

Welcome to CESS

An introduction to the Epilepsy Surgery Service at BCH



BCH CESS Pathway

Introduction to CESS

The Children's Epilepsy Surgery Service (CESS) in England is a specialist service that aims to improve the quality of epilepsy brain surgery available for children. It does this by reviewing children with difficult to control epilepsy, to see if they would benefit from epilepsy surgery.

The CESS is funded by NHS England for children with epilepsy in England. There are 4 specialist CESS centres that will treat children from all over England, not just those in their local area.

Each CESS centre has an expert team of surgeons, doctors, healthcare professionals and specialist facilities needed for epilepsy brain surgery.

Research shows around 340 children each year could benefit from epilepsy brain surgery. This surgery is done to help reduce, or even completely stop seizures.

Being on the pathway doesn't mean you will definitely be able to have surgery, but as part of the pathway we will explore all the options available to you

Contents

Page

- 2. CESS Structure
- 3-4 CESS Pathway stage description and flow chart.
- 5. Investigation summary
- 6. Investigation and clinic summary

Appendix.

Patient information leaflets for potential investigations for your reference. Travel information/Accommodation. This is an example of the professionals who will involved in your journey on the CESS pathway.

Clinical Lead for CESS

• Dr Shakti Agrawal

Neurologist Fellow

• Dr Rana Mohamed

CESS Consultants

- Dr Ratna Kumar
- Dr Anu Sudarsanam

Neurosurgeon

- Mr Richard Walsh
 Consultant Neurosurgeon
- Mr William Lo Consultant Neurosurgeon

Nurses

• James Lewis – Epilepsy Surgery Nurse

CESS co-ordinator/ Secretary

- Colin Salmon Co-ordinator and
- Reena Satsangi Secretary

Other professionals that will help with your CESS journey

Radiologists

Dr Lesley MacPherson - Consultant Radiologist Dr Helen Williams - Consultant Radiologist Dr Adam Oats - Consultant Radiologist

Neurophysiologists

Peter Bill - Lead Clinical Neurophysiologist Professor Stefano Seri - Consultant Neurophysiologist Caroline Scott - VT Service Lead

Neuropsychologists

Dr Shauna Kearney - Consultant Neuropsychologist Dr Rebecca Wilson - Consultant Neuropsychologist Dr Clare Baker-Ellis - Consultant Neuropsychologist

Occupational Therapists

Helen Jackson - Lead Occupational Therapist Deanne Middleton - Advanced Occupational Therapist

Neuropsychiatrists

Dr Laavanya Damodaran Consultant Neuropsychiatrist

Physiotherapists

Claire Rylance - Physiotherapist Nicola Birchall - Physiotherpist

Speech and Language Therapist

Zoe Healey -Speech and Language Therapist

Rachel Evans Speech and Language Therapist

If you need any help, information or advice during your journey on the CESS pathway please contact the CESS Co-ordinator or the CESS epilepsy nurse at BCH Tel: 0121 333 8184.

Your community paediatrician will still manage your care and medication until you've been seen in CESS clinic by the neurologists.

TYPICAL EXAMPLE OF CESS PATHWAY

Welcome to **Birmingham Children's Hospital** and **The Epilepsy CESS team**. This is an example of the typical journey that a child and family make during their time with CESS. By being on the pathway doesn't mean that you will definitely have surgery, each step taken is to find out more about your seizures and where in the brain they are coming from. From this and in dis cussion with you and your family we decide what the best options for you are. It can be a long journey, but the CESS team will support you along the way.



TYPICAL EXAMPLE OF CESS PATHWAY

Stage	Description of stage
1	Referral/Prelim MDT-3 weeks* Your doctor will have sent a referral to the CESS consultants. They will review your infor- mation and request any outstanding investigations that are required for the referral. They will discuss your case in a Preliminary Multi-disciplinary team meeting (MDT) with several professionals who will decide if you are a potential candidate for surgery.
2	Investigations-3-4 months* Following the Preliminary MDT you will receive a letter explaining the outcome of the meeting and if a candidate, what other investigations are required. You will then receive appointments for these investigations. Consultants may also want to meet you in an out-patients appointment before deciding any investigations or to get more details from you before discussing in Full MDT.
	Full MDT* Once you have had all the planned investigations and the results have been received these will be taken into a Full MDT to discuss if any surgical options are possible. In complex cases it may be decided that a National MDT discussion is also needed.
	National MDT -If required add additional 2 months* For patients that are 2yrs or under or are complex cases will be discussed in a National MDT. This is when professionals discuss your case with other hospitals to explore what are the best options. This happens once a month, so in these cases time on the pathway can take a little longer.
3	Possible further investigations If required, allow 3-4 months* Following the MDT they may decide that further tests are required to pin point the exact area of the brain seizures are coming from or what parts of the brain is responsible for certain functions (like language). Possible tests may be required like; MRI, fMRI, MEG, PET, Neuropsychology, Ophthalmology and Therapy clinic. Some tests may also have to be repeated like VT.
	sEEG Investigation- If sEEG or Grid required allow 6 months* If following the MDT it is decided that sEEG OR Grids are required, this will go to a sEEG MDT meeting. This is to plan the operation and where the location that the invasive electrodes will be positioned in order to best capture your seizures. (see sEEG information leaflet)
	Following all these investigations the results will all be compiled and it will be decided in MDT if or what are the possible surgical options. You will then be seen in clinic to discuss all of the results and if surgery is recommended, the consultants and surgeon will explain the procedure, any risks and chance of success.
4	Surgery waiting time- approx. 6-8 months If following the discussion with the consultants and surgeon you are happy to proceed with surgery you will be placed on the waiting list. You will normally be given a rough prediction of when this will happen and then receive a confirmed date 2-4 weeks prior to the surgery. *If have already waited for sEEG this will be taken off your waiting time for surgery.
	If surgery is not an option this will be discussed with you and other possible treatments will be explored. Other possible treatments include; the Ketogenic diet or a Vagel Nerve Stimulator (VNS). You will then be moved off the CESS pathway and into the care of the complex epilepsy clinic.
Follow be red Ketoge	ing surgery you will be regularly reviewed and if seizure free over 1 year medication may uced. If still having seizures other options will be explored like; additional surgery, VNS or enic diet.

