended to perceive the internet as a reliable resource that could help them to understand what health professionals had told them about their child's injury and treatment (40/57, 70.2%). Parents looked for information and images regarding scar progression and management (33/57, 57.9%), and how they might alleviate or improve their child's scarring (37/57, 64.9%). These figures are illustrated in Figure 10.

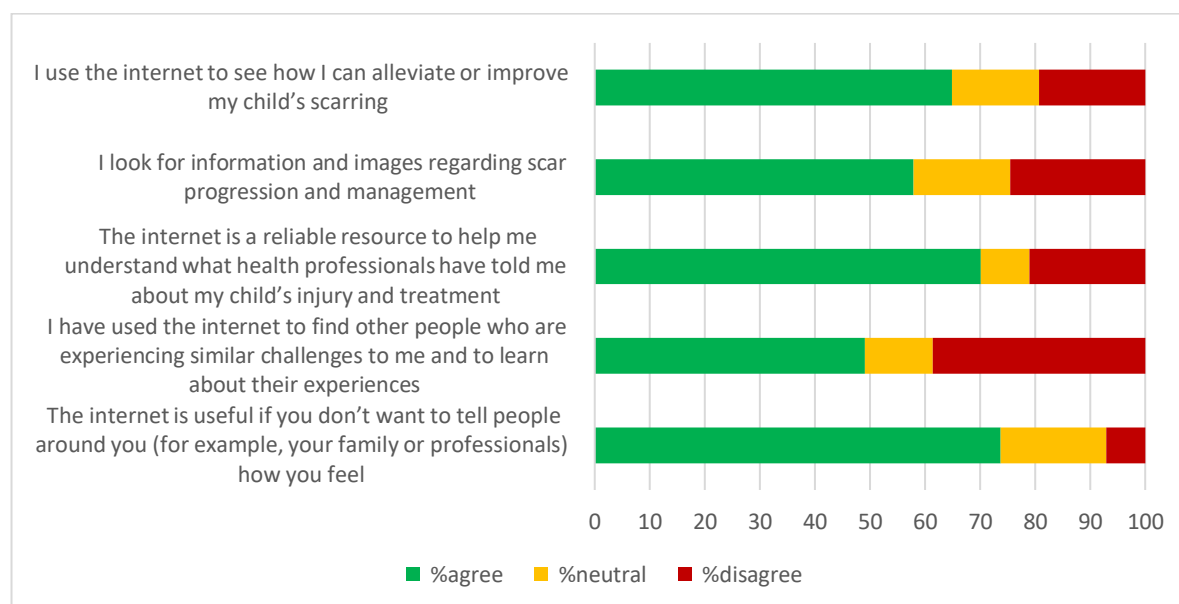


Figure 10. Participants' responses to statements about seeking support online

All participants felt that peer support would, at some point, be valuable to parents (57/57, 100%). The majority believed that peer support would be valuable to them personally (46/57, 80.7%). More parents felt that peer support would be most valuable during recovery, prior to wound healing (40/46, 87.0%), than at any other time (during rehabilitation, before scar maturation [38/46, 82.6%]; beyond scar maturation [30/46, 65.3%]) and a minority also highlighted the importance of considering the context (4/46, 8.7%). For example, the value of support "as child grows and faces new challenges such as realising she is different from her peers", it being dependent "on the needs and situations" such as "on hospital admission" or "through the whole process."

More than half of those who thought that peer support would be valuable to them thought that they would like to have access to a peer support group (29/46, 63.0%) but many also stated that they were unsure of whether they would like to have one-to-one peer support (25/46, 54.3%). There was a stronger preference for peer support being provided online (31/46, 67.4%) than by any other method (face-to-face, 25/46, 54.3%; email, 18/46, 39.1%; telephone, 10/46, 21.7%; Skype, 5/46, 10.9%).



In terms of face-to-face support, nearly half of parents agreed that accessing a face-to-face peer support group would be too difficult or demanding for them (27/57, 47.4%), however some (25/57, 43.9%) did feel able to engage in such a group. Most parents were not worried about who they might encounter should they engage in peer support (24/57, 42.1%). Many participants felt that it was important that parents could contact other parents whose child's injury was similar to their own child's (50/57, 87.7%) and reported that they would have liked to have met someone a little bit ahead of themselves who could explain to them what the future would be like (46/57, 80.7%). The majority of parents agreed that it would be helpful to hear about other parents' experiences of parenting a child following a burn injury on the internet (48/57, 84.2%), that looking at a burn-specific website would reassure them that they were not alone (49/57, 86.0%), and that the internet can be useful to help parents decide if they themselves should seek support (40/57, 70.2%). These figures are illustrated in Figure 11.

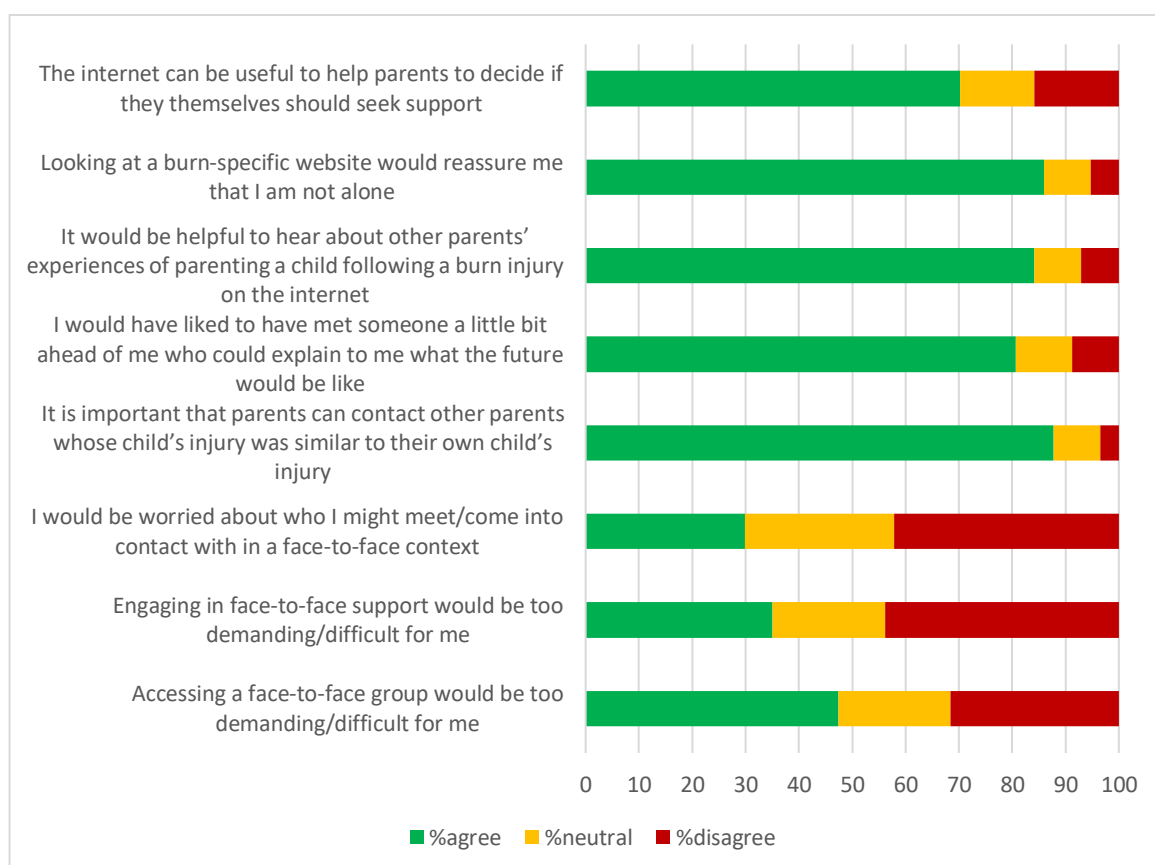


Figure 11. Participants' responses to statements about support preferences online and face-to-face

### 5.6.3 Content analysis

Participating parents were provided with the opportunity to add any additional information they felt might be relevant to the research. Additional comments were provided by 19 parents and these were grouped into four categories.

The **timing** of support is important: Two parents raised this issue with one commenting, “Staff at the hospital are helpful but I would like something that I could access for support in my own time” [Participant 46]. This is especially important if access to support from the hospital is time limited, or at least perceived to be limited to the time whilst the child is being treated.

Appreciating that “**everyone is different**” and so are their emotional responses [Participant 7]. This issue was noted four times emphasising that “what is useful for some isn't useful to others” [Participant 7] and therefore the importance of creating support that is “client friendly” and sensitive in how it communicates to different parents [Participant 21]. Whilst it is important to acknowledge difference, one parent spoke of the importance of parents being treated equally by staff who are providing care to their child and also to them. For some parents, it might be important that a support provision provides “somewhere where people know how you really feel, where you can get upset about what happened and not feel like you have to put on a brave face for anyone” [Participant 46] but for others who perceive their “guilt and pain” as a “punishment” [Participant 7] for not protecting their child or preventing the accident, it can be more difficult to engage with support offered. In the development of an online resource, it would be important to acknowledge that not all parents feel the same and not all parents want to access support.

Acknowledging that “**you can learn a lot from other [parents] on the internet** but there isn't really anywhere online for people whose child had a burn accident” [Participant 46]. Generally, parents were in support of an online support resource, and it was noted by two respondents that there is a lack of up to date information currently online for parents. Ideas for useful content were made in nine of the comments: “a hosted forum” [Participant 1] or “anonymous national online peer group where people can post questions and discussion threads” [Participant 33]. Valuable topics for discussion would include “websites for good UV protective clothing” [Participant 12], information regarding hospital accommodation and parking charges, and sources of financial support to assist with these, “reliable information on natural healing remedies” [Participant 17], “scar progression/treatment information... including a visual guide” [Participant 3], a chance to discuss with other parents their experience of different treatments, and how to get counselling or support for the affected child or wider family.

However, four participants also raised the concern that they “**do not trust advice from others via websites**” [Participant 24]. Concerns raised were regarding fabrication of stories for personal benefit, the “wrong information” being given [Participant 40] , and ensuring that users could be trusted to manage their own emotions “to retain a perspective that enables [the user] to benefit and move forward in how [they] deal with the situation” [Participant 38]. Such concerns could result in a preference for support from “parents that have been through the same situation, face to face” [Participant 32].

## 5.7 Discussion

The purpose of this study was to validate the findings of the qualitative study (Chapter 4) in a larger sample of parents and, in the event of peer support being identified as valuable, collect data to inform the development of an intervention going forward. The questions included in the survey related directly to the themes and subthemes emerging from the Study 1. It was apparent that all of the themes and subthemes were supported, but some found stronger support than others. It was also evident that, whilst parents shared the experience of having a child suffer a burn injury, their experiences and needs were unique. Therefore, it is important that a range of support options are available for parents and families to meet these diverse needs of this population (Harcourt & Rumsey, 2012). Providing parents with a menu of different options could mean that more parents can find support and/or resources to suit them and this could facilitate the implementation of a national stepped care model within UK paediatric burn care.

In this study, almost three quarters of parents reported that their child's scars reminded them of what they "did not do right at the time" [quote from Trish, Study 1 participant], and slightly more reported that feeling guilty was a reason they had not accessed support for themselves. In over three quarters of cases, scars reminded participating parents of their feelings of guilt. Previously, Mason (1993) found that 81% of mothers reported self-blame for not being able to protect their child. As a result of guilt, parents can become over-protective, needing to know where their child is at all times (McGarry et al., 2015; Rizzone et al., 1994), contributing to the majority of the sample reporting that they are more safety conscious, less care-free and more overprotective since the accident. This finding also received support.

An increase in safety-consciousness could be driven by the desire to protect children from future harm but also a desire to appear responsible in the presence of others, a need born from concerns about negative evaluation from others. Around half of participating parents reported to worry about whether their child's injury would lead others to think that they were a bad parent, and reported that feeling embarrassed or ashamed prevented them from accessing support. Although, for nearly two thirds, it helped to be told that the accident was not their fault, over a third of participants reported that the support available to them did not meet their needs. Feelings of guilt and shame are known to maintain difficulties such as PTSD and depression, and are associated with poorer adjustment in parents (Hawkins et al., 2019). 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) (Hawkins et al., 2019).

A burn injury to a child can also have a significant impact on the parents' relationship with their spouse/partner. Increased stress can lead to more arguments and feelings of guilt from those who were present at the event (Griffiths, Rumsey, Pleat, & Harcourt, 2015). In this study, almost half of participants reported that the accident had a negative impact on their marriage/relationship, and that they have never spoken about how they feel regarding the accident with their partner. Yet, only one fifth of participants reported that their child's injury had had a negative impact on family life. Perhaps some participants thought the actual occurrence of the accident had a more detrimental impact than the long-term consequences. It may be that elements of blame, guilt or shame impacted on parents' relationships and communication more than the accident does on family life more generally.

Blakeney et al. (1993) found that the concerns most frequently reported by parents related to disrupted family life, financial difficulties, the amount of time they spent caring for the injured child, and the effect of the burn on siblings. There is limited research on the psychosocial needs of other family members (Thompson, Boyle, Teel, Wambach, & Cramer, 1999), although it is evident in the findings of this study that parents were also concerned about the impact on siblings with almost two thirds of participants reporting that they worry they neglected their other children after the accident. As well as impacting on parents' relationships, almost half of participants in this study reported that their child's injury had a negative impact on their work life, but a smaller proportion reported financial difficulty in the context of this having a detrimental effect on their access to support.

In this study, all participants reported that peer support would be valuable at some point following their child's accident but 18.5% of parents did not think it would be valuable to them personally. It is unclear why this cognitive dissonance occurs, but one parent expressed that they did not deserve support because carrying the guilt was their punishment for not preventing the accident. Another parent did not feel that they required support as they felt that their child's injury was not very serious. It is possible that other parents decline support as a form of self-punishment or because they do not recognise the impact of the injury on themselves, potentially minimising their own feelings and justifying this with thoughts that their child's injury is not serious enough for them to warrant such support. Pugh et al. (2015) have also found evidence of this, highlighting that psychologists should be mindful of guilt and shame becoming barriers to treatment if they are not addressed. The existence of other psychological barriers inhibiting access to support were also confirmed in this study, such as concern about appearing weak, feeling embarrassed or ashamed, worrying about what other people might think, and not wanting to talk about feelings, emotions or thoughts.

When psychological barriers prevent access to support, psychoeducation might be perceived as a more acceptable option, with participants able to attend sessions in order to learn more about their emotional response, reducing their perception of being weak or self-indulgent for needing support. Legg et al. (2017) found support for this. They found that when participants were asked to describe the type of person who would seek peer support, and rate how similar they were to that person, those rating low similarity described peer support users as more needy, when high similarity was rated peer support users were thought to be more resilient. Such findings suggest that when advertising a support intervention, it is important to speak to the strengths and resilience of the target audience.

Parents also reported real-world or practical barriers that made it difficult for them to access support, such as not knowing where to get it from, not having the time to access it, childcare problems, the long distance to the hospital and transport issues. Over half of parents agreed that they would access support if it was more local. Whether parents find psychological or practical barriers more deterring, almost half of the participants felt that, in terms of peer support, accessing a support group face-to-face would be too difficult or demanding. An online support provision may offer support to a much wider range of parents. Research has indicated that internet support groups can provide similar benefits to face-to-face sessions (Baum, 2004) and many of the parents in this study agreed that it would be helpful to hear about other parents' experiences of parenting a child following a burn injury on the internet, and that this would reassure them that they are not alone. This is particularly noteworthy as it is common for people to search for health information online, with 51% of users doing so in the UK in 2016 (Office for National Statistics, 2016).

The internet can be a valuable method of seeking information and support for those who have limited social support and/or feel socially isolated (Plantin & Daneback, 2009). This research has demonstrated that parents of burn-injured children can feel alone and isolated, and almost half of those surveyed had sought out others who were experiencing similar challenges in order to learn about their experiences over the internet. However, it is apparent from this study that those searching the internet for support can have difficulty finding it. Support was most likely to be found when the search utilised several different avenues, including hospital staff.

The findings of this study suggest that a website created to host the experiences of other parents could provide knowledge and reassurance, practical advice and coping strategies, inspiration, encouragement and a sense of hope and camaraderie, whilst also decreasing isolation, and offering opportunities for social comparison as has been found in studies of peer support (Davis, Gorgens, Shriberg, Godleski, & Meyer, 2014; Kornhaber et al., 2015; Locock & Brown, 2010; Macvean, White, & Sanson-Fisher, 2008). Hosting such information online could reduce issues

related to recruitment and maintenance of peer supporters (Batchelor & Williams, 2013); however, parents' experiences could differ based on geographical location, type of burn, location of burn and post-burn complications. Therefore, if information was to be hosted on a website it must be generalizable to many different burn and family characteristics in order to meet varying needs in relation to the different parental experiences, and also changing needs over time.

When considering these findings and the development of an online resource, it is worth noting that, compared with the parents who took part in study 1, this online survey attracted participation from parents whose child had burns with a smaller TBSA (16% versus 20%) and was older at the time of injury (4.6 years vs 3.6 years), and a higher proportion of children were treated as outpatients in this study (22.8% versus 7.7%). Time since injury in this study was also slightly longer than that of the first study (3.1 years vs 2.9 years). Perhaps related to this, the theme of isolation finds support from a smaller proportion of parents than other themes in this study. It could be the case that parents of children with larger burns feel more isolated as they spend longer in hospital away from their friends and family, and are likely to find fewer parents who have experienced similar events following discharge, as most children (98%) experience small burns with a TBSA less than 10% (Dunn et al., 2015).

Although it is well documented that burn size does not correlate with adjustment of the injured child (Blakeney et al., 1993; Lawrence, Rosenberg, & Fauerbach, 2007; LeDoux et al., 1998; Robert et al., 1999), perhaps the experience of isolation in hospital and beyond affects the adjustment of parents. A lack of opportunity to share their experience with someone who understands what they have been through may be what prompted parents of children with larger burns to want to share their experience in more detail with me in the first study. Nevertheless, most of the parents in this study also had children who had been treated in hospital as inpatients, many requiring surgical intervention. It may also be the case that older children are able to attend burn camps and so their parents also have the opportunity to meet others at family camps and social events. Perhaps some of the parents in Study 2 reported to feel less isolated as their children were accessing such support, thereby facilitating some peer contact for themselves.

It is also worth noting that Qualtrics logged that 12 people read the study information but then checked a box to indicate that they did not want to participate in the research. It is not clear why these people declined to participate but it could be that they did not meet the inclusion criteria, they were not interested in taking part in a study with a focus on peer support or online support, or they did not want or feel able to share their experiences for research purposes. Potential participants were given my contact information should they have wanted to participate by different means (paper or telephone) and so it is unlikely that potential participants were put off solely by the fact that the survey was based online. Another possibility is that these people

were seeking support, not opportunities for research participation. Several months after the closure of this study, one parent contacted me after searching for information and support online following their child's burn injury. They indicated that during their search they had struggled to find much relevant and up to date information but they had found my recently published article (Heath et al., 2018). This parent had read that article and indicated that they agreed with my conclusion and they wanted to assist where they could in the development of support for parents.

## **5.8 Limitations**

When considering the limitations of this study, it is important to reflect on factors which may have had a bearing on the participation rate, the first of these being 'research fatigue' (Clark, 2008). Research fatigue can be a particular concern in that which focuses on limited groups as they are approached more often than those from other groups (Pagano-Therrien, 2013). Although there is a lack of research into research fatigue within the burns population, it is likely that this was unfortunately experienced by this sample in particular, with only 7% responding to the email invitation. This hypothesis was born from discussion with colleagues about response rate following the study that revealed that, shortly before this study, these parents were sent four separate emails asking for their input into the development of patient-reported outcome measures (PROMs). The PROMs research asked parents to complete questionnaires, not only about their own experience but also their child's experience (Griffiths et al., 2017), and the high volume of emails regarding burns questionnaires and this survey may have contributed to the participant pool engagement rate of only 7%. This issue highlights the importance of good communication within research teams, particularly when utilising participant tools and was a significant learning point regarding research ethics.

Way (2013) suggested that the research fatigue hypothesis may relate to subjective interest in the research topic and mistrust of the researcher, and Clark (2010) suggested that research engagement can be facilitated by subjective interest or participant curiosity. Explicitly stating the aims of the research was done to increase trust and attract interest. Whilst curiosity may have been increased, it may have contributed to a self-selecting sample of those with an interest or strong views about the topic of peer support or online support participating in the research. Although this could explain the 100% agreement in the value of peer support, several parents did voice that they would not want to engage in internet-based support, and almost one fifth of participants did not think peer support would be valuable to them personally. Perhaps some of the participants were motivated by altruism and a belief that this research would be valuable to others, as found by Chambers et al. (2013). Perhaps parents who felt that they were strong or resilient wanted to do something to help those who might need more support (Legg et al., 2017). Regardless of participants' motivations, the helper therapy principle would suggest that giving to

others puts one on a positive upward spiral helping to build social capital (Riessman, 1965), which would in turn have a positive impact on the participant.

As McQuaid et al. (2003) have previously found that parents of burn-injured children suspected an alliance between researchers and social services, and were far less willing to engage if they had had previous contact with mental health or social services, it is important to consider that this factor may have had an impact on recruitment and the results obtained in the current study. This is particularly relevant as the results of this study indicate that previous negative experiences of mental health services impeded engagement with support for 16% of participants. Such findings demonstrate the importance of transparency throughout the research process, ensuring that participants can appreciate the true purpose of the research and understand why it is being conducted in the way that it is.

As the study explicitly sought to ascertain parents' options on peer support and online support in particular, it is also possible that participants answered to please the researcher. Questions which may highlight social desirability in responding are that 100% of participants rated peer support as valuable (possibly to please the researcher) and 93% reported that they do everything they can to try to reduce their child's scarring (possibly to please professionals). Despite this, research on participant effects by Weber and Cook (1972) found little evidence of participants responding as the researcher might wish, and Masling (1966) even suggested that knowing the aims of research might influence participants to respond away from expectancy.

Another limitation to note is the method of data collection used: an online survey platform. The advertisement of the study was also largely done online. One advantage of remote recruitment is that the perceived distress of a family does not introduce bias into the sample through professionals not sharing information about the research with them. (For example, in a face-to-face capacity, bias could be introduced by not approaching families who appeared distressed.) However, it is important to note that participants in this study, the majority of whom rated online support as potentially beneficial, were all online already in order to access the study materials. This in itself may be a bias as those not online, or at least comfortable in this medium, may have been reluctant to participate. Despite these limitations, as this study validated the findings of the previous qualitative study, it can be inferred that the external validity of these findings was good, as it has been argued that external validity is better demonstrated by a number of small studies with specified examples rather than a single larger study (Cook & Campbell, 1979).

It is clear that the development of an online information resource could be a valuable contribution to the range of information and support on offer for parents of children with burn-injuries. A parent-focused website may also be beneficial for a much wider parent-audience than



traditional face-to-face support. As a result of the findings of studies 1 and 2, it was proposed that a website disseminating burn-focused information and psychoeducation about the impact of children's burns on parents, as highlighted in the literature review (Chapter 2), be developed. This would cover a range of topics including parent stories, coping skills, as well as signposting to other information and sources of support. During this process evidence-based psychoeducation will be sought and parents will be consulted, ensuring that the information presented is trustworthy, appropriate, and meets the needs identified to date.

## **5.9 Conclusion**

This study validated the findings of Study 1, but it was also evident that, whilst parents shared the experience of having a child suffer a burn injury, their experiences and needs were unique. For this reason, it is important that a range of support options are available for parents which could enable more parents to find support and/or resources that suit their individual needs. One option could be to develop an online peer-informed resource.

Whilst some previous studies within the literature have suggested that parents may benefit from group peer support, no information exists about whether parents of burn-injured children may actually prefer an online resource. This study has suggested that this may be the case.

Developing online support services for parents of burn-injured children containing peers' personal experiences offers promising and exciting opportunities to empower parents. Such a resource could provide accessible advice for supportive care, which can be vetted and promoted by professionals. The next chapter will relate the findings of studies one and two to the wider literature and propose a suitable intervention for parents of burn-injured children.

## **Chapter 6: What has this mixed methods research uncovered regarding the experiences and support needs of parents of burn-injured children?**

This chapter considers relevant literature on peer support in line with the findings of the qualitative and quantitative studies, presented in the previous two chapters, conducted with parents of burn-injured children in the UK.

### **6.1 Interview study overview**

Key themes emerging from the interview data, which were verified by one participant via member checking, referred to loss, change, isolation and the importance of support from someone who knows what it feels like, whether these be trained professionals or peers. Parents described many different experiences, both positive and negative, but the overwhelming message from most was that the burn injury could have a devastating impact, and the treatment was challenging for both parents and children. A variety of surgery and treatments had been faced by the children of participating parents, including treatment in intensive care units, skin grafts, scar revision surgery, scar management with creams and pressure garments, and physiotherapy.

The experiences described included the initial fear parents had of losing their child, which could return, or be prolonged, when there were medical complications or when repeated surgical interventions were required. These events could change many things for parents. Scars that remained acted as a reminder of the incident and this could challenge parents' views of themselves as parents, and impact upon relationships and interactions with those around them. In some cases, the accident and ongoing engagement with medical services reduced their contact with friends and family, and impacted on their relationship with their spouse. Some parents were also concerned that whilst their injured child was unwell, siblings may have been neglected.

Parents took action to attempt to repair the damage done to their child. This could be in terms of physical action to reduce scarring and also attempts to compensate the child for the distress and pain that they had experienced. When a child had scarring, regardless of how parents felt about their child's scars, they had concerns about the negative impact that the scars might have on their child's future. The desire to prevent future harm led many parents to becoming hypervigilant, which could lead to some becoming over-protective of their children.

Following the injury event, parents could feel isolated in both a physical and psychological sense. Although parents were surrounded by teams of different health professionals, and often other family members and friends, they could still feel very much alone and as though they were the only one who had ever had that experience or felt that way.

Most parents had been offered one-to-one support by a professional, such as a clinical psychologist, and the majority of those who accepted support found this to be helpful. Some parents found other key members of staff (such as nurses and play specialists) to be supportive, offering advice, comfort and distracting the child during procedures. Those who had accessed peer support, often informally, also found it helpful. In most cases, support was offered to parents whilst their child was in hospital.

Although most parents said they knew that professionally-led support was available to them, they discussed challenges that could act as barriers to them accessing this support. These included the demands on their time of caring for their injured child, the financial impact, their distance from the hospital, feelings of guilt or blame, and their blinkered focus on their priority of getting their child well as they were the ones injured, rather than a focus on themselves and their own needs.

It was felt that support from peers would be valuable at different stages of their child's recovery. Whilst face-to-face interaction was important to some, as talking about the event and its impact could be emotionally painful, other parents felt more confident communicating their feelings remotely. Some parents had already looked on the internet for other parents that they could share experiences with or learn from, however, appropriate resources and online support was noticeably lacking.

Parents discussed different ways support could be provided. Advantages of support via the internet that were discussed by parents included the chance for anonymity, opportunity for easy access to images, accessibility if/when needed and in their own time, and ability to receive support from many other parents. Most importantly, parents would be able to access consistent and accurate information and support.

## **6.2 Quantitative study overview**

Responses from a larger number of parents provided overall confirmation of the themes described above, although some subthemes received stronger support than others. Within the theme of loss, loss of the perfect child and action to repair were agreed with more frequently than fear of losing the child. Most parents said they had done everything they could to try to reduce scarring, and continued to hope that their child's skin would go back to the way it was.

In terms of the theme of changes imposed upon parents, the subthemes regarding scarring as a reminder and the impact of the injury on parents' self-perception consistently received most support, with more variable responses being received to questions referring to the subtheme regarding parents' engagement with others. Although it is not known whether all of the participant's children had scarring, above all else, participants rated that their child's scars were a

reminder of how brave and strong their child had been and continues to be. Despite this, it was apparent that many parents were looking on the internet for ways to reduce the visibility or severity of their child's scars.

In terms of the theme of isolation, just over half of parents reported feeling isolated when their child was in hospital; just under half continued to feel that way when they returned home. Again, just over half agreed with the statement, "I felt like I was the only person that felt like this", and the fact that half of participants reported that they and their partner had never spoken about how they felt regarding the accident could contribute to this.

The majority of parents who completed the questionnaire had accessed support, most frequently, support was received from nursing staff, family, and psychosocial professionals. Support from family members had not been discussed in the previous qualitative study. The majority of parents agreed that the support they received was helpful, but, despite this, more than half of the participants agreed that there were significant barriers to accessing support – the most significant being guilt and a focus on getting their child well and therefore not thinking about their own needs.

In terms of support, most parents reported that they would rather access professional support in a face-to-face context. However, parents also looked for supportive resources on the internet. Many parents believed that peer support would be valuable to them and the strongest preference was for this to be provided online. There was also agreement that the internet was a useful source of support if parents do not want to tell people around them (family or professionals) about how they feel.

Most participants felt that it was important to be able to contact other parents whose child's injury was similar to their own child's, that it would be helpful to hear about other parents' experiences on the internet, and that looking at a burn-specific website would reassure them that they are not alone. Most parents also said that they would have liked to have met someone a little bit ahead of themselves who could explain to them what the future would be like. Parents tended to agree that the internet was a reliable resource that could help them to understand what health professionals had told them about their child's injury and treatment. Parents also agreed, and that the internet could be useful to help parents decide if they themselves should seek support.

Parents participating in Study 2 also submitted qualitative responses raising some additional important points: 1) It is important that parents have access to support in their own time, when they feel ready and want to access it; 2) There is a lack of up to date information currently online

for parents; 3) Everyone has different emotional responses, so what is useful to some parents might not be useful to others; and 4) Not all parents trust advice or information on websites.

### **6.3 Consideration of the relevant literature**

Interestingly, parents opting to be interviewed about their experiences reported both real-world/physical barriers and psychological barriers to accessing support; however, those responding to the survey more often reported the presence of psychological barriers to accessing support. Those choosing to respond anonymously to a survey more often reported that it was difficult to speak about their experiences and therefore were more likely to perceive psychological barriers to accessing support. In terms of access to online support, these parents may form the majority group, known as 'lurkers' (those who do not contribute to online content).

There is strong evidence that online social support is most attractive to people who are unable to easily access face-to-face support because of issues related to geographical location, employment or childcare responsibilities. Other issues making online support more attractive are unavailability of in-person social support, and low numbers of people sharing a similar condition, (Cummings, Sproull, & Kiesler, 2002; Scharer et al., 2009). Campbell, Phaneuf, and Deane (2004) suggested that internet programs can overcome geographic isolation, but they also have drawbacks. Lack of computer resources, skills, and time to keep up with discussions are potential barriers to online support (Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000).

It has been suggested that those who seek social support online have needs and characteristics that differ from those who select in-person social support. For example, Chung (2013) found that people who lacked support from their friends, family, partners, and physicians, and were experiencing difficulties coping with their condition, were more likely than those with strong support and effective coping skills to participate and remain in online social support interventions. It has also been found that people with less support in offline contexts tend to appraise the support received in online social interaction more positively than people with a greater amount of social support from offline contexts (Chung, 2013). With 50% of participants reporting that they did not talk to their spouse/partner about what had happened, despite 74% (52/70 participants from Studies 1 and 2) reporting that they were married or in a civil partnership, it is possible that this is also a factor influencing their advocacy for an online resource.

A potential concern here is that heavy reliance on social relationships in online support groups can reduce the likelihood of people seeking external support from offline contacts (Chung, 2013). A decrease in contacts with offline support networks can be particularly problematic when online groups normalize negative expression and behaviours. An example of this being pro-anorexia online support groups that have been shown to reinforce the secretly held identity as pro-ana and

inhibit seeking interaction with people other than fellow support group users (Gavin, Rodham, & Poyer, 2008). This could be of concern for parents of burn-injured children, with some parents reporting that they were to blame for the accident and that their psychological suffering is their deserved punishment. When social interaction in online support groups is preferred over offline interaction, the emotional gap between a patient and their loved ones in offline settings can widen (Helgeson, Cohen, Schulz, & Yasko, 1999, 2000). This is also important to consider as an impact on social and family life was already reported by a significant proportion of parents participating in this research, as well as concerns held about what other people would think of them for seeking support, or of them appearing weak (Study 2).

People engaging frequently in online support may become increasingly resistant to the supportive acts offered by people outside of the support groups. The possible decline in face-to-face interaction can be particularly undesirable for those who need more instrumental assistance in day-to-day needs because tangible support is hard to receive through online contacts (Chang, 2009; Hwang et al., 2011). This could be problematic for parents in the early stages following their child's injury where there are immense pressures on their time as they try to balance competing demands. This demonstrates that appreciation of supportive behaviours is dependent on the needs of individuals (Cutrona & Russell, 1990) and may point to a need for burn services to better identify parents lacking in support (Griffiths, 2016). Regardless of parents' specific needs, the aims of the intervention developed as part of this PhD should not be to reduce the seeking of support from professionals, rather to complement it.

With parents participating in the studies included within this PhD often seeking information on scar management and treatment developments, rather than support with their own coping or the impact on relationships, it is likely that parents of burn-injured children are only partly aware of their own support needs. The Johari's Window model (Luft & Ingham, 1961) illustrates the challenge that we only know what we know, but not what we do not know. Therefore, in order to identify all areas in which support or psychoeducation might be required, different tools are required to explore the different areas of need.

Amery and Lapwood (2004) suggested that children's hospice doctors were able to assess their own clinical skills (symptom control, pharmacology, management of specific conditions) but were less skilled at assessing their own 'intrapersonal' skills (understanding underlying values and attitudes, coping strategies, and communication, problem solving, and information management skills) and 'interpersonal' skills (skills needed to manage across disciplines and agencies, work with teams, apply various tools and theories in problem assessment and management; and to deal with spiritual, cultural and societal issues). In their study, Amery and Lapwood (2004) found that the educational resources for doctors in a children's hospice were strong on specific 'craft'

(clinical) subjects; but weaker on 'intrapersonal' and 'interpersonal' skills. With many parents reporting (in Study 2) that they felt prepared for caring for their child following their discharge from hospital, the findings of Amery and Lapwood (2004) could be echoed with potentially more information being available to parents regarding the medical procedures that their child may undergo rather than the emotional challenges that they may face. This situation can prevent the resolution of the problem (Amery & Lapwood, 2004) if parents are unaware of their needs and not supported to discover them through the available resources available. These findings have implications for the design of any intervention developed (Amery & Lapwood, 2004).

Despite the aforementioned concerns, Hoey, Ieropoli, White, and Jefford (2008) found that patients reported high levels of satisfaction with peer support programs; however, evidence for their psychosocial benefit was mixed. Positive effects of peer support can be seen in practical, social and emotional ways (Hoey et al., 2008), in terms of increased knowledge, improvement in general health perception, less disturbances of body-image, and reduction in negative feelings (anxiety, fatigue, tension, and confusion) and phobias (Van den Borne, Pruyn, & Van Dam-de Mey, 1986) but other trials have found no significant effect of peer support on health-related quality of life or psychological distress. When considering ways to offer peer support for people with cancer specifically, Hoey et al. (2008) suggested that one-to-one face-to-face and group internet peer-support programs should be given priority. Bakker et al. (2009) also suggested that a group intervention, designed for parents of severely disabled children (Nixon & Singer, 1993), could help parents of burn-injured children.

When a lack of psychological or other support or information is perceived by parents of burn-injured children during treatment and rehabilitation (Willebrand & Sveen, 2016), Sveen et al. (2015) suggested that this could be improved by healthcare professionals providing educational programs and written information about both the physiological and psychological aspects of burn injuries. During this program of PhD research, an internet-based information and self-help program with therapist contact for parents of children and adolescents with burns was developed in Sweden (Sveen et al., 2017). However, with Johari's Window in mind, it may be that parents do not all recognise the value of such educational material as they have voiced within this research that they want support at the right, time, that is accessible and from 'someone who has seen it before' (Study 1). Perhaps supporting this, as reported earlier, Sveen et al. (2017) found that, whilst their program had a short-term beneficial effect on posttraumatic stress, it did not affect general stress or parental stress and some parents thought that it was time-consuming.

Whilst it is evident that psychological support can be helpful for many of those who access it, development of peer-led resources containing more practical, experiential knowledge, could also be beneficial, particularly when psychological isolation is identified as a concern, or there is a

reluctance to talk to a professional, at least initially. In these cases, healthcare professionals can refer patients and family members to an appropriate resource. Parent perspectives can both normalise the experience and allow others to make an informed decision about whether engaging with peers or professionals, and through which mode, might be right, or not, for them at that time.

UK health policies acknowledge the value of patient choice, self-care, and public involvement in healthcare (Department of Health, 2008), leading to experiential information being routinely incorporated into mainstream health websites such as 'NHS Choices', charities and private company websites (Kelly et al., 2013). Having a national organisation manage this information, rather than individual burn services which are geographically based, would remove some of the bureaucratic challenges of an NHS initiative (NHS Confederation, 2013). As a website could be funded for two years initially, it will be important to present data about its use, alongside feedback from users over the first year, to the BBA and other national burns support organisations, such as the Children's Burns Trust and Dan's Fund for Burns. This will be necessary to attract an organisation who are able to maintain it long-term. This is preferable to it remaining with CAR, a university research centre, as it will require those working within burn-care to review the content periodically to ensure that it is still up-to-date and relevant to parents whose children are receiving burn care.

