

# Family Information Sheet

## *The Victorian Childhood Cancer Outcomes Registry (VCCOR)*

### What is VCCOR?

This registry (database) has been built to **track the care and outcomes of children treated for cancer in Victoria.**

It will strengthen research into how childhood cancer and its treatments affect patients throughout their journey. The information will be used to **improve cancer care and outcomes for patients.**

This will be done by **combining data that is already regularly collected** from different places and systems into one secure database.

### Who will be included in VCCOR?

All children, adolescents, and young adults who have been diagnosed with cancer, and have been treated in Victoria.



### What information is collected in VCCOR?

1. Name, Date of Birth, Hospital UR number, Postcode
2. Sex, Nationality, language spoken at home
3. Details about the diagnosis
4. Treatment and outcome information
5. Long Term Follow up consultations
6. Family member cancer diagnosis (if applicable)

Collecting family cancer diagnosis data will HELP healthcare providers study cancer patterns in families. Family member names will only be recorded if they are already in VCCOR (like a sibling); in that case, their names and diagnoses will show in each other's records.

## Privacy and safety

We understand your right to privacy, therefore:

- Access to this database is restricted, and data is protected according to strict ethics, hospital protocols, and the Australian Privacy Principles.
- The database is managed by the Victorian Paediatric Integrated Cancer Service (PICS).
- VCCOR data can be shared with cancer researchers who have approval from an accredited Ethics Committee and the VCCOR Governance Committee.

## Taking part in VCCOR

- Patient registration is automatic, and no further steps are required to be involved.
- Participation in research is voluntary, and you can opt out anytime.
- Each participant has the right to access their stored information.



**To opt out, or for more information, contact PICS**

Phone: (03) 9345 4433

Email: [pics.admin@rch.org.au](mailto:pics.admin@rch.org.au)

or visit

[www.vics.org.au/pics/vccor](http://www.vics.org.au/pics/vccor)