



British Spine Registry

- Patient Information

*Helping to improve patient care
through knowledge*

British Spine Registry

The British Spine Registry aims to collect information about spinal surgery across the UK to improve outcomes for patient care in the future.

Information collected by the registry will be used to pinpoint the most effective operations and the patients in which they work best.

As a patient at UHB, you have the opportunity to participate by providing invaluable feedback on the outcome of your surgery and your satisfaction with the care you receive here.

Within your admission pack you will find a leaflet and consent form from the British Spine Registry. We are keen that you take part in order to support the improvement of care for other spinal patients in the future.

If you are happy to partake in the British Spine Registry please complete the enclosed consent form, making sure to add a personal email address. Please bring this form with you to your pre-admission screening appointment or at your hospital admission.

A questionnaire will be emailed to you from the registry a few days prior to your surgery. Please complete the questionnaire online before you come to hospital for your procedure.

Further questionnaires will be sent to you at 4, 6, 12 and 24 months after your surgery.

Should you have any questions or you do not receive an email, please contact Mike Steadman on **0121 371 5353** or email: **BSR@uhb.nhs.uk**

Yours sincerely,

Neurosurgery Team

University Hospitals Birmingham NHS Foundation Trust

What is the British Spine Registry (BSR)?

Being part of the British Spine Registry is mandatory for surgeons and voluntary for patients.

It aims to collect information about spinal surgery across the UK to help us to find out which spinal operations are the most effective and in which patients they work the best. This will help shape and improve patient care in the future.

BSR will allow patient outcomes to be assessed using questionnaires, allowing surgeons to see how much improvement there has been from individual procedures. This has been seen to work for hip and knee joint replacements through the National Joint Registry.

We need your help to improve spinal surgery in the UK.

What data is collected?

Your personal details allow the BSR to link you to the surgery you have had. They also allow us to link together all the questionnaires you complete. If you need any further spinal surgery in the future, details of previous operations will be available to your surgeon.

Personal details needed by the BSR are: name, gender, date of birth, address, email and NHS number.

Your personal details are treated in full confidence at all times and will be kept secure in accordance with all relevant legislation. This data is controlled by the British Association of Spine Surgeons (BASS) and held outside the NHS.

Personal details are removed before any data analysis is performed - retaining only age and gender.

Your personal data and email address will not be available to anyone outside BASS and its secure IT provider. Anonymised data may be released to approved organisations for approved purposes but a signed agreement will restrict what they can do with the data so that your confidentiality is protected at all time.

Your personal data is very important as this will allow us to link details of your diagnosis and surgery with any problems or complications after

surgery. You may also be asked to complete questionnaires before and after surgery to work out how successful the surgery has been. These will only be possible if we can connect you to the questionnaires through your personal details.

British Spine Registry (BSR)

By providing your email address we are able to gather clinical outcomes for the BSR in a far simpler and easier way to manage.

This also help to reduce the cost of postage to the NHS and it reduces the amount of time taken to process paper forms. Providing your email address also helps towards our sustainability goals as we're able to use less paper by printing less.

We promise:

- To not send more than two reminder emails
- To not share your personal data with third parties
- To store your data securely in accordance with General Data Protection Regulations (GDPR) and the Data Protection Act 2018

Do I have to give consent?

No, your participation in the BSR is completely voluntary and whether you consent or not, your care will be the same. Your personal details cannot be kept without your consent. This will be obtained either by physically signing a consent form or electronically signing a consent form via an email link to a questionnaire, or at a questionnaire kiosk in the outpatient clinic.

You can withdraw your consent at any time or request access to your data by any of the following:

- access to the patient section of the BSR website:
www.britishspineregistry.com
- write to your spinal surgeon at your hospital

Please state if you are happy for us to keep existing data but do not want to be contacted, or whether you want your data to be anonymised (so it cannot be identified).

Research

Your consent will allow the BSR to examine details of your diagnosis, surgical procedure, any complications, your outcome after surgery and your questionnaires. These are known as service evaluations or audits.

Operation and patient information, including questionnaires, in the BSR may be used for medical research. The purpose of this research is to improve our understanding and treatment of spinal problems.

The majority of our research uses only anonymised information that means it is impossible to identify individuals.

From time to time researchers may wish to gather additional information and in these cases we would seek your approval before disclosing any contact details for you.

You do not have to take part in any research study you are invited to take part in and saying no will not affect the care you receive.

All studies using data from BSR will be recorded on their website:

www.britishspine registry.com

If you require additional spinal surgery information, please visit:

www.spinesurgeons.ac.uk

Children

Looking at the outcome of spinal surgical procedures is just as vital in children as it is in adults and therefore parents will also be given the opportunity to provide consent for data to be collected from their child.

Where can I find out more information?

The BSR website (**www.britishspine registry.com**) contains more information, including details of any studies and any information obtained through the registry data.

If you have already consented and would like to see what data is stored on you. Please contact your hospital's BSR administrator or speak to your consultant.

Contact Details:

Visit our website at: www.britishspineregistry.com

Send an email to: mail@britishspineregistry.org.uk

Contact the BSR co-ordinator at UHB: mike.steadman@uhb.nhs.uk

Spinal surgery – information for patients

For more information on your spinal surgery, including an explanation of the risks and expected benefits, please look at the following webpage:

www.spinesurgeons.ac.uk/patients

Click on: **"Booklets"** then choose the following booklet from the list:

- Lumbar Facet Joint Injection
- Pars Injection for Lumbar Spondylolysis
- Vertebroplasty
- Lumbar Nerve Root Block
- Anterior Lumbar Interbody Fusion
- Anterior Cervical Discectomy
- Lumbar Discography
- Transforaminal
- Lumbar Interbody Fusion
- Posterior Cervical Discectomy
- Degenerative Spondylolisthesis of the Lumbar Spine
- Lumbar Spondylolysis and Spondylitic Spondylolisthesis
- Lumbar Spine Stenosis
- Lumbar Disc Protrusions

This information is published by the British Association of Spinal Surgeons and can be viewed online or printed if required.

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