



British Spine Registry – Patient Information

Helping to improve patient care through knowledge

What is the British Spine Registry (BSR)?

It aims to collect information about spinal surgery across the UK. This will help us 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 Registry 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. We need your help to improve spinal surgery in the UK.

What data is collected?

Your personal details allow the BSR to link you to the surgery you have had. They also allow us 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, 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 us 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 we 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 any of the following:

Access to the patient section of the BSR website: www.bsrcentre.org.uk

Writing to us at the BSR centre (see below). Please state if you are happy for us to keep existing data but do not want to be contacted or whether you want your data to be anonymised (so it cannot be identified).

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 our understanding and treatment of spinal problems. The majority of our 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 we 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.co.uk

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.co.uk) 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 write us at the BSR Centre (see below).

Contact Details:

Visit our website at

www.britishspineregistry.co.uk

Send an email to

Customer.support@amplitude-clinical.com

Write to:

The BSR Centre

c/o UKSSB Administrator

The British Orthopaedic Association

35-43 Lincoln's Inn Fields

London

WC2A 3PE



British Spine Registry Consent Form

Helping to improve patient care through knowledge

Please tick to confirm that you have been given / read the 'BSR patient information leaflet'

Surname: _____

First Name: _____

Date of Birth: ____/____/____

Postcode: _____

Email address (if you are happy for us to send you email links to questionnaires):

I CONSENT to:

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

Patient / Parent agreement to data collection for Registry and Research:

Signature: _____ **Date:** ____/____/____

To be completed by the person accepting patient consent

Name: _____ **Position:** _____

Signature: _____ **Date:** ____/____/____

This form should be retained.



INSTRUCTIONS: We are carefully evaluating the condition of your back and it is **IMPORTANT THAT YOU ANSWER EACH OF THESE QUESTIONS YOURSELF.** Please **CIRCLE THE ONE BEST ANSWER TO EACH QUESTION**

1. Which one of the following best describes the amount of pain you have experienced during the past 6 months?

- None
- Mild
- Moderate
- Moderate to severe
- Severe

2. Which one of the following best describes the amount of pain you have experienced over the last month?

- None
- Mild
- Moderate
- Moderate to severe
- Severe

3. During the past 6 months have you been a very nervous person?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

4. If you had to spend the rest of your life with your back shape as it is right now, how would you feel about it?

- Very happy
- Somewhat happy
- Neither happy nor unhappy
- Somewhat unhappy
- Very unhappy

5. What is your current level of activity?

- Bedridden
- Primarily no activity
- Light labour and light sports
- Moderate labour and moderate sports
- Full activities without restriction

6. How do you look in clothes?

- Very good
- Good
- Fair
- Bad
- Very bad

7. In the past 6 months have you felt so down in the dumps that nothing could cheer you up?

- Very often
- Often
- Sometimes
- Rarely
- Never

8. Do you experience back pain when at rest?

- Very often
- Often
- Sometimes
- Rarely
- Never

9. What is your current level of work/school activity?

- 100% normal
- 75% normal
- 50% normal
- 25% normal
- 0% normal

10. Which of the following best describes the appearance of your trunk; defined as the human body except for the head and extremities?

- Very good
- Good
- Fair
- Poor
- Very Poor

11. Which one of the following best describes your pain medication use for back pain?

- None
- Non-narcotics weekly or less (e.g., aspirin, paracetamol, ibuprofen)
- Non-narcotics daily
- Narcotics weekly or less (e.g. Co-codamol, tramadol, codeine)
- Narcotics daily

12. Does your back limit your ability to do things around the house?

- Never
- Rarely
- Sometimes
- Often
- Very Often

13. Have you felt calm and peaceful during the past 6 months?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

14. Do you feel that your back condition affects your personal relationships?

- None
- Slightly
- Mildly
- Moderately
- Severely

15. Are you and/or your family experiencing financial difficulties because of your back?

- Severely
- Moderately
- Mildly
- Slightly
- None

16. In the past 6 months have you felt down hearted and blue?

- Never
- Rarely
- Sometimes
- Often
- Very often

17. In the last 3 months have you taken any days off of work, including household work, or school because of back pain?

- 0 days
- 1 day
- 2 days
- 3 days
- 4 or more days

18. Does your back condition limit your going out with friends/family?

- Never
- Rarely
- Sometimes
- Often
- Very often

19. Do you feel attractive with your current back condition?

- Yes, very
- Yes, somewhat
- Neither attractive nor unattractive
- No, not very much
- No, not at all

20. Have you been a happy person during the past 6 months?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

21. Are you satisfied with the results of your back management?

- Very satisfied
- Satisfied
- Neither satisfied nor unsatisfied
- Unsatisfied
- Very unsatisfied

22. Would you have the same management again if you had the same condition?

- Definitely yes
- Probably yes
- Not sure
- Probably not
- Definitely not

DATE _____

Thank you for completing this questionnaire.

