PUBLIC AND PATIENT GUIDE
TO THE NJR’S 11TH ANNUAL REPORT 2014

Ankle replacement edition

The National Joint Registry for England, Wales and Northern Ireland is working to improve your experience of joint replacement

Patient FAQs
Summary of key facts
Hospitals and surgeons
Procedures and implants
Welcome to this Public and Patient Guide to the NJR Annual Report 2014

As joint replacement patients, we know how important it is to receive good quality information to help you understand more about your options and the treatment that has been recommended for you. That’s why the NJR continues to produce a patient guide alongside its main report.

We know that access to NJR data can be a helpful tool for thought and discussion. The NJR has recorded ankle replacements since 2010 and so far, more than 2,000 ankle replacement procedures have been recorded.

Joint replacement is a highly successful operation that can bring relief from pain and improve mobility. However, going through the process can be baffling and many patients do not always understand their options or the detail of their treatment plan. There are also lots of variables that can affect the final outcome for each individual, particularly for ankle replacement as it is a complex joint – moving in multiple directions, bearing high loads, often several times body weight, and association with up to 30 surrounding joints that can also have arthritis.

We hope this guide provides information to help you consider questions for your surgeon and healthcare team about the treatment and implant recommended for you. The same is true for friends and family members who might be supporting you at this time. We hope you seek out support, or share this guide with others in order to get a better sense of how the information and data inside can help you.

Whatever the reason for your ankle replacement, there are many others going through the same process, and it may help to know you are not alone. There is additional support out there for you on shared decision-making as well as advice on looking after yourself before and after surgery. We have listed some of the organisations that can help at the back of this guide.

The National Joint Registry doesn’t work in isolation – the information in this document is just one source that we hope will help you feel more confident in asking questions about your surgery, your implant and your recovery.

We will produce this guide each year, as the NJR continues to report on the growing number of ankle joint replacement records it holds. Feedback is welcome at any time and you can contact NJR Communications on 020 7997 7370 or email: communications@hqip.org.uk

We would like to extend thanks as always to our NJR Patient Network, for their helpful thoughts, ideas and comments in ensuring this guide is as useful to patients as it can be.
About the NJR

How does the NJR help patients?
We record information about joint replacement operations in England, Wales and Northern Ireland in order to monitor the results of joint replacement surgery and protect patient safety. Using those records, we provide information and evidence to:

• Help surgeons choose the best artificial joints (implants) for patients
• Empower patients by helping them find out more about the implants available to them
• Improve patient safety by showing how well implants, surgeons and hospitals perform and take action where it is needed
• Give hospitals, surgeons and implant manufacturers feedback about their performance to help them improve patient care
• Help surgeons quickly decide whether patients need to return to hospital if implant problems are found

We currently collect information on hip, knee, ankle, elbow and shoulder procedures however elbow and shoulder joint replacements have only been part of the registry since April 2012.

England and Wales have been covered since 2003 and Northern Ireland joined in February 2013. Currently, Scotland has its own joint replacement registry.

What information is collected?
Your hospital will input specific details of your operation into the NJR. This will include the type of implant you received, which surgical technique was used, which side of your body the implant went into as well as your age and gender.

The NJR asks all patients to consent to have their personal details (name, date of birth, address and NHS or national patient number) recorded with their operation details – this allows the NJR to be more effective in its role of monitoring and improving patient care.

Why does the NJR need my personal details?
Your details allow the NJR to link you to the implant(s) you received during surgery. If for instance, you need an operation in the future to replace a first-time implant, the NJR can measure the time between the operations. Adding together this time from all patients’ operations tells us how well different implants, hospitals and surgeons perform.

Also, in the rare event that a problem is found with a particular prosthesis, recording your personal details on the NJR can also speed up and support the hospital process of reviewing affected patients.

Please be assured that your personal information is kept confidential at all times and secure protocols are in place to ensure it is kept safe. If you would like more information about this then please see the NJR patient consent form and NJR patient information leaflet. Alternatively, you can find out more on our website at www.njrcentre.org.uk

Giving your consent is voluntary however, 91.8% of patients agreed to have their details added to the NJR last year.

Who else do you share the data with?
There are lots of different ways we share and use the data, ensuring that the evidence we collect is used to inform clinical decisions and improve joint replacement surgery. For example, surgeons, hospital management and manufacturers of implants can all use their own unique online system (via a secure log-in) designed to give them access to information that can inform, influence and improve their work.

Security and confidentiality is always paramount and there are multiple safeguards in place to ensure that patient identities are protected.

