Patient Sticker

Non-Arthroplasty Hip Registry

www.nahr.co.uk

Non Arthroplasty Hip Registry Patient Consent Form

Patient Information

What is the Non Arthroplasty Hip Registry (NAHR)?

The NAHR is a database of information collected, from across the UK, about hip surgery that does not involve the use of implants. This will help us to find out which operations work best by observing the outcomes of surgery as measured from questionnaires and monitoring of any complications. There is a separate registry for patients having hip replacement surgery included as part of the National Joint Registry (NJR).

What data is collected?

a) Personal details are needed in order to link you to your surgery and the outcome, and in case you need any further hip surgery in the future so that your surgeon knows what previous surgery you have had. The personal information stored includes name, gender, date of birth, telephone number, postal address, email address and NHS number.

b) In addition, we store information about your general health, diagnosis, surgical procedure and your answers to the questionnaires (which is classed as sensitive personal information under the Data Protection Act).

This data is entered into the registry by a member of the team involved in your care.

Do I have to participate? No, your consent is entirely voluntary and if you prefer not to participate, your medical care will be delivered in the normal way. Your personal details in particular cannot be kept without your consent.

What would I be asked to do? You are asked to complete questionnaires before and 1 month, 3 months, 6 months, 12 months and 2 years after surgery. This is why your telephone number and email address is important as we will send links to these questionnaires when they are due. The telephone number can also be used for two-factor authentication and calling you to facilitate completion of the questionnaire.

If I do participate, what are my rights? You are entitled to:

a) Withdraw consent at any time.

b) Request access to your data

c) Request correction

d) Request erasure

e) Request restriction of processing

f) Request the transfer of your personal data

Further information on these rights can be found on the Information Commissioner's Office (ICO) website: www.ico.org.uk

If you wish to exercise any of the rights set out above, you can contact us through either

the NAHR website www.nahr.co.uk or by emailing customer.support@amplitude-clinical.com.

This form should be retained securely by the hospital.

Conditions regarding requests;

a) Time limit to respond

We try to respond to all legitimate requests within one month. Occasionally it may take us longer than a month if your request is particularly complex or you have made a number of requests. In this case, we will notify you and keep you updated.

b) Fee

You will not have to pay a fee to access your personal data (or to exercise any of the other rights). However, we may charge a reasonable fee if your request is clearly unfounded, repetitive or excessive. Alternatively, we may refuse to comply with your request in these circumstances.

Who is the data controller? The data controller organisation (see www.ico.org.uk) for your personal data in the registry will be the British Hip Society (and not the NHS).

The data protection officer (DPO) is responsible for overseeing questions in relation to this consent form. If you have any questions about this consent form, including any requests to exercise your legal rights, please contact the DPO using the details set out below:

Name: NAHR Data Protection Officer
Email Address: dpo@nahr.co.uk
Postal Address: Specialist Societies Office, British Orthopaedic Association, 35-43 Lincoln's Inn Fields, London WC2A 3PE

Data Retention

Details of retention periods for different aspects of your personal data are available in our retention policy which you can request from us by contacting us using the contact details above.

Is my data stored securely? Your personal details are treated as confidential and will be stored safely. We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. Your personal details will not be available to anyone outside the NAHR and its secure IT provider, with the following exceptions:

(1) BHS may approve a specific research project related to your diagnosis or surgery. The majority of this research uses only anonymised information that means it is impossible to identify individuals. From time to time researchers may wish to gather further information. In these cases we would seek your approval prior to disclosing your contact details. You would be free to decline and again this would not affect your care.

(2) We may in future consider linking to other healthcare information resources (including Hospital Episode Statistics (HES) and other orthopaedic registries). Linking this data allows us to collect information on other aspects of your health, e.g. if you ever have further surgery or develop health problems. We do this to improve our ability to monitor patient safety and patient outcomes, and so that people and organisations involved in improving surgery can better understand and develop improved or more cost-effective medical treatments. In order to obtain any linked data about you, we would provide your operation and personal details to the body responsible for these other datasets so that they can match with records they hold – this may be NHS Digital (e.g. for HES) or the relevant Data Controller (for other orthopaedic registries).

