

Core Outcome Set for Burn Care (COSB) Research

Invitation to a survey for young people who have had a burn, aged 10-15 years.

Why are we doing this survey?

- There are different ways to help people after they have had a burn. Doctors, nurses and scientists do research to find out which treatments work best for patients.
- We want to know what “outcomes” to measure in this research, by finding out which are the most important to patients of all ages.
- An “outcome” is something we can measure that tells us how well a treatment is working, or how the burn or treatment affects a patient’s life. This might include how quickly a burn heals, the amount of pain a patient has, or how long a patient stays in hospital.
- We are also asking nurses, doctors, scientists who work with patients with burns to tell us what outcomes they think should be measured.
- The final outcomes chosen by patients and healthcare workers will have to be measured in all research about burns.

What do I have to do?

- You will need to answer two surveys a couple of months apart. The survey asks what you think are the most important outcomes for burns patients while they get better, and after they get better.
- We have found that the survey takes young people around 25 minutes to complete.
- The first survey can be answered after you complete a consent form to show you are happy to take part in the survey. Your parent or guardian will also have to give their consent for you to do the survey, because you are aged under 16.
- The second survey will be sent to you by email to your parent/guardian 6 to 12 weeks later.
- It is very important to us that you complete both sets of survey questions. If people don’t complete all the questions then the COSB study might not show us which are the most important outcomes for patients.

- Please try to answer all the questions yourself, but you can ask for help from your parents if you need to. If you think we have missed out any important outcomes, you can write them down in the box at the end of the questions.
- After the two surveys are finished we will invite all people who completed the survey to come to a meeting about what we have found out. You and your parent may come to the meeting if you wish to. You don't have to come to the meeting if you don't want to, **and you can still take part in the survey even if you don't want to come to this meeting.**
- You do not have to take part in this survey if you do not want to. If you have started the survey but you want to change your mind and don't want to take part in it anymore, this is fine and it will not change the care you are getting for your burn.
- Some of the outcomes you will be asked about are experienced by many of the people who have had a burn injury. Others are experienced by only some of the people who have had a burn. **If you haven't experienced a problem, you can still try to assess how important it might be to measure it for all patients who have had a burn.**

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

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

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 parent's email address, you will be entered into a prize draw to win one of fifteen £10 shopping vouchers.

Who is doing the research and who should I contact if I have a question? The research is being done by Dr Amber Young and Professor Jane Blazeby at the University of Bristol. You may contact Dr Young at COsBresearch@gmail.com if you have any queries.

Only the people doing the research will know what your answers were. We will not share who you are or what you answered with anyone else. All research in the NHS is looked at by a group of people called a Research Ethics Committee. They make sure all research is safe. This survey has been looked at by the South West Frenchay Research Ethics Committee.

HOW TO COMPLETE THE SURVEY: The questionnaire is split into two parts:

Consent and about you and your burn: This means telling us that you are happy to take part. Once you and your parent have completed this section and given your signature, you will be able to answer the other questions in the survey. The second part of this section asks questions about you and your burn.

Survey questions: This section has two different sets of questions, we ask you about outcomes:

1. before a burn has healed (i.e. when you are in hospital, or within a few weeks or months after the burn), and
2. after a burn has healed (i.e. after your burn has healed or has scarred).

In each section you are asked to rate the importance of medical outcomes, and outcomes about the experience of having a burn injury.

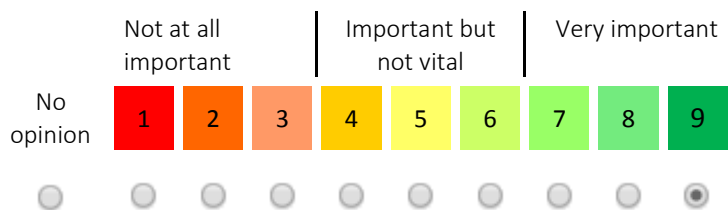
Please rate **for every question** how important you think it is that these outcomes are measured in research trials for patients with burns. Remember that you are being asked to rate these outcomes for all patients with burn injuries.

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.

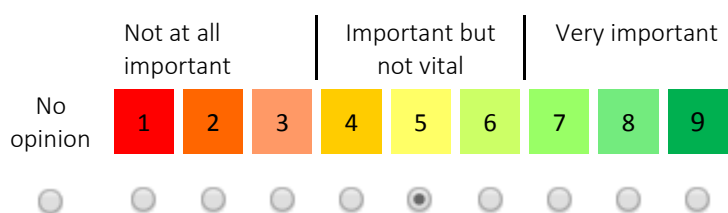
Please note that some outcomes are the same in both sections, as they could be important to patients and hospital workers before or after burn healing.

