

An evaluation of Children's Burns Trust Family Weekends 2022

An independent evaluation by the VTCT Foundation
Research Team at the Centre for Appearance Research

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Executive summary

Family weekends offer an opportunity for children with burn injuries and their families to meet others with similar experiences and learn about topics such as scar management and managing anxiety. Between March 2020 and November 2021, family weekends were temporarily suspended due to the global COVID-19 pandemic and several 'online family events' were run in their place. These events took place via video-conferencing, were facilitated by burns professionals, and were evaluated through a collaboration between Children's Burns Trust and the Centre for Appearance Research (CAR). With a return to in-person family weekends in 2022, Children's Burns Trust and CAR have collaborated to evaluate experiences of these family weekends (which took place in April, September, and November 2022). This evaluation was funded by the VTCT Foundation and aimed to examine family and staff experiences of these weekends. Importantly, this collaboration between Children's Burns Trust and CAR allowed for an independent evaluation of the events, with families reassured that their feedback was confidential and would have no impact on the support provided to them by healthcare professionals (including those present at the events) or Children's Burns Trust.

In order to evaluate this return to face-to-face family weekends, researchers from CAR conducted a mixed-methods evaluation, including online surveys for families who attended and for staff involved in planning and delivering the events. Survey questions relate to motivations, expectations, and challenges regarding the event, as well as the impact of the event on parent's perceptions of their child.

Findings of this evaluation of the 2022 family weekends suggested that these events represented a positive and valuable experience for the families and staff who attended. Staff and parents identified the benefits of spending an extended period of time together face-to-face and away from a hospital environment, allowing attendees to spend time together as a family, meet others with similar experiences, and build strong interpersonal

connections. When comparing this family weekend to the online family-events held in 2020/2021, it is clear that many of the benefits emphasized the face-to-face and residential nature of the event, whilst many of the benefits of online events had focused on increased access to support and enabling more families to attend. Importantly, both types of event demonstrated the value of learning more about burns treatment, sharing experiences with other families, and building links between families and hospital staff.

Several evidence-based recommendations informed by the 2022 evaluation findings have been made regarding the implementation and evaluation of future family weekends. These recommendations included considerations about the planning and delivery of the events, as well as strategies to increase the reach of the family weekends. Suggestions for changes aimed at increasing family engagement with follow-up surveys are also discussed. Finally, plans to gain feedback from stakeholders and pilot any changes are considered.

In conclusion, family and staff experiences of the 2022 family weekends were overwhelmingly positive. Evaluation findings provide an evidence-base to suggest changes to future family weekends and ensure continued positive impact for families and staff.

Background

Children's Burns Trust is a small, national charity dedicated to providing rehabilitation support for burned and scald injured children and their families, as well as prevention and awareness campaigns. As part of their ongoing support for children and their families, Children's Burns Trust run three 'family weekends' per year. These are residential events, where children and parents are invited to meet with others who have had similar experiences and learn more about topics relevant to burns care (e.g., scar management and coping strategies). Qualitative studies of residential camps for children and families have shown the benefits of attending can include increased confidence and improved coping (Gaskell, 2009), as well as reduced isolation, improved social skills, and acceptance of an altered appearance (Kornhaber *et al*, 2020); although it is noted that these results have not been replicated in quantitative studies, representing an ongoing challenge for clinicians and researchers.

As a result of the global COVID-19 pandemic and resulting restrictions in the UK, Children's Burns Trust suspended all face-to-face support from March 2020, including their planned 'family weekends'. This encouraged the charity to explore alternative methods of providing support, including a series of online family-events for children with a burn injury and their families. An evaluation of these events by researchers at the Centre for Appearance Research (CAR) suggested an online alternative to family weekends was a highly acceptable alternative to face-to-face support by both families and staff. Strong links with local burns services, interactive activities for children, and the opportunity to meet others with similar experiences were identified as important elements of such events, with both face-to-face and online events seen as having a role in burns support in the future.

With a return to face-to-face family weekends, CAR were expertly placed to build upon this previous collaboration and conduct an independent evaluation of these events. Researchers at CAR have substantial expertise in research relating to the psychosocial impact of burn

injuries, including specific experience investigating the psychosocial impact of attending burn camps (Armstrong-James, et al, 2018a, b) and parent's attitudes towards participating in burns research (Tollow et al, 2022). More broadly, research at CAR has led to the development of a UK parent-focused peer-informed website to support families of burn-injured children (Heath, et al, 2019), development and validation of the CARE burn scales (a suite of patient reported outcome measures for use with adults, children, young people and parents of children with a burn injury; Griffiths et al, 2019), and ongoing work developing online support for people affected by burn injuries (including forthcoming research to develop a module on the Healthtalk website).

Therefore, the aim of this evaluation was to **evaluate the experiences of both staff and families attending the Children's Burns Trust family weekends in 2022, as well as the longer-term impact of these weekends on families who attend them.**

Evaluation Methodology

About the family weekends

Three family weekends were organised and delivered by the Children's Burns Trust in 2022 (April, September, November). The family weekends were conducted over two locations and supported by two of the **UKs burns networks**. Two family weekends were conducted in Penrith (**Northern Burn Care Network**) and one family weekend was conducted in Littlehampton (**London and Southeast England Burn Network**). Overall, 8 hospitals took part in the planning and delivery of these events, with a total of 18 families and 36 members of staff attending the events. Please see a detailed breakdown of family weekend attendance in Table 1 below.