(3) Your surgeon and his / her clinical team can also access and analyse your data to check they are individually giving good care.

Transfer of identifiable data outside of the European Economic Area is not permitted. Anonymised data, your identifying details removed, may be released to approved organisations.

How will my data be processed? We process the data which participating patients provide to improve our understanding of orthopaedic problems and of their treatment, thus helping us provide future patients with the best care. The BHS is responsible for all acts of processing. We retrieve and analyse your data so that we can compare large numbers of patients, usually removing anything that can identify you as an individual. Such analysis may have to be performed by a specialised third party, in which case they will be bound by the same high security standards and legal contract, whether identifying details had to be included or not.

You will not be identifiable within the results of any analyses which are shared, and any transfer of data will be encrypted. All studies using data from the Registry are recorded on the NAHR website; the NAHR annual report can also be downloaded from the website.

Children: Monitoring the outcome of surgical procedures in children is as important as it is for adults. It is the child's parents or guardian who is asked to consent for data to be collected.

Where can I find out more information? The NAHR website (http://www.nahr.co.uk/) contains more information including details of any studies and any information obtained through analysis of the Registry data. If you want to see what data is stored on you, please contact the registry.

Contact Details

Visit our website http://www.nahr.co.uk/
Send an email to: customer.support@amplitude-clinical.com

If you would like to contact the ICO, the UK supervisory authority for data protection issues, the details are as follows:

Address: Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Tel: 01625 545 745

Email: international.team@ico.org.uk

Website: www.ICO.org.uk

Signatures for NAHR Consent

Please tick the box to confirm that you have been given, read and fully understand the NAHR patient information leaflet ☐

Please tick the box to confirm that you consent to us sending you a questionnaire before and after surgery, so that we are able to monitor any complications and overall outcomes from this kind of surgery. ☐

Surname _____ First Name _____

Date of Birth ____ / ____ / ____

Mobile number (in order to contact you to complete the questionnaire) _____

E-mail address (in order for us to send you email links to questionnaires):

✉ _____

I HAVE READ THE INFORMATION SHEET AND I CONSENT TO:

- Personal details being recorded in the NAHR and controlled by BHS.
- My data being processed for the purposes set out in the patient information leaflet.

I UNDERSTAND THAT:

- I can ask for my details to be removed at any time and can request access, to my personal data, as well as the right to request correction, object to processing, request restriction of processing and request the transfer of my personal data. To make a request regarding your data, please contact us through the NAHR website:http://www.nahr.co.uk/ or by emailing customer.support@amplitude-clinical.com.

Patient / Parent agreement to data collection for Registry and Research:

Signature ✘_____ Date ____ / ____ / ____

Counter signature of person accepting patient consent:

Name _____ Position _____

Signature _____ Date ____ / ____ / ____

iHOT-12

Patient Sticker

Please mark a point along the line that most appropriately represents the level of your typical situation in the last month.
Tip – If you don't do an activity, imagine how your hip would feel if you had to try it.

1. Overall how much pain do you have in your hip/groin?
Extreme pain — No pain at all

2. How difficult is it for you to get up and down off the floor/ground?
Extreme difficulty — No difficulty at all

3. How difficult is it for you to walk long distances?
Extreme difficulty — No difficulty at all

4. How much trouble do you have with grinding, catching or clicking in your hip?
Severe trouble — No trouble at all

5. How much trouble do you have pushing, pulling, lifting or carrying heavy objects at work?
Severe trouble — No trouble at all

6. How concerned are you about cutting/changing directions during your sporting or recreational activities?
Extreme concern — No concern at all