*Time frames for pathway sections are approximate and may be longer as emergency patients will take priority.

Investigations

There are number of Investigations that we may ask for during your time within the CESS pathway. These different investigations enable us to build a picture of your epilepsy and to find out what parts of the brain your seizures are coming from and what areas of the brain are responsible for what functions (like language and memory). We will review the results of the investigations in MDT meetings to decide what are the best options moving forward, whether this be resective surgery or other options.

Investigation	Summary		
EEG	Electrodes on the scalp records the electrical activity of the brain. By looking at which electrodes detect abnormal electrical activity during a seizure can help workout which area of the brain the seizures are coming from. It also shows how a seizure develops and spreads. This is important information when deciding whether surgery is an option or which part of the brain future investigations should be focused.		
VT Or home LTM	This stands for Video Telemetry. This is the same as a EEG but your are also video recorded at the same time. By comparing the video of the seizures with the EEG helps the CESS team to work out which part of the brain is responsible for our epilepsy. This requires a hospital stay of up to 5 days. Sometimes a home LTM (Long-term electroencephalographic monitoring) may be possible. This is the same idea as a VT but done at home. The data from this is not can sometimes be not as detailed as a VT.		
3T MRI	This is the same as a MRI but on a 3T scanner. This is a stronger scanner than in most hospitals so the images are clearer and helps us find any abnormalities on the brain that might be causing your epilepsy.		
fMRI	This is another version of a MRI. By doing tasks during the scan it helps the CESS team work out which parts of the are responsible for language and memory. This information will determine what surgery might be possible.		
MEG	Your brain works by means of tiny electrical signals, which are often called "brain waves" or "brain activity". A MEG system (MEG stands for <i>Magnetoencephalography</i>), can measure brain activity and the scans produce an "activity map" of your brain.		
PET	This scan detects how your brain uses sugar. Areas in the brain that are responsible for seizures don't use sugar as well the rest of the brain. You are injected with a special dye and these areas are highlighted on the scanner.		
sEEG/ Grids	 sEEG -This is a small operation where electrodes are carefully implanted into the brain to detect the electrical activity from within the brain. Once implanted an EEG is recorded with video (like the VT) for up to a week. Then the electrodes are surgically removed. Grids - This is where strips of electrodes are placed on the surface of the brain, this is a larger operation than sEEG as it requires a flap in the skull to be made to place the grids. (Craniotomy) One of these may be required if the EEG/VT hasn't pinpointed accurately enough the exact area of the brain the seizures are coming from. 		
We may not ask for all of these investigations if we feel we have enough information to decide what options there are in your epilepsy treatment. Also some of these investigations are not done at BCH, fMRI and MEG are done at Aston University Birmingham and PET is done at St Thomas' in London.			

Investigations/Clinics

There will also be clinics that you will be asked to attend. These are to assess how your epilepsy is affecting you, what side of the brain some functions are coming from and how surgery may affect you. Clinics with the neurologists will be to help manage your epilepsy Pre/Post surgery and explain any procedure that is offered. If Surgery is an option you will also see Mr Walsh in clinic who will discuss the procedure, risks and the chances of success.

Investigation	Summary			
Neuropsychology	You will be asked to carry out some simple tasks. Some of them will be regarding your memory, some about your written skills, some about your speech skills and some about your number skills. Your parents will also have to fill in a questionnaire about how epilepsy has affected your life and skills. The idea of this assessment is to see whether the area within your brain that we are considering doing surgery on is responsible for any important functions. This assessment is also useful to determine if your epilepsy has left you with any memory or learning problems.			
Ophthalmology	Depending where in your brain the seizures are coming from you may need to see an ophthalmologist to see whether your visual fields have been affected by your epilepsy and how much surgery would impact on this.			
Therapy Clinic	Depending on the type of surgery that you may go on to have and your age, it might be beneficial to have a Therapy assessment of your speech and mobility skills - before and after surgery. This is done by out Therapy team either as an inpatient just before your surgery or in an outpatient clinic depending on individual circumstances and condition. We do this assessment because after surgery you may feel weaker and you may feel like you need a bit of extra help to get you back to your original strength. When you're sent home from hospital, the Therapy team will liaise with the teams that you may already be working with in your local area, to carry on with your different therapies. If you have a therapy assessment prior to surgery, this will be repeated 3 months and 12 months after you have had surgery.			
CESS Clinic	You will have a clinic with the CESS Neurologists who will explain the results of the investigations and any options moving forward with surgery. They can give you advice on your epilepsy and manage your medication once you have been seen.			
CESS Surgery Clinic	When you have had all the tests if surgery is an option you will have a CESS surgery clinic alongside the Neurologist CESS clinic . The surgeon will discuss the surgery with you and explain the risks and benefits and the chances of success. If you are happy with the proposed surgery you will then be put on the surgical waiting list.			
Following surgery you will have follow up clinic appointments with both the neurologists and surgeon to check how you are doing and if you have had any seizures. If you have haven't had any seizures 1 year post surgery they may be able to start weaning off your medication. If you have had seizures they will explore the other possible options like VNS.				

Ketogenic Diet or explore the possibility of further surgery.

What is a Clinical Psychologist?

Clinical Psychologists work with a wide range of psychological and physical health difficulties. This may include supporting children, young people and their families with medical procedures, making decisions about procedures or treatment and managing symptoms. Clinical psychology aims to promote wellbeing and adjustment, to help you manage the daily challenges associated with being under the CESS pathway.

