

An overview of the National Joint Registry

Background information and getting started

Document control

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1	04/06/18	Change from MDSv6 to MDSv7
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1 About the National Joint Registry

1.1 Background and mission statement

The National Joint Registry (NJR) for England, Wales, Northern Ireland, the Isle of Man, and Guernsey collects information on joint replacement surgery and monitors the performance of joint replacement implants. It was established in 2002 by the Department of Health and the Welsh Assembly Government, with Northern Ireland joining in 2013, the Isle of Man in 2015, and Guernsey in 2020. Its mission statement is:

'The purpose of the National Joint Registry for England, Wales, Northern Ireland, the Isle of Man, and Guernsey is to collect high quality and relevant data about joint replacement surgery in order to provide an early warning of issues relating to patient safety. In a continuous drive to improve the quality of outcomes and ensure the quality and cost effectiveness of joint replacement surgery, the NJR will monitor and report on outcomes, and support and enable related research.'

1.2 The goals of the National Joint Registry

The NJR's specific goals are to:

- Monitor in real time the outcomes achieved by brand of prosthesis, hospital and surgeon, and highlight where these fall below an expected performance in order to allow prompt investigation and to support follow-up action.
- Inform patients, clinicians, providers and commissioners of healthcare, regulators, and implant suppliers of the outcomes achieved in joint replacement surgery.
- Evidence variations in outcome achieved across surgical practice in order to inform best practice.
- Enhance patient awareness of joint replacement outcomes to better inform patient choice and patients' quality of experience through engagement with patients and patient organisations.
- Support evidence-based purchasing of joint replacement implants for healthcare providers to support quality and cost effectiveness.
- Support suppliers in the routine post-market surveillance of implants and provide information to clinicians, patients, hospital management and the regulatory authorities.

Further information about the governance of the NJR can be found on its website at www.njrcentre.org.uk.

On 1 April 2008, the management of the NJR was transferred from the Department of Health to the Healthcare Quality Improvement Partnership (HQIP), a consortium

comprising the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices, as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The NJR and the NJR Management Team are now hosted by HQIP. For further information about HQIP, please visit the website at www.hqip.org.uk.

The work of the NJR is overseen by the NJR Steering Committee which is an NHS England Committee of Experts. Further information about the structure, governance, and operating model of the Steering Committee can be found on the [NJR Reports](#) website.

Further information about the governance of the NJR can be found on its website at www.njrcentre.org.uk.

1.3 NJR Funding

The NJR is funded by a subscription based on the number of procedures submitted to the NJR by hospitals in NHS Trusts, NHS Foundation Trusts, Health Boards, and Independent sector healthcare companies. The subscription includes a number of free reporting services for clinicians, trust and company management, and procurement organisations.

A number of paid subscription services are also available to the medical device industry. Approximately 20% of the NJR's income is from industry.

1.4 What is the NJR Centre?

The NJR Centre is responsible for the collection and processing of all NJR data as well as the continuing development of the data entry system and its supporting databases and all NJR reporting services. Additionally, the NJR Centre also provides a Service Desk for all stakeholders and a team of Compliance Officers to provide direct support to all hospitals.

The NJR Centre is currently managed by Northgate Public Services (UK) Limited (NPS).

1.5 Security and Confidentiality

All data is collected via a secure, web-based data entry system and stored and processed in NPS' secure data centre. NPS is certified to ISO/IEC 27001: 2013, the UK Government's Cyber Essentials Plus, and is compliant with NHS England's Data Security and Protection Toolkit (DSPT). Strict controls and safeguards exist to protect the data and a formal governance process is in place to ensure that all requests for NJR data are carefully considered before either being approved or rejected. For the NJR, HQIP is the Data Controller and NPS acts as a Data Processor.

For further details about how the data is processed, please see the [NJR's Privacy Statement](#).