To ensure participant safety, online group peer support requires commitment from people trained to act as moderators. Within the scope of this PhD, it was proposed that a peer-informed psychoeducational and supportive website would be created in the first instance.

#### **6.4 Theories behind online support**

In the development of an online resource, it was important to be sensitive to the fact that not all parents feel the same and they do not all want the same kinds of support. This section explores online support and theories that could explain the value of this type of support for parents of burn-injured children. The experiences, beliefs, and goals of individuals will lead to different perceived affordances (Norman, 1988). Affordance theory, which examines how individuals perceive the objects in their environment (in terms of what they are and what their uses are) helps to explain why some parents might seek support online and find it useful, whereas others do not (Gibson, 2014). Shoebottom and Coulson (2016) identified four therapeutic affective and cognitive affordances of online support communities, 1) connection: the ability to connect to support one another, exchange advice, and attempt to overcome feelings of loneliness; 2) exploration: the ability to look for information, learn, and improve knowledge; 3) narration: the ability to share their experience as well as read about the experiences of others; and 4) self-presentation: the ability to manage how they present themselves online. Another affordance



identified by Merolli, Gray, and Martin-Sanchez (2014) was adaption: the ability of users to adapt their self-management needs in relation to their condition. Different media platforms will offer specific affordances to individuals.

Considering these affordances in relation to parents of burn-injured children, an online resource could meet at least two of the four affordances identified by Shoebottom and Coulson (2016) – exploration and narration - and those identified by Merolli et al. (2014): explanation, narration, and adaption. For example, an online resource could provide an avenue for parents to seek information and advice from other parents who were ‘ahead’ of them in the process, and from professionals. It could also have the potential to facilitate the sharing of experiences, particularly when this is too emotionally difficult in a face-to-face context. This opportunity could help to reduce the psychological perception of isolation and, when there is concern about judgement from others or anonymity, parents can choose to share only the information that they feel comfortable to. Paterson, Brewer, and Stamler (2013) supported this idea finding that parents were most likely to engage in an online social support intervention to meet their need for information and their need to communicate with other parents who share a similar reality.

The affordances described above relate to the four most frequently used attributes of social support, which are: emotional, instrumental, informational, and appraisal (Langford, Bowsher, Maloney, & Lillis, 1997). Due to the virtual nature of interactions within online support groups, instrumental support (the provision of tangible goods, services, or aid) is scarcely provided by them (Chang, 2009; Hwang et al., 2011). However, within the UK, instrumental support can be provided by some charities with an online presence (e.g. Dan’s Fund for Burns who provide help and guidance regarding where to find the right practical support, financial assistance, rehabilitation equipment, and support following discharge from hospital with things such as job retraining). Emotional, informational and appraisal based support can be provided via four main types of online therapeutic intervention: 1) websites providing information; 2) peer-delivered therapeutic support and advice (such as online self-help or peer-support groups); 3) professionally delivered therapy (such as email responses to queries or live chat rooms); and 4) self-management psychological interventions (often cognitive behavioural therapy [CBT]-based interactive activities with automated responses) (Bergström et al., 2010).

In terms of online psychosocial support, it has been found that parents want current, valid and reliable information from online interventions (Paterson et al., 2013). This information needs to be relevant to their personal situation and offered in a site that is easy to navigate. This finding was also supported by this research. Receipt of the support parents need to cope with their child’s situation can result in parents experiencing a sense of empowerment (Paterson et al., 2013). However, in terms of interactive interventions, too few or too many messages from other

parents or health care practitioners in the intervention can cause parents to leave or never engage in the intervention (Paterson et al., 2013). A resource that is not interactive will not have to be concerned about ongoing interactions but will need to ensure that it is up to date and reliable.

Sveen et al. (2015) and Sveen et al. (2017) reported that self-help/management interventions should be based on CBT principles rather than purely educational (Gellatly et al., 2007) and it is also noteworthy that self-management psychological interventions with interactive activities and automated responses, which are often CBT-based, have been found to be as effective as group-based CBT (Bergström et al., 2010). However, not all parents want or indeed would need a psychological intervention, rather they want access to trustworthy information and interactions with others who have shared similar experiences (Paterson et al., 2013). In support of this, Sveen et al. (2017) found that negative aspects of their online support reported by participants were that the program was time-consuming and some felt they had insufficient time, 9% of parents found the study intervention boring and 2% felt upset or sad because of it. Ensuring that the self-help information that is developed is CBT-based will also fit with NICE guidance and ensure that it is evidence-based (National Institute for Health and Care Excellence, 2005, 2009, 2011a, 2013; National Institute for Health and Clinical Excellence, 2005).

A literature review of the potential effects of seeing and sharing experiences online (Ziebland & Wyke, 2012) identified five themes relevant to the impact of health websites containing scientific information and/or experiential information: 1) information, 2) feeling supported, 3) relationships with others, 4) experiencing health services, and 5) affecting behaviour. With people increasingly turning to the internet for health information, it is important to understand the impact that both medical and experiential information hosted on health websites can have on users, and also the effect of peer-led internet discussion forums (Kelly et al., 2013).

To date, one study has evaluated an online support intervention for parents of burn-injured children (Sveen et al., 2017). The program designed by Sveen et al. (2015) and Sveen et al. (2017) consisted of six psychoeducational modules, one module per week, based on CBT as well as Acceptance and Commitment Therapy principles, and was accessed via a secure website. Modules included information about burns and rehabilitation, common psychological reactions after trauma, general information about stress and sleep, and family communication. The modules also included instructions for selected exercises such as validation, visualization, mindfulness, metaphor and acceptance strategies, exposure training, and progressive relaxation. The participants received a homework assignment each week based on these techniques. After each module, participants received written feedback on the assignments from a therapist (a psychologist or psychotherapist) via the online platform.

Sveen et al. (2017) found that their program had a beneficial effect on posttraumatic stress symptoms in the short term but did not affect general stress or parental stress. The authors also employed an evaluation form at the end of their program (n = 11). All of their participants answered that the program was informative and comprehensible, and the majority thought it was meaningful (n = 9) and supportive (n = 8). Whilst some participants reported that the program was upsetting (n = 2) or boring (n = 3), no one answered that participating in the program had made the situation worse. Some parents answered that the program had made the situation better (n = 4) and that the program had helped them with their problems (n = 6).

With parents involved in the research within this PhD stating that lack of time can be a barrier to accessing support for them, it is important to note that this was also a problem identified in the feedback received by Sveen et al. (2017). Most participants reported that it was good to access the program via the internet but negative aspects of the Sveen et al. (2017) program were that it was time-consuming and that some participants felt they had insufficient time. Time spent working with the texts provided varied greatly from about 20 minutes per module up to two hours per module, and time spent on homework assignments varied from 20 minutes to three hours per module (Sveen et al., 2017).

Although only one study has evaluated an online support intervention for parents of burn-injured children (Sveen et al., 2017), research has demonstrated the benefit of online support for parents of children with a range of other conditions, including cancer (Han & Belcher, 2016), clubfoot (Oprescu, Campo, Lowe, Andsager, & Morcuende, 2013), cystic fibrosis (Kirk & Milnes, 2016), and diabetes (Merkel & Wright, 2012). Positive effects of engagement with such groups are attributed to the chance to discuss experiences with others who have shared something similar, gaining specific advice relating to the condition, as well as more generalised peer support (Suzuki & Kato, 2003).

In addition to considering the attributes that support positive outcomes, it is also important to consider those that support participation and engagement, particularly as maintaining enthusiasm and interest has been shown to be an area of difficulty for burn-specific peer support in the UK (Batchelor & Williams, 2013). Several attributes of online social support shown to influence user participation and retention include: 1) the ability to communicate with others; 2) the perception that there is an expert presence who monitors the site; 3) the perception that others share a similar experience; 4) users who do not know one another and who have the opportunity to interact with people who have a variety of expertise; 5) the ability to compose messages in the way one wants and in the time one wants; and 6) having credible, accessible, and relevant information, privacy and anonymity, and social influence (Walther, Pingree, Hawkins, & Buller, 2005). However, it is important to acknowledge that different users will place varying degrees of

importance on these attributes. For example, it may be the case that some people choose not to participate in an online program because they regard the presence of a moderator as too intrusive (Walther et al., 2005).

Whilst moderation may be off-putting for some, it is important. Lack of face-to-face communication online offers privacy, but it can also give rise to the potentially problematic possibility of misinterpretation, misinformation, and interpersonal conflicts due to delayed feedback and the inability to read the tone of comments or see nonverbal cues (Preece & Ghozati, 2001; Preece & Maloney-Krichmar, 2003). Whilst Shoebottom and Coulson (2016) reported largely positive outcomes of engaging with online support communities, they also identified negative perceptions, such as concerns surrounding the accuracy of information exchanged, arguments between members of the community, over-reliance, being upset by items, and confidentiality. Where there is no moderation of online support groups, inaccurate and out-dated information can also spread because groups do not necessarily limit who can author and post (Coulson, 2005).

Whilst misinformation or the promotion of problematic and unhealthy behaviours is a risk (Gavin et al., 2008; Haas, Irr, Jennings, & Wagner, 2011; McCormack, 2010), Esquivel, Meric-Bernstam, and Bernstam (2006) found that the majority of incorrect and unreliable information is corrected by other members soon after it is posted. Concern for the downward spiral of negative thoughts and emotions also exists (Takahashi et al., 2009), such as excessive dependency on groups that can exacerbate negative thoughts and feelings. It is therefore important to acknowledge that an active peer support website does require supervision and moderation to ensure that the information shared is appropriate and accurate. However, there could be an alternative to an active website; it is also possible for support to be provided online which is informational in nature without being interactive (Langford et al., 1997).

A website without interactive content may not help a parent to meet others, and therefore may struggle to address perceptions of loneliness or isolation; however, it may help to alleviate the sense that they are the only one that feels that way. In fact, online support communities can have thousands of registered members, but the majority are not active contributors to the content (Coulson, 2017). Only around 1% of users actively create new content with the other 99% preferring to read content rather than generate it (Katz, 1998). It is well known that a large proportion (between 50% and 90%) of online communities are estimated to be lurkers (Preece, Nonnecke, & Andrews, 2004). However, lurkers may still benefit through the exploration of information hosted online (Coulson, 2017).

It is important to note here that mothers and fathers can differ in their amount and type of engagement in online social support interventions. Bragadóttir (2008) reported that online messages in parent discussions were read daily or weekly by mothers, but weekly or monthly by fathers. Bragadóttir (2008) also found that whilst both mothers and fathers perceived mutual support, mothers produced most of the messages with most fathers never writing messages by the end of their four-month trial of a computer-mediated support group. It can be difficult to gauge the benefits gained from those who view an intervention but do not actively participate. For example, Alat (2006) found that 10 of the 140 parents who enrolled in an online social support group for parents of children with autism posted a message only once in 5 years. Thirty-nine others never posted a message. Alat (2006) interviewed parents who posted messages in the intervention, but the lurkers were not interviewed. Without interviewing the lurkers, it is hypothesised that decisions not to interact or post messages could be due to distrust of members of the online community and reduced perceived responsibility toward social exchange (Preece et al., 2004; Ridings, Gefen, & Arinze, 2006) but, if someone continues to read the messages, it can be argued that this is evidence that the user perceives some value in the intervention.

An area that parents of burn-injured children might be seeking support for is in relation to scarring. For example, how to manage distressing social encounters when other people ask about, comment on, or stare at their child's scars. When returning to school, children and their family members can often feel anxious about the reactions of others to the child's new appearance, fearing rejection or ridicule (Blakeney, 1994). In these cases, experiential knowledge can be highly valued with parents potentially seeking advice about preparing for social situations that they anticipate will be challenging (Phillips et al., 2007; Rossi et al., 2005). This might be particularly helpful for parents preparing for significant transitions in their child's life such as starting/moving school and developing relationships. Peer support may be perceived by parents navigating this journey to be more valuable than that provided by professionals, because they can learn from those further ahead about ways in which they might support their child through this process. Therefore, in considering the development of the intervention going forward, it was necessary to consider the importance of the peer voice and how to best utilise the experiences articulated in Study 1. This was particularly important as parents recognised that they could learn from others, but the risks of untrained or disingenuous people sharing information was noted as present within peer support.

Whilst distrust of members of the support community can be a reason to not engage or to disengage, distrust of information offered by healthcare professionals can promote the initial online information seeking (Attfield, Adams, & Blandford, 2006). Healthcare professionals' communication styles, trust in information offered by them, and satisfaction with the medical

service received have been found to affect the degree to which patients seek support and information from online sources (Adler, 2002; Ommen et al., 2008). In a survey of users of online support groups, the majority (approximately 70%) reported to search online following visits to their physicians (Bell, Hu, Orrange, & Kravitz, 2011). It was found that those who felt that their doctors provided too little information, poor quality care, or inaccurate information relied more heavily on the internet following the visits than those who did not. AlGhamdi and Moussa (2012) and Tustin (2010) also reported that patients go online to verify diagnosis and to read about other patients' experiences, especially when they are dissatisfied with the quality and amount of information received from physicians.

Additionally, Hou and Shim (2010) found that patients have a greater tendency to engage in various types of online health activities, such as using websites for healthy lifestyles, searching for healthcare providers, and seeking health information, when healthcare professionals are perceived to use less patient-centred communication styles. With many parents of burn-injured children reporting to search for information online about scar management, scar outcomes, and new treatments that might be available, it is important to consider why this might be the case. Lack of certainty provided by clinicians, limited information, and the distress that this can cause for parents may drive online support seeking as it is often the case that professionals are unable to give definite answers about scarring and aesthetic outcomes. Whilst a significant proportion of parents participating in this PhD research felt that the internet could be useful to help them to understand what their doctor had told them, there was no evidence from the studies of mistrust or dissatisfaction in their communication with professionals.

Professionals within burn care may be concerned that parents might try to use an internet-based resource in place of healthcare professionals, but studies have repeatedly shown that patients trust and turn first to physicians for health problems (Fox, 2011). Chung (2013) also found that patients are not using online support groups to compensate for unsatisfactory care received from healthcare professionals. Even when there is discontent with the medical care received, people are no more likely to use online support groups as their preferred source of social interaction (Chung, 2013). There remains the possibility that those who go online because of unsatisfactory care received from healthcare professionals do not have much interest in building relationships with other users of the online community. In these cases, the main motivation for seeking online support groups may be to obtain further information and increase awareness about their particular health condition (Chung, 2013).

## **6.5 Limitations**

Although the idea of a website arose from studies 1 and 2 in this program of research, at no point were the participants asked whether they would use/visit a website specifically designed to offer

support to parents of burn-injured children. Schoenebeck and Bruckman (2013) stated that designers of social systems often ask themselves, 'If we build it, will they come?' Designers operate on the belief that a well-designed, functional system should be adopted by users. Yet, it is common for this not to be the case. For every successful deployment of a new system, many go by barely noticed, and others experience momentary peaks of interest, followed by an abrupt decline (Schoenebeck & Bruckman, 2013).

Limitations of developing online peer-based support for parents of burn-injured children include that the internet is used less frequently by those with a lower socio-economic status (SES), which relates to the availability of resources rather than differences in help-seeking behaviour (Plantin & Daneback, 2009). This is a significant issue as burn injuries happen more regularly in lower SES families (Park et al., 2009). Whilst public internet access has improved significantly since the study by Plantin and Daneback (2009), it is important to consider how support that is hosted online could be made available to those who might not have access to the internet, particularly as parents may not feel comfortable accessing support in a public area, such as a library or coffee shop. The charity [Dan's Fund for Burns](#) has recently launched an [adult burn support forum](#) and it can be hypothesised that similar issues may also be found by them. It may be that this charity, which provides instrumental and financial support to people affected by burns (which includes providing iPads for therapy), could consider ways of assisting families affected by burns to access the internet in private, particularly if online support for this population is shown to be beneficial and becomes increasingly popular.

Although the internet is generally perceived to be readily accessible, Schoenebeck and Bruckman (2013) found that parents had interrelated issues which led to them not contributing to a community based website for parents. These included not having enough time (a barrier already identified to accessing current support services within burn care), having too much communication in their lives already, and trying to spend less time with technology rather than more. A smaller number said they preferred face-to-face interaction (talking), or that it was unclear what the benefits of the website were for them (Schoenebeck & Bruckman, 2013). When parents were asked what could be different or what they wanted, many emphasized that they did not necessarily want to discuss what was going on, rather they wanted instructions for how to manage it (the issues referred to their child's technology use). However, parents also wanted the ability to override any advice that was given to them.

Schoenebeck and Bruckman (2013) found that use of their forum mirrored other patterns of participation online where a few parents contributed the most, many read the content but did not post frequently, and some joined but did not return (Guzdial & Turns, 2000; Lampe & Roth, 2012; Lampe, Wash, Velasquez, & Ozkaya, 2010). An online resource, rather than an interactive

forum, would mean that there was no need for parents to discuss their experiences with a stranger, rather they could access *peer-informed* and CBT-based information about how to manage their situation and then make an informed decision about whether to try to implement it or not.

## **6.6 Conclusion**

This chapter has presented a summary of the results from the first two studies, combining them with the relevant literature and theories behind the use of online support, to suggest the development of a peer-informed support resource for parents of burn-injured children. Developing online support resources for parents containing peers' personal experiences could offer promising and exciting opportunities to empower parents to engage in self-care or seek other sources of support when necessary. Chapter 7 will describe the development and testing of a prototype website designed specifically for parents of burn-injured children, informed by the previous studies and reviews in this thesis. This website would be the first of its kind.



## **Chapter 7: A feasibility study following development of a prototype online peer-informed intervention**

This chapter describes a participatory action approach, taken with parents and professionals from academic, NHS, and charity sectors, to determine the acceptability and feasibility of a website for parents of children with a burn injury. A paper describing this work has been published and is included in the secure pocket (Heath, Williamson, Williams, & Harcourt, 2019).

### **7.1. Introduction**

It is now well documented that if parents are to cope well during their child's burns rehabilitation then their welfare must be considered as they have also suffered and, therefore, should also be considered patients themselves (Blakeney & Creson, 2008; Blakeney et al., 1993; Young, 2004). Research has also identified that family support has an important role in influencing the psychosocial adjustment of the burn-injured child (Landolt et al., 2002; LeDoux et al., 1998). In addition to improving outcomes for children with burns, support for parents may also have a positive impact on the physical health of parents. Dorn et al. (2006) proposed that there is a need to incorporate a family perspective when treating those families who have been affected by a traumatic event and that it is of public health importance that interventions (short-term or long-term) are provided to help people overcome the negative impact of disaster-related stress. Studies 1 and 2 demonstrated that parents recognised the potential value of psychosocial support, including peer support, although factors such as guilt, the pain of recollection, perceived stigma, time pressures, and distance to the hospital could make accessing support difficult. Therefore, online delivery of supportive information could be particularly appealing to parents.

With wide-spread access to the internet 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 (Office for National Statistics, 2018), thereby benefitting from immediate and easy access to online psychological interventions (National Institute for Health and Clinical Excellence, 2005). Previous research has also found that caregiver vulnerability to burnout can be significantly reduced by providing appropriate psychoeducational support (Stam & Cuijpers, 2001), so such a provision should not be ignored when developing parent-focused post-burn support.

However, research examining the efficacy of support interventions for the improvement of psychosocial wellbeing in parents of children following burn injury is limited as advances in the medical/physical treatment of burns continue to outweigh those addressing the psychosocial rehabilitation of the patient and family. In terms of research into online social support interventions, several omissions have been identified in meta-analyses and critical reviews. These include the neglect of user participation in the development of interventions (McDaniel, Casper,

Hutchison, & Stratton, 2004), since most interventions tend to be designed solely by health care practitioners (Paterson & Hopwood, 2010) and health care researchers often do not involve the target audience in the development and/or design process. As a result of limited user participation, many interventions do not effectively reflect the needs of these specific populations (Nikolova-Houston, 2005). Therefore, the inclusion of future users of an online resource in the development process is a vital step in order to ensure that it is attractive to the target population and better able to address their expectations (Slomian, Vigneron, Emonts, Reginster, & Bruyère, 2018).

In addition to the content needing to be driven by the needs of the target population (Slomian et al., 2018), when creating a new resource for patients, Groen et al. (2015) highlighted the importance of involving the potential users in order to ensure that the resource is attractive and easy to use. In the field of Information Technology, it is widely recognized that members of the user population need to be involved in these design and development activities (Armstrong, Hearnshaw, Powell, & Dale, 2007). However, it is still necessary to involve burn care professionals in this process as it has been found that parents who are searching for information about diseases are more likely to trust websites that are recommended by their child's physician (Taylor, Alman, & Manchester, 2001). For this reason, the involvement of parents (the target audience), professionals in burn care, and those working in the burns charity sector, was vital in ensuring that the content was accessible and trustworthy and something that professionals would be happy to promote.

A participatory action approach (Greenwood, Whyte, & Harkavy, 1993), emphasising co-learning, participation, and transformation, and the involvement of those with lived experience, helped to ensure that the resource developed as part of this PhD was parent-centred, attractive, trustworthy, appropriate, and intuitive for users with varying levels of traditional and computer literacy, and sociodemographic characteristics (Greenwood et al., 1993). This was critical as acceptability of an intervention is necessary to ensure its implementation, effectiveness, and users' motivation to maintain use of it (Nastasi et al., 2000). There would be little point releasing a website to the general public if it was not deemed appropriate by the target audience, or if it was unlikely to be promoted by professionals working within burn care. Likewise, if the proposed method of continued evaluation of the website was thought to be unfeasible then results about clinical utility would not be valid, thereby making it difficult for any stakeholders (such as parents and burn care professionals, policy makers, and commissioners) to decide whether or not to support the long-term maintenance of the intervention.

Although studies have highlighted the advantages of tailored interactive health information (Barak & Grohol, 2011; Barak, Klein, & Proudfoot, 2009), for pragmatic reasons, the website

developed in this program of work was a simple static information website with text and simple graphics. This was also done by Berk et al. (2013) in a similar project for caregivers of people with bipolar disorder. An informative, rather than interactive, website was felt to be appropriate due to the concerns raised by participating parents in the previous studies regarding mistrust and misinformation, and also because the resources needed to moderate an interactive support group or forum were not available. As previous research has identified that few parents contribute to interactive websites, with many reading the content but not posting frequently, and some joining but not returning (Guzdial & Turns, 2000; Lampe & Roth, 2012; Lampe et al., 2010), the initial development of a non-interactive website was not felt to be problematic. This was also supported by the “1% rule,” also known as the 90-9-1 principle, which asserts that 1% of people will create content, 9% will contribute, and 90% will lurk (although this data omits people who join and rarely or never return). This pattern is also seen on popular sites like Twitter and Facebook, where up to 60% of users are estimated to join and then not return (Cashmore, 2009).

The website was built by a professional website designer from YellowRoad Designs using a WordPress theme that would accommodate an interactive forum at a later date, should that be indicated in the feedback that followed. The existence of a static informative peer-informed website would also enable ‘traffic’ to be monitored, to gauge interest and use, before any commitment needed to be made to a more expensive and demanding resource/intervention. In order to maximize user engagement with the website, the literature about what consumers and caregivers themselves appreciate about the content, design and the way information is conveyed on health-related websites was examined (Morrison, Yardley, Powell, & Michie, 2012; Sillence, Briggs, Harris, & Fishwick, 2006; Wang, Walther, Pingree, & Hawkins, 2008). This suggests that a consumer’s positive perception of the credibility or trustworthiness of the website, which may encourage engagement and systematic processing of information, is influenced by a professional but friendly tone and, although subjective, a pleasant appearance (Kerr, Murray, Stevenson, Gore, & Nazareth, 2006; Wang et al., 2008). Other attributes determined by researchers to be important to parents are: 1) being able to navigate the site easily, 2) having easily understood language, and 3) having operational links to other sites (Paterson et al., 2013).

It is important that online interventions are accessible to parents. Padalko et al. (2019) found that children in lower income families who were living rurally had an increased incidence of burn injury. The creation of freely available resources, accessible by phone or computer, increases the possibility that support is readily available to families who might have previously struggled to access it due to the cost of, or difficulty, travelling. Han and Belcher (2016) and Cook, Rule, and Mariger (2003) also found that parents valued the 24-hour access to online interventions, as they needed to be able to access them when they had the time and the need for them. Supporting this,

Jones and Lewis (2001) found that most parents were active on their forum at times of the day when alternative interventions (for example, face-to-face social support groups or meetings with practitioners) were not available. In terms of technological barriers to engagement, Cook et al. (2003) found that parents disliked experiencing technological difficulties, such as not being able to access videos in the site. If such difficulties were experienced, they could cause some parents to leave the site permanently. However, participants did vary considerably in their preference as to whether textual or video information was provided, with approximately half preferring one over the other. Considering these factors, it was important that the website produced was accessible, simple, and presented information in different formats.

As mentioned previously, it has been advised that self-help interventions should be based on cognitive behavioural therapy (CBT) principles rather than being purely educational (Gellatly et al., 2007). To confirm that CBT was the most appropriate psychological approach in which to ground the information on this website, NICE guidelines were consulted on treatment for depression, post-traumatic stress disorder, anxiety disorders, and computerised CBT for depression and anxiety (National Institute for Health and Care Excellence, 2005, 2009, 2011a, 2013; National Institute for Health and Clinical Excellence, 2005). As well as being the theoretical model underpinning support offered in recent mobile technology-based support for burns patients (Abrams, Lloyd, Elzey, & Hickerson, 2019) and parents of burn-injured children (Sveen et al., 2017), CBT was also the most frequently reported theoretical orientation used by UK burns psychologists (Lawrence et al., 2016). Therefore, it was logical to provide parents with information that could compliment that which may be provided during professionally-led interventions. However, it was also important to be mindful of the fact that popularity and acceptability of the CBT approach should not be confused with evidence of effectiveness within this clinical area (Jenkinson, 2012).

Areas in which parents might need support have been identified in the literature, such as: stress management, family communication, managing the reactions of others, supporting children through medical procedures, and developing coping skills. The content for a prototype website was created based on the experiences of parents already described in Studies 1 and 2, the relevant literature, and the clinical knowledge possessed by the research team. The information was supported throughout with quotes from the parents in studies 1 and 2 who had previously consented to the use of their anonymised quotes. In addition to the use of quotes, there was a 'Parent Stories' section.

Rozmovits and Ziebland (2004) found that users of a website presenting qualitative interview studies about people's experiences of health and illness reported that having access to the experiences of others would have greatly reduced their feelings of fear and isolation. They

explained that hearing others describe what they had gone through would have been informative and reassuring. Rozmovits and Ziebland (2004) also found that even if potentially distressing information did not seem to pose a problem as participants said they would simply click off anything they did not want to see. For this reason, parents who participated in Study 1 via spoken interviews (face-to-face, Skype, and telephone) were contacted and asked whether they would be willing to share an anonymised and edited transcript of their interview. Several parents consented to this and approved the 'story' prior to its inclusion.

With the content being driven by parents' experiences and illustrated using their quotes, it was hoped that the website would have the feel that peers and professionals had created and contributed to the resource equally. The website also offered people who accessed the website the option to offer their own contributions if they wished to, via the feedback section or contact form. The prototype website template is presented in Appendix C.i.

## **7.2 Aims**

This study aimed to determine the acceptability of the website for parents of burn-injured children using a participatory action approach during individual or group sessions with parents and professionals from academic and charity sectors.

## **7.3 Methods**

### ***7.3.1 Ethical Approval***

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (REC Ref. HAS.18.03.139; Appendix C.ii). Although participants were providing feedback on a newly developed resource, the risks to participants, and the researcher, were that they may hear about other parents' (potentially distressing) experiences. Therefore, participants were offered the chance to debrief with the researcher following their involvement in an interview/group that informed the development of the website.

### ***7.3.2 Public involvement***

Involving the 'users' of the product is important to ensure that the resource developed addresses the aspects of the injury event or care that parents consider significant to them. Therefore, participants were recruited from around the UK to provide feedback on the prototype website. All participants were involved in burn care in some way. They were either a parent of a child who had experienced a burn injury, a professional working within burn care, or a member of a charitable organisation providing support to people affected by burn injuries. Nine participants opted to receive a summary of the results which also invited any further comments that they may have about the study or the interpretation of the findings. Considering public involvement in terms of

resource co-production, there are important considerations to remain mindful of, in particular the way in which the psychosocial circumstances of the patients, or in this case parents, may compromise their ability to engage in true partnership (Batalden et al., 2015).

### **7.3.3 Recruitment**

A presentation of the results of the quantitative study, and the plans to test a prototype website, was made at the BBA Annual Meeting in Swansea (April 2018). The presentation invited interested burn care professionals to become involved in the testing the prototype website. Written information was disseminated to the general population between July and August 2018 via advertisements on social media (Facebook, Instagram and Twitter) and sent directly to those participants who had previously participated in Studies 1 or 2 and had consented to being contacted about further studies in this program of work. An email advertising the study was sent to members of the BBA Psychosocial SIG (Appendix C.iii) and the study was also listed on Mumsnet. In addition to this, a blog post was written for the Children's Burns Trust that advertised the study to parents and professionals (Appendix E.iii). Wide and varied dissemination of information about the research facilitated the recruitment of parents not already in contact with burns charities/support services.

### **7.3.4 Participants**

Participants were recruited from a diverse range of locations around the UK using the methods described above. For inclusion in the study, parents had to be able to communicate in English, be at least 18 years of age, with a child who experienced but survived a burn injury before the age of 18 years, which required hospital treatment as either an inpatient or an outpatient in a specialist burns service. Exclusion criteria were non-accidental injury, and if the child had since died because of their injury or subsequent complications. Participants were not asked to provide evidence that they met the inclusion/exclusion criteria; it was left to them to judge their eligibility to participate in the research. Participating professionals and members of charitable organisations also had to be aged at least 18 years of age and involved in some way in providing care to families affected by paediatric burn injuries.

### **7.3.5 Design**

Data was collected from parents and professionals, by observation, qualitative real-time feedback, and using surveys in order to cross-validate different sources of data and capture different dimensions for triangulation. A survey including the e-Health Impact Questionnaire (Kelly et al., 2013), the NHS Friends and Family Test (FFT), and demographic questions was used in this study (Appendix C.vi). Observations along with the Think Aloud method (Cotton & Gresty, 2006; Ericsson & Simon, 1993) were also used. These will all be described below.

### **7.3.5.1 e-Health Impact Questionnaire**

The e-Health Impact Questionnaire (EHIQ) (Kelly et al., 2013; Kelly, Ziebland, & Jenkinson, 2015) is a two-part, self-report measure, which assesses the impact of using health-related websites. The eHIQ-Part 1 consists of two scales (11 items in total) asking about a person's general attitudes towards health-related websites using a five-point response category for all items ranging from 'strongly disagree to strongly agree'. The two scales relate to: 1) Attitudes towards online health information - general attitudes towards using the internet to access health information, and 2) Attitudes towards sharing health experiences online - a person's ease with using online information, particularly emphasising a person's openness to learning and gaining support from other people's experiences.

The eHIQ-Part 2 consists of three scales (26 items in total) asking for the participant's views on the health-related website under examination. The three scales relate to: 1) Confidence and identification – confidence to discuss health with others and a person's ability to identify with the website, 2) Information and presentation - trust and suitability of the website content, and 3) Understanding and motivation – understanding and learning about relevant information and motivation to take action. Responses on each scale in Part 1 and 2 are converted to a 0 – 100 metric, where 0 represents low perceived value of the website for health, and 100 represents high perceived benefit of using the website in relation to health.

Kelly et al. (2015) confirmed good psychometric properties in both the eHIQ-Part 1 and the eHIQ-Part 2, finding that the scales within each part had high construct validity, internal consistency and test-retest reliability. Convergent validity, measured using Pearson's correlation coefficients, confirmed expectations that the scales are significantly related to selected reference measures but also sufficiently divergent. Internal consistency was tested for each unidimensional sub-scale using the Cronbach's alpha statistic ( $>0.7$ ) and for the five scales this ranged between 0.77 and 0.92. The test-retest procedure was used to establish reliability over time. The level of agreement between scores from the two occasions was assessed using the intra-class correlation coefficient (ICC), and this indicated good test-retest reliability for all subscales (ICC = 0.76 to 0.91). The eHIQ has previously been used in studies of eHealth technology, for example, the efficacy, cost-utility and reach of an eHealth self-management application (van der Hout et al., 2017) and to investigate effect of an experience-based internet intervention for smoking cessation (Powell et al., 2016). Within this PhD study, for professionals, this questionnaire was modified in order to reflect on how they imagined parents would receive the website. Although the eHIQ response format has been adapted in other studies, for example in one examining patients expectations and navigation of an illness experiences website (Engler et al., 2016), no studies have been identified where similar adaptations have been made to those made here.

### **7.3.5.2 NHS Friends and Family Test (FFT)**

The FFT is used in the NHS to give service users the opportunity to submit feedback to providers of NHS funded care or treatment. The FFT uses a simple question which asks how likely, on a scale ranging from extremely unlikely to extremely likely, the service user is to recommend the service to their friends and family if they needed similar care or treatment. The same question used by the NHS was used in this study, with the service being evaluated being the prototype website.

### **7.3.5.3 Demographic Questions**

Demographic information was collected from all participants regarding their age, sex, and ethnicity. In addition to this, professionals were asked for their professional background, and parents were asked for child's injury characteristics.

### **7.3.6 Procedure**

Information about the study was disseminated to potential participants (Appendix C.iii) as described in the above description of recruitment procedures. When interest in the study was expressed then the detailed study information was provided (Appendix C.iv) and testing sessions were arranged. Some willing participants then invited others (colleagues or partners) to the session and therefore created a group session which allowed data to be collected from more participants. At the beginning of the sessions, personal introductions were made and the purpose of the session was reiterated, to assess the acceptability of the website for parents of burn-injured children. After providing informed consent (Appendix C.v), data were collected via face-to-face group sessions or individual meetings with participants. Data from parents and professionals was gathered separately. For parents, these sessions occurred at a location of their choice, and this was at home, at work or at UWE Bristol. For professionals, the sessions were at their place of work. Following consent, participants were instructed to complete part 1 of the eHIQ. They were then presented with the home page of the website on either a personal or laptop computer, or using a projector in the group sessions with professionals. When more than one person was viewing the website, one person was nominated to be in control of navigation.

Participants were asked to try to use the prototype website as they would outside of the research setting and to 'think out loud' as they reviewed it, identifying aspects that could be modified to improve its usability or relevance to parents. The concurrent think-aloud (CTA) method (Ericsson & Simon, 1993) was chosen as it was felt that access to participants' reasoning about their interactive decisions, alongside observation of the different pages they viewed of the prototype website, would provide valuable insights into the learning, support, or help seeking process in which they engaged. It was also felt that development of the resource would be assisted by information regarding the viewing experience of individuals, particularly any difficulties they encountered whilst using the website. The CTA approach is often used to investigate problem



solving within cognitive psychology research and more recently, the approach has been used to study human–computer interactions and to evaluate new software, often under the guise of ‘usability testing’ (Crowther, Keller, & Waddoups, 2004) and for optimising behavioural health interventions (Bradbury et al., 2018; Morrison, Muller, Yardley, & Bradbury, 2018).

Researchers are advised to give very general instructions, simply to ‘think aloud’, and verbalise ‘everything that passes through your head’. Ericsson and Simon (1984) cautioned that changing these verbalisation instructions may change the structure of the thought process itself. However, Cotton and Gresty (2006) found that participants needed more guidance regarding what kinds of thoughts to articulate in response to this very general instruction, and also that when a large part of the resource being reviewed is in text form, it is not realistic to expect participants to read and simultaneously vocalise their thoughts about a piece of text.

Therefore, considering the caution by Ericsson and Simon (1984) and also the reflections by Cotton and Gresty (2006), more flexible instructions were generated for participants including the general request that they ‘try to think-aloud—talk as much as you can about what is going through your head as you use the resource’ in addition to a range of standardised prompts presented in Text Box 1 below. The prompts were used during pauses in participants’ articulations, rather than interrupting them, such as when participants were making navigational decisions/viewing menus, or when they had finished a section of the resource. The prompts aimed to initiate verbalisations during periods of silence, to avoid incoherent or irrelevant verbalisations, and to gain specific feedback about individual sections of the website.

What part of the website/page are you drawn to first? (Why?)  
What do you think of the way the website looks? (Could it be improved?)  
Is the website easy to use?  
What do you think of the website’s layout and navigating around it? (Could this be improved?)  
Does the information presented make sense?  
How easy is the information to understand? (Did you have any difficulties?)  
How does the information presented reflect parents’ experiences? (Could it be improved?)  
What do you think about the information and techniques presented to help users?  
Would you like to add or change anything?  
Have you learnt anything from it? (What?)

Text Box 1: CTA prompts

Professionals were also asked to comment on the appropriateness of the psycho-educational content and evidence-based information/advice provided. Finally, all participants were asked to propose a name for the website, or to suggest appropriate search terms that they would expect to use to find such a website. All verbalised data was audio-recorded for verbatim transcription.

