



# NATIONAL CARDIAC REGISTRY

## PRIVACY POLICY

### 1. Purpose of the National Cardiac Registry Privacy Policy

The National Cardiac Registry (NCR) is committed to protecting the privacy of individuals. This Policy sets out how the NCR complies with its obligations under the Australian Privacy Act 1988 (Commonwealth Privacy Act), which includes the Australian Privacy Principles (APPs). The APPs govern the way in which we collect, use, disclose, store, secure and dispose of your Personal Information. This Privacy Policy also explains how you can access and correct your personal information or make a complaint about a breach of privacy.

This Privacy Policy applies to personal information collected by the NCR. In this Privacy Policy, the expressions "NCR", "we", "us", "our" are references to the National Cardiac Registry (NCR) and the expressions "you", "your" are references to any group or individual who may interact with the NCR.

The NCR is committed to ensuring the privacy and confidentiality of personal information. The NCR will endeavour to handle personal information in accordance with the Australian Privacy Principles. This Privacy Policy explains in general terms how NCR protects the privacy of the personal information that is provided to us and to personal information that we collect under any other arrangement.

### 2. Personal information

The Australian Privacy Act defines personal information as information or an opinion, whether true or not, and whether recorded in a material form or not, about an identified individual, or an individual who is reasonably identifiable.

Sensitive information, is a subset of personal information, and is defined as health information about an individual, genetic information (that is not otherwise health information), biometric information that is to be used for the purpose of automated biometric verification, biometric identification, or biometric templates and information or an opinion (that is also personal information) about an individual's; racial or ethnic origin, political opinions, membership of a political association, religious beliefs or affiliations, philosophical beliefs, membership of a professional or trade association, membership of a trade union, sexual orientation or practices, or criminal record.

### 3. Information collected by the NCR

We only collect personal information where it is reasonably necessary to conduct our functions or activities. Information is collected by the NCR for the program:

1. To operate, maintain and promote the national cardiac registry; and
2. For use of data within the registry.

### 3.1 Operate, maintain and promote the National Cardiac Registry

The kinds of personal information we collect about you may include your name, address, and contact information. If we have provided you services e.g., event attendance; then we might also hold employment details, research areas of interest, information of services you have obtained from us, event attendance and payment details.

We collect personal information from people who are connected to our operations and activities, including committee members, participating clinicians and consumers, suppliers and service providers and other stakeholders.

We collect personal information from our supporters including information to process payments and activities that you have indicated you may be interested in being involved with. We collect information from publicly available sources to enable us to make personalised and tailored approaches to individuals and organisations relating to possible partnership opportunities. Sometimes we may collect photos or stories about you if you have gone to one of our events or have visited our promotion booth at a relevant conference.

### 3.2 Data within the registry

Data is submitted to the NCR by participating state or territory registries (see: <https://nationalcardiacregistry.org.au/participating-registries/>). Personal information, including sensitive information (health and racial or ethnic origin) is submitted to the NCR after the individually identifying variables have been encoded. This is in order to carry out the primary function of the NCR. The NCR does not store any individually identifiable information in the registry but stores a code whereby the NCR can work with Participating Registries to reidentify patients for future data linkage projects. The NCR will never store individually identifiable data and will use encoded linkage keys to assist with future linkage activities.

## 4. How the NCR collects and holds personal information

NCR will only collect personal information by lawful and fair means and not in an unreasonably intrusive way. We collect personal information from you in various ways, including: data that is submitted to the NCR by Participating Registries, or when you register your details with us, update your details, provide a product or service to NCR, complete a survey or questionnaire, or participate in activities and events that we organise, participate in programs that we organise and conduct, or communicate with NCR by email, telephone or in writing.

Where it is reasonable and practicable to do so, we will only collect personal information about you directly from you. However, we may sometimes collect personal information from a third party. For example, NCR utilises a federated model of data collection, with patients' health information collected and stored by a Participating Registry and then after individual identifiers are encoded, that information is submitted to the NCR. The individual's identifiers are kept within the Participating Registry. Data is only collected where it is reasonably necessary to conduct our functions and activities.

Sometimes we collect personal information from third parties such as contractors, charitable and other like-minded organisations, health professionals, or from a publicly available source. If we collect information about you from a third party, and it is unclear that you have consented to the disclosure of your personal information to us, we will take reasonable steps to ensure that you are aware of circumstances surrounding the collection and the purposes for which we are collecting your personal information, other persons or organisations to which we might give your personal information, the existence and content of this Privacy Policy and any other matters required by relevant privacy laws.