1.6 Changes to the data collection

All changes to the data collected by the NJR are considered by the Data Review Committee. Whilst anyone can propose changes to the Minimum Dataset (MDS), all changes are considered by the NJR's Regional Clinical Coordinators' Network and the professional societies, e.g. the British Association for Surgery of the Knee (BASK), the British Elbow and Shoulder Society (BESS) and the British Orthopaedic Association (BOA). Regular reviews (every two years) of the MDS are necessary due to changes in clinical practice, changes in clinical guidance, and developments in implant technology.

1.7 Current version - Minimum Data Set Version 7

The current version of the MDS is MDSv7. To ensure that the correct proformas are used, users should check the version number in the top right of each procedure form. The most recent forms are available from the [NJR website](#).

 National Joint Registry www.njrcentre.org.uk Working for patients, driving forward quality	MDS VERSION 7.0 Hip Operation	Form: MDSv7.0 H1 v1.0
H1 Hip Primary	Patient Addressograph	
Important: Please tick relevant boxes. All component stickers should be affixed to the accompanying 'Minimum Dataset Form Component Labels Sheet'. Please ensure that all sheets are stapled together.		

2 What Data is collected by the NJR?

The NJR MDS represents a 'snapshot' of a patient's procedure, with details being recorded at the time of the operation. There is no requirement to enter supplementary data, e.g. histology, following surgery. Currently the NJR collects data about primary (first joint operation) and revision (subsequent operations for the same joint) for the following joints:

- Hips
- Knees
- Ankles
- Elbows
- Shoulders.

Primary and revision procedures for the same patient and same joint are linked using patient identifiers. It is the linkage of primary and revision procedures that enables the NJR to calculate the outcomes of joint replacement surgery at a surgical, hospital, and implant level.

2.1 Patient Identifiable Data

Where patients consent, the following personal data will be collected:

- Name (first name and last name)
- Date of Birth
- Gender
- Postcode
- NHS/National Patient number
- Email address
- Mobile phone number.

Data will be submitted to the NHS Personal Demographic Service (PDS) for batch tracing. For each patient this will either validate or correct or supply a patient's NHS number, a patient's address, and, if applicable, a patient's date of death. In Northern Ireland, similar batch tracing takes place twice a year under a Data Access Agreement with the Northern Ireland Health and Social Care Business Services Organisation.

2.2 Consent

Patient consent can be recorded in one of three ways:

- 'Yes'
- 'No'
- 'Not Recorded' (England and Wales only).

The NJR has support under Section 251 of the NHS Act 2006 (18-CAG-0146) to obtain and store patient identifiable data where 'Not Recorded' is indicated for consent. Section 251 only applies in England and Wales and the 'Not Recorded' option is, therefore, only available for procedures submitted by hospitals in those countries.

Where 'Yes' and 'Not Recorded' are indicated for consent, the system requires patient identifiable data to be entered.

Where 'No' is recorded for consent, the system does not allow users to enter any patient identifiable data, including local hospital identification numbers. Such a record can never be linked to another procedure for the same patient and its value is reduced to being simply a 'count' within the data base. It has no value for establishing revision rates or survivorship.

It should also be noted that whilst records with 'Not Recorded' for consent indicated are used for analyses, they will not be used for studies involving patient follow-up. Patients will only be contacted directly if consent has been recorded as 'Yes'.

2.3 Patient Identifiable Data - NJR Privacy Statement

The NJR's Privacy Statement can be [read here](#). It contains detailed information on why patient identifiable data are collected, how they are protected, and for what processing activities they are used. It also explains how patients can access data held about them or to request data removal.

2.4 Who can use NJR data?

Anyone with a legitimate use can request access to NJR data. However, patient identifiable data will only ever be provided where a research application has gone through formal ethical approvals with the NHS Health Research Agency and the NJR has contacted the patient directly, offering them the chance to consent to take part in the proposed study. Whilst record-level or patient-level data are provided for NJR approved studies, all patient (and surgeon) identifiers are removed and the published analyses use aggregated data. These measures ensure that individual patients cannot be identified.