When participants finished viewing the website, they were asked to complete the eHIQ-Part 2, the NHS FFT question, and demographic questions. For professionals, all questions related to the website were modified to ask how they perceived parents/carers would be impacted by it.

### **7.3.7 Analysis**

Quantitative data was entered into SPSS Statistics Version 22. eHIQ-Part 1 and Part 2, and the FFT question, were analysed for parents and professionals separately. Non-parametric tests were used due to the small sample size.

Qualitative data was analysed using a mix of inductive and deductive content analysis based on established guidelines (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Initially, a categorisation coding matrix was developed that reflected the information sought regarding the content and design of the website but also allowed participants to raise new issues and permit the inclusion of new categories. The transcripts were read and words or statements related to a central meaning were encoded into either pre-existing or new categories. Analysis was conducted at a manifest level, describing the visible and obvious components of the text rather than interpreting the underlying meaning (Graneheim & Lundman, 2004). The data was then displayed in a person-based changes table (Bradbury et al., 2018) to see where modifications could be made to the prototype website (Appendix C.vii). The benefits of this processes being that use of the table is a systematic process of recording which increases the transparency of the decisions made, the table acts as a prompt to think about why a change should, or should not be made, and it is an efficient process as the coding framework allows priorities for discussion to be filtered (Bradbury et al., 2018).

## **7.4 Results**

Convenience sampling resulted in a total of 31 participants from nine UK locations, providing feedback on the prototype website. The participant groupings and interviews are described in Table 12. Nine participants were parents of children with a burn injury, two worked for UK charities that provide support to families following burn injuries, two were researchers in the field of burn injury and psychosocial care, and 18 were healthcare professionals working in English paediatric burn services.

Seven of the health professionals were qualified clinical psychologists - these participants were able to draw upon their expertise in delivering psychosocial interventions to families following burn injury. Also included were two assistant psychologists, three physiotherapists, one occupational therapist and one play therapist. Their input was valued in ensuring that the information was easy to understand and accurate. The remaining four professionals had nursing, administration and managerial roles within burn services that meant they interacted with families

within the hospital environment. This skill mix was included to determine the acceptability of the resource from a professional perspective and to recommend any necessary changes or additions to the information provided.

The majority of the participants in both groups were female (21 female professionals, 7 mothers). Most participants (86%) were aged between 25 and 54 years old with the highest proportion (31%) being aged between 35 and 44. The sample was predominately White British with only two professionals identifying as Asian/British Asian.

Overall, participants viewed the website for a mean of 65.5 minutes (range = 24 - 108), with parents viewing the website for longer than professionals (mean viewing times were 90.6 minutes and 55.3 minutes, respectively). Some participants viewed every page and others appeared to view those with personal relevance, reflecting on the appropriateness and value of the information for themselves in the past.

#### **7.4.1 Demographic information**

Participant information is presented in Table 11. Nine parents participated and four of these were couples, each parenting one child. Therefore, the nine parents who took part related to seven children with a burn injury. A mean time of seven years, four months (SD = 6.55 years, range 2.9 – 20.0 years) had passed since the child’s injury. The mean age of the child at the time of injury was one year, 6 months (SD = 0.93 years, range = 0.0 – 3.0 years). The mean TBSA was 16.5% (range = 3 - 50) (TBSA data missing for one child).

<b>Participant Information</b>		<b>n</b>
Relationship to Child	Mother	7
	Father	2
Child’s Sex	Male	4
	Female	3
Cause of Injury	Scald	5
	Hot Surface	1
	Flame	1
Child’s Initial Treatment	Inpatient	6
	Outpatient	1
Was surgery required?	Yes	5
	No	2
Professional Roles	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 11: Information regarding the participants in Study 3

Participant(s)	Group size	Length of session (minutes)	Location
Researchers	2	76	Bristol
Healthcare Professionals	6	67	London
Healthcare Professionals	6	24	Bristol
Charity Employee	1	54	London
Healthcare Professionals	6	64	Manchester
Mother	1	63	Gloucestershire
Mother	1	96	Cambridgeshire
Mother	1	61	Surrey
Mother and Father	2	99	Wiltshire
Mother	1	108	Berkshire
Mother and Father	2	105	Gloucestershire
Mother	1	79	Bath
Charity Employee	1	81	London

Table 12: Participant groupings and information regarding the interviews in Study 3

#### 7.4.2 Quantitative results

Mann-Whitney U tests indicated that, prior to viewing the prototype website, professionals and parents had similar opinions in relation to online health information and sharing health experiences online, as measured by the eHIQ-Part 1 (Table 13).

After viewing the prototype website, the results of the eHIQ-Part 2 demonstrated that for each domain, parents generally rated the website more highly than professionals did (Table 9). However, in relation to the information and presentation of the website, parents rated it significantly more positively. As measured by the FFT, all participants reported that they would be either likely or very likely to recommend the website to others (Table 14).

		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

Median scores (and the interquartile range) are provided. Potential scores on each subscale ranged from 0-100; higher scores indicate responses that are more positive.

Table 13. Professional and parent scores on the eHIQ subscales in Study 3

	Likely to recommend	Extremely likely to recommend
Professionals	9 (40.9 %)	13 (59.1 %)
Parents	1 (11.1 %)	8 (88.9 %)
Total	10 (32.3 %)	21 (67.7 %)

Table 14. Professional and parent FFT responses in Study 3

### **7.4.3 Qualitative results**

The qualitative data produced by participants 'thinking aloud' was analysed at a manifest level (Graneheim & Lundman, 2004). Much of the qualitative data collected related to the presentation of information on specific pages (for example, "there is a lot of text") and how modifications might be made to improve the presentation and usability of the information (for example, "you could add some headings"). However, other thoughts were also spoken throughout the testing and, overall, this data formed seven topic areas; 1) need, 2) structure and navigation, 3) trust and relevance, 4) language and comprehension, 5) therapeutic content, 6) mode of delivery, and 7) suggested improvements, and also informed the website's name. These areas are presented and discussed below. Anonymised quotes are used for illustrative purposes.

#### **7.4.3.1 Need**

It was recognised by professionals and parents alike that the concerns of parents are not always recognised or addressed and that resources can be lacking. Participants unanimously commented on the value of a parent-specific online resource in burn care. The rationale for the website was supported by responses considering the lack of support and the value of online/easily accessible support that would be available whenever parents needed it. Comments pertaining to the need for such a resource made up 5% of the responses.

"There's the nurses, they come out to help you with the burn, but there's no one there to help you with the mental afterwards. Like, how do I get her in the bath? And how do I get her to go back to sleep at night? And they say, 'you've just got to find a way around it.'" [Mother-Kirsty]

"It's such a gap with burns care I think, parent support and resources. Parents just seem to be left to work it out themselves." [Clinical Psychologist]

The online resource could also be accessed privately when parents did not feel like they could ask for help.

"Once I'd had the lady pop in and check on me the first couple of times in the burns unit, there was no real psychological support, and it would have felt very weird me asking them to help me. Because they're to help fix his leg. They're not there to deal with my crap." [Mother-Miki]

It also meant that parents would be able to return to the resource as many times as they needed, for as long as they needed to.

"To have it all in one place, because the trouble with burns is it goes on for years and years and unfortunately it will come up in different ways and manifest itself in different ways. So just having one source of information for that entire period of time... you can think, oh, I've seen that, let's go

and have a look, and just keep referring back to it. It's all here. It's a one stop shop from day 1 to week 1 to year 5. I feel like everything is there." [Mother-Christine]

#### **7.4.3.2 Website structure and navigation**

Comments related to the structure and ease/difficulty of navigation made up 14% of the responses. As the content was largely based on the results of Studies 1 and 2, some parents found that the structure of the website fitted with the chronicity of their experience.

"It's really sectioned out well and it's kind of done in a timeline as well isn't it 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." [Mother-Christine]

However, finer details, such as the order that certain emotions were felt after the injury were criticised, with a new order suggested according to their personal experience.

"I would have put the numbness first, then guilt, then anger then depression." [Mother-Christine]

Others felt that the structure might be better laid out according to the subject of the information and their perceived priority to parents.

"Impact on your child should come first. Then impact on family and impact on yourself for the three sort of areas." [Mother-Sara]

Participants also highlighted the fact that some information was unexpected given the headings used in the respective sections. Therefore, the placement of information about the stress response, post-traumatic stress disorder, and supporting siblings needed to be addressed. The changes suggested are discussed under the therapeutic content section below.

"Maybe move siblings under child." [Mother-Kirsty]

"I would always put in the stress management underneath the impact on parents, as that is a separate bit under there. And under there you've got the impact, and it becomes then the impact of trauma. And then you explain around PTSD, explain what the symptoms are and explain where they might like to go to get help." [Mother-Sara]

Nevertheless, it was felt that the website was "not difficult to navigate" [Mother-Kara].

#### **7.4.3.3 Trust and relevance**

Comments about how relatable, relevant and reliable the information on the website was made up 16% of the total comments. The inclusion of an "about us" (about the research team) section on the home page of the website was proposed in order to enhance the perceived trustworthiness of it.

“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.” [Mother - Miki]

Trust was also felt to be enhanced by the use of quotes from parents throughout each section.

“[The quotes] kind of back up all the things that you’ve got on the website. It’s, you’re reading through it and thinking, you can see where that links to places.” [Mother - Kara]

Participants also appreciated the unedited, conversational nature of the quotes.

“I like the illustration, the live illustration by a parent talking about their kid” [Clinical Psychologist].

“I like that it’s not necessarily grammatically perfect in the quotes. You’ve got likes and you know, and it makes it a bit more personal.” [Assistant Psychologist].

Although the design of the website was felt to be inclusive, there was concern about whether the lack of diversity explicitly mentioned would reflect the lack of diversity in the research that preceded its creation.

“The advantage of having the child in silhouette is it doesn’t necessarily ‘genderise’, age, or give the child a specific ethnicity. You could read into it how you wanted. And similarly with the parents. The difficulty with using a real image, of an actually identifiable child, is you then pin this is who this is for and you would definitely want to avoid that in my opinion with the burns population. It’s quite inclusive in terms of burns as well. It’s not showing a child with a specific burn injury or scar or like no scar.” [Clinical Psychologist]

“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, except for implicitly, because there’s not something to reference that actually there might be something different for different communities.” [Assistant Psychologist]

#### **7.4.3.4 Language and Comprehension**

The language used and people’s ability to comprehend the website made up 15% of the comments. The website had a Flesch–Kincaid grade-level of 8.5 and a Flesch Reading Ease score of 65.4 (Kincaid, Fishburne, Rogers, & Chissom, 1975). These scores indicate that ‘plain English’ was used and the website would be easily understood by 13- to 15-year-old students in the eighth and ninth grade levels. A review conducted in the UK assessing the readability of 34 postnatal mental

health websites found that the readability of all of the websites was eighth-grade or higher (Moore & Ayers, 2011). Although this suggests that the readability of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is in line with other websites designed to support parents' mental health, Freda (2004) recommended that health education materials developed for the general public should not exceed eighth grade levels. Freda (2004) highlighted that it has been shown that materials written at readability levels of sixth to eighth grade are more effective in conveying health messages and have higher rates of recall across all educational levels.

However, age does not always reflect ability to read and understand the information presented. During the testing one parent participant disclosed that they were dyslexic but, despite this, they read the content with interest and requested additions to be made.

Participants also commented that they "like the infographic" [Clinical Psychologist] and suggested that, "it would be nice to have illustrations, or pictures of something" [Assistant Psychologist].

Another participant offered ideas for neutral images, "just pictures of children playing. A family sitting round a table. Someone reading their child a story at bedtime." [Mother-Hannah]

No participants reported any difficulties understanding the text, with feedback including, "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" [Father-Frank].

"It's really nicely written. The tone is just perfect." [Mother-Christine]

The eHIQ-Part 2 also suggested that the majority of parents and professionals found the text easy to understand.

#### **7.4.3.5 Therapeutic content**

The topic most discussed in the transcripts was the therapeutic content, with 25% of comments relating to this topic. Parents felt that the quotes used throughout were as important as the psychoeducational text.

"It is where the more emotional support comes from. You've got the practical support and then the emotional support. I guess if you're looking specifically for information about something practical, you'll read the practical stuff, but if you're just skimming then all you really want is the reassurance anyway." [Mother-Miki]

Parents commented on the breadth of information presented, "You've covered a hell of a lot on this website." [Father-Chris].



However, parents also requested more quotes be added throughout, “I’d have to say more quotes because I think more quotes are really valuable.” [Mother-Hannah]

Whilst some professionals were critical of longer quotes, “I do think it’s quite a long quote. It looks a bit overwhelming. As I looked at it, I slightly glazed over” [Clinical Psychologist]; most participants felt that they were important, “I’d want those quotes as a parent. I don’t think anyone’s going to look at that and think ‘ohh that’s a big quote’. I’d be sort of reading it and thinking oh that’s helpful you know or that’s make me feel better” [Father-Frank]. “The quotes are what attract people to the pages. Definitely. It’s parent led.” [Clinical Psychologist]

The core therapeutic elements, that is the peer-informed information to normalise and validate concerns, and the psychoeducation about the biopsychosocial aspects of distress and strategies to manage these, were thought to be acceptable to parents.

“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. You know, 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-Kara]

Professionals also recognised the importance of the website directing parents back to their burns care team if they had any specific questions or concerns about their child’s treatment. This was particularly important as the purpose of the website is to provide psychosocial support information, not to address medical concerns.

“You’ve got a good balance though 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.” [Researcher]

However, substantial changes were discussed as professionals highlighted the fact that some information was unexpected and inappropriate under a particular heading. Therefore, the placement of information about the stress response and post-traumatic stress disorder needed to be addressed. One parent with experience in mental health work agreed with this.

“The thing that I’m finding a little bit tricky is that its entitled stress management but then you talk about PTSD. And for me, they’re two very different things. I think it’s pathologizing 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 more like it would be the impact on them, and then the stress management is the things like the mindfulness and relaxation.” [Clinical Psychologist]

In terms of the use of the CBT model to explain the stress response, one parent queried whether this was necessary.

“Do you think people know this anyway? Or not really? They don’t understand that they feel this way because they’re in stress?” [Mother-Hannah]

They were informed that not everyone was aware of this and responded, “Gosh, that’s a bit scary. It’s probably important to keep it in then. Maybe it’s just because I’ve done a bit of training on it.” [Mother-Hannah]

However, other participants thought that the explanation and animation used to explain the stress response were appropriate.

“A nice little video. That’s really interesting. I think people would be really interested to hear about that. It’s surprising as psychologists we expect everyone to know what the fight or flight response is but actually most people don’t know what it is, so this is quite reassuring. I think that’s perfect for explaining something quite complicated like the fight or flight response for someone who doesn’t know it.” [Researcher 1]

It was queried whether the examples could be made more interactive but the operation of interactive media on phone, tablet and PCs would need to be considered.

“Could you make these interactive? “Click feelings and then you get the info. Click on your thoughts feelings and physical symptoms to see how they all interact? “Because that’s kind of the whole point of your showing them this, is you’re just trying to teach them, look your thoughts affect your feelings, your feelings affect your symptoms, affect your behaviours and if we can get that interactive element then it make it a bit more instantaneous for them to get that point.” [Researcher 2]

Nearly all participants requested that more examples be added to the sections on dealing with the reactions of others and answering other people’s questions. It was felt that having examples that they could practice alone or with their child, and recited, would be beneficial as opposed to families having to think of their own responses to difficult social situations and negative reactions.

“People often do find it difficult to come up with examples of things they could do. If you give them enough examples, it might make it easier for people to use this idea.” [Mother-Miki]

Following on from this, professionals and parents praised the prompt question sheet for parents to use when preparing for a procedure as this could strengthen their ability to ask questions from healthcare professionals.

"I think that having those questions is really helpful actually, and I'd add the option of a link where you could print them out a little card and take them with you to the dressing change and then it could say find somebody to discuss these questions with." [Charity]

"If the parent knows to prompt them and ask these questions, then that would have been just... really useful." [Father-Frank]

Some participants highlighted the value of sharing parents' 'top tips' via the website, and most participants recognised the potential benefit of parents sharing their own experiential knowledge with others.

"Top tips would be fantastic" [Mother-Sara].

As the website was developed following the acknowledgment of the value of peer support, enabling parents to share their top tips with other parents was important, although ensuring the safety of users by not allowing the sharing of misinformation was also necessary. Although it was explained that the website would not enable users to interact with one another, the idea that parents could contribute to the website via the 'contact form' was proposed. A site with regular new content is also beneficial in terms of search engine optimisation (discussion of how this might work in practice is provided in Chapter 9).

During testing, many participants mentioned how isolating a child's burn injury could be, and how the quotes on the website engendered feelings of camaraderie, validated concerns, and facilitated a feeling of social support.

"Part of me wishes that there was almost a way of just, I don't know, you kind of want to pass on information to the people who've, I know it doesn't work and there really isn't a way to do it but you kind of want to be able to say, not 'like' it, but, you know on Facebook when someone agrees or whatever, they show that they get you? You want to be able to say, 'ahhh crap, I know exactly where you're coming from. I get you.' To the person who's shared that quote, you want to be able to just say, 'you are so not alone with that'." [Mother-Miki]

None of the participants made any negative comments about the therapeutic content and some commented how the suggested strategies to manage distress had been useful to them personally.

"I totally agree with that. I use breathing exercises and it really does help. Even things like doing the mindfulness colouring things is very relaxing." [Mother-Kara]

"Ooooooh, these look good. I've started getting books together to deal with emotions. We've found a really nice one. He seemed to really latch onto it as a, oh hang on, she's in a situation that I recognise and I've wanted to do that." [Mother-Miki]

The professionals also endorsed the content, commenting that “this contains just about all the answers to all the questions” [Charity], “it’s really driven by the parents which is really nice” [Researcher], “the normalisation comes across... it’s so in depth. There’s so many aspects to it.” [Clinical Psychologist] and, more generally, “it’s really good, it’s brilliant.” [Physiotherapist]. They also felt that the website would be a valuable addition to the care they provide because “It’s such a gap with burns care I think, parent support and resources [Clinical Psychologist].

#### **7.4.3.6 Mode of intervention delivery**

The mode of delivery was discussed least, with only 8% of the total comments.

“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.” [Charity]

All participants agreed that the website should be viewed as an addition to current care provision, not a replacement for therapist-led interventions. Participants also articulated the benefits of an online intervention in targeting barriers that might prevent parents’ access to support.

“We get a lot of people avoiding for a long time. So the stories are all useful, especially someone saying we actually got support from this service. 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]

It was also felt by parents that having information online was more beneficial to parents who were separated by the incident (for example, one in hospital and one at home), allowing them to view the same information simultaneously.

“When I arrived at the hospital, I got handed like a wodge of leaflets, which I was ‘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.” [Mother-Christine]

#### **7.4.3.7 Recommendations for improvements**

In addition to the relocation of some information, most suggested improvements related to the addition of headings and a reduction of the amount of text on the pages. The addition of a search function could also help parents tailor the information that they viewed to their own needs. Comments relating to changes that could improve the website made up 17% of the total comments.

“I think a lot of the pages are quite text heavy. And it’s not necessarily to remove any of the text but if you could, so maybe for example the explain reassure distract you could put into some like, make it a bit more colourful, or like a feature or graphic to break up the text, like three little speech bubbles or something.” [Clinical Psychologist]

“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-Miki]

“A search bar would be a really good idea.” [Mother-Sara]

One group of professionals discussed the use of more ethnically diverse quotes. The addition of images was also suggested as a way to break up text.

“If you wanted to, you could probably put more imagery in but it’s always something that’s hard to get right because it’s so personal and so emotional. I don’t think it needs more images because it doesn’t need images. Because 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-Miki]

“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-Hannah]

“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]

A father also commented on the need to represent the voice of other fathers.

“I think there should be a bit more of the bloke’s perspective.” [Father-Chris]

#### **7.4.3.8 Name suggestions**

Each participant was invited to suggest a name for the website. Parents tended to favour names that involved the words ‘child’ or ‘children’, whereas professionals offered names that included the words ‘parents’ or ‘family’.

“I think probably support for burn-injured children, something like that. Because that’s whoever you are when you’re with that child.” [Mother-Hannah]

“I said child burn support in the search terms because I wouldn’t be looking for support for myself.” [Mother-Miki]

“Parent burns support.” [Psychologist]

“Family burn support – does what it says.” [Psychologist]

“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]

## 7.5 Discussion

In response to the findings from Studies 1 and 2 (described in Chapters 4 and 5), a prototype website was designed to provide trustworthy burn-specific information to parents, as well as relevant quotes from parents who had shared a similar experience. Although content did not enable interpersonal interactions (interaction with the website is intrapersonal, i.e. with the user considering the content within the context of their own thoughts, feelings, and behaviours), it was hoped that such content would decrease users’ sense of isolation, whilst providing psychoeducation and direction to other sources of current and relevant psychosocial support. Providing patient-centered information online would mean that it was accessible if and when parents needed it, without any need for them to travel or to talk about what had happened, which would be particularly helpful to those not accessing support due to such barriers.

During this process, the aim was to ensure that 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 (Kelly et al., 2015). It was hoped that the resulting website could provide 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.

The partnership-based method of website development utilised in this study promoted the formation of non-hierarchical collaborative relationships that acknowledged the expertise of relevant stakeholders (parents, health professionals and the research team) (Power et al., 2005). This research team was able to work towards the creation of an evidence-based intervention to be evaluated, 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 (Cotton & Gresty, 2006). For example, it was evident when participants struggled to locate sections, were confused about

where to click for information, had to scroll excessively to read all of the information, or did not see hyperlinks within the text. Vocalisation the researcher's observations as participants worked through the site also prompted discussions about its navigability and the impact of certain elements, such as the positioning of parent stories and the choice of quotes.

Previously, it has been found that parents whose children require paediatric care might question the trustworthiness of online information or become overwhelmed by the quantity of information on the site (Bernhardt & Felter, 2004; Zaidman-Zait & Jamieson, 2007). Feedback following the testing of the website was that it could have a positive impact on parents' emotional wellbeing and transform the delivery of parent-focused psychosocial information following a child's burn injury. Participants felt that the website would have been a valuable resource for them in place of information booklets that were given out by burn services. Access to the website would have enabled all parents/family members to access the same information at the same time, even when the family was separated.

It has previously been suggested that most people can benefit from 'low-level' interventions/general population campaigns (e.g. information booklets), with far fewer requiring intensive and expensive higher-level face-to-face interventions (Rumsey & Harcourt, 2012). Therefore, this website should be regarded as a low-level 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. The feedback received from all stakeholders suggested that the aim to create an online peer-informed and trustworthy burn-specific information and psychoeducation resource was achieved. Although, it is important to acknowledge that, in addition to the positive feedback, the website received constructive criticism. This, alongside observations of where information was overlooked, informed changes made to the website before its public launch. The website was found to be very text heavy and so subheadings were added to help users find personally relevant information, sections were reorganized to avoid pathologizing normal emotional responses, and subsections were created to allow users to drill-down to more specific information as needed. The template of the final version of the website is presented in Appendix C.viii.

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 use of informal language used was also praised but some of the language was further simplified following feedback on the use of certain clinical/scientific terms. This 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 (Williamson &

Martin, 2010), with the scores indicating that 'plain English' was used and 13 to 14-year-old (8th grade) students would easily understand it.

All parents praised the use of quotes throughout the website to emphasise the parent voice on which the resource was based. Zaidman-Zait and Jamieson (2007) suggested that the trustworthiness of websites for parents of children with disabilities may be enhanced if the site includes an "ask the expert" or "frequently asked questions" feature. In the case of this peer-informed website, it could be argued that the 'expert' is in fact the parents themselves. One parent suggested the value of a section in which parents could share their 'top tips' or important messages with other parents. For example, advice on how to disguise the taste of medicine, or words of hope and encouragement. In response to this suggestion, all parents involved in testing the website were invited to contribute a 'top tip' to this new section. All of those submitted were included and published on the public website (the release and evaluation of which are described in Chapter 8).

It is important to note that the suggestion for a 'top tips' section did not appear to be born out of a belief that parents could provide better information or advice than professionals could, as feedback was that the information and quotes complemented each other. Hu, Bell, Kravitz, and Orrange (2012) and Chung (2013) also showed that patients' use of the internet does not reflect their low trust in or dissatisfaction with physicians, rather it signifies their desire to participate in healthcare. Research has suggested that the internet can serve as an additional and complementary resource for health information but does not displace the role of healthcare professionals (Lee, 2008).

Social learning theory (Bandura & Walters, 1977) supports the value of these contributions. The theory posits that peer supporters act as role models for coping and positive adjustment, demonstrating skills and influencing knowledge, attitudes, beliefs and values through modelling and reinforcement. Through the seeking and use of information on the internet, including online peer support, patients can also strengthen their ability to ask questions about the care they received from healthcare professionals (Lee, 2008). In line with this, the printable sheet of question prompts contained on the website received praise.

When making decisions about what changes should and could be made to the prototype website it was important to consider the associated costs and benefits. For example, adding headings could easily break up text, enhancing the navigability of the website, and 'top tips' could enhance the peer-support element of the website. As suggested in this study, ensuring that the website had a search function so that users could find content specific to their individual needs was also identified as important (in keeping with a finding by (Lewis, Gundwardena, & El Saadawi, 2005)).



These changes could also be made at no additional financial cost. However, it was noted that, whilst the website was designed to be viewable by computer, tablet or phone, feedback was that it is more suited to viewing on a computer screen and the addition of illustrated and animated content was suggested. Making amendments or changes such as these would have had a significant prohibitive financial cost.

In terms of images, parents thought that pictures of different types of burn injuries should be added to illustrate the healing process. Although there may not be a financial cost in providing this information, there was the possibility that the addition of this content could have a detrimental short- or long-term psychological impact on at least some of the website users. For example, images showing the reduction of redness or flattening of raised scars attributed to certain treatments could lead to false hope for parents whose child may not be a suitable candidate for such treatment, or lead to disappointment or upset in parents whose child may have received the treatment but not seen the same benefits. Scarring is determined by numerous factors from individual skin type, the mechanism of injury, initial first aid received and subsequent treatments. Therefore, it was felt impossible to provide appropriate images that would be able to provide a representation of all of the possible outcomes in a way that was well managed from a psychological perspective.

It was hypothesized that parents' desire to see images such as these was likely driven by their hope that their child's skin would one day return to 'normal' or that they may discover an effective new treatment that their child could try, as discussed under the theme of 'loss' and subtheme 'action to repair' in Chapter 4. The addition of such images would not be able to address these psychological or medical needs. Therefore, as the resource developer, it was important to hold in mind where discrepancies might exist in what parents said they wanted and what could be provided.

All participants in this study were asked to propose a name for the website. Whilst there was agreement that the inclusion of key words and potential search terms was important, parents and professionals had differing opinions about what the name should be. Parents favoured the insertion of the word 'child' and professionals favoured 'parents' or 'family'. Therefore, 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 their attention was focused. However, a name that suggested its suitability for anyone surrounding the injured child was also necessary to avoid exclusion of other carers and promote the fact that all those around the child are affected by a burn injury. An inclusive and action-oriented name may also help to emphasise that this resource is not just for 'needy' parents, thereby speaking to the strength and resilience of the

audience (Legg et al., 2017). For this reason, the website was named

[SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk).

Due to the limited availability of information for parents of burn-injured children online (a problem reported during Studies 1 and 2), it was anticipated that the website would attract traffic from both within and outside of the UK. For this reason, the domain name [SupportingChildrenWithBurns.com](http://SupportingChildrenWithBurns.com) was also purchased. Once it was released to the public, this would enable the resource to be promoted outside of the UK using .com, although services doing this would need to be mindful of the fact that the use of the .com domain name directs parents to the .co.uk website, which contains information about professional and charity-based support that is specific to UK residents.

A strength of this research was the participatory action approach (Greenwood et al., 1993). 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.

## **7.6 Limitations**

Participants (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 (93.5% White-British, 6.5% Asian-British) and, again, was not representative of patients and families seen within UK paediatric burn services (Richards et al., 2017). However, lack of participant representativeness can be considered a limitation of any participatory research (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998). It may be that the largely positive feedback received was also indicative of a lack of representation. With some participants from Studies 1 and 2 providing this feedback, and with their sharing of experiences, opinions, and support needs having directly led to a resource that had the potential to help others, this may have contributed to a degree of social desirability (attempts to please the researcher and website creator), as the research design did not permit anonymous feedback.

Lack of anonymity was also an issue for the professionals providing feedback. Feedback on the prototype website was gathered from these participants in a group format. It is possible that group participation such as this could mean that some participants did not feel able to share their thoughts or feelings, particularly if they contradicted those of others. Such risks of group participation have been identified across support group evaluation designs (Campbell et al., 2004), although it was hoped that a dynamic that might prevent the sharing of feelings regarding the intervention would not be present in a group of burn care professionals with patients' best

interests in mind. As there is a possibility that all participants may have over-emphasised positive aspects of the website and the anticipated benefits for parents, whilst being reluctant to criticise it, further research was a necessary and important next step and is presented in the next chapter.

A further limitation is that there remains a necessity to conduct investigations to see if the eHIQ subscales provide meaningful data (Kelly et al., 2015). Currently, it is unclear what score would be expected to indicate a 'bad' website and what would indicate a 'good' one. One way in which this may be investigated would be ascertain what a meaningful change in eHIQ scores is recorded by participants viewing what the literature would suggest is a 'poor' website (for example, with negative trust cues such as pop-up advertisements) versus viewing what would be considered a 'good' website (for example, with positive trust cues such as quality indicator markers) (Kelly et al., 2015). As an indicator of participant experience of the prototype website in this study, the eHIQ scores are more favourable in this study for all but one of the subscales, the professional-rated information and presentation subscale (which is lower by only 1.3 points), when compared to those found by Kelly et al. (2015) whose participants viewed relevant condition-specific health-related website, for example Asthma UK, the MND Association or NHS Choices.

## **7.7 Conclusion**

The previous studies and literature demonstrated that many practical and psychological barriers can prevent parents of burn-injured children from accessing psychosocial support and contribute to a feeling of isolation. Using a partnership-based method of website development, parents and professionals contributed to an innovative patient-centered resource.

Both parents and professionals had favorable opinions of the prototype website. It was considered to be a highly acceptable and accessible psychosocial intervention, designed to meet the specific needs of parents or carers of children with a burn injury. Parents' ratings of the prototype tended to be more favorable than professionals', which was significant for the information and presentation. 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.

As a result of this study, the website was named [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk). It was felt that this website would be a valuable addition to UK pediatric burn care, helping to normalise parents' experiences of their child's injury, reduce their perceived isolation, and encourage support seeking when they are struggling. The next chapter presents a study of the public performance of the website.

## **Chapter 8: Testing the website [www.SupportingChildrenWithBurns.co.uk](http://www.SupportingChildrenWithBurns.co.uk)**

This program of research identified practical and psychological barriers that can prevent parents of burn-injured children from accessing psychosocial support. Participants also felt that an online resource would be the most accessible mode of support for them and could meet many of their needs. This led to the development and testing of a prototype website for parents, which participants ultimately felt would be a valuable addition to UK paediatric burn care. Therefore, it was important to verify this finding through further research following the public release of the website itself. This chapter explains how [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) was tested following its public launch.

### **8.1 Introduction**

[SupportingChildrenWithBurns.co.uk](http://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. There is 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 share their 'top tips' and coping strategies, and quotes from them are included throughout. Staff working within paediatric burn services can direct parents to this resource and parents can view it in their own time, when they feel ready. Parents participating in Studies 1, 2 and 3 highlighted that this may be less overwhelming than being presented with an information pack containing multiple leaflets and will allow parents or family members who are not present at the hospital to concurrently read the same information.

Participants involved in the feasibility study (Chapter 7) reiterated the findings in Studies 1 and 2 regarding the many barriers to accessing psychosocial support following a child's burn injury. The easily accessible information and psychoeducation within [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) 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 can care for themselves and support their children through what is often a very stressful time for everyone involved. It was 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 professional sources of support if and when they need it. [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) can also be used to educate professionals about parents' post-burn experiences. All visitors to the website also have the opportunity to feed into its future development.

Following the public release, ongoing evaluation of the website was necessary to ensure that it was being accessed and that the anticipated benefits were realised. This chapter describes the performance of the website [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) over the first six months of its public existence, between its release on 17th October 2018 (National Burn Awareness Day in the UK) and 16th April 2019. The data regarding its use has been gathered using Google Analytics and feedback on the acceptability and value of the website was collected via the 'Feedback' section of the website, which contained a link to an online survey hosted by Qualtrics.

Health behavior research suggests that positive appraisal of health information influences positive attitudes and actual use of the information (Cameron, 2009). Thus, users of the website were invited to provide feedback about the content, design, and way the information was conveyed, whether they actually used it, and to suggest improvements. In keeping with the language used to describe the use of websites, people accessing the website will be known as 'users' in this chapter. The term 'users' represents the number of people who visited the website. Even if they visited the website multiple times, they only counted as one user. However, it should be noted that this figure can be confounded by multiple users using one device to access the website.

Active promotion of the website required professionals to recommend it to parents or to disseminate flyers or cards promoting its existence in burn services. For the health care workforce, three broad factors have been found to be important for them when recommending or referring patients to peer support. These are: 1) that it objectively works, 2) that they believe that it will help and 3) that it's accessible (Patel & Pagel, 2018). Patel and Pagel (2018) posit that these factors are important regardless of whether professionals had previously referred to peer support or not. This emphasised the importance and value of the prior public involvement work involving parents and professionals in the development of the resource prior to its dissemination. It also highlights the importance of continuing to collect data regarding the acceptability of the website. Patel and Pagel (2018) inferred that unless all three factors are met, health care professionals will be less likely to refer people to peer support services. Therefore, it was hoped that professionals believed that the website could be helpful, and that they found the content and method of delivery to be appropriate prior to this data being collected. It was also hoped that this study would provide further evidence of its acceptability going forward.

## **8.2 Aims**

This study aimed to examine the use and acceptability of the newly developed online peer-informed support resource for parents of burn-injured children, [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), whilst the website existed in the public domain.

## **8.3 Method**

### ***8.3.1 Design***

This was a naturalistic study (Eysenbach & Till, 2001); a study in which data was gathered through observation and recording of behaviour over a six-month period, via Google Analytics. The use of Google Analytics meant that data was recorded from users in their natural setting, with no interference, so as to record normal activity. Data was collected regarding how users came across the website, how often the website was visited by new users and returning users, which pages were viewed, how long users viewed the website and the individual pages, along with their approximate geographical locations.

In addition to this, users were invited to provide feedback on the website and their experience of using it via an online survey. This part of the study was not naturalistic in nature and participation was compensated with optional entry into a prize draw for a £50 Amazon voucher.

### ***8.3.2 Ethical approval and considerations***

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (REC Ref. HAS. 18.03.139; Appendix D.i).

Data regarding the website's use was collected using Google Analytics and therefore did not place any demands on the users. Those users who chose to provide feedback on the design and content of the website were asked for demographic information but not about their own individual experiences. However, due to the emotive nature of the subject area, there remained a risk that, in thinking about the website's content and its relevance to them (not only in the past but also in the present), parents participating in the study may have reconnected to pre-existing distress.

Prior to accessing the online survey, participants were provided with information about the study (Appendix D.iii) and with contact information for different sources of support. It was important to be aware during this study that participants were likely accessing the website because they wanted support/information and would not necessarily be wanting or seeking to participate in research. They may have been in distress at the time but would have been able to find information and links to sources of support that they might have found helpful on the website (for example, GP services, charities, counselling services, other websites, books and apps etc.) Offering the option of research participation, after ensuring that participants had been informed about different sources of support and provided with the study information, would enable them to make an informed decision about whether participation and/or support seeking was appropriate for them. If participants decided that they would like to access support, they had information about different sources and how to seek a referral/make a self-referral to an appropriate service.

It was also important to consider that the feedback received may suggest that the website was not meeting the intended aims to provide a supportive resource to parents, and may in fact cause distress due to the sharing of parents' stories and use of emotive quotations. For this reason, the decision matrix (Figure 12) was developed and submitted with the ethics application in order to facilitate decisions about whether to continue hosting the website or to remove it from the public domain.

Professional Opinion ->		Positive	Negative
Parent Opinion ->	Positive	Explore options for hosting website long-term and further research for development.	Explore options for hosting website long-term and further research for development. Further work might include that which highlights the importance of public involvement and examination of the discrepancy between what patients want and what professionals think they want/will be most helpful.
	Negative	Website taken off-line. Further research might include examination of the discrepancy between what patients think they want and what professionals know to be helpful.	Website taken off-line.

Figure 12. Decision matrix used when considering the feedback received regarding the website content in Study 4

### 8.3.3 Recruitment

Data regarding visits to and time on the website were collected from every user of the website. However, users participating in the study by providing feedback via the online survey were self-selected. In order to take part, participants had to have visited the website itself, and seen the advertisement requesting their feedback. It was important that only the website shared the link to the survey in order to ensure that participants had actually seen the resource under investigation and were not just completing the survey for entry into the voucher prize draw.

