

British Spine Registry Patient User Privacy Notice

This privacy notice was created on 1st May 2018. It is effective upon acceptance for all new users and from 1st June 2018 for all other users.

If you have an unresolved privacy or data use concern, please contact the British Spine Registry at the following link:

customer.support@amplitude-clinical.com

This privacy notice applies to any data collected on the British Spine Registry whether collected via the internet using computer or mobile interfaces and also through paper communication.

Personal Information We Collect

Personal information is information relating to an identified or identifiable person. An identifiable natural person is one who can be identified directly or indirectly by reference to an identifier such as a name, an identification number, location data, date of birth, or specific physical, physiological, pathological, genetic, mental, economic, cultural or social identity of that person.

We do not consider personal information to include information that has been anonymised or aggregated so that it can no longer be used to identify a person or user.

By giving your consent when you register with us we will be saving your personal information along with clinical information about your health and your subsequent treatment.

How we will use your personal information

Your personal information will be used to keep an accurate record of your treatment and to allow interpretation of the efficacy of your treatment. Data collected will allow us to assure the quality of your treatment by allowing comparison of different hospital and surgeons. Your data may be aggregated with other patients to allow us to conduct clinical research to provide us with evidence for which treatments are best for our patients.

Your Choices about how we use your personal information

By agreeing to our consent policy, you are allowing us to collect the above information. You are free to withdraw your consent at any time. By doing so, all of your identifiable personal data is removed. We will still keep data about your surgery and outcomes, but it will not be coupled to your personal data, so you may not be identified.

Ways you can access, control and correct your personal information

We respect your right to access, correct, request deletion or request restriction of your personal data.

You have the right to know what personal data we maintain about you. We will provide a copy of your personal data upon request. If your data is incorrect you have the right to ask us to update it.

You have the right to object to our processing of your personal information.

How we might share your personal information

Your personal information may be shared with surgeon users of the British Spine Registry who are directly involved in your care. Any data which is to be shared with clinical users of the British Spine Registry for the purposes of research or audit will be anonymised.

Any data which is shared with third parties such as spinal implant manufacturers or external research agencies will be anonymised.

Data which is shared within NHS organisations, for the purposes of quality assurance or for the calculation of the Best Practice Tariff, will not be anonymised. The information, which will also be gathered by the hospital you attend, will be shared with NHS England where it is lawful to do so, and via a secure gateway, to support NHS England's/NHS Improvements statutory duties.

To learn more about NHS England's Privacy Policy, [follow this link](#).

To learn more about NHS Digital's Privacy Policy, [follow this link](#).

How long will we keep your personal information

Your personal information such as name, address and date of birth is stored, without any clinical information such as your diagnosis or treatment plan, on the BSR at the time when you agree to undergo surgery. There is then a period of 180 days for your treating clinicians to obtain your consent. If consent is not given, then your personal data is removed. If consent is not recorded after 180 days, then your personal data is removed, although your diagnosis and treatment information may be kept in an anonymised form.

How do we protect your personal information

We protect your personal information using technical and administrative security measures to reduce the risk of loss, misuse, unauthorised access, disclosure and alteration. Some of the safeguards we use include firewalls and data encryption, physical access controls to our data centres and information access authorisation controls.

Data Controllers and Data Processors

Decisions regarding how your data will be used and interpreted, including with whom your data may be shared, are made by the executive board British Association of Spine Surgeons (BASS). They are your Data Controllers.

Decisions regarding how your data will be entered, stored, altered, amended or removed are made by Amplitude Clinical Solutions Ltd. They are your data processors.

Updated 19/11/2019