

PATIENT INFORMATION SHEET

INTRODUCTION - *about the Registry*

You are about to have an operation on one of your joints. More than 100,000 people have a joint replacement or knee osteotomy operation each year in Australia. Most of these operations are very successful. However, a number of 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, if you have had a joint replacement the most common cause is that the joint replacement has worn out. How quickly this occurs depends on which of the many different types of artificial joints have been used. For those patients having a knee osteotomy the aim is to delay or prevent the need for having a joint replacement. In order to improve the success of these operations, the Australian Orthopaedic Association set up the National Joint Replacement Registry in 1999. The purpose is to monitor and report on the results of these operations. This information helps everyone working in the health system to ensure patients get the best treatment possible both now and in the future. Another important Registry role is that it assists hospitals and doctors to locate people in the uncommon event a problem with any medical device used is identified.

To do this it is important for the Registry to record a small amount of information on as many people having these operations as possible. It is also important to record if any subsequent operations have occurred. 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 operation.

Your Involvement - *the information we need*

The information we require includes your name, date of birth, address, Medicare number, hospital identity number, the name of the hospital and the reason you are having a joint replacement or knee osteotomy. This information is necessary to accurately link you to the medical device inserted as well as linking any following joint surgery you may have, to your previous records. 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 died.

Information - *how we will keep your information confidential*

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 government 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.

How we will collect the 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, Adelaide, 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 to be in the Registry

We understand that not everyone is comfortable about having his or her personal details documented in a registry. If you feel this way and do not want your details recorded, please contact the Manager on 1800 068 419 (*freecall*) 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 Ms Cindy Turner.