Patient Information

Cambridge University Hospitals
NHS Foundation Trust

Patient Information and consent to excision of spinal intradural tumour

Key messages for patients

- Please read your admission letter carefully. It is important to follow the instructions we give you about not eating or drinking or we may have to postpone or cancel your operation.

- Please read this information carefully, you and your health professional will sign it to document your consent.

- It is important that you bring the consent form with you when you are admitted for surgery. You will have an opportunity to ask any questions from the surgeon or anaesthetist when you are admitted. You may sign the consent form either before you come or when you are admitted.

- Please bring with you all of your medications and its packaging (including inhalers, injections, creams, eye drops, patches, insulin and herbal remedies), a current repeat prescription from your GP, any cards about your treatment and any information that you have been given relevant to your care in hospital, such as x rays or test results.

- Laxatives and painkillers may be required after your hospital stay; please ensure you have appropriate supplies at home.

- Take your medications as normal on the day of the procedure unless you have been specifically told not to take a drug or drugs before or on the day by a member of your medical team. If you have diabetes please ask for specific individual advice to be given on your medication at your pre-operative assessment appointment.

- If you have any questions or concerns about this procedure please call the clinical nurse practitioner or secretary for your consultant. Any concerns regarding the organisation of your admission date may be dealt with by the neuroscience admissions office on 01223 217100.

After the procedure we will file the consent form in your medical notes and you may take this information leaflet home with you.

Important things you need to know

Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent and the procedure has started (as long as it is safe and practical to do so). If you are having an anaesthetic you will have the opportunity to discuss this with the anaesthetist, unless the urgency of your treatment prevents this.

We will also only carry out the procedure on your consent form unless, in the opinion of the health professional responsible for your care, a further procedure is needed in order to save your life or prevent serious harm to your health. However, there may be procedures you do not wish us to carry out and these can be recorded on the consent form. We are unable to guarantee that a particular person will perform the procedure.

Excision of spinal intradural tumour, CF387, V5, July 2017
However the person undertaking the procedure will have the relevant experience. All information we hold about you is stored according to the Data Protection Act 1998.

**About excision of spinal intradural tumour**

This operation removes the spinal tumour from your neck or back. The tumour is causing pressure on the spinal cord or spinal nerves. This results in pain, numbness or weakness and sometimes disturbance to your bladder/bowel function. Without surgery, the tumour will progressively increase in size and your symptoms will worsen over time.

**Intended benefits**

The aim of the surgery is to remove the spinal tumour in your neck or back. For most patients, this will result in an improvement in their symptoms. The success rate for this operation is high. In with most patients the tumour is totally removed.

**Who will perform my procedure?**

This procedure will be performed by a consultant neurosurgeon or neurosurgery specialist registrar operating under the supervision of a consultant.

**Before your procedure**

Most patients attend a pre-admission clinic, when you will meet the consultant neurosurgeon, his specialist registrar and the clinical nurse practitioner.

At this clinic, we will ask for details of your medical history and carry out any necessary clinical examinations and investigations. Please ask us any questions about the procedure, and feel free to discuss any concerns you might have at any time.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring all your medications and any packaging (if available) with you. Please tell the ward staff about all of the medicines you use. If you wish to take your medication yourself (self-medicate), please ask your nurse. Pharmacists visit the wards regularly and can help with any medicine queries.

We need to know if you are taking any of the following tablets as they thin the blood which may cause excessive bleeding at the time of surgery:

- Aspirin
- A prescription for Warfarin, Aspirin Rivaroxaban, Dabigatran, Apixaban or Clopidogrel (Plavix®)
- Or any other medication which may thin your blood
Patient Information

If to your knowledge the answer to any of the following is yes, it is important that you tell us:

- Have you ever received Human Growth Hormone;
- Have you had brain surgery prior to 1992 or;
- Has anyone in your family been diagnosed with CJD?

A positive answer will not prevent any treatment, it will however allow us to take infection control advice and plan your procedure so as to minimise any risks.

