



USER AGREEMENT AND DATA POLICY

British Spinal Registry

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 Objectives

The goal of the British Spine Registry (BSR) is to improve the quality, outcomes, and cost-effectiveness of Spinal surgery through the achievement of our objectives:

- Establish an infrastructure and a uniform system for collecting information and monitoring outcomes of Spinal Surgery throughout the U.K.
- Identify patients who may need follow-up evaluation thereby increasing patient safety.
- Establish a uniform system that can be used to define the epidemiology of Spinal pathology for outcomes research to improve the quality and outcomes of patient care.

Registry Principles

- The British Spine Registry (BSR) is an independent Spinal registry, governed by an independent, not-for-profit organisation, under the direction of spinal surgeons in partnership with stakeholders.
- The Registry Committee of the British Association of Spine Surgeons (BASS) 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 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 maximize 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 GDPR data access policies, and technical safeguards in partnership with the developer Amplitude.
- The BSR believes that the analysis and interpretation of Registry data must be objective and scientific.

Registry Usage Terms and Conditions

Welcome to our Registry

If you continue to use this Registry, you are agreeing to comply with and be bound by the following terms and conditions of use, which together with our privacy policy govern British Spine Registry's relationship with you in relation to this site. If you disagree with any part of these terms and conditions, please do not use our Registry.

The term 'British Spine Registry' or 'us' or 'we' refers to the owner of the website whose registered office is British Spine Registry, British Association of Spine Surgeons, 35-43 Lincoln's Inn Fields, London, WC2A 3E. The term 'you' refers to the user or viewer of our Registry.

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

- The content of the pages of this website is for your general information and use only. It is subject to change without notice.
- This website 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.
- All trademarks reproduced in this website, which are not the property of, or licensed to the operator, are acknowledged on the website.
- 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 is to be used in a publication, the BSR 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 BASS Registry Committee for discussion and resolution.
- For multicentre projects, at least one clinician from the BSR or Executive of BASS or clinician advising on behalf of BASS plus the relevant statistician and epidemiologist giving advice on behalf of BASS should be included as authors, if applicable.
- Undergraduates, trainees, fellows and post graduates are encouraged to use BSR data; however a spinal consultant who is a member of the British Association of Spine Surgeons must be leading the project

- Unauthorised use of this website may give rise to a claim for damages and/or be a criminal offence.
- From time to time, this website may also include links to other websites. These links are provided for your convenience to provide further information. They do not signify that we endorse the website(s). We have no responsibility for the content of the linked website(s).
- Your use of this website and any dispute arising out of such use of the website is 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

This Registry enables the collection of Personal Data regarding Patients undergoing Spinal treatment. The data is to be collected in pursuance of the above Goals and Objectives, following the Registry Principles.

All data is subject to the GDPR, and as such is collected under the following principles:

The BSR/ BASS are the Data Controller, and Amplitude are the Data Processor under Data Protection rules. The BSR is registered with the Information Commissioner's Office (ICO).

Whilst there is no requirement for you to register as a Data Controller with the ICO, terms and conditions of usage of this Registry require you to abide by the GDPR, and as such:

- You will ensure appropriate security of your login details, and will contact the BSR/ Amplitude immediately 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 is 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 the 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 BSR's pursuance of the above Goals and Objectives under the Registry Principles.

Disclaimer

- Every effort is made to keep the website up and running smoothly. However, BSR takes no responsibility for, and will not be liable for, the website being temporarily unavailable due to technical issues beyond our control.
- The listing of suppliers' components in the BSR database does not indicate approval of such components by the BSR, or BASS or any regulatory body.
- You give the Amplitude support team rights to correct any incorrect patient data in your system that is directly prohibiting the patient accessing their portal. e.g. date of birth correction

Copyright Notice

This website/ database and its content are copyright of British Association of Spine Surgeons. All rights reserved. Any redistribution or reproduction of part or all of the contents in any form is prohibited other than the following:

You may print or download to a local hard disk extracts for your personal for non-commercial use only, subject to the Data Protection Policy above.

You may not, except with our express written permission, distribute or commercially exploit the content. Nor may you transmit it or store it in any other website or other form of electronic retrieval system.