



Joint Approach

ISSUE THREE
SEPTEMBER 2003

THE NEWSLETTER OF THE
NATIONAL JOINT REGISTRY
WWW.NJRCENTRE.ORG.UK

NJR training

Research and
the NJR

Data entry
progress

NJR minimum
dataset

“A younger
patient’s
perspective”



National Joint Registry
www.njrcentre.org.uk

This Newsletter is also available from the NJR Centre in Welsh

Latest NJR news

NJR research subcommittee

The Steering Committee has recently appointed Jan van der Meulen as chair of the NJR Research subcommittee. Dr van der Meulen is Director of the Clinical Effectiveness Unit, Royal College of Surgeons. Once fully formed the subcommittee will act as an advisory group to advance clinical outcomes. See page 4 for further details.

Barcode reader scoping study

There has been a significant number of requests from surgeons for the NJR to incorporate a barcode reader function to facilitate component data entry into the NJR. Similarly, the Regional Clinical Co-ordinator Network has made a formal request to the NJR Steering Committee for a scoping study to be undertaken. In direct response to these requests the Steering Committee has agreed to a scoping study that will examine the feasibility of introducing a barcode reader system.

The scoping study will explore a number of issues, including:

- the lack of an international standardised barcode format
- not all manufacturers supply barcode stickers
- funding of the software / hardware required

NJR Minimum Dataset working groups

Two working groups have been set up to ensure that the NJR MDS reflects current practices. See page 4 for more information.

Bulk data upload

Many hospitals collect data in their own database systems. There have been requests for the provision of a bulk data upload facility, i.e. a system that can export the data currently stored in a hospital's database directly into the NJR. This would avoid duplicate data entry and hence preserve data quality.

It has been agreed that the bulk upload facility will be developed once the current version of the MDS has been thoroughly reviewed to ensure that the facility reflects any subsequent amendments to the MDS.

CONTENTS

CONTENTS	2
LATEST NJR NEWS	2
EVENTS DIARY	2
HOW NJR DATA ENTRY IS PROGRESSING	3
RESEARCH AND THE NJR	4
MAKING THE MOST OF THE NJR MINIMUM DATASET	4
THE AUSTRALIAN ORTHOPAEDIC ASSOCIATION NATIONAL JOINT REPLACEMENT REGISTRY	5
HINTS AND TIPS FOR NJR DATA ENTRY	6 & 7
REGISTERING FOR A NEW USER ACCOUNT	7
THE COMMITMENT OF YOUR REGIONAL CLINICAL CO-ORDINATOR	8
THE INDEPENDENT HEALTHCARE SECTOR AND THE NJR	9
NJR TRAINING IS STILL AVAILABLE - APPLY WITHIN!	10
NJR DATA REPORTING AND ANALYSIS	11
THE NJR - A VITAL TOOL FOR ENHANCING ORTHOPAEDIC SERVICES	11
LIVING WITH A FAILING JOINT AS A YOUNG ADULT	12

Events Diary

The Hastings Cementless THR Forum

12 September 2003 Speaker: David Carter, NJR Programme Manager.

British Orthopaedic Association: Annual Congress 2003

17 – 19 September 2003 Come and visit the NJR on stand 203.

Orthopaedic Clinical Outcomes Research Symposium 2003, Berlin

26 – 28 September 2003 Speaker: Martin Pickford, NJR Orthopaedic Adviser.

NJR Training Workshops

If you are interested in attending one of the following workshops contact Amanda Hoare, the NJR Training Co-ordinator, via the Helpline. All workshop dates are to be confirmed.

SEPTEMBER Queen Elizabeth Hospital, Woolwich, London and Basildon Hospital, Essex.

OCTOBER Royal Bournemouth General Hospital, Dorset, and Hillingdon Hospital, Middlesex.

What would you like to see in the next issue of the Newsletter?

Let us know what you would find useful and we'll endeavour to meet your wishes.

NEXT PUBLICATION: DECEMBER 2003

If you would like to make a contribution to this Newsletter please contact us.

We are also keen to receive NJR related high-resolution photographs.

Tel: 01235 433433 Fax: 01235 433961 Email: enquiries@njrcentre.org.uk

How NJR data entry is progressing

A great deal has already been achieved since the contract for developing the Registry was awarded to AEA Technology plc in September 2002. The work and commitment of all involved have helped the NJR concept to become a reality.

Figures 1, 2 and 3 below, show the number of operations recorded electronically by the NJR to date. Some hospitals are collecting data on NJR paper proformas, and will enter the data once their IT systems are ready.