If you are referred, a Clinical Psychologist may meet with you to complete an assessment and observation with the child, young person or family. This could be while you are an inpatient in hospital or as an outpatient, and could lead to advice, signposting to local services or charities, access to group support, or therapy sessions.

What is a Paediatric Neuropsychologist?

A Paediatric Neuropsychologist is a Clinical Psychologist who has completed additional training within the area of Paediatric Neuropsychology. Paediatric Neuropsychology aims to help understand how medical conditions (such as epilepsy) and any damage caused to the brain can have an impact on the development of skills such as memory and language.

What does Clinical Psychology do within CESS?

Clinical Psychologists work closely with the CESS clinical team, attending the multidisciplinary meetings. They undertake neuropsychological assessments as part of the decision making process and evaluation of surgery. They may also offer advice to the team on how best to support any emotional and mental health needs.

When to talk to a Clinical Psychologist?

There could be lots of reasons you may wish to talk with a clinical psychologist and these can change depending on where you are on the surgery pathway. Parents or the young person may wish to talk with a psychologist for emotional support, to talk about the assessment process or surgical treatment. Parents may have concerns about the child's behaviour, development or fears for the future. There could be concerns about the young person's anxiety, mood or risky behaviour. Sometimes it can be helpful to talk about difficulties or concerns. However, it is your decision if you would like to talk to a psychologist.

How can Clinical Psychology help?

The CESS Clinical Psychologists are part of the Health in Mind team. The Health in Mind team includes Clinical Psychologists, Learning Disability Liaison Nurses and Liaison Psychiatrists. It provides a service to children, young people and their families currently experiencing mental health difficulties associated with their underlying physical health condition.

The Health in Mind service offers group therapy programmes and individual therapy sessions for parents, the child or young person if appropriate. This may be face to face, by telephone or by video call. You can talk to the psychologist about which type of support would suit you and your family best.

Appendix-

1)Patient Information Leaflets

2) Travel/accommodation information

Investigations-				
EEG				
VT				
fMRI				
MEG				
PET				
SEEG				

Travel Information-Coming to BCH by- Train, Car etc. Parking Accommodation

EEG (electroencephalogram) for CESS

What is an EEG?

An Electroencephalogram (EEG) records the electrical activity of the brain by picking up the electrical signals from the brain cells. These signals are picked up by electrodes attached to the head and are recorded on paper or on a computer. The recording shows how the brain is working.

What does an EEG show?

An EEG gives information about the electrical activity of the brain during the time the test is happening. When someone has an epileptic seizure their brain activity changes. This change, known as epileptiform brain activity, can sometimes be seen on an EEG recording. Some people can have epileptiform brain activity even when they do not appear to be having a seizure, so an EEG can be particularly useful for them. Epileptiform activity can sometimes be provoked (brought on) by deep breathing. The test may include deep breathing to see if epileptiform activity can be provoked and recorded.



An example of an EEG recording

EEG for the CESS Pathway

By looking at which electrodes are stimulated during a seizure can help workout which area of the brain the seizures are coming from. It also shows how a seizure develops and spreads. This is important information when deciding whether surgery is an option or which part of the brain future investigations should be focused.

Video Telemetry (VT)

Video Telemetry is where you will have the EEG electrodes attached to your head and also be filmed. For this to happen, you will need to come into hospital for a period of up to five days - usually on a Monday and discharged on a Friday. You will stay on the ward where a video camera is attached to your bed to capture your seizures. This is so that we can see when you're having a seizure and from which part of the brain the abnormal epileptic electrical activity is coming from.

Ambulatory EEG/ Home LTM (Long Term electroencephalogram Monitoring)

An ambulatory EEG works in the same way as a normal EEG but is portable. During the test, you wear a small machine on a belt around your waist. Because it is portable you can move around and carry on with your normal day-to-day routine while the recording happens.

This type of EEG allows brain activity to be recorded for several hours, days or weeks. Because the brain activity is recorded for longer, there is more chance of a seizure being recorded than during the normal 30 minute test.

With LTM similar to ambulatory but like with VT you will also have cameras to record any seizures Sometimes this may be chosen instead of VT, If the VT hospital admission would be difficult, but VT is preferred option.

Video Telemetry information

Your Doctor has asked you to come in to Birmingham Children's Hospital for a Video Telemetry Investigation. Video Telemetry is similar to an EEG but you will be monitored continuously for up to 5 days while you stay in hospital. Small discs will be placed on your head with a sticky paste and fixed with special skin glue. These wires are connected to a computer and record your brain activity alongside video monitoring throughout your stay.

The investigation is painless, once the electrodes are in place you will probably forget they are there. We ask that an adult family member stay with you on the ward for the week, to look after you and to let us know when attacks occur. You will have to stay in the bedspace with the equipment throughout your stay. Please bring games, books, DVDs and homework (if you want!) to keep you entertained. We have a hospital school and play specialists that can come and help you with your own homework or do some activities. It is easier to wear tops that button up, shirts, pyjamas or onesies as it makes it easier once the electrodes are in place, but don't worry if you don't have any items like this.

As a result of staying in the bedspace you will not be able to have showers or baths, just washes. In addition if you need the toilet you will be asked to use a commode which will be outside camera sight, next to your bed. We are aware that this is very difficult and can be worrying for some children but we need to monitor you for as much as we can over the space of 5 days and cannot afford to miss data if you are disconnected from the equipment.

If you have any problems or questions about the test, please contact us on the number on the attached letter. Please be aware on the morning of your test prior to leaving to come to us, before you set off to come to the hospital wait till you receive a call from us. This is to ensure bed availability and confirm your appointment.