The NJR provides a number of reporting services and, whilst surgeons can see data about their own patients on the 'NJR Clinician Feedback' reporting service, patient

identifiers are not available anywhere else. Some of the reporting undertaken by the NJR can be seen on the following websites:

- The NJR's reporting website is reports.njrcentre.org.uk
- The NJR's research website is www.njrcentre.org.uk/njrcentre/Research/tabid/197/Default.aspx
- The NJR's Consultant Outcomes Publication website is at surgeonprofile.njrcentre.org.uk/
- The latest NJR Annual Report is at reports.njrcentre.org.uk/downloads
- The latest NJR Public and Patient Guides can be found at reports.njrcentre.org.uk/patient-guide.

2.5 Statistical support to the NJR

Statistical support to the NJR is provided by the University of Bristol under contract to HQIP. In addition to completing the Clinical Section of the NJR's Annual Report and other approved analyses, the University of Bristol also undertakes the analysis to identify potential outlier performance. Even as a contracted processor, however, the data provided to them by NPS does not contain patient identifiable data.

3 Getting Started

Before starting to submit data to the NJR, it is essential that the NJR Centre is contacted via the NJR Service Desk. Contact details are included below. A Compliance Officer will be allocated to provide initial set up support, including training, and ongoing support. Details of how to contact the Compliance Officer in the local area can be found on the [NJR website](#).

3.1 Appointing an NJR Hospital Data Manager

The NJR Hospital Data Manager (HDM) is the individual responsible for the coordination of all NJR data collection activities within a hospital or trust. HDMs will provide the key point of contact for the NJR Centre and the Compliance Officers and will act as the conduit for all NJR-related communications. Apart from maintaining and monitoring the processes by which NJR data are collected and submitted, the HDM will need to identify, and provide the contact details for, all members of staff involved in the NJR process. These staff may comprise of the following roles:

- NJR Data Entry staff
- Pre-assessment Manager
- Department Manager
- NJR Clinical Lead
- Clinical Governance/Data Quality Audit Lead
- Clinical Director/Matron
- Theatre staff
- Surgeons.

3.2 Who needs access to the data entry system?

Anyone who has a requirement to submit procedure data can be registered to access the data entry system. Whilst some surgeons may wish to enter their own procedure data, many will leave it to theatre staff, dedicated data entry staff, or their secretary.

All users can be registered using the contact details at the end of this document. The following information will be required:

- The user type, e.g. Hospital Data Entry/Hospital Data Manager/Data Quality Audit Data Uploader (see below)
- Full name
- The name of the hospital(s) from which data will be submitted
- User job title e.g. theatre admin/nurse/ODP/HCA etc.

- Work email address and phone number
- GMC code and grade (for surgeons).

3.3 Types of user account

There are different types of user account, dependent upon the role of the user. These are based on the need to maintain patient confidentiality and it is essential that, when registering a user, the appropriate user account is requested.

- **NJR Hospital Data Manager (HDM) account:** An HDM user has access to the most data and can access all NJR data for the hospital to which they are registered. An HDM can view all data for all surgeons and may add surgeons to, or remove them from, the hospital. Please be aware that an HDM account can only have one hospital associated with it. If an HDM works in more than one hospital then multiple HDM accounts will be required. Once a record has been submitted only an HDM user will be able to amend the Consultant in Charge and Operating Surgeon fields.
- **NJR Hospital Data Entry account:** A data entry user can submit procedure data but does not have access to any reports and cannot delete or create user accounts. A data entry user account can be associated with multiple hospitals
- **Surgeon User account:** A surgeon with a Surgeon User Account can submit procedures via the data entry system and also access reports about their own practice via 'NJR Reports Online' (accessed via the data entry system). Surgeons indicated as 'Consultant in Charge' can access all their own procedure data, whilst a surgeon indicated as a 'Lead Surgeon' will only be able to see data for those procedures where they are recorded as being the Operating Surgeon. A Surgeon User account can be associated with multiple hospitals.
- **Data Quality Audit data uploader account:** A data uploader user account can upload PAS files to the data entry system for the automated data quality audit. A data uploader user account can be associated with multiple hospitals.