Figure 1
The number of operations* recorded by the NJR from 1 April to 31 July 2003 for NHS hospitals in England

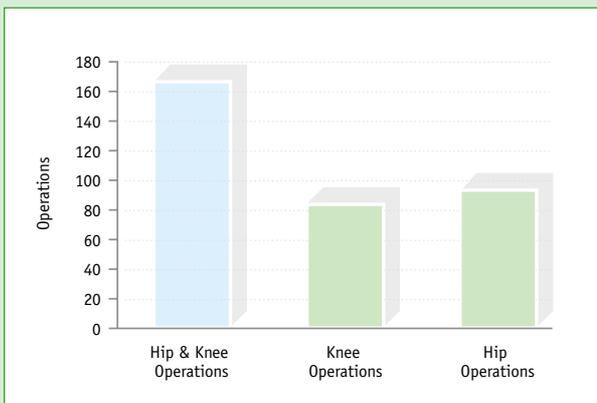


Figure 2
The number of operations* recorded by the NJR from 1 April to 31 July 2003 for NHS hospitals in Wales



Figure 3
The number of operations* recorded by the NJR from 1 April to 31 July 2003 for independent hospitals in England and Wales

For those hospitals that are not yet participating in the NJR, it is essential that clinicians and managers consider what is needed within their hospitals for its introduction. This may be deciding who will gather and enter the data, how they will use the data or preparing the IT system.

By submitting the data to the NJR it will be the hospitals themselves that will make the NJR a success and improve the quality of care provided to patients needing hip or knee implants.



All NJR information and documents are available on the NJR website
www.njrcentre.org.uk

If you do not have access to the web, contact the NJR to receive a copy by email or by post.

NJR Centre
329 Harwell
Didcot
Oxfordshire OX11 0QJ

Tel: 01235 433433

Fax: 01235 433961

Email: enquiries@njrcentre.org.uk

*Completed records submitted to the NJR up to 31 July 2003

Research and the NJR

Around 100,000 total hip and total knee procedures take place in England and Wales every year. Data related to these procedures will be entered into the NJR database, consequently making it the largest database of its kind in the world within a short time. The NJR has the potential to become a powerful tool for clinical outcomes research.

NJR research subcommittee

An NJR research subcommittee is currently being developed to act as an advisory group to the Steering Committee to advance clinical outcomes research.

The Steering Committee has recently appointed Jan van der Meulen as chair of the NJR research subcommittee. Dr van der Meulen is Director of the Clinical Effectiveness Unit, Royal College of Surgeons.

In addition to Dr van der Meulen's expertise, the subcommittee will benefit from significant representation from the surgical profession, including a knee specialist, a hip specialist and a further two clinicians. Other stakeholder groups that will be represented on the subcommittee include patients and implant suppliers.

Research proposals

The detailed mechanism for granting permission for using the NJR to collect data for research purposes has not yet been agreed. Further details will be made available in due course.

Patient Feedback Questionnaires

As part of its role, the research subcommittee will be considering the patient feedback questionnaire process as research activities are strongly related to collection of patient outcome data.

Making the most of the NJR Minimum Dataset

The Minimum Dataset (MDS) is the core set of data fields that have been collected by the Registry from 1 April 2003.

To aid data entry, the MDS allows default techniques for a surgeon to be built in (for Primary Hip, Primary Knee, Revision Hip, and Revision Knee). Some free text fields have also been included to allow surgeons to capture information that is not held within the MDS as a specified data field, e.g. this may be related to their own research interests.

The current NJR MDS is available for reference on the NJR website. It is considered largely fit for purpose, with its design and content being informed by other existing regional and national MDSs, and the views of the NJR Steering Committee (which includes representatives of the surgical profession). However, to ensure that it fits with the aims of the NJR and is optimised, the Steering Committee has developed a process for ongoing review of the scope and use of the NJR MDS.

The key elements of the review process are:

- feedback from hospitals of their experiences of using the MDS and paper proformas
- interrogation of the NJR system to determine where potential problems lie (e.g. fields that are rarely completed or tend to be completed inaccurately)
- views and experiences of all stakeholder groups represented on the Steering Committee
- expert consensus of two Regional Clinical Co-ordinator working groups, one focussing on hips and the other on knees (see the NJR MDS working groups information box).

Some issues that are being considered as part of the review process are:

- whether there are any obvious

omissions in the NJR MDS that need to be addressed to take epidemiological case mix into consideration in subsequent reporting

- incorporation of "Reoperations other than Revision", e.g. where there is infection or dislocation
- the usability (including length) of the MDS in an average district general hospital, and guarding against the MDS becoming a tool for expert users only

The expectation is that only minimal modifications will be required to the existing MDS. It is intended that the revised MDS will be piloted ahead of its full launch in Spring 2004.

NJR MDS working groups

Working groups have been set up to ensure that the NJR MDS reflects current practices. The working groups are chaired by Professor Paul Gregg and all members are part of the Regional Clinical Co-ordinator Network. The working groups will report their findings and recommendations to the Steering Committee.

