



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.



PLEASE ANSWER BY CIRCLING THE WORDS THAT BEST FIT YOUR PROBLEM.

What is your current employment status? E.g. Student, housewife, working, retired, disabled

How much time have you lost from work in the last year?

None
Less than a week
Between one and three weeks
Three to six weeks
Six to twelve weeks
Three to six months
Six to twelve months
One year

Are you receiving Disability Benefit? YES or NO

Is there any personal injury claim pending regarding your neck problem?
YES or NO

Have you had to retire because of your neck problem? YES or NO

Is your posture abnormal? YES or NO
If Posture is abnormal please explain

How many sessions of physiotherapy have you had?

None
< 3
3-6
6-12
> 12

How long have you had your present pain?

Less than 7 weeks
7-12 weeks
More than 12 weeks

Where do you have pain? NECK or ARM or BOTH

Which pain is the worse pain? NECK PAIN or ARM PAIN

Do you have any problems with walking or balance? YES or NO



Mark the area on your body where you feel the described sensations.

Use the appropriate symbol. Mark the areas of radiation. Include all affected areas as best you can.

Numbness

Pins and Needles

Burning

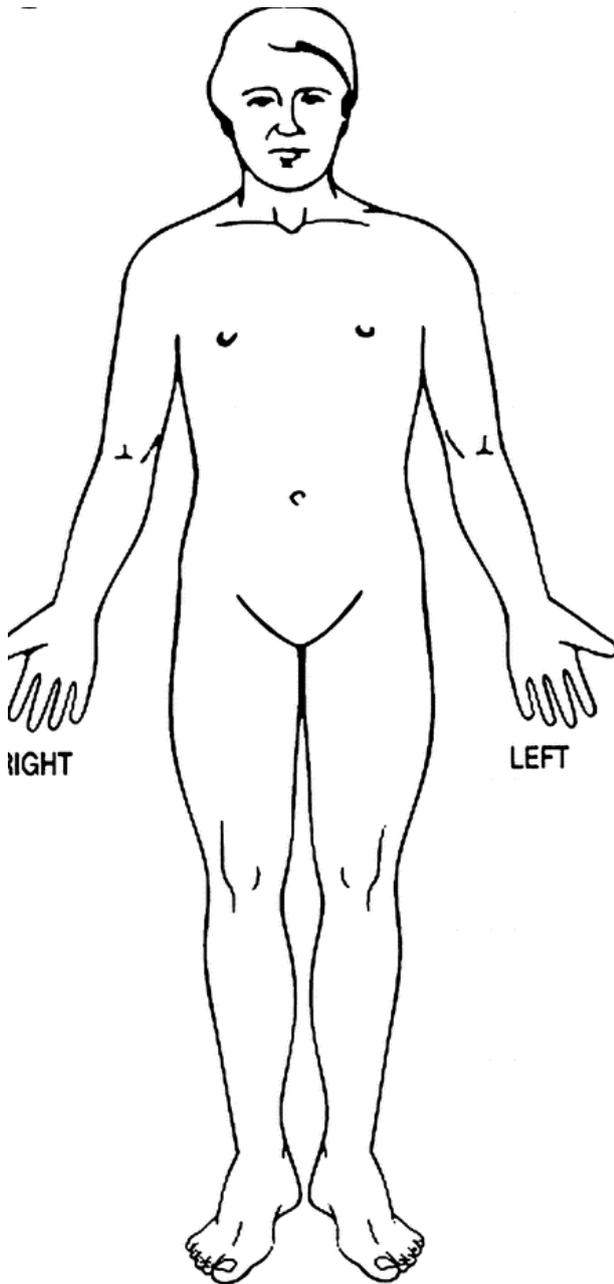
Stabbing

=====

oooooooo

xxxxxxxx

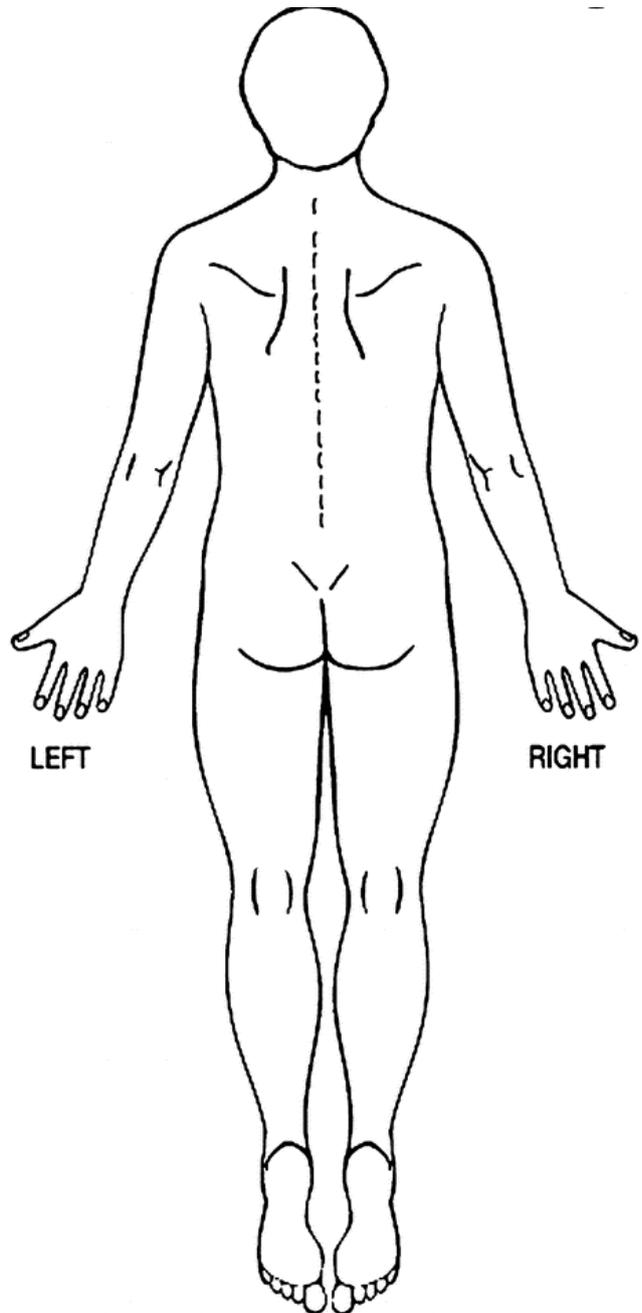
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RIGHT

LEFT

FRONT



LEFT

RIGHT

BACK



Please complete this questionnaire. It is designed to give us information as to how your neck (or arm) 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**.

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

2. Personal care (washing, dressing etc)

- 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

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 weights off the floor but I can manage if they are conveniently positioned, eg on a table
- Pain prevents me from lifting weights off the floor 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