This procedure involves the use of general anaesthesia. We explain about the different types of anaesthesia or sedation we may use at the end of this leaflet. You will see an anaesthetist before your procedure.

Most people who have this type of procedure will be admitted on the day of surgery, occasionally people will be admitted the day before if we feel this is necessary. We will advise you when to stop eating and drinking; this is usually from midnight the day before your operation. Your doctor will discuss the length of stay with you.

During surgery, you may lose blood. If you lose a considerable amount of blood your doctor may want to replace the loss with a blood transfusion as significant blood loss can cause you harm. The blood transfusion can involve giving you other blood components such as plasma and platelets which are necessary for blood clotting. Your doctor will only give you a transfusion of blood or blood components during surgery, or recommend for you to have a transfusion after surgery, if you need it.

Compared to other everyday risks the likelihood of getting a serious side effect from a transfusion of blood or blood component is very low. Your doctor can explain to you the benefits and risks from a blood transfusion. Your doctor can also give you information about whether there are suitable alternatives to blood transfusion for your treatment. There is a patient information leaflet for blood transfusion available for you to read.

During the procedure

An incision will be made in the skin of your neck or back above the region of the tumour. Small portions of the bones will then be removed. The thin membrane covering the spinal canal is opened to expose the tumour, which would then be surgically removed. This membrane is repaired after the tumour removal. Finally, the wound is then closed with stitches.

After the procedure

Once your surgery is completed you will usually be transferred to the recovery ward where you will be looked after by specially trained nurses, under the direction of your anaesthetist. The nurses will monitor you closely until the effects of any general anaesthetic have adequately worn off and you are conscious.
They will monitor your heart rate, blood pressure and oxygen levels too. You may be given oxygen via a facemask, fluids via your drip and appropriate pain relief until you are comfortable enough to return to your ward. Another small, plastic tube attached to a drainage container will exit just next to the wound. This will be removed two days after surgery.

After certain major operations you may be transferred to the intensive care unit (ICU/ITU), high dependency unit (HDU), intermediate dependency area (IDA) or fast track/overnight intensive recovery (OIR).

These are areas where you will be monitored much more closely because of the nature of your operation or because of certain pre-existing health problems that you may have. If your surgeon or anaesthetist believes you should go to one of these areas after your operation, they will tell you and explain to you what you should expect.

If there is not a bed in the necessary unit on the day of your operation, your operation may be postponed as it is important that you have the correct level of care after major surgery.

**Eating and drinking.** After this procedure, you should not have anything to eat or drink until your medical team considers it to be safe. This is usually about two hours after the procedure provided you do not feel sick.

**Getting about after the procedure.** We will help you to become mobile as soon as possible after the procedure. This helps improve your recovery and reduces the risk of certain complications. Typically, you will be able to get out of bed the day after the operation. Occasionally you may need to be on bedrest for one or more days if the lining over the spinal cord has been opened. If you have any mobility problems, we can for the physiotherapy team to review you.

**Leaving hospital.** Generally most people who have had this operation will be able to leave hospital two to four days after surgery. However, the actual time that you stay in hospital will depend on your general health, how quickly you are recovering from the procedure and your doctor's opinion.

**Resuming normal activities including work.** Most people who have had this procedure should gradually increase your activity towards normal levels. You might need to wait a little longer before resuming more vigorous activity. When you will be ready to return to work will depend on your usual health, how fast you recover and what type of work you do. Please ask your doctor for his/her opinion. You can resume driving when you feel comfortable; this is provided that you were considered safe to drive by a doctor before the operation.
Special measures after the procedure:

Care of your wound

It is likely that your wound will be closed with absorbable stitches. We advise that a dressing is kept in place for 48 hours, after which it can be removed. You can shower when you get home but avoid getting water directly on the wound and do not have a bath for the first two weeks. If you have any concerns about the healing of the wound (redness, swelling or discharge) you may see either your GP or practice nurse. If there are persistent problems please contact the clinical nurse practitioner or your consultant and we would be happy to review you.

