

# Participant Information Statement

## Athletes



### **Research Study: The Australasian Registry for ECGs of National Athletes (ARENA) Project**

Dr Jessica Orchard (Responsible Researcher)  
School of Public Health, Faculty of Medicine and Health  
Phone: +61 2 8627 1664 | Email: [jessica.orchard@sydney.edu.au](mailto:jessica.orchard@sydney.edu.au)

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#### **1. What is the ARENA project about?**

The Australasian Registry for ECGs of National Athletes (ARENA) Project is a large database collecting information on elite athletes who have undergone cardiac screening at sporting organisations in Australia and New Zealand. The information in the Registry will be used by researchers to improve our understanding of cardiac outcomes in screened athletes and how the heart is affected by exercise. The information in the Registry will help make screening programs more accurate and improve preventive cardiac care for athletes.

The ARENA project has been endorsed by the Australasian College of Sport & Exercise Physicians (ACSEP) and Sports Medicine Australia (SMA).

Taking part in this study is voluntary. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

#### **2. Who is running the study?**

The study is being carried out by the following researchers Dr Jessica Orchard, Senior Research Fellow, University of Sydney. Co-investigators include Dr John Orchard (Sport and Exercise Physician and Chief Medical Officer, Cricket Australia), Associate Professor Andre La Gerche (Sports Cardiologist), Professor Rajesh Puranik (Cardiologist) and Dr Simon Eggleton (Cardiologist). This study is being funded by an Australian Government National Health and Medical Research Council (NHMRC) Investigator Grant.

#### **3. Who can take part in the study?**

We are seeking elite sporting organisations in Australia and New Zealand that conduct cardiac screening of athletes that includes a resting 12-lead electrocardiogram (ECG). Your sporting organisation has agreed to take part and will supply data to the Registry.

#### **4. What will the study involve for me?**

If you are happy to have your cardiac screening information included, you will not need to do anything. Data on your screening results will be collected from your sporting organisation in about 6 months.

Data will include some demographic information (including name, sex, ethnicity (if available), date of birth, sport/distance/event), together with the date and result of each cardiac screening, a copy of the ECG and any other cardiac tests/reports, whether follow-up tests were required and the outcome, any cardiac diagnosis, and any major adverse cardiac events. This information allows ARENA to link multiple screenings to the same athlete. As set out below, the data will be deidentified and securely stored. You will not be identifiable in any publications.

## 5. What will happen to information that is collected?

Information that is collected about your cardiac screening will remain confidential and will be stored in a secure password protected database. De-identified information (only) will be used for research purposes and results will be published. You will not be identifiable in these publications. De-identified data may be used for other research projects and may be shared with other national and international collaborators, subject to the Registry's data sharing policy. This will be managed by the Steering Committee and subject to strict protections, including the requirement for ethics approval and secure data storage procedures.

Data will be securely stored at the South Australian Health and Medical Research Institute (SAHMRI). Once the information is entered into the Registry, it will be given a unique identification number which links to your name and date of birth. The code list will be stored separately. Access to re-identifiable information will be limited to the Registry Director and SAHMRI Registry personnel allocated to the project. Data will be re-identifiable only for the following purposes: to link multiple screening results from the same athlete or to identify duplicates; to add later outcome data to an athlete in the Registry (e.g. details of a cardiac diagnosis, retirement or sudden cardiac arrest) including potentially linking to another registry or database; if a previously unrecognised ECG abnormality is noticed by the Registry team; if an athlete later requests their data be withdrawn; or on request of the sport/athlete.

In the rare event that a previously unrecognised ECG abnormality is noticed by the Registry team, we will contact the chief medical officer of your sporting organisation by email and they will then contact you and determine the appropriate follow up. Within 2 weeks of the first email, we will contact the chief medical officer a second time to confirm that they have received the notification.

## 6. Can I opt-out or withdraw?

Yes, if you wish. Being in this study is completely voluntary and you do not have to take part. It is an opt out study, so your data will be included unless you tell us or your sporting organisation that you would like to opt out. Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you would like to opt out, please do so within one month of receiving this information. You can opt out by contacting Dr Jessica Orchard ([jessica.orchard@sydney.edu.au](mailto:jessica.orchard@sydney.edu.au)) or your sporting organisation's chief medical officer (if you are a cricket player, please contact the Cricket Australia Sports Medicine and Sports Science Manager or the Research Coordinator, as they have delegated responsibility in relation to this research). If you opt out, your sport will not provide us with any of your data.

If you change your mind and would like to withdraw later, you can do so at any time by contacting Dr Jessica Orchard ([jessica.orchard@sydney.edu.au](mailto:jessica.orchard@sydney.edu.au)) or your sporting organisation's chief medical officer. If you choose to withdraw later, we will not collect any more information about you from your sporting organisation and remove the data we already have from the Registry (and from future analyses and publications).

## 7. Are there any risks or costs?

You will not need to have any additional tests. Data will be stored securely (see below) and we have implemented strict data security protocols to ensure the risk of a breach is extremely low. There are no costs, nor will you be paid.

**8. Are there any benefits?**

Your sporting organisation's participation in this study will be an important contribution to research (including athlete outcomes from cardiac screening) and could lay the foundation for a more standardised and streamlined best practice model for screening across sports, with the ultimate goal to improve preventive cardiac care for athletes. Participation will also contribute to quality improvement (by providing a 'double check' on ECGs and completeness of follow-up) and improved accuracy of screening.

**9. Will I be told the results of the study?**

You have a right to receive feedback about the overall results of this studies in this project. We will provide these to your sporting organisation in the form of a brief lay summary, together with a copy of any published research papers.

**10. What if I would like further information?**

When you have read this information, if you would like to know more at any stage, please contact:

Dr Jessica Orchard

Email: [jessica.orchard@sydney.edu.au](mailto:jessica.orchard@sydney.edu.au) Phone: +61 2 8627 1664

Dr John Orchard

Email: [john.orchard@sydney.edu.au](mailto:john.orchard@sydney.edu.au) Phone: +61 2 9351 8118

**11. What if I have a complaint or any concerns?**

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney (Project No. 2023/551) according to the *National Statement on Ethical Conduct in Human Research (2007)*. If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager

[human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au) +61 2 8627 8176

***This information sheet is for you to keep***