Activities at the family weekend included: farm park visits, swimming, a music workshop, a trip to the beach, a llama walk, storytelling, and kid's crafts and party. Parents were also given the opportunity to take part in activities by themselves including the option to have a massage, a hydro-relaxation session, and a parent-only sit-down meal.

In addition, parent support sessions were run on the topics of ‘scar management’ and ‘parents experiences after a burn’, and there were also many opportunities for families to socialise together.

Table 1: Summary of Family Weekend 2022 attendees

Family weekend	No. of families	No. of parents	No. of children	No. of staff
Penrith April	6	10	12	11
Littlehampton September	6	11	12	12
Penrith November	6	9	10	13
Total	18	30	34	36

Design

This evaluation included both qualitative and quantitative components to gather feedback about the family weekends from both parents and staff members.

In order to take part in the evaluation, participants were required to:

- Be attending a Children’s Burns Trust family weekend in 2022.
- Be 18 years old or older at the time of the evaluation.
- Be able to read and write in English, sufficient to provide informed consent.

Data was collected from event attendees and staff through the use of several online questionnaires. Families were asked to complete **two questionnaires** relating to their experience of the event and their wellbeing:

- **Post-event questionnaire** (online link provided to all those who attended the family weekends)
- **Follow-up questionnaire** (sent 10 weeks after the event to all those who completed the post-event questionnaire)

In addition, all staff involved in planning or delivering the event were invited to complete a **staff evaluation questionnaire**. Details of the evaluation were given to families via a handout distributed in the final session of the family weekend, and details of the staff evaluation were distributed via an email following the event.

All online questionnaires included a participant information sheet, privacy notice (including adherence to the General Data Protection Regulation (GDPR)), and participant consent form (see Appendices A-D). All participants were required to create a unique participant ID and questionnaires were hosted on Qualtrics, a secure online survey platform (see Table 2 for a summary of the survey questions; see Appendices E-G for full details of all survey questions).

Analysis

Descriptive statistics were used to analyse each of the quantitative measures described above. Open-ended qualitative responses to the questionnaires were analysed using content analysis, before the results from each of these data collection methods were triangulated in order to present them thematically in this report.

Ethical considerations

Ethics approval for this evaluation was sought from the University Research Ethics Committee at the University of the West of England (ref: HAS.22.02.068). In particular, consideration was given to issues of informed consent, participant distress and right to withdraw.

Table 2. Summary of the questions included in the evaluation questionnaires

Post-event questionnaire	Follow-up questionnaire	Staff evaluation questionnaire
<ul style="list-style-type: none"> - Reasons for attending the family weekend. - Expectations of the weekend and whether these were met. - Most liked element of the weekend. - Anything they would change about the weekend or any other types of events they would like to see. - Any changes to their thoughts about their child's burn injury as a result of attending the weekend. - Challenges associated with attendance. - Child's and sibling's experience of the weekend. - Whether they would recommend the weekend to others. - Overall rating of the weekend. 	<ul style="list-style-type: none"> - Impact of the weekend on their family in the last 10 weeks. - Any changes to their thoughts about their child's burn injury as a result of attending the weekend. - Changes in their child/children/other family members since the event. - Additional comments about the weekend. 	<ul style="list-style-type: none"> - Elements of the weekend that worked well. - Benefits to staff/families from attending the weekend. - Improvements to the planning process and the weekend itself. - Challenges associated with attendance. - Overall experience of taking part in the event. - Additional comments about the weekend.

Evaluation Results

Participants

Out of a total 30 parents (from 18 families) who attended the family weekends, 37% (n=11) participated in the evaluation through the completion of an online survey (see Table 3). Eight of these parents identified as mothers and three identified as fathers. The majority of parents identified as White British (n=6), whereas two identified as British Indian, two identified as Black African, and one identified as Iranian.

Children with a burn injury were aged between 1-8 years old at the time of the family weekend, and their injuries happened between the ages of 5 months and 6 years old. It was reported that the majority of burn injuries were caused by liquids (n=9; e.g., hot water, cooking oil), whereas a couple of burns were as a result of contact with a heated surface (n=2; e.g., iron, hot cooking pan), and one injury was caused by flame. All participants felt they have had the support they needed since their child had their burn and 73% of parents reported that they or their child were still receiving medical treatment from their burns service (n=8).

The 11 parents who completed the online evaluation were also sent a follow-up survey 10-weeks after the event. Unfortunately, although several reminders were sent, none of the parents chose to complete this second survey.

Of the total 36 members of staff who attended the family weekends, 64% (n=23) completed an online survey to provide feedback on their experiences. Five members of staff had not previously attended a family weekend, with the remaining 18 staff members having attended an average of 6 previous family weekends (range 1-15).

Table 3. Number of evaluation participants

Data collection method	Number of responses
Post-event questionnaire	11
Follow-up questionnaire	0
Staff evaluation questionnaire	23

Post-event Questionnaire Results

Overall experience of the weekend

Participants were asked several questions relating to their overall experience of the weekend (see Table 4).

Table 4. Quantitative results regarding participants' overall experience of the weekend

	Participant response
How would you rate your overall experience of the weekend? (n=11)	81% 'Very good' 9% 'Good'
Would you recommend this family weekend to other families? (n=9)	100% 'Yes'
Did you experience any challenges taking part in the family weekend? (n=11)	100% 'No'

Parents were also asked to provide qualitative feedback of their overall experiences and why they would recommend the family weekend to others. See below for several quotes provided by parents:

Would you recommend the family weekend to others? If so, why?