Check-ups and results: Results from the tumour tissue which is sent to the laboratory take about five to seven days. You will be informed about the results as soon as possible. Your condition will be reviewed three months following the operation to make sure that progress is satisfactory.

Significant, unavoidable or frequently occurring risks of this procedure

- At the time of surgery, there is a risk of damage to the spinal cord or nerve roots. This risk is less than 5% (five in 100). If it occurs, you might notice increased numbness in parts of your arm or leg and/or some weakness in movement. There is a small risk of complete paralysis with loss of function below the level of the tumour.
- If the tumour is in your neck this could result in paralysis of arms and legs and impairment to bladder and bowel function.
- If the tumour is in your back then the paralysis would affect your legs and impairment to bladder and bowel function
- Sometimes, the tumour arises from the nerve roots and these may have to be cut to remove the tumour. If this occurs, you might notice numbness in parts of your arm or leg.
- The risk of a blood clot in the wound requiring a second operation to remove it is between 1 and 2%.
- There is a risk of leakage of fluid from the wound despite the repair of the waterproof membrane during the surgery. If persistent, this might require further surgery to repair this membrane.
- The risk of wound infection is less than 1%, but this can sometimes need prolonged treatment with antibiotics.
- There is a small risk of tumour re-growth in the future.

General risks associated with all major operations and from being hospitalised: eg bleeding, infection, blood clots.
Alternative procedures that are available

The alternative to this surgery is to decide not to have surgery.

Information and support

You can contact the clinical nurse practitioner or the neurosurgical secretary for your consultant via the hospital switchboard if you have any further concerns.

Further information on spinal conditions is available via the website:

- Brain & Spine Foundation: http://www.brainandspine.org.uk

Anaesthesia

Your operation will be carried out under general anaesthetic.

Anaesthesia means ‘loss of sensation’. There are three types of anaesthesia: general, regional and local. The type of anaesthesia chosen by your anaesthetist depends on the nature of your surgery as well as your health and fitness. Sometimes different types of anaesthesia are used together.

Before your operation

Before your operation you will meet an anaesthetist who will discuss with you the most appropriate type of anaesthetic for your operation, and pain relief after your surgery. To inform this decision, he/she will need to know about:

- your general health, including previous and current health problems
- whether you or anyone in your family has had problems with anaesthetics
- any medicines or drugs you use
- whether you smoke
- whether you have had any abnormal reactions to any drugs or have any other allergies
- your teeth, whether you wear dentures, or have caps or crowns.

Your anaesthetist may need to listen to your heart and lungs, ask you to open your mouth and move your neck and will review your test results.

Pre-medication

You may be prescribed a ‘premed’ prior to your operation. This is a drug or combination of drugs which may be used to make you sleepy and relaxed before surgery, provide pain relief, reduce the risk of you being sick, or have effects specific for the procedure that you are going to have or for any medical conditions that you may have. Not all patients will be given a premed or will require one and the anaesthetist will often use drugs in the operating theatre to produce the same effects.
**Moving to the operating room or theatre**

You will usually change into a gown before your operation and we will take you to the operating suite. When you arrive in the theatre or anaesthetic room and before starting your anaesthesia, the medical team will perform a check of your name, personal details and confirm the operation you are expecting.

Once that is complete, monitoring devices may be attached to you, such as a blood pressure cuff, heart monitor (ECG) and a monitor to check your oxygen levels (a pulse oximeter). An intravenous line (drip) may be inserted. If a regional anaesthetic is going to be performed, this may be performed at this stage. If you are to have a general anaesthetic, you may be asked to breathe oxygen through a face mask.

It is common practice nowadays to allow a parent into the anaesthetic room with children; as the child goes unconscious, the parent will be asked to leave.

**General anaesthesia**

During general anaesthesia you are put into a state of unconsciousness and you will be unaware of anything during the time of your operation. Your anaesthetist achieves this by giving you a combination of drugs.

