

British Spine Registry

Information for patients

This leaflet provides information for spinal surgery patients about giving consent for personal details to be included on the British Spine Registry. If you have any questions or concerns, please do not hesitate to speak to the doctors or nurses caring for you.

What is the British Spine Registry (BSR)?

The BSR is a web-based database that aims to collect information about spinal surgery across the UK. This will help the BSR 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 BSR 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. The BSR needs your help to improve spinal surgery in the UK.

See the consent form on p 3 of this leaflet or [download here](#).

What data is collected?

Your personal details allow the BSR to link you to the surgery you have had. They also allow the BSR 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 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 the BSR 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 the BSR 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 the BSR's understanding and treatment of spinal problems. The majority of the BSR's 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, the BSR 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

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) 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 email the BSR Centre (see below).

Contact details:

For further information, please contact the King's Spinal Administrator, via telephone: 020 3299 1876 or email: kch-tr.britishspineregistry@nhs.net

Contact the BSR via email: Customer.support@amplitude-clinical.com

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

British Spine Registry Consent Form

Helping to improve patient care through knowledge

We would like to include the information about your surgery on the British Spine Registry.

The British Spine Registry (BSR) is a web-based database, which may be linked to other national health databases for the collection of information about spinal surgery in the UK.

The Registry helps your consultant spine surgeon and other medical practitioners to understand how to improve patient care and procedures for you, and future patients.

To give consent for your information to be included on the British Spinal Registry please complete the details below:

First Name	
Last Name	
Date of Birth	
Post Code	
Email Address	

I CONSENT to my personal details being recorded in the British Spine Registry.

I understand that by consenting to including my information on the Registry that:

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

I DO NOT CONSENT to my personal details being recorded in the British Spine Registry.

Please return this form to: kch-tr.britishspineregistry@nhs.net

For further questions please contact the Spinal Administrator, call 020 3299 1876, or email: kch-tr.britishspineregistry@nhs.net

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND

Tel: 01689 863252

Email: kch-tr.palspruh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net