"It's hard to describe the experience we had other than magical and special. Relaxing and fun and just brilliant."

"it helps you realise that you are not in that situation alone"

"Help with feeling better, knowing more and a fun place to be for a weekend."

"Yes. For them to be able to see other children and parents and their stories is really important to realise how accidents to happen and how to deal and cope with this roller coaster."

"The full weekend was packed full of different things and suited all ages. All the kids were brilliant, and all families got on and interacted with each other"

Motivations to attend

Parents were asked to consider their top three reasons for attending the event. These answers fell into five categories:

- For parents and children to meet others with similar experiences.
- Learn more about burns and treatment.
- Learn from other experiences, in terms of physical/mental recovery and coping with guilt.

- To spend quality time together as a family.
- To provide a positive experience for their children.

Parents highly valued the opportunity to meet other families and wanted their children to have a chance to spend time with others who have had similar experiences to their own. Parents also viewed the family weekends as a learning opportunity and a place to obtain knowledge and coping skills from other families and professionals. Finally, parents reported the desire to have time and space to spend time together and provide a positive experience for their child to play and have fun.

Parents experiences of the weekend

Several parents suggested that the family weekend **exceeded their expectations** (n=5), with no parents answering this question negatively (*“It exceeded expectations beyond anything we could have imagined”*).

When asked what they **most liked** about the family weekend, parent’s answers indicated several elements that stood out to them:

- “Good balance of fun activities, and also learning and calming group sessions”
- “Interaction with other families and the psychology sessions”
- “The ability for people to share and offer support and the chance for the children to play.”
- “Overall, the care and dedication of the support staff from each hospital. I felt completely relaxed and taken care of and that my son was having the time of his life.”
- “The whole weekend was amazing. The staff were excellent, so much to do and was tailored for all age groups. Meeting other parents who had been through the same thing was probably the best thing, as we as parents thought it was just a freak accident that no one else would have been through.”

“It was the people that made it [...] all of the staff at the centre and all of the staff coming from each hospital had true passion for their work and clearly loved the children. To give up their weekends and work so hard is completely beyond the call of duty and very, very much appreciated.”

In addition, parents were asked whether they felt they **gained** anything from attending the family weekend. These answers appeared to fall under six categories:

- Meeting new people and finding community.
- Learning about psychological impact of burn injuries and helpful coping strategies.
- Learning about treatments and practical management.
- Learning relaxation and coping strategies.
- Being able to share experiences with others.
- Growth in child confidence.

Parents perceptions of their child's burn

Parents were asked whether attending the weekend had changed their thoughts about their child's burn. Six parents reported that attending the weekend had changed their perceptions of their child's injury, whereas three parents said they were 'not sure' and one parent said it had not changed their perceptions.

Of those who reported their thoughts had changed, parents suggested that meeting others with burn injuries and learning more about the trajectory of recovery had given them an insight into the future of their child's burn injury. They also described feeling that their own experiences were similar to others, and therefore were able to normalise these, and learn from others' experiences and advice.

Finally, one parent's reflections suggested that the weekend allowed them to re-frame the accident that led to the burn injury and that this had a profound emotional impact:

"I came away from the weekend feeling completely different about the accident that left my son with a burn. We both came away happy and fulfilled."

Children and siblings experiences of the family weekends

Of the 11 parents who completed the evaluation, seven parents completed the section reporting on their children's experiences of the event. Of those parents who answered this

question, all suggested that their children had a positive experience of the weekend, rating this **5 out of 5 in terms of overall enjoyment**.

When asked what their child had **enjoyed most** about the weekend, most parents reported that the children really enjoyed the activities and particularly the swimming sessions. When asked if they felt their child had **learnt** anything whilst attending the weekends, parents suggested that they were pleased that their child had had the opportunity to interact with others with similar experiences to them, as well as those from different backgrounds.

Parents suggestions for future weekends

When asked if anything about the family weekends could be improved or if there were any barriers to engagement in the events, parents made the following suggestions:

- Allowing a longer break between activities (e.g., between swimming and workshops) (*this point was echoed by staff*).
- A shift in timetabling to allow more activities on Sunday morning as Saturday felt very busy.
- Starting the day earlier (e.g., 9am).
- An opportunity for families to get snacks during the day.
- Cooked breakfast on the Saturday rather than the Sunday to prepare for a longer day.
- Meeting at the farm was felt to be a good way to start the weekend and a fantastic experience for parents and children.

Anything else to tell us?

"The hospital staff that attend with us were amazing, I couldn't fault anyone. They were supportive, understanding, and very accommodating. Even those that we hadn't met were very approachable and caring. We really feel blessed to have these kind of people in our children's lives who genuinely care for them. "

"Thank you for organising the family weekend. It has brought us closer together as a family."

"I feel very grateful that the weekend was put on, at no expense to me or my family. The fact that everything is included, and staff are polite, kind, and friendly, made the event even better. I felt an overwhelming sense of care from everyone, staff, parents, and children. I hope no one ever has to go through a burns injury, but if they do, I would highly recommend them to go to the event. "

"No - just a huge thank you to everyone. You are all truly special people. Xx"

Staff Evaluation Questionnaire Results

Overall experience of the weekend

Staff were asked several questions relating to their overall experience of the weekend (see Table 4).

