



## **British Spine Registry – Patient Information**

*Helping to improve patient care through knowledge*

### **What is the British Spine Registry (BSR)?**

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

The Registry will allow patient outcomes to be assessed using questionnaires. These will allow surgeons to see how much improvement there has been from treatment.

This has worked 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, NHS number

Your personal details are treated as confidential at all times and will be kept secure. This data is controlled by the British Association of Spine Surgeons (BASS) and held outside the NHS. Personal details will be removed before any data analysis is performed retaining only age and gender. Your personal data and e-mail 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 patient confidentiality is protected.

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.

### **Do I have to give consent?**

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

You can withdraw your consent at any time or request access to your data by contacting your Consultant.

## **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. In these cases, we would seek your approval before disclosing your contact details. You do not have to take part in any research study you are invited to take part in and saying no does not affect the care you receive.

All studies using data from the Registry will be recorded on the BSR website: [www.britishspineregistry.com](http://www.britishspineregistry.com)

## **Children**

Parents are asked to consent for data to be collected from their child. Looking at the outcome of spinal surgical procedures is just as vital in children as it is in adults.

## **Can I find out more information?**

The BSR website ([www.britishspineregistry.com](http://www.britishspineregistry.com)) contains more information including details of any studies and any information obtained through the Registry data.

If you want to see what data is stored on you, please write us at the BSR Centre (see below).

## **Contact Details:**

Visit our website at:

[www.britishspineregistry.com](http://www.britishspineregistry.com)

Send an email to:

[Customer.support@amplitude-clinical.com](mailto:Customer.support@amplitude-clinical.com)



## British Spine Registry Consent Form

*Helping to improve patient care through knowledge*

Please tick to confirm that you have been given / read the 'BSR patient information leaflet'

**Surname:** \_\_\_\_\_

**First Name:** \_\_\_\_\_

**Date of Birth:** \_\_\_\_/\_\_\_\_/\_\_\_\_

**Postcode:** \_\_\_\_\_

**Email address** (if you are happy for us to send you email links to questionnaires):

\_\_\_\_\_

**I CONSENT to:**

- Personal details being recorded in the British Spine Registry.
- I understand information in the Registry will be used to look at the outcomes of treatment and may be used for research purposes and results will be published.
- I understand that data identifying me will not be released to anyone unless required by law or where there is a clear public need to do so.
- Your data may be accessed by other spinal medical professionals in the future who are involved in your medical care.
- I understand that I may ask for my details to be removed at any time and may request access to my personal data.
- I understand that my health data may be linked to other national health databases.

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

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_/\_\_\_\_/\_\_\_\_

To be completed by the person accepting patient consent

**Name:** \_\_\_\_\_ **Position:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_/\_\_\_\_/\_\_\_\_

This form should be retained.