The website itself, and the fact that research and development was ongoing, were advertised in a BBC news article, on Heart West Radio, in a University press release (Appendix D.iv), using social media advertising via Facebook, LinkedIn and Twitter, via burn clubs and camps, and also by charities that work in the field of burn injuries (Children's Burns Trust, Changing Faces, the Katie Piper Foundation, and Dan's Fund for Burns). The initial advertisement was made on the UK's National Burn Awareness Day 2018 (17<sup>th</sup> October 2018) and was repeatedly promoted via social media over the following 6 months. An audience had been built on social media (predominantly Twitter and Linked In) through the demonstration of awareness, engagement, connection and

loyalty to the area; key 'ingredients' for audience generation recommended by Schaefer (2017). Professionals working within burns services were also notified about the existence of the website via email from the BBA (Appendix D.ii) and the dissemination of 5,000 flyers and business cards to UK burn services. In addition to this, the opportunity for new users to submit tips and stories to be added to the website (following screening) was advertised in order to provide ongoing search engine optimisation benefits (Hampson, 2018).

Professional awareness of the research encouraged the dissemination of promotional materials, and also meant that it may have been advertised by word of mouth. However, other avenues of public advertisement helped to ensure that any implicit assumptions held by professionals about a parent's need for support or interest in research, particularly as these conversations can be difficult for untrained staff to raise, especially when appointments are time-limited, did not prevent details of the resource or the research from being shared with them.

#### **8.3.4 Participants**

Data regarding the use of the website were collected from all users. Those who were at least 18 years of age were invited to provide feedback, whether they be parents, carers, other family members, burn care professionals, members of support organisations (for example, camps and charities), or members of the public. Rather than detail strict inclusion and exclusion criteria, the study information invited participation from parents/carers who have a child who has experienced but survived an accidental burn injury requiring hospital treatment. It was stated that both parents did not have to take part but could if they wanted to as the study was examining parents' opinions of the acceptability of the resource rather than being about their child's injury. The information also stated that participation from professionals in the NHS and from charitable organisations was also being sought.

For parents/carers/family members, no minimum or maximum time since injury was specified as the website could be accessed at any time following a child's injury. Although the website was created with parents, carers and professionals from the UK, following its release, the website could be accessed from anywhere in the world. This meant that participants could originate from anywhere if they were able to understand written English. Parents who took part in Studies 1, 2, or 3 were also eligible to participate in this study.

#### **8.3.5 Measures**

To allow comparison to the prototype website, the survey used the questions that were asked in the test of the prototype (Study 3 in Chapter 7). These included Part 2 of the EHIQ, the FFT, and demographic questions (Appendix D.vi). In this study the questions were ordered purposefully, starting with the FFT question, then the EHIQ questions, and then the demographic questions.



This was in case participants dropped out part way through the survey. It was felt that the most valuable data (in the case of an incomplete data set) was that about onwards recommendation.

#### **8.3.5.1 NHS Friends and Family Test (FFT)**

As in the previous study, the FFT question, 'on a scale ranging from extremely unlikely to extremely likely, how likely are you to recommend the website to your friends and family if they needed similar care or treatment?' was used to enable website users to submit a basic level of feedback quickly.

#### **8.3.5.2 e-Health Impact Questionnaire Part 2 (eHIQ)**

The e-Health Impact Questionnaire (EHIQ) (Kelly et al., 2013), as described in the previous chapter, is a two-part, self-report questionnaire which assesses the impact of using health-related websites. Only the eHIQ-Part 2, consisting of three scales, was used in this study to ascertain participants views on [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk). The three scales examined: 1) Confidence and identification, 2) Information and presentation, and 3) Understanding and motivation. For professionals, these questions were modified to reflect how they thought parents would receive the website.

#### **8.3.5.3 Demographic Questions**

Demographic information was asked of all participants regarding their age, sex, ethnicity, and how they found out about the website prior to their participation in the study. Burn care professions were asked for their professional background, and parents were asked for their marital status, and their child's injury characteristics.

#### **8.3.5.4 Google Analytics**

Data was collected from the website itself using Google Analytics. This included the number of users (new and returning), channels by which the website was accessed, the number and duration of sessions and page views, the bounce rate, and the geographical location of users. It should be noted that the largest potential threat to the accuracy of this data comes from users deleting or blocking Google Analytics cookies. Any individual web user can block or delete cookies resulting in the loss of data for those visits. However, 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 was included on this website.

#### **8.3.5.5 Social Media Comments**

Comments and feedback received via social media (for example, Facebook, Twitter, Instagram) and email were logged in a spreadsheet for content analysis.

### **8.3.6 Procedure**

The website was advertised and available to the general public from 17<sup>th</sup> October 2018 via the mechanisms described earlier. Comments and feedback received in response to this initial dissemination was recorded in a spreadsheet.

The 'Feedback' tab on the website contained an advertisement about the study and provided a link which presented the study information (Appendix D.iv) and consent form (Appendix D.v) via the online survey platform, Qualtrics. Consenting participants were taken to the online survey containing the measures described above as well as demographic questions. A free text box also invited participants to share their personal views about the website (Appendix D.vi).

As the survey was hosted online, participants did not have to decide to participate straight away, they could return at a later date to take part. Participants were not required to submit their name or contact information unless they wanted to be entered into the prize draw – in that case they were invited to provide an email or postal address.

### **8.3.7 Analysis**

Quantitative data gathered via Qualtrics was entered into SPSS Statistics Version 22. eHIQ-Part 2 and FFT data were analysed for parents, professionals and others separately where possible. Non-parametric tests were used due to the small sample size.

Average eHIQ-Part 2 scores as well as the response to the FFT question in Study 3 were compared to the results obtained from the public website. This was done to ascertain whether the changes made to the prototype website had enhanced the information provided and the usability of the website.

Qualitative data collected via the open-ended questions in the online survey, as well as the feedback received following dissemination, were analysed using content analysis.

## **8.4 Results**

### **8.4.1 Google Analytics**

Google Analytics was used to track the activity of users visiting [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk). Google Analytics was able to provide insights into the geographical location of users, their age, gender, session duration, pages viewed per session, and bounce rate. However, as Google Analytics for web statistics are mainly cookie based, without cookies being set, the data could not be collected. For this reason, some of the data presented below is incomplete and should be interpreted with caution.

### 8.4.1.1 User Demographics

**8.4.1.1.1 Geographical Location.** It should be noted that, 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. Google Analytics showed that 937 new users had accessed the website from 21 countries around the world. The top five countries from which the website appeared to be accessed, based on the users' browser language, are shown in Table 15.

User's Language	n	%
English - UK	538	57.36
English - USA	356	37.95
English - Australia	14	1.49
English - Canada	4	0.43
Dutch - Netherlands	4	0.43

Table 15. The top five countries from which the website appeared to be accessed based on the user's browser language

Google Analytics also produced data on the top 8 cities from which the website was accessed. These are shown in Table 16.

Users Location (City, Country)	n	%
London, UK	150	15.06
NOT SET	141	14.16
Bristol, UK	108	10.84
Ashburn, VA, USA	46	4.62
Sheffield, UK	22	2.21
Glasgow, UK	16	1.61
Birmingham, UK	15	1.51
Manchester, UK	15	1.51
Chicago, IL, USA	15	1.51

Table 16. The top 8 cities from which the website was accessed

**8.4.1.1.2 Sex.** Google Analytics was able to provide data regarding the sex of 18.36% of the total users, with 23.8% of those being male and 76.2% being female.

**8.4.1.1.3 Age.** Google Analytics also provided data on 17.72% of users regarding age. From the data available it appears that the highest proportion of users were aged between 25 and 34 years of age, which could suggest that parents of young children are likely to make up the largest proportion of those accessing the website (Table 17).

Age range	%
18-24	9.0
25-34	33.5
35-44	27.5
45-54	21.5
55-64	8.5

Table 17. The age ranges of users accessing the website (based on data for 17.72% of the users)

#### **8.4.1.2 Acquisition Behaviour**

**8.4.1.2.1 Channels.** The mechanisms by which users found the website are known as channels.

They are mediums grouped together with several traffic sources. The definitions of each channel type are (Weddle, 2019):

- Organic: visits from organic search results from search engines
- Direct: visits from a visitor typing the exact URL or visits from places that Google cannot determine
- Social: visits from social networking platforms such as Facebook, Twitter, and Instagram
- Email: visits from links clicked in emails
- Paid Search: visits from search pay-per-click campaigns
- Referral: visits from links clicked on other websites
- Display: visits from display advertising like remarketing or banner ads
- (Other): visits that cannot be tracked by Google and are most likely spam

Google Analytics revealed that the four channels through which the users found the website were: direct (54.97%), social (28.59%), then organic (12.57%), followed by referral (3.87%). This suggests that most people finding the website have done so after receiving the promotional flyers and cards that were distributed by burn services throughout the UK as they typed in the exact URL. It also suggests that social media advertisement has been beneficial for promoting that site. The presence of the organic channel in this list suggests that people are searching for information or support online and this website is being found by the key words that they type into their search engine. Finally, the fact that some users are finding the website via the referral channel shows that other websites sharing the URL to [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is helping people to find the website. Paid search and display were not possible access channels for this website as there were no such advertising campaigns.

Table 18 provides more information about how users found the website and their behaviour upon doing so. The paragraphs below describe the terminology and data contained in this table in more detail.

**8.4.1.2.2 Sessions.** The term ‘sessions’ represents the number of times a user was active on the website. A session resets after 30 minutes of inactivity, or at the end of the calendar day. This metric does not recognize users; it counts a new session if the user has been to the site previously. Therefore, users can have multiple sessions if they visit the website more than once. The data reveals that on average, the number of sessions per user was 1.32.

Channels	Acquisition			Behaviour		
	Users	New Users	Sessions	Bounce Rate	Pages / Session	Avg. Session Duration
	937	924	1235	59.27%	2.97	2:21
Direct	525			64.45%		
Social	273			54.95%		
Organic Search	120			49.46%		
Referral	37			50.00%		

Table 18. User access channels and their behaviour

**8.4.1.2.3 Page views.** Google Analytics also provides data on the total number of pages that were viewed on the website within each session; this is known as ‘page views.’ This includes repeated site users and repeated page views. The total number of page views was 3,667. The total number of “unique page views” was 2,966. A unique page view aggregates page views that are generated by the same user during the same session. This means that page views of the same page, in the same session, from the same user are combined and counted as one. However, a session is thought to be a more important metric to measure than page views because it groups each page view together in its relationship to the user. The average time that users spent on each page was 1 minute and 12 seconds.

**8.4.1.2.4 Pages/Session.** The terms ‘pages/session’ represents the average number of pages on the website that users were viewing per session. This includes repeated page views. Generally, one would want this number to be high as this indicates that a large number of the website’s pages are being explored each time someone comes to the website (unless the website has very few pages). For [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), this figure is 2.97. The top 5 pages on which users spent the most time are presented in Table 19.

Website Page	Time on Page
<a href="#">/supporting-your-child/</a>	4:05
<a href="#">/top-tips/</a>	3:39
<a href="#">/supporting-your-child/behaviour-change-regression/</a>	2:39
<a href="#">/[home page]</a>	2:33
<a href="#">/impact-on-parents/parent-stories/</a>	2:05

Table 19. The top 5 pages on which users spent the most time

The 10 most frequently viewed pages are presented in Table 20.

Website page	Number of visits	% of total visits
<a href="#">/[home page]</a>	1,140	31.09
<a href="#">/where-can-i-find-support/</a>	212	5.78
<a href="#">/impact-on-parents/common-feelings-after-the-injury/</a>	206	5.62
<a href="#">/top-tips/</a>	163	4.45
<a href="#">/impact-on-parents/</a>	158	4.31
<a href="#">/supporting-your-child/</a>	143	3.90
<a href="#">/impact-on-parents/parent-stories/</a>	85	2.32
<a href="#">/supporting-your-child/supporting-your-child-through-a-painful-procedure</a>	84	2.29
<a href="#">/where-can-i-find-support/professional/</a>	79	2.15
<a href="#">/where-can-i-find-support/charities/</a>	71	1.94

Table 20. The 10 most frequently viewed pages of the website

**8.4.1.2.5 Average Session Duration.** In Table 16, ‘average session duration’ represents the average amount of time a user spent during a session on the website. Along with ‘pages/session’, a longer amount of time indicates that users are interacting with the content. On average, users spent 2 minutes and 21 seconds on the website per session, however a breakdown of session duration, total number of sessions, and total page views within them are presented in Table 21.

Session duration (seconds)	Number of sessions	Number of page views
0-10	754	778
11-30	61	149
31-60	86	275
61-180	134	585
181-600	110	722
601-1800	73	759
1801+	17	399

Table 21. Information regarding the number of sessions of different durations and the number of page views within these

Table 21 suggests that, of the total number of sessions, 901 had a duration of one minute or less. One-hundred and thirty-four sessions lasted between one and three minutes, 110 lasted between three and 10 minutes and 90 lasted for over 10 minutes. As a session resets after 30 minutes of inactivity, it shows that 17 different users interacted with the website for over 30 minutes in one session.

**8.4.1.2.6 Bounce Rate.** ‘Bounce rate’ refers to the percentage of sessions occurring where a user only accessed one page of the website and then left. For example, they did not interact with it, they did not scroll down, click any links, or go to any other pages of the website. Google Analytics calculates this metric by dividing single-page sessions by all sessions. The preferable bounce rate depends on the content of the website and on whether the end goal is to have the user explore

the site or not. A good average rate is 40 to 60 percent, and no higher than 75% (Ocreative, 2016). A high bounce rate can be a good indicator that the page is not well received by the user and that users are not engaging with the content. Although, if there is content that provides quick information or answers a user's question and it is appropriate that person would only go to one page of the website, then a high bounce rate would be desirable. In this case, a high bounce rate may occur because the user is finding what they need quickly and leaving. However, if the end goal is to have people explore the website and engage with the content, the bounce rate should be low as low as possible.

In the case of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), the overall average bounce rate during the first six months of its launch was 59.27%. Interestingly, this figure varies depending on the channel through which the user found the website. Table 15 demonstrates that those finding the website directly left more frequently after accessing the home page (64.45%), whereas those actively searching for something on the internet (organic search), or seeing the link on another website and clicking on it (referral), were less likely to leave after seeing only one page, with bounce rates of 49.46% and 50.00% respectively. When visits occurred following links in social networking platforms, the bounce rate was 54.95%.

**8.4.1.2.7 Percent of New Sessions.** 'Percent of new sessions' represents the estimated percentage of the total sessions that came from new users; users who have never been to the website before. For a new website, this is a good metric to track month to month to determine how many new people are coming to the website. In the first six months, new users made up 86.4% of those accessing the website, with 13.6% being returning users. Table 22 shows that the website is now receiving an average of 116 visits per month from new and returning users.

Month since release	Total number of views
1	525
2	75
3	137
4	112
5	118
6	140

Table 22. The number of website views per month

#### **8.4.2 User Feedback**

Twenty-seven website users chose to provide feedback on the website itself. Eleven of these were parents, 11 were burn care professionals, and five identified themselves as 'other'. Participants varied in how much feedback and demographic information they provided. Participant characteristics and information which was provided are presented in Table 23.

<b>Participant Characteristics</b>		<b>n (unless otherwise stated)</b>
Relationship to Child	Mother	3
	Father	5
	Cousin	1
	Missing data	7
Ethnicity	White	5
	Mixed/Multiple ethnic groups	1
	Other ethnic group	1
	Missing data	9
Marital Status	Single	1
	Married/Civil Partnership	6
	Widowed	2
	Missing data	2
Parents Age	25-34	4
	35-44	3
	Missing data	4
Child's Sex	No data provided	
Child's Age at Injury (n = 6)	Mean (SD)	3 years, 1 month (2.55 years)
	Missing data	10
Time Since Injury (n = 6)	Mean (SD)	3 years, 8 months (4.60 years)
	Missing data	10
Cause of Injury	Scald	6
	Missing data	10
Initial Treatment	Inpatient	5
	Outpatient	2
	Missing data	9
Surgery Required	Yes	3
	No	3
	Missing data	10
Total Burn Surface Area (n = 2)	Mean (SD)	29.50% (20.51)
	Missing data	14
Professional Roles	Clinical Psychologist	2
	Management	1
	Play Specialist	1
	AHP	1
	HCA	1
	Missing data	5
Professionals age	25-34	1
	35-44	1
	45-54	1
	55-64	1
	75-84	1
	Missing data	6
Professionals' sex	Male	1
	Female	3
	Missing data	7
Professionals' ethnicity	White	3
	Asian	1
	Other ethnic group	1
	Missing data	6
Other age	35-44	1
	45-54	1
	65-74	1
	Missing data	2

Table 23: Information regarding the participants in Study 4



### 8.4.2.1 Quantitative Feedback

**8.4.2.1.1 Channel.** Participants providing feedback were asked how they had first heard about the website. Nineteen participants provided this data which is shown in Table 24. Comparing this data to that collected by Google Analytics shows that social media, whilst being the second most popular channel via which users found the website, was the most popular channel for those users willing to provide feedback.

	n	Parent	Professional	Other
Charity	1		1	
Social Media	13	7	3	3
Professional told them	2		2	
Email from CAR	1		1	
Burn camp	2	1	1	

Table 24. How participants in Study 4 first heard about the website

**8.4.2.1.2 FFT.** As measured by the FFT, all participants reported that they would recommend the website to others. The proportion of users rating themselves as ‘extremely likely’ to recommend the website is also higher for the public website than it was for the initial prototype version tested in Study 3 (Table 25).

		n	Likely	Extremely Likely
Prototype	Parents	9	1	8
	Professionals	22	9	13
	Total	31	10 (32.3 %)	21 (67.7 %)
Public version	Parents	11	3	8
	Professionals	12	2	10
	Other	4	1	3
	Total	27	6 (22.2%)	21 (77.8%)

Table 25. Participants’ responses to the FFT in Study 4

**8.4.2.1.3 eHIQ-Part 2.** The results of the eHIQ-Part 2 demonstrated that for each domain, parents generally rated the website more highly than professionals or ‘others’ (Table 26). However, none of these differences were significant.

eHIQ-Part 2	Parent (n = 5)	Professional (n = 4)	Other (n = 1)	Significance
Confidence and identification (9 items)	100 (12.50)	97.22 (24.31)	100	$H = .692$ $p = .707$
Information and presentation (8 items)	84.38 (12.50)	82.81 (14.84)	81.25	$H = .234$ $p = .890$
Understanding and motivation (9 items)	100 (8.33)	90.23 (16.67)	97.22	$H = 4.331$ $p = .115$

Independent sample Kruskal-Wallis Test. Median scores (and the interquartile range) are provided. Potential scores on each subscale ranged from 0-100; higher scores indicate responses that are more positive.

Table 26: Professional and parent scores on the eHIQ subscales in Study 4

When compared to the eHIQ-Part 2 data from the testing of the prototype, the amended public version of the website performed significantly better in the domains of ‘confidence and identification’ and ‘understanding and motivation’. Due to the low numbers of users providing feedback, parent, professional and ‘other’ scores have been combined for this comparison in Table 27.

eHIQ-Part 2		n	Median (IR)	Significance
Confidence and identification (9 items)	Prototype	31	77.78 (16.67)	$U = 251.5$ $p = .002$
	Final	10	100 (11.81)	
Information and presentation (8 items)	Prototype	31	75.00 (21.88)	$U = 186.0$ $p = .360$
	Final	10	82.81 (12.50)	
Understanding and motivation (9 items)	Prototype	31	77.78 (16.67)	$U = 246.0$ $p = .005$
	Final	10	95.83 (13.89)	

Table 27. A comparison of eHIQ-Part 2 subscale scores between the prototype website (Study 3) and the public website (Study 4)

#### 8.4.2.2 Qualitative Feedback

Limited qualitative data was provided via the online survey, however, that which was received from a burn survivor, a grandparent and a clinical psychologist was positive. This feedback referred to the design and content, the support and reassurance provided, and the potential ability for the resource to reduce parents’ feelings of isolation, whilst also functioning as a pedagogic resource for professionals.

“Great work on the design and content, having one place to go when looking for support will help parents and burn victims to let them see they aren’t alone, help is out there.” [Burn Survivor, location unknown]

“A very informative website. A useful tool for getting support and reassurance.” [Grandparent, location unknown]

“Really valuable resource. The patient stories and videos will be very useful for me in delivering training for wider MDT colleagues. I will definitely be recommending this website to families and professionals alike.” [Clinical Psychologist, UK]

Some website users took the time to offer feedback directly via email, Twitter or Facebook. This feedback was overwhelmingly positive and was received from members of the public, the research participants, burn care professionals, and charity workers. It highlighted the value of the website for parents and professionals alike in terms of support and also staff training.

“I’ve just been spending some time going through your website properly, and just wanted to email and say how fantastic I think it is! Such a great resource for parents, and also for us as professionals. The video clips and patient stories are great, and I plan to use them in my next psychosocial training as I think they really bring the issues alive. Thanks so much for all your work and effort developing this, I will make sure I signpost everyone to it!” [Clinical Psychologist, UK]

“Amazing job Jenny – WELL DONE YOU! How I wish I’d had this a couple of years ago. So many families will benefit from your great work on this, you should be so proud.” [Mother, UK]

“Thank you!! There was not a lot to help us when we desperately needed this. The staff support was amazing but they couldn’t always be with us. Parent support is just so necessary in all areas of life.” [Mother, UK]

“We have put details about it in our new leaflet for parents.” [Burns Club Volunteer, UK]

“Well done, it’s going to be an excellent resource for families.” [Burns Network Manager, UK]

“Amazing website. What a great resource.” [Applied Psychology PhD Researcher, UK]

“Invaluable support for those effected by burn injuries.” [Occupational Therapist, UK]

Positive feedback was even received from outside of the UK. For example, an email was received from a clinical psychologist based in Australia who had reviewed the website with their team and a Tweet was received from a Professor within burn care in the USA.

“We allocated the topics to various staff members to review and the resounding conclusion is that this is “awesome; excellent” and we would like to provide the link through our website and add it to our list of resources in our discharge information.” [Clinical Psychologist, Australia]

“An excellent resource for parents of burn survivors.” [Director/Professor, USA]

A nurse based in the UK even reviewed the website and then began promoting it herself on social media.

“If you only ever access a single paediatric burn survivor’s support site - it has to be this! A fantastic resource for parents and carers of children with burn injuries, highlighting its impact on parents, strategies for stress management and supporting a child with a burn. A passionately executed project by the amazing Dr Jennifer Heath, this website offers top tips from other parents who have accompanied their child on a journey to recovery. By addressing challenges such as accepting help, boundaries, confidence, finances and coping, the expert voices of parents who have the most essential part in rebuilding bodies and souls are offering Top Tips from their own experiences to support any new parents battling through their family's burn injury journey.”  
[Nurse, UK]

## 8.5 Discussion

This study aimed to assess the acceptability of the website during the first six months following its public release. This was important to ensure that it was being accessed and was found to be of value by users, especially as it was found by Schoenebeck and Bruckman (2013) that new websites could go unnoticed or 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) experienced an early peak in interest, the data for monthly visits has been consistent suggesting that use has stabilised rather than being in decline.

Using Google Analytics, this study was able to identify the channels by which users found the website and provide both user and session characteristics; all of which are important considerations to assist future dissemination and promotion of the resource. Some website users provided additional data by completing, or part completing, a survey which included questions about whether they would recommend the website to others, and the impact of the website on themselves in terms of confidence and identification, information and presentation, and understanding and motivation.

As anticipated, [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) was accessed by users from around the world with Google Analytics reporting users from 21 different countries. Interestingly, when looking more specifically at the cities from which the website was accessed, the top two were predictable

1) London – the capital city (with the largest population) of the country in which the website was created (also the city where Dr Lisa Williams [the third supervisor] was based); 2) Bristol - the city in which the website was created, which includes the regional burn centre and charity for which the PhD researcher volunteered. The third city from which the website was most frequently accessed was Ashburn, Virginia. All other top ranked cities were in England and were locations of specialist paediatric burn centres (those facilities that treat the most complex burns cases in children) and one of the Scottish burn units.

The data provided regarding the age and sex of website users suggests that the majority could be mothers of young children. However, with the potential that almost 25% of users could be male, it is notable that this is a much higher proportion than the number of males choosing to participate in the development of the resource. Although this potential finding 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 never wrote any messages themselves. Perhaps the fathers of burn-injured children do find value in this online information but, during the research process, they did not feel able to contribute to it themselves, or believed that their contribution was unnecessary. It may be that once a resource/intervention was provided, fathers felt more able to provide feedback as the dynamic had shifted; the researcher was not taking from them (their experience), instead something had been given to them.

Data regarding the mechanisms by which users found the website is valuable when considering the best ways to promote it based on who is accessing it. Within their review of 17 studies, Campbell et al. (2004) reported that only one study asked participants how they heard about the peer support program being delivered. It is important to seek this information as many people may not be aware of the available support whilst others may hesitate to access it.

In the case of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), most users found the website by typing the exact URL into their search engine (or were visits from places that Google could not determine). This suggests that the flyers and business cards containing the URL, which were sent to burn services to be disseminated to parents to promote the website, had been effective. More flyers were also requested by some services after approximately four months, suggesting that professionals were recommending the website to parents and disseminating the flyers.

Campbell et al. (2004) reported that most articles in their review identified low referral rates as a barrier to the success of peer support. Therefore, it is encouraging to find that this does not seem to be a problem faced by this website. After receiving the suggestion following a conference presentation, a QR code has been generated and added to waiting room/clinic posters for burn services. 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. With internet access, this will then link them directly to the website from the hospital without them needing to type in the website address.

Following the direct channel of access, the next most common channel via which the website was accessed was social networking platforms such as Facebook, Twitter, and Instagram. All three of these platforms were used to promote the research and resulting website by the PhD researcher and also by CAR, charities, and the BBA, thereby supporting the value of dissemination of support information and resources via social media. Next most popular was users finding the website in the search results of internet search engines. This suggests that people are typing in key words that bring the website to their attention. Although the website was shared with research participants and members of the BBA by email, it appears that no one clicked on the link provided in emails. However, links embedded in other websites, such as charities, are being clicked on to refer (take) users to [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk).

Whilst the factors identified as important for professionals referring patients to peer support (discussed in the introduction to this chapter) appear to have been met by virtue of the flyers and cards being disseminated to patients, Patel and Pagel (2018) identified that, for members of the public who had not accessed peer support, three different factors were important if they were going to access the support on offer. These were: 1) a belief that it will help, 2) trustworthiness, and 3) accessibility. For those who had previously accessed peer support, although accessibility and belief it will help were important, the opportunity to meet people with similar experiences was also considered to be extremely important (although Patel and Pagel (2018) did not conclude whether this was related to preference or the value gained from meeting others during previous experiences of peer support). The fact that the website is being accessed via different channels, and also being accessed more than once by some parents, suggests that it is accessible and there is a belief that it is 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 the research that led to the development of the website is displayed. However, the website does fall short of the factors that Patel and Pagel (2018) identified as important as there is no opportunity for users to meet others. Users seeking only a place to meet others are likely to 'bounce', that is, to leave the website. However, those who do read about different sources of support and are seeking a place to meet others, can click on a hyperlink and be directed to the [Adult Burns Support UK forum](#) – a place for adult burn survivors to connect and support each other and discuss and share their personal experiences of burns-related issues.

When considering the information about acquisition alongside the respective bounce rates, it was apparent that those searching for information and finding the website organically were most

likely to stay on the website for longer. This suggests that those who turn to the internet to search for support are finding the website and viewing it. Study 2 found that those most frequently turning to the internet for support were most likely to struggle to find it, suggesting that a gap in paediatric burn care has at least been partially addressed by [SupportingChildrenWithBurns.co.uk](https://www.supportingchildrenwithburns.co.uk). The next group most likely to visit several pages of the website were those being referred from other websites. These maybe people who are seeking information, finding relevant resources, and then drilling down to more specific information. The group with the highest bounce rate were those typing the exact URL into their search engine. This is likely to be the target audience of the website and so this is surprising, but it should be noted that these statistics do not tell us anything about whether those who 'bounce' return to the website later. It may be that those receiving a lot of information following their first visit to the burns service are not ready to read any more at that time. For the social, organic and referral acquisition channels the bounce rate should be considered 'good'. Although the bounce rate for the directly referred group is higher than that usually considered good, it is not so high as to be considered problematic (CXL Institute, 2019).

On average, users during the first six months of its launch visited the website more than once, and each time they viewed a mean number of three pages. The average time that users spent on each page was 1 minute and 12 seconds, which is perhaps not enough time to read the information in any detail. However, with sections having headings and subheadings, the content can be scanned by the user for relevance to them. Based on the findings of Studies 1 and 2, one might have expected 'parents' stories' and information on 'scar management' to be the most viewed pages. However, the pages that actually received the most attention were: 'Supporting your child', and the sub-page of this section 'Behaviour change & regression', the section providing 'Top tips' from parents for parents, the 'Home page' and the sub-section of 'Impact on parents' in which personal 'Parent Stories' are provided. Considering the findings of Study 1, this suggests that parents' primary focus is indeed the injured child. However, accessing information and advice, and seeking shared experiences from peers, is sought and valued, confirming the results of Study 2.

Overall, the most frequently viewed pages, after the home page (which is the landing page for the majority of users), were: 'Where can I find support?' and the specific subsections 'Professional' and 'Charities'; 'Impact on parents' and the specific subsections 'Common feelings after the injury' and 'Parent Stories'; 'Top tips'; and 'Supporting your child' and the specific subsection 'Supporting your child through a painful procedure'. Again, this suggests that parents are in need of support but may not know where to find it or how to access it – this issue was identified by some parents in Study 2. Perhaps users are interested in finding out about the experiences of other parents following similar injuries/incidents, potentially to decrease their sense of isolation or to find out how others have coped. It also suggests that they are keen to find out how best to

support their child, particularly during painful procedures. This indicates that burn services should pay special attention to ensuring that parents are aware that they can access support via them. It is also important that burn services provide the necessary information to parents, as well as offering the opportunity for them to ask any questions before and after medical procedures that their child must undergo.

A minority of website users (approximately 2.9%) chose to provide feedback on the website by at least partly completing the survey. Although the ongoing research was advertised alongside the existence of the website, recruitment was not actively pursued. This meant that all participants were users of the website and, more specifically, were those self-selected and motivated to complete a survey about their experience of using it. Unless participants wanted to enter the prize draw, participation was completely anonymous. Interestingly, this is the first study to recruit more fathers than mothers, with five of the parent participants being fathers (55.6%). It was assumed for the analysis that those completing the survey for the public version of the website were a different sample to those who provided data during the testing of the prototype.

This survey enabled the comparison of the public version of the website to the initial prototype version. This comparison demonstrated that the amended public version was rated more highly by users than the prototype had been during testing. It is important to consider that the feedback was received from parents (the target audience), professionals, and also others that had experience of burn injuries to children. Usually, evaluation of the quality of online health information focuses on clinicians' assessments of the methodological rigor used to develop and report the information (Reavley & Jorm, 2011). However, although these assessments are important and necessary, they do not shed light on the acceptability and usefulness of the information to users (Reavley & Jorm, 2011). This study was able to overcome this criticism, with the data collected naturalistically, enabling the assessment of the applicability of the resource to users themselves. Although a criticism is that the volume of this data is currently limited, continued collection of the data will be able to inform future amendments in order to enhance the information and resources provided (Steimle & Duncan, 2004).

All self-selecting participants completed the FFT question regarding how likely they were to recommend the website to others if they needed similar care or treatment. This suggests a high degree of user satisfaction. As with the prototype, the FFT rating suggests that, overall, the website was well received, as all participants rated that they were either likely or extremely likely to recommend it. The live version of the website was rated by a higher proportion of users to be a resource that they would be 'extremely likely' to recommend to others compared to the prototype, with ratings for this response being 77.8% for the public website and 67.7% for the prototype.



The eHIQ-Part 2 (Kelly et al., 2013) was completed by 10 users. This data illustrated that users' confidence and identification with the website and understanding and motivation was significantly increased compared to that rated by those viewing the prototype version. That is, their perceived confidence to discuss their situation with others and their ability to identify with the website, as well as their understanding and learning about relevant information and motivation to take action was improved. However, although the mean rating for information and presentation was raised slightly, it was not significantly different to the prototype and was rated much lower than the other two domains. Presentation was the area in which least changes were made following feedback. Whilst more information was added about the team who developed it and the research behind it, the colour scheme and look of the website did not change between the prototype and public versions. As 'information and presentation' reflects trust and suitability of the website content, it may be that the lack of images and interactive resources added, despite being recommended during feedback, has meant that improvements in this area are not seen as they were in the other domains.

With overall high ratings for confidence and identification, information and presentation, and understanding and motivation on the eHIQ-Part 2, it is likely that professionals and parents accessing the website found the factors found by Patel & Pagel (2018) to be satisfactory in terms of this website. For professionals, these being that it works, will help, and is accessible, and for parents these being that it is believed to be of help, is trustworthy, and accessible. Therefore, the feedback gained suggests that [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is meeting the aims set out at the beginning of the PhD. Parents appear to feel able to identify with the peer-informed resource, which may help them to feel less alone, and there is confidence that it can help them as it contains information that can encourage users to take positive action to help themselves. Despite these findings and the high user satisfaction, peer support should not be considered a panacea for supportive care issues. These findings simply suggest that when peer-informed support is provided within a broad framework of care, it has the potential to complement professional service models of care (Dunn, Steginga, Rosoman, & Millichap, 2003).

## **8.6 Limitations**

As discussed in the previous chapter, it is important to remain mindful that this study may have been vulnerable to bias as it recruited a self-selecting sample of participants who may have been highly motivated to support an intervention that is web-specific, according to their beliefs about the appropriateness of such an intervention and a need that they identify with. This may be particularly the case here, with more fathers than mothers being recruited. It is also important to emphasise that this is a small sample and there may be differences between those who chose to take part in the research and those who did not, and also those who chose to access the website

and those who did not. Parents who choose to use a peer-informed website may not consent to participate in a research study about that resource and therefore the results may lack generalisability. Peytchev (2013) has highlighted that survey response rates have been in decline over recent decades but that higher rates of nonresponse do not necessarily lead to greater nonresponse bias. In fact, Peytchev (2013) suggest that response rates are poor indicators of nonresponse bias.

Nevertheless, where participants are in favour of this style of intervention, and have also had a role in its development, a degree of social desirability may be present in their responses. It is not known whether those providing feedback were any of the participants that had taken part in the other studies, but this is a possibility. It could be that those who chose to participate in the study might have over-emphasised the positive aspects, or been reluctant to provide criticism of it, because it is the first resource of its kind. However, as this data was collected online, rather than in person (as was the case when testing the prototype version), this study is likely to be less biased by a desire of participants to please me, the investigator.

In this vein, when considering the data gathered from Google Analytics, it is also important to note that promotion of the public website via social media means that many of the PhD researchers friends and family members may have viewed the website, artificially inflating the early user statistics and bounce rate, as well as the proportion of people who did not navigate past the home page. Examination of Google Analytics beyond the first few months when promotion is only via professional channels, rather than a personal social media account, has provided more accurate data regarding 'normal' use of the website, with new monthly sessions being estimated at an average of 116 for months two to six, as opposed to 525 in the first month.

The small sample recruited in this study also meant that average eHIQ-Part 2 scores could not be compared between mothers and fathers, or parents of younger and older children. It was also not possible to compare feedback received from professionals within different professional groups. Continued data collection may allow for analysis of these in the future.

## **8.7 Practice Implications**

With most people accessing the website by typing in the exact URL, it can be inferred that these are likely to be parents who are seeing or receiving cards or flyers at the hospital. Therefore, they are parents who have either a recently injured child or a child who is still undergoing treatment or follow-up. The timing of a recommendation or referral to different sources of support can be important. For example, those accessing support upon completion of treatment are likely to benefit less from the informational content provided by the website. It would be interesting to investigate further whether parents whose children have been discharged from burns services

find the peer voice beneficial. To do this, more consideration needs to be given to recruitment of parents to complete the survey about [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk). It could be that future research is promoted within NHS burn services (following NHS ethics approval) in order to recruit a pre-discharge group, and awareness is also raised with GPs as well as non-healthcare professionals (such as those working in education and social work) in order to promote the website to families post-discharge from hospital for comparison.

Recruitment into this study, and future studies, could have been assisted by pop up study advertisements when users navigated the website. However, research into online survey response rates also shows that general response rates to online surveys are low (Peytchev, 2013) and so the proportion of responses received, whilst low, are not out of the ordinary when also considering the reluctance of parents to participate in this type of research (Braun & Clarke, 2013; Pyer & Campbell, 2012).

Within this study, pop-up advertisements were avoided as these would likely detract from the original aim to provide a source of support, rather than a combined resource and data collection facility. It is possible that the intrusiveness of this form of study advertisement would potentially be unethical and may provide little gain in terms of data collection. Pop-up advertisements have also been identified as negative trust cues in the literature on health-related website (Kelly et al., 2015). The best-case scenarios being that users would see the advertisement and complete the survey, or see it, close it, and continue to browse the website. The worst-case scenario being that it would cause a user to leave the site and not return. Advertisement blocking systems on computers may also mean that development of a pop-up would have been ineffective.