Table 4. Quantitative results regarding participants' overall experience of the weekend

	Participant response
How would you rate your overall experience of the weekend? (n=23)	100% 'Very good'
Did you experience any challenges taking part in the family weekend? (n=23)	78% 'No' 22% 'Yes'

Staff reported some difficulties with the planning process including the challenges associated with identifying appropriate families, managing family drop-out, and the planning meetings occurring on a day they could not attend. A few practical challenges were

also mentioned including arranging meal choices in advance, coordinating travel for families, and being the only representative of their professional specialism present at the event.

Staff experiences of the weekend

Staff were asked what they felt worked well about the family weekend, and they highlighted many areas that they felt were successful. These included:

- Teamwork between staff.
- Presence of parents at different stages of recovery allowed them to share experiences and learn from each other.
- Passionate and experienced staff.
- High engagement from families in workshops and activities.
- Well organised timetable with a good balance of activities for the whole family and just for the adults.
- Good ratios of staff to parents and children.

“I think it was a lovely opportunity for the families to connect and network with others who have undergone similar experiences.”

“Staff are very passionate about the weekend, which shows in their engagement, activities, and the way the weekend is run!

“It is lovely to see how much the families get from this experience and also new staff who attend. It helps give a better insight into what families go through outside of the clinic/hospital environment.”

“Families got a lot out of the psychology sessions and children enjoyed all the activities”

Staff were also asked what they gained from the weekend. Their responses can be summarised into the following categories:

- Opportunity to connect with staff from other services.
- Opportunity to interact with families outside of the hospital setting.
- Rewarding and enjoyable experience.
- Opportunity to recognise the complexities of family life and how important it is to consider when delivering care.
- Learning opportunity for staff, reminded them of parent's expertise and the value in parents learning from each other.

"It's always really valuable to attend as a staff member. It's good to network with other staff from centres in the region. I also find it really helpful to see families in a setting outside of the hospital and feel it really fosters families relationships with the hospital staff. It is always a motivating and re-energising experience."

Do you think families gained anything from attending the family weekend? If so, what do you feel they gained?

"I think the families gained a huge amount from the weekend. Meeting other families who have been through a burn injury and sharing ideas of how they have managed and how feelings have changed over time. The fact the families were at different points of their journey seemed to work well for this group of families. Sharing feelings helps to normalise how they felt and getting this from other families who have been through it was really powerful. "

"The feeling they are not on their own and that their feelings are normal. All the families got on very well together it was a very supportive environment."

"The children seemed to form friendships as well which was lovely to see. Parents I spoke to commented on how this made them feel less alone, and also helped their children accept the injury."

"It brought people together and enabled them to build empathetic, trusting, and caring relationships as well as discuss issues with others and seek further support"

Staff suggestions for future weekends

Staff feedback was overwhelmingly positive, with a few suggestions for improvements for future weekends. Their suggestions were:

- Allowing a longer break between activities (e.g., between swimming and workshops) (*this point was echoed by parents*).
- More information provided to new staff attending.
- Beginning the planning processes earlier to aid with difficulties related to identifying and signing up appropriate families.
- Consideration of more varied activities if older children are going to be attending.
- Potential for the food at the children's party to be cold, rather than cooked.
- Music at the children's party.
- Consider future use of the storyteller, as some children were less engaged in this activity.

Conclusions

The results of this evaluation suggest that the 2022 Children's Burns Trust family weekends represented a positive and valuable experience for many of the families and staff who attended, with clear benefits of spending an extended period of time together face-to-face and away from a hospital environment. Both families and staff emphasized the value of shared experiences and meeting others who were at different stages of their recovery after a burn injury. This was felt to be an important element of the weekend for both adults and children. These results appear to reflect the findings of published research relating to burn camps (Gaskell, 2009; Kornhaber *et al*, 2020) and reinforce the value of these weekends.

When comparing these face-to-face family weekends to the online family-events held in 2020/2021, it is clear that many of the benefits of this event emphasized the face-to-face and residential nature of the family weekend. In particular, families suggested that they benefited from spending time with other families who had shared experiences. Parent

feedback indicated that the in-person nature of these events was central to their children's positive experiences of the weekends. Whilst the online events allowed increased access to this support and enabled more families to attend, the results of this evaluation suggest that the face-to-face events offered benefits in terms of spending time together as a family, meeting others with similar experiences, and building strong connections and community with others. Importantly, both the online and face-to-face events have demonstrated the value of learning more about burns treatment, sharing experiences with other families, and building links between families and hospital staff.

In conclusion, family and staff experiences of the family weekends were overwhelmingly positive. This evaluation has identified some key evidence-based recommendations for future weekends, which will be discussed below.

Recommendations for future weekends

Although the results from the 2022 family weekend evaluation demonstrated largely positive feedback from both parents and staff, several recommendations related to the implementation and evaluation of future family weekends have been suggested. These recommendations are based on the findings of the 2022 evaluation.

Changes to planning and weekend program

Qualitative responses from parents and staff indicated several suggested changes to the planning and delivery of the family weekends. Firstly, staff respondents reflected on some of the challenges related to planning the weekends. This included the difficulties associated with identifying appropriate families, finalising the attendee list, managing drop-out, and other arranging other practical aspects of the day (e.g., meal choices). Although staff acknowledged that some aspects of planning (e.g., family drop-out) are outside of their control, they suggested a longer planning process to allow more time to manage these challenges. Another suggestion was to alternate the days on which the planning meetings take place to ensure as many staff members can be involved as possible. Some staff also suggested that it may be beneficial to provide more information to staff who are attending

their first family weekend. They felt this would help them to prepare for the event and communicate expectations.