3.4 Account Details

Having been registered for an account, users will be sent a unique user name, memorable data and password. The memorable data and password must be changed when first logging onto the data entry system. Passwords and memorable data, must:

- Be between 8 and 16 characters
- Contain a mixture of upper and lower case letters
- Contain at least one number

- Not use spaces or special characters (e.g. /,*,+,-).

Passwords and memorable data can be re-set by contacting the NJR Service Desk.

3.5 Accessing the data entry system

The web-based data entry system can be accessed via the [NJR website](#) or directly using [this link](#). The system supports the major Internet browsers (Internet Explorer, Chrome, and Safari) but if difficulty is experienced with either accessing or using the data entry system, it may be due to one or both of the following:

- The browser on the PC or device may be an older, unsupported version
- The network security in the hospital may prevent local PCs from being able to access the NJR website and data entry system.

If difficulty is experienced when attempting to access the Internet and the data entry system, local IT departments should be contacted in the first instance. If the problem cannot be resolved locally, please log a call with the NJR Service Desk.

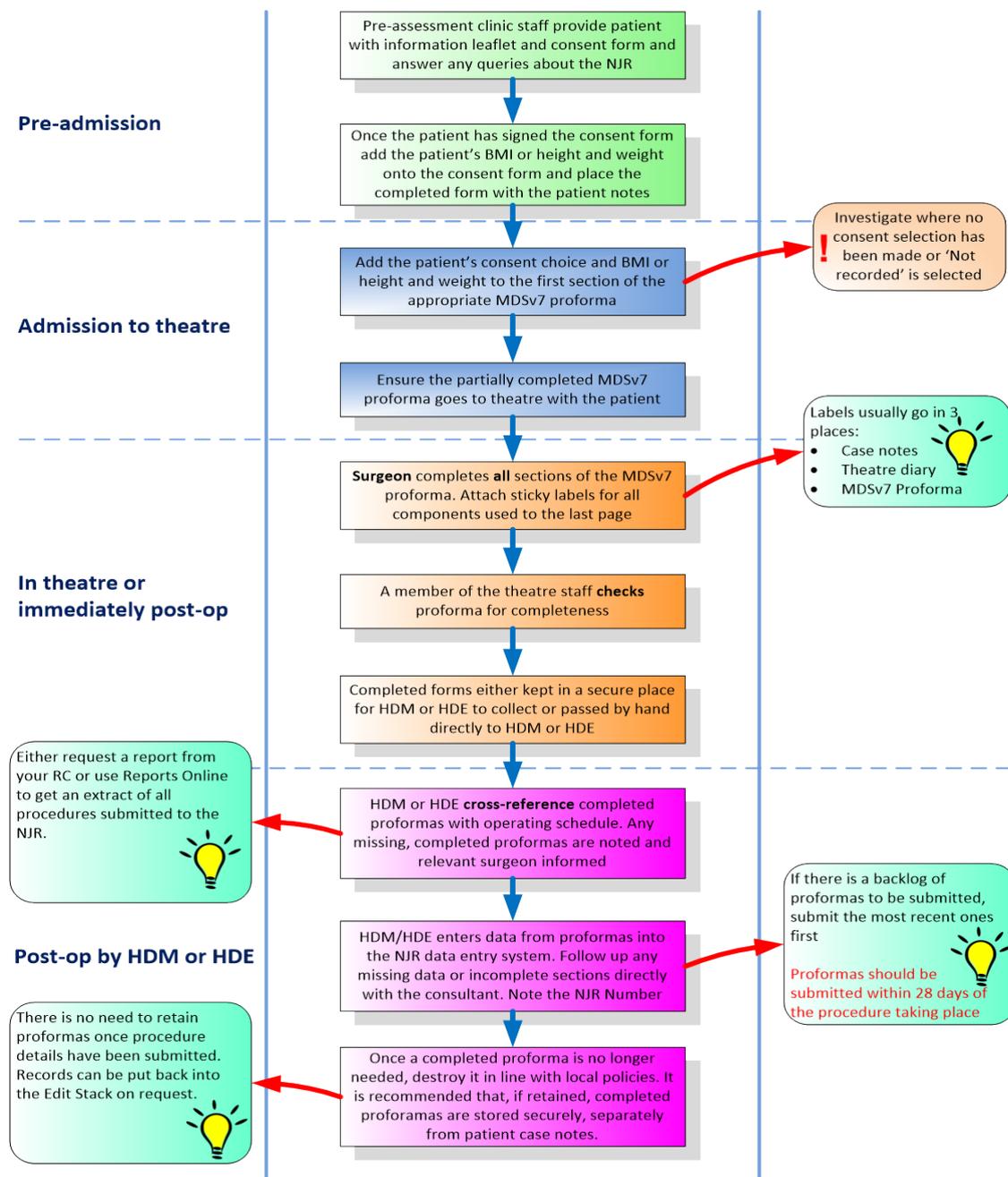
4 Collecting the Data

Many hospitals already collect NJR data effectively and this guide offers ideas and suggestions to support a high quality data collection.

It is important that staff are aware of how NJR data are collected in each hospital - this can be done using a process map, an example of which is shown below.

The NJR is a mandatory requirement and it is therefore recommended that the locally adopted NJR process is included in hospital policy and procedure documents.

4.1 Example of NJR data collection Process Map



4.2 Data Completeness

Hospitals which have high volumes of procedures have established a process that ensures all relevant hip, knee, ankle, elbow, and shoulder operations are recorded on the NJR. The theatre list is commonly used as a way of cross-referencing against a locally kept log which might include:

- A comparison of the number of completed NJR forms received to the number of relevant procedures scheduled for the day or week on the theatre list
- The number of missing MDS forms
- The number of incomplete MDS forms
- Any actions that need to be completed and by whom (incomplete procedure details must be completed by the operating surgeon)