In making the decision not to use pop-up adverts in this PhD, the TARES test (Baker & Martinson, 2001) was considered, alongside the fact that many people now operate ad blocking systems on their computers (Redondo & Aznar, 2018). The TARES test is a conceptual model of advertising guidelines which establishes five principles for ethical persuasion: 1) trustfulness of the message, 2) authenticity of the persuader, 3) respect for the persuadee, 4) equity of the persuasive appeal, and 5) social responsibility for the common good. Considering these five principles, it could be argued that intrusive advertising formats are not respectful and that they are persuasive and therefore may lead to a lack of fully-informed consent. Even if the advert looks as though it is directly linked to the website itself, and therefore deemed trustworthy and equitable, it could be perceived as highly annoying or inappropriate given the context that parents are accessing the website. Whilst it is unlikely that the use of a pop-up in this study would have been deemed unethical, future public involvement group feedback could be valuable to gauge opinion about users' best interests and the likely effectiveness of such persuasive communication (Belanche, 2019), because without more feedback, the further development of the resource could stall.

Establishing the limits of recruitment 'drives' should be a considered with participants themselves and so the use of such adverts and their value is certainly an area that can be investigated further in collaboration with public involvement groups (Redondo & Aznar, 2018).

## **8.8 Conclusion**

[SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is an innovative patient-centered resource - the first of its kind in the UK. During the first six months of its use it received visitors from around the world at a rate of approximately 116 per month. The majority of these users were directed to the website by the flyers or business cards provided by UK paediatric burns services and, on average, each visit lasted a duration of almost 2.5 minutes in which time the user visited three pages.

As found in Study 3, the data collected so far 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. The easily accessible information and psychoeducation within this resource has the potential to help parents and carers overcome some of the emotional barriers that limit access to professionally-led 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.

Going forward it would be helpful to consider ways in which data can be collected from paediatric burn services regarding the number of families who have accessed the website, whether they actively use elements of the resource, and whether it has influenced help seeking behaviour.

The final chapter will reflect back on this program of PhD work overall, and suggest future avenues for research, clinical practice, and the development of support for parents of burn-injured children.

## **Chapter 9: Discussion and areas for future development**

The final chapter of this thesis reflects on the work that has taken place, discussing the process and the methods used, the application of the findings, and their relation to the available literature, in the context of UK burn care. The limitations of the research and suggestions for further research are also discussed.

### **9.1 Summary of the research process**

Initially, this PhD had a broad scope of investigating peer support for people affected by burn injuries. When the PhD began, the National Burn Care Standards stated that, for both child and adult services, across all levels of specialist burns services, “a support group should be available whereby patients, their families and/or carers have access to peer support from others who have experienced burn injuries (pg.10)” (National Network for Burn Care, 2013). Despite this, few burn services within the UK provided self-help and/or support groups for patients (Batchelor & Williams, 2013) and, although some family burn camps existed, no support groups specifically for parents of people with burn injuries were identified when this program of PhD research began in 2016. Since then, [Adult Burns Support UK](#) has been developed by the charity Dan’s Fund for Burns, offering an online [forum](#) and weekly [live chat](#) to adults. Since 2019, parents have also been able to access that forum.

As a previous NHS employee within burn care, it was important to me to strive towards an outcome that could facilitate an improvement in the care that patients might receive from UK burn services, in addition to that which was already provided by both the NHS and existing support organizations. Identifying that there was a gap between what was recommended in the evidence-based standards (access to peer support for all those who might want it) and what was delivered by services and charities provided an area for research and development. Stepping away from my role in the NHS in order to do this work meant that I could facilitate the engagement of staff and service users in the processes, so that each had a space to voice their opinions and concerns with the common aim of improving the way that care was provided. Sitting outside of both groups allowed me to think more objectively about the best way to meet the needs identified as I was a member of neither group (Heath, 2018; Herod, 1999) (Appendix E.i). The aim to examine the role of peer support for parents of children with burn-injuries, and to improve the provision of care, led to this research being cited in the 2018 UK National Standards for Provision and Outcomes in Adult and Paediatric Burn Care (British Burn Association, 2018) referencing the findings of Study 1 (Heath et al., 2018) (Appendix E.i) and stating that, “Burn-specific support resources are available and are highlighted to patients at all stages of their treatment (Heath et al, 2018). With guidance from the psychological care team, burn care staff

facilitate access to the range of support resources available locally, nationally and internationally such as support groups, peer-support opportunities, charities, websites and events.” (pg. 8)

This updated recommendation could lead to significant impact and improvement in burn care in the future with more services considering the value of peer support for patients and parents. Reflecting on the process of achieving this, it is helpful to consider the evolution of the research and resource development within this PhD over the five stages presented in Figure 13. First, a gap between recommended and delivered care was identified. Members of the affected population (parents) were then consulted to increase understanding of the issue, and to develop change ideas. The option that received the most support in Study 2 was then developed and tested with key stakeholders (parents and professionals) – online peer-informed support – and implemented through the release of [SupportingChildrenWithBurns.co.uk](https://www.supportingchildrenwithburns.co.uk). Work is now focused on sustaining this new intervention.

The PDSA cycle (Deming, 1986) used within NHS QI projects (previously described in section 3.1) is able to summarise what occurred over the final three stages of the research, since the development of change ideas (Figure 13). QI utilises the expertise of those closest to the identified issue, in order to identify potential solutions and test them. Therefore, once the ‘problem’ was identified and better understood (i.e. parents’ barriers to engaging in psychosocial support, and the lack of reliable online information and peer support), with suggestions made by parents, the most popular idea (ascertained in the quantitative survey, i.e. online support) could be tested using the PDSA cycle below.

It is important to clarify that, within this PhD, only one way to potentially increase parents’ access to support has been tested using the PDSA cycle - access to the peer-informed website [SupportingChildrenWithBurns.co.uk](https://www.supportingchildrenwithburns.co.uk). However, other methods, such as a parent-specific forum, could have been tested if the appropriate resources had been available. As discussed in Chapter 5, peer support can be delivered in many different forms depending on the model chosen. Whilst some of these models have been tried and tested by individual burn services and charitable organisations (Batchelor & Williams, 2013), further developments might have been difficult due to a commitment to the standards of care dictated by the NHS more widely. For example, NHS England (2019) wrote that, whilst it is well documented that standards and performance targets have encouraged improvements in care and outcomes, in some cases the same targets can restrict the ability to innovate.

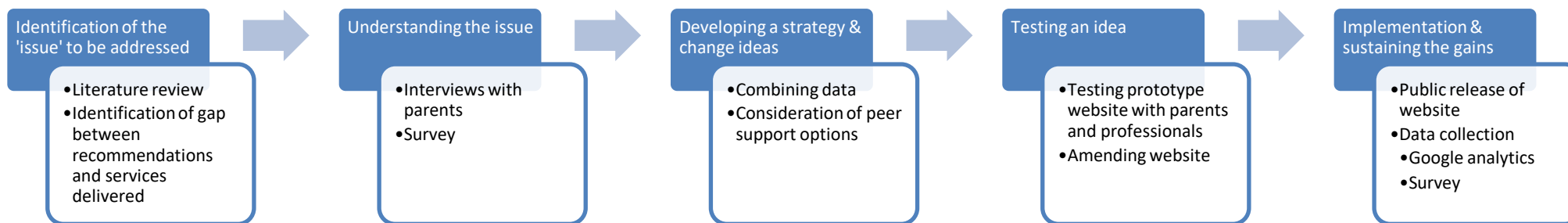


Figure 13. Five stages of the research

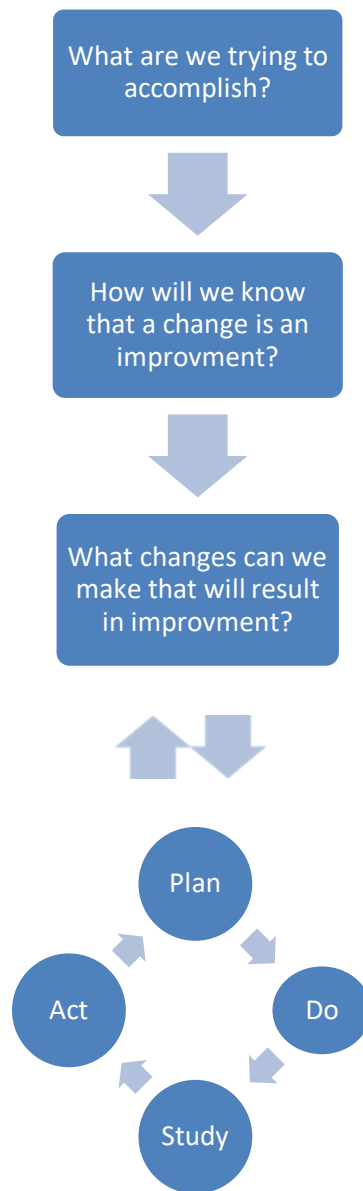


Figure 14. PDSA cycle (Deming, 1986)

It was recognised that, throughout a family’s post-burn journey, the occurrence of strong parental emotions concerning the burn-event and their long-term impact called for clinical care initiatives (Bakker, Van der Heijden, et al., 2013). Whilst websites can never replace the services offered by the NHS, or address the challenges faced by these services, it is hoped that the completion of this PhD, and the development of the innovative resource [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) will support NHS burn services and charities in providing the best care to patients and families. Thereby supporting the aims of NHS England (2019) in ensuring that their standards promote safety and outcomes, drive improvements in patients’ experience, ensure the most urgent patients are given priority, ensure patients get the right service in the right place, and do not



worsen inequalities. The availability of a trusted source of online support may mean that, in line with models of stepped care, some parents might be initially directed to this resource by clinicians, leaving clinicians with time to prioritise those in more urgent need of support in the first instance. Having a resource that parents can access online, at a time and place that is right for them, providing advice for self-care, whilst also normalising access to support, and directing parents to different forms of formal and informal support, may mean that more parents find that their needs are, or can be, met. For example, seeing that their experience is shared by others in similar situations and that, to some extent, their own experience is to be expected, could facilitate parents in making a shift to feel that their own concerns are valid and their wellbeing is important. If parents can make this shift, then they might be more inclined to acknowledge their feelings and seek support for themselves. This might be especially true if this is positioned as being ultimately helpful for their child.

Before considering the application of the PDSA cycle in this process, the question, 'what are we trying to accomplish?' needed to be considered. Following the identification of parent-perceived barriers to accessing psychosocial support following their child's burn injury (Study 1), the primary objective became the facilitation of parents' access to this. To do this, exploration of parents' experiences and support needs was required. With parents preferring support from 'someone who has seen it before', initially, my predictions were that a peer support group would be desired but the PhD would need to examine ways to overcome challenges to group recruitment and the maintenance of parents' interest, as was found by Batchelor and Williams (2013) when looking at peer support groups for adults with burn injuries. However, this turned out not to be the case, with participating parents suggesting that online peer-informed support might be more accessible and beneficial to them (Chapters 4 and 5).

It was necessary to consider, realistically, what changes could be made that could result in improvement. For the provision of online support to be the direction of the PhD, it was important to take into account the risks and benefits, not only from the parents' point of view, but also from a professional point of view. Any decisions also had to consider practical aspects such as funding and longevity beyond the PhD itself. For example, in the development of online peer support, it would be unrealistic to pursue the development of a moderated peer support forum without assurances that there would be appropriately trained people to moderate it. Finally, it was necessary to consider, following the release of an online resource, 'how will we know that a change is an improvement for parents?'

Considering the experiences that had been articulated in Study 1, and the results of the survey in Study 2, the next phase of the work was the entry into the PDSA cycle (Figure 14). The prototype website content was designed to attempt to address as many of the experiences described by

parents as possible. The prototype website was created and tested in Study 3 with a group of parents, some who had participated in the earlier research, and also with burn care professionals. Those testing the prototype generally spoke highly of the resource but made suggestions for improvement prior to its public release. This emphasised the importance of public involvement in the research process and the necessity of studying a potential intervention before ‘acting’. Parents participating in Study 3 (the feasibility study of the online peer-informed intervention) spoke of the need for such a resource, made suggestions to enhance user navigation, to increase the trustworthiness of the website, and to enhance its relevance to members of different cultural groups as well as to mothers, fathers and others with caring responsibilities.

Following the necessary changes, the website was publicly released on UK National Burns Awareness Day 2018, with an online survey (accessible from the website’s feedback page) and Google Analytics enabled to collect data on its real-world performance. Although at submission of this PhD, the data collected was still from a limited self-selected sample, it suggests that the website is highly acceptable. Within the first six months, the website was being visited by people across the world with 13.6% of users visiting more than once. Although feedback suggested that the resource “filled a gap in the market” [parent, Study 3], no research into the impact that [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) has had on the psychosocial outcomes of parents of burn-injured children has been carried out.

## **9.2 Reflection on the research methods used**

A pragmatic, mixed methods approach was used for the studies in this thesis, focusing on the most appropriate method of answering each research question (Johnson & Onwuegbuzie, 2004). It has been suggested that mixed methods can offer a range of benefits (Doyle, Brady, & Byrne, 2009) including triangulation (corroboration between qualitative and quantitative results), completeness (combining approaches to provide a more comprehensive representation of the phenomenon studied), and explanation of findings (using one approach to explain the findings from the other). However, there is a great deal of debate within the research community about the suitability of mixed methods, with several criticisms being directed at the approach due to differences in terms of ontological, epistemological and methodological assumptions underpinning qualitative and quantitative methods.

Johnson, Onwuegbuzie, and Turner (2007) emphasize the importance of understanding the strengths and weaknesses of qualitative, quantitative and mixed research, and recognising that each approach is significant in varying circumstances. Quantitative research is considered by many to be the ‘gold standard’ (Doyle et al., 2009), suggesting from an ontological and epistemological perspective that there is a ‘single truth’ in the world, which can only be uncovered by objective measures of confirmation (Johnson & Onwuegbuzie, 2004). While quantitative techniques may be

effective, they may also be limiting when used as the sole technique within psychosocial research. Rejection of the qualitative view that reality is created by the participants involved in the research, and uncovered through the researcher's interaction with these participants (Creswell & Creswell, 2017), means that the researcher is likely to prevent themselves from reaching a true understanding of the social and cultural contexts of the research question.

This PhD was approached with a degree of inter-subjectivity, accepting that individuals may differ in their unique perceptions and interpretations of the world and their experiences. The pragmatic approach lends itself to answering 'real world' questions in a practical way, reducing restrictions imposed by a strict adherence to the principles of positivism or constructivism (Feilzer, 2010). However, it is important to recognise the limitations of that approach. Methodologists have not yet created a definitive pragmatic technique for conducting mixed methods research (Johnson & Onwuegbuzie, 2004), although this should not restrict the approach as a paradigm within research as other research paradigms also poses inconsistencies (Denscombe, 2008). Therefore, mixed methods should be viewed as a way of combining approaches to ensure the best chance of answering specific research questions (Doyle et al., 2009), and each study within this PhD utilised a different approach, with a mixture of both quantitative and qualitative techniques as deemed appropriate.

As well as using mixed-methods, this PhD also employed multiple methods of qualitative data collection in Study 1. Whilst this facilitated parents' engagement and participation in the research, it posed challenges in terms of the data collection process. Challenges included seeking clarification on responses and ethical concerns about the timing of responses. These factors impacted on the depth of data that was collected by the various methods with face-to-face or Skype interactions producing the most in-depth data, and email interviews providing the least in-depth data (Heath et al., 2018).

Triangulation of results requires the comparison of the qualitative and quantitative findings to assess convergence/agreement or dissonance/disagreement between the two techniques (O'Cathain, Murphy, & Nicholl, 2010). The convergence of results between Studies 1 and 2 using different techniques, and then in Study 3 which used mixed methods, suggested that the findings were credible (Fetters, Curry, & Creswell, 2013). Whilst Mason (2006) recognised that findings do not necessarily have to be "neatly consistent to have meaning and to have the capacity to explain" (p. 20), the sources of the differences should be explored where dissonance does occur (Farmer, Robinson, Elliott, & Eyles, 2006). Rather than assuming that either one of the qualitative or quantitative techniques must be incorrect, inconsistencies may simply relate to the way that objective outcome measures evaluate one aspect, such as performance/functioning, whereas qualitative techniques explore subjective views (Slonim-Nevo & Nevo, 2009).

However, this complementary approach suggested by Slonim-Nevo and Nevo (2009) may introduce difficulties when research is used to influence changes to practice or policy recommendations. For example, the British Burn Association (2018) now recommend that burn care staff facilitate patient access to a range of support resources (including websites), and whilst quantitative data from Study 3 suggested that the prototype resource was well received, the qualitative data highlighted all of the areas that needed attention prior to the public release. Therefore, when research is relating to the efficacy of interventions, inconsistencies such as these could reduce the impact of the findings, without further exploration of the difference (Erzberger & Prein, 1997).

For this PhD, mixed methods research was appropriate and enabled the aims of the research to be achieved within each study. To enable future research into peer-support or peer-informed support interventions within burn care to fully explore the range of opinions and experiences regarding different aspects in terms of form, function and impact, it is recommended that, where appropriate, mixed methods with public involvement continues to be employed. Public involvement is valuable when considering how to address specific research questions and make any subsequent changes in care practices or services as it has been noted that health care practitioners often fail to involve users in the process with the result being that many interventions do not effectively reflect the needs of specific populations (McDaniel et al., 2004; Nikolova-Houston, 2005). However, a challenge in relation to identifying which parents are likely to be engaged in online and/or peer interventions is that parents who agree to participate in a particular intervention may not consent to participate in a research study about it and vice versa (Paterson et al., 2013).

It is also important to consider recruitment into studies such as these. Consideration was given to ways to maximise recruitment given the sensitive nature of the subject under investigation as well as to recruiting a representative sample of parents and children accessing UK paediatric burn care in Chapter 3. Despite this, throughout this research there have been low recruitment rates resulting in small sample sizes (although, as discussed in Chapters 3 and 4 this is not always problematic). In order to highlight the most effective way of recruiting parents into research such as this, Studies 2, 3 and 4 included a question which asked participants how they found out the study in which they were participating. At this point, it is important to note that this PhD did not recruit participants directly from the NHS as NHS ethical approval was not sought. Therefore, recruitment into Studies 1 and 2 (prior to the introduction of the General Data Protection Regulation on 25<sup>th</sup> May 2018) was largely carried out via the CAR participant pool, which was an existing mailing list of parents of burn-injured children who had signed up to receive information about psychosocial burn care research that may be relevant to them. As this method could create

bias in the sample, with these parents already being highly motivated to participate in research, in addition to this, the research was advertised online via social media and charitable organisations to attract those outside of current burns research activity.

Parents in the CAR participant pool had previously been recruited from different NHS services and consented to their contact information being retained by CAR and used for this purpose. As demonstrated by the participant demographics in Studies 1 and 2, this allowed a largely nationally representative sample to be obtained, although the sample lacked representation of parents from ethnic minorities and fathers. It is likely that a presence at an NHS site and recruitment directly from clinics could have led to larger samples of parents as obtained by Hawkins et al. (2019) in a UK study of parents' adjustment following paediatric burn-injuries. However, this could also have meant that participants would be recruited from a limited number of services and therefore have limited geographical diversity and a more homogenous experience of burn care. Recruitment from NHS services would also likely mean that many of parents would have been recruited within the first two years post-injury as many patients are discharged following scar maturation at approximately two years. Using the employed recruitment methods obtained samples for the first three studies of parents with experience of life post-injury ranging from 0.0 to 17.2 years.

The use of a mailing list of parents previously recruited into burns-focused research at CAR (Griffiths et al., 2017; Griffiths, Rumsey, et al., 2015) also meant that many newly affected families may not have been made aware of the work being done or may not have recognised (or taken) the opportunity to become involved. Although the data collection does not entirely support this. Whilst the method of recruitment attracting the most participants in Study 2 was the CAR participant pool (38%), the second most successful method was via communication with burn care professionals (32%). In Study 3, this was also cited as the way in which most participants found out about the study (61%). Burn care professionals were made aware of the work via conference presentations and at SIG meetings.

Whilst it may have been the case that clinicians and care teams were able to recognise families ready to take a more active role in research and resource development, reliance on professionals to disseminate information about research opportunities can be problematic due to gatekeeper bias (Grogger et al., 1999). In addition to gatekeeper bias, another factor limiting research participation may have been time pressures that parents felt they were under, as this was also a barrier identified during this research to accessing support. Gatekeeper bias does not seem to have been problematic in this research and in Study 4 it can be seen that social media was effective in facilitating recruitment, with 48% of participants in that study hearing about the research online. Public involvement will be invaluable for informing future research with regards to the most effective methods of recruitment to encourage parent involvement in burn care

research in general, such as whether or not to recruit from NHS services directly. It seems that recruitment following sharing information about the research with burn care professionals as well as social media could be particularly effective, in addition to the use of GDPR compliant participant pools. In relation to any further research that involves [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), it would also be valuable to learn more about the use of 'pop-up' adverts on the website itself (an ethical issue discussed previously).

### **9.3 Discussion of findings in relation to wider literature**

Peer support is ubiquitous, and it is evident from the interviews in Study 1 and the online survey in Study 2 (described in Chapters 4 and 5) that parents of burn-injured children do seek it. However, as discussed in Chapter 6, the emergence of peer support and engagement with the opportunities available within burn care has been limited in the UK (Batchelor & Williams, 2013), despite some conditions, such as cancer, having many peer support systems delivering this form of support. Research has found benefits of peer support for adults who have experienced burn injuries (Kornhaber et al., 2015; Tolley & Froushani, 2014) and so it is important to reflect on the theory behind the benefits and limitations of peer support, to understand the mechanisms responsible, help to predict the effects, and influence better outcomes in the development of peer-informed support for parents. In an attempt to understand why this resource received such positive feedback and what the effective 'ingredients' of the website might be, it is important to consider different theories of peer support and such discussions have most frequently focused on peer support for people with cancer. However, the experiences and support needs of adults with cancer and parents of burn-injured children are quite different, therefore comparisons made between these two areas should be done with caution.

Van den Borne et al. (1986) reviewed 18 studies on the effects of contact between cancer patients, finding that most studies do not satisfy the methodological conditions necessary to draw firm conclusions. As some studies were not well-grounded in theory, and with poor methodology, conflicting hypotheses were generated. Of those studies deemed to have a sound methodological design, four out of six reported positive effects of peer support. None of these studies found a negative effect of peer contacts and so it was concluded that group contact may improve the coping process. It is noteworthy that common problems neglected by researchers as criteria for effectiveness in these studies were those highlighted as significant by parents of burn-injured children, such as uncertainty, losses, and negative feelings like loneliness.

Just as Cahners and Bernstein (1979) described the apparent comfort parents gained from retelling their experiences to those who had shared a similar experience, in another review of 25 studies of peer support in the context of cancer care, it was suggested that peer support programs helped by providing emotional and informational support from the perspective of

shared personal experience (Dunn et al., 2003). Whilst the sharing of personal experiences may be helpful for some, this research highlighted that other people can be wary of misinformation, particularly on the internet.

The nature of online discussions is often based in personal experience which can result in the sharing of misleading information (Sharf, 1997). Participants in online groups have little control over the number or behaviour of other participants (Till, 2003). Therefore, such potential issues can leave patients feeling vulnerable and without support to resolve abusive, unsupportive or confrontational online discussions. Whilst the same could happen in face-to-face or group support, most of those who lead peer groups receive training and ongoing supervision from sponsoring organisations and can respond to inappropriate behaviour (Campbell et al., 2004).

When considering these issues, it may have seemed intuitive to pursue the development of a peer support group, particularly as 63% of participants in Study 2 reported that they would like access to such a group. However, it is also important to consider the business of running a group, such as fundraising, training, advocacy, public relations and outreach activities that become the responsibility of different stakeholders. These activities may reduce the emotional and informational support benefits for peers involved in such activities (Campbell et al., 2004).

Within this PhD, participants also advocated for an online resource with nearly half of participants stating that access to a face-to-face group would be too difficult or demanding for them. As discussed earlier, without access to volunteers who would be willing to offer such support in an online environment, it was not appropriate to attempt to provide interactive online peer support within the context of this PhD. However, [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) was created with the capability to host a forum should feedback from its ongoing evaluation suggest that this is the next step in its evolution. To date, none of the feedback received from the public website has suggested a need for a forum.

Macvean et al. (2008) reviewed 28 studies of peer support finding that most papers reported the programs to be beneficial, yet few presented data from studies using rigorous research methodologies to support those claims. This criticism can also be held against this work as, whilst users suggested that the website was useful, evidence of the benefit does not exist at this stage and should be a priority for future research. Another criticism that has already been raised within this thesis is that most studies recruited female participants and so the appropriateness of this kind of support for males is not well studied.

Klemm et al. (2003) reviewed the literature focusing on computer-mediated or internet cancer support groups, finding that 90% reportedly helped patients to cope, but studies mainly focused on women and lacked experimental rigor, with small and homogenous samples, and a lack of

outcome measures, thereby limiting applicability of results. Gottlieb and Wachata (2007) reviewed 44 professionally-led support groups, again finding limited support for men. However, as noted previously, it may be that men lurk and choose not to actively participate in research or resource development such as this. Men's lack of involvement does not necessarily mean that there will be limited benefit for fathers, but more research in this area is needed. Particularly as it has been demonstrated that fathers and mothers may respond to the burn event differently, with women being more vulnerable to the development of PTSD than men after a traumatic event (Stein, Walker, & Forde, 2000) and exhibiting higher levels of stress symptoms after a child's burn injury (Bakker et al., 2013).

Within cancer-focused peer support, it has been suggested that connecting diverse cancer survivors (male and female with different cancers) to culturally appropriate, evidence-based online support and resources is a strategy to enhance health outcomes (Hong, Peña-Purcell, & Ory, 2012). One way of increasing the different types of support available to parents of burn-injured children would be through the development of more generic support for parents of children with other appearance altering and/or traumatic injuries. There is an ongoing debate within appearance research as to whether or not research and support should be condition-specific (Harcourt & Rumsey, 2012), and a new website [childtraumarecovery.com](http://childtraumarecovery.com) was released in May 2019. The Child Trauma Recovery website aims to provide parents and caregivers with help, advice and reassurance after their child has experienced a frightening or traumatic event. Despite one section on 'looking after yourself', the focus is largely on support for the child rather than the parent, with the website informing the reader about the reactions of their child, how to help them to cope, and available resources and services for the child.

The development of generic resources may mean that the 'pool' of parents interested in both providing and accessing peer support may be larger, however key differences in the cause or mechanism of injury or disfigurement may mean that generic support is felt to be inappropriate. For example, due to the preventable nature of burn-injuries, many parents feel shame or guilt (Hawkins et al., 2019). These experiences may not be shared, at least as acutely, by parents of children with a birthmark or cleft lip and/or palate. Such feelings may also act as barriers to parents of burn-injured children accessing or engaging in support (Hawkins et al., 2019). The potential downside of increasing peer diversity was also raised in the context of burn severity in Study 1, with one parent not feeling able to relate to parents of children whose burns were smaller or less severe than their own child's burns. This was also supported in Study 2 with 88% of participants agreeing that it would be important that peer support was from other parents whose child's injury was similar to their own child's injury.



Within peer support, it is important to consider such differences carefully as social comparison - the drive for self-evaluation through comparison with others (Festinger, 1954) – can mean that those accessing a peer support resource make upward and downward comparisons depending on the experience shared by another. These comparisons can lead to behavioural and affective outcomes, and it was important to consider the basis on which parents might compare themselves with others in the intervention offered. For example, it was decided not to include pictures of other children’s burn injuries on the website since images of scar progression that might initially offer hope may later cause disappointment if they become an unattainable outcome.

Another theory that may have a key role in whether or not peer support is effective is social identity theory. This is because self-identity and self-concept are challenged by adversity such as a burn injury, particularly when stigma is also present (failing to protect), as this causes identity conflict. Identity conflict may lead to social action, such as engagement with peers, and the construction of a new social identity (Legg et al., 2017). When such action brings the person into contact with others, a person's past experiences, expectations, and reinforcements will influence whether and why a person chooses to engage in a specific behavior, such as utilising peer support in order to help others (Legg et al., 2017). This is important when considering engagement in peer support because, according to social cognitive theory, engagement may be better when similarity is perceived between oneself and others engaging in that activity. A study by Legg et al. (2017) identified two contrasting images of peer support consumers based upon women's perception of similarity to that image. Women who felt dissimilar to peer support members described the typical peer support consumer as worse off in their unmet need for social support. Women who felt similar described the typical peer support consumer as psychologically resilient. These findings suggest that if we are seeking to build a supportive peer community, positive images that portray strength and effective coping may be more acceptable to women than images about struggle and isolation.

It may be important to consider social cognitive theory further in future research of the website and in the designing of promotional material and messages about [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk). However, the website was developed with the aim of meeting unmet needs. This theory supports the need for advertisements that portray strength and resilience rather than the potential of the intervention to help meet unmet needs. Following the study of the prototype website, the recommendations to add elements such as ‘Top Tips’ and additional information about positive growth suggested that the importance of strength and effective coping may have also been important and relevant to parents involved in this research. The addition of these elements may have contributed to the higher eHIQ scores obtained for the

public version. In a social cognitive theory based approach, the connection of shared personal experience provides insight into effective ways to cope, decreases social isolation, and promotes hope and optimism for the future (Legg et al., 2017). If parents can be supported to connect with the experiences described through the stories and/or quotes on the website, then it may be more likely that they will engage with the information and advice that the website has to offer. This could then be transformative and lead to participants describing post-traumatic growth (Legg et al., 2017).

Although peer support can be very beneficial for many people and is often cost-effective, it is important to consider it as a unique care model based on shared experience, not a less expensive version of professional care (Heisler, 2009). Professional care providers cannot provide the peer benefits of role modelling and social comparison and it must also be acknowledged that peer support cannot replace professionally-led support, particularly in contexts such as burn care when the input of a multidisciplinary team is vital for optimum recovery (National Network for Burn Care, 2013). However, peer support could add to professionally-led work and should be a valuable part of integrated support, particularly in a context in which no single intervention will appeal to, or be suitable for, everyone. This is recognised by the BBA who include recommendations for peer support in the burn care guidelines (British Burn Association, 2018). For peer support to be better integrated into the care model for all of those affected by burns, more evidence of what works and for whom needs to be generated in order to inform any infrastructure, training, leadership and support required for its sustainability.

#### **9.4 Areas for further research**

Reviews of the peer support literature have highlighted limitations in research that evaluates it. There is a lack of research (particularly of well designed, adequately powered research) and gaps also exist between theory and practice (Dunn et al., 2003; Hoey et al., 2008). Dunn et al. (2003) suggested that the difficulty studying peer support may be due to the inherent difficulties in isolating a naturalistically occurring interpersonal dynamic from the complex social and community contexts in which it arises. It may be simpler to explore the impact of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) as interactions with this peer-informed resource are intrapersonal rather than interpersonal.

[SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) can be evaluated in several different ways. Data regarding access, use, satisfaction, impact, and value can be collected but what is key is that there is an action research cycle (Dick, 2015). Future research needs to be participative, rigorous and cyclic, considering the original aims, outcomes, and interests of all stakeholders. For different stakeholders the scope may be different. For example, as the developer of the website, I am currently interested in process level details such as new user numbers and acceptability.

However, as a psychologist, along with professionals within burn care, and those involved in future research into the impact of this intervention, I am also concerned with outcome level details that move beyond acceptability, such as returning user numbers, whether needs are met, and whether this resource improved psychosocial outcomes for users. A service evaluation could be carried out in collaboration with members of the BBA Psychosocial SIG in which burn services ask parents who access support whether they have heard of the website and viewed it, and, if so, whether they found it beneficial or whether it influenced their decision to seek further support or not, in order to understand more about patient experiences and outcomes regarding the website. Data gathered could inform further work to ensure that it is meeting the needs of parents as intended.

The value of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is already indicated by the traffic that it is receiving following its public release, with some users returning more than once, and the positive feedback collected is an indication of user satisfaction. However, it is important to be mindful that use of the resource does not necessarily equate to a positive outcome. Therefore, there is also a need for further research to investigate why parents do or do not engage in online interventions such as this. Understanding more about the attributes of online interventions that will attract and retain their engagement is vital in order to ensure that as many parents benefit from the resource as possible (Paterson et al., 2013).

It has been recognised that peer support can offer practical/instrumental support, assist with coping, decrease anxiety and depression, and increase knowledge of a condition (Campbell et al., 2004). At this time there is no indication of whether or not parents engage with, or implement, the information and advice provided through [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk). It would be valuable to set up a pre-post designed study with paediatric burn units in which psychosocial outcomes such as depression, anxiety, hopelessness, guilt, self-efficacy and self-esteem are measured with robust psychometric measures before parents view the website, and then several weeks later after a period where they have had chance to view it in their own time.

As this research has demonstrated that there are practical and psychological barriers reducing their access to support, it would also be valuable to know whether parents' engagement with the material on the website increases their engagement with other organisations, such as the NHS or charities. Does normalisation and validation mean that parents are more open to support-seeking, and therefore are these organisations seeing a rise in people feeling able and willing to talk about their experiences? Are more people seeking peer support following normalisation of their feelings provided by the peer voice throughout the website? Or, are the services seeing a fall in those accessing support as they think that their needs have already been addressed? Even if services did report an increase in parents accessing them, ascertaining whether or not this was because of the

website would be difficult to establish because there are potentially so many other factors/influences at play. In an attempt to establish impact of the website in this way, burn services could ask parents who access support whether they have viewed the website and found it beneficial, or whether it has influenced their decision to seek further support or not in order to ensure that it is meeting the needs of parents as intended. The application of theoretical models, such as Social Comparison Theory (Festinger, 1954), Social Information Processing Theory (Walther, 1992), and the Buffering Effect Model (Cobb, 1976), to future evaluation designs will further increase understanding of the psychological mechanisms involved in potential health-related benefits of participation in peer support and inform its future development (Coulson, 2017; Legg, Occhipinti, Ferguson, Dunn, & Chambers, 2011).

There is a need for strong, rigorous evidence guided by theory in the evaluation of support for parents, and peer support generally, but also the impact of this newly developed intervention. If it is identified that [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is not meeting parents' needs, then the data can be used to inform changes to be made, or even for a new model of peer/peer-informed support to be developed and tested in a new PDSA cycle. For such research to take place, recruitment of parents from NHS burn services would be beneficial to increase sample sizes.

It would also be valuable to study how and when users interact with the website.

[SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) was designed to be compatible with mobile phones, tablets and PCs but the fact that it is text heavy means that it is easier to navigate when accessed on a computer. This is because less scrolling is involved to read the text and see the subheadings within each section. Although the website theme is compatible with mobile phones, the emergence and dispersion of an 'app' culture means that the normal mode for accessing information is now via mobile phones (Purcell, Entner, & Henderson, 2010) and often this is via apps rather than websites. During the testing of the prototype, the website was presented on a laptop or desktop computer and therefore feedback was based on parents and professionals viewing it in this format. Now that the website is being accessed by professionals and parents from around the world, it would be interesting to know whether satisfaction with this peer-informed resource is equal across those accessing it by phone and those accessing it via a computer. It may be the case that users would prefer the website to be modified and delivered via an app that is better suited to presentation on a mobile phone.

As Google Analytics can indicate the most visited pages of the website, it is possible to start to consider how this data might enable the tailoring of advertisements to communicate the elements which are considered most important to new potential users. These findings could also prompt local conversations within burn services between parents and health care professionals about the aspects of burn care that parents might need more support with. For example, parents

could rank different factors as being more or less important to them and then these could be explored and responded to as appropriate by the service (Patel & Pagel, 2018).

Further research could also explore factors such as sex differences (mothers versus fathers), aspects of the child's injury (e.g. whether or not they were hospitalised and the age of their child when the injury occurred), and time since injury in the use of the website. Exploration of pages of the website visited by mothers versus fathers, parents of younger children versus older children, or newly injured children versus a longer duration since injury, may highlight different needs. For example, if bounce rates are higher for one group than another, then this may be indicative that the website does not address their needs as well as it might for others who remain on the website for longer. However, this is also difficult to interpret without qualitative data because if parents are looking for a specific answer then the number of page views will be low, time on page likely low, and bounce rate high. With fewer males (fathers/grandfathers) contributing to the development and content of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) than females, they may not find that it addresses their needs as well as it might for mothers. Therefore, it may be necessary to consider a new PDSA cycle initially with the aim of promoting the resource to fathers, accessing whether their needs are adequately met, and making any necessary amendments. This can then be repeated for different identifiable groups.

The fact the [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) could be used as a training resource was also raised in Study 4 in the qualitative feedback received from professionals. The NHS has been collecting data on patients' experiences of care but this information is rarely used to improve services (Coulter, Locock, Ziebland, & Calabrese, 2014). As well as using resources such as this website to support and educate patients, the peer voice, often hosted on the internet can also facilitate education of staff. Training that raises awareness amongst all health professionals who are likely to be in contact with parents of burn-injured children (for example, those in primary care, trainees, and qualified professionals) of the stresses that parents are under would be invaluable. Psychologists within burn care are also often involved in delivering psychosocial education to the multi-disciplinary team. With staff on different shift patterns, and in the busy hospital environment, it can be difficult to deliver training to a wide enough audience to make a significant difference to practice. Resources such as this website can allow professionals to access training resources (such as parent stories) at a time and location that suits them best. An investigation into the value of this resource for staff training would be another valuable insight into its impact.