Both parents and staff respondents indicated that they could have benefitted from some changes to the timetabling of the weekend activities. Both parents and staff indicated that although they enjoyed the activities, the program felt quite busy, and it could be beneficial to include longer breaks between activities. Another suggestion was to rearrange the program to include more on Sunday, so that Saturday was less busy.

Finally, staff reflected on some of the activities included within the program and made a few suggestions for consideration. Staff commented that although the activities worked well for the particular families who attended the 2022 family weekends, it would be important to consider having a more varied range within the program if older children were to attend in future. Individual staff also made some small specific comments about various elements of the program and how they could be adapted (see page 18).

Increased reach of family weekends

The evaluation findings have indicated that the family weekends provided an array of valuable benefits for attendees. However, these events are currently only run in the London Southeast and the Northern burn service regions. Given the demonstrated positive impact of these events, Children's Burns Trust aim to broaden the reach of the family weekends in 2023 to include families and staff from the Southwest and Midlands burns services. This would increase the accessibility of support to families of children from these regions.

The data from the 2022 evaluation highlights that the family weekends are key in supporting parents to meet other families, build community, and learn from each other. In addition, staff members also stated the importance of spending time with other professionals and identified the family weekends as a valuable learning and development opportunity.

Growing this network of support will mean that these benefits will be accessible to a greater number of families, thereby increasing the reach of this support provision and developing closer links between burns services.

To record the impact of this new approach, the Children's Burns Trust staff will monitor the number of families and staff from each burns network. Therefore, the number of families

and staff present from each service can be measured and reported as part of this continued evaluation. In line with recommendations presented above (see page 19), it is important to ensure that any new staff attending their first family weekend are provided with clear and comprehensive information about the content of the program, the aims of the event, and their role as a staff attendee.

Follow up survey

Following the 2022 family weekends, parents who responded to the post-event survey were asked to complete a follow-up survey 10 weeks after the family weekend. The aim of the follow-up survey was to evaluate longer term impact of the family weekends. Unfortunately, none of the families chose to respond to this follow-up survey. To increase engagement and better understand the long-term impact of family weekends, several recommendations have been made:

- 1) Firstly, the follow-up period should be shortened from 10 weeks post-event to six weeks post-event. It is possible that the length of time in the present design is a barrier to parents completing the survey. Six weeks would still provide an indication of longer-term impact of attending the family weekend without too much time passing that parents forget to complete the survey.
- 2) The link to the follow-up survey and reminders are currently sent to participants via email. Evaluation of future weekends will utilise reminders via phone call or messaging service (e.g., WhatsApp) to encourage engagement and survey completion.
- 3) The follow-up survey should be shortened and be comprised of just two questions based on the NHS Friends and Family test: 1) What was your overall experience of the family weekend? and 2) Would you recommend the family weekends to other families of children with a burn injury? If parents have any further feedback, they will be directed to an online survey link to provide qualitative feedback.
- 4) All families who complete the follow-up survey will be offered a £10 shopping voucher as an incentive to participate and to say thank you for their time.

The impact of these changes will be evaluated by monitoring the engagement and completion of follow-up surveys following the 2023 family weekends.

Feedback and piloting

It is important to gain feedback and pilot these proposed changes to the implementation and evaluation of the family weekends. Incorporating Public Involvement into the design and implementation stages is essential to conduct relevant, appropriate, and meaningful research (Brett et al., 2014). Therefore, representatives from Children's Burns Trust and CAR will meet with staff members from burns services to conduct a stakeholder feedback session. Representatives from CAR will present the findings of the 2022 evaluation and will hold a discussion about the proposed changes to the family weekends and evaluation design listed above. Staff members will be asked for feedback on these changes. The stakeholder feedback will be collated and will inform the family weekend 2023 evaluation design.

The first 2023 weekend will also act as a pilot for implementing these proposed changes. Data collected in the post-event surveys from parents and staff will be analysed and any changes required will be implemented at the remaining 2023 family weekends.

Limitations

It is important to remember that participation in this evaluation was voluntary and thus it can only represent the views of those who took part. Overall, 37% of parents and 64% of staff attendees completed the post-event surveys. Although this represents over half of total attendees, these findings may not be representative of the views of all who attended, and this should be considered when interpreting the findings. Furthermore, none of the parents chose to complete the follow-up survey, as a result it is not possible to draw conclusions about the long-term impact of the 2022 family weekends for those who attended.

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Appendix

Appendix A – Information Sheet (Family)



Participant Information Sheet

An evaluation of the Children's Burns Trust family weekends

You are invited to take part in research taking place at the University of the West of England (UWE), evaluating the Children's Burns Trust family weekend.

Before you decide whether to take part, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries, or would like more information, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

What is the aim of the research?

This research is evaluating the Children's Burns Trust family weekends. It aims to find out participants experiences of the event and the impact that the event had on them and their family. This information will help the researchers make recommendations about future events run by the Children's Burns Trust.

Why have I been invited to take part?

We are interested in finding out about your experiences of taking part in the Children's Burns Trust family weekend and the impact that the event has had on you and your family.

Do I have to take part?