- Any outstanding corrective actions (e.g. low rates of consent or high numbers of records that cannot be submitted because of missing component details).

The NJR HDM will usually take responsibility for updating and administering the log and resolving any outstanding actions.

4.3 MDS proformas

Paper proformas have been developed to help hospitals record the required NJR dataset prior to electronic submission. They can be downloaded from the [NJR website](#). These can be completed in theatre and the information then used to enter the data subsequent to the operation.

Alternatively, if an Internet connected PC is available in the operating theatre, data can be directly entered into the NJR Data Entry system. Direct data entry is a good alternative to paper completion and supports the NHS' Paperlight initiative.

Detailed instructions on how to enter data are provided in the NJR Data Entry User Guide available via the NJR website on the [Manual and Training](#) page.

Please ensure that the latest version of the MDS paper pro-forma is being used (Version 7.0 from 4th June 2018).

A guide to the operations included in, and excluded from, the NJR can be found on the [Manual and Training](#) page of the NJR website. It may be useful to print the guide and keep it for future reference.

There are a total of ten proformas: a primary and a revision form for each joint. The table below shows which form should be used for the various procedure types.

Joint	Form	Procedures
Hips	H1	Primary Hip. Used for all Primary hip operations.
	H2	Single Stage revision (includes modular exchange for indications other than infection) Stage 1 of 2 stage revision Stage 2 of 2 stage revision Excision Arthroplasty Insertion of PLAD/Stabiliser Debridement and Implant Retention (DAIR)
Knees	K1	Primary Knee. Used for all Primary knee operations.
	K2	Single Stage revision (includes modular exchange for indications other than infection) Stage 1 of 2 stage revision Stage 2 of 2 stage revision Conversion to Arthrodesis Amputation Secondary resurfacing of patella Secondary/subsequent partial replacement (Unicompartmental or PFJR) Debridement and Implant Retention (DAIR)
Ankles	A1	Primary Ankle. Used for all Primary ankle operations.
	A2	Single Stage revision (includes modular exchange for indications other than infection) Stage 1 of 2 stage revision Stage 2 of 2 stage revision Conversion to Arthrodesis Amputation Debridement and Implant Retention (DAIR)
Elbows	E1	Primary Elbow. Used for all Primary elbow operations.
	E2	Single Stage revision (includes modular exchange for indications other than infection) Stage 1 of 2 stage revision