4. Reading

- I can read as much as I want to with no pain in my neck
- I can read as much as I want to with slight pain in my neck
- I can read as much as I want to with moderate pain in my neck
- I cannot read as much as I want because of moderate pain in my neck
- I can hardly read at all because of severe pain in my neck
- I cannot read at all

5. Headaches

- I have no headaches at all
- I have slight headaches which come infrequently
- I have moderate headaches which come infrequently
- I have moderate headaches which come frequently
- I have severe headaches which come frequently
- I have headaches almost all the time

6. Concentration

- I can concentrate fully when I want to with no difficulty
- I can concentrate fully when I want to with slight difficulty
- I have a fair degree of difficulty in concentrating when I want to
- I have a lot of difficulty concentrating when I want to
- I have a great deal of difficulty concentrating when I want to
- I cannot concentrate at all

7. Work

- I can do as much work as I want to
- I can only do my usual work, but no more
- I can do most of my usual work, but no more
- I cannot do my usual work
- I can hardly do any work at all
- I cannot do any work at all

8. Driving

- I can drive my car without any neck pain
- I can drive my car as long as I want with slight pain in my neck
- I can drive my car as long as I want with moderate pain in my neck
- I cannot drive my car as long as I want because of moderate pain in my neck
- I can hardly drive at all because of severe pain in my neck
- I cannot drive my car at all

9. Sleeping

- I have no trouble sleeping
- My sleep is slightly disturbed (less than 1 hour sleepless)
- Sleep is mildly disturbed (1-2 hours sleepless)
- Sleep is moderately disturbed (2-3 hrs sleepless)
- My sleep is greatly disturbed (3-5 hrs sleepless)
- My sleep is completely disturbed (5-7 hrs sleepless)

