



# What is child health research?

Information for families





# Child health research

## Why we do research?

Research is important because it helps us find new ways to prevent, diagnose and treat health conditions in children and young people. Health research helps us achieve our vision of *healthy kids, healthy communities*.

Research is an important part of what we do at the Child and Adolescent Health Service (CAHS) in our three service areas: Perth Children's Hospital (PCH), Community Health services and Mental Health services.

We have a wide range of research areas because we work with and care for a diverse range of children, young people and families.

## What is health research?

Research usually starts with an idea for how something can be done better, and a research project tests the theory or idea. Health research focuses on improvements in healthcare, clinical treatment and ways to prevent people getting sick in the first place. It is sometimes called medical research or clinical research.

Over 250 researchers are working across our health service on research projects. Many of these researchers are the same health professionals who work with our children every day, and they are passionate about making positive changes to child health and wellbeing.

## What is involved?

Children, young people and families play a valuable role in research.

Researchers need children and families who match a specific criteria for each research study. This may include children with a specific illness or injury, or even healthy children.

You and your family can be part of research in many ways, such as:

- filling in surveys
- giving permission for researchers to look at existing samples or medical records
- being involved in a clinical trial for new treatments
- prevention programs
- medical tests or screening tests
- being interviewed about your family's history or your experience of caring for your child.

We may invite you to take part while your child is receiving services from us, or it could involve regular contact over a period of time.

## Is it safe to be involved?

Before starting a research study, researchers need approval from an ethics committee who ensure that any research is carried out in a safe way that meets national standards and legal requirements. Ethical approval also makes sure that research is culturally appropriate.

## Did you know?

Nearly 90,000 families are involved in over 450 research projects across the Child and Adolescent Health Service.

## What happens if I am asked to be involved in research?

Your decision to be involved is made AFTER you have received and understood all the information about the study. You will be able to talk to your doctor, healthcare team or the researcher about the study and ask any questions that you may have.

You do not have to enrol in research if you or your child does not want to. Whether or not you participate in a study will not change the care your child receives from us in any way.

You should always include your child in decisions about participating in research.

You can help us make a difference!





# Participating in research

We welcome all families to be part of the life-changing research happening across our health service.

Together we can make a difference and contribute to a healthier future for children, young people and families everywhere.

## May we contact you about Child Health Research?

We would like to contact you about being part of future research studies. Any research would be conducted by us or one of our research partners.

If you agree to be on a contact list, we may contact you if your child or family matches the criteria for a new study. We will need your phone number, email address and home address.

## Does being on the contact list mean we are part of a research project?

No. It just shows that you have agreed to be contacted about future research studies. There is a chance that you will never be contacted.



Lauren with Elijah, participants in the 'B2: I can communicate' research project.

*We participate in research to help improve the assessment and intervention options available for kids and families in the future.*

– Lauren

## How will researchers know who is suitable for a study?

A researcher will submit a request to the CAHS Research Department seeking children/families who match specific criteria for their research study. This could be something like the child's age or a discharge diagnosis from a recent admission.

## What about privacy of information and medical records?

Only approved health service staff can access personal information or medical records. Researchers will only be given the contact details of families who match the required criteria a specific study.

## What happens next?

If someone on the contact list is suitable, researchers will get in touch. If the research study is of interest to the family, more information will be provided.

If you are still happy to be considered, then the researcher will ask a few questions about the study they are conducting to check if your child/family is suitable.

If you have changed your mind about being contacted for future research, you can let the researcher know when they contact you.

## How long will you keep our details if we agree to being contacted?

If you agree to being contacted about research, you will remain on the list until your child turns 14.



## What if we change our mind about being contacted?

It is ok to change your mind about being on the contact list. Just let us know and we will remove you from our contact list.

## What should we do if we have questions/concerns or if we want to be on the contact list?

You can contact us if you have any questions or concerns about being contacted for research opportunities. We can also provide more information about research at our health service or add you on to the list if you want to be considered for future research.

## Did you know?

Severe pain in children can be distressing for the whole family.

Thanks to pioneering research started by us over 18 years ago, a breakthrough treatment was discovered that controls pain more quickly, reducing the child's distress.

This medication (intranasal fentanyl) for children who come to emergency departments with severe pain is now standard treatment around the world.

## Contact

### Department of Research

**Email:** [CAHS.Research@health.wa.gov.au](mailto:CAHS.Research@health.wa.gov.au)

### Websites:

[www.pch.health.wa.gov.au/Research](http://www.pch.health.wa.gov.au/Research)

[www.pch.health.wa.gov.au/Research](http://www.pch.health.wa.gov.au/Research) National Statement on Ethical Conduct in Human Research

## Compliments and complaints

We welcome your feedback, both positive and negative.

For further information and ways to provide feedback visit:

[www.pch.health.wa.gov.au/For-patients-and-visitors/Compliments-and-complaints](http://www.pch.health.wa.gov.au/For-patients-and-visitors/Compliments-and-complaints)

**Email:** your feedback to [cahsfeedback@health.wa.gov.au](mailto:cahsfeedback@health.wa.gov.au)

## National Statement on Ethical Conduct in Human Research

[www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018](http://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018)

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Government of **Western Australia**  
**Child and Adolescent Health Service**



## Telephone: (08) 6456 2222

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**Compassion**

**Accountability**

**Excellence**

**Equity**

**Collaboration**

**Respect**

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This brochure is part of a project to increase involvement in child health research at CAHS. The processes and details relating to a future research database may change if or when implemented across CAHS.