All hospitals should ask patients whether they wish to consent to have their details added to the NJR and ensure the responses are recorded on the NJR database.
Can I access the information recorded about me?
Yes. As a patient, if you gave consent to have your details added to the NJR, you can request to see your records at any time by completing a patient operation request form. This is available to download from www.njrcentre.org.uk

I’ve heard the data are also used for research?
We are pleased to have an active research policy and make sets of data available for specific research so that more can be learnt about implants, surgery and their results. The release of data for projects are subject to very strict scientific and ethical controls and are only approved where they can prove that the work will enhance the understanding of joint problems and how they can be best treated.

An example here is the NJR’s extended Patient Reported Outcome Measures (PROMS) project. These are questionnaires sent to patients before and after surgery to collect measurements of pain and physical function.

We are following-up with a group of 50,000 patients at the moment and have recorded information at 1 and 3 years and will soon be planning to do this again at 5 years. This research project was approved because it can help build up a very detailed picture of the factors that are most important in ensuring a successful surgical outcome from the patient’s perspective.

About ankle replacement

There are many organisations that provide additional general information about joint replacement, including specific guidance before and after surgery as well as online discussion forums. Please see page 11 for their contact details.

What is an ankle replacement?
An ankle replacement, often referred to as an ankle implant (and sometimes simply as a ‘device’), is, in basic terms, an artificial implant that replaces an ankle joint that is damaged.

Joint replacements are nearly always carried out because of pain that cannot be controlled by other methods such as painkillers, physiotherapy or other surgery. The most common cause of pain is osteoarthritis or inflammatory arthritis.

What healthcare staff will be involved with my treatment?
Once it has been suggested to you (commonly by your GP) that an ankle replacement may be an option, they may refer you to a musculoskeletal triage (clinic) who will look at non-operative ways of managing your joint problems. If you are then referred onto a hospital you will see an orthopaedic surgeon or a member of his or her team. They will discuss various treatment options including ankle fusion (where the joint is stiffened) and ankle replacement.

If you jointly decide on an ankle replacement then you may then attend a pre-surgery assessment clinic(s) where you may be seen by nurse practitioners. Either at this clinic, or on the day of your surgery, you will also see an anaesthetist to discuss options for anaesthesia and pain relief. These appointments are also the times when you are most likely to receive information about the registry and be asked whether you would like to consent to have your personal details recorded. Your hospital should ask you to consent to your details being entered into NJR, and we recommend that you do. Please ask for the NJR consent form if it is not offered to you.

During your hospital stay, you might also see an occupational therapist or physiotherapist who will advise you on your aftercare and help you prepare for your recovery after the hospital stay.

Together, these healthcare staff make up what is commonly called your healthcare or clinical team.

Do I have to have an ankle replacement? What are the alternatives to surgery?
The final decision to have an operation or not remains with you the patient. It will be based on the risks and benefits of having an ankle replacement or choosing not to (these
choices should be made clear to you. It may be that other options are available including, but not limited to, medication, physiotherapy, weight loss or other lifestyle changes.

Can I get a second opinion?
The appointments you have prior to the operation (referrals to a musculoskeletal clinic and/or hospital-based assessments) are designed to further analyse your GP's initial diagnosis. If you are unsatisfied having met with your surgeon, you can return to your GP and ask to see a different surgeon.

You could also use services like NJR Surgeon and Hospital Profile at www.njrsurgeonhospitalprofile.org.uk and NHS Choices to find out more about the hospitals and surgeons that provide services in your area. The service currently covers England but may extend to Wales and Northern Ireland in the future.

Can I choose which hospital and surgeon perform the operation?
In principle, yes — as part of the NHS Choices initiative, you do have the option in England to be referred to a specific hospital or surgical team (options may be more limited elsewhere). Of course each individual case is unique, and the reasons for requesting a specific hospital need to be justified, as do any costs and other implications associated with a request to be treated at a non-local hospital. The NHS is not able to provide a commitment that a specific surgeon will carry out your operation.

What are the risks involved with having an ankle replacement procedure?
The overall risk involved in ankle and other types of joint replacement surgery is very low. With any surgical procedure there is a small risk of medical complications such as heart attack, stroke and developing blood clots (thrombosis). Infection is rare, typically less than 1%.

Other surgical problems are also uncommon but include wound healing problems, nerve damage, fracture, and pain and stiffness.

Your surgeon will go through all of the risks before you sign a surgery consent form.

With time, some implants wear out or become loose and occasionally break, leading to the need for further replacement (revision) surgery.

What kind of implant (artificial joint) will be used? Are there options?
The ankle is a complex joint and there are several types of implant involved in ankle replacement. While the material of the implant predominantly remains the same, the method of fixing it into place may vary. As part of your hospital-based assessments, the most suitable procedure for your individual situation will be established and you will be able to discuss this choice with your surgeon. Please see page 8 of this guide for more information.