7. How much pain do you experience in you hip after activity?
Extreme pain — No pain at all

8. How concerned are you about picking up or carrying children because of your hip?
Extreme concern — No concern at all

9. How much trouble do you have with sexual activity because of your hip? ☐ **N/A**
Severe trouble — No trouble at all

10. How much of the time are you aware of the disability in your hip?
Constantly aware — Not aware at all

11. How concerned are you about your ability to maintain your desired fitness level?
Extreme concern — No concern at all

12. How much of a distraction is your hip problem?
Extremely distracted — Not distracted at all

EQ-5D

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ☐
I have slight problems in walking about ☐
I have moderate problems in walking about ☐
I have severe problems in walking about ☐
I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐
I have slight problems washing or dressing myself ☐
I have moderate problems washing or dressing myself ☐
I have severe problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(eg. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐
I have slight problems doing my usual activities ☐
I have moderate problems doing my usual activities ☐
I have severe problems doing my usual activities ☐
I am unable to do my usual activities ☐

PAIN/DISCOMFORT

I have no pain or discomfort ☐
I have slight pain or discomfort ☐
I have moderate pain or discomfort ☐
I have severe pain or discomfort ☐
I have extreme pain or discomfort ☐

ANXIETY/DEPRESSION

I am not anxious or depressed ☐
I am slightly anxious or depressed ☐
I am moderately anxious or depressed ☐
I am severely anxious or depressed ☐
I am extremely anxious or depressed ☐

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.
100 means the best health you can imagine. 0 means the worst health you can imagine.
Mark an X on the scale to indicate how your health is TODAY.

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY ☐

SURGEON

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MDS version 3.0

PATIENT DETAILS			
Patient Consent Obtained	Yes ☐	No ☐	
Patient Hospital ID	NHS Number		
Forename	Surname		
Gender	Male ☐	Female ☐	
Date of Birth DD/MM/YYYY	Mobile phone number		
Email		Post Code	

DIAGNOSIS (including arthroscopic findings)			
FAI (including associated chondrolabral lesions) ☐			
Central compartment			
Labral tear ☐	Ligamentum teres tear ☐	Chondral defect (non FAI) ☐	Post-traumatic osteochondral defect ☐
AVN ☐			
Extra-articular			
Snapping psoas ☐	Snapping ITB ☐	Trochanteric bursitis ☐	Gluteal tear ☐
Subspinous impingement ☐	Ischiofemoral impingement (IFI) ☐	Deep Gluteal Syndrome ☐	Hamstring tendonopathy ☐
Hamstring avulsion ☐			
DDH ☐	Perthes' ☐	SUFE ☐	Hypermobility ☐
Osteoarthritis ☐	Inflammatory ☐	Post-traumatic ☐	Loose bodies ☐
Undiagnosed hip pain ☐	Previous hip arthroscopy ☐		

OPERATION DETAILS			
Side	Left ☐	Right ☐	
Operation Date DD/MM/YYYY	Hospital		
Consultant in Charge			
Operating Surgeon			
Operating Surgeon Grade	Consultant ☐	Fellow ☐	SPR/ST3-8 ☐
	Specialty Doctor/SAS ☐		Other ☐
NHS Funding ☐	Independent Funding ☐		
Weight /kg	Height /cm		
Approach			
Arthroscopic ☐	Open ☐	Combination of arthroscopic & open ☐	

CAPSULAR MANAGEMENT

Capsulotomy

Interportal ☐	T-capsulotomy ☐	⅂-capsulotomy ☐
Portal widening (without inter portal cut) ☐	Capsular thinning ☐	Other ☐

Capsular repair

Vertical ☐	Horizontal ☐	Both ☐	None ☐

OPERATION DETAILS

Acetabulum

Labral Debridement ☐	Labral Resection ☐	Labral Repair ☐
Pincer Removal ☐	Type of Pincer Removal: Simple ☐	Labral Reattachment ☐
Labral graft ☐	Type of Labral Graft: Autograft ☐	Allograft ☐
Length of graft in cm	Number of anchors	Producer:
Anchor material: PEEK ☐ All-Suture ☐ Absorbable ☐	Anchor type: Knotted ☐ Knotless ☐	
Sub-spinous resection ☐	Cartilage Debridement ☐	Cartilage Reattachment ☐