- In some situations, beds are not available due to emergencies and your test may have to be rescheduled, to another time or another day.
- You will be asked to come straight to Neurophysiology on the Ground floor of BCH to have the electrodes applied before we then take you to Ward 10 and settle you in your bedspace.
- Whilst you are in hospital your medicines may be reduced and you may have some of your usual attacks. Don't worry, someone will always be with you. (Do not reduce your medications unless you have been advised to by your Doctor or the Clinical Neurophysiologist performing the test). Please can you bring all your medicines in their original packaging when you come in for this test.
- We might ask that on some nights you stay up late and we wake you up early to try and increase the chance of capturing some of your attacks. Once we capture a few examples of your attacks we will be able to remove the electrodes and let you go home. If your medications have been stopped we may wait until your medication is restarted to make sure you are well enough to go home.
- There are no side effects from this investigation, although some children can become sore from the electrodes as they are applied for the whole week. This will subside after showering/bathing and some cream is applied.
- After the investigation has been completed the recording has to be analysed by the Consultant Neurophysiologist. The results will be sent back to your Doctor and discussed in a Multi-Disciplinary Meeting which can take several weeks.

Functional MRI (fMRI) - Information Sheet

These notes give some information about functional MRI scan for language mapping

MRI is a method for producing images of the brain. It involves placing the participant inside a large, powerful magnet which forms part of the brain scanner. In addition MRI can be used to determine which parts of the brain are active during different tasks – this is known as functional MRI or fMRI. When particular regions of the brain are active, they require more oxygen, which comes from red corpuscles in the blood. As a result, the flow of blood increases. This can be detected as changes in the echoes from brief pulses of radio waves. These changes can then be converted by a computer into 3D images. This enables us to determine which parts of the brain are active during different tasks.

As far as we know, this procedure poses no direct health risks. However, the Department of Health advises that certain people should NOT be scanned. Because the scanner magnet is very powerful, it can interfere with heart pacemakers and clips or other metal items which have been implanted into the body by a surgeon, or with body-piercing items. If you have had surgery which may have involved the use of metal items you should NOT take part. Note that only ferro-magnetic materials (eg steel) are likely to cause significant problems. Thus normal dental amalgam fillings do not prohibit you from being scanned, though a dental plate which contains metal would do so, and you would be asked to remove it. You will be asked to remove metal from your pockets (coins, keys), remove articles of clothing which have metal fasteners (belts, bras, etc), as well as most jewellery. Watches and credit cards should not be taken into the scanner since it can interfere with their operation. You will be asked to complete a Consent & Safety Information Form which asks about these and other matters to determine whether it is safe for you to be scanned.

In addition, you are asked to give the name and address of your Family Doctor. This is because there is a very small chance that the scan could reveal something which requires investigation by a doctor. If that happens, we would contact your doctor directly. By signing the consent form, you authorise us to do this.

To be scanned, you will lie on your back on a narrow bed on runners, on which you will be moved until your head is inside the magnet. The scanning process itself creates intermittent loud noises, and you must wear ear-plugs or sound-attenuating headphones. We are able to talk to you while you are in the scanner through an intercom. During the scan you will be able to alert the staff by activating an alarm and will then be removed from the scanner quickly. It is important that you keep your head as still as possible during the scan, and to help you with this, your head will be partially restrained with padded headrests. We shall ask you to relax your head and keep it still for a period that depends on the task you are performing but may be more than one hour, which may require some effort on your part. If this becomes unacceptably difficult or uncomfortable, you may demand to be removed from the scanner.

You will be asked to look at a screen through a small mirror (or other optical device) placed just above your eyes therefore you must be able to see the screen. **If you need to wear contact lenses please make sure you wear them on the day of the scan.** The details of the task will be explained to you just before the scan. Detailed instructions will be given just before the scan, and from time to time during it.

We usually allow 2 hours for this procedure although this may be shorter on the day. If you have any questions before the scan appointment please contact us as soon as possible.

MEG Information Sheet

What is MEG?

Your brain works by means of tiny electrical signals, which are often called "brain waves" or "brain activity". A MEG system (MEG stands for *Magnetoencephalography*), can measure brain activity and the scans produce an "activity map" of your brain. MEG doesn't hurt, and there are no known side effects. You won't feel any differently afterwards, and you won't need to change your activities or rest after your scan.

What sort of information does MEG provide?

People have MEG recordings for many different reasons. Sometimes their doctor sends them for a recording to help decide how to best treat them. Some people volunteer for a recording to help in research. MEG recordings can help answer questions such as:

- 1. What activity is the brain producing and where in the brain does it come from? For example, MEG can be used to measure brain activity associated with relaxation, migraine, or epilepsy.
- 2. Which part of the brain undertakes different tasks? For example, MEG can determine exactly which bit of your brain controls actions such as speaking or moving arms and legs.
- 3. *How does the brain work?* MEG researchers are working to further understand the way in which the brain functions, both normally, and when something goes wrong.

What will happen during my MEG recording?

When you arrive, one of the MEG team will meet you, explain what will happen, and answer any questions you have.

Please arrive for your appointment with your hair down with no grease, oil or other hair products in your hair. Please do not have your hair in plaits, braids, cornrows, dreadlocks or with any additional permanent hair weaves or hair extensions, as the excess height may not allow your head to fit in the scanner. Also some braids may have metal clips. If you wear metal braces please contact our Clinic Administrators on 0121 204 3882 in advance of your appointment.



Before your recording you will be asked to remove any metal objects you are wearing; this is because metal objects interfere with the MEG system. Metal objects include mobile phones, watches, coins, credit cards, jewellery, glasses, and clothes that contain metal (e.g. tops with zips, bras, shoes). It is therefore a good idea to wear as little metal as possible when you come for your recording – a tracksuit or similar is ideal. Also, some make-up contains metal fragments so therefore we ask that you do not wear any make-up.

