



PARENT INFORMATION SHEET

Submission of Data to the Australian and New Zealand Burn Association (ANZBA) Burn Registry of Australia and New Zealand

Why are we doing the study?

The information collected in the BRANZ helps to describe the occurrence and causes of serious burn injuries across Australia and New Zealand and how these injuries can be prevented. It is also used to understand the type and quality of burn care management and to monitor patient outcomes over time.

Who is carrying out the study?

The Burn Registry of Australia and New Zealand is a partnership between Monash University and the Australia New Zealand Burns Association (ANZBA).

What will the study tell us?

The information on the registry will help us understand:

- How and why burns happen.
- Which treatments work best.
- What the long-term results/outcomes are for people with a burn injury.

Does my child have to take part?

No. If you consent to your child's information being recorded in the the BRANZ registry you do not need to do anything. If you prefer not to have this information recorded or have any questions about use of your information, please tell us. This will not affect your child's care in any way and we will continue to provide you with care to the best of our ability. If you withdraw your permission at a later date we can remove your child's information from the registry.

What will you be asked to do if you decide to take part in this study?

Routine data is collected from your child's records. Most of your child's information can be collected this way but we may have to ask you and your child for some extra details.

What does my child need to do to be in the study?

There is nothing that your child will need to do to be part of this registry.

Is there likely to be a benefit to my child?

We do not expect any direct benefit to your child.

Is there likely to be a benefit to other people in the future?

Yes, we anticipate that the registry will be used to initiate further research and burn injury prevention strategies, to examine the performance of burns services, and to help improve and maintain services as the highest possible standard.

What are the possible risks and/or side effects?

We do not expect any major risks; however, there is always a risk of maintaining privacy of personal information. A lot of attention has been paid to this and a number of strategies are used to ensure that this risk is minimal.

What are the possible discomforts and/or inconveniences?

There are no major discomforts or inconveniences.



Where is your information kept?

Your child's coded information will be kept on an encrypted web-based database on the server at Monash University.

What about my privacy?

Your child's information will be confidential.

The information will be coded. This means that we will remove your child's name and give the information a special code number.

Only the research team at Perth Children's Hospital can match your child's name to the code number, if it is necessary to do so.

Your child's information will be kept indefinitely. If the registry ceases to exist, your child's information will be disposed of appropriately. The electronic information will be erased, including any back-ups of the database.

Your child's individual information will not be identified in any report or summary that may be written.

Who has approved the study?

The study has been approved by the Princess Margaret Hospital Ethics Committee, and has also been approved by 11 other similar committees in Australia and New Zealand.

Who to contact for more information about this study:

If you would like any more information about this study, please do not hesitate to contact one contact one of the research team. They are very happy to answer your questions. The switchboard number at PCH is 6456 2222 and you can ask to speak to one of the following:

Professor Fiona Wood (Consultant Surgeon), Suzanne Rea (Consultant Surgeon), Tania McWilliams (Clinical Nurse Consultant), Lisa Martin (Study Coordinator).

Who to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Clinical Director of Medical Services at PCH (Telephone No: (08) 6456 2222). Your concerns will be drawn to the attention of the Ethics Committee who are monitoring the study.

What to do next if you would like your child to take part in this research:

If you consent to your child's information being recorded in the BRANZ registry you do not need to do anything. If you prefer not to have this information recorded or have any questions about use of your information, please tell us.

THANK YOU FOR YOUR TIME



CHILD INFORMATION SHEET

Submission of Data to the Australian and New Zealand Burn Association (ANZBA) Burn Registry of Australia and New Zealand

Why are we doing the study?

So that we can better understand how often and why burns happen, how bad they are and how best to look after them.

Who is carrying out the study?

This is being done by Monash University in Victoria and the Australian and New Zealand Burns Association

What will the study tell us?

How and why burns happen and what is the best way of treating them.

Do you have to take part?

No, just tell us if you don't want to. That's fine.

What will you be asked to do if you decide to take part in this study?

Probably nothing. All information is taken from your notes. We might have to ask one or two extra questions from you or your Mum or Dad.

Is there likely to be a benefit to me?

Probably not.

Is there likely to be a benefit to other people in the future?

Yes. Hopefully this will help other people who have had a burn like yours in the future.

What are the possible risks and/or side effects?

The only risk is that someone might see your information other than the people who run the study.

What are the possible discomforts and/or inconveniences?

There are no discomforts to you.

Where is your information kept?

It is kept on a computer at Monash University.

What about my privacy?

The computer is protected with a password. Passwords are only given to the people who run the study.

Who has approved the study?

This has been approved by an Ethics Committee at Perth Children's Hospital. An Ethics Committee is a group of people who are able to let the study happen or not depending on whether the study is ok to do from your point of view.

Who to contact for more information about this study:

If you would like any more information about this study, please do not hesitate to contact one contact one of the research team. They are very happy to answer your questions. The switchboard number at PCH is 6456 2222 and you can ask to speak to one of the following:

Professor Fiona Wood (Consultant Surgeon), Suzanne Rea (Consultant Surgeon), Tania McWilliams (Clinical Nurse Consultant, Lisa Martin (Study Coordinator).

Who to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Clinical Director of Medical Services at PCH (Telephone No: (08) 6456 2222). Your concerns will be drawn to the attention of the Ethics Committee who are monitoring the study.

What to do next if you would like to take part in this research: If you would like to be included in the BRANZ registry you do not need to do anything. If you prefer not to take part please tell us. **THANK YOU**