How can I find out how many joint replacement procedures my local hospital carries out?
As part of NHS England’s transparency initiative, the NJR now publishes surgeon performance information along with information about the hospitals where those surgeons work. The information is not contained in the NJR Annual Report but can be found online at www.njrsurgeonhospitalprofile.org.uk

In 2014, more than 2,000 records were available to search. For each ankle surgeon listed, it is possible to access information about their practice including how many procedures they carried out and which hospitals they work at. See page 7 of this guide for more information about this service.

Did you know that many hospitals run ‘Joint Replacement Schools’ as part of the NHS Enhanced Recovery Programme?
This is a chance to meet patients who have had or will be having a joint replacement operation.
Facts about ankle replacements in 2013

Ankles

605 replacement procedures were recorded 2013

recorded on NJR since April 2010

590 in 2012

58%

average ages:

68.6 67.5

Diagnosis

*Facts shown relate to primary operations in 2013 – the first time a total joint replacement is carried out on any individual joint in a patient

90% osteoarthritis

10% inflammatory arthritis

88%

average BMI

29.2 = ‘overweight’

NHS funded:

85%

*Facts shown relate to primary operations in 2013 – the first time a total joint replacement is carried out on any individual joint in a patient
Information on more than 2,000 joint replacement surgeons carrying out orthopaedic surgery for the NHS in England is available for public access at www.njrsurgeonhospitalprofile.org.uk.

The data, published for the second time, are collected and presented by the NJR. Around 500 additional surgeons are covered this year for the first time as surgeons carrying out ankle, elbow and shoulder joint replacement surgery are now included alongside hip and knee surgeons.

The published surgeon profiles cover:
- Hospitals where a Consultant in charge works
- Number of primary and revision joint replacement procedures undertaken and overseen by each Consultant in charge over 1 and 3 years

An A-Z listing:
- A-Z OF HOSPITALS
- A-Z OF SURGEONS

Why can’t I find my surgeon on the website?

Your surgeon might not be listed on NJR Surgeon and Hospital Profile website if they have not undertaken NHS-funded joint replacement surgery in England since 2011 as Consultant in charge (a Consultant in charge is responsible for the operation but may not have performed the surgery). Consultant surgeons who only practice in Wales, Northern Ireland or the independent (private) sector are not automatically included.

Remember you can also talk to your surgeon about their experience. If you would like to ask but feel uncomfortable doing so, perhaps consider taking a friend or family member to your appointment.

Find out more: This website service will be updated with additional hospital and surgeon information in 2015, so check back to see how the online profiles have been updated. Share www.njrsurgeonhospitalprofile.co.uk with your friends and family.
To help you digest the information and analysis included in this section, we have included an explanation of general orthopaedic terms for ankle replacement. Ankle replacements are less common than hip and knee replacements. This is for two reasons:

- Arthritis develops in hip and knee joints more often than it does in ankle joints
- The ankle joint is more complex and therefore, so too is the replacement surgery. This is because the joint sits upon a mobile foot which moves in multiple directions. The joint is also put under high loads, often several times body weight

**The ankle joint**

The ankle joint is made up of the tibia (main shin bone), the fibula (the bone that runs down the outside of the leg), and the talus, which is the bone deep inside the ankle, that sits between the shin bone and the heel bone and connects the leg to the foot.

There are two main types of ankle replacement. A fixed bearing (two part) or a mobile bearing (three part) implant. In either type the bones are covered by a metal component and then a plastic component is placed in between them. In a two-part implant, the plastic is fixed to the tibial component. In a three-part implant the plastic component moves freely between the metal parts. We do not yet know which type is better.

**Tibial component**

The tibial component covers the top part of the ankle joint – the bottom of the main shin bone (tibia). It is either a flat or curved tray and is fixed to the bone with either a short stem or small pegs.

**Talar component**

This covers the lower half of the ankle joint and the bone deep inside the ankle (talus). It is normally curved and fixed into place using pegs. Both of these components are made of metal and have a special coating to encourage the patient’s bone to grow into them.

**Meniscal (mobile) component**

The meniscal component is made of hard wearing plastic (ultra-high molecular weight polyethylene) and sits between the talar and tibial parts. In a three-part ankle implant it moves forwards and backwards slightly when the ankle moves (mobile bearing implant). In a two-part implant design, the plastic component is not mobile but instead is fixed to the tibial component (fixed bearing implant).

Ankle replacement implants must be aligned properly in order to work properly and additional surgical procedures may be required at the same time as the replacement to help this to happen. For example, realignment surgery to ensure your heel is under your knee or soft tissue surgery to establish the right range of motion of the joint.
Ankle replacement operations in 2013

Operations

The NJR started recording ankle joint replacement information in April 2010. This is the third complete year of ankle data entered onto the NJR and the number of records is still growing – the NJR anticipates that the numbers below represent about 77% of all the ankle replacement procedures that were carried out.

