

Joint Approach

The newsletter of the National Joint Registry

Contents

What should you ask your clinical team? 2 Helping shape the future 3 NJR PROMs 3 Giving something back 4

A patient's introduction to the NJR

The role of the National Joint Registry (NJR) for England and Wales is to improve patient safety and monitor the results of joint replacement surgery. The Registry helps to find out which are the best performing artificial joints and the most effective types of surgery.

Patients in England and Wales who have a hip, knee or ankle replacement are asked to consent to store their details on the NJR, alongside the details of their operation. This information is used to monitor the performance of joint replacements.

The NJR contract is managed by the Healthcare Quality Improvement Partnership (HQIP). Northgate Information Solutions manage the development and running of the NJR.

The NJR helps patients by:

- Helping surgeons choose the best artificial joints (commonly known as implants).
- Improving patient safety by checking how well implants, surgeons and hospitals perform.
- When implant problems are found, helping surgeons to decide quickly whether a patient needs to come back to hospital.
- Giving hospitals and implant manufacturers feedback to help them improve patient care.

8th Annual Report to feature patient summary

The NJR's 8th Annual Report, to be published in the autumn, will include a summary specifically written for patients. The new section will present results in a user-friendly format, minimising the use of jargon and technical language.

Martyn Porter, Chair of the NJR Editorial Board has endorsed this implementation: "I am delighted that the 8th Annual Report will be including a patient friendly summary. At the NJR we are keen to ensure patients are kept abreast of key issues and findings from the Registry that might impact on crucial choices about their health."

The 2011 report is due to be published in a combined meeting of the British Orthopaedic Association (BOA) and the Irish Orthopaedic Association (IOA) to be held in Dublin in September. The report will be published on the NJR website: www.njrcentre.org.uk

Patient focus



This edition of Joint Approach focuses on the work of the NJR from a patient perspective. We hope it gives patients a better understanding of the role of the National Joint Registry (NJR) in supporting better patient care.

Patients: What should you ask your clinical team?

Shital Shah works for the Arthritis Care Helpline. She discusses with *Joint Approach* some of the questions patients might like to ask when they are referred for joint replacement.

Shital encourages patients to ask questions, as this may help to minimise anxiety and build trust with the clinical team. The questions to ask may depend on the joint and the individual patient's circumstances, but listed below are some of the more frequently asked questions that Shital hears through the Helpline.

What are the alternatives?

One of the first things people want to know is whether they can avoid joint replacement. Ask the consultant on your clinical team.

How much range of movement will I have?

Many people make assumptions that the new joint will be the same as the original. In fact, there will still be a degree of limitation in movement, but the pain should be gone.

What kind of prosthesis will be used?

There are many different implants available. You can ask about different types, and the pros and cons. Some patients do their own research and say "I want that one". But it does not always occur to people to ask the surgeon "what kind of prostheses are you familiar with?" and "what is suitable for my particular joint?" Patients may not always consider that their hip or knee would be different to anyone else's.

How much experience does your surgeon have?

People are reluctant to ask about this, you can ask specific, non-confrontational questions, such as "how many operations of this sort have you performed?". You can also ask about their success rate, though there are many ways of measuring success. You also need to ask who will perform the operation. It is not necessarily the consultant, so you might want to ask questions about the surgeon operating.

What kind of anaesthetic is available and do I have a choice?

You might have a general anaesthetic or a spinal anaesthetic. It is not always mentioned when you first meet your surgeon, so if it matters to you, it is worth asking.

How long will I have to wait, and what happens in the meantime?

You could ask how your condition will be managed while you are waiting, and what you can do to prepare for the operation. For example, should you do exercises?

How long will I be in hospital for and what aftercare will I need?

This is important, particularly if you are on your own, elderly, frail or perhaps have pets or dependants. Arrangements will need to be made with care agencies, etc. You will also need to ask how soon you can expect

to weight-bear and start walking either aided or unaided, as it can be a frightening experience for some whilst getting used to a new joint. Many people avoid joint surgery due to other responsibilities like caring for a spouse.

What changes do I need to make at home?

You need to ask your clinical team about the changes you may need to make in preparation for when you go home after the operation. For example, you may need a raised toilet seat or a raised chair.

What is the infection rate?

You might want to ask how common it is to get an infection after the operation.

How long is my recovery going to be?