#### ***9.4.1 Involving health professionals***

For [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) to be of benefit to parents, they need to know that it exists. Data shows that parents do find it when searching for information relating to paediatric

burns and the website also receives returning visitors. However, it will continue to be important for the website to be promoted to those working with families, whether they are professionals working within burn care, GPs, or non-healthcare professionals, such as those working in education and social work. Burn Care Advisors work with the non-specialist burns community and could be one avenue to continue to promote the website to families, as well as further media coverage facilitated by annual promotion on UK National Burn Awareness Day. Patel and Pagel (2018) identified difficulty in engaging health care professionals as a major barrier to referring people to peer support. Therefore, to improve parent referrals to, and recommendations of, [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), it is important to ensure that healthcare professionals know about it and to understand whether they need, or would value, any more information about its content and development to increase their willingness to recommend it to parents (Patel & Pagel, 2018).

Another important area of work could be involving professionals in considering ways in which information about wound healing and scar progression could be provided to parents. Whilst it is possible that a visual guide for scar progression and treatment would be valuable, as this is what many parents reported to search for on the internet, parents also recognised that everyone is different and what is useful for some might not be for others. Carefully selected images could be incorporated as educative examples. As previously discussed, this would need careful consideration in order to manage parents' expectations.

There are also issues such as the practicalities of hosting and funding a website in the longer-term. A performance report, written at the end of the first year since the live release, will gauge whether the website is continuing to be widely used and this will be submitted to the BBA and relevant charities such as the Children's Burns Trust and Dan's Fund for Burns to ascertain whether they would be willing to fund its continued existence. It could then be that a group such as the BBA Psychosocial SIG, who already has members delivering national training, works with CAR going forward to update the website periodically based on any feedback received. Since the live release of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), feedback regarding the content and requests for information or updates have not been received from parents or professionals via the website's contact form. Although professionals have made some suggestions, such as the inclusion of pressure garment care guidelines and the addition of a link to a newly developed trauma website during face-to-face meetings. If, in the future, updates are made, a subscription service could be created where automated emails are sent to subscribers to advertise when updates have been made and new content exists. This could encourage parent engagement and, depending on the content, potentially also the continuing professional development of staff.

The involvement of all those dedicated to the delivery of burn care is vital to ensure that the available information is up-to-date and helpful. Not only is this important to ensure that parents receive accurate information, but new content also helps to optimise the website for search engines. Although the resource has been co-designed with parents, it is important that professionals lead on decisions regarding future new content to ensure that the information targets the needs identified by parents, rather than presenting irrelevant, unhelpful or potentially damaging information. Such unhelpful and potentially harmful information could be the careless use of images of burn wound and scar progression that were often requested by individual parents but are likely to not be helpful for all.

#### **9.4.2 Public involvement**

If it is felt that [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) requires further development by those who deliver burn care, then involvement of parents is vital, whether these are parents interested in supporting others or parents seeking support themselves. Increasing attention on the importance of self-care and self-management in healthcare services contributes to effective partnerships for coproducing good outcomes (Lorig et al., 1999; Taylor et al., 2014). Seemingly the most important factor influencing whether someone chooses to access peer support or not is whether the service is easy to access. This has been found to be more important than the ability to access it quickly (Patel & Pagel, 2018). If we lack understanding about why parents are choosing to access this resource (or not) then it will be difficult to develop it further and promote it effectively. Peer support is unlike many other clinical interventions in that it can be available to all without a prescription. As this resource has been created without reference to burns of a certain size or with a particular cause or treatment, potential users and beneficiaries of the website are any members of the public who have supported a child with a burn-injury. Therefore, it is crucial to understand the viewpoint of parents who choose to use the website as well as those who do not (Patel & Pagel, 2018).

A next step in public involvement with parents could also be to consider the value of extending this research to look at supporting parents of young people or adults with burns. Whilst this research did recruit some parents of older children/young people at the time of injury, most injured children were much younger when they experienced their burn. Although fewer older children experience burn injuries than younger children, their needs, and therefore their parents' needs, may be different as the mechanism of injury, and therefore the responsibility felt by parents, changes. This is highlighted by evidence that differences should be expected in the role of parents' appraisal and emotions after a child's burn injury between parents of young children, school-aged children, and adolescents (Vloemans et al., 2011). Therefore, it is likely that there are some families for whom certain aspects of this website may not be as well suited. If this was found to be a problem, a resolution could be the development of website sections that present

information for parents of children in different age groups. I know from my clinical work that parents of adults with burns can also be unsure of how to best support their 'child'. However, for parents of adults with burns, it may be that a different mode of support is more appropriate or accessible, as it is important to consider the demographic of the audience and develop the most appropriate support for them to access.

The relationships within and between groups of patients and professionals are key to a co-design partnership and, during coproduction, roles for patients and professionals can blur (Batalden et al., 2015). The co-creative relationship has different levels (Batalden et al., 2015). At the first level, co-production requires discourse with respectful interaction and effective communication, such as that occurring in the interviews of Study 1. Shared planning then invites deeper understanding of the expertise and values of patients and professionals and this occurred in Study 3 (the feasibility study of the online intervention). Shared execution requires deeper trust, development of shared goals and increased shared responsibility and accountability for performance. This level of co-production was not reached within this PhD, but it could be a future goal.

A concern about coproduction is that the model may appear to diminish the value of professional expertise by transferring care responsibility to patients and families (Batalden et al., 2015). However, when considering power and responsibility within this type of work it is important to note that, whilst many might welcome opportunities to engage with their healthcare professionals at a discursive level, the idea of mutual accountability for outcomes is controversial (Ewert & Evers, 2014). It is neither possible nor desirable to share power and responsibility equitably between patients and professionals in all situations. As discussed in Chapter 3, not all parents of burn-injured children have the desire or capacity to be active participants in coproducing their own and their peers' source of support. Some parents need a health professional to relieve a burden rather than to facilitate self-care, whilst others may need to access self-care resources initially before deciding whether to access professionally-led care. The burden of responsibility for 'error' within healthcare must also fall disproportionately on healthcare professionals (Batalden et al., 2015). Whilst it was necessary to involve parents in the development of [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) to ensure that it was acceptable to them as the target audience, the responsibility had to lie with the research team and healthcare professionals to ensure that it was appropriate. This would safeguard against potentially unhelpful developments, such as the addition of images (even when parents spoke of searching for them on the internet anyway, a behaviour that might be considered unwise or unhelpful by the burn care team).

Despite the challenges, it is vital to remember that each level of coproduction requires specific knowledge of the subject matter and processes, dispositions and behaviours and therefore there



are challenges to the application of such a framework. For example, it is clear that there was a lack of diversity among parents in this program of work. Whilst parents were recruited from different sociodemographic backgrounds and geographical locations, thereby with disparate coproduction dispositions and capacities, the sample was not ethnically diverse.

### **9.5 Final reflection**

The original aims of this program of work were to: (1) provide an in-depth exploration of the experiences and support needs of parents of burn-injured children, from the perspective of parents themselves, before (2) developing an intervention that would be accessible and meet the needs identified. Following the trauma of a child's burn injury, parents have a unique and integral role in their child's medical care and psychosocial recovery, most notably emotional containment. However, the impact of a child's burn injury and associated treatment impose significant psychological and practical challenges on parents. Investigating parents' experiences and peer support for parents in Studies 1 and 2 led to the identification of that fact that there were limited peer support opportunities for parents, compounded by psychological and 'real-world' barriers to accessing that support which was available to help them to cope with these challenges (Heath et al., 2018).

During this program of research, parents' experiences of support and their opinions regarding their preferred mode of support was assessed. Study 2 found that parents preferred professionally-led support to be in a face-to-face format but that they would prefer peer support to be online. Therefore, there was consideration of how an online peer support resource could effectively address parents' needs before a prototype website was created and tested in Study 3, then modified, prior to its public release (Heath et al., 2019).

The provision of information for parents, not only on how to support their child but also about why they might be feeling the way they do, may reduce the distress experienced by parents during this time (Garland & Kenny, 2006; Piira, Sugiura, Champion, Donnelly, & Cole, 2005; Simons, Franck, & Roberson, 2001). Normalising the common difficulties and challenges experienced by parents, as well as the act of help-seeking, was felt to be important. The accessible peer-informed resource developed could also act as a hub to share up-to-date information about where parents and family members could find other sources of support. It was hoped that this resource could help to reduce parents' sense of isolation and normalise speaking out about their experience, factors that could potentially help them to overcome some of the barriers to accessing currently available psychosocial support.

When recommending or referring to peer support, it is important for professionals to know that evidence exists that the intervention in question makes a positive impact. For users who have not

previously engaged in peer support, a belief that it will improve health and wellbeing is also a necessary prerequisite to engaging with it (Patel & Pagel, 2018). Knowing that the intervention is endorsed by a health care professional is also important to the potential user (Patel & Pagel, 2018).

[SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk) is now available to people from all over the world and Study 4 has shown that it has been well-received by parents and professionals alike. It is hoped that these positive preliminary findings regarding the acceptability of the website, in addition to the active involvement of professionals and parents of burn-injured children in the development of it, means that professionals will feel able to endorse the website and parents will feel confident that it can be of benefit.

Developing the peer-informed website, [SupportingChildrenWithBurns.co.uk](http://SupportingChildrenWithBurns.co.uk), has been incredibly rewarding. The website offers psychoeducation, information, and peers' stories to facilitate coping, decrease isolation, and share experiential information from parents to parents. In addition to describing parents' experiences of the injury, treatment and support, this thesis has presented the process of the development of this new resource, in addition to ideas regarding research to support its sustainability and development into the future.

Considering the doctoral descriptors for a PhD, this thesis has provided a critical overview of the current knowledge regarding the experiences of parents of burn-injured children and the field of peer support. Using both qualitative and quantitative research methods to conduct original research, new knowledge has been created and interpreted, not only about parents' experiences but also about the strengths and weaknesses of the methods of enquiry. This program of work has demonstrated an ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of developments in parent support within the context of UK paediatric burn care, resulting in peer-reviewed publications for professional audiences, in addition to lay communications for the target population and also the general public.

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## Appendices



## A. Study 1

## A.i Study 1 Ethical Approval



**UWE REC REF No: HAS/16/06/151**

**7 July 2016**



Dear Jennifer

**Application title: Use of support by parents of people affected by burn-injuries**

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the outstanding issues sent through via email on 6<sup>th</sup> July 2016 and the study has been given ethical approval to proceed.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at <http://www1.uwe.ac.uk/hls/research/researchethicsandgovernance.aspx>

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: <http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely

[REDACTED]

Chair  
Faculty Research Ethics Committee

c.c [REDACTED]

## A.ii PI Invitation Email



Dear [parent's name],

I am a PhD Researcher at the Centre for Appearance Research based at the University of the West of England (UWE). I am contacting you because you have recently participated in some research to develop a patient-reported outcome measure within burns care. When you did that you indicated that you would like to be informed about other research projects that you would be eligible to participate in.

I am currently developing a study to investigate the availability of support for parents and also the support needs of parents when their son or daughter suffers a burn injury. I would like to survey the opinions of parents who have received support, as well those who have not. This is in order to establish the extent to which avenues of support are accessed by parents, why they are accessed (or not) and whether they are beneficial. I would also like to establish what type of support parents would find most desirable/useful, and when after the burn injury it would be best to offer such support. I have received ethical approval from the University of the West of England Faculty Research Ethics Committee and would like to check with a small group of parents whether my study information and research questions are worded appropriately, and that my research questions allow parents to fully discuss their opinions and experiences of support following their son/daughter's burn injury.

If you would be willing to provide feedback on my information and research questions, please respond to this email. I will then send the documents to you. If, after viewing the information, you think that you would like to participate in the research, please let me know and we can arrange this.

Many thanks for taking the time to read this.

Yours sincerely,

Dr Jennifer Heath.

### A.iii Study 1 Participant Invitation Email



Dear parents,

We are investigating the support needs of parents whose son or daughter has previously sustained a burn injury. We are writing to ask if you would be interested in taking part, regardless of your son or daughter's age now or at the time of the injury. However, we do ask that at least six months have passed since your child sustained the injury.

You may or may not have felt that you needed any support of any kind, either now or at any other time since their injury. We are interested to find out whether parents' support needs are met, not just at the time of injury but also during their child's recovery and longer-term.

Please help us to investigate this important topic by answering some questions about your experiences and the services you have received or would have liked to receive. There are no right or wrong answers to any of these questions - we are interested in your honest opinions, whether they are positive or negative, and whether your son or daughter was a child or an adult themselves at the time of injury.

If you are interested in knowing more about what taking part would involve, please read the study information sheet which can be found here: <http://tinyurl.com/parents-support-1> and complete the consent form if you would like to take part. Alternatively, you can contact the researcher, Jennifer Heath, using the contact details below.

#### **Dr Jennifer Heath**

PhD Researcher

Centre for Appearance Research  
Faculty of Health and Applied Sciences  
University of the West of England  
Frenchay Campus  
Bristol  
BS16 1QY

Email: [REDACTED]

Tel.: [REDACTED]

Website: [www.uwe.ac.uk/research/car](http://www.uwe.ac.uk/research/car)

## A.iv Study 1 Information Sheet



### **Use of support by parents/guardians of people affected by burn-injuries**

You are being invited to take part in some research. Before you decide whether you want to do this, it is important for you to know why the research is being done and what it will involve. Please take time to read the following information carefully and, if you wish to, discuss it with anyone you think could help you to make a decision about whether to take part. Contact Jennifer Heath (Researcher) or Diana Harcourt (Supervisor) if there is anything that is not clear or if you would like more information, their contact details are provided below. Take time to decide whether you want to take part. If you decide to take part, please save and keep this information. Thank you for reading this.

#### **What is the research that is being carried out?**

We are investigating whether peer support can address the support needs of parents/guardians of people who have suffered a burn-injury. That is, whether parents who have already been through this can help those who also have an injured son/daughter. This study is open to any parent regardless of the age of their son/daughter; your son/daughter can be young or an adult themselves.

We would like to know more about what the support needs of parents in this situation might be, whether they already have access to adequate support, and what that support is. We also want to know which types of support parents prefer to access, why they chose these, and whether they are beneficial or not.

We would like to establish whether there is parental demand for peer support following their son/daughter's burn injury so that we can look further into how to provide the most useful support to parents and families who find themselves in this situation in the future.

#### **Why have I been invited to take part?**

You are being invited to participate in the research project because you are a parent/guardian of someone who has experienced a burn-injury. Both parents do not have to take part but can if they want to.

#### **If I decide to take part, what is involved and what will I have to do?**

If you would like to participate in the research, we will ask you to complete a consent form on the next page and also complete a recorded interview with the researcher. When completing the consent form, you must add your phone number or email address so that the researcher can contact you to arrange the interview. The interview will last up to 60 minutes, but if you would like to add more detail to your answers you can continue the interview beyond this if you wish to. The interview with the researcher will cover details such as your experience of the injury event and treatment; any support you might have accessed after your son/daughter was injured, whether you found the support beneficial, your social circumstances, and what other support you would have liked to have been available/still available to you. You can take part in the interview over the phone, via Skype, via email, or face-to-face with the researcher, but all interviews will be recorded to collect the data/information. If you would prefer for the interview to be face-to-face, this can be at the University of the West of England in Bristol or at a location more convenient for you. All of the information we collect from you will be kept confidential. You might decide that



both you and your partner want to take part. This is ok but the interviews will be conducted separately so that all participation is confidential.

**Do I have to take part?**

It is up to you to decide whether or not you should take part. If you decide to take part, you can change your mind up to 2 weeks after being interviewed by calling the researcher using the contact details below. You do not have to give a reason and your recorded answers can be deleted. Two weeks after you take part your answers will have been analysed and unfortunately cannot be excluded from the study. They will remain anonymously as part of the data set. If you do not want to take part that is fine, this research is not connected to the care you or your son/daughter receives in any way, now or in the future.

**What are the possible advantages or disadvantages of answering the questions?**

The questions ask about your experiences, needs and the support you received when your son/daughter was injured and the impact that this had/has on you. You can view the questions before you answer them if that will help you to decide if it is okay for you to be asked about these things. If you have any worries about any part of this research, you can get in touch with Jennifer Heath who is organising the work using the contact details below.

If, when answering the questions, you feel that you need further support to help you with any distress you are experiencing, please let the researcher know, speak to your GP or contact a member of the burns service where your son/daughter was treated, they will be able to help you find the best support for you. You can also contact an organization listed at the end of this sheet. As the research uses your time, we are offering £10 to parents who take part in order to say thank you for your time and effort. If you have to travel to take part in an interview, we will also cover your travel expenses.

**Will my participation in this research be kept confidential?**

All information that is collected from you during the course of the research will be anonymised and stored on a computer – that is, your name and any identifying information will be separated from your answers to the questions. Instead of your name, an individual code will be used and all the identifying information that links you to the code will be kept on a password-protected database that is strictly confidential. Recorded answers from the interview will be typed out and your name, any other names mentioned, and any information that could identify you will be removed so that you cannot be identified. The recordings (or emails) will then be deleted. Anonymised quotations may be used with your consent. The typed anonymous interviews will be password protected and kept secure. At all times the information will be treated in accordance with the Data Protection Act.

**What will happen to the results of the research?**

A report will be written by the end of the research to inform healthcare professionals working in burns care about the support needs of the parents due to the emotional impact of the experience. It will talk about any experiences of currently available support that parents have accessed, whether this was beneficial, or whether it would be more helpful for parents if things were done differently. Healthcare professionals will not have direct access to the data or participant details at any time. Where appropriate, papers will be prepared for conferences and journals. A summary of the research findings will also be available at the end of the research project. If you wish to have a copy, please contact the research team or tick the box on the consent form.

**Who has reviewed the study?**

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

### Contacts for Further Information

If you need further information, please contact Jennifer Heath or Diana Harcourt who are in charge of this research.

Dr Jennifer Heath  
PG Researcher

Email:

Tel.:

Email:

Tel.:

If you have concerns about any aspect of this study you should ask to speak to the researchers, as detailed above, who will do their best to answer your questions.

### What should I do now?

If you do decide that you want to take part, you should save and keep this information sheet. If you are happy to take part, please complete the consent form on the next page and the researcher will contact you to arrange an interview at a time convenient for you. Please remember to provide contact details.

**Thank you for taking the time to read this information.**

### Where can I find support?

If you think you would benefit from further support, please **contact your GP**. Your GP can discuss with you how you are feeling and refer you to an appropriate support service.

The **burns service** where your son/daughter was treated could also be a value source of support or help you to access support.

Alternatively, charities such as the **Children's Burns Trust, Dan's Fund for Burns, The Katie Piper Foundation** and **Changing Faces** can provide advice to parents, guardians or carers of people affected by burn-injuries on how to access information and support. If you need any information or support, you can email your questions to them using the webpages:

<http://www.cbtrust.org.uk/aboutus/contact/index.shtml>

<http://www.dansfundforburns.org/index.php>

<https://katiepiperfoundation.org.uk/contact/>

<https://www.changingfaces.org.uk/get-support>

Please remember to give them your contact details along with your question.

Also, the **Counselling Directory** is a website designed to provide a UK-wide counselling support network, enabling people to find a counsellor close to them and appropriate for their needs. This is a free, confidential service and the website also contains useful information.

<http://www.counselling-directory.org.uk/>

**A.v Study 1 Consent Form**



**Use of support by parents/guardians of people affected by burn-injuries**

Please read this form and complete it once you have read the information sheet and understand the aims and procedures of the study.

	Please check to indicate agreement
I voluntarily agree to take part in this study. I understand that taking part will involve being interviewed, and this interview being recorded.	
I understand that data collected during the study may be looked at by individuals who are part of the research team. I give permission for these individuals to have access to my research records.	
I confirm that I have received a full explanation of the study and that I understand the information sheet (version 3 dated 18.8.16) given to me.	
I have been given contact numbers so that I may ask questions and discuss aspects of the study with the researcher or their supervisor and have understood any advice and information given.	
I authorise the investigators to disclose the results of my participation in the study, but not my name or personal details.	
I understand that information about me, obtained during the study, will be kept in a secure database. Data will be kept for 3 years after the PhD, of which this research if part of, has been submitted to the University of the West of England.	
I understand that I can ask for further instructions or explanations at any time.	
I understand that I am free to withdraw myself from the study at any time, without having to give a reason for withdrawing.	
I understand that my participation in this research will be kept confidential unless information is disclosed that makes the researcher concerned about my safety, or my son/daughter's safety. In this case the researcher will discuss concerns with me first before anyone else.	
It is OK for any answers I give to be used as anonymous examples in the reports written. My name will be removed so that they cannot be identified.	
I would like to have a copy or any summary reports produced as a result of this research. Please provide your address/email address: .....	
I would like to be informed about other research projects that might be relevant to me. This would involve no more than two advertisements per year.	

**Name:** .....

**Telephone number/email address:** .....

**Signature:** ..... **Date:** .....

## A.vi Semi-structured Interview Schedule and Question Justification

Question	Justification
Demographic information: Date of interview; Parents date of birth; Gender; Ethnicity Marital/relationship status; Current occupation; County lived in; (Approx.) Date of injury; Child's date of birth; Location of burn on body; Cause of injury; Burn depth; TBSA	Demographic information. Desired to help gauge the generalisability of results as families from different back grounds may have different needs and access support differently.
Other children? Relationship of the child with the injury to any siblings	Demographic information. Desired to help gauge the increase in demands on parents' time due to the injury if parents have to tend to the injured child and the needs of any uninjured siblings.
Parent history of any significant medical or mental health problems	Demographic information. Research has demonstrated that children may be at higher risk of injury in families where parents have physical or mental health issues.
Therapies experienced by son/daughter	Demographic information. Sproul, Malloy and Abriam-Yago (2009) asked for list of current therapies. List of therapies experienced (since injury) was chosen to open up conversations about what the parent had gone through with their child and any challenges these had caused.
What was your reaction when you saw the burn for the first time? What went through your mind?	Questions asked by Phillips, Fussell & Rumsey (2007). There is considerable support for the claim that emotional intensity enhances memory for central details of negative events - tunnel memory (Christianson, 1992). These questions aimed to explore what parents remembered/believed about the injury event, exploring the impact of the event on parents.
In your view, what do you think has changed most for you since the burn?	Question asked by Phillips, Fussell & Rumsey (2007). Phillips and Rumsey (2008) state that exploratory data gained to date from small samples requires confirmation through subsequent research. It is also possible that support provisions will have changed since the 2007 study impacting on how parents are able to manage post-injury.
What has been the most difficult thing for you to cope with as a result of the burn?	
Which parts of the burn treatment do you/did you find most difficult to accept or understand?	Question asked by Phillips, Fussell & Rumsey (2007). Smith, Murray, McBride, & McBride-Henry (2011) found that the stress involved in caring for a child undergoing unpleasant or painful procedures is often unrecognized by staff. I wanted to ask this question again to see if similar issues arose 9 years later.
Do the scars/burns bother you? If so, can you explain why?	Question asked by Phillips, Fussell & Rumsey (2007). With increasing public information about visible difference, but also an increasing emphasis on appearance because of social media, I wanted to gauge how parents felt about the scars 9 years later.
Was support for yourself available to you? (support for you as a parent, not for your son/daughter)	Question asked to ascertain whether support is available to parents, regardless of whether they chose to accept it.
Who provided this support?	Question asked to ascertain who provides support, or at least which members of staff parents perceived/remembered as being supportive to them.
What kinds of things did this support aim to help you cope with?	Question asked to ascertain what support offered within paediatric burn services aims to help parents cope with. This could highlight areas where needs are met and potentially unmet.
Did you accept any support following your child's injury?	Question asked to gage how many parents accepted support following their child's injury.

What was your motivation for accessing/not accessing support?	Question asked to gage parent's reasons for accessing/not accessing support following their child's injury.
If you did access support, was it helpful? In what way was it helpful/not helpful?	Question asked to gage whether the support offered met parent's needs.
What else could be done or provided by the hospital that could help parents affected by a burn injury to a child of theirs?	Question asked by Phillips, Fussell & Rumsey (2007) but important to ask again as needs change over time and with changes in service provision.
Do you think peer support would have been valuable to you? Please explain	Question asked to gage whether parents feel they would have valued the opportunity to access support for parents who had previously shared their experience.
Would you have accepted it at the time? Please explain	Question asked to gage whether parents feel, with hindsight, they would have felt able to turn to other parents who had previously shared their experience for support.
When do you think that it is most important for parents to be offered support following their child's injury?	Question asked to gage when, with hindsight, parents felt it would be most valuable to receive support from others (professionals or peers) following their child's injury.
Thinking about your experiences what kinds of support would have been/would be most beneficial to you as a parent of a burn injured child? Please explain why?	Question asked to gage, with hindsight, what kind of support parents feel would have been most beneficial to them. This could highlight support that met their needs but also areas of unmet need.
Is there anything I did not ask about that you wanted to say or ask?	Similar question asked by Phillips, Fussell & Rumsey (2007). It important to ensure participants have said everything they wanted to on a topic.
Parents have been given the choice of how to participate in this research. You chose to complete the interview over the phone/via Skype/face-to-face. Can you tell me why you chose this method of participation?	
I would like to use some anonymised quotations from interviews for examples in my reports. Could I use anything I have recorded here today in my reports? Your name and any identifying information would be removed so that no one would know who it was from.	Question asked to ensure consent for using quotes when reporting results.

A.vii Study 1 Example of Analysis Coding

Extract from transcript		Subtheme	Theme
[REDACTED]	?Shock	Fear of losing the child  Physical isolation Psychological isolation  Barriers to support Seeking support online	Change Isolation Access to psychosocial support
[REDACTED]	Normalising experience	Engagement with others	Change
[REDACTED]	Reassurance	?Loss of the perfect child	Loss
[REDACTED]	?Realisation of consequences		
[REDACTED]	Fear of unknown  Uncertainty	Engagement with others	Change
[REDACTED]	Fear of death		Loss
[REDACTED]	Not being able to provide adequate care Helplessness	Impact on self-perception	Change
[REDACTED]	Alone	Physical isolation	Isolation

<p>[REDACTED]</p>	<p>[REDACTED]</p>	<p>Appearance ?significance of gender</p> <p>Future impact</p> <p>Vulnerability</p> <p>Blame</p>	<p>Loss of perfect child</p> <p>Impact on self- perception</p>	<p>Loss</p> <p>Change</p>
<p>[REDACTED]</p>	<p>[REDACTED]</p>	<p>Previous MH difficulties</p> <p>Anxiety Hypervigilance</p> <p>Overprotective Less carefree</p> <p>Other people's perceptions</p>	<p>Impact on self- perception</p> <p>Engagement with others</p>	<p>Change</p>
<p>[REDACTED]</p>	<p>[REDACTED]</p>	<p>Appearance</p> <p>Slow progress</p> <p>Impact Scarring</p> <p>Visibility Reaction of others</p>	<p>Loss of perfect child</p> <p>Loss of perfect child</p> <p>?Scars remind me Reaction of others</p>	<p>Change</p> <p>Loss</p> <p>Change</p>

[Redacted]	Desire to protect	Engagement with others	Change
[Redacted]	Impact on family life	Engagement with others	Change
[Redacted]	Anxiety Appearance Scarring Itching	Action to repair Loss of perfect child	Loss
[Redacted]	Challenges of caring for burns on top of normal routine Negative impact of peer support/info	?Barrier to accessing support	Access to psychosocial support (?-ve)
[Redacted]	Importance of trust in relationship with others Involved in decisions	Engagement with others Impact on self-perception	Change
[Redacted]	Out of control		
[Redacted]	Desire to protect	Action to repair	Loss



		Scarring	Loss of perfect child	Loss
		Information	Engagement with others Support from SWHSIB	Change Support
		Guidance		
		Itching		
		Uncertainty		
		Desire to protect from further damage		Change
		Visibility of scarring	Loss of perfect child	Loss
		Appearance		Loss
		Support	Engagement with others	
		Psychologist		
		Blame Acceptance		Loss Change
			?Barriers	
		Helpful to talk Outside of family		Psychosocial support (+ve)



### **Use of support by parents/guardians of children affected by burn injuries Summary of the interview findings (May 2017)**

#### **What was the aim of the study?**

When a child suffers a burn, it can also have a major impact on their family. Parents may experience distress including anger, anxiety and guilt, and often extra caring responsibilities, such as looking after the injured child, their siblings, travelling to and from hospital, and trying to get life back to normal. National Burn Care Guidelines recommend that professional support for parents and families is provided by children's burn units, but also that there should be support from parents who have shared a similar experience – peer support. However, this peer support is very limited within the UK. Therefore, the study you took part in had three broad aims, to:

- 1) Explore parents' experiences of having a child suffer a burn injury
- 2) Explore whether parents access support following their child's injury and whether they find it beneficial
- 3) Establish parents' opinions of peer support and whether they would value this following their child's burn injury

This study was the first in a series of studies funded by the University of the West of England, Bristol. The information we gather from parents during this research aims to inform the care and support provided to them and others in the future.

#### **What did I do?**

I interviewed 13 parents/caregivers who had a child who suffered a burn injury. Interviews took place via Skype, telephone, face-to-face, or by email. The interviews explored parents' experience of the injury, treatment, support, and opinions of peer support.

#### **What did I find?**

Several key themes were apparent in the interviews; these are listed and described below. Parents described many different experiences, both positive and negative, but the overwhelming message from most was that the burn injury had a devastating impact and the treatment was challenging for both parents and children. A variety of surgery and treatments had been faced including treatment in intensive care units, skin grafts, scar revision surgery, scar management with creams and pressure garments, and physiotherapy. Overall, parents found the support they received from professionals to be helpful but it was also felt that online support might be useful.

## Theme 1: Loss

***Fear of losing the child.*** Some parents talked about how, in the immediate aftermath, they feared that they would lose their child due to the injury itself, or because their child would go into shock. Some parents also feared that social services may deem the accident to be evidence that they were a bad parent and take their child away. The fear of losing a child could also return if there were medical complications.

***Loss of the perfect child.*** Some parents talked about their child's burn scarring and being saddened at the loss of their 'perfect' child. Regardless of how parents felt about their child's scars, parents had concerns about the negative impact this might have on their child's future.

***Action to repair.*** For most parents, there was a wish that the scars could be undone. Some parents described a "constant quest" for new treatments to repair the damage, anxious that there might be a new treatment available that they didn't know about. Some parents also tried to compensate their child for the injury and its impact in other ways. Parents spoke about "spoiling" and being "soft" on their injured children to compensate them for what they had been/were going through.

## Theme 2: Change

***Scars remind me.*** For some parents, their child's scarring would always be a reminder of the traumatic event, something that they didn't do right, their guilt, and the worst day of their life. However, some parents also saw their child's scars as marks of bravery.

***Impact on self-perception/Failed protector.*** Some parents felt that their child's accident occurred because they had in some way failed their child. They felt that they had, for a split second, not adequately fulfilled their role of protecting their child. The desire to prevent a future accident led many parents to become wary of danger, which could lead to some parents becoming over-protective.

***Engagement with others.*** For many parents, the injury led to them using services that they had never thought about or even knew existed, such as social services, physiotherapy and occupational therapy, psychology services and burns camps. In some cases, this reduced their contact with friends and family, and impacted on their relationship with their spouse. Some parents were also concerned that whilst their injured child was unwell, siblings may have been neglected.

## Theme 3: Isolation

***Physical isolation.*** Parents described the hospital as being like a "cocoon" or a "bubble", being "cut off from the outside world", often alone with their injured child and in single rooms due to hospital infection control procedures.

***Psychological isolation.*** Although parents are surrounded by a team of different health professionals, and often other family members and friends, they can still feel very much alone and as though they are the only one who has ever been through this or felt this way.

## **Theme 4: Access to psychosocial support**

**Support from someone who has seen it before.** Most parents had been offered support by a professional, such as a clinical psychologist, and the majority of those who accepted it thought it was helpful. Access to one-to-one professional support could help parents to manage feelings of blame, allowing them to accept what had happened and move on. Some parents also found key members of staff (such as nurses and play specialists) to be supportive, offering advice, comfort and distracting the child during procedures. In most cases, support was offered to parents whilst their child was in hospital.

Some parents had accessed other forms of support, such as peer support, burns camps, social services, and chance meetings with other parents at the hospital. For some parents, having face-to-face interaction was important when sharing personal experiences and those who had accessed peer support, often informally, found it helpful.

**Barriers to support.** Parents differ according to their individual needs and these needs might change over time. Although most parents said they knew that professionally-led support was available to them, they discussed challenges that could act as barriers to them accessing this support. These included the demands on their time of caring for their injured child, the financial impact, their distance from the hospital, feelings of guilt or blame, and their focus on getting their child well as they were the ones injured, not themselves. Talking about the event and its impact could also be too emotionally painful for parents.

**Seeking support online.** It can be difficult for parents to receive support because they need to overcome the challenges and barriers described above. Some parents had already looked on the internet for other parents that they could share experiences with or learn from, however, appropriate resources and online support was noticeably lacking. Parents discussed different ways support could be provided. Whilst face-to-face interaction was important to some, other parents felt more confident writing to somebody. Some advantages of support via the internet discussed by parents were that the internet provides anonymity, allows images to be accessed, is accessible if/when needed and in their own time, and support can be received from many other parents.

### **What's next?**

This study has provided a lot of information and opened up a number of interesting areas which will be explored in more detail in the next study. The results highlight that a burn injury is a very challenging and emotional experience that does not simply get better when the child leaves hospital. Although support is available, it can be difficult for parents to access this. Parents' needs, and how they might better access support, needs to be looked at in more detail.

There has been a lot of positive interest in the research, from parents, charities, and health professionals involved in the treatment and care of young burn patients and their families. Therefore, following on from the study you took part in, we are currently developing a questionnaire study with a larger group of parents of burn-injured children. This questionnaire will aim to make sure the key themes and issues are also important to other parents. Overall, we hope that this research will contribute to the development of a peer support resource for parents.

Parent involvement in the design of my research is important to me. If you would like to look at and provide feedback on the questionnaire that I have designed for the next study, please contact me: [REDACTED] I would really appreciate your feedback. Thank you.

### **What do you think? Do you have any comments?**

I hope this summary provides you with some details about the results of the study you took part in. If you have any comments about this summary, or any additional questions about the research (now or in the future), please feel free to contact me: [REDACTED]

Address: Dr Jennifer Heath, [REDACTED]  
[REDACTED]  
[REDACTED]

If you have any medical questions about your child's injury, scars, or treatment, you can contact the children's burn service where your child was treated. Charities such as the Children's Burns Trust, Dan's Fund for Burns, The Katie Piper Foundation and Changing Faces can also provide advice to parents on how to access information and support. You can contact them using the webpages:

<http://www.cbtrust.org.uk/aboutus/contact/index.shtml>

<http://www.dansfundforburns.org/index.php>

<https://katiepiperfoundation.org.uk/contact/>

<https://www.changingfaces.org.uk/get-support>

Alternatively, the Counselling Directory is a UK-wide counselling support network, enabling people to find a counsellor close to them and who is able to meet their needs.

<http://www.counselling-directory.org.uk/>

**Thank you again for taking part in this study!**



## B. Study 2



[Redacted text block]

UWE REC REF No: HAS.17.05.160

22 June 2017

Dr Jennifer Heath

[Redacted text block]

Dear Jennifer

**Application title: Validation of themes to focus the development of support for parents of burn-injured children**

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 9th June 2017 and the study has been given ethical approval to proceed.

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web:  
<http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:



**1.** You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

<http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx>

**2.** You must notify the University Research Ethics Committee if you terminate your research before completion;

UREC/FREC Standard Approval Letter Version 1 1/8/2013

**3.** You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely

██████████

Chair

Faculty Research Ethics Committee

████████████████████

## B.ii Study 2 Social Media Advertisement and UWE Bristol Press Release

### Parents of children with burn injuries needed for UWE Bristol study focusing on online support for parents

Parents whose son or daughter have suffered a burn injury are being sought for a project being carried out by Dr Jennifer Heath, a Clinical Psychologist and PhD researcher at the world-renowned Centre for Appearance Research based at UWE Bristol.

Jennifer is asking mums and dads about the kinds of support that might have helped them, particularly whether online support would have been useful. Her questionnaire is available at <http://tinyurl.com/peersupportforparents>

Jennifer, who has worked in an NHS burns unit said, “this information will directly benefit other parents by helping me to shape support for parents, possibly by providing an online resource which would be accessible and meets the needs identified during my research.”

Every year in the UK, approximately 58,000 children attend accident and emergency departments for treatment after experiencing a burn injury. More burns are seen in children under 5 years of age than in any other age group, so this research is looking at how to provide support that could benefit many parents around the country, both now and in the future.

Jennifer said, “I am hoping to collect the views of at least 100 parents. All parents of children who have suffered but survived a burn injury requiring hospital treatment are invited to take part. I am recruiting parents from all over the country and it doesn’t matter how long ago the injury took place. Either both parents, or just one, can participate in the research, and all participants will remain anonymous.”