Taking part in this research is entirely voluntary and won't have any impact on you taking part in the family weekend or the healthcare provided by your burns service. If you do decide to take part, you will be asked to sign a consent form. You are able to withdraw from the research (without giving a reason) up to one month after taking part in the research. If you wish to withdraw from the study within this period, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

Deciding not to take part or to withdraw from the study does not have any penalty and will not impact on you taking part in the family weekend.

What will happen to me if I take part?

If you agree to participate in this research, you will be asked to complete an online questionnaire. The focus of the questionnaire will be on your motivation for attending the weekend, the support you've received previously, how you felt about the weekend, and your feedback on the weekend. There will also be questions about your child/children's experiences of the weekend and their feedback on how it could be improved. We expect that this questionnaire will take 20 minutes to complete.

You will also be asked whether you wish to take part in a future questionnaire in 10 weeks' time to ask for further feedback regarding the event and the impact that the event may have had on your family. If you indicate yes to this question, a further questionnaire will be sent to you via email in 10 weeks' time. There is no obligation to complete this second questionnaire. We expect this questionnaire will take 10 minutes to complete.

As part of the research, you will be asked to create a unique participant ID, which will keep your information anonymous but can be used to re-identify you if you choose to withdraw from the study.

Who is doing this research?

This research is being conducted by researchers from the Centre for Appearance Research (based at the University of the West of England, Bristol) in collaboration with Children's Burns Trust. This research is being conducted by Dr Maia Thornton.

What are the benefits of taking part?

If you decide to take part, you will be helping us to understand what families thought of the family weekend and help to improve these events for people attending in the future.

What are the possible risks of taking part?

We do not anticipate any significant risk to you in taking part. However, if you feel uncomfortable with any of the questions at any time then you can choose not to answer a question, or a group of questions, and you don't need to provide a reason for this. If you need any support during or after the research then the researchers will be able to put you in touch with suitable organisations. These are also detailed at the bottom of this information sheet.

What will happen to your information?

All the information that you give will be kept confidential and anonymised. Research material will be kept in a secure setting to which only the researchers at the University of the West of England will have access, in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements. Your anonymised data will be

analysed together with other individual's data, and we will ensure that there is no possibility of identification or re-identification from this point. This anonymised data will be destroyed 5 years after the close of this study.

Where will the results of the research study be published?

The findings will be used to produce a report for the Children's Burns Trust, as well as a conference presentation about the events. No participants will be identifiable in any of these reports or presentations, and only anonymous and non-identifying participant quotes will be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by University of the West of England University Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can be addressed to: researchethics@uwe.ac.uk .

Who is funding this research?

This evaluation is being funded by the Children's Burns Trust, as part of a grant awarded to them by the VTCT Foundation.

What if I have more questions, concerns, or do not understand something?

If you would like any further information about the research please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

If you have any concerns, queries and/or complaints relating to this research, please contact the University of the West of England Research Ethics Committee (researchethics@uwe.ac.uk).

What if I would like further support around the issues discussed?

If you would like any further support, then you might find it helpful to get in touch with the organisations below.

Children's Burns Trust

A national charity dedicated to providing rehabilitation support for burned and scald injured children and their families, as well as prevention and awareness campaigns.

<https://www.Children's Burns Trust.org.uk/>
info@Children's Burns Trust.org.uk / 07802 635590

Changing Faces

Changing Faces is the UK's leading charity for everyone with a scar, mark or condition on their face or body that makes them look different.

<https://www.changingfaces.org.uk/about-us>
info@changingfaces.org.uk / 0300 012 0275

Supporting Children with Burns

This is a website developed at the Centre for Appearance Research (CAR) and the University of the West of England, Bristol. It contains information to help support parents or carers of children and young people who have experienced a burn injury of any kind or size.

<http://supportingchildrenwithburns.co.uk/>

Thank you for reading this information sheet.



Participant Information Sheet (Staff evaluation)

An evaluation of the Children's Burns Trust family weekends

You are invited to take part in research taking place at the University of the West of England (UWE), evaluating the Children's Burns Trust family weekends.

Before you decide whether to take part, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries, or would like more information, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

What is the aim of the research?

This research is evaluating the Children's Burns Trust family weekends. It aims to find out participants experiences of the event and the impact that the event had on them and their family, as well as the experiences and views of staff involved in organising the event. This information will help the researchers make recommendations about future events run by the Children's Burns Trust.

Why have I been invited to take part?

We are interested in finding out about your experiences of taking part in the Children's Burns Trust family weekend, as someone involved in delivering the event.

Do I have to take part?

Taking part in this research is entirely voluntary and won't have any impact on your role delivering the family weekend. If you do decide to take part, you will be asked to sign a consent form. You are able to withdraw from the research (without giving a reason) up to one month after taking part in the research. If you wish to withdraw from the study within this period, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817). Deciding not to take part or to withdraw from the study does not have any penalty.

What will happen to me if I take part?

If you agree to participate in this research, you will be asked to complete a short questionnaire about your experiences of the family weekend. We expect this questionnaire will take approximately 10 minutes to complete. As part of the research, you will be asked to create a unique participant ID, which will keep your information anonymous but can be used

to re-identify you if you choose to withdraw from the study.

Who is doing this research?

This research is being conducted by researchers from the Centre for Appearance Research (based at the University of the West of England, Bristol), in collaboration with the Children's Burns Trust. This research is being conducted by Dr Maia Thornton.

What are the benefits of taking part?

If you decide to take part, you will be helping us to understand staff experiences of the family weekend and help to improve these events for people attending in the future.

