



## Core Outcome Set for Burn Care (COSB) Research

Invitation to a survey for parent/guardian of a child of any age who has had a burn injury

### *Why are we doing this study?*

Research trials are used to find out which treatment/s work best for patients. “Outcomes” are things that we measure in a research trial that tell us how well a treatment is working - for example, how quickly a burn wound heals, how long a patient needs to stay in hospital, or what impact it has on a patient’s life.

We are carrying out this study to find out what patients and their families think are the most important outcomes for us to measure in burns research trials. We are also doing this survey with the doctors, nurses and therapists who work with patients with burns to get their views.

The purpose of this study is to agree the most important outcomes that will be measured in all trials in the future to allow us to compare research and provide evidence for best care.

### *What does the study involve?*

You will be asked to complete two surveys a couple of months apart. The surveys contain a number of outcomes we could include in research trials. You will be asked to rate how important you think it is to measure each outcome for all patients with burns.

We anticipate that it would take around 20-25 minutes to complete each survey.

You can complete the survey once you have given your consent to take part. You will receive the second survey by email to complete around 6-12 weeks later. To make sure our results accurately represent parents’/guardians’ views, it is important that participants complete both surveys.

If you are happy to take part, please complete the consent part of the survey after this introduction. This will allow you to proceed to the first survey.

After the second survey we will be inviting all participants to a meeting to discuss the results of the study. Attendance at this meeting is optional; **you can still take part in the survey even if you don’t want to attend this meeting.**

There is short video explaining the study. Please use the link below:

<https://youtu.be/9DYH072uPrQ>

*How do I take part?*

To take part in this study you should be the parent or guardian of a child of any age who has had a burn injury. You should complete the consent form before completing the survey.

**Your participation in this study is voluntary. Your decision about whether to take part will not affect your child's medical care and treatment. You can withdraw from the survey at any time if you no longer wish to take part.**

*Will I receive any financial reward for taking part?*

We are not paying people for taking part in this study. However, to thank you for taking part, if you complete the survey and enter your email address, you will be entered into a prize draw to win one of fifteen £10 shopping vouchers.

*Who is conducting the research and who should I contact if I have a question?:*

The study is led by Dr Amber Young, Senior Research Fellow, and Professor Jane Blazeby at the University of Bristol. If you have any queries about the study please contact Dr Young at [COsBresearch@gmail.com](mailto:COsBresearch@gmail.com)

All the information that is collected from you during the research will be kept strictly confidential. Information will be collected, stored and analysed only by study researchers at the University of Bristol and University Hospitals Bristol researchers.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and given a favourable opinion by the South West Frenchay Research Ethics Committee.

**HOW TO COMPLETE THE QUESTIONNAIRE:** The questionnaire is split into two sections

**Consent and information about you, your child and their burn.** Once you have completed the questions to say that you consent to take part in the survey, and you have put your signature at the end, you will be able to proceed to the questions. Please complete the questions to give us information about you, your child and their burn by ticking the most appropriate box. All personal details will be kept strictly confidential.

**Survey questions:** Two sets of outcomes are presented:

1. A list of outcomes that happen **before** a burn has healed (i.e. when you your child was in hospital, or within a few weeks or months after the burn).
2. A list of outcomes that happen **after** the burn has healed (i.e. after the wound has healed or has scarred).

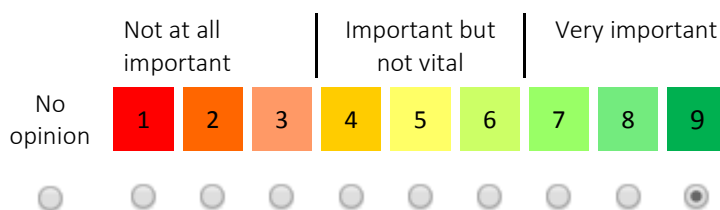
Please rate **for every question** how important you think it is that these outcomes are measured in research trials for patients with burns. Remember that you are being asked to rate these outcomes for all patients with burn injuries.

The order in which you receive the questions has been randomly decided and you should read the instructions at the start of each page to see which questions you are answering.

Please note that some outcomes are the same in both sections, as they could be important to patients and staff before or after burn healing.

**How to rate the importance of each outcome:**

- If you think that any outcome is **very important** to measure in research trials, please select one of the circles under 'very important' (numbers 7-9).



- If you think the outcome is **quite important but not vital** to measure in research trials, please select one of the circles under 'important but not vital' (numbers 4-6).



- If you think the outcome is **not important** to measure in research trials, please select one of the circles under 'not at all important' (numbers 1-3).

	Not at all important			Important but not vital			Very important		
No opinion	1	2	3	4	5	6	7	8	9
	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- If you **don't have an opinion or don't know about** the outcome, please select the circle where it says 'no opinion'.