Hip working group members:

John Britton
John Skinner
Evert Smith
John Timperley
Keith Tucker

Knee working group members:

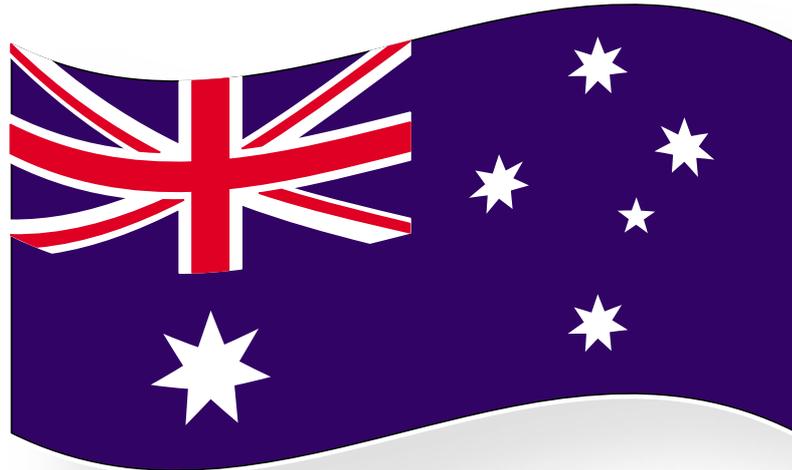
Colin Esler
Peter Howard
Anthony Hui
David Murray
Richard Parkinson

The Australian Orthopaedic Association National Joint Replacement Registry

The Australian Orthopaedic Association National Joint Replacement Registry (AOA NJRR) is an initiative of the Australian Orthopaedic Association. The AOANJRR has been implemented to monitor all types of prostheses used for hip and knee replacement. The Commonwealth government provided funding for the implementation of the AOANJRR and continues to provide ongoing funding for the immediate future. In March 1999 and again in November 2001 the AOANJRR was declared a Federal Quality Assurance Activity.

A Registry is the most effective method of determining which prostheses and surgical techniques are the most successful for given demographic and diagnostic subgroups within the community. The information collected by the AOANJRR includes patient demographics, diagnosis and prosthesis details. This information allows the AOANJRR to report on characteristics of patients undergoing joint replacement as well as simultaneously monitoring all types of prosthetic design. The AOANJRR provides a mechanism to identify the best performing prostheses as well as the very important function of device tracking. It is able to identify patients in the event of a prosthesis recall as the recording of patient information and catalogue and lot numbers accurately links prostheses to patients.

The AOANJRR commenced implementation in South Australia in 1999. Following this the Registry was implemented on a state-by-state basis and by mid 2002 implementation was complete with 296 public and private hospitals participating. While participation in the AOANJRR is voluntary there is 100% participation from both surgeons and hospitals that undertake joint replacement. Patient participation is also voluntary and to date only four people have contacted the AOANJRR to ask that their information is not included in the Registry*. The Registry now has information on over 110,000 patients and procedures.



Hip and knee joint replacement surgery has increased from between 5% and 10% per year for the last five years. Joint replacement, particularly knee replacement, due to its success in treating a variety of disorders, is a procedure that is no longer reserved for the elderly but is increasingly used in younger patients. As the number of primary joint replacements performed increase so too will there be an increase in the number of revision surgeries as people outlive the life of their joint replacement. Variation in survivorship depends on the joint replacement and the surgical techniques used as well as the age and activity level of the person receiving the joint replacement. The outcomes of revision surgery are not as successful as primary joint replacement and therefore it is important to identify which joint replacement in particular clinical situations performs best.

During the last twelve months the number of hip replacements (partial, primary and revision) performed in Australia was 26,689, an increase of 9.9% from the previous year. For the same period the number of knee replacements performed was 26,089, (patella/trochlear, unicompartmental, primary and revision) which was an increase of 17.2%. Data collected shows that more

women than men undergo hip replacement for all types of procedures. The youngest recipient was 13 and the oldest was 105. The data is similar for knee replacement with the youngest recipient being 13 and the oldest 100. More women than men receive knee replacement except for unicompartmental replacement in which more men than women were recorded.

For information on the Registry and for access to the annual reports please visit the web site at www.aoa.org.au and enter via the related links or www.dmac.adelaide.edu.au/aoanjrr/

Lisa Ingerson

Co-ordinator

AOA National Joint Replacement Registry

*Australia functions under an "opt-out" system, i.e. consent is assumed unless a patient requests that their data is not stored.

This Newsletter will feature articles on national joint registries operating in other countries in future issues. The Australian Orthopaedic Association National Joint Registry is an example of a recently established registry.

Hints and tips for NJR data entry

Provided below are some helpful hints and tips to help you use the data entry system.