What are the possible risks of taking part?

We do not anticipate any significant risk to you in taking part.

What will happen to your information?

All the information that you give will be kept confidential and anonymised. Research material will be kept in a secure setting to which only the researchers at the University of the West of England will have access, in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements. Your anonymised data will be analysed together with other individual's data, and we will ensure that there is no possibility of identification or re-identification from this point. This anonymised data will be destroyed 5 years after the close of this study.

Where will the results of the research study be published?

The findings will be used to produce a report for the Children's Burns Trust, as well as a conference presentation about the events. No participants will be identifiable in any of these reports or presentations, and only anonymous and non-identifying participant quotes will be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by University of the West of England University Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can be addressed to: researchethics@uwe.ac.uk .

Who is funding this research?

This evaluation is being funded by the Children's Burns Trust, as part of a grant awarded to them by the VTCT Foundation.

What if I have more questions, concerns, or do not understand something?

If you would like any further information about the research please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

If you have any concerns, queries and/or complaints relating to this research, please contact the University of the West of England Research Ethics Committee (researchethics@uwe.ac.uk).

Thank you for reading this information sheet.



Privacy Notice For Research Participants – An evaluation of the Children’s Burns Trust family weekends

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE Bristol) collects, manages and uses your personal data before, during and after you participate in ‘**An evaluation of the Children’s Burns Trust family weekends**’. ‘Personal data’ means any information relating to an identified or identifiable natural person (the data subject).

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Ethical Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together “the Data Protection Legislation”). General information on Data Protection law is available from the Information Commissioner’s Office (<https://ico.org.uk/>).

How do we use your personal data?

We will only process your personal data when the law allows us to. In addition, we will always comply with UWE Bristol’s policies and procedures in processing your personal data. Our lawful basis for using your personal data for research purposes is fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

You can find out more information about lawful bases at the following webpage:

<https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/>

We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by the University Research Ethics Committee [HAS.22.02.068] (researchethics@uwe.ac.uk).

The research team adhere to the the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

Who do we share your data with?

We will only share your personal data in accordance with the Participant Information Sheet and your Consent.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project, UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification. Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including

the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

Under the Data Protection legislation you have the following **qualified** rights:

- (1) The right to access your personal data held by or on behalf of the University;
- (2) The right to rectification if the information is inaccurate or incomplete;
- (3) The right to restrict processing and/or erasure of your personal data;
- (4) The right to data portability;
- (5) The right to object to processing;
- (6) The right to object to automated decision making and profiling;
- (7) The right to [complain](#) to the Information Commissioner's Office (ICO).

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet or UWE Bristol's research governance manager (researchgovernance@uwe.ac.uk).

v.2: This template Privacy Notice was last amended in November 2020 and will be subject to regular review/update.



CONSENT FORM

An evaluation of the Children's Burns Trust family weekends

Thank you for taking part in this evaluation of the Children's Burns Trust family weekends.

On the previous page, you will find a Participant Information Sheet with information about this study. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

If you are happy to take part in this research, please indicate this by selecting the appropriate option at the bottom of this page.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- [if applicable] I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Please tick this box to show that you have read the contents of this form and that you consent to participate in the research.

Please tick this box if you DO NOT wish to participate in the research.

CREATE YOUR UNIQUE PARTICIPANT IDENTIFICATION CODE

You have the right to withdraw from the study up to four weeks after you have taken part in this research.

Should you wish to withdraw, you will need to inform us by email (maia.thornton@uwe.ac.uk) or phone (011732 85817) quoting your unique participation identification code. This will enable us to identify all the material that needs to be deleted due to your withdrawal from the study.

To create your unique participation identification code please enter the first three letters of your mother's first name and the year you were born.

EXAMPLE: If your mother's first name is Mary and you were born in 1969 you would enter MAR69.

Please enter your code in the box below:



Family evaluation questionnaire

An evaluation of the Children's Burns Trust family weekend

Please answer the following questions honestly and openly. If you are not sure about any of the questions, or have any concerns, please contact the researcher Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).

First, we would like to know a bit about you and your family, and the support you have received.

1. What is your age?

2. How would you describe your gender?

3. How would you describe your ethnicity?

4. What is your relationship to the child that had a burn (e.g. mother/father/parent/grandparent/carer/other relation)?

5. How old was your child/the child you care for when they had their burn injury?

6. How old is your child/the child you care for now?

7. What caused the burn?

- Flame (e.g. flame on cooker, clothes caught fire)
- Liquid (e.g. hot water/steam or other liquid, such as cooking oil)
- Contact (e.g. hot cooking pan, iron, friction)
- Electricity (e.g. electric socket, live wire/object)
- Chemical/acid (e.g. cleaning products, caustic soda)
- Other (please specify)_____

8. Are you or your child/the child you care for currently receiving support from your burns service? (please tick all that apply)

- Medical treatment (including physiotherapy and scar management)
- Psychological support for my child
- Psychological support for myself or other family members
- No, none

9. Do you feel you have had the support you need since your child/the child you care for had their burn?

- Yes
- No

If you would like to tell us more about this, please write this below:

10. How many people live in your household?

_____ children _____ adults

11. How many people from your household attended the Family Weekend?

_____ children _____ adults

The next set of questions are about your expectations and experiences of the family weekend – please answer openly and honestly, your feedback will be used to improve the family weekend for other parents and children.

