



PHRN Population
Health
Research
Network



Long term benefits for Fontan procedure

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NCRIS 
National Research
Infrastructure for Australia
An Australian Government Initiative

Excellent outcomes

A Fontan procedure is an operation done for children who have heart abnormalities. The life expectancy of patients who undergo the Fontan procedure is unknown. The study evaluated the long term outcomes of patients who had Fontan surgery in Australia and New Zealand.

The study reported excellent long term survival outcomes for patients.



HOW DID THE PHRN INFRASTRUCTURE HELP?

The Australian Institute of Health and Welfare linked the clinical data from the Australian and New Zealand Fontan Registry with the National Death Index for the research team to analyse.

AUTHORS/CONTRIBUTORS

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REFERENCE

d'Udekem Y, Iyengar AJ, Galati JC, Forsdick V, Weintraub RG, Wheaton GR, et al. Redefining expectations of long-term survival after the Fontan procedure: twenty-five years of follow-up from the entire population of Australia and New Zealand. *Circulation*. 2014;130(11 Suppl 1):S32-8. Access 12 April 2016 http://circ.ahajournals.org/content/130/11_suppl_1/S32.abstract



Privacy and security

Privacy protection and data security lie at the heart of the Population Health Research Network. The collection, use and disclosure of personal information by government agencies and other agencies are bound by strict legislative and regulatory conditions. Researchers wishing to access linked data must also adhere to stringent conditions, including ethics approval, data custodian approval and the development of a detailed data security plan.

Researchers are typically given access to a linked data set put together to meet the specific needs of their project. This de-identified data includes only the minimum information required for the research, such as age rather than date of birth.

Government agencies handle personal information in highly-secure environments. Data is delivered to researchers through a secure remote access facility, ensuring no information is stored on the researcher's personal computer or their institutional network. Researchers cannot export raw data from this system, only their analyses, and these are checked.

Researchers must only use the data for the approved purpose and are not allowed to link any other information. At the conclusion of the project, all data must be destroyed or returned.

Penalties for researchers and government employees can include criminal conviction, jail time or substantial fines. In the more than ten years since the network began, there has never been a breach.

