Want to know more?

If you have questions about the Registry or the follow up survey, the best person to talk to is the ICU specialist looking after your child.

Scan the QR code for more information about the Registry and the survey or visit **www.anzics.org**

It's OK to say NO

Participation in the survey is voluntary. You can choose to opt out. You may also request that the anonymous information about your child's ICU admission is not included in the Registry.

To opt out speak to the ICU specialist looking after your child. Saying no will not affect the care your child receives in the ICU.

ANZICS acknowledges the Traditional Custodians of country throughout Australia and New Zealand and their connections to land, sea, and community. We pay out respect to their elders past and present and extend that respect to all Aboriginal, Torres Strait and Māori peoples.

Contacts

Your ICU
XXX Children's Hospital
Paediatric Intensive Care Unit Research Team
Phone: XX XXXX XXXX
Email: XXX@XXX.com

ANZICS
For more information about the ANZPIC Registry
Email: anzics@anzics.org

For more information about the ICU survey
Email: ICUSurvey@anzics.org

Complaints

The Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC) has approved both the Registry procedures and survey. If you have any concerns or complaints about the project, the way it is being conducted, or your child's rights, and would like to speak to someone independent of the Registry or Survey, please contact:

The HREC Co-ordinator
Phone: **07 3069 7002**
Email: **CHQETHICS@health.qld.gov.au**
OR
The Research Governance Office
Phone: **07 3069 7008**
Email: **CHQ_RGO@health.qld.gov.au**

XXX Hospital Site Specific Brochure version X dated dd mmm yyyy based on
Master Registry & Survey Brochure version 3.0 dated 04 Oct 2024
ANZPIC Registry HREA 90011, PAED PROEMs HREA 99529

Sponsors

ANZICS · The Australian & New Zealand Intensive Care Foundation · NSW Government Communities & Justice · telematics trust · Monash University · Australian Government Department of Health and Aged Care · Medical Research Future Fund

INFORMATION FOR FAMILIES

Australian and New Zealand

PAEDIATRIC INTENSIVE CARE REGISTRY

Monitoring:

- **Quality of care**
- **Health outcomes**
- **Parent and carer experiences**

ANZICS

About the Registry

Since 1997 the Registry has been collecting and reporting on paediatric intensive care unit (ICU) admissions across Australia and New Zealand. This enables us to monitor the activity, quality of the care and outcomes of our ICU with those of similar ICUs across the country. Data held in the Registry can also be used for research to improve the care of critically ill children and young people.

How is the Registry managed?

The Registry is hosted by the Australian and New Zealand Intensive Care Society (ANZICS). It is funded by Health Departments in Australia and New Zealand.

What information is collected?

- The reason for the ICU admission
- Diagnosis
- Age and characteristics of the child
- Severity of illness
- Treatments
- Outcomes

Who collects the information?

Health information is recorded in the hospital health record as part of routine care by the staff looking after your child. Hospitals extract only relevant information from the health records to send to the Registry.

Maintaining privacy

Your child's privacy is important to us. The information received by the Registry **does not** include your child's name or information that could identify your child.

Data security measures are in place to protect access to the information and ensure that it is only used for the purpose for which it was collected.

Who has access to the data?

Registry staff access the data to prepare reports for ICUs, hospitals, and health departments. Individual cases are never described in these reports.

Research staff can apply to access the data for specific research projects. Projects need to be approved by a Research Ethics Committee before the data can be accessed for research.

Government departments may use the data for health policy and planning purposes.

About the follow-up survey

It is important we understand how children and young people **recover** from serious illness. For this reason, you are invited to provide feedback about your child's health after leaving the ICU. The information will help to improve care in ICU and during recovery.

We also value hearing your feedback about your **experience** in ICU. This will help us improve the experience for other children, young people, and their families.

When to expect the follow up survey

The hospital will send you (the parent or carer) an SMS soon after your child is discharged from ICU, inviting you to complete a survey. You will receive a second shorter survey 6 months later.

Survey 1 (10 mins) asks you about your child's health 1 month before the ICU admission as well as your experience of the care received in ICU.

Survey 2 (2 mins) asks about your child's health and recovery 6 months after discharge from ICU.

How will your response be used?

Information about your experience and your child's recovery will be included in the information sent to the Registry. The identity of your child will not be included.

Your contact details will only be used to provide you with access to the surveys. These contact details will not be sent to the Registry.