12. What were your top 3 reasons for attending the Children’s Burns Trust family weekend?

- 1. _____
- 2. _____
- 3. _____

13. What were you hoping to get from the family weekend?

14. Did the family weekend meet your expectations?

15. What did you like most about the family weekend?

16. What would you have changed about the family weekend?

17. Do you feel you gained anything from attending the family weekend? If so, what?

18. Do you feel that attending the family weekend has changed your thoughts about your child’s burn injury at all?

- Yes
- No

If yes, how do you feel this has changed?

19. How would you rate your families overall experience of the Children’s Burns Trust family weekend?

1 (very bad)	2 (bad)	3 (average)	4 (good)	5 (very good)

20. Did you experience any challenges attending the family weekend? (e.g. travel, access, communication, accommodation) (please tick one)

- Yes

- No

If yes, please tell us about these challenges:

ADDITIONAL ADULT

Did another adult attend the family weekend with you? If they would also like to complete the questionnaires above, please tick 'yes' and the questions above will be repeated for them to complete.

- Yes, another adult also attended the family weekend with me and would like to complete this questionnaire now.
- No

[If yes, display questions 12-20 for additional adult to complete]

YOUR CHILD'S EXPERIENCE OF THE EVENT

These questions are regarding your child with a burn injury and their experience of the family weekend.

We would encourage you to discuss these questions with your child and ask for their ideas when answering these questions. If this is not possible, please answer these questions with them in mind.

If you feel these questions aren't relevant because of the age of your child/children, please skip to the next page.

21.

How much did your child enjoy the family weekend? Please move the slider to indicate their response.



22. What did your child with a burn injury enjoy most about the family weekend?

21. What did your child with a burn injury not enjoy about the family weekend?

22. What (if anything) has your child with a burn injury learned while they were at the family weekend?

SIBLING'S EXPERIENCES OF THE EVENT

These questions are regarding sibling's experiences of the family weekend.

We would encourage you to discuss these questions with your child/children and ask for their ideas when answering these questions. If this is not possible, please answer these questions with them in mind.

If you feel these questions aren't relevant because of the age of your child/children, please skip to the next page.

23.

How much did your child enjoy the family weekend? Please move the slider to indicate their response.



24. What did your child/children enjoy most about the family weekend?

25. What did your child/children not enjoy about the family weekend?

26. What (if anything) has your child/children learned while they were at the family weekend?

FINAL QUESTIONS

27. Would you recommend the Children's Burns Trust family weekend to other families of a child with a burn?

(please tick one)

- Yes
- No

Please tell us why you chose this answer?

Would you be interested in taking part in a short follow-up questionnaire about the impact of this event on you and your family in ten weeks' time?

The follow-up questionnaire will be shorter than this questionnaire and will ask about how your family have felt since the event.

If you select 'yes', a link to this online follow-up questionnaire will be emailed to you approximately 10 weeks after the family weekend.

- Yes
- No

28. Would you like to tell us anything else about your experience of the family weekend?

Thank you for completing this questionnaire regarding the Children's Burns Trust family weekend.

If you have any questions about this evaluation, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).



Family follow-up evaluation questionnaire

An evaluation of the Children's Burns Trust family weekend

Please answer the following questions honestly and openly. If you are not sure about any of the questions, or have any concerns, please contact the researcher (Dr Maia Thornton; maia.thornton@uwe.ac.uk, 011732 85817).

1. Please enter your unique participant identifier here.

You were asked to create this code when completing the first questionnaire in this evaluation. This is the first three letters of your mother's first name and the year you were born.

If you do not know your unique participant identifier, please contact Maia (maia.thornton@uwe.ac.uk, 011732 85817).

2. What impact, if any, has attending the Children's Burns Trust family weekend had on your family in the last ten weeks?

3. Do you feel that attending the family weekend has changed your thoughts about your child's burn injury at all?

- Yes
- No

If yes, how do you feel this has changed?

4. Have you noticed any changes in your child/children in the last ten weeks since the family weekend?

5. **Have you noticed any changes in yourself or other family members in the last ten weeks since the family weekend?**

6. **Do you have any other comments about the Children's Burns Trust family weekend that you would like to share with us? If so, please write these below.**

Thank you for completing these questionnaires regarding the Children's Burns Trust family weekend.

If you have any questions about this evaluation, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).



Family weekend - Staff Evaluation

An evaluation of the Children’s Burns Trust family weekend

Please answer the following questions honestly and openly. If you are not sure about any of the questions, or have any concerns, please contact the researcher (Dr Maia Thornton maia.thornton@uwe.ac.uk, 011732 85817).

1. What do you think worked well about the family weekend?
2. What would you have changed about the family weekend?
3. Do you feel families gained anything from attending the family weekend? If so, what do you feel they gained?
4. Do you feel you gained anything from attending the family weekend? If so, what do you feel you gained?
5. Do you feel anything could be improved in the planning process of the family weekend? If so, what?
6. How would you rate your overall experience of taking part in the Children’s Burns Trust family weekend?

1 (very bad)	2 (bad)	3 (average)	4 (good)	5 (very good)

7. Did you experience any challenges taking part in this family weekend? (e.g. travel, access, communication)
 - o Yes
 - o No
 - o

If yes, please tell us about these challenges:

8. Do you have any other comments about the event?

Thank you for completing this questionnaire regarding the Children's Burns Trust family weekend. If you have any questions about this evaluation, please contact Dr Maia Thornton (maia.thornton@uwe.ac.uk, 011732 85817).