Joint	Form	Procedures
		Stage 2 of 2 stage revision Failed Hemi-arthroplasty Conversion to Arthrodesis Excision Arthroplasty Amputation Debridement and Implant Retention (DAIR)
Shoulders	S1	Primary Shoulder. Used for all Primary shoulder operations.
	S2	Single Stage revision (includes modular exchange for indications other than infection) Stage 1 of 2 stage revision Stage 2 of 2 stage revision Conversion to Arthrodesis Excision Arthroplasty Amputation Debridement and Implant Retention (DAIR)

4.4 Linking NJR patient consent to data entry

Patients must be given both the NJR patient information leaflet and NJR consent form so that they can make an informed choice about consent. It is also important that the patient's decision on consent is available to the person entering details of the procedure into the NJR system.

If none of the consent boxes are selected, every effort should be made to determine whether or not a patient has actually declined or given consent for their personal data to be recorded: simply selecting either 'No' or 'Not Recorded' (the latter in England and Wales only) is not acceptable. The NJR is totally reliant on patient identifiers to provide the necessary linkage of primary and revision procedures: without consent, the NJR will not be able to determine the outcomes of joint replacement surgery.

Patients very rarely decline consent and response rates of 85% in follow up audits (PROMs) show that joint replacement patients take a close interest in their treatment. High rates of 'No' for consent are generally indicative of poorly defined local processes or processes that are simply ignored. A number of NJR data quality indicators are also included in the Best Practice Tariff (BPT): high rates of 'Not Recorded' will result in financial penalties to trusts.

All staff should be aware of how consent is obtained and of the process by which it is made available to the person entering the procedure data. Every effort must be made to

determine what a patient has decided where no indication for consent is completed or where 'Not recorded' has been selected.

Further information can be found in the document [NJR Consent Process](#) on the NJR website.

4.5 Bulk Upload

Data can also be entered using the Bulk Upload facility. Bulk Upload enables hospitals to upload data directly to the NJR from third party orthopaedic or PAS applications. In most cases, those third party systems will require development to ensure that they hold all the data required by the NJR in the correct format. Designed to prevent the need for double-data entry, the Bulk Upload currently support hip and knee procedures only.

There are two steps to using the Bulk Upload. Third party systems must be able to access the NJR's component database when recording procedure data. When scanning a barcode, for example, into an orthopaedic system, it will automatically download a small set of data about the implant from the NJR. The second step is to access a messaging interface which enables those external systems to upload multiple procedures, including implant information, in a single exchange.

Technical information for developers can be accessed via the [Bulk Upload](#) page on the NJR website.

5 Examples of Good Practice

Examples of good practice include:

- Having an orthopaedic consultant as the NJR Clinical Lead in each trust or hospital. The NJR Clinical Lead is the focus for NJR communications, especially for the NJR's data quality audits
- Having a single point of contact for the local NJR process e.g. a theatre/ward manager or a Specialist Orthopaedic nurse. This person would usually be the HDM for the hospital
- Checking that all NJR proformas are fully completed before submitting the record to the NJR. Make a note of any omissions and ensure that the operating surgeon provides the missing information
- Submitting all procedure to the NJR as soon as possible and certainly no later than 30 days after the procedure. Many annual reports are based on data submitted within a particular date range and it is essential that all procedures are included
- The establishment and maintenance of a submission log
- Using coloured paper for the NJR Patient Consent form for easy identification
- Sending the NJR consent form and Patient information leaflet to patients with pre-assessment appointment information. This will ensure that the patient has had time to consider the information and reduce the length of time taken to complete pre-assessment.

6 Contact Details

The NJR Centre can be contacted using the following details:

Email: enquiries@njrcentre.org.uk

Telephone: 0845 345 9991

Compliance Officers: Details on the [Compliance Officers](#) page on the NJR