While you are unconscious and unaware your anaesthetist remains with you at all times. He or she monitors your condition and administers the right amount of anaesthetic drugs to maintain you at the correct level of unconsciousness for the period of the surgery. Your anaesthetist will be monitoring such factors as heart rate, blood pressure, heart rhythm, body temperature and breathing. He or she will also constantly watch your need for fluid or blood replacement.

**Regional anaesthesia**

Regional anaesthesia includes epidurals, spinals, caudals or local anaesthetic blocks of the nerves to the limbs or other areas of the body. Local anaesthetic is injected near to nerves, numbing the relevant area and possibly making the affected part of the body difficult or impossible to move for a period of time. Regional anaesthesia may be performed as the sole anaesthetic for your operation, with or without sedation, or with a general anaesthetic. Regional anaesthesia may also be used to provide pain relief after your surgery for hours or even days. Your anaesthetist will discuss the procedure, benefits and risks with you and, if you are to have a general anaesthetic as well, whether the regional anaesthesia will be performed before you are given the general anaesthetic.

**Local anaesthesia**

In local anaesthesia the local anaesthetic drug is injected into the skin and tissues at the site of the operation. The area of numbness will be restricted. Some sensation of pressure may be present, but there should be no pain.
Local anaesthesia is used for minor operations such as stitching a cut, but may also be injected around the surgical site to help with pain relief. Usually a local anaesthetic will be given by the doctor doing the operation.

**Sedation**

Sedation is the use of small amounts of anaesthetic or similar drugs to produce a ‘sleepy-like’ state. Sedation may be used as well as a local or regional anaesthetic. The anaesthesia prevents you from feeling pain and the sedation makes you drowsy. Sedation also makes you physically and mentally relaxed during an investigation or procedure which may be unpleasant or painful (such as an endoscopy) but where your co-operation is needed. You may remember a little about what happened but often you will remember nothing. Sedation may be used by other professionals as well as anaesthetists.

**What will I feel like afterwards?**

How you will feel will depend on the type of anaesthetic and operation you have had, how much pain relieving medicine you need and your general health.

Most people will feel fine after their operation. Some people may feel dizzy, sick or have general aches and pains. Others may experience some blurred vision, drowsiness, a sore throat, headache or breathing difficulties.

You may have fewer of these effects after local or regional anaesthesia although when the effects of the anaesthesia wear off you may need pain relieving medicines.

**What are the risks of anaesthesia?**

In modern anaesthesia, serious problems are uncommon. Risks cannot be removed completely, but modern equipment, training and drugs have made it a much safer procedure in recent years. The risk to you as an individual will depend on whether you have any other illness, personal factors (such as smoking or being overweight) or surgery which is complicated, long or performed in an emergency.

**Very common (1 in 10 people) and common side effects (1 in 100 people)**

- Feeling sick and vomiting after surgery
- Sore throat
- Dizziness, blurred vision
- Headache
- Bladder problems
- Damage to lips or tongue (usually minor)
- Itching
- Aches, pains and backache
- Pain during injection of drugs
- Bruising and soreness
- Confusion or memory loss
**Uncommon side effects and complications (1 in 1000 people)**

- Chest infection
- Muscle pains
- Slow breathing (depressed respiration)
- Damage to teeth
- An existing medical condition getting worse
- Awareness (becoming conscious during your operation)

**Rare (1 in 10,000 people) and very rare (1 in 100,000 people) complications**

- Damage to the eyes
- Heart attack or stroke
- Serious allergy to drugs
- Nerve damage
- Death
- Equipment failure

Deaths caused by anaesthesia are very rare. There are probably about five deaths for every million anaesthetics in the UK.

For more information about anaesthesia, please visit the Royal College of Anaesthetists’ website: [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
Information about important questions on the consent form

1 Creutzfeldt Jakob Disease (‘CJD’)
We must take special measures with hospital instruments if there is a possibility you have been at risk of CJD or variant CJD disease. We therefore ask all patients undergoing any surgical procedure if they have been told that they are at increased risk of either of these forms of CJD. This helps prevent the spread of CJD to the wider public. A positive answer will not stop your procedure taking place, but enables us to plan your operation to minimise any risk of transmission to other patients.