How to rate the importance of each outcome:

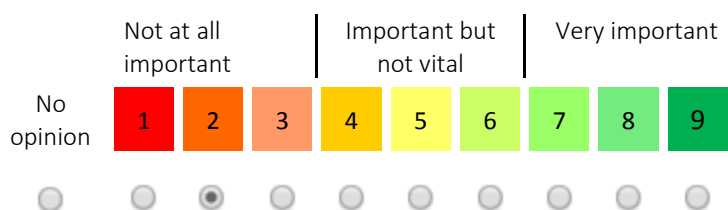
- If you think that any outcome is **very important** to measure in research trials, please select one of the circles under 'very important' (numbers 7-9).



- 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).



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



Core Outcome Set for Burn Care (COSB) Research

Invitation to a survey for a young person who has had a burn injury- parent/guardian information

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 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.

We are inviting young people aged 10-15 years who have experienced a burn injury to give their views about what is important to them. Before they can take part, their parent or guardian must give consent for their child to be in the survey. **Without parent/guardian consent they cannot take part.**

What does the study involve?

We have written an information sheet in age-appropriate language for them to read. Once they and you have read the information about the study, you will each be asked to complete a consent form at the start of the survey. Your child can only complete the survey once you have both given your consent for them to take part. **You are welcome to sit with your child and help them to complete the survey if they want your help.**

Your child will be asked to complete two surveys a couple of months apart. The surveys contain a number of outcomes that we could measure in research trials. Your child will be asked to rate how important they think it is to measure each of the outcomes.

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

A second survey will be sent to you by email for your child to complete in 6 to 12 weeks’ time. It will be sent to your email address and not your child’s.

For our results to properly represent the views of young people, it is very important that your child completes both surveys.

After the second survey we will be inviting all participants to a meeting to hear about the results of the survey. You may come with your child. Attendance at the meeting is optional; **they can still complete the survey even if they don't want to attend the meeting.**

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

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

Will they receive any financial reward for taking part?

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

Please be assured that their participation in the study is voluntary. Their decision to take part will not affect their medical care and treatment. If they have begun the surveys but they wish to stop taking part, they can withdraw at any time.

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 survey, please email Dr Young at COsBresearch@gmail.com.

All the information that is collected from your child during the research will be kept strictly confidential. Information will be collected, stored and analysed only by study researchers at the University of Bristol. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your and your child's 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 SURVEY: There are two parts to the survey.

Consent and information about them and their injury: Once both you and your child have completed your respective consent sections and given your signatures, they will be able to proceed. Without your agreement for them to take part, they will not be able to. After this they will be asked for some brief information about them and their burn injury. They should check the appropriate boxes. 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 are 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).

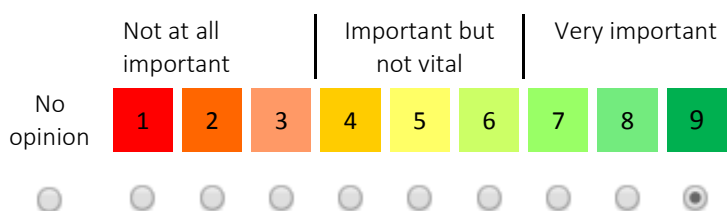
Your child should rate for **every question** how important they think it is that these outcomes are measured in research trials for patients with burns. They should remember that they are being asked to rate these outcomes for all patients with burn injuries.

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

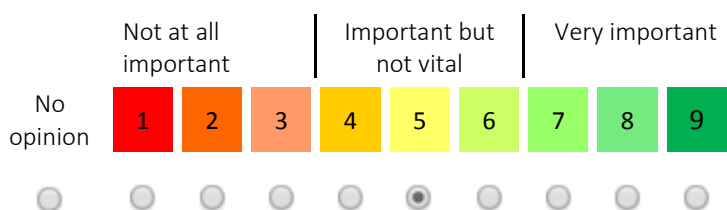
Please note that some outcomes are the same in both sections, as they could be important to patients and staff before or after burn healing.

How to rate the importance of each outcome:

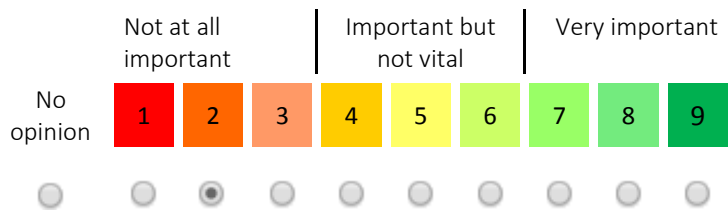
- If you think that any outcome is **very important** to measure in research trials, please select one of the circles under 'very important' (numbers 7-9).



- 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).



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