HOW TO LOG ON TO THE NJR DATA ENTRY SYSTEM

Only registered users will have access to the NJR Data Entry System. Refer to the 'Registering for a new user account' box on page 7 to see how to register.

The NJR Data Entry System is accessed via the Internet. You can log on to the NJR Data Entry System by following either method outlined below.

Method 1

Type in the following URL

<https://dataforms.njrcentre.org.uk>

This will take you to the NJR Data Entry System log on screen, see Figure 1.

Method 2

Click on the 'Data Entry' option on the NJR website homepage www.njrcentre.org.uk shown in Figure 2. This will take you to the NJR Data Entry System log on screen as shown in Figure 1.

HOW TO EDIT AND DELETE RECORDS

Editing records

The NJR gives the user the ability to start entering data into a record and then save the record partially completed. This allows the user to edit the record at a later date when all the operation or patient details become available. It is important for users to ensure all partially filled records in the edit queue are completed as soon as possible. If a record is no longer relevant it should be deleted.

Every time a record is created for data entry, the system will generate and assign it a unique ID number (the NJR Index number). To be able to go back at a later date and edit a record, the data inputter must make a note of the NJR Index number; without this number you will not be able to identify easily which record you need to select.

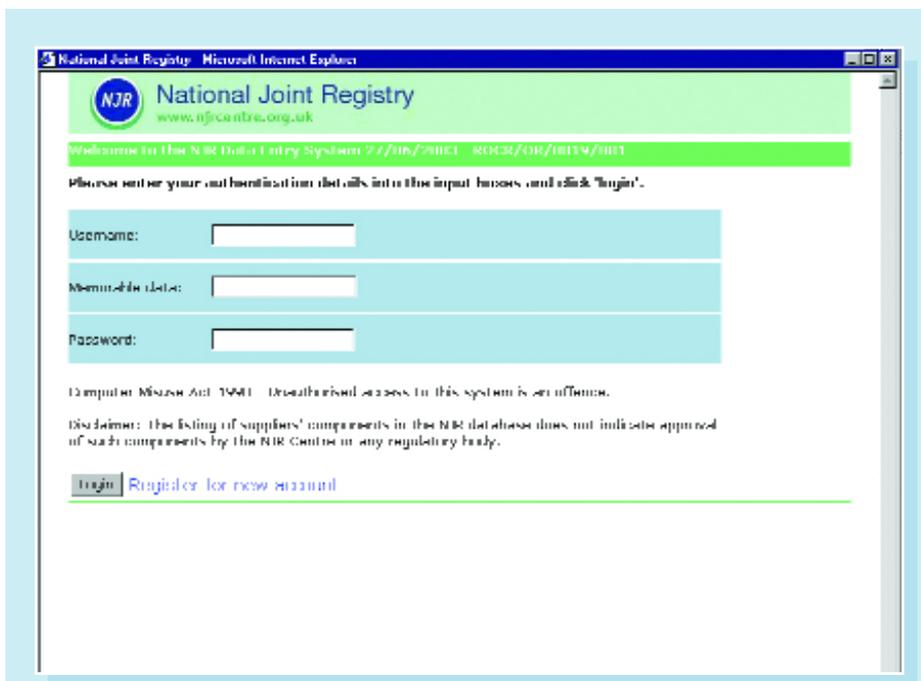


Figure 1 - The NJR Data Entry System log on screen

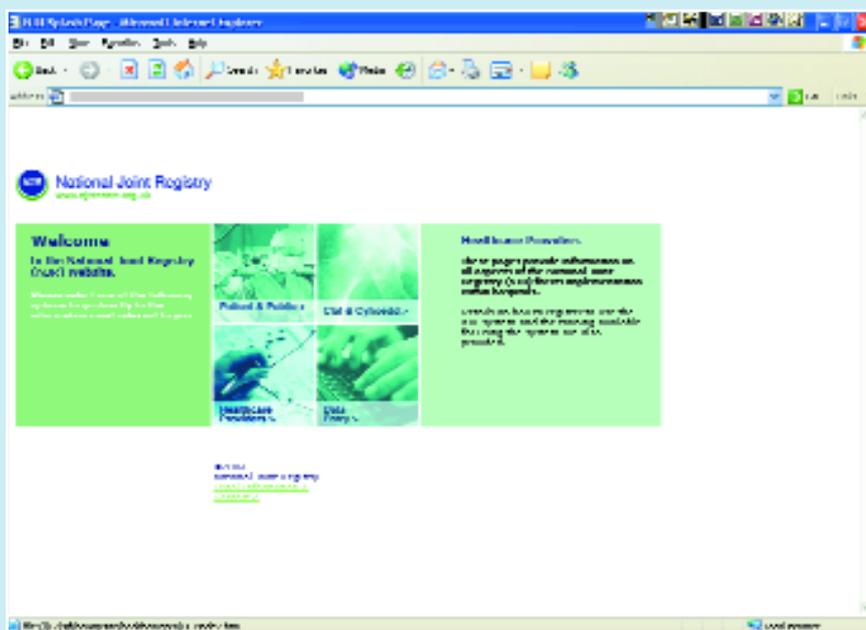


Figure 2 - The NJR website homepage

Deleting records

Sometimes the data inputter may choose to delete a record that is sitting in the edit queue, for example two records may have been created for the same operation. To delete a record of no further use, follow the simple steps below.

