



# USER AGREEMENT AND DATA POLICY

If you need help, advice or guidance, please contact  
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[www.bsrcentre.org.uk](http://www.bsrcentre.org.uk)

## User Agreement

### Objectives

The British Spinal Registry (BSR) was established in May 2012 with the aim to improve patient safety and monitor the results of spinal surgery. It has been designed by UK surgeons primarily for the benefit of our patients.

The information captured and tracked on the Registry helps to find out which are the best and the most effective types of spinal surgery. The registry automatically collects outcome data for patients undergoing spinal surgery, giving surgeons instant access to their patients' results.

The Registry now has 679 users registered and 25 985 pathways added. The number of patients added to the Registry has almost doubled over the past year.

The registry's aims are simple. Data collected will be used to provide better insight, knowledge and understanding to aid the continuous improvement of surgical outcomes. Particular research will focus on a deeper understanding of the nature of injury, the identification of trends in practice, tracking and monitoring new developments and detecting techniques that may have suboptimal outcome at the earliest opportunity.

For surgeon users, the registry provides a tool for monitoring patient outcomes effectively. You can link functional outcome data and complication rates to better advise patients on expectations, complete your own research or analysis of your performance and create reports for your appraisal and revalidation purposes. The overall analysis of the collected data will be organised through the appointed steering group.

### Goals and aims

One of the Registry's main aims is to ensure the quality and validity of data is of a high quality and accurate. That is why it is so important patients supply their own PROMS and the data is clinically validated resulting in meaningful data for individual surgeons, as well as for wider research and analysis.

The future vision for the BSR is that every BASS member and their associated unit will contribute to the Registry, allowing more representative research and enabling a more robust and unified way for spinal surgeons to conform to revalidation using the reporting function. Another key vision is that every surgeon will be provided with data relating to their clinical practice for audit and feedback purposes.

### Registry Principles

- The role of the BSR is to improve patient safety and monitor the results of spinal surgery through effective and meaningful data capture.
- The data collected includes clinical data, outcome scores, procedure details and complications. This secure and completely anonymised data set is available to BASS members and will help facilitate important research and development, audit and national comparisons in which we (the BSR Executive Committee and BASS) hope to draw conclusions on which are the best and the most effective types of spinal surgery.
- The BSR committee will establish the policies and procedures that will govern data use, dissemination, and reporting, including the relationship with organisations external to the registry, such as the BOA Quality Outcomes Committee, Department of Health, patient groups, and Industry partners.
- Initial core data elements to be captured by the registry will be defined with input from stakeholder groups.
- The BSR believes that for the most comprehensive collection of core data, the reporting system must maximise existing data collection systems and rely upon participating hospitals, and individual surgeon members for submission of data to the registry.
- The security of registry data, patient privacy and data integrity are of the utmost importance and will be protected by the manner of the General Data Protection Regulation (GDPR), data access policies, and technical safeguards in partnership with the developer and data processor Amplitude Clinical.
- The BSR believes that the analysis and interpretation of registry data must be objective and scientific.

## **Terms and Conditions of Usage**

By using the British Spinal Registry (BSR) you are agreeing to comply with and be bound by the terms and conditions of use set out below. These shall constitute BSR's relationship with you in relation to the Registry. If you disagree with any part of the terms and conditions you must not use the Registry.

The terms 'British Spinal Registry', 'us' or 'we' refer to the owners of the British Spinal Registry whose contact.

The term 'you' refers to the user or viewer of the BSR.

The use of this online Registry is subject to the following terms of use:

- The content of this Registry is for your general information and use only. It is subject to change without notice.
- The Registry contains material which is owned by or licensed to us. This material includes, but is not limited to, the design, layout, look, appearance and graphics. Reproduction is prohibited other than in accordance with the copyright notice, which forms part of these terms and conditions.
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- Anyone wishing to retrieve data from the BSR for research purposes must contact the BSR Committee for approval to do so.
- The BSR must be acknowledged as the source of data in any publication (including electronic versions) in which BSR data is used.
- If data provided by the BSR for more than one Hospital/Centre are to be used in a publication, the BSR Committee must be able to review the manuscript and must agree details of the submission including appropriate authorship, nomination of contact person and details of the review process to be followed for the manuscript.
- Where consensus between authors cannot be reached concerning the interpretation of BSR data the document shall be circulated to the BSR Steering Group for discussion and resolution.
- Undergraduates, trainees, fellows and post graduates are encouraged to use BSR data; however a consultant who is a member of the Registry must be leading the project
- Unauthorised use of this website may give rise to a claim for damages and/or be a criminal offence.
- Your use of the Registry and any dispute arising out of such use are subject to the laws of England, Northern Ireland, Scotland and Wales.
- Computer Misuse Act 1990 - Unauthorised access to this system is an offence.

## **Data Protection Policy**

The BSR enables collection of personal data related to patients undergoing spinal surgery. All data is to be collected in pursuance of the above Objectives, following the Registry Principles.

All data is subject to the General Data Protection Regulation (GDPR).

The British Spinal Registry Committee is the Data Controller and Amplitude Clinical is the Data Processor under Data Protection rules. Your [user] must ensure all of your patients are appropriately consented.

The British Spinal Registry is registered with the Information Commissioner's Office (ICO) and recommend that you also register with the ICO.

Use of the registry requires you to abide by GDPR and to meet the following requirements:

- You will ensure appropriate security of your login details, and will contact Amplitude Clinical immediately if you suspect a breach of security.
- You will ensure that explicit patient consent is sought, given and recorded.
- You understand that failure to correctly indicate the acquisition of consent will lead to the deletion of identifying data upon your patients' records.
- You are entirely responsible for indicating patient's consent where this is done non electronically.
- All data will be accurate, and up to date.
- Only necessary and appropriate data will be recorded.

- You only grant access to appropriate individuals under your account, and that you remain responsible for the data entry upon your patients entered by said individuals.
- You only download stored information via reports, for appropriate use. This can include but is not exclusive to audit, research, and teaching purposes.
- Patient identifiable data can be obtained for a single patient and this must be kept secure in accordance with GDPR at all times.
- Express Research and Ethics approval must be in place for specific research data to be utilised.
- By using the Registry under these Terms and Conditions, you agree to anonymised use of your data for the purposes of the BSR's pursuance of the above Goals and Objectives under the Registry Principles.

## **Disclaimer**

Every effort is made to keep the Registry running smoothly. The BSR and Amplitude Clinical take no responsibility for, and will not be liable for, the website being temporarily unavailable due to technical issues beyond our control.

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