



British Spine Registry – Patient Information

Helping to improve patient care through knowledge

What is the British Spine Registry (BSR) ?

This is voluntary for both surgeon and patient. It hopes 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 will hopefully improve patient care in the future.

The Registry will allow patient outcome 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 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. Personal details will be removed before any data analysis is performed retaining only age and gender. Your personal data will not be passed to any other organisation.

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 sign a consent form or electronically through an email link to a questionnaire or a questionnaire kiosk in the outpatient clinic.

You can withdraw your consent at any time by any of the following:

The patient section of the BSR website: www.bsrcentre.org.uk

Emailing: mail@britishspineregistry.org.uk

Writing to us at the BSR centre (see below)

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'. You will be consented separately for any other research studies where specific data may be collected using the Registry.

All studies using data from the Registry will be recorded on the BSR website: www.bsrcentre.org.uk

Can I find out more information ?

The BSR website (bsrcentre.org.uk) 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.bsrcentre.org.uk

Send an email to

mail@britishspineregistry.org.uk

Write to:

The BSR Centre

c/o UKSSB Administrator

The British Orthopaedic Association

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