2 Photography, Audio or Visual Recordings
As a leading teaching hospital we take great pride in our research and staff training. We ask for your permission to use images and recordings for your diagnosis and treatment, they will form part of your medical record. We also ask for your permission to use these images for audit and in training medical and other healthcare staff and UK medical students; you do not have to agree and if you prefer not to, this will not affect the care and treatment we provide. We will ask for your separate written permission to use any images or recordings in publications or research.

3 Students in training
Training doctors and other health professionals is essential to the NHS. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a registered professional. You may, however, prefer not to take part in the formal training of medical and other students without this affecting your care and treatment.

4 Use of Tissue
As a leading bio-medical research centre and teaching hospital, we may be able to use tissue not needed for your treatment or diagnosis to carry out research, for quality control or to train medical staff for the future. Any such research, or storage or disposal of tissue, will be carried out in accordance with ethical, legal and professional standards. In order to carry out such research we need your consent. Any research will only be carried out if it has received ethical approval from a Research Ethics Committee. You do not have to agree and if you prefer not to, this will not in any way affect the care and treatment we provide. The leaflet ‘Donating tissue or cells for research’ gives more detailed information. Please ask for a copy.

If you wish to withdraw your consent on the use of tissue (including blood) for research, please contact our Patient Advice and Liaison Service (PALS), on 01223 216756.

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Privacy & dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

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Department

Contact number
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Publish/Review date
July 2017/July 2020 (amendment made March 2019)

File name
CF387_excision_intradural_tumour.doc

Version number/Ref
5/CF387/Document ID 8852
Consent Form

Patient agreement to investigation or treatment for neurosurgery, spinal surgery or vitreoretinal surgery

Interpreters statement (if appropriate)

I have interpreted the information to the best of my ability, and in a way in which I believe the patient can understand:

Signed (Interpreter): .................................................. Date: .............

Name (PRINT): .................................................................

Or, please note the language line reference ID number: .................................................................
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Includes: Damage to spinal cord or nerve roots / increased numbness in parts of your arm or leg / paralysis of arms and legs and impairment to bladder and bowel function / blood clot in wound / leakage of fluid from wound / wound infection / tumour re-growth.

excision of *…………………………… Spinial intradural tumour
(*health professional to state level)

Statement of health professional (details of treatment, risks and benefits)

1 I confirm I am a health professional with an appropriate knowledge of the proposed procedure, as specified in the hospital’s consent policy. I have explained the procedure to the patient. In particular, I have explained:

a) the intended benefits of the procedure (please state)
To remove the spinal tumour in your neck or back

b) the possible risks involved. Addenbrooke’s always ensures any risks are minimised. However all procedures carry some risk and I have set out below any significant, unavoidable or frequently occurring risks including those specific to the patient
Includes: Damage to spinal cord or nerve roots / increased numbness in parts of your arm or leg / paralysis of arms and legs and impairment to bladder and bowel function / blood clot in wound / leakage of fluid from wound / wound infection / tumour re-growth.

c) what the treatment or procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient:

d) any extra procedures that might become necessary during the procedure such as:
□ Blood transfusion □ Other procedure (please state)

e) Was the patient born after 1 January 1997? □ Yes □ No

2 The following information leaflet has been provided: Excision of spinal intradural tumour

Version reference and date: CF387 version 5 July 2017

or □ I have offered the patient information about the procedure but this has been declined.

3 This procedure will involve:
□ General and/or regional anaesthesia □ Local anaesthesia □ Sedation □ None

Signed (Health professional): _____________________________ Date: DD/MM/YYYY
Name (PRINT): _____________________________ Time (24hr): H.H : M.M

Designation: _____________________________ Contact/bleep no: _____________________________

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C  Consent of patient/person with parental responsibility

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and that my questions have been answered to my satisfaction and understanding.

