



# NATIONAL CARDIAC REGISTRY

## PRIVACY POLICY

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

#### 1.1 Privacy and the National Cardiac Registry

The National Cardiac Registry (**NCR**) is committed to protecting the privacy of individuals. This Privacy Policy sets out how the NCR complies with its obligations under the Australian *Privacy Act 1988* (Cth) (**Australian 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 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 APPs. 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.

#### 1.2 About us

The NCR is managed and administered by the National Cardiac Registry Limited (**NCR Ltd**), a not-for-profit organisation, through its board and its steering committee, with key funding from the Commonwealth Government through the Department of Health and Aged Care (**Department**). NCR Ltd subcontracts Monash University to undertake the day-to-day functions and operations of the NCR.

### 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 which requires additional protections and controls, 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 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.

The NCR may collect, use, hold and disclose both personal information and sensitive information, including health information in accordance with this Privacy Policy and the APPs.

### 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 NCR; 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 (**Participating Registry**) and from hospitals that contribute directly (see: <https://nationalcardiacregistry.org.au/participating-registries/>). Personal information, including sensitive information (e.g. details on any cardiac procedures undertaken, your health and racial or ethnic origin) is submitted to the NCR, in order to carry out the primary function of the NCR. The NCR stores individually identifiable information in the registry from participating hospitals that contribute directly to NCR.

Data submitted by participating State or Territory registries **does not** contain individually identifiable information e.g. Name, Date of birth, but stores a code whereby the NCR can work with Participating Registries to re-identify patients for future data linkage projects.

### 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, from participating hospitals that contribute directly to the NCR, or when you register your details with us, update your details, provide a product or service to NCR, complete a survey or questionnaire, participate in activities, events or programs that we organise, 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 collaborative model of data collection, with some patients' health information collected and stored by a Participating Registry and then after personal information is 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. How the NCR uses and discloses personal information

### 5.1 How we use personal information

The NCR collects personal information in order to fulfil our primary objective of creating and maintaining a national registry for cardiac outcomes. We collect personal information from you in order to:

- establish and maintain the registry;
- communicate with you;
- answer enquiries and provide information or advice about the registry;
- assess the performance of our websites and to improve the operation of the websites;
- conduct business processing functions including providing personal information to our contractors, service providers or other third parties;
- conduct administrative, promotion, planning, product or service development, quality control and research functions;
- update our records and keep your contact details up to date;
- process and respond to any complaint made by you; and
- comply with any law, rule, regulation, lawful and binding determination, decision or direction of a regulator, or in co-operation with any Australian governmental authority.

### 5.2 How we may disclose NCR Data

NCR collects and aggregates data from across different sources to form the NCR data held within the registry (**NCR Data**). We may disclose and share NCR Data to the Department (to whom we assign the intellectual property in the NCR Data) and to our contributors. NCR has in place a Data Governance Framework and a Data Access Policy which we will comply with in order to ensure that NCR Data is accessible and used to support the objectives of the NCR.

### 5.3 Do we disclose your personal information to anyone outside of Australia?

NCR will not disclose any personal information to anyone outside of Australia, except with the consent of the affected individuals.

However, from time to time, NCR may disclose NCR Data (which has been aggregated and processed to remove any personal information) to individuals located outside of Australia, in accordance with the NCR Data Access Policy.

## 6. 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** store personal information for patients that are treated in a hospital that contributes directly to the NCR. We **do not** store personal information comprising patient data provided from a Participating Registry, rather 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 survivorship over time. 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 an 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.

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

You have the right to request access to the personal information NCR holds about you, for example Name, Phone Number, Email. 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), or call us on 03 9903 0984.

Patients or clinicians wanting to correct any information stored within the registry will be able to do so by contacting their Participating Registry or participating hospital that contributes directly, who will then manage any correction on your behalf.

## 8. Security

We take reasonable steps to ensure your personal information is protected from misuse and loss and from unauthorised access, modification or disclosure. We may hold your information in either electronic or hard copy form. Personal information is destroyed or de-identified when no longer needed.

As our websites are linked to the internet, and the internet is inherently insecure, we cannot provide any assurance regarding the security of transmission of information you communicate to us online. We also cannot guarantee that the information you supply will not be intercepted while being transmitted over the internet. Accordingly, any personal information or other information which you transmit to us online is transmitted at your own risk.

## 9. 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, participating hospital, 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.

## 10. 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>.

## 11. Sharing of personal information

The NCR is a national project with stakeholders in Australian States and Territories. Information may be shared, in a de-identified 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.

## 12. Further information

The OAIC is an additional source of information about your privacy rights (<http://www.privacy.gov.au>).

## 13. Amendments

The NCR Ltd 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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