## 5. Objectives for the NCR to collect personal information

The objectives of the NCR are to; measure performance in cardiac healthcare as determined by agreed quality indicators, transparently report on clinical, procedural and patient outcomes to hospitals, clinicians, government and the community, and to provide national benchmarking of key quality performance measures for cardiac conditions/procedures/devices and secondary prevention.

Delivering these objectives involves the collection of information that supports the functions required to operate, maintain and promote the registry, and the collection of information within the registry (about relevant patients including demographics, risk factors, procedures, outcomes, discharge and follow-up data). The collection and storage of this information makes the delivery of this important quality initiative possible. We do not store individual identifiers, but a code is stored within the registry which will enable future data linkage, for example, the NCR intends to link with the Australian Institute of Health and Welfare's (AIHW) National Death Index (NDI) to assess long term patient mortality. This code will enable the NCR and AIHW to work together without the disclosure of sensitive information. This code also allows Participating Registries to update individual patient's data if they identify errors or match follow-up data to the appropriate case.

In order to achieve the objectives of the NCR, other personal information may be collected, held and disclosed to support the NCR in its primary role. This includes such information as; from and about supporters, researchers, hospital and health services, suppliers and service providers and other individuals or groups who may be involved or correspond with the NCR in order to achieve the primary goal.

## 6. How to access or correct my personal information

You have the right to request access to the personal information NCR holds about you. However, we may charge a fee to recover the cost of meeting your request. We aim to ensure that all personal information that we hold is accurate, complete and up to date. Please advise us if you become aware that any information that we hold about you is inaccurate or incomplete.

If you want to change any information that you have previously given us, if you want to opt out of future communications, or if you would like to access the information we hold about you, you can:

Email a request to [info@nationalcardiacregistry.org.au](mailto:info@nationalcardiacregistry.org.au) call us on 03 9903 0984.

No individual identifiers are held within the NCR for patients or clinicians. Patients or clinicians wanting to correct any information stored within the system will be able to do so by contacting their Participating Registry who will then manage any correction on your behalf.

## 7. Complaint process on privacy breach

If you believe the NCR has breached your right to privacy, you may make a written complaint providing full details, to [info@nationalcardiacregistry.org.au](mailto:info@nationalcardiacregistry.org.au).

A complaint can be made via any stakeholder, Participating Registry, partner organisation, community or individual with whom the NCR has an established relationship, in addition to any member of the public, whether an individual, organisation or entity. The NCR takes privacy and data management responsibilities seriously and welcomes any feedback on how to protect the rights of individuals and improve the quality of its work. Complaints will be handled in a sensitive and timely manner and will protect the rights of those involved.

If patients or other stakeholders have any ethical concerns about this project, participant rights, or would like to make a complaint about research being conducted, they should contact the approving Human Research and Ethics Committee (HREC) or auspicing government body. Details of the appropriate HREC or government body can be provided by contacting the NCR, or via your local Participating Registry.

## 8. Dealing with complaints

A complaint can be made by any stakeholder, partner organisation, community or individual with whom we work or any member of the public whether an individual, organisation or other entity. NCR takes privacy and our obligations seriously and welcomes any feedback in order to improve the quality of our work and, if required, to initiate action to resolve any issues.

Complaints will be handled in a timely and sensitive manner protecting the privacy of respective parties. Should you feel your complaint has not been completely satisfied you can contact The Office of the Australian Information Commissioner (OAIC) <https://www.oaic.gov.au/privacy/privacy-complaints>.

## 9. Sharing of personal information

The NCR is a national project with stakeholders in Australian states and territories. Information may be shared, in a deidentified form where practical, between stakeholders when reasonably necessary to conduct our functions or activities. Personal information will not be disclosed to parties overseas. The NCR will take such steps as are reasonable to ensure that stakeholders will abide by Australian privacy laws, as applicable, when dealing with personal information. NCR data is stored and backed up on servers hosted in Australia.

## 10. Further information

For further information Office of the Australian Information Commissioner (OAIC) is an additional source of information (<http://www.privacy.gov.au>)

## 11. Amendments

The NCR Limited Board reserves the right to modify or amend this privacy policy at any time, provided that those modifications or amendments comply with the Australian Privacy Act and any other relevant legislation. The current privacy policy will be made available upon request and is on the NCR website (<https://nationalcardiacregistry.org.au/>).

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