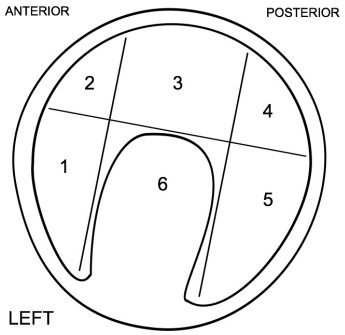
Acetabular Cartilage repair

Microfracture ☐	BMAC ☐	Bone Marrow Aspirate ☐
Membrane Yes ☐ No ☐		

Select which type of membrane

Chondro-Gide ☐	Hyalofast ☐	Chondrotissue ☐
ACI ☐	Other synthetic membrane ☐	

Location and severity of **single worst** area of acetabular cartilage damage
(Ilizaliturri et al Arthroscopy 2008;24:534, Konan et al JBJSB 2011;93:332)



Location (tick one)	Severity (tick one)	
None ☐	None ☐	3A ☐
1 ☐		3B ☐
2 ☐	1A ☐	3C ☐
3 ☐	1B ☐	
4 ☐	1C ☐	4A ☐
5 ☐		4B ☐
6 ☐	2 ☐	4C ☐

Severity	Extent
1 Wave Sign with intact chondrolabral junction	A Lesion less than one-third of the distance from the
2 Chondrolabral junction separation but no delamination	acetabular rim to the cotyloid fossa
3 Delamination	B One-third to two-thirds of this distance
4 Exposed bone	C Greater than two-thirds of this distance

Femur

Cam removal ☐	Osteophyte removal ☐	Cartilage Debridement ☐
Microfracture ☐	Core decompression ☐	Graft/ACI ☐
Lesser trochanteric resection ☐		

Severity of Femoral Cartilage Defect (Outerbridge)

None ☐ Normal Cartilage	1 ☐ Rough surface, chondral softening	2 ☐ Irregular surface defects <50% cartilage thickness	3 ☐ >50% loss of cartilage thickness	4 ☐ Full thickness loss

Soft Tissue		
Ligamentum Teres Debridement ☐	Ligamentum Teres Reconstruction ☐	
Loose body removal ☐	Biopsy ☐	ITB release ☐
Psoas release ☐	Gluteal tendon repair ☐	Troch Bursa debridement ☐
Sciatic neurolysis ☐	Piriformis tendon release ☐	Hamstring tendon repair ☐

Pelvic osteotomy			
PAO ☐	Triple ☐	Chiari ☐	Shelf ☐

Femoral osteotomy		
Varus ☐	Valgus ☐	Derotation ☐
Shortening ☐	Troch advancement ☐	Complex ☐
Open reduction (DDH) ☐		

Femoral osteotomy fixation method				
IM Nail ☐	Blade Plate ☐	Simple Plate ☐	Locking Plate ☐	Sliding Hip Screw ☐

THROMBOPROPHYLAXIS

Was the patient given any medication for thromboprophylaxis? Yes ☐ No ☐

Select which:

Aspirin ☐	LMWH ☐	Pentasaccharide (e.g. Fondaparinux) ☐
Warfarin ☐	Direct Thrombin Inhibitor (e.g. Dabigatran) ☐	Factor Xa Inhibitor (e.g. Rivaroxaban) ☐

If other please specify:

Duration of prescription/days (intention to treat)

HETEROTOPIC OSSIFICATION

Was the patient given any medication for Heterotopic ossification? Yes ☐ No ☐

Select which:

Indomethacin ☐	Naproxen ☐	Diclofenac ☐	Celecoxib ☐

If other please specify:

Duration of prescription/days (intention to treat)

ADHESION PREVENTION

Was the patient given Losartan for prevention of post-operative adhesions? Yes ☐ No ☐

INTRA-ARTICULAR ADJUNCTS

Was the patient given any other intra-articular medication to aid with recovery from hip preservation surgery? Yes ☐ No ☐

Select which:

Hyalgan ☐	Ostenil ☐	Durolane ☐
Platelet Rich Plasma ☐	Stem Cell Preparation ☐	Other ☐

If other please specify: