



**Non-Arthroplasty
Hip Registry**

www.nahr.co.uk

Patient Sticker

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, 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 6 months, 12 months and 2 years after surgery. This is why your email address is important as we will send links to these questionnaires when they are due.

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.

PATIENT

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 ____ / ____ / ____

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 **X** _____ Date ____ / ____ / ____

Counter signature of person accepting patient consent:

Name _____ Position _____

Signature _____ Date ____ / ____ / ____

iHOT-12

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.

Patient Sticker

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.

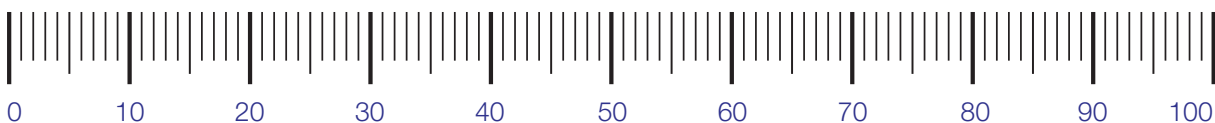
ANXIETY/DEPRESSION

- 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



Patient Sticker

MDS version 2.0

PATIENT DETAILS

Patient Consent Obtained	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Patient Hospital ID	NHS Number	
Forename	Surname	
Gender	Male <input type="checkbox"/>	Female <input type="checkbox"/>
Date of Birth DD/MM/YYYY	Mobile phone number	
Email	Post Code	

DIAGNOSIS (including arthroscopic findings)

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

OPERATION DETAILS

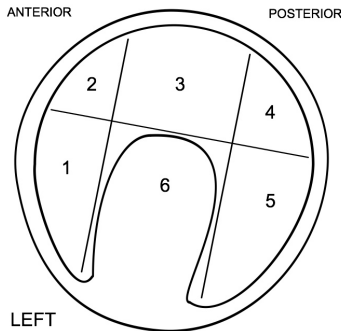
Side	Left <input type="checkbox"/>	Right <input type="checkbox"/>	
Operation Date DD/MM/YYYY	Hospital		
Consultant in Charge			
Operating Surgeon			
Operating Surgeon Grade	Consultant <input type="checkbox"/>	Fellow <input type="checkbox"/>	SPR/ST3-8 <input type="checkbox"/>
	Specialty Doctor/SAS <input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

EXTENDED DATA SET – OPERATION DETAILS

Acetabulum

Labral Debridement	<input type="checkbox"/>	Labral Resection	<input type="checkbox"/>	Labral Repair	<input type="checkbox"/>	
Pincer Removal	<input type="checkbox"/>	Type of Pincer Removal:	Simple <input type="checkbox"/>	Labral Reattachment	<input type="checkbox"/>	
Labral graft	<input type="checkbox"/>	Type of Labral Graft:	Autograft <input type="checkbox"/>	Allograft	<input type="checkbox"/>	
Length of graft in cm		Number of anchors		Producer:		
Anchor material:	PEEK <input type="checkbox"/>	All-Suture <input type="checkbox"/>	Absorbable <input type="checkbox"/>	Anchor type:	Knotted <input type="checkbox"/>	Knotless <input type="checkbox"/>
Sub-spinous resection	<input type="checkbox"/>	Cartilage Debridement	<input type="checkbox"/>	Microfracture	<input type="checkbox"/>	
Cartilage Reattachment	<input type="checkbox"/>	Cartilage Graft/ACI	<input type="checkbox"/>			

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 <input type="checkbox"/>	None <input type="checkbox"/> 3A <input type="checkbox"/>
1 <input type="checkbox"/>	3B <input type="checkbox"/>
2 <input type="checkbox"/>	1A <input type="checkbox"/> 3C <input type="checkbox"/>
3 <input type="checkbox"/>	1B <input type="checkbox"/>
4 <input type="checkbox"/>	1C <input type="checkbox"/> 4A <input type="checkbox"/>
5 <input type="checkbox"/>	4B <input type="checkbox"/>
6 <input type="checkbox"/>	2 <input type="checkbox"/> 4C <input type="checkbox"/>

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

Femur

Cam removal	<input type="checkbox"/>	Osteophyte removal	<input type="checkbox"/>	Cartilage Debridement	<input type="checkbox"/>
Microfracture	<input type="checkbox"/>	Core decompression	<input type="checkbox"/>	Graft/ACI	<input type="checkbox"/>
Lesser trochanteric resection	<input type="checkbox"/>				

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	<input type="checkbox"/>	Ligamentum Teres Reconstruction	<input type="checkbox"/>		
Loose body removal	<input type="checkbox"/>	Biopsy	<input type="checkbox"/>	ITB release	<input type="checkbox"/>
Psoas release	<input type="checkbox"/>	Gluteal tendon repair	<input type="checkbox"/>	Troch Bursa debridement	<input type="checkbox"/>
Sciatic neurolysis	<input type="checkbox"/>	Piriformis tendon release	<input type="checkbox"/>	Hamstring tendon repair	<input type="checkbox"/>

Pelvic osteotomy

PAO	<input type="checkbox"/>	Triple	<input type="checkbox"/>	Chiari	<input type="checkbox"/>
Shelf	<input type="checkbox"/>				

Femoral osteotomy

Varus	<input type="checkbox"/>	Valgus	<input type="checkbox"/>	Derotation	<input type="checkbox"/>
Shortening	<input type="checkbox"/>	Troch advancement	<input type="checkbox"/>	Complex	<input type="checkbox"/>
Open reduction (DDH)	<input type="checkbox"/>				

Femoral osteotomy fixation method

IM Nail	<input type="checkbox"/>	Blade Plate	<input type="checkbox"/>	Simple Plate	<input type="checkbox"/>	Locking Plate	<input type="checkbox"/>	Sliding Hip Screw	<input type="checkbox"/>
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