If you are interested in taking part, please visit <http://tinyurl.com/peersupportforparents> or contact Jennifer on [REDACTED]



## **Use of Peer Support by Parents of Burn-Injured Children**

You are being invited to take part in some research. Before you decide whether you want to do this, it is important for you to know why the research is being done and what it will involve.

Please take time to read the following information carefully and, if you wish to, discuss it with anyone you think could help you to make a decision about whether to take part. Contact Jennifer Heath (Principle Investigator) or Diana Harcourt (Supervisor) if there is anything that is not clear or if you would like more information, their contact details are provided below. Take time to decide whether you want to take part. If you decide to take part, please keep this information. Thank you for reading this.

### **What is the research that is being carried out?**

We are investigating whether peer support can address the support needs of parents of burn-injured children. That is, whether parents who have already been through this can help those who also have an injured child.

We would like to know more about what the support needs of parents in this situation might be, whether they already have access to adequate support, and what that support is. We also want to know which types of support parents prefer to access, why they chose these, and whether they are beneficial or not.

We would like to establish whether there is parental demand for peer support following a child's burn injury so that we can look further into how to provide the most useful support to parents and families who find themselves in this situation in the future.

### **Why have I been invited to take part?**

You are being invited to participate in the research project because you are a parent of a child who has experienced a burn-injury.

### **If I decide to take part, what is involved and what will I have to do?**

You will be asked for your permission/consent to take part based on the information you have read here. If you would like to participate in the research, we will ask you to complete some questions in an online survey. This could take up to 30 minutes. The questions will ask about your experience of the injury event and treatment; any support you might have accessed after your child was injured, whether you found the support beneficial, your social circumstances, and what other support you would have liked to have been available/still be available to you.

If you want to take part but you do not want to take part in the survey online, you can contact the researcher, Jennifer Heath, using the contact details below, to ask for a paper version of the questionnaire to be sent to you. You will also be sent a stamped addressed envelope for its return. Alternatively, you could arrange a time to answer

the questions over the phone. It is up to you. All of the information we collect from you will be kept confidential.

### **Do I have to take part?**

It is up to you to decide whether or not you should take part. If you decide to take part, you can change your mind at any time and exit the survey without giving a reason. If you complete the survey and then change your mind you can contact the researcher by {date} using the contact details below. You do not have to give a reason and your answers can be deleted. After this time your answers will have been analysed and so will remain anonymously as part of the data set. If you do not want to take part, don't worry, this research is not connected to the care you or your child receive in any way, now or in the future.

### **What are the possible advantages or disadvantages of answering the questions?**

The questions ask about your experiences, needs and the support you received when your child was injured and the impact that this has on you. If you have any worries about any part of this research you can get in touch with Jennifer Heath who is organising the work, using the contact details below. If, when answering the questions, you feel that you need further support to help you with any distress you are experiencing, please speak to your GP or contact a member of the burns service where your child was treated, they will be able to help you find the best support for you.

As the research uses your time, we are offering parents who complete the survey the opportunity to be entered into a prize draw for Amazon vouchers in order to say thank you: 1<sup>st</sup> prize £50, 2<sup>nd</sup> prize £30, 3<sup>rd</sup> prize £20. The prize draw will take place one week after the survey is closed (3 months after it opens).

### **Will my participation in this research be kept confidential?**

All information that is collected from you during the course of the research will be anonymous and stored securely on a computer – no identifying information will be stored with your answers to the questions. Instead of your name, an individual code will be used. Anonymised quotations may be used in reports but no one will know who wrote them. At all times the information will be treated in accordance with the Data Protection Act.

### **What will happen to the results of the research?**

A report will be written by the end of the research to inform healthcare professionals working in children's burns care about the support needs of the parents due to the emotional impact of the experience. It will talk about any experiences of currently available support that parents have accessed, whether this was beneficial, or whether it would be more helpful for parents if things were done differently. Healthcare professionals will not have direct access to the data or participant details at any time. Where appropriate, papers will be prepared for submission to conferences and journals. A summary of the research findings will also be available at the end of the research project. If you wish to have a copy, please contact the research team.

### Who has reviewed the study?

This study has been reviewed and approved by the University of the West of England Research Ethics Committee. A Patient and Public Involvement group have also been involved in the design and content of the study.

### Contacts for Further Information

If you need further information, please contact Jennifer Heath or Diana Harcourt who are in charge of this research.

Dr Jennifer Heath  
PG Researcher



Email:

Tel.:



Email:

Tel.:

If you have concerns about any aspect of this study you should ask to speak to the researchers, as detailed above, who will do their best to answer your questions.

### What should I do now?

If you do decide that you want to take part, you should save this information sheet. If you are happy to take part, please complete the consent form and answer the questions on the following pages.

**Thank you for taking the time to read this information.**

### Where can I find support?

If you think you would benefit from further support, **please contact your GP**. Your GP can discuss with you how you are feeling and refer you to an appropriate support service.

The **burns service** where your child was treated could also be a value source of support or help you to access support.

Alternatively, the **Children's Burns Trust** can provide advice to parents or carers of a burn injured child on how to access information and support. If you need any information or support you can email your questions to them using the webpage: <http://www.cbtrust.org.uk/aboutus/contact/index.shtml>

Please remember to give them your contact details along with your question.

Also, the **Counselling Directory** is a website designed to provide a UK-wide counselling support network, enabling people to find a counsellor close to them and appropriate for their needs. This is a free, confidential service and the website also contains useful information. <http://www.counselling-directory.org.uk/>

**B.iv Study 2 Consent Form**



**Use of Peer Support by Parents of Burn-Injured Children**

Please read this form and complete it once you have read the information sheet and understand the aims and procedures of the study.

	Please initial to indicate agreement
I voluntarily agree to take part in this study.	
I understand that data collected during the study may be looked at by individuals from the University of the West of England, who are part of the research team. I give permission for these individuals to have access to my research records.	
I confirm that I have received a full explanation of the study and that I understand the information sheet (version 1 dated 20.4.16) given to me.	
I have been given contact numbers so that I may ask questions and discuss aspects of the study with one of the above investigators or their deputies and have understood any advice and information given.	
I authorise the investigators to disclose the results of my participation in the study, but not my name or personal details.	
I understand that information about me, obtained during the study, will be kept in a secure database. If data is transferred to others, it will be made anonymous. Data will be kept for 3 years after the results have been published.	
I understand that I can ask for further instructions or explanations at any time.	
I understand that I am free to withdraw myself from the study at any time, without having to give a reason for withdrawing.	
It is OK for any answers I give to be used as anonymous examples in the reports written.	
I would like to have a copy, or any summary reports produced as a result of this research Please provide your address/email address: .....	

**Name:** .....

**Signature:** ..... **Date:** .....

## B.v Study 2 Survey Template (inputted into Qualtrics)

Questions	Answer format
<p>We have identified some key experiences of parents following their child's burn-injury. We now want to find out whether these experiences are also common to other parents. This will allow us to investigate whether parents' support needs are met, not just at the time of injury but also during their son/daughter's recovery and longer-term.</p> <p>Please help us to investigate this important topic by answering some questions about yourself and the services you have received. We are interested in your honest opinions, whether they are positive or negative. Please try to answer all of the questions but if you feel you can't, you can skip a question or stop at any time.</p> <p>Create a password in case you want to delete your answers. Use the first 3 letters of your surname and the day of the month you were born e.g. Jennifer Heath born on 27/4/84 would make the password: HEA27</p>	
<p>First, a bit about you and your son/daughter's injury.</p>	
1. Your relationship to your child	<ul style="list-style-type: none"> <li>a. Mother</li> <li>b. Father</li> <li>c. Other... please specify</li> </ul>
2. Your ethnicity	<p>White: British; Irish; Any other White background</p> <p>Mixed: White and Black Caribbean; White and Black African; White and Asian; Any other mixed background</p> <p>Asian or Asian British: Indian; Pakistani; Bangladeshi; Any other Asian background</p> <p>Black or Black British: Caribbean; African; Any other Black background</p> <p>Other Ethnic Groups: Chinese; Any other ethnic group</p> <p>Not stated</p>
3. Your marital/relationship status	<p>Single</p> <p>Married/Civil Partner</p> <p>Divorced/Person whose Civil Partnership has been dissolved</p> <p>Widowed/Surviving Civil Partner</p> <p>Separated</p> <p>Not disclosed</p>
4. The county where you live	Free Text
5. Your date of birth	Date
6. The approximate date of child's injury	Date
7. Your child's date of birth	Date
8. The cause of injury	<ul style="list-style-type: none"> <li>a. Scald – Hot fluid</li> <li>b. Hot surface</li> <li>c. Flame</li> <li>d. Friction</li> </ul>

	<ul style="list-style-type: none"> <li>e. Chemical</li> <li>f. Electrical</li> <li>g. Radiation</li> </ul>
9. The location of injury	[Select all that apply] <ul style="list-style-type: none"> <li>a. Head</li> <li>b. Neck</li> <li>c. Chest</li> <li>d. Back</li> <li>e. Abdomen</li> <li>f. Arms</li> <li>g. Hands</li> <li>h. Legs</li> <li>i. Feet</li> <li>j. Buttocks</li> <li>k. Genitals</li> </ul>
10. Total Burn Surface Area (If known)	..... %
11. My child's initial treatment was as an...	Inpatient/Outpatient
Some parents have explained to us how they felt following their child's accident. Please rate how much you agree/disagree with the following statements.	
12. Initially, I was scared my child would die	Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree
13. Initially, I was worried that social services might take my child away from me	
14. I was sad that, all of a sudden, my child was different	
15. I worry about how my child will be affected by their scars in the future	
16. I see my child's scars as being part of them	
17. I am hurt by other people's comments about my child's scars	
18. I experience distress when others ask about my child's injury or scars	
19. I hope that my child's skin will go back to the way it was	
20. I do everything I can to try to reduce my child's scarring	
21. I worry that there might be new treatments for scarring available that I haven't heard about	
22. I spoil my child because of what they have been through	
23. I am softer on my child because of what they have been through	
24. My child's scars remind me of what we/I didn't do right at the time	
25. My child's scars remind me of the worst day of my life	
26. My child's scars remind me of all the pain they have been through and will go through in the future	



27. My child's scars remind me of how brave and strong my child is	
28. My child's scars remind me of how guilty I feel	
29. Since the accident, I am very conscious of safety	
30. Since the accident, I am overprotective	
31. Since the accident, I am less care-free	
32. It helped when I was told that the accident was not my fault	
33. I am concerned that I might be seen as a bad parent by others	
34. Since the accident, life hasn't been 'normal'	
35. My child's injury has had a negative impact on my social life	
36. My child's injury has had a negative impact on family life	
37. Because of the accident, I interact with services that I wouldn't normally expect to	
38. I felt like I was the only person that felt like this	
39. I felt like I was the only person this had ever happened to	
40. I felt like I was completely by myself	
41. I felt isolated when my child was in hospital	
42. I felt isolated following my child's discharge from hospital	
43. I don't think the professional staff recognise how devastating this type of injury is for parents	
44. I am aware that I still have a lot of feelings about the accident and its impact, but I haven't dealt with them	
45. I had not anticipated the challenges I would face when my child was discharged from hospital	
46. The hospital staff warned me that life would be challenging when we were discharged from hospital	
47. I felt prepared for caring for my child once they were discharged from hospital	
48. I worry that I neglected my other children after the accident	Please rate how much you agree/disagree with the following statements. If these questions are not applicable to you, select Not Applicable. Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree; Not Applicable
49. My child's injury has had a negative impact on my work life	
50. The accident has had a negative impact on my marriage/relationship	

51. My partner and I have never spoken about how we feel regarding the accident	
Support for parents can be provided by friends and family, peers, and/or professionals. We are trying to establish which types of support parents have access to.	
52. I had support whilst my child was an...	<p>inpatient/outpatient/both/I didn't access support</p> <p>53. If support was accessed... I received support from: [Select all that apply]</p> <p>a. A psychosocial professional (psychologist/counsellor/psychotherapist)</p> <p>b. Nursing staff</p> <p>c. Play specialist</p> <p>d. Peer support group</p> <p>e. Individual peer support</p> <p>f. Support from community health worker</p> <p>g. Social worker</p> <p>h. Support from family</p> <p>i. Support from friends</p> <p>j. Other: Please specify...</p> <p>54. I received enough support</p> <p>55. The support I received was helpful</p> <p>56. The support I received met my needs</p> <p>57. The support I received was accessible when I needed it</p> <p>Answer with: Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree</p>
58. I would rather access professional support:	<p>[Select all that apply]</p> <p>a. Face-to-face</p> <p>b. Via Skype</p> <p>c. By email</p> <p>d. Over the phone</p> <p>e. I am not interested in accessing professional support</p>
Have any of these issues ever stopped, delayed or discouraged you from getting, or continuing with, face-to-face support following your child's injury? Please rate how much you agree/disagree with the following statements.	
59. Being unsure where to go to get support	Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree
60. Concern that you might be seen as weak for needing support	
61. Problems with transport or travelling to appointments	
62. Concern about what other people might think, say, do or feel	
63. Feeling embarrassed or ashamed	
64. Preferring to get alternative forms of care (e.g. religious healing)	

65. Not being able to afford the financial costs involved in travelling and accessing support	
66. Thinking that support probably would not help or that things would get better by themselves	
67. Dislike of talking about your feelings, emotions or thoughts	
68. Having had previous bad experiences with accessing support or mental health care	
69. Preferring to get help from family or friends	
70. Thinking that you do not have a problem	
71. The distance to the hospital/medical centre	
72. Not having the time to access support for yourself	
73. "My focus was on getting my child well, I didn't think about my own needs"	
74. Feeling guilty	
75. It was too painful to talk about what happened and how I felt	
76. Having problems with childcare	
77. "I would have accessed support if it was more local"	
78. Have you ever looked for supportive resources or information from the following places?	<p>[Select all that apply]</p> <ul style="list-style-type: none"> <li>a. Hospital staff</li> <li>b. Family/friends</li> <li>c. Internet</li> <li>d. Peers that have shared a similar experience</li> <li>e. Support groups</li> <li>f. Burn camps</li> <li>g. Charities</li> <li>h. Other...</li> <li>i. I didn't find any supportive resources/information</li> </ul>
We are interested to know whether you feel that peer support would be valuable to parents - that is support from other parents who have also been through a similar experience.	
79. I think peer support would be valuable to me	<p>Yes/No</p> <p>If yes, answer: Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree to the questions below...</p> <p>80. I would like to have one-to-one peer support Yes/No/Not sure</p>

	<p>81. I would like to have access to a peer support group Yes/No/Not sure</p> <p>82. I would rather access peer support: [Select all that apply]</p> <ul style="list-style-type: none"> <li>a. Face-to-face</li> <li>b. Online (website)</li> <li>c. Via Skype</li> <li>d. By email</li> <li>e. Over the phone</li> </ul> <p>83. I think peer support is most valuable: [Select all that apply]</p> <ul style="list-style-type: none"> <li>a. During recovery, prior to wound healing.</li> <li>b. During rehabilitation, before scar maturation.</li> <li>c. Beyond scar maturation.</li> <li>d. Other, please specify:</li> <li>e. I don't think it would be valuable to parents</li> </ul>
84. I would have liked to have met someone a little bit ahead of me who could explain to me what the future would be like	<p>Please rate how much you agree/disagree with the following statements. Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree</p>
85. I think it is important that parents can contact other parents whose child's injury was similar to their own child's injury	
86. Accessing a face-to-face group would be too demanding/difficult for me	
87. Engaging in face-to-face support would be too demanding/difficult for me	
88. I would be worried about who I might meet/come into contact with	
<p>Based on what other parents have told us, we are interested in whether you think the internet is, or could be, a useful resource for parents following their child's injury. Please rate how much you agree/disagree with the following statements.</p>	
89. When looking for information and support in relation to my child's burn-injury, I have used the internet to find other people who are experiencing similar challenges to me and to learn about their experiences	<p>Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree</p>
90. The internet is a reliable resource to help me understand what health professionals have told me about my child's injury and treatment	
91. The internet can be useful to help parents to decide if they themselves should seek support	

92. I look for information and images regarding scar progression and management	
93. I use the internet to see how I can alleviate or improve my child's scarring	
94. It would be helpful to hear about other parents' experiences of parenting a child following a burn injury on the internet	
95. The internet is useful if you don't want to tell people around you (for example, your family or professionals) how you feel	
96. Looking at a burn-specific website would reassure me that I am not alone	
97. Is there anything that we have not asked you about in relation to online support, that you think it would be useful for us to know?	Free Text
98. How did you hear about this research?	<ul style="list-style-type: none"> <li>a. Charity website: i. Changing Faces; ii. Katie Piper Foundation; iii. Dan's Fund for Burns; iv. Children's Burns Trust</li> <li>b. Social Media: i. Facebook; ii. Instagram; iii. Twitter</li> <li>c. From a professional</li> <li>d. Email from the Centre for Appearance Research</li> <li>e. Support Group</li> <li>f. Burns Camp</li> <li>g. Other</li> </ul>
99. Would you like to be informed of the results of this study?	Yes/No
100. Would you like to be informed about other research that you might be eligible to participate in?	Yes/No
101. Would you like to be entered into a prize draw for the chance to win Amazon vouchers?	Yes/No
If you have answered yes to any one of these questions, please provide your email address or name and postal address.	
Thank you for taking the time to respond to this survey. Your answers will contribute to the development of support for parents of children following burn-injury.	



### **Support for parents/guardians/carers of burn-injured children Summary of the questionnaire findings (December 2017)**

#### **What was the aim of the study?**

When a child suffers a burn, it can also have a major impact on their family. Parents may experience distress including anger, anxiety and guilt, and often extra caring responsibilities, such as looking after the injured child, their siblings, travelling to and from hospital, and trying to get life back to normal. National Burn Care Guidelines recommend that professional support for parents and families is provided by children's burn units, but also that there should be support from parents who have shared a similar experience – peer support. However, this peer support is very limited within the UK.

Previously, I interviewed 13 parents/guardians to explore their experiences of having a child suffer a burn injury, whether they accessed support following their child's injury, and whether they found it helpful. I also asked them about their opinions of peer support and whether they would value this following their child's burn injury. The questionnaire that you completed aimed to confirm the findings of the interview study with a larger number of parents. It was the second in a series of studies funded by the University of the West of England, Bristol. The information I gather from parents during this research aims to inform the care and support provided to parents in the future.

#### **What did I find?**

Fifty-seven parents/guardians completed the questionnaire. Whilst it is clear they had different experiences, both positive and negative, some experiences are common to most parents; these are listed below.

Following the accident, the majority of parents said that they were sad that, all of a sudden, their child was different and they hoped that their skin would return to the way it used to be. Most parents said that they did everything they could to try to reduce the scarring, and more than half of parents said they were concerned that there might be new treatments available that they had not heard about.

Although most parents reported to see their child's scars as part of them, many said they worry about how they will be affected by them in the future. For most parents, the scars are a reminder, not only of the pain their child has been through and might go through in the future, but also of how brave and strong their child is.

Many parents said that they feel guilty about what happened and, since the accident, they are more safety conscious than they used to be and can be over-protective. Some parents also worry about how the accident impacted on the injured child's sibling(s). In addition to this, it can be upsetting for parents when other people ask about their child's injury.

Just over half of parents reported to feel isolated when their child was in hospital; some parents continued to feel this way when they went home. Half of parents agreed with the statement, “I felt like I was the only person that felt like this” and reported that they and their partner had never spoken about how they felt regarding the accident.

The majority of parents who completed the questionnaire had accessed support, but some had not. Most frequently, support was received from nursing staff, family, and psychosocial professionals (psychologist/counsellor/psychotherapist). The majority of parents agreed that the support they received was helpful but there was less agreement that they received enough support, or that it met their needs. Generally, parents were in agreement that support was accessible when they needed it.

Most respondents would rather access professional support face-to-face. However, parents also looked for supportive resources on the internet. The majority of parents believed that peer support would be valuable to them and the strongest preference was for this to be provided online. Participants felt that it was important to be able to contact other parents whose child’s injury was similar to their own child’s. Most parents also said that they would have liked to have met someone a little bit ahead of themselves who could explain to them what their future would be like.

More than half of the participants agreed that significant barriers to accessing support were not knowing where to get it; feeling too embarrassed, ashamed or guilty; the experience being too painful to talk about; and not having the time to access it. Therefore, many parents focussed on getting their child well and did not think about their own needs.

Many parents had looked to the internet for supportive resources, and almost half had used the internet to try to find other people who were experiencing similar challenges. Parents tended to think that the internet is a reliable resource that could help them to understand what health professionals had told them about their child’s injury and treatment. Parents also agreed that it would be helpful to hear about other parents’ experiences on the internet, that looking at a burn-specific website would reassure them that they are not alone, and that the internet can be useful to help parents decide if they themselves should seek support. There was also agreement that the internet is a useful source of support if parents do not want to tell people around them (family or professionals) about how they feel.

Parents who participated in this research raised some additional important points:

1. It is important that parents have access to support in their own time, when they feel ready and want to access it.
2. There is a lack of up to date information currently online for parents.
3. Everyone has different emotional responses, so what is useful to some parents might not be useful to others. In the development of an online resource, it would be important to be sensitive to the fact that not all parents feel the same and they do not all want the same kinds of support.
4. Not all parents trust advice or information on websites.

### **What’s next?**

The results highlight that a burn injury is a very challenging and emotional experience and, although support is available, it can be difficult for parents to access this for a number of reasons.

There has been a lot of positive interest in this research, from parents, charities, and health professionals involved in the treatment and care of young burns patients and their families.

The next step will be to develop a website specifically for parents of children who have had a burn injury. This will provide trustworthy information on a range of topics including parents' stories; their role in rehabilitation and pain management; managing trauma, stress and sleep; strategies for living with the consequences of a burn-injury; relaxation techniques; as well as signposting to other information and sources of support.

### **What do you think? Do you have any comments?**

Parent involvement in my work is important to me. If you have any comments about this summary, any additional questions about the research (now or in the future), or you would like to contribute your story to the website that I am now developing, please contact me:

Email: [REDACTED]

Telephone: [REDACTED]

Address: Dr Jennifer Heath, PG Researcher, [REDACTED]  
[REDACTED]

I hope this summary provides you with some interesting details about the study you took part in.

If you have any medical questions about your child's injury, scars, or treatment, you can contact the children's burn service where your child was treated. Charities such as the Children's Burns Trust, Dan's Fund for Burns, The Katie Piper Foundation and Changing Faces can also provide advice to parents on how to access information and support. You can contact them using the webpages:

<http://www.cbtrust.org.uk/aboutus/contact/index.shtml>

<http://www.dansfundforburns.org/index.php>

<https://katiepiperfoundation.org.uk/contact/>

<https://www.changingfaces.org.uk/get-support>

Alternatively, the Counselling Directory is a UK-wide counselling support network, enabling people to find a counsellor close to them and who is able to meet their needs.

<http://www.counselling-directory.org.uk/>

**Thank you again for taking part in this study!**



### C. Study 3

**C.i. Prototype website template**

<b>Home</b>	<b>Impact on Parents</b>	<b>Stress Management</b>	<b>Supporting Your Child</b>	<b>Where Can I Find Support?</b>	<b>Feedback</b>
More information	Parents Stories	Flashbacks  Managing flashbacks Dealing with flashbacks as they happen Managing flashbacks at night	Scar Management	Professional	
	Common feelings after the injury  Guilt Anger Numbness Depression	Fight or Flight Response	Managing Itchy Scars	Charities	
	Adjustment	Relaxation	Supporting your child through a painful procedure	Other resources	
	Dealing with the reactions of others	Mindfulness	Regression		
	The impact on your relationship with your spouse/partner	Sleep Problems	Responding to other people's questions		
	Supporting Siblings	Avoidance	Bullying		
			Your child, their scars, and the future		

Headings in bold denote major section headings of the website. The subsections within these are listed below.

## C.ii Study 3 Ethical Approval



[REDACTED]

UWE REC REF No: HAS.18.03.139

4<sup>th</sup> May 2018

Dr Jennifer Heath

[REDACTED]

Dear Jennifer

### **Application title: Development of a website for parents of burn-injured children**

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 23<sup>rd</sup> April 2018 and the study has been given ethical approval to proceed.

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: <https://intranet.uwe.ac.uk/tasks-guides/Guide/writing-and-creating-documents-in-the-uwe-bristol-brand>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee. <http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx>
2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: <https://teams.uwe.ac.uk/sites/HASgovernance>.

We wish you well with your research.

Yours sincerely

[Redacted Signature]

Chair

Faculty Research Ethics Committee

c.c.

[Redacted]

### C.iii Study 3 Advertisements

**Parent Invitation Email (if they have consented to being contacted but not participated in other research within this program of studies)**

Subject: \*Contribute to the development of a new parent-focused burns support website\*



Dear parent,

You have received this email because you took part in one of our burns-related research projects and you indicated your interest in hearing about future projects. The aims of this research are to offer support to better meet parents' needs. Based on the findings of my previous research, **I am now developing a burn-specific website for parents**. The website will provide information on a range of topics, including:

- Parents' stories
- Parents' role in their child's rehabilitation and pain management
- Managing trauma, stress, and sleep
- Strategies for living with the consequences of a burn-injury
- Relaxation techniques
- Signposting to other information and sources of support.

If you would like to contribute to the development of this website, you can do this in one of two ways:

1) **View a prototype website** with me and describe your experience of using it. I will ask you questions such as: What part of the website are you drawn to first? What do you think of the way the website looks? Is it easy to use? How easy is it to understand? What do you think about the information and techniques presented to help users? Have you learnt anything from it? What do you think the website should be called? What search terms would you expect to use to find a website like this?

2) **Contributing your story** anonymously to a 'parent stories' section of the website.

If you are interested in participating the development of the website, please read the attached information and contact me on: [REDACTED] or by telephone: [REDACTED]

I would really appreciate your input.

Thank you.

Dr Jennifer Heath

PhD Researcher & Clinical Psychologist

**Parent Invitation Email (if they have consented to being contacted and have participated in other research within this program of studies)**

Subject: \*Contribute to the development of a new parent-focused burns support website\*



Dear parent,

You have received this email because you took part in a research project looking at parents' experiences of their child's burn injury and the support that is available, and you indicated your interest in participating in future projects. Going forward, the aims of the research are to offer support to better meet parents' needs. Based on the findings of the research that you took part in, **I am now developing a burn-specific website for parents**. The website will provide information on a range of topics, including:

- Parents' stories
- Parents' role in their child's rehabilitation and pain management
- Managing trauma, stress, and sleep
- Strategies for living with the consequences of a burn-injury
- Relaxation techniques
- Signposting to other information and sources of support.

If you would like to contribute to the development of this website, you can do this in one of two ways:

- 1) **View a prototype website** with me and describe your experience of using it. I will ask you questions such as: What part of the website are you drawn to first? What do you think of the way the website looks? Is it easy to use? How easy is it to understand? What do you think about the information and techniques presented to help users? Have you learnt anything from it? What do you think the website should be called? What search terms would you expect to use to find a website like this?
- 2) **Contributing your story** anonymously to a 'parent stories' section of the website.

If you are interested in participating the development of the website, please read the attached information and contact me on: [REDACTED] or by telephone: [REDACTED]

I would really appreciate your input.

Thank you.

Dr Jennifer Heath

PhD Researcher & Clinical Psychologist

## Professionals Invitation Email

Subject: \*Contribute to the development of a new parent-focused burns support website\*



Dear professional,

You may already be aware of my work to develop remote support for parents of burn-injured children. After conducting both qualitative and quantitative research on the experiences of parents following their child's burn and access to support, **I am now developing a burn-specific website to provide low level support to parents.** The website will provide information on a range of topics, including parents' stories; their role in their child's rehabilitation and pain management; managing trauma, stress, and sleep; strategies for living with the consequences of a burn-injury; relaxation techniques; and signposting to other information and sources of support.

**If you would like to contribute to the development of this website, you can do this by viewing a prototype website with me and describing your experience of using it.**

I will ask you questions such as: What part of the website are you drawn to first? What do you think of the way the website looks? Is it easy to use? How easy is it to understand? What do you think about the information and techniques presented to help users? Have you learnt anything from it? Do you think parents will learn anything from it? What do you think the website should be called? What search terms would you expect to use to find a website like this?

If you are interested in participating in the development of the website, please read the attached information and contact me on: [REDACTED] or by telephone:

[REDACTED]

I would really appreciate your input.

Thank you.

Dr Jennifer Heath

PhD Researcher & Clinical Psychologist

### **Study 3 Social Media Advertisement**

[removed]



## C.iv Study 3 Information Sheets

### Parent Information Sheet



### Development of a website for parents of burn-injured children

You are being invited to take part in some research that could influence the support available for parents of burn-injured children. Before you decide whether you want to do this, it is important for you to know why the research is being done and what it will involve.

Please read the following information and, if you wish to, discuss it with others. Contact Jennifer Heath (Researcher) or Diana Harcourt (Supervisor) if there is anything that is not clear or if you would like more information, their contact details are provided below.

#### **What is the research that is being carried out?**

We are developing a website specifically for parents of children who have experienced a burn injury. The website contains information based on what parents have told us about their experiences following the accident. We would like some parents to look at a new website and tell us in a one-to-one interview or within a group what they think of it. We will use this feedback to make changes to the website before it is made available to everyone on the internet.

#### **Why have I been invited to take part?**

We are asking for parents/carers who have a child who has experienced but survived an accidental burn injury requiring hospital treatment to participate in this research. Both parents do not have to take part but can if they want to. We ask that at least six months have passed since the accident so that parents have had time to adjust to their situation.

#### **If I decide to take part, what is involved and what will I have to do?**

If you would like to participate in the research, we will ask you to complete a consent form. We will arrange to meet with you at a convenient time and location to view the website and ask you for your opinions of the website, and to complete a short questionnaire. This can be done one-to-one or in a group situation with other parents whose child has also had a burn injury. Providing feedback could take an hour and this may be longer within a group. Feedback will be recorded using a voice recorder. It is important that these sessions are face-to-face so that we can ask you questions directly about the part of the website you are viewing.

#### **Do I have to take part?**

It is up to you to decide whether or not you should take part. If you decide to, you can change your mind up to 2 weeks after completing an interview by calling or emailing the researcher using the contact details below. After 2 weeks, your answers will have been analysed and unfortunately cannot be excluded from the study. If you take part in a group session, we are unable to delete your answers because they will be recorded alongside other people's opinions and feedback. Your answers will remain anonymous as part of the

data set. If you do not want to take part that is fine, this research is not connected to the care you or your child receives in any way, now or in the future.

### **What are the possible advantages or disadvantages of answering the questions?**

This research is developing a new website for parents. The interview or group discussion will ask for feedback on the content of the website rather than your own experiences, but we will ask for some information about you and your child using a questionnaire (which will be kept confidential). We do not expect that parents will be upset by taking part in the interviews or groups but, due to the topic, it could be that thinking about the content of the website and how it applies to you could be upsetting. Parents in a group situation may also hear about the experiences of others, which could be upsetting. If you have any worries about any part of this research you can get in touch with Jennifer Heath who is organising the work, using the contact details below.

### **Will my participation in this research be kept confidential?**

The personal information collected in this research project (e.g. your contact details, the interview recording, your completed questionnaire) will be processed by the University (data controller) in accordance with the terms and conditions of the Data Protection legislation. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. All information that is collected from you will be stored separately from any contact information you provide. Once interviews have been typed for analysis, they will be stored as password protected documents that are strictly confidential and the audio recordings will be deleted. Your personal information will be used/processed as described on this participant information sheet. The data collected will be used to develop the website and to present or publish the findings. Once any amendments to the website have been made, the work has been examined for the award of a PhD, and the final output has been accepted for presentation/publication then it will then be destroyed.

You have a number of rights in relation to your personal data. For data protection queries, please write to the Data Protection Officer, [REDACTED]  
[REDACTED]

### **What will happen to the results of the research?**

A report will be written to inform any changes to the website before it is accessible to the general public later in the year. My supervisor and internal/external examiners may have or request access to the anonymised data but nobody will be given access to any participant details at any time. Where appropriate, papers will be prepared for conferences and journals. A summary of the research findings will also be available at the end of the research project. If you wish to have a copy, please contact the research team or tick the box on the consent form.

### **Who has reviewed the study?**

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

### **What should I do now?**

If you do decide that you want to take part, you should save and keep this information. If you are happy to take part, please complete the consent form on the next page.

## Contacts for Further Information

If you need further information, please contact Jennifer Heath or Diana Harcourt who are in charge of this research.

### Dr Jennifer Heath

PG Researcher

Centre for Appearance Research  
Faculty of Health and Applied Sciences  
University of the West of England  
Frenchay Campus  
Bristol  
BS16 1QY

[Redacted contact information]

Email: [Redacted]

Tel.: [Redacted]

Email: [Redacted]

Tel.: [Redacted]

If you have concerns about any aspect of this study, you should ask to speak to the researchers (detailed above) who will do their best to answer your questions.

**Thank you for taking the time to read this information.**

### Where can I find support?

If you think you would benefit from further support, please contact your GP. Your GP can discuss with you how you are feeling and refer you to an appropriate support service.

The burns service where your child was treated could also be a value source of support or help you to access support.

Alternatively, charities such as the Children's Burns Trust, Dan's Fund for Burns, The Katie Piper Foundation and Changing Faces can provide advice to parents or carers of a burn injured child on how to access information and support. If you need any information or support you can contact them using the webpages:

<http://www.cbtrust.org.uk/aboutus/contact/index.shtml>

<http://www.dansfundforburns.org/index.php>

<https://katiepiperfoundation.org.uk/contact/>

<https://www.changingfaces.org.uk/get-support>

Also, the Counselling Directory is a website designed to provide a UK-wide counselling support network, enabling people to find a counsellor close to them and appropriate for their needs. This is a free, confidential service and the website also contains useful information.

<http://www.counselling-directory.org.uk/>



#### **Development of a website for parents of burn-injured children**

You are being invited to take part in some research that could influence the support provided for parents of burn-injured children. Before you decide whether you want to do this, it is important for you to know why the research is being done and what it will involve.

Please take time to read the following information carefully. Contact Jennifer Heath (Researcher) or Diana Harcourt (Supervisor) if there is anything that is not clear or if you would like more information, their contact details are provided below.

#### **What is the research that is being carried out?**

We are developing a website specifically for parents of children who have experienced a burn injury. The website contains information based on what parents have told us about their experiences following the accident. We would like a sample of professionals who are experienced in providing support to parents of burn-injured children to look at the website and provide us with feedback in a one-to-one interview, or as part of a focus group. We will use these results to make any necessary changes to the website before it goes live on the internet.

#### **If I decide to take part, what is involved and what will I have to do?**

If you would like to participate in the research, we will ask you to complete a consent form. We will arrange to meet with you at a convenient time to complete a short questionnaire, view the website and interview you about your opinions of it, or we will arrange for you to provide this feedback in a group situation with other professionals (which ever you would prefer). Providing feedback could take an hour and this may be longer in a group scenario. Feedback will be recorded using a voice recorder.

#### **Do I have to take part?**

No, you do not have to participate in this research. If you decide to take part, you can change your mind up to 2 weeks after your participation by contacting the researcher using the details below. After 2 weeks your answers will have been analysed and unfortunately cannot be excluded from the study. If you take part in a group session, we are unable to delete your data because it will be recorded alongside the opinions and feedback of others. In this case, your answers will remain anonymously as part of the data set.

#### **Will my participation in this research be kept confidential?**

The personal information collected in this research project (e.g. your contact details, the interview recording, your completed questionnaire) will be processed by the University (data controller) in accordance with the terms and conditions of the Data Protection legislation. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. All information that is collected

from you will be stored separately from any contact information you provide. Once interviews have been typed for analysis they will be stored as password protected documents that are strictly confidential and the audio recordings will be deleted. Your personal information will be used/processed as described on this participant information sheet. The data collected will be used to develop the website and to present or publish the findings. Once any amendments to the website have been made, the work has been examined for the award of a PhD, and the final output has been accepted for presentation/publication then it will then be destroyed.

You have a number of rights in relation to your personal data. For data protection queries, please write to the Data Protection Officer, [REDACTED]  
[REDACTED]

### **What will happen to the results of the research?**

A report will be written to inform the further development of the website before it is made public later in the year. My supervisor and internal/external examiners may have or request access to the anonymised data but nobody will be given access to any participant details at any time. Where appropriate, papers will be prepared for conferences and journals. A summary of the research findings will also be available at the end of the research project. If you wish to have a copy, please contact the research team or tick the box on the consent form.

### **Who has reviewed the study?**

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

### **What should I do now?**

If you do decide that you want to take part, you should save and keep this information. If you are happy to take part, please complete the consent form on the next page and then the questionnaire that follows.

### **Contacts for Further Information**

If you need further information, please contact Jennifer Heath or Diana Harcourt who are in charge of this research.

Dr Jennifer Heath  
PG Researcher

[REDACTED]

Email:

Tel.:

[REDACTED]

Email:

Tel.:

If you have concerns about any aspect of this study you should ask to speak to the researchers, as detailed above, who will do their best to answer your questions.

**Thank you for taking the time to read this information.**

**C.v Study 3 Consent Form**



**Development of a website for parents of burn-injured children**

Please read this form, complete it once you have read the information sheet and understand the aims and procedures of the focus group.