1. From the main menu select **Edit existing operation**.

You should see a list of all the NJR records that are waiting in the edit queue; they will be listed in numerical order, i.e. by the NJR Index number.

Each record also shows:

- the surgery date
- the hospital name
- the data inputter (i.e. who in the hospital last edited the record)
- the hospital ID (i.e. a reference number that may be assigned to a patient by the hospital).

2. Next to each record you will see an edit and a delete button, select the appropriate button. If you select delete, you will be prompted to confirm that you want to delete the record, if you do, click on **OK**.

Users will not be able to delete a record once it has been submitted to the NJR. If at a later date a user realises that a record is not correct, they should contact the NJR Centre.

HOW TO CREATE A SURGEON'S DEFAULT HIP OR KNEE TECHNIQUE

To ease data entry, the NJR system has provided a facility for creating a default

technique for each surgeon. A surgeon can create their own default technique, for a primary and revision for both hip and knee, by following the steps below.

1. From the main menu select **System Functions** and then **Modify Surgeon Profile**.
2. You should see four tabs across the screen. Click on a tab to select the area of relevance.
3. Enter your default for hip technique and then select the knee tab to enter your knee default. To save your default technique, move to another tab or click on the save button.

HOW TO CHANGE YOUR PASSWORD

A user can change their password at any time. Follow the process below to change your user password if it reaches its expiry date. When your password has expired you will get the following message when you try to logon to the system:

“You have been redirected to the change password screen because your password has expired. If you do not change your password now, you will not be able to log back into the system in the future”

Click on **OK** and you will be taken to the **Change password** screen.

1. In the **Change password** screen you will see three boxes. Enter your old password and your new password where prompted. Your new password is entered twice simply to confirm your choice

of password, i.e. to ensure you did not mistype your intended new password.

Your password **MUST**:

- be between 8 and 16 characters
- contain a mixture of upper and lower case letters (at least one of each)
- contain at least one number
- **NOT** contain spaces

2. When you are happy that you have entered the password you want, click on the **Change password** button. You will now be logged into the system.

You will need to use your new password the next time you login. Password expiry periods can be changed. The default period is 30 days but users may choose to increase this up to the maximum period of 90 days.

HOW TO ADD AND REMOVE YOUR CONSENT IF YOU ARE A SURGEON

If you are a surgeon you can give your hospital data manager permission to download your data.

1. From the main menu select **System Functions** and then **Modify Surgeon Profile**.
2. Select the **Personal Options** tab and select your grade from the dropdown box.
3. Tick the consent box to enable your data to be downloaded by your hospital data manager.

If you do not want to give your hospital data manager access to your data, ensure that the consent box is not selected, i.e. it should not contain a tick mark.

Registering for a new user account

The NJR Helpline handles the setting up of new user accounts; also commonly known as ‘registering on the NJR system’. All users of the NJR data entry system need to register on the system via the NJR Helpline.

To register, contact the NJR Helpline and ask for a new user account. The following information will be required:

- Your user type (i.e. NJR data entry, NJR Hospital Data Manager, surgeon or supplier)
- your name (in full)
- the hospital(s) at which you work
- GMC number and grade, if you are a surgeon.

Hospital Data Manager access is required if:

- you are the main contact at the hospital for the NJR
- you need to associate surgeons to your hospital
- you need the ability to download data from the system for your unit / hospital.

The commitment of your Regional Clinical Co-ordinator

The Regional Clinical Co-ordinator Network is now firmly established and has been active in:

- Providing support to the initial set-up of the NJR
- Facilitating feedback to orthopaedic surgeons
- Communicating between the regionally based hospitals / units and the NJR Centre and NJR Steering Committee
- Hosting regional training roadshows

The Regional Clinical Co-ordinators (RCCs) are also providing considerable advice on the content of the NJR Minimum Dataset (MDS), and contributing towards the way in which the NJR data entry system functions.

The aims of the NJR hold the patient's best outcomes at its heart and the Regional Clinical Co-ordinators are committed to reinforcing the benefits the Registry will bring to patients and helping to improve orthopaedic care.

