



## **THE NON ARTHROPLASTY HIP SURGERY REGISTER (NAHSR)**

**Data collection in the UK – can we lead the world in defining the natural history of orthopaedic conditions and the outcomes of surgical interventions?**

Orthopaedic surgery has historically been a clinical specialty with a poor evidence base for many surgical interventions and yet we have some of the most effective surgical procedures performed by *any* surgeon of *any* specialty to improve the quality of life of patients. We have usually been passed over for national research funding despite the fact that orthopaedic surgeons constitute 40% of the entire UK surgical workforce and a slightly higher proportion of all surgical procedures in the UK are T&O. The historical paucity of data in our specialty is now being addressed with initiatives such as the National Joint Registry (NJR), National Hip Fracture Database (NHFD), the collection of national PROMS data and future planned national Registers for spinal surgery through the British Association of Spinal Surgery (BASS) and soft tissue knee surgery (ACL Injury Registry).

A national register to collect data on the outcome of hip conditions not treated by arthroplasty is due to go live in March, launched at the 2012 British Hip Society Annual Meeting in Manchester. With the formation of all of these national registers the UK may indeed be entering a golden era of data collection.

### **Formation of the Non Arthroplasty Hip Surgery Register (NAHSR)**

The creation of a Non Arthroplasty Hip Surgery Register was unanimously supported by the Membership of the British Hip Society at the Annual General Meeting in Torquay (March 2011) and development of the Registry has been funded by the members of that Society (see: <http://britishhipsociety.com/NAHSR/Index.htm>).

### **Scope of the NAHSR**

The NAHSR has been set up to collect longitudinal outcome data for any type of hip condition and/or surgery other than arthroplasty and the treatment of acute fracture. It has been constructed so that paediatric conditions can also be studied for the lifetime of the patient.

Clinicians will be able to use the Register to collect and display comprehensive outcome and audit data for all of their own patients using scores and outcome measures of their own choice. Data can be entered for patients who do not undergo surgery for any specific condition so that their clinical course can be followed. Only one hip 'pathway' can be started for left or right hips in an individual so patients are not lost if they move between clinicians. If the patient has consented for their data to be collected only an arthroplasty or the patient's demise will close the record.

The independence of the reporting of data remains critical to the credibility of the NAHSR. The BHS will protect the confidentiality of the information contained in the NAHSR and maintains high level data security procedures. No other clinician, including members of the NAHSR Subcommittee, will be able to view an individual surgeons data or outcomes. All data will be anonymised. A Policy document has already been agreed setting out who can request data of the Registry and how access to information can be requested.

NICE Interventional Procedure Guidance on Arthroscopic (IPG 408) and Open (IPG 403) Femoro-Acetabular Surgery for Hip Impingement Syndrome notes that clinicians should submit details to this national register. For the condition of femoro-acetabular impingement, clinicians may choose to facilitate only collection of an initial Minimum Data Set (as they do with the NJR) and leave the Registry to collect further outcome data but the functionality is there for the clinician to organise any outcome measure or clinical score he/she desires.

### **How surgery for Femoro-Acetabular Impingement (FAI) led to the creation of the NAHSR**

It is thought that contact between part of the femur and the rim of the socket at the hip joint (femoral-acetabular impingement or FAI) is a cause of internal damage to the hip joint and is important in the genesis of osteoarthritis of the hip. This has never been proven.

Some forms of impingement may be amenable to surgical treatment to eradicate pain and improve function and/or to prevent the onset and progression of osteoarthritis. There is no doubt that if the procedure is undertaken in the presence of significant degenerative change at the hip then it will be of limited value and not prevent the need for hip replacement in the future. In addition there are a group of patients whose

symptoms will significantly deteriorate after this procedure.

Currently there is only short-term, generally poor quality, data available for the efficacy of this procedure. There has been no significant improvement in the quality of data to define the place of this surgery since the original NICE report on FAI surgery in 2007. The indications for the procedure have never been defined nor the population group who may benefit from the intervention. Details of the surgical technique employed are likely to be important in defining the outcome but the optimal techniques are not known.

The lack of evidence proving the efficacy for surgical intervention has been a driving force for hip surgeons to set up this Register to prove the role for this type of surgery. In some Regions significant time and resources are being allocated to the procedure whereas elsewhere Purchasers are refusing to fund hip arthroscopies at all, given the current level of knowledge. It is believed that 6-8,000 associated procedures are carried out in the United Kingdom each year and worldwide there is predicted to be a compound annual growth rate of 30.3% between 2009 and 2014 (Procedural data source: Solucient).

Why FAI surgery needs the NAHSR. Why NICE requires that data should be entered.

We clearly need data to prove the long-term safety and efficacy of this type of surgery and define which patients are most likely to benefit. We need to establish the details of the surgical intervention important to bring the best results for these patients. The creation of the Non-Arthroplasty Hip Surgery Register at some point linked to the National Joint Registry and HES data, used alongside Patient Reported Outcome Measures (PROMS data), will define the place of this type of surgery.

### **Who benefits from the creation of the NAHSR?**

If we can define the indication for all types of non-arthroplasty hip surgery everyone benefits:

**The Patients.** Patients will only undergo surgery if it is likely to reduce their pain, improve their function (ability to undertake activity and work) and/or prevent the progress of arthritis of the hip and ultimately a hip replacement. Patients who will not benefit are spared the risk of surgery and the potential for the procedure to exacerbate their symptoms and accelerate the progression of arthritis.

**The Purchasers of Healthcare.** Funding will be targeted on patients who

will benefit from a surgical procedure. Funds will not be used where the outcome clearly does not justify the resource.

**Surgeons.** Surgeons will be able to define which patients will benefit from surgery and what details of the operative procedure will define a good result. The surgeon will have validated outcome data available to them.

**The National Registries.** No other national registry is collecting this data and establishing this project will give us the only outcome data for these conditions in the world.

### **Getting started**

The NAHSR is due to go live in March 2012. Clinicians, whether members of the BHS or not, will be able to Register to enter data via links on the BOA, BHS and NAHSR websites (<http://britishhipsociety.com/NAHSR/Index.htm>).

#### **Which patients should I enter?**

The NAHSR has been set up to allow data collection for any patient with hip conditions other than arthroplasty or fracture (e.g. trochanteric bursitis, iliopsoas impingement, SUFE, Perthes etc.).

The NAHSR can track the outcome of conservative or surgical treatment for any hip condition.

NICE *requires* that data are entered onto the Registry for patients undergoing surgery for femoro-acetabular impingement (FAI) whether the surgery is open or arthroscopic.

#### **Why enter data?**

For all conditions you can choose to enter as many scores and procedures as you wish to over any time interval. The NAHSR will plot the results over time and display them graphically to you. The data on your patients is confidential to you.

For patients with FAI, a system need to be put into place to collect pre-operative scores (EQ5-D, Modified HHS, UCLA activity) but you may then leave the Registry to collect outcomes automatically (**it is imperative**

that you collect the e-mail address of the patient or someone close to the patient who has contact with them).

## Getting started

### *Patient Consent*

We suggest you print off the patient consent forms from the download area on the NAHSR website and set up an identical process for filling these in as for the NJR.

### *Initial registration of the patient*

You need to decide who is to enter the data on your behalf. With all forms the data can be entered directly on-line or collected on hard copy (downloaded from the NAHSR website) and entered by your secretary or a clerk later.

The screenshot displays the Bluespier Clinical Registry user dashboard. The main header shows the user's name, 'McCormack, Gary', and navigation links for 'My Dashboard', 'My Settings', 'Reports', 'Admin', 'Help', and 'Logout'. The user's name 'Smith' is also visible in a search bar. The dashboard is divided into several sections: 'Patient Worklist' with a table of patients, 'Notifications' with recent updates, and a 'Create Patient' modal form. The 'Create Patient' form contains the following fields: 'NHS Number' (6567458938), 'Local Id' (ID83838), 'Name' (Mr Gregory Smith), 'Address' (23 Long Road, Leeds), 'Postcode' (LS1 2RT), 'Gender' (Male), 'DoB' (02 Jul 1956), 'Deceased' (No), 'Email' (gregory.smith@btinternet.co.uk), and 'DC Consent' (Yes). A warning message states: 'Please note we cannot automate the collection of outcome data without an email address.' At the bottom of the form are 'Save' and 'Cancel' buttons. To the right of the form, a list of medical conditions is visible, including 'blood tests', 'nerve Diagnostic', 'Operation', 'nerve Diagnostic', 'Scale', 'tion Diagnostic', 'Operation', 'ha Diagnostic', 'ha Diagnostic', 'Procedure Details', and 'Operation'. A bar chart at the bottom right shows data for the months from February to January, with a significant peak in January.

It is essential to make sure that accurate e-mail addresses are registered in the appropriate field on the Form.

If you choose to delegate data entry please give that person instructions to view the NAHSR website and log in to the Registry.

## *Initial scores*

For conditions other than FAI you can choose to collect whatever scores you wish from those available (see Minimum Data Set listed on NAHSR website).

For cases of FAI the Minimum Data Set includes EQ 5-D, Modified Harris Hip Score and UCLA Activity. Forms for these scores will be available to be downloaded from the NAHSR website.

A system needs to be put into place to allow all patients to complete these forms prior to surgery. The data can then be entered onto the Registry by someone delegated to do so. In due course a system will be developed to allow patients to enter the data directly.

## *Operative details*

The most convenient method for data entry will most probably be the one you use for entry of NJR data.

The screenshot shows a web browser window displaying a clinical assessment form for 'SMITH, Gregory - Adult Hip Assessment'. The form is organized into several sections:

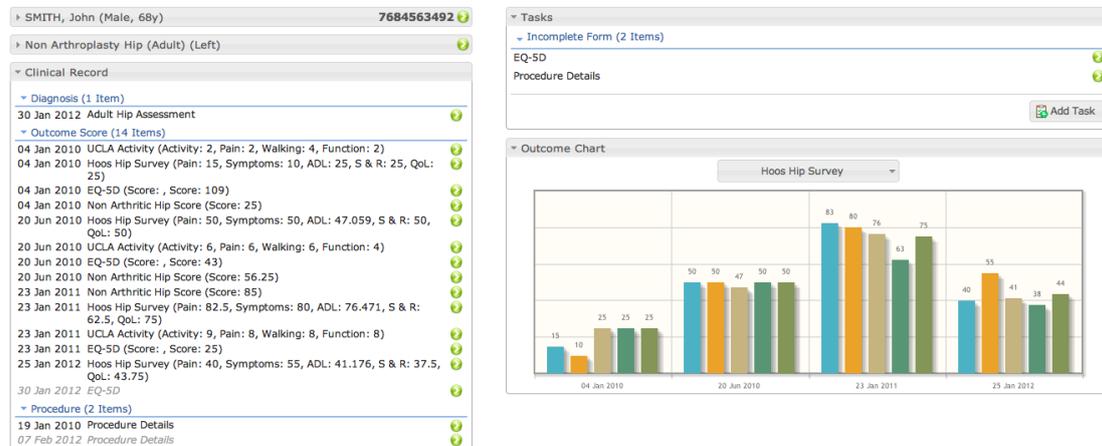
- Diagnosis details:** Includes 'Diagnosis Category' with buttons for FAI, Central compartment, Extra-articular Pathology, Other, and Unknown. Below it, 'FAI Type' has buttons for Cam, Pincer, and Mixed.
- Investigations:** A list of diagnostic tests with 'Yes' and 'No' buttons and 'Date of Investigation' text boxes:
  - Xray: Yes/No buttons, Date of Investigation: 04 Jan 2012
  - MR Arthrogram: Yes/No buttons
  - MRI: Yes/No buttons
  - CT: Yes/No buttons, Date of Investigation: 04 Jan 2012
  - 3-D CT: Yes/No buttons
  - EOS: Yes/No buttons
  - Previous arthroscopy: Yes/No buttons
  - Other Procedure: Yes/No buttons
- Radiological Measurements:** Includes 'Severity of Osteoarthritis (Tennis Grade)' with buttons for Grade 0, Grade I (selected), Grade II, and Grade III. Below it, 'Acetabular Anteversion' is set to 0, with a tooltip that reads: 'Increased sclerosis, slight joint space narrowing, no or slight loss of head sphericity'.

The browser's address bar shows the URL: 109.228.25.116/ClinicalRegistry/pathway-dashboard.aspx?pwd=bcf5351d-6000-403b-a072-ae0f6840fb5c. The user is logged in as 'McCormack, Gary'.

## *Outcome data after surgery*

For FAI patients, the NAHSR is being constructed to collect longitudinal outcome data automatically via e-mail. **This is why it is so important to make sure the system you put into place collects accurate e-mail addresses when they are available.**

If you want more comprehensive data you can put a system into place to enter as many scores into the Registry as you wish.



***What happens if a patient moves or the care is taken over by another surgeon?***

Only one Pathway can be opened for each hip on a patient. If you try to Register a patient where a Pathway has already been started you will be prompted to contact the previous surgeon through the Registry and allowed to add to the data pathway for that patient.

### **Getting to grips with the layout of the Registry**

There are instructions on the NAHSR website, and within the Registry. Telephone support from Bluespier is also available.

***If you treat patient with hip disorders please Register and organise the protocol for data collection for patients under your care.***

This is an exciting time for orthopaedics in the UK - please help British Orthopaedics lead the world with acquisition of these data!

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Vice President BHS  
Chairman NAHSR Subcommittee