You will then have 5 small sensors attached to your head (3 on your forehead and one behind each ear), which record where your head is in the scanner, and a special pen is traced around your head. This is so that an accurate computer picture of the shape of your head can be produced.

MEG Information Sheet - Cont.

You will then be taken into the special room where the MEG system is – this room has been specially designed to reduce artefacts from the environment so the small brain waves can be recorded by the system. In the MEG room you will sit on a chair, which moves you up slightly so that the top of your head is in the MEG helmet. (A picture of this is shown to the right).

Somebody will be with you all the time, and if you would like a friend or relative to sit with you, just ask one of the MEG team.

The MEG system is very quiet, so you will be told when the

recording starts, and to keep very still during the scan. You may be asked to perform a task while you are being scanned, such as

tapping your fingers, or looking at pictures.

How long will my MEG recording take?

Different types of recording take different amounts of time. As a rough guide, you can expect to be in the MEG unit for around 1-3 hours for a clinical recording, and between 1-2 hours for a research study.

What happens to my results?

After your recording you may have other tests done, such as an MRI (this stands for Magnetic Resonance Imaging and gives a picture of the structure of your brain). You will be given details of these tests separately.

Your MEG recording takes a long time to analyse, so you won't be given any results on the day (although you can ask to see your brain activity on the computer screen). If your MEG recording is for clinical reasons, the results of your recording will be sent to your doctor, who will contact you when they are ready. You will probably have other tests done and your doctor will use the information from all the tests to help decide on the best way of treating you. If your MEG scan was for research (not arranged by your doctor), then there are no results, as your recording is simply used to help find out about how the brain works.

Do I need to do anything before my MEG recording?

Generally, you do not need to do anything before your scan: you can eat and drink normally and do everything you normally do. You should dress in comfortable clothes and avoid wearing any clothes that contain metal. If you are on medication, you should continue to take it as normal UNLESS your doctor has told you not to. If you have a mobile phone, you should turn it off when you arrive at the MEG unit, as it interferes with the MEG system.

MEG Information Sheet - Cont.

Where is the MEG system?

The MEG system is in the Aston Brain Centre at Aston University in the centre of Birmingham. At the University you should go to the Aston Brain Centre and use the phone at the front door to tell the team of your arrival. You will then be directed to a waiting room. There are some free car parking spaces next to the Aston Brain Centre; please ask for a permit when you arrive as this needs to be displayed in your vehicle. If your doctor has arranged for an ambulance or taxi to collect you, and it does not arrive, please telephone to let us know.

What is the difference between a clinical and a research recording?

Both clinical and research work is carried out at the MEG unit, and the procedures are very similar. Someone having a clinical recording is referred by their doctor, and the results are used to answer a specific question that will help their doctor make a diagnosis, or decide on the best course of treatment. Their results are sent to their doctor. Someone having a research recording has volunteered to take part in a research project that aims to find out more about how the brain works, or to improve a clinical test. The researchers analyse the MEG recording, but there are no results. Only doctors can refer people to have a clinical recording, but anybody can volunteer for a research recording. Please tell one of the MEG team if you would like to know more about current research projects, or would like to volunteer to take part in research projects.

Remember

- MEG doesn't hurt and it isn't harmful.
- The MEG team are very friendly just ask if you want them to explain something to you or if you are unsure about anything.
- Try not to wear any metal, and if you have contact lenses, wear them instead of your glasses.
- If you require any further information please contact our Clinic Administrators on: 0121 204 3882 or <u>abc_admin@aston.ac.uk</u>



Your child's PET - CT scan at Guy's and St Thomas' NHS Foundation Trust The aim of this leaflet is to answer some of the questions you may have about PET-CT scanning and to help you prepare your child for the scan. If you have any further questions or concerns, please contact the PET Imaging Centre on 020 7188 4988. They will be happy to speak with you about the procedure.

What is PET-CT scanning?

A PET-CT scan - Positron Emission Tomography coupled with Computerised Tomography takes three dimensional images of your child's body. This allows us to see if your child's organs are working normally. Before your child has a PET-CT scan, we inject him or her with a small dose of a substance called a 'tracer' (usually a form of slightly radioactive sugar – the dose varies with the weight of your child). The tracer goes to the tissues which can then be seen by the scanner as a three dimensional image. PET-CT scans are different from other scans your child may have had, such as X-rays, diagnostic CT, ultrasound or MRI. This is because these scans show us what tissues look like, while PET-CT scans show us how the tissues are working.

What are the benefits of PET-CT scans?

PET-CT scans help us to get important information about a range of conditions that can affect the organs of a child. For example, they can help to tell us more about epilepsy, cancer and heart conditions. PET-CT scans help your child's doctor to plan the best possible treatment.

Are there any alternatives?

Other imaging tests, such as a CT or MRI give different information than a PET-CT scan and are not considered an alternative. Your child has been referred for a PET-CT scan because your doctor feels it is the best way to get the information he/she needs to decide which treatment is best for your child.

Are there any risks associated with PET-CT scans?

Tracer injections

There have been no documented side-effects with tracer injections, such as sickness or feeling unwell.

Radiation

All radiation carries a risk but the risk of radiation-induced cancer is much smaller than the natural risk of cancer. 1 in 3 people in the UK develop cancer, where as the additional risk of a fatal cancer associated with this type of imaging examination using radiation, is about 1 chance in 1000.

We always check that the PET-CT scan is the best way to get an answer to your child's medical problem. And we always use the lowest possible radiation dose to get the scan your doctor needs. The amount of radiation your child will receive is equivalent to four years exposure to natural background radiation.

Any examination with general anaesthetic carries a slight risk. The level of risk depends on your child's general health and the complexity of the procedure he or she is having. These risks will be discussed fully with you by the staff caring for your child. The Trust's leaflet, Having an anaesthetic, gives more information about the risks and side-effects associated with having a general anaesthetic. If you do not have a copy, please ask us for one.

Your child's PET - CT scan. Cont.

How co-operative will my child need to be?

PET-CT scanning is a relatively simple test but to get the best results some co-operation is needed from both the child and the parents or carers.

Parents and carers can stay with the child throughout the scan. However, exposure to radiation should be avoided if you are pregnant – please speak to the PET Centre staff about this before attending the appointment.

Asking for your consent

We want to involve you in all the decisions about your child's care and treatment. If you decide to go ahead, you will be asked to sign a consent form on behalf of your child. This confirms that you agree to your child having the procedure and understand what it involves. You should receive the leaflet, Helping you decide: our consent policy, which gives you more information. If you do not, please ask us for one.

If your child is very young, has behavioural difficulties or is unable to lie still for the scan he/ she may need sedation or a general anaesthetic.

In this case:

- we may ask your GP or hospital doctor to do some blood tests before the procedure
- to make sure it is safe for your child to have the anaesthetic
- he/she will need to stay in hospital longer either for the day or overnight
- you will be asked to sign a consent form to give us permission to do the procedure with an anaesthetic.

How can I prepare my child for the PET-CT scan?

Food and drink

We will ask you not to give your child anything to eat:

- 1) for three hours before the scan for a brain scan
- 2) for six hours before the scan for a body scan.

If your child is having a heart scan, he or she may have to go without food - it depends on the type of scan being performed. We will give you clear instructions in the appointment letter.

Unflavoured water can be given at anytime. This makes sure that your child does not get

dehydrated and also helps us to get the best scan possible. If however your child is having a general anaesthetic we will give you specific instructions.

Clothing

If your child is having a body or a heart scan we suggest that he/she wears something loose and comfortable for the scan. As part of the exam includes a limited CT scan it is important that your child is not wearing any metal, including jewellery, watches, zips and bra hooks. We will provide a hospital gown.

Talk to your child

Preparing your child for the visit to hospital and the PET-CT scan will help him/her to understand what is happening. From a young age, children are keen to talk about what they know about hospitals. Talking to your child in advance will give him/her time to ask any questions or raise any concerns. Children tend to be more co-operative when they know what is happening to them. Use familiar words that your child will understand and give truthful, factual information. Explain that your child will meet doctors and nurses and that they should only have to stay in hospital for about half a day (or maybe overnight if they are having an anaesthetic). More information can be found in the leaflet, **Your child's outpatient visit to the Evelina Children's Hospital**. If you do not have a copy, please ask us for one or contact the Knowledge & Information Centre (see back page for contact details).

Your child's PET - CT scan. Cont.

Will my child feel any pain?

The scan itself is not painful. However, a cannula (plastic tube) will be put in the back of his/ her hand or arm to give the tracer injection and any anaesthetic. We can make this as pain free as possible by using Emla cream. This cream temporarily numbs the skin and helps to reduce any discomfort when putting the cannula in.

What happens during your visit for the scan?

This depends on the type of scan, and will be fully explained to you and your child by ourstaff when you arrive.

General procedure

- Emla cream will be put on the back of your child's hand or arm (if this has not been done at home).
- The imaging staff will explain the procedure in full and take a short medical history.
- A nurse will then place a small cannula (plastic tube) in the most easily available vein (usually in the back of the hand or in the arm).
- We will then move your child to a quiet room to have the tracer injection and to relax for up to 90mins before the scan. This period of time, called the 'uptake period', allows the tracer to circulate in the blood stream and go into the tissues this helps us see them on the scan.

If your child is having a brain scan he/she should not be distracted (by for example talking, music or games) during this period as these activities can affect the look of the scan.

- If your child is having a body scan, this is not such a problem. He/she can watch a DVD or listen to music. However, it is still important that your child relaxes quietly so the tracer goes to the areas we need to do the scan, rather than his or her muscles.
- Your child can also use the toilet if needed
- After this period of relaxation, a nurse will position your child on the PET/CT scanner couch and make him or her as comfortable as possible. Your child will be asked to lie very still for the scan. You can stay with your child throughout the procedure although we do ask that you do not distract them and cause them to move their head or wriggle.
- We may take pictures of all of your child's body or just the part that we have been asked to examine.
- Once the scan is completed you can give your child refreshments and either go home or recover on the ward (if he/she has had sedation or a general anaesthetic).

PET-CT brain scans

PET/CT brain scans are performed for children with a variety of conditions including epilepsy, brain tumours and movement disorders. The scan usually takes about 10 -15 minutes.

- If your child is suffering from epilepsy it is important to tell the PET Centre doctors if your child has an epileptic fit during the period between the tracer injection and the scan. We will also do an EEG (electro-encephalogram) after the injection of the tracer to monitor brain activity this will also spot any fits that cannot be seen by just watching your child. The doctors reporting the scan need to know if a fit has happened as this can change how they report the scan findings. Most children who suffer from epilepsy will be familiar with having an EEG.
- If your child has a brain tumour it may be necessary to use two different radiotracers to look at brain tumours. If this is the case then two scans, one after the other, will be performed on the same day. We can deliver both injections through the same cannula so will only need one needle. The procedure is longer and a bit more complicated but staff will explain this to you and your child in more detail.
- If your child has a movement disorder it is usually necessary to give your child an anaesthetic for the scan so that they can remain still.

Your child's PET - CT scan. Cont.

PET-CT brain scans

PET/CT brain scans are performed for children with a variety of conditions including epilepsy, brain tumours and movement disorders. The scan usually takes about 10 -15 minutes.

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Invasive monitoring with Stereoelectroencephalography (sEEG)

This leaflet explains about invasive monitoring with steroelectroencephalography (sEEG) for epilepsy and what to expect when your child comes in to Birmingham Children's Hospital (BCH) to have this procedure.

What is invasive monitoring?

Invasive monitoring is a very specialised and detailed way of confirming the exact area of the brain causing your child's seizures (fits) and the exact areas of the brain being used for important tasks such as speech or movement. sEEG involves an operation to insert electroencephalogram (EEG) electrodes into the brain. These EEG electrodes are then connected to an EEG (electroencephalogram) monitor so that clinical physiologists can record your child's brain activity over several days.

Why does my child need this test?

The procedure will be carried out if doctors think that your child's epilepsy might be relieved by an operation to remove part of their brain but previous tests have not been able to determine the exact area or we believe the area involved may have an important function. Previous tests will have already given the team some idea which area of your child's brain needs closer observation. This test will help to confirm which area of your child's brain is causing seizures. sEEG, together with other tests, can sometimes also help the epilepsy team to check exactly which areas of the brain your child needs for essential tasks, like movement or speech. This is important to know, as it indicates whether surgery to help their epilepsy would put these functions at risk.

How do the doctors decide if my child needs this procedure?

Once the epilepsy team has seen all the results from previous tests, they will discuss whether sEEG will help them to decide whether surgery is an option for your child. You will be asked to attend the epilepsy surgery clinic to discuss this with the team. At this clinic, you will meet both a neurologist and a neurosurgeon and we will explain fully the risks and benefits of the test to you and your child. We will send you a letter following your epilepsy surgery clinic appointment summarising the benefits and risks of surgery for your child. The epilepsy team will then ask you to think about the information given to you and decide whether you want your child to have this procedure. If you decide to proceed, the team will then plan a date for the procedure and offer you the date by letter.



X-ray showing electrodes and holders in place in the brain

What are the risks of this procedure?

Your child will be given a general anaesthetic (which puts them deeply to sleep) for the operation to put the electrodes in place. Healthy children usually cope well with the anaesthetic, but the risk increases if your child has other health problems. However, the specialist doctors (anaesthetists) who look after vour child during the operation will keep any risks to a minimum. Your child may feel sleepy, dizzy or sick afterwards. Children are routinely given medicine for sickness and for pain. There is a small chance of bleeding (about one per cent) within the brain. Occasionally, if this bleeding is putting pressure on the brain, a further operation may be needed to remove the blood, but this is very rare. There is also a very small chance of surgery causing damage to the brain. After the operation to put the electrodes in place, it is often necessary to reduce or stop your child's antiepileptic drugs while they are having sEEG. This is so that your child is more likely to have a seizure while in hospital. The

doctors will decide this with you when you and your child come into hospital for the procedure. If your child has had a number of seizures recently, even though they are taking antiepileptic drugs, they may be able to continue taking them during the test. There is always a risk in reducing or stopping your child's drugs suddenly for this procedure, as it may cause your child to have a longer or more intense seizure than usual. However, the doctors and nurses will monitor your child closely to try to stop this happening and an emergency medication plan will be in place to ensure your child's safety.

What happens before the operation?

You will need to come to Ward 10 the day before the operation. This is to make sure that your child is well enough to have the operation. A doctor will examine your child and may take a repeat blood sample to check that his or her blood parameters (for example, clotting tests, full blood count) are fine. The neurosurgeon will explain about the surgery in more detail, discuss any worries you may have and ask your permission for the operation, by signing a consent form. Another doctor will also visit you to explain about the anaesthetic. Occasionally, some children need neuropsychology testing and a further scan before the operation, but we will let you know if this is likely before you come into hospital. If your child has any medical problems, for instance, allergies, please tell the doctors about these. If your child has had any infectious diseases like chicken pox or head lice recently, please tell the doctors. The procedure may be cancelled if head lice have not been treated successfully before admission. Before the operation, your child will need to have a bath and a hair wash with a special soap.

What does sEEG surgery the involve?

The operation to insert the electrodes will be carried out under a general anaesthetic. This means that your child will not feel any pain during the operation. Part of your child's head will be shaved to allow the surgeon to see clearly where the electrodes will go. This will be done while your child is under the anaesthetic. The procedure involves applying a Leksell stereotactic frame followed by a CT scan which is fused to the MRI scan used to plan the position of the SEEG electrodes. This enables us to precisely insert the electrodes to the planned predetermined points and avoid the brain's blood vessels. The electrodes are inserted with the aid of a surgical robot. The electrodes themselves are very small (0.8mm diameter), the surgeon will drill a number of small holes (just over 1mm in diameter) in your child's skull to thread the electrodes into his or her brain and a small metal holder is attached to secure each electrode in place. After the operation, your child will have many wires coming from his or her head. These wires will be fastened with tape and bandages so that they cannot be pulled out of place while your child is on the ward. Also, your child will have a allocated nurse with them 24 hours a day to make sure this does not happen.

What happens following surgery?

Once the operation to insert the electrodes is over, your child will stay on Ward 10 in one of the telemetry beds. He or she will be connected to the EEG and video monitoring equipment, usually for seven days, while the epilepsy team confirm which area of the brain is causing your child's seizures. We need 3 clear examples of a seizure to clarify the areas the seizures start. Your child will have to remain in the bed space 4 during this time attached to the monitors which means you will need to use the commode or urinal bottles at the bedside. Your child will have their own nurse for this time, who will look after and monitor them closely. He or she will take various measurements like blood pressure and heart rate every hour while the electrodes are in place and also take blood samples for testing. Your child will have a CT the day after implantation to check the position of the electrodes and to make sure that nothing has occurred (like bleeding etc.) You may notice that your child's face is a little swollen. This is temporary and will begin to improve after two to three days. Your child may also feel, or be, sick after the operation to insert the electrodes and may need some medicine to treat this.



What happens after the procedure?