Important: please read the patient information on ‘Consent’ and then put a tick in the relevant boxes for the following questions:

1  Creutzfeldt Jakob disease (CJD)
   a) Have you ever been notified that you are at risk of CJD or variant CJD for public health purposes? If yes, please inform your health professional.  
      □ Yes □ No

   b) Have you had a history of CJD or other prion disease in your family?  
      □ Yes □ No

   c) Have you ever received growth hormone or gonadotrophin treatment? If yes, please give details below:
      Please specify:
      (i) whether the hormone was derived from human pituitary glands  
          □ Yes □ No

      (ii) the year of treatment

      (iii) whether the treatment was received in the UK or another country  
          □ UK □ Other

   d) Have you ever had surgery on your brain, eye or spinal cord?  
      If yes, please give details below:

   e) Since 1980, have you had any transfusions of blood or blood components (red cells, plasma, cryoprecipitate or platelets)?  
      If yes, please answer questions below:
      Have you either:
      (i) received more than 50 units of blood or blood components,  
          □ Yes □ No

      or

      (ii) received blood or blood components on more than 20 occasions  
          □ Yes □ No

Where possible, please provide the names of all the hospitals where you received blood or blood components:

In the case of a positive reply to any CJD question, staff should immediately inform Infection Control on ext 3497 (bleep numbers 152-198 or 151-803) and the theatre co-ordinator (24 hour bleep number 152-585); out of hours contact the on call medical microbiologist via the hospital contact centre.

2  Photography, Audio or Visual Recording
   a) I agree to the use of any of the above type of recordings for the purpose of diagnosis and treatment.  
      □ Yes □ No

   b) I agree to unidentified versions of any of the above recordings being used for audit and medical teaching in a healthcare setting.  
      □ Yes □ No

3  Medical Training
   I agree to the involvement of medical and other students as part of their formal training.  
   □ Yes □ No
4 Use of Tissue

a) I agree that tissue (including blood) not needed for my own diagnosis or treatment can be used and stored for ethically approved research which may include ethically approved genetic research. □ Yes □ No

b) Where additional clinical information is needed for the purposes of ethically approved research, I agree that relevant sections of my medical record may be looked at by researchers or by relevant regulatory authorities. I give permission for these individuals to have access to my records. □ Yes □ No

I have listed below any procedures that I do not wish to be carried out without further discussion.

I have read and understood the Patient Information entitled Consent and the above additional information. I agree to the procedure or treatment.

Signed (Patient): .......................................................... Date: ...D.D./M.M./Y.Y.Y.Y...

Name of patient (PRINT): ..........................................................

If signing for a child or young person; delete if not applicable.

I confirm I am a person with parental responsibility for the patient named on this form.

Signed: .......................................................... Date: ...D.D./M.M./Y.Y.Y.Y...

Relationship to patient:

If the patient is unable to sign but has indicated his/her consent, a witness should sign below.

Signed (Witness): .......................................................... Date: ...D.D./M.M./Y.Y.Y.Y...

Name of witness (PRINT): ..........................................................

Address:

D Confirmation of consent

Confirmation of consent (where the treatment/procedure has been discussed in advance)

On behalf of the team treating the patient, I have confirmed with the patient that she/he has no further questions and wishes the treatment/procedure to go ahead.

Signed (Health professional): .......................................................... Date: ...D.D./M.M./Y.Y.Y.Y...

Name (PRINT): .......................................................... Job title:

Please initial to confirm all sections have been completed:

E Withdrawal of patient consent

□ The patient has withdrawn consent (ask patient to sign and date here)

Signed (Patient): .......................................................... Date: ...D.D./M.M./Y.Y.Y.Y...

Signed (Health professional): .......................................................... Date: ...D.D./M.M./Y.Y.Y.Y...

Name (PRINT): .......................................................... Job title:
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 contacting your Consultant.

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.britishspineresegistry.com

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.com) 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.britishspineresegistry.com

Send an email to:
Customer.support@amplitude-clinical.com
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: _____/_____/_____