

Does my information have to go to the Register?

Yes, in 2011 the WA State Government mandated statutory reporting of developmental anomalies.

How is your privacy protected?

We take privacy seriously and all information held by the Register is maintained securely. Register staff abide by the WA Health Code of Conduct which highlights confidentiality as an important part of Responsible Care.

Reports released from the Register are in statistical form, without identification of individuals, doctors or hospitals.

The Health Department has rigorous confidentiality and research protocols in place before any confidential information can be provided strictly for research purposes.

Families who do not want to be contacted for research purposes can tell the Register this by telephone or mail.

Can I see my child's record?

Yes. You have the right to request a copy of the information that is held about you or your child.

For further information, please visit the website or phone the Register on (08) 9340 2735.

Can I remove my child's information?

No, information cannot be removed from the Register but, it can be de-identified after it has been recorded for six years. For further information, please visit the website or phone the Register on (08) 9340 2735.

For independent help on any of these matters, please contact the Health Consumers Council on telephone 1800 620 780 or email info@hconc.org.au

Contacts:

Website: www.kemh.health.wa.gov.au/services/register_developmental_anomalies/

Address:

WA Register of Developmental Anomalies
King Edward Memorial Hospital
PO Box 134
SUBIACO WA 6904

Phone: (08) 9340 2735

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Western Australian Register
of Developmental Anomalies

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Information for parents and families



Some babies are born with developmental anomalies. Most developmental anomalies are not severe or life threatening. In many cases, the cause of a developmental anomaly is unknown.

What is a developmental anomaly?

A developmental anomaly is a broad term used to define conditions which are present at conception or occur before the end of pregnancy.

An anomaly is considered as a departure from normal development and can affect structure (how the body is built) or function (how the body works).

Anomalies can be diagnosed at any time during pregnancy, after stillbirth or termination of pregnancy, or after live birth, but before six years of age.

Developmental anomalies include cerebral palsy, spina bifida, Down syndrome and phenylketonuria (PKU). In the case of cerebral palsy, a small number also occur after birth.

Developmental anomalies are also sometimes called birth defects, congenital malformations or congenital anomalies.

Did you know?

Each year 1 in 20 children in WA is born with a developmental anomaly

Questions Often Asked

Parents who have a child who has a developmental anomaly often have many questions including:

- Why does my child have an anomaly?
- If we have another child, will the same or similar anomaly occur?
- Did my family history, the place where I live or the substances I was exposed to during my pregnancy contribute to the occurrence of the developmental anomaly?

These questions are often difficult to answer, especially if there is little known about the anomaly and the reasons for its occurrence. The collection of accurate information about developmental anomalies helps to answer these and other questions.

What is the West Australian Register of Developmental Anomalies?

The West Australian Register of Developmental Anomalies (the Register) maintains a record of babies and children who have been diagnosed with developmental anomalies before six years of age. Records of developmental anomalies have been collected in WA for over 30 years. In 2011, reporting of developmental anomalies was made mandatory by the State Government.

Where does the information come from?

The chief executive officer of the hospital in which the diagnosis of a developmental anomaly is made and/or the doctor making the diagnosis or caring for the patient diagnosed are responsible for notifying the Register. This is required within six months of the diagnosis. Register staff gather further details from medical records and/or doctors if required.

Why is information about developmental anomalies collected?

The information held by the Register is used to:

- monitor developmental anomalies in WA
- plan, monitor and evaluate services for the prevention, screening, treatment and management of developmental anomalies
- compile and publish information relating to developmental anomalies
- carry out research into the causes of developmental anomalies.

What information is collected by the Register?

The Register collects:

- details about the child and parents including names and dates of birth
- mother's address
- descriptions of the developmental anomalies.

Names are included in the database so that information can be correctly updated and the same child is not included several times. All information is coded and maintained in the strictest confidence.