Part of the NJR Regional Clinical Co-ordinator's role is to ensure that the NJR penetrates their Strategic Health Authority / Welsh NHS region. Without the full participation of orthopaedic units and hospitals the NJR will not reach its potential for being one of the most powerful tools for improving orthopaedic care. To provide reliable information and help prevent another episode such as the failure of the 3M Capital hip, it is essential that as many total hip and knee operations be entered into the NJR database as possible.

To understand what the key issues are for hospitals to implement the Registry or any hindrances they might be experiencing, the RCC needs to stay in touch with the hospitals within their region.

With limited time due to other work commitments, the easiest way that one RCC

has found to stay in touch, is to place direct calls through to the key NJR contact in each hospital on a regular basis. These calls allow him to see how things are progressing locally and provide an opportunity for any questions to be raised and to chat over any issues with an orthopaedic colleague.

One of the most common concerns for hospitals in implementing the Registry is how to resource data entry. For many orthopaedic teams, data entry is facilitated by the completion of the NJR proforma by the orthopaedic surgeon, followed by data entry staff providing the on-line submission of data.

A plea from an RCC "Spend time providing the data, it only takes 10 minutes to fill a form, remember its in the patient's best interest!"

Input from the orthopaedic surgical community is vital to the successful operation of the NJR, it's the surgical interface that helps determine the quality of data recorded.

Contact details for Regional Clinical Co-ordinators can be found on the NJR website or call the NJR Helpline.



The independent healthcare sector and the NJR

During 2002, approximately 25% of all hip and 20% of all knee prosthetic implant procedures in the UK were performed in the independent healthcare sector. In total, over 200 independent hospitals currently perform either or both procedures. From inception of the NJR, it was therefore essential that the project was developed and implemented with the potential contributions from acute independent hospitals in mind.

To help achieve this, Dr Chris Dark, Director of Clinical Services, BUPA Hospitals, sits on the NJR Steering Committee as a representative of the Independent Healthcare Association (IHA). For those unfamiliar with their work, the IHA is the UK's largest trade association representing the independent health and social care sector. In doing so, the organisation strives to protect and promote high standards of treatment and care for patients treated in the independent sector.

Sally Taber, Head of Operational Policy, IHA, says "IHA members are delighted to participate in the NJR in order to ensure that the registry can adequately benchmark across the whole of healthcare not just the NHS. It is now part of the overall clinical governance frameworks within independent hospitals in order to strive to improve patient care."

The IHA have therefore played a key role in ensuring the NJR Steering Committee are

"BUPA Hospitals' experience of implementation / on-going management of the NJR has been excellent"

Chris Dark
Director of Clinical Services
BUPA Hospitals



fully advised of the issues that participation in the NJR raise for independent acute hospitals. IHA member hospitals are also kept up-to-date with developments of the NJR through monthly IHA mailings.

Independent acute hospitals are mandated to participate in the NJR through the National Minimum Standards for Independent Healthcare, set down by the Department of Health and overseen by the National Care Standards Commission. This provided an extra incentive to ensure that policies and procedures were brought in as near as possible to 1 April 2003.

Essentially, the issues around the collection and submission of minimum data sets are the same for independent sector hospitals as for NHS Trusts. Guidance provided by the NJR

was therefore relevant across the whole of the UK Acute Healthcare Sector. Said Dr Chris Dark, "After some initial teething problems, BUPA Hospitals' experience of the implementation and ongoing management of the NJR has been excellent."

With support from the IHA, the Regional Clinical Co-ordinators and the NJR Centre itself, acute independent sector hospitals continue to work toward increasing the number of patients registered with the NJR. Patients undergoing hip and knee prosthetic implant procedures in independent hospitals will therefore enjoy the same benefits as those treated in NHS Trusts.

Phil Etherington
Quality Improvement Manager
Nuffield Hospitals



"IHA members are delighted to participate in the NJR in order to ensure that the registry can adequately benchmark across the whole of healthcare not just the NHS"

Sally Taber
Head of Operational Policy
Independent Healthcare Association



NJR training is still available - apply within!

In the weeks prior to the launch of the National Joint Registry, NJR Centre staff ran a series of training events in central locations across England and Wales. These provided orthopaedic unit and hospital staff with the opportunity to learn about the aims and objectives of the NJR and receive training on how to enter data into the NJR database.

The NJR Centre remains committed to providing training and support to orthopaedic hospital and unit staff and is offering in-house workshop sessions. To fit with your busy schedule, we are asking **YOU** to invite **US** to train you and your colleagues in **YOUR HOSPITAL** setting.

The workshops are being co-ordinated by the NJR Centre with the help of the Regional Clinical Co-ordinator Network. By drawing on the local knowledge of the Regional Clinical Co-ordinators we are able to invite staff from other hospitals in the local vicinity who also need to learn how to use the system.

The NJR Centre requires a minimum of 2 weeks' notice to co-ordinate a workshop and 10-15 orthopaedic unit / hospital staff for each workshop session. We suggest running two sessions if you have more than 15 staff who require training.

