

PARTICIPANT INFORMATION SHEET



Australian
Orthopaedic
Association
National
Joint
Replacement
Registry

ABOUT THE REGISTRY

The Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) was established by the Australian Orthopaedic Association in 1999 to improve outcomes for patients having joint replacement surgery.

To do this, the Registry records a small amount of information on as many people having certain joint procedures as possible. In collecting this data, the Registry aims to further improve the quality and value of healthcare delivery now and in the future.

JOINT OPERATIONS IN AUSTRALIA

You are about to have an operation on one of your joints. More than 110,000 people have a joint operation each year in Australia. Occasionally, people who have a joint operation may at some time require another operation on that joint. This may occur due to a variety of reasons. For instance, when the joint replacement has worn out. How quickly this occurs depends on which of the many different types of artificial joints have been used or operation selection. This includes instances when the operation was aimed to delay or prevent the need for having a joint replacement, such is the case for a knee osteotomy or ankle arthrodesis operation. An important Registry role is that it assists hospitals and doctors to locate people in the uncommon event a problem with a medical device is identified.

To do this it is important for the Registry to record a small amount of information on as many people having these procedures, including subsequent procedures, as possible. By analysing this information, it is possible to identify which of the medical devices are working best and the best type of operation for each patient. We are asking you to participate in the Registry, by allowing us to document information relevant to your procedure.

YOUR INVOLVEMENT

The information we require includes your name, date of birth, address, Medicare number, hospital identity number, the name of the hospital and surgeon (when available), and the reason you are having a joint operation. This information is necessary to accurately link you to the medical device inserted as well as linking any following joint surgery you may have. We will also record the day of the operation, which joint was operated on and the type of medical device used. No other personal information is recorded. Government departments also provide information so that the Registry can check the accuracy of the data and update records to reflect if someone has passed away.

INFORMATION SECURITY

Your personal information is confidential, and safety measures are in place to protect this information. Your personal information is protected by an Act of Parliament. This means you cannot be identified in any reports produced by the Registry. On occasion, your data may be linked to other health datasets to further enhance the Registry's ability to improve patient outcomes. Your de-identified data may be used for other research projects and may be shared with national and international collaborators.

COLLECTING INFORMATION

Although we are asking to record your operation details in the Registry you are not required to do anything. Your surgeon and/or theatre staff will complete the form that contains your personal details at the time of your operation and send it to us. The information will be entered into the secure Registry database which is stored in the South Australian Health & Medical Research Institute in South Australia.

RISKS AND BENEFITS TO YOU

There are no risks to you by having your details in the Registry. The Registry produces general reports on a variety of factors that influence the success of joint operations. The results of joint operations have greatly improved because of this information.

WHAT TO DO IF YOU DON'T WANT YOUR INFORMATION IN THE REGISTRY

We understand that not everyone is comfortable about having their personal details documented in a registry. If you feel this way and do not want your details recorded, please contact the Registry on 1800 068 419 (tollfree) as well as making your decision known to hospital staff. A decision on whether or not you wish to be involved in the Registry does not affect your treatment in any way. If you have any questions, concerns or require further information on the National Joint Replacement Registry please do not hesitate to contact the AOANJRR on 1800 068 419 (tollfree).

Concerns or complaints related to the data collection process may be directed to the AOANJRR on 1800 068 419 (tollfree) or alternatively the Australian Government, Office of the Australian Information Commissioner on 1300 363 992.