

British Spine Registry (BSR) Policy

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:

- Collect data on surgical procedures for appraisal / revalidation
- Improve understanding of outcomes after spinal surgery
- Unit-level dashboard data
- Provide accurate clinical data for commissioning
- Collect data on implants / new implants (NICE)
- Co-ordinate multi-centre audit / research
- Identify patients who need long term follow-up evaluation thereby increasing patient safety

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 British Association of Spine Surgeons (BASS) is the data controller.
- 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 organizations external to the Registry, such as the Department of Health, patient groups, and Industry partners. This will be done in conjunction with the BASS Executive on behalf of the BASS Membership.
- Mandatory data to be captured by the BSR will be defined with input from stakeholder groups
- The BSR believes that for the most comprehensive collection of mandatory 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 the manner of the Data Protection Act 1998, 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

All users agree to the following access and usage terms and conditions on first access.

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 uses cookies to monitor browsing preferences. If you do allow cookies to be used, the following personal information may be stored by us for use by third parties: [insert list of information]. None at this time.
- 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 two Hospitals/Centres 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.
- Individuals can extract their own data but for data protection purposes, patient identifiable data will be removed. The BSR will give a mechanism where the surgeon can look at individual patients from a report from within the BSR.
- Individuals / Groups / Hospitals cannot use outcome data from the BSR to promote or advertise their practice as being 'better' than the 'average for data within the BSR' unless a peer review of data has been performed and statistical tests performed to show a significant difference to the satisfaction of the BASS Registry Committee.
- 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 Data Protection Act (1998), and as such is collected under the following principles:

The BSR/ BASS are the Data Controller, and Amplitude is the Data Processor under Data Protection rules. The BSR is registered with the Information Commissioner's Office (ICO) – Z3204782.

Submitted Data will be stored securely, as per ICO requirements.

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 Data Protection Act (1998), and as such:

- You will co-operate fully with any investigation into a potential or confirmed breach of security where required.
- You will ensure appropriate security of your login details, and will contact the BSR/ Amplitude-Bluespier 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 Data Protection Act (1998) 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.
- You will advise BSR / Amplitude if there is a Subject Access Request from the patient wanting to obtain a copy of their data from the BSR or if a patient wishes to no longer participate or withdraw their data.

Caldicott Principles and Caldicott Guardian

Each Consultant is responsible for informing the Caldicott Guardian within each NHS Trust (a full list can be found at <http://systems.hscic.gov.uk/data/ods/searchtools/caldicott/index.html> and Private Hospital informing them of their proposed data submission to the BSR. An approved information pack will be downloadable from the BSR Website (www.bscentre.org.uk).

Data Access by Third Parties

Surgeon level data will not be released unless required by law. This Policy would need to be amended and approved by the BASS Executive who may defer to the Society either at an AGM or on-line vote (if speed is required) to allow release of Surgeon level data. This will include any data that could potentially be attributed to a single surgeon eg rarely used implants and one/two surgeons in one hospital.

All data accessed by third parties will be subject to the third party defining their exact use of the information and signing a legal contract with penalties for misuse of the data and restrictions of use to protect patient confidentiality. The BSR Committee will consider these requests and will send these through to the BASS Executive with a recommendation as to whether to grant the request and which data should be included. The BASS Executive will be responsible for a final decision and the contents of the anonymised data. The third party will be responsible for reasonable costs.

Access to data reports will be agreed with Stakeholders and these will be provided at agreed time intervals and at agreed costs.

Requests for data access from Department of Health, NHS England and HSCIC will be considered by the BASS Executive but until there is robust peer review and mandatory data collection, surgeon level data will not be available.

If Euroqol allow access to EQ-5D but require anonymous EQ-5D, ODI and VAS data combined with age and diagnosis, this can be released if required by the licensing agreement. No patient or surgeon identifiable data will be released.

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.

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