The workshop **AIMS** to:

- give an overview of the NJR Project
- train users how to enter data successfully into the NJR database
- present an opportunity to ask questions and talk through issues
- provide the NJR Centre with feedback from the hospital's perspective

The **BENEFITS**

- the workshop can be structured to meet your needs
- a flexible timescale – we will work around your hospital schedule whenever possible
- up to 15 hospital staff trained within 2 hours
- there is **NO COST** to the hospital, other than the costs of any room hire (and refreshments if they are provided)

A typical workshop **FORMAT**

- Introduction (10 minutes)
- Overview of the Data Entry System (30 minutes)
- 'Hands on Training' & Problem Solving (approximately 1.5 hours)

What is required?

What we need you to provide:

- a selection of convenient dates
- a meeting room that is large enough to seat up to 15 people, with tables and power to run 6 PCs
- 6 PCs with Internet access (if this is not possible the NJR Centre will endeavour to provide IT equipment)
- refreshments (optional but welcome)
- pre-workshop co-ordination within your hospital, i.e. advertisement to and invitation of all staff within your hospital who would benefit from NJR training, especially orthopaedic and administration staff
- a list of attendees to enable the NJR Centre to pre-register participants onto the NJR system (so that we can provide attendees with username and password details at the workshop)

What the NJR Centre will provide:

- pre-workshop support, e.g. liaison with hospital staff to ensure that the location is suitable, and that the PCs have the required specification to connect to the NJR database over the Internet
- co-ordination with other local hospitals that may wish to send orthopaedic staff to the workshop session
- on-the-day training
- workshop handouts
- an NJR information pack
- IT and projection equipment (if required)
- answers to your questions!

What to do next?

To talk through your training requirements, or to arrange a date for the NJR Centre to visit your hospital, please contact: **Amanda Hoare, NJR Centre Training Co-ordinator**, via the Helpline, or by email:

amanda.hoare@aeat.co.uk

Alternatively, you can complete the training request form on the NJR website.



TO RESERVE A ONE-TO-ONE TRAINING SLOT AT THE BOA ANNUAL CONGRESS 2003 ON THE 17 - 19 SEPTEMBER CONTACT AMANDA HOARE, VIA THE NJR HELPLINE

The NJR visits North Wales

The first NJR data entry training workshop held in a local hospital setting worked well and took place at Abergele Hospital, Conwy, at the end of July.

Ian Smith, the Regional Clinical Co-ordinator for North Wales, invited the NJR Centre to run a workshop for hospital staff in his region. Thanks to Ian's tireless support, the number of attendees was so high that the NJR Centre organised two workshop sessions, one for the morning and one for the afternoon. For those that could not attend the main sessions, one-to-one training was provided at the end of the day.

The workshops were well attended by staff from four different hospitals, based in England and Wales, and representing the NHS and the independent sector. There was strong attendance from surgeons, consultants and theatre nurses, with administration and IT staff also present.

The NJR Centre received positive feedback on the workshop sessions and the ease of using the NJR data entry system.

"Thank you, I found the workshop session very informative, and good fun too!"

NJR data reporting and analysis

The NJR reporting and analysis strategy is currently under detailed development. Jan van der Meulen, Director of the Clinical Effectiveness Unit, Royal College of Surgeons, is providing significant input into the strategy's development particularly as to what would be of most value to surgeons and other stakeholders.

Some indication of what can be expected is given here.

The NJR data will be checked and analysed to provide information to:

- Patients (and the public), to enable them to make an informed choice
- Surgeons, for them to identify best orthopaedic practice
- Manufacturers, to aid post-market surveillance
- Healthcare managers, to help with capacity planning and budgeting

NJR data reporting will focus on variations in clinical practice and patient outcomes.

Data reports

Reports will provide a summary of the data with an interpretation and discussion of results. Where possible an

explanation of the implications for clinical practice will also be given.

All results will be analysed using robust and recommended statistical techniques and will take into consideration the three following key variations:

- random variation
- differences in surgical case mix
- factors related to the practice of care.

Data reports will be made accessible according to the user type:

- National data reports, accessible to patients and the general public
- Trust and hospital data reports, where Trusts and hospitals are identified (unless this would lead to identification of individual surgeons)
- Surgeon data reports, accessible only to the individual surgeon (and their Trust and hospital where the surgeon has given their consent)

Special data reports addressing topical issues in detail will be commissioned by the Steering Committee when appropriate.

National reports will be made accessible via the NJR website.

The NJR - a vital tool for enhancing orthopaedic services

The NJR is a vital tool for helping to deliver a quality orthopaedic service to patients by improving orthopaedic care through clinical audit and learning from good practice.