Please comment if you wish.



Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

We would like to know how good or bad your health is **TODAY**.

This scale is numbered from 0 to 100.

100 means the best health you can imagine.

0 means the worst health you can imagine.

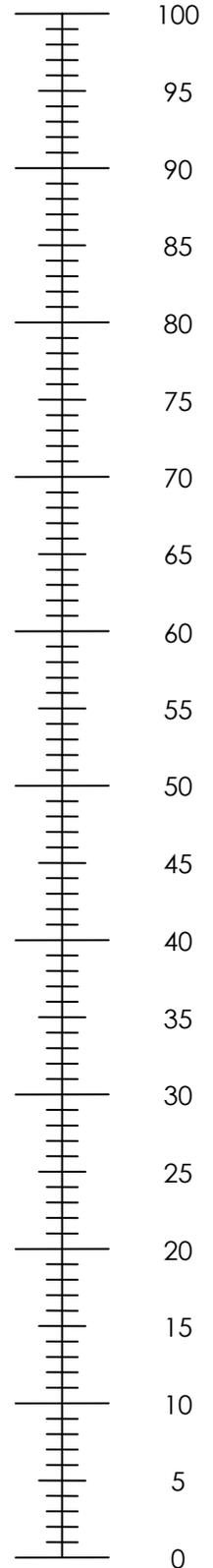
Mark an X on the scale to indicate how your health is **TODAY**.

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

DATE _____

The best health you can imagine



The worst health you can imagine



Please complete this questionnaire. It is designed to give us information as to how your back (or leg) trouble has affected your ability to manage in everyday life. Please answer **every section**. Mark **one box only** in each section that most closely describes you **today**.

Section 1 - Pain intensity

- I have no pain at the moment.
- The pain is very mild at the moment.
- The pain is moderate at the moment.
- The pain is fairly severe at the moment.
- The pain is very severe at the moment.
- The pain is the worst imaginable at the moment.

Section 2 - Personal care (washing, dressing ...)

- I can look after myself normally without causing extra pain.
- I can look after myself normally but it is very painful.
- It is painful to look after myself and I am slow and careful.
- I need some help but manage most of my personal care.
- I need help every day in most aspects of self-care.
- I do not get dressed, wash with difficulty and stay in bed.

Section 3 - Lifting

- I can lift heavy weights without extra pain.
- I can lift heavy weights but it gives extra pain.
- Pain prevents me from lifting heavy weights off the floor but I can manage if they are conveniently positioned, e.g. on a table.
- Pain prevents me from lifting heavy weights but I can manage light to medium weights if they are conveniently positioned.
- I can lift only very light weights.
- I cannot lift or carry anything at all.

Section 4 - Walking

- Pain does not prevent me walking any distance.
- Pain prevents me walking more than 1 mile.
- Pain prevents me walking more than half of a mile.
- Pain prevents me walking more than 100 yards.
- I can only walk using a stick or crutches.
- I am in bed most of the time and have to crawl to the toilet.

Section 5 - Sitting

- I can sit in any chair as long as I like.
- I can sit in my favourite chair as long as I like.
- Pain prevents me from sitting for more than 1 hour.
- Pain prevents me from sitting for more than half an hour.
- Pain prevents me from sitting for more than 10 minutes.
- Pain prevents me from sitting at all.

Section 6 - Standing

- I can stand as long as I want without extra pain.
- I can stand as long as I want but it gives me extra pain.
- Pain prevents me from standing for more than 1 hour.
- Pain prevents me from standing for more than half an hour.
- Pain prevents me from standing for more than 10 minutes.
- Pain prevents me from standing at all.

Section 7 - Sleeping

- My sleep is never disturbed by pain.
- My sleep is occasionally disturbed by pain.
- Because of pain I have less than 6 hours sleep.
- Because of pain I have less than 4 hours sleep.
- Because of pain I have less than 2 hours sleep.
- Pain prevents me from sleeping at all.

Section 8 - Sex life (if applicable)

- My sex life is normal and causes no extra pain.
- My sex life is normal but causes some extra pain.
- My sex life is nearly normal but is very painful.
- My sex life is severely restricted by pain.
- My sex life is nearly absent because of pain.
- Pain prevents any sex life at all.

Section 9 - Social life

- My social life is normal and causes me no extra pain.
- My social life is normal but increases the degree of pain.
- Pain has no significant effect on my social life apart from limiting my more energetic interests, e.g. sport, etc.
- Pain has restricted my social life and I do not go out as often.
- Pain has restricted social life to my home.
- I have no social life because of pain.

Section 10 - Travelling

- I can travel anywhere without pain.
- I can travel anywhere but it gives extra pain.
- Pain is bad but I manage journeys over two hours.
- Pain restricts me to journeys of less than one hour.
- Pain restricts me to short necessary journeys under 30 minutes.
- Pain prevents me from travelling except to receive treatment.

Please see reverse

DATE _____ SCORE _____