In 2013, 605 ankle replacement procedures were recorded and of these:
- 532 were a first-time or primary ankle replacement
- 73 were a re-do or revision procedure

About first-time ankle replacements 2013

Age and gender

Of the first-time procedures that were carried out:
- The average age for women was 67.5 years
- The average age for men was 68.6 years
- 58% of patients were male and 42% were female

Diagnosis and patient health before surgery

- 90% had a diagnosis of osteoarthritis
- 83% of patients had a risk or higher risk of medical problems before or after surgery

Treatment for the prevention of blood clots (known as thromboprophylaxis)

- The most common chemical treatment used was low molecular weight heparin, used in 81% of procedures. This was followed by direct thrombin inhibitor and aspirin, both at 5%
- The most commonly used mechanical treatment was TED (anti-embolism) stockings at 61%, followed by use of intermittent calf compression at 28%
- Most procedures used both a chemical and mechanical treatment combined

Surgical technique

- 97% of patients had a surgery using the anterior approach. This involves a small incision to the front of the ankle and access to the bones is gained by working between muscle and tissues. The approach aims to reduce disruption to the joint as a whole
- 38% of patients had an additional ankle related procedure. For 12% of patients, this included achilles tendon lengthening and for 5%, subtalar joint fusion (this is the joint below the ankle joint)
- 14% of patients had a surgery that used bone graft. This is where missing bone tissue is replaced with bone tissue either from yourself or someone else (your surgeon will discuss these options with you prior to surgery)
- Only 1% of procedures used image-guided surgery

How implants were fixed into place

- Nearly all ankle replacements were fixed into place without the use of bone cement

Find out more: Further information can be found pages 123-125 of the full NJR Annual Report and at a new, dedicated website www.njrreports.org.uk
Over time, implants will wear and need to be revised, often due to loss of function or pain. These operations are commonly known as revision procedures.

The NJR records operation information and patient details (by consent) so that we can measure the length of time an implant lasts. This is to ensure that any implants are failing earlier than is expected are picked up and the information acted upon.

About revision procedures 2013

In 2013, 73 patients had a revision ankle replacement procedure. The reasons why they were revised included pain, for 41% of patients, and infection (low suspicion of infection) for 26% of patients.

How long ankle implants last 2010-2013

The NJR has only recorded ankle data for three full years. A total of 2,004 primary ankle replacements have been recorded in this time (April 2010 and December 2013) so there are limited findings on revision rates for implants.

- Only 29 of the reported 2,004 procedures had been revised before the end of 2013

The British Orthopaedic Foot and Ankle Society (BOFAS) feel that the low numbers of revised implants reported might be lower than actually takes place.

It is mandatory for all first time and revision operations to be submitted to the NJR and hospitals and surgeons are encouraged to ensure that all relevant operations are submitted.

Mortality after surgery

Overall, the risk of dying after ankle replacement surgery is very low at 90 days after surgery and is unlikely to be related to the procedure itself.
Questions, useful contacts and information

Please use this page to make notes and questions, either for your surgeon or clinical team at the hospital. Some commonly asked questions are listed below:

Do I need joint replacement surgery?
Are there other options available to me?

If I do, how should I prepare for surgery?

What type of implant are you recommending?
What are the pros and cons?

What surgical technique would be used?
What are the pros and cons?

What should I know about my aftercare?

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Age UK
www.ageuk.org.uk
0800 169 6565

Alkaptonuria Society
www.alkaptonuria.info
01223 322897

Arthritis Care
www.arthritiscare.org.uk
020 7380 6500

Arthritis and Musculoskeletal Alliance
www.arma.uk.net
020 7842 0910/11

Arthritis Research UK
www.arthritisresearchuk.org
0300 790 0400

BOFAS
www.bofas.org.uk
Contact via website including a request for this booklet.

British Orthopaedic Association
www.boa.ac.uk
020 7405 6507

NHS Choices
www.nhs.uk
www.nhs.uk/mynhs

NHS Improvement Enhanced Recovery
www.improvement.nhs.uk/enhancedrecovery
www.nhsiq.nhs.uk/improvement-programmes/acute-care/seven-day-services/enhanced-recovery

NORRAD

National Rheumatoid Arthritis Society
www.nras.org.uk
0800 298 7650

TARVA
A national NHS clinical trial comparing ankle replacement with ankle arthrodesis (fusion).
www.anklearthritis.co.uk
Follow @TARVA_Trial

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Our Surgeon and Hospital Profile service? www.njrsurgeonhospitalprofile.org.uk
Our online NJR Reports service? www.njrreports.org.uk
Our other patient guides?

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To find out more about the NJR:

- Visit our website at www.njrcentre.org.uk
- Call the NJR helpline on 0845 345 9991
- Send an email to enquiries@njrcentre.org.uk
- Write to NJR Centre, Peoplebuilding 2, Peoplebuilding Estate, Maylands Avenue, Hemel Hempstead HP2 4NW
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