The NJR will allow for the first time, a true measure of the number of total hip and knee replacement operations carried out across England and Wales in both the NHS and the independent healthcare sector. The Registry is collecting data on all the implant types in use today and its scrutiny will build a picture of their performance year on year. Furthermore, it will provide a means of assessing the variation in surgical techniques and practice across the regions. The NJR will quickly become one of the largest databases of its kind and a valuable resource for research opportunities into the factors that influence patients' progress and outcome after surgery.

By submitting data to the NJR database on all total hip or knee replacement operations performed, it will be the hospitals themselves that will make the NJR a success and improve the quality of care provided to patients needing hip or knee implants.

NJR Information

All NJR information and documents are available on the NJR website www.njrcentre.org.uk

The NJR website provides a wealth of information on the data entry system, training, the proformas, the NJR levy and much more. We are always happy to receive comments and suggestions you may have about the site, please contact the Helpline with your suggestions. If you do not have access to the website, contact the NJR Helpline to receive a copy of NJR documents by email or by post.

NJR Centre, 329 Harwell, Didcot, Oxfordshire OX11 0QJ

Tel: **01235 433433** Fax: **01235 433961** Email: enquiries@njrcentre.org.uk

The NJR Helpline is available Mon - Fri from 9am to 5pm to answer your questions, provide information or pass your call onto a specialist in the given area to assist you.

Living with a failing joint as a young adult

In a young adult, joint replacement is very effective but much less common. Kate Llewelyn is 31 and has had adult form rheumatoid arthritis since she was 13. She had a total knee replacement six years ago.

"I was the youngest person to have had a knee replacement at the hospital, and S4C were filming me and my operation as part of a fundraising exercise for an arthritis charity, so I became a bit of a celebrity there."

Kate shares her experience of coping with arthritis and a failing knee joint during young adulthood, and the effect a knee replacement has had on her life since.

Learning to slow down

"It's hard to remember what life was like before I got arthritis. Every now and then I remember being crazy about swimming and cycling everywhere. That all stopped when arthritis appeared. My life had to slow down and I had to adapt, but being so young I think it was easier for me. My life has been shaped by having to live with rheumatoid arthritis – school, university and my working life have all been influenced by it.

Living with pain and an immobile knee

By the time it came to having my knee replacement operation, living with the pain and immobility was gruelling. I've lived with constant pain for 18 years, but this was one of my worst periods. The pain had become particularly bad for the last three years before the operation. It began to affect my work as my concentration levels dropped off; I think that's a side effect of pain many people don't realise. I must have had a constant grimace on my face and I swore that if anyone else said to me: 'Cheer up it

may never happen', I'd swing for them. Having a new knee has literally brought a smile to my face.

Even though the pain was difficult, my reason to have the operation was to improve my mobility more than to ease the pain. The lack of mobility was hampering my daily life. Every time I went out in public I was terrified that someone would trip over my leg. I couldn't bend it or straighten it properly, it just got in the way.

Adapting to a new knee

I don't think I'd fully prepared myself for how hard I had to work to get my new knee going. After not having bent my knee for about three years, I had to completely change the way I thought about walking. It was only when the physiotherapist told me to imagine I was kicking a football as I walked that I began to get the hang of it.

The pain in my knee has improved considerably. Once the pain of my knee wore off, I began to feel more pain in some of my other joints and it became clear just how bad my knee pain had been. So, unfortunately for me, having a knee replacement hasn't solved all my problems, but it really has improved things.

Big benefits

Being able to move around more easily has been the most significant benefit for me. It was important to me that I could get up and down stairs again. Going upstairs is better, but I still find coming down difficult and painful due mainly to the rheumatoid arthritis in my feet and ankles. Nevertheless, I'm doing it much better than before.

I've found other benefits too. I'm able to

wear different clothes again. For such a long time I hadn't been able to wear anything that was heavy on my knee or anything that constricted it. And once the pain died down I became a nicer person to my family and friends; pain can make a person ugly and I imagine this was me for quite a time. I've also been able to take more exercise since my recovery and, as a result, I've lost some weight.

It's become easier to get out and about which means I have reclaimed my social life and I've got more energy now. My work has benefited too – my concentration levels are back up since the pain has eased, and travelling to work is easier and less stressful.

The benefits of having the operation for me may sound really insignificant to other people, but to me they mean the world.

Six years later

For six years my knee has done me proud, though I am worried about it running out of steam and needing a revision – I've grown quite attached to the one I've got. But in order to keep my improved quality of life, it will be well worth considering further surgery down the line. I'm just pleased my other knee is holding out!"

Kate Llewelyn
Head of
Publications
Arthritis Care



This Newsletter seeks to share patient experiences of joint replacement and the benefits this type of surgery can bring. If you have experiences to share to help other people understand what's involved, contact the NJR Helpline.