Your consultant should be able to anticipate the length of your recovery, and you may also want to ask specific questions such as "how long before I can drive again?".

What do I need to do to maintain my joint?

You might want to ask your clinical team about the physiotherapy available, as well as more general advice on keeping your new joint in good condition. On the Helpline we sometimes hear from people who have had no physio. or rehabilitation at all. People can be fearful of moving, so they don't, which is not good for a new joint.

How long is my joint going to last for?

This varies between different joint types, and also from individual to individual. You can ask your surgeon what you should expect.

For how long will the hospital provide aftercare, and will I need to have follow up appointments?

This will vary for each patient, but you can ask your clinical team about the frequency of your appointments and an approximate end date.

Where can I get in touch with someone who has had the same procedure?

This may be possible, and is worth asking your clinical team for information, but you might also be able to talk to other people through online forums, such as the Arthritis Care's discussion forum (details below).

Can I be part of the National Joint Registry?

Your hospital should ask you to take part in the NJR, and we recommend that you do. Recording the procedure on the NJR can speed up the process of reviewing patients in the rare event that a problem is found with a particular type of prosthesis.

The Arthritis Care Helpline is a free service which provides confidential information and emotional support to individuals, family, carers and professionals affected by arthritis.

Freephone: **0808 800 4050** or write to: Helplines Team, Arthritis Care, 18 Stephenson Way, London NW1 2HD. Or email: helplines@arthritiscare.org.uk, or join the discussion forum at <http://www.arthritiscare.org.uk>

Patients help shape the future of the NJR

The views of patients are vital to shaping the continued development of the National Joint Registry. Since it began in 2002, the NJR Steering Committee has included two patient representatives who feed in to all strategic decision making.

"The patient representative role on the Steering Committee is integral to the NJR understanding the views and needs of patients," explains Elaine Young, National Development Lead at HQIP. "The NJR is committed to strengthening this representation, and to developing a patient engagement strategy that facilitates communication with patients, carers and relevant patient organisations, to ensure their views, advice and influence is reflected in our work and strategic direction."

This year, the new Stakeholder Engagement Group will develop a communications strategy which will seek to improve engagement with all the NJR's stakeholders, including patients. Mary Cowern (see below), the current Steering Committee patient representative, will play a key role in the new group. There is currently a vacancy for another patient representative and the recruitment process will get underway in the near future.

To follow the latest news please check the NJR website (www.njrcentre.org.uk) or sign up to receive Healthcare Quality Improvement Partnership's (HQIP) monthly e-bulletin (www.hqip.org.uk).



Mary Cowern

I have been a patient representative on the NJR Steering Committee since 2006. I applied to join the Committee because I have a long history in representing patients, including working with the Welsh Assembly Government, and also because of my personal experience of joint replacement surgery. My first knee replacement at the age of 30 went wrong, due to surgeon error, and turned into a lengthy saga to get put right. When I heard about the NJR I realised that if the registry had been around when I had my first operation, the problem could have been picked up sooner. Hence my passion that all patients should be made aware of the NJR and its importance.

Whilst the Steering Committee is made up of different professions, we are all equal around the table. In some

organisations, patient representation can be rather tokenistic, but that is definitely not the case with the NJR. The patient representatives are involved in all of the strategic decisions. It is my role to make sure patient interests are always kept at the top of the agenda.

NJR ramps up PROMs focus

The NJR is shortly to commence a project to extend the national Patient Reported Outcome Measures. Joint Approach finds out more.

Currently, all NHS patients who are having hip or knee replacements, varicose vein surgery or groin hernia surgery are being invited to fill in PROMs questionnaires, as part of the Department of Health's PROMs programme. PROMs stands for Patient Reported Outcome Measures. The NHS is asking patients about their health and quality of life before they have an operation, and about their health and the effectiveness of the operation after it. This will help the NHS measure and improve the quality of its care. Combining these "patient outcomes" with the "clinical outcomes" data from the NJR will give a much more complete picture of the success, or otherwise, of operations.

Extending PROMs

Last year, the NJR announced that it was to undertake its own study to extend PROMs follow-up, in order to help

surgeons to understand what influences the success of joint replacement in the long term. Around 35,000 NHS patients in England who have their operation over a six-month period, and who agree to take part in both PROMs and the NJR, will receive a questionnaire after 12 months in addition to the six-month questionnaire in the national study. As part of NJR PROMs, it is planned to send out further questionnaires at three and five years.