	Please check to indicate agreement
I am over 18 years of age.	
I voluntarily agree to take part in this interview/focus group.	
I understand that this will involve being audio recorded.	
(Focus group only) I will treat anything that I hear from other people within the focus group as confidential.	
I understand that data collected during the interview/focus group may be listened to and looked at by individuals who are part of the research team.	
I confirm that I have received a full explanation of the purpose of the research and that I understand the information sheet (dated 23.4.18).	
I have been given a contact number so that I can ask questions and discuss aspects of the research with the researcher.	
I authorise the investigators to disclose the results of my participation in the research, but not my name or personal details.	
I understand that I can ask for further instructions or explanations at any time.	
I understand that I am free to withdraw myself from the interview/focus group at any time, without having to give a reason (however [focus group only], I understand that my data cannot be removed from the focus group recording).	
I would like to receive a summary of the results.	
I would like to receive information about other research I may be eligible to participate in.	
If you have ticked either of the above: please provide a contact email or postal address: .....	

**Participant's Name:** .....

**Signature:** ..... **Date:** .....

**Researcher's Name:** Dr Jennifer Heath

**Signature:** ..... **Date:** .....

## C.vi Study 3 Questionnaires

### Study 3 Parent Questionnaire

#### Part 1

Are you a...?

<b>Parent:</b> Mother / Father	<b>Carer:</b> Male / Female	<b>Other:</b> Please state your relationship to the injured child:
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This section asks about **your** general attitudes towards health-related websites.

'Health-related websites' can include websites that contain factual health information, stories of people's experiences of health, blogs about health or health discussion forums.

Please begin by completing the questions below.

To what extent do you agree or disagree with the following statements?	Select the box that applies to you				
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The internet is a reliable resource to help me understand what a doctor tells me.					
2. The internet can help people know what it is like to live with a health problem.					
3. The internet can be useful to help people decide if their symptoms are important enough to go to see a doctor.					
4. I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).					
5. I would use the internet to check that the doctor is giving me appropriate advice.					
6. The internet is a good way of finding other people who are experiencing similar health problems.					
7. It can be helpful to see other people's health-related experiences on the internet.					
8. The internet is useful if you don't want to tell people around you (for example, your family or people at work) how you feel.					
9. It can be reassuring to know that I can access health-related websites at any time of the day or night.					

10. The internet is a good way of finding other people who are facing health-related decisions I may also face.					
11. Looking at health websites reassures me that I am not alone with my health concerns.					

**Part 2**

<b>Thinking about the website you have just looked at, to what extent do you agree or disagree with the following statements?</b>	<b>Select the box that applies to you</b>				
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The website encourages me to take actions that could be beneficial to my own wellbeing.					
2. The website has a positive outlook.					
3. The information on the website left me feeling confused.					
4. The website includes useful tips on how to make positive changes to my situation.					
5. The website provides a wide range of information.					
6. The language on the website made it easy to understand.					
7. I feel more inclined to look after my own wellbeing after visiting the website.					
8. I have learnt something new from the website.					
9. I can easily understand the information on the website.					
10. The website prepares me for what my child and I might experience.					
11. The people who have contributed to the website understand what is important to me.					
12. I trust the information on the website.					
13. I would consult the website again in future.					
14. I feel I have a sense of solidarity with other people who might be using the website.					
15. I feel like I could identify with other people who might be using the website.					
16. On the whole, I find the website reassuring.					



17. I value the advice given on the website.					
18. The website gives me confidence that I am able to manage my own concerns.					
19. I feel I have a lot in common with other people who might be using the website.					
20. The website gives me the confidence to explain my concerns to others.					
<b>Select the box that applies to you</b>					
<b>Thinking about the website you have just looked at, to what extent do you agree or disagree with the following statements?</b>	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
21. The website helps me to have a better understanding of my own concerns and wellbeing.					
22. The website encourages me to play a more active role in my own wellbeing.					
23. The website makes me more confident to discuss my concerns and wellbeing with the people around me (e.g., my family or people at work).					
24. Photographs and other images were used appropriately on the website.					
25. I found the images on the website distressing.					
26. The website is easy to use.					

Please circle the relevant response option:

<b>How likely are you to recommend this website to friends and family if they needed similar support?</b>					
Don't know	Extremely unlikely	Unlikely	Neither likely nor unlikely	Likely	Extremely likely

In thinking about ways in which the website could be improved, it would be helpful to know why you have chosen this answer.

**What was good about the website?**

**What would have made the website better?**

Please circle the relevant response options:

<b>What age are you?</b>						
16-24	25-34	35-44	45-54	55-64	65-74	75-84
<b>What is your ethnicity?</b>						
White / White British	Mixed / Multiple ethnic groups	Asian / Asian British	Black / African / Caribbean / Black British	Other Ethnic Group Please Specify:		

<b>What is your marital/relationship status?</b>					
Single	Married / Civil Partner	Divorced / Person whose Civil Partnership has been dissolved	Widowed / Surviving Civil Partner	Separated	Not disclosed

<b>What caused your child's injury? Please select all that apply:</b>						
Scald – Hot fluid	Hot surface	Flame	Friction	Chemical	Electrical	Radiation

<b>Roughly where on your child's body was the injury? Please select all that apply:</b>			
Head/face	Abdomen/Stomach	Back	Buttocks
Neck	Arms	Legs	Genitals
Chest	Hands	Feet	

<b>What is your child's sex?</b>	Male	Female
<b>Was your child's initial treatment as an inpatient or outpatient?</b>	Inpatient	Outpatient
<b>Did your child's injury need surgery?</b>	Yes	No
<b>Do you know what the Total Burn Surface Area (TBSA) was?</b>	%	
<b>How old was your child when they had the injury?</b>		
<b>How old is your child now?</b>		
<b>What county do you live in?</b>		

<b>How did you hear about this research?</b>						
Charity Please specify:	Social Media Please specify:	From a professional	Email from the Centre for Appearance Research	Support Group	Burns Camp	Other Please specify:

Thank you for taking the time to complete this questionnaire. Your answers will contribute to the further development of support for parents of children following burn-injury.

Would you like to be informed of the results of this study?	<b>Yes</b>	<b>No</b>
Would you like to be informed about other research that you might be eligible to participate in?	<b>Yes</b>	<b>No</b>
If you answered yes to either of the above, please provide an email address:		

**Study 3 Professionals Questionnaire**

**Part 1**

Are you a...?

<p><b>Burn Care Professional</b> Please state your profession:</p>	<p><b>Other</b> Please state your involvement in burn care:</p>
--	---

This section asks about **your** general attitudes towards health-related websites.

'Health-related websites' can include websites that contain factual health information, stories of people's experiences of health, blogs about health or health discussion forums.

Please begin by completing the questions below.

To what extent do you agree or disagree with the following statements?	Select the box that applies to you				
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The internet is a reliable resource to help me understand what a doctor tells me.					
2. The internet can help people know what it is like to live with a health problem.					
3. The internet can be useful to help people decide if their symptoms are important enough to go to see a doctor.					
4. I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).					
5. I would use the internet to check that the doctor is giving me appropriate advice.					
6. The internet is a good way of finding other people who are experiencing similar health problems.					
7. It can be helpful to see other people's health-related experiences on the internet.					
8. The internet is useful if you don't want to tell people around you (for example, your family or people at work) how you feel.					
9. It can be reassuring to know that I can access health-related websites at any time of the day or night.					

10. The internet is a good way of finding other people who are facing health-related decisions I may also face.					
11. Looking at health websites reassures me that I am not alone with my health concerns.					

**Part 2**

<b>Thinking about the website you have just looked at, to what extent do you agree or disagree with the following statements?</b>	<b>Select the box that applies to you</b>				
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The website would encourage parents to take actions that could be beneficial to their wellbeing.					
2. The website has a positive outlook.					
3. The information on the website left me feeling confused.					
4. I think the information on the website would leave parents feeling confused.					
5. The website includes useful tips on how parents could make positive changes to their situation.					
6. The website provides a wide range of information.					
7. The language on the website made it easy to understand.					
8. Parents would feel more inclined to look after their own wellbeing after visiting the website.					
9. I have learnt something new from the website.					
10. I think parents would learn something new from the website.					
11. I can easily understand the information on the website.					

12. I think parents would find the information on the website easy to understand.					
13. The website prepares parents for what they and their child might experience.					
14. The people who have contributed to the website understand what is important to parents following their child's injury.					
15. I trust the information on the website.					
16. I think parents would trust the information on the website.					
17. I would consult the website again in future.					
18. I feel that parents would have a sense of solidarity with other people who might be using the website.					
19. I feel that parents could identify with other people who might be using the website.					

<b>Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?</b>	<b>Select the box that applies to you</b>				
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
20. On the whole, I believe parents would find the website reassuring.					
21. I value the advice given on the website.					
22. I think parents would value the advice given on the website.					
23. I think that the website would give parents confidence that they are able to manage their own concerns.					

24. I think parents would feel that they have a lot in common with other people who might be using the website.					
25. I think the website would give parents the confidence to explain their concerns to others.					
26. The website helps me to have a better understanding of parents' concerns.					
27. I believe that the website would help parents to have a better understanding of their concerns and wellbeing.					
28. I think the website encourages parents to play a more active role in their own wellbeing.					
29. The website makes me more confident to discuss parents' concerns and their wellbeing with them.					
30. I think the website would make parents more confident to discuss their concerns and wellbeing with the people around them.					
31. Photographs and other images were used appropriately on the website.					
32. I think parents would find the images on the website distressing.					
33. The website is easy to use.					

Please circle the relevant response option:

<b>How likely are you to recommend this website to friends and family if they needed such support?</b>					
Don't know	Extremely unlikely	Unlikely	Neither likely nor unlikely	Likely	Extremely likely

In thinking about ways in which the website could be **improved, it would be helpful to know why you have chosen this answer.**

**Space is provided on the next page.**

What was good about the website?

What would have made the website better?

Please circle the relevant response options:

<b>What is your sex?</b>	
Male	Female

<b>What age are you?</b>						
16-24	25-34	35-44	45-54	55-64	65-74	75-84

<b>What is your ethnicity?</b>				
White	Mixed/ Multiple ethnic groups	Asian / Asian British	Black / African / Caribbean / Black British	Other Ethnic Group Please Specify:

<b>How did you hear about this research?</b>						
Charity Please specify:	Social Media Please specify:	From a professional	Email from the Centre for Appearance Research	Support Group	Burns Camp	Other Please specify:

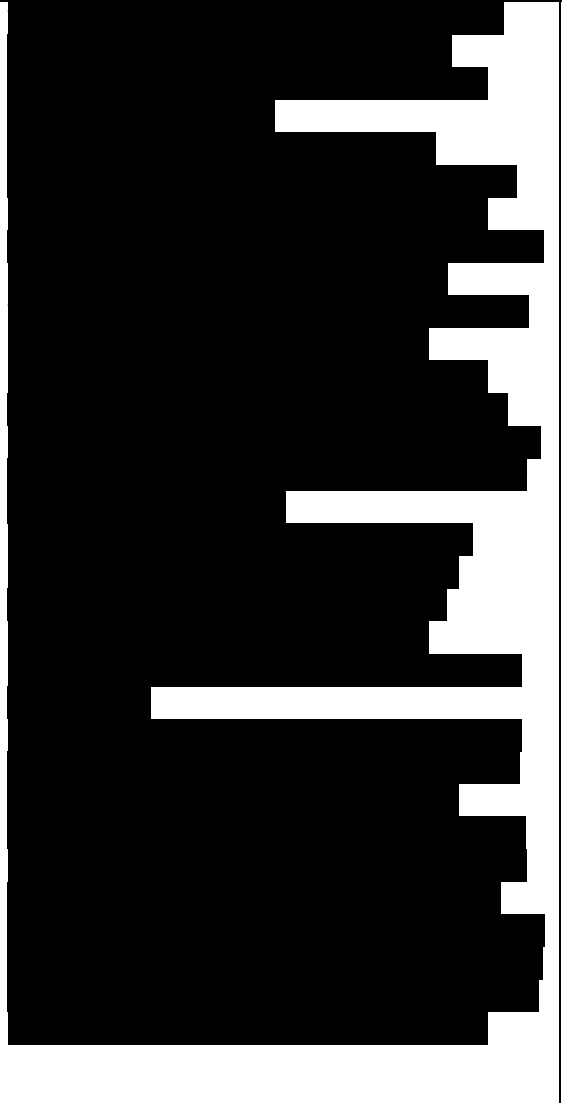
Thank you for taking the time to complete this questionnaire. Your answers will contribute to the further development of support for parents of children following burn-injury.

Would you like to be informed of the results of this study?	<b>Yes</b>	<b>No</b>
Would you like to be informed about other research that you might be eligible to participate in?	<b>Yes</b>	<b>No</b>
If you answered yes to either of the above, please provide an email address:		

C.vii Study 3 Person-based Decision Table

Page	Negative Comments	Positive Comments	Proposed Changes	Reason for Change	Agreed Change*
Home	<p>[Redacted Negative Comments]</p>	<p>[Redacted Positive Comments]</p>	<p>Make more info button more obvious                      Make photo fit the screen                      Take Parents out of title and be more inclusive (parents and carers) in the welcome message.                      Make sure that title doesn't get cut off when user uses the more info button                      Keep photo</p>	<p>Improved usability                      Better look/finish                      More inclusive                      The advantage of having the child in silhouette is that it doesn't necessarily genderise, age, or give the child a specific ethnicity, and similarly with the parents, which is important for the inclusivity of the website. It's not showing a child with a specific burn injury or scar. The difficulty with using a real image of an actually identifiable child, you then pin this is who this is for and you would definitely want to avoid that.</p>	<p>EAS/EXP/must                      EAS/would like                      EAS/NCON/IMP/must                      Would like                      EAS</p>



<p>Home Page – more info</p>			<p>Add headings (questions) to break up the text ‘About us’ research info should be a drop down to reduce words on page Amend info to specifically mention talking therapies and burn services. Add research message e.g. “This is a new website. It has been created with parents but we want you to help us to make it as good as it can be. Be entered into a prize draw for giving us your opinions on this new website.” Remove image at the bottom and add photos of the research team ‘Button’ at side should link to support rather than just resources.</p>	<p>When people go on to the internet, especially if they’re on their phone looking at a website, people don’t always read a lot of information. They might want to direct themselves or if you put a heading then it kind of leads them into what they’re going to read Parents reported that 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.</p>	<p>EAS/EXP/IMP/must  EAS/NCON/Should  IMP/EAS/Must  EAS/Should    EAS/Could</p>
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					EAS/IMP/EXP/must
--	--	--	--	--	------------------

**\*Key for codes in 'agreed changes' column**

Code	Meaning
IMP – Important for behaviour change	Likely to impact behaviour change or a precursor to behaviour change (e.g. acceptability, feasibility, persuasiveness, motivation, engagement).
EAS – Easy and uncontroversial	Easy change that does not involve major design changes.
REP – Repeatedly	Said repeatedly by more than one participant.
EXP – Experience	Something supported by experience from PI panel, experts/clinician, evidence from the literature.
NCON – Does not contradict	Does not contradict experience.
NC – Not changed	Not feasible, or only one person said this.
Must have	Must be made for the intervention to be effective in changing a participant's behaviour (given what we know about the evidence base).
Should have	Should be made if possible as it may impact effectiveness, but may be able to be delivered in a different way, or is less critical than a must have.
Could have	Would be useful. May be less critical to behaviour change than a should have and may only be implemented if time and resources are available.
Would like	This modification is not needed to support behaviour change, but could be useful if time and resources allow.

**C.viii Final website template**

<b>Home</b>	<b>Impact on parents</b>	<b>Stress Management</b>	<b>Supporting your child</b>	<b>Top tips</b>	<b>Where can I find support?</b>	<b>Feedback</b>
1.More info 2.About us	<p>1. Common feelings after the injury</p> <ul style="list-style-type: none"> <li>-Numbness</li> <li>-Guilt</li> <li>-Stress (inc. fight or flight response)</li> <li>-Anger</li> <li>-Depression</li> <li>-Traumatised (inc. flashbacks)</li> </ul> <p>2.Adjusting and adapting</p> <ul style="list-style-type: none"> <li>- Loss and Sadness</li> <li>- Changes and Challenges</li> <li>- Unexpected Gains</li> </ul> <p>3.Dealing with the reactions of others</p> <ul style="list-style-type: none"> <li>- Think of different ways to respond</li> <li>- Show confident body language</li> </ul> <p>4. The impact on your relationship</p> <ul style="list-style-type: none"> <li>- 4 common issues</li> <li>- Active listening</li> </ul> <p>5.Parent stories</p>	<p>1. Talk about it</p> <p>2. Self-care</p> <p>3. Relaxation</p> <p>4. Mindfulness</p> <p>5. Managing sleep problems</p> <ul style="list-style-type: none"> <li>-Stress and anxious thoughts</li> <li>-Nightmares and/or flashbacks</li> <li>-Your sleeping environment</li> </ul> <p>6. Managing avoidance</p>	<p>1.Scar Management</p> <ul style="list-style-type: none"> <li>-Managing uncertainty</li> <li>-popup of types of burns</li> </ul> <p>2.Managing itchy scars</p> <ul style="list-style-type: none"> <li>-What causes the itch?</li> <li>-What can reduce the itch?</li> </ul> <p>3.Supporting your child through a painful procedure</p> <ul style="list-style-type: none"> <li>-The B word</li> <li>-Babies/toddlers</li> <li>-Before a medical procedure</li> <li>-During the procedure</li> <li>-Preparing for subsequent procedures</li> </ul> <p>4.Regression/ Behaviour Change</p> <p>5.Responding to questions</p> <p>6.School &amp; bullying</p> <p>7.Your child, scars and the future</p> <p>8.Supporting siblings</p> <ul style="list-style-type: none"> <li>- Keep their routines in place</li> <li>-Tell them what they should expect</li> <li>-When possible, plan in advance</li> </ul>	<p>1.Bathing</p> <p>2.Creaming</p> <p>3.When other people look</p> <p>4.Maintaining boundaries</p> <p>5.School</p> <p>6.Self-care</p> <p>7.Taking medicine</p>	<p>1.Professional</p> <p>2.Charities</p> <p>3.Financial/Legal Support</p> <p>4.Social Care</p> <p>5.Forums</p> <p>6.Books and Apps</p> <ul style="list-style-type: none"> <li>- Books for children (aged 3 to 9)</li> <li>Books for young people (aged 10+)</li> <li>Book for parents/carers</li> <li>Apps</li> </ul>	<p>1.Research</p> <p>2.Contact us</p>

Headings in bold denote major section headings of the website. The subsections within these are listed below.



#### D. Study 4

## D.i Study 4 Ethical Approval



[REDACTED]

UWE REC REF No: HAS.18.03.139

4<sup>th</sup> May 2018

Dr Jennifer Heath

[REDACTED]

Dear Jennifer

**Application title: Development of a website for parents of burn-injured children**

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 23<sup>rd</sup> April 2018 and the study has been given ethical approval to proceed.

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: <https://intranet.uwe.ac.uk/tasks-guides/Guide/writing-and-creating-documents-in-the-uwe-bristol-brand>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee. <http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx>
2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: <https://teams.uwe.ac.uk/sites/HASgovernance>.

We wish you well with your research.

Yours sincerely

[Redacted Signature]

Chair

Faculty Research Ethics Committee

c.c. [Redacted]

## D.ii Study 4 Website Notification Email

Subject: \*New parent-focused burns support website\*



Dear parent/professional,

We wanted to let you know that a team at the Centre for Appearance Research has developed a burn-specific website for parents. The website provides information on a range of topics, including:

- Parents' stories
- Parents' role in their child's rehabilitation and pain management
- Managing trauma, stress, and sleep
- Strategies for living with the consequences of a burn-injury
- Relaxation techniques
- Signposting to other information and sources of support.

Please visit the website at [www.supportingchildrenwithburns.co.uk](http://www.supportingchildrenwithburns.co.uk)

We hope that this will be a useful resource for parents and would appreciate it if you would visit the website and provide some feedback. We welcome feedback from parents, professionals, or anyone else visiting the site. In return for your feedback, we are offering entry into a prize draw for a £50 Amazon voucher. A link to the evaluation form is on the website [here].

Should you need more information, an information sheet regarding this research is attached to this email.

We hope you find this new resource useful and want to thank you in advance for your feedback.

Kind regards,

Dr Jennifer Heath

PhD Researcher & Clinical Psychologist



### **D.iii Study 4 Website Advert (within the feedback section of the website)**

We hope you have found this to be a valuable resource and we would appreciate your feedback on your experience. We welcome feedback from parents, professionals, or anyone else visiting the site. To find out more about our ongoing research to evaluate this resource, please take a few moments to read the [information sheet](#) and complete the [evaluation form](#).

As a thank you for providing feedback, there will be a prize draw for a £50 Amazon voucher in July 2019.

#### [Evaluation Form](#)

The collective feedback will contribute to the future development of the website. The evaluation form will ask you about yourself and your circumstances, and the impact that this website has had on you. You will also have the opportunity to provide comments about any aspect of the website.

Nobody outside of the research team who developed this website will have access to individual peoples' feedback or data. As this information is being gathered as part of ongoing research, where appropriate, papers describing the combined data will be prepared for conferences and journals. A summary of the research findings will also be available by the end of 2019. If you wish to have a copy, please contact the research team or provide your contact details at the end of the evaluation form.

[Click here](#) to read our privacy policy.

Thank you in advance for your feedback.



### **Testing of a website for parents of burn-injured children**

You are being invited to take part in some research evaluating a new website for parents of burn-injured children. Before you decide whether you want to do this, it is important for you to know why the research is being done and what it will involve.

Please read the following information and, if you wish to, discuss it with others. Contact Jennifer Heath (Researcher) or Diana Harcourt (Supervisor) if there is anything that is not clear or if you would like more information, their contact details are provided below.

#### **What is the research that is being carried out?**

We have developed a website specifically for parents of children who have experienced a burn injury. The website contains information based on what parents have told us about their experiences following the accident. We would like feedback from parents and professionals who have used the website to inform future development of this resource.

#### **Why have I been invited to take part?**

We are asking for parents/carers who have a child who has experienced but survived an accidental burn injury requiring hospital treatment to participate in this research. Both parents do not have to take part but can if they want to. We are also seeking participation from professionals in the NHS and from charitable organisations.

#### **If I decide to take part, what is involved and what will I have to do?**

If you would like to participate in the research, you will be directed to an online survey. We will ask you to indicate consent on a consent form. You will then be presented with a short questionnaire that may take as little as a few minutes, or up to around ten minutes, depending on each individual.

#### **Do I have to take part?**

It is up to you to decide whether or not you should take part. If you decide to, you can change your mind up to 2 weeks after completing the questionnaire by calling or emailing the researcher using the contact details below. After 2 weeks your anonymous answers will have been analysed and unfortunately cannot be excluded from the study. If you do not want to take part that is fine, this research is not connected to the care you or your child receives in any way, now or in the future.

#### **What are the possible advantages or disadvantages of answering the questions?**

This research is evaluating the acceptability of a new website for parents. The questionnaire will ask for feedback on the content of the website rather than your own experiences, but we will ask for some information about you and your child using a questionnaire (which will be kept confidential). We do not expect that parents will be

upset by completing the survey, but it could be that thinking about the content of the website and how it applies to you could be upsetting. If you have any worries about any part of this research you can get in touch with Jennifer Heath who is organising the work, using the contact details below.

### **Will my participation in this research be kept confidential?**

The personal information collected in this research project (e.g. your completed questionnaire) will be processed by the University (data controller) in accordance with the terms and conditions of the Data Protection legislation. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. All information that is collected from you will be stored separately from any contact information you provide. Your personal information will be used/processed as described on this participant information sheet and data will be kept for 3 years after the examination of this program of research.

You have a number of rights in relation to your personal data. For data protection queries, please write to the Data Protection Officer, [REDACTED]  
[REDACTED]

### **What will happen to the results of the research?**

A report will be written to inform any future changes to the website. Nobody will be given access to the data or any participant details at any time. Where appropriate, papers will be prepared for conferences and journals. A summary of the research findings will also be available at the end of the research project. If you wish to have a copy, please contact the research team or tick the box on the consent form.

### **Who has reviewed the study?**

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

### **What should I do now?**

If you do decide that you want to take part, you should save and keep this information. If you are happy to take part, please complete the consent form on the next page.

### **Contacts for Further Information**

If you need further information, please contact Jennifer Heath or Diana Harcourt who are in charge of this research.

Dr Jennifer Heath  
PG Researcher

Email: [REDACTED]

Tel.: [REDACTED]

Email: [REDACTED]

Tel.: [REDACTED]

If you have concerns about any aspect of this study you should ask to speak to the researchers, as detailed above, who will do their best to answer your questions.

**Thank you for taking the time to read this information.**

### **Where can I find support?**

If you think you would benefit from further support, you may find the new website helpful. It may also be a good idea to contact your GP. Your GP can discuss with you how you are feeling and refer you to an appropriate support service.

The burns service where your child was treated could also be a value source of support or help you to access support.

Alternatively, charities such as the Children's Burns Trust, Dan's Fund for Burns, The Katie Piper Foundation and Changing Faces can provide advice to parents or carers of a burn injured child on how to access information and support. If you need any information or support, you can contact them using the webpages:

<http://www.cbtrust.org.uk/aboutus/contact/index.shtml>

<http://www.dansfundforburns.org/index.php>

<https://katiepiperfoundation.org.uk/contact/>

<https://www.changingfaces.org.uk/get-support>

Also, the Counselling Directory is a website designed to provide a UK-wide counselling support network, enabling people to find a counsellor close to them and appropriate for their needs. This is a free, confidential service and the website also contains useful information.

<http://www.counselling-directory.org.uk/>

#### **D.v Study 4 Consent Form (displayed on Qualtrics)**

Thank you for visiting the Supporting Children with Burns website. We hope that you found it useful. Whether you have found it to be a valuable resource or not, we would appreciate your feedback. We welcome feedback from parents, professionals, or anyone else visiting the site so that we can work to improve it.

In return for your feedback, we are offering entry into a prize draw for a £50 Amazon voucher. Thank you in advance for taking the time to complete this survey.

If you want to contact us to ask any questions about this research, contact information is provided below:

Dr Jennifer Heath  
PG Researcher  
Centre for Appearance Research  
Email: [REDACTED]  
Tel.: [REDACTED]

[REDACTED]  
[REDACTED]  
[REDACTED]  
Email: [REDACTED]  
Tel.: [REDACTED]

Please read this form and check the box at the end if you are happy to provide feedback on the website.

I am over 18 years of age, I voluntarily agree to take part in this research, and I understand the research being carried out.

I understand that data collected from this evaluation may be looked at by individuals who are part of the research team.

I have been given contact numbers so that I may ask questions and discuss aspects of the study with the researcher or their supervisor.

I authorize the investigators to disclose the results of my participation, but not my name or personal details.

I understand that information obtained during the study, will be kept in a secure database. Data will be kept for 3 years after the PhD, which this research is part of, has been examined by the University of the West of England.

I understand that I am free to withdraw myself from the research, without having to give a reason for withdrawing.

I understand that my participation in this research will be kept confidential.

Check to indicate agreement

#### D.vi Study 4 Survey Template (inputted into Qualtrics)

Are you a...?

- Parent
- Burn care professional
- Other... Please state:

- For parents and others:

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements? Strongly disagree Neither agree nor disagree Agree Strongly agree

1. The website encourages me to take actions that could be beneficial to my own wellbeing.
2. The website has a positive outlook.
3. The information on the website left me feeling confused.
4. The website includes useful tips on how to make positive changes to my situation.
5. The website provides a wide range of information.
6. The language on the website made it easy to understand.
7. I feel more inclined to look after my own wellbeing after visiting the website.
8. I have learnt something new from the website.
9. I can easily understand the information on the website.
10. The website prepares me for what my child and I might experience.
11. The people who have contributed to the website understand what is important to me.
12. I trust the information on the website.
13. I would consult the website again in future.
14. I feel I have a sense of solidarity with other people who might be using the website.
15. I feel I could identify with other people who might be using the website.
16. On the whole, I find the website reassuring.
17. I value the advice given on the website.
18. The website gives me confidence that I am able to manage my own concerns.
19. I feel I have a lot in common with other people who might be using the website.

20. The website gives me the confidence to explain my concerns to others.
21. The website helps me to have a better understanding of my own concerns and wellbeing.
22. The website encourages me to play a more active role in my own wellbeing.
23. The website makes me more confident to discuss my concerns and wellbeing with the people around me (for example, my family or people at work).
24. Photographs and other images were used appropriately on the website.
25. I found the images on the website distressing.
26. The website is easy to use.

Please provide any other comments or suggestions in the space below:

What is your ethnicity?

- White
- Mixed
- Asian or Asian British
- Black or Black British
- Other Ethnic Groups

What caused the injury?

Please select all that apply

- Scald – Hot fluid
- Hot surface
- Flame
- Friction
- Chemical
- Electrical
- Radiation

Roughly where on your child's body is the injury?

Please select all that apply

- |  |                                   |
|--|-----------------------------------|
| <input type="checkbox"/> Head/face       | <input type="checkbox"/> Hands    |
| <input type="checkbox"/> Neck            | <input type="checkbox"/> Legs     |
| <input type="checkbox"/> Chest           | <input type="checkbox"/> Feet     |
| <input type="checkbox"/> Back            | <input type="checkbox"/> Buttocks |
| <input type="checkbox"/> Abdomen/Stomach | <input type="checkbox"/> Genitals |
| <input type="checkbox"/> Arms            |                                   |

Total Burn Surface Area % (If known)

My child's initial treatment was as an...

- Inpatient
- Outpatient

Did your child's injury need surgery?

- Yes
- No

What is your marital/relationship status?

- Single
- Married/Civil Partner
- Divorced/Person whose Civil Partnership has been dissolved
- Widowed/Surviving Civil Partner
- Separated



Not disclosed

What country do you live in?

If UK, what county do you live in?

What was the approximate date of your child's injury? (DD/MM/YYYY)

What is your child's date of birth? (DD/MM/YYYY)

What is your date of birth? (DD/MM/YYYY)

How did you hear about this research?

- Charity website
- Social Media
- From a professional
- Email from the Centre for Appearance Research
- Support Group
- Burns Camp
- Other:

(If 'Charity website' is selected, present participant with:) Please select one:

- Changing Faces

- Katie Piper Foundation
- Children's Burns Trust
- Dan's Fund for Burns
- Other:  )

(If 'Social Media' is selected, present participant with: Please select one:

- Facebook
- Instagram
- Twitter
- Other:  )

Thank you for taking the time to respond to this survey. Your answers will contribute to the further development of support for parents of children following burn-injury.

- |  | Yes                   | No                    |
|--|-----------------------|-----------------------|
| Would you like to be informed of the results of this study?                                      | <input type="radio"/> | <input type="radio"/> |
| Would you like to be informed about other research that you might be eligible to participate in? | <input type="radio"/> | <input type="radio"/> |

Please create a password in case you want to delete your answers. Use the first 3 letters of your surname and the day of the month you were born e.g. Jennifer Heath born on 27/4/84 would make the password: HEA27

- For professionals:

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements? Strongly disagree; Disagree; Neither agree nor disagree; Agree; Strongly agree.

1. The website would encourage parent to take actions that could be beneficial to their wellbeing.
2. The website has a positive outlook.
3. The information on the website left me feeling confused.
4. I think the information on the website would leave parents feeling confused
5. The website includes useful tips on how parents could make positive changes to their situation.
6. The website provides a wide range of information.
7. The language on the website made it easy to understand.
8. Parents would feel more inclined to look after their own wellbeing after visiting the website.
9. I have learnt something new from the website.
10. I think parents would learn something new from the website.
11. I can easily understand the information on the website.
12. I think parents would be able to easily understand the information on the website.
13. The website prepares parents for what they and their child might experience.
14. The people who have contributed to the website understand what is important to parents following their child's injury.
15. I trust the information on the website.
16. I think parents would trust the information on the website.
17. I would consult the website again in future.
18. I feel that parents would have a sense of solidarity with other people who might be using the website.
19. I feel that parents could identify with other people who might be using the website.
20. On the whole, I believe parents would find the website reassuring.
21. I value the advice given on the website.
22. I think parents would value the advice given on the website.
23. I think that the website would give parents confidence that they are able to manage their own concerns.
24. I think parents would feel that they have a lot in common with other people who might be using the website.
25. I think the website would give parents the confidence to explain their concerns to others.
26. The website helps me to have a better understanding of parents' concerns.

27. I believe that the website would help parents to have a better understanding of their concerns and wellbeing.
28. I think the website encourages parents to play a more active role in their own wellbeing.
29. The website makes me more confident to discuss parents' concerns and their wellbeing.
30. I think the website would make parents more confident to discuss their concerns and wellbeing.
31. Photographs and other images were used appropriately on the website.
32. I think parents would find the images on the website distressing.
33. The website is easy to use.

Please provide any other comments or suggestions in the space below:

How did you hear about this research?

- Charity website
- Social Media
- From a professional
- Email from the Centre for Appearance Research
- Support Group
- Burns Camp
- Other:

(If 'Charity website' is selected, present participant with:) Please select one:

- Changing Faces
- Katie Piper Foundation
- Children's Burns Trust

Dan's Fund for Burns

Other:

(If 'Social Media' is selected, present participant with:) Please select one:

Facebook

Instagram

Twitter

Other:

Thank you for taking the time to respond to this survey. Your answers will contribute to the further development of support for parents of children following burn-injury.

	Yes	No
Would you like to be informed of the results of this study?	<input type="radio"/>	<input type="radio"/>

Would you like to be informed about other research that you might be eligible to participate in?	<input type="radio"/>	<input type="radio"/>
--	-----------------------	-----------------------

Please create a password in case you want to delete your answers. Use the first 3 letters of your surname and the day of the month you were born e.g. Jennifer Heath born on 27/4/84 would make the password: HEA27



## E. Dissemination

## E. i Publications

The following papers have been published as a result of the research and reflections within this thesis. They are enclosed in the secure pocket at the end.

Heath, J., Williamson, H., Williams, L. & Harcourt, D. (2020). [www.SupportingChildrenWithBurns.co.uk](http://www.SupportingChildrenWithBurns.co.uk): A website developed with parents and professionals for the psychosocial support of parents of burn-injured children. *Burns*, [in press].

Heath, J., Williamson, H., Williams, L. & Harcourt, D. (2019). Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children. *Patient Education & Counseling*, 102(9), 1730-1735.

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). 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*, 4, 1-12.

Heath, J., Williamson, H., Williams, L. & Harcourt, D. (2018). "It's just more personal": Using multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects. *Applied Nursing Research*, 43, 30–35.

Heath, J. (2018). Reflections on researcher positionality when using multiple techniques of qualitative data collection to facilitate participation in research focusing on a sensitive subject. In B. Clift, J. Hatchard & J. Gore (Eds), *How Do We Belong? Researcher Positionality Within Qualitative Inquiry: Proceedings of 4th Annual Qualitative Research Symposium* (pp. 71-82). Bath, UK: University of Bath.

Heath, J. (2016). Depression: An antecedent and consequence of burn-injuries to children. *Austin Journal of Emergency and Critical Care Medicine*, 3(1), 1046-1050.



## **E.ii Newsletters**

Heath, J. (2018). Help the parents, help the child: Developing support for parents of burn-injured children. *Association for Child and Adolescent Mental Health Newsletter*. Retrieved from <https://www.acamh.org/blog/help-parents-help-child-developing-support-parents-burn-injured-children/>

Heath, J. (2019). Supporting Children with Burns. *South West UK Burn Care Operational Delivery Network Bulletin*. Retrieved from <http://www.southwestukburnnetwork.nhs.uk/website/SWUK001/files/SWUK%20ODN%20Burns%20Bulletin%20Q1%202019-20.pdf>

### **E.iii Blogs**

#### **Children's Burns Trust**

Three blog posts were written by the Children's Burns Trust to promote the research in 2016 and 2018 (retrieved from <https://www.cbtrust.org.uk/2016/09/21/support-parents-burns-research-opportunity/> and <https://www.cbtrust.org.uk/2018/07/17/interview-with-jennifer-heath-centre-for-appearance-research/>) and to promote the website in 2019 (retrieved from <https://www.cbtrust.org.uk/2019/03/06/jennifer-heath-updates-cbt-on-the-supporting-children-with-burns-website/>).

#### **YellowRoad Designs**

A blog post was also written by the website developer at YellowRoad Designs following its release in 2018 (retrieved from <https://yrdesigns.co.uk/2018/10/18/supportchildrenwithburns/>).

#### **E.iv Press Release**

A press release, which included a video, was also disseminated by UWE Bristol in October 2018 (retrieved from <https://info.uwe.ac.uk/news/UWENews/news.aspx?id=3873>). This led to media coverage from Heart West News, BBC Bristol and the British Psychological Society.

BBC coverage (retrieved from <https://www.bbc.co.uk/news/uk-england-bristol-45879004>)

British Psychological Society coverage (retrieved from <https://thepsychologist.bps.org.uk/one-stop-shop-living-burn-injuries>).