10. Recreation

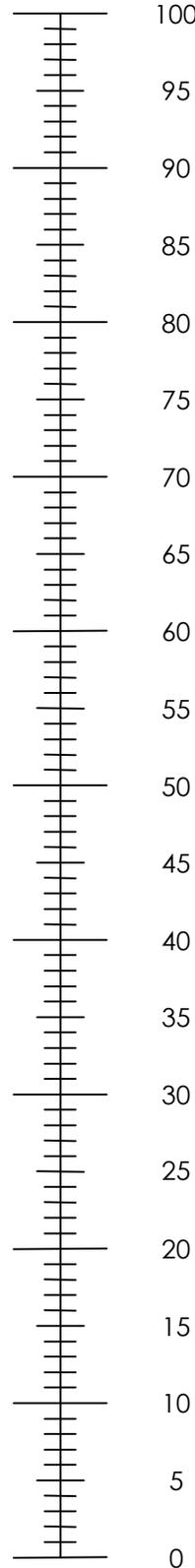
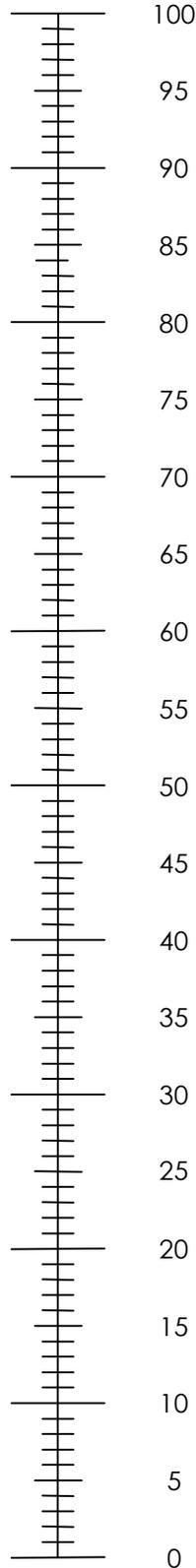
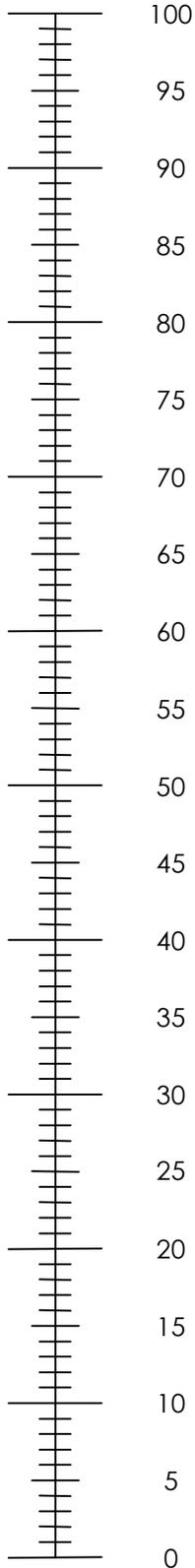
- I am able to engage in all of my recreational activities with no neck pain at all
- I am able to engage in all of my recreational activities with some pain in my neck
- I am able to engage in most, but not all of my recreational activities because of pain in my neck
- I am able to engage in a few of my recreational activities because of pain in my neck
- I can hardly do any recreational activities because of pain in my neck
- I cannot do any recreational activities at all



Worst **LEFT ARM** pain
you can imagine

Worst **NECK** pain
you can imagine

Worst **RIGHT ARM** pain
you can imagine



Visual Analogue Score: Neck and Arm Pain

Please mark on the
lines to the left how
much pain you have
had from your **neck**
and **arms**, on average,
over the past week:

No **LEFT ARM** pain

No **NECK** pain

No **RIGHT ARM** pain

DATE _____



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.

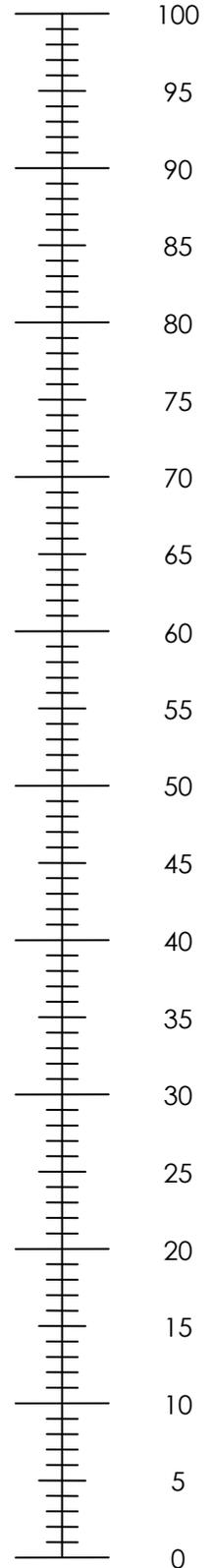
Mark an X on the scale to indicate how your health is **TODAY**.

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 spinal 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**.

Rising - Are you able to stand up from an armless straight chair?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Rising - Are you able to get in and out of bed?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Eating - Are you able to cut your meat?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Eating - Are you able to lift a full cup or glass to your mouth?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Walking - Are you able to walk outdoors on flat ground?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Walking - Are you able to climb up five steps?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Hygiene - Are you able to wash and dry your entire body?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Hygiene - Are you able to get on and off the toilet?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Grip - Are you able to open jars which have been previously opened?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do

Activities - Are you able to get in and out of a car?

- Without ANY difficulty
- With SOME difficulty
- With MUCH difficulty / assistance required
- Unable to do