Improving care

The aim is to provide data that will allow surgeons to understand what influences the success rate, from a patient's perspective. It is hoped this will feed into continued improvements in the treatment of patients.

"This extended data will provide the largest and most comprehensive contemporary assessment of the long term consequences of hip and knee joint replacement and their determinants in England and Wales", explained Alex MacGregor, Chair of the NJR Research Subcommittee.

Giving something back

15-year-old Kyrun Spraggs cannot wait for his second hip replacement in March 2011 because he has big plans for the summer. Assuming he is fit enough, Kyrun will walk all 120 km of the South Downs Way, with his fellow RAF cadets, to raise money for Arthritis Care.

Kyrun was seven years old when his hip problems began. He had been playing county football for Hampshire when he appeared to pick up a groin strain. When the limp did not go away, he was admitted to hospital for weeks of tests before he was finally diagnosed with junior idiopathic arthritis. He was put on a course of drug therapy to manage his condition.

Determined to carry on with his active lifestyle, Kyrun continued playing football. When that finally became impossible, he took up swimming and was soon swimming for his county (pictured right). He always knew he may eventually need a hip replacement, but what came as a shock was how fast he deteriorated. "It was six months from moving about to being in a wheelchair," he explains.

Kyrun could not find anyone else in his age group who had undergone a hip replacement because his condition is so rare, so he was very grateful to find that the older people on the Arthritis Care Internet forum were so supportive. "It was reassuring to know that older people had already had it and had benefited," he recalls.

At the pre-operative assessment clinic, Kyrun had the opportunity to discuss the type of hip replacement that was suitable for him. He was also pleased to participate in the NJR. "It's really good to know the information you give will help to understand joint replacements," he says.

On the morning of the operation, he arrived at the hospital at 8 o'clock. Two hours later, the surgeon and the anaesthetist came to discuss the procedure. The fact that he got on so well with his surgeon really helped to reduce his anxiety. He recalls being nervous, but excited. "I knew in a week's time, I could actually do bits and pieces without the bad hip. It would be a new lease of life - so I just focused on that".

The operation took place under general anaesthetic. After an hour in the recovery room, the surgeon came to see Kyrun. The damage had been worse than expected; "He said my joint was just crumbling away, which was a shock".

Two days after the operation, Kyrun began physiotherapy, starting with basic movements to keep the blood flowing. The exercises slowly progressed, and



by day seven he could walk more than ten metres. "This made me feel a lot more comfortable about being discharged," he recalls.

He arrived home on his birthday to find the house full of relatives waiting to surprise him and welcome him home. Since coming home, his recovery has been progressing well. As a result, he can now go into the town centre with his crutches and a friend for support, but his remaining bad hip is tiring him out. "I'm frustrated now," he says, "because I want the other side done as well."

Kyrun is having his other hip replaced this March. While he will not be able to play club football again, he is looking forward to getting back into cadets once he has recovered, and to the opportunity to give something back to Arthritis Care through his sponsored walk. "I would like to say a big thank you to Arthritis Care, my surgeon, the rheumatologists and all the hospital staff," he says. "They always managed to cheer me up when I was down. I liked the fact that after the operation my surgeon came to have a joke with me about the fact that my implant was pink!"

His surgery has also influenced Kyrun's choice of career. His original plan had been to become a physical training instructor in the RAF, but his hip replacements rule that out. However, his recent experiences have inspired him to pursue a career in the NHS. He is looking into becoming either a physiotherapist or a paramedic. "The way I want to lead my life is to give something back," he explains. "That is why I wanted to be a PTI in the Air Force, and that is why I want to go into the NHS."

If you would like to make a contribution to [Joint Approach](#) or have suggestions about subjects you would like to see in a future issue, please contact the NJR Helpline or email the Service Desk. All NJR information and documents are available on the NJR website. Alternatively, contact the NJR Helpline to receive copies by email or post. If you have any queries, please contact us via: The NJR Centre, Peoplebuilding 2, Peoplebuilding Estate, Maylands Avenue, Hemel Hempstead HP2 4NW. [NJR Helpline: 0845 345 9991](tel:08453459991) [Email: health_servicedesk@northgate-is.com](mailto:health_servicedesk@northgate-is.com) [Website: www.njrcentre.org.uk](http://www.njrcentre.org.uk)