Your child's stay in hospital is likely to last between around 7 days may be a little longer. The electrodes are usually removed in the operating theatre with a general anaesthetic after seven days, but sometimes a longer period of recording is needed. The length of recording depends on what happens in the first few days of the test and we will keep you and your child updated during the monitoring. Once the neurophysiology team have carried out all the monitoring, the epilepsy team will discuss the results with you. This may include whether the area responsible for seizures has been located, whether an operation can be offered and what risks there are. Sometimes more analysis of the results will be needed after your child has had their test and if this is the case for your child, the results will be discussed with you in clinic after the test. In 20 per cent of cases, despite invasive monitoring, it is still not possible to identify the area where the seizures are starting.



Stimulation Studies

The epilepsy team will let you know if they are planning to carry stimulation studies. This involves the doctors using the electrodes to stimulate parts of the brain. In some children having sEEG, the stimulation may be used to try to find out more about the activity which occurs when a seizure is happening. The team will also sometimes use stimulation to test if the areas of the brain where seizures start are also important for other functions such as moving arms or legs Your child will probably have an intravenous drip via a cannula until he or she is drinking enough fluids.

Are there any alternatives to this procedure?

Your child's doctors can tell a lot from an EEG and other tests and brain scans, but sEEG can help them to be sure exactly which part of your child's brain is responsible for their epilepsy. This is particularly helpful where brain scans have not shown an abnormality, but is also useful if your child has a large abnormality on their brain scan or may have seizures starting near an area that is also controlling one of your child's useful functions.

Traveling and Accommodation

Traveling to BCH



1) Parent & visitor parking

Parking is available at the NCP Royal Angus Car Park located on Whittall Street, B4 6HD opposite the hospital or Printing House Car Park located on Printing House Street B4 6DE.

Blue Badge holders must pay to park in any of the car parks highlighted but they can park for free if they use the "Disabled Spaces" allocated on the roads around the hospital site. A current blue badge must be displayed.

Please refer to the <u>parkopedia website</u> for the most up to date information on local car parks and charges.

Traveling to BCH Cont -



Key:

- 1. NCP Royal Angus Car Park which offers Birmingham Children's Hospital PAYG subsidised rates.
- 2. Loveday Street drop off point only.
- 3. Printing House Street is a PAYG car park.
- 4. NCP Londonderry House Car Park.
- 5. NCP High Street Car Park £1 per hour for the first 8 hours.
- 6. Birmingham Children's Hospital main entrance drop off point only.

Car parking charges

Royal Angus - The Pay as You Go validation is at the Welcome Desk which allows users to access the tariff in the table below. You take your ticket as you enter the Royal Angus then validate your ticket at the Welcome Desk at the main entrance either as you come in or as you leave the site; once the ticket is validated you pay at the pay machine within the car park the charges outlined

Printing House Car Park (pay & display) – the payment machine for this is located within the car park and you do not need to validate your ticket.

Train

It is easier and cheaper if possible to travel by train. The closest train station to Birmingham Children's Hospital is Birmingham New Street Station. Directions from each station are below.

New St Birmingham	Birmingham Snow Hill	Birmingham Moor Street
Walk east on New St	Walk north-east on	Walk north-east on Moor
towards Stephenson Pl	Colmore Row towards	Street Queensway
	Colmore Circus	towards Carrs Ln
Turn left onto	Queensway	
Corporation St		Turn left onto Albert St
	Turn right onto	
At the roundabout, take	Colmore Circus	Turn right onto Dale End
the 2nd exit onto The	Queensway	
Priory Queensway		Turn left onto Newton St
	Turn left to stay on	
At the roundabout, take	Colmore Circus	At the roundabout, take
the 1st exit onto	Queensway	the 1st exit onto
Steelhouse Ln		Corporation St
	At the roundabout,	
Turn left onto Whittall St	take the 1st exit onto	Slight left onto Newton St
	Steelhouse Ln	
		Turn right onto
	Turn left onto Whittall	Steelhouse Ln
	St	Turn left onto Whittall St
Pirminghom Children/s	Birmingham Childron's	Birmingham Childron's
birningham Children's		Hospital
Hospital	nospital	Ποδριταί

Traveling and Accommodation

Accommodation

If your child is going to be in hospital for more than three days - or there are special circumstances - you may be able to stay in the parents' accommodation, which is on the second floor of the hospital, or at Ronald McDonald House nearby.

On the second floor of the hospital

The parents' accommodation, which is free-of-charge, has nine twin rooms and four single rooms. Rooms are usually available for parents and carers whose children are very poorly or if there are particular considerations, such as if you're disabled or have travelled a long distance.

Ronald McDonald House

A house next door to the hospital where parents can stay if there is room.

Ronald McDonald House Birmingham, which is run by independent charity Ronald McDonald House Charities, is a free-of-charge "home-away-from-home," just a few minutes' walk from your son or daughter's ward.

Unfortunately, it's not possible to reserve a room ahead of your stay or to be guaranteed a room. If you would like to stay, please tell the nurse on the ward when you first arrive. He or she will contact the relevant accommodation. If there isn't a room immediately available, your name will be put on a waiting list and you'll be informed when a room becomes vacant.

Hotels

Birmingham Children's Hospital has secured preferential rates with the following local suppliers, all of which are within a 2 mile radius of the hospital. Please quote Birmingham Children's Hospital when you are booking.

Holiday Inn Express Snow Hill (Hotel)	Staybridge Suits Birmingham (Apart- ments & Hotel)
Colmore Plaza	
Birmingham B4 6HY	One Martineau Place
Reservation: 0121 647 3999	Corporation Street
	Birmingham
Premier Apartments Birmingham	B2 4UW
	Reservations: 0121 289 3636
Dean House	Email: reservations@birmingham.staybridge.
38 Upper Dean Street	com
Birmingham	
West Midlands	IBIS Styles Birmingham Centre (Hotel)
B5 4SG	
Reservations: 0121 666 4444	65 Lionel Street
Email: gm@premierapartmentsbirmingham.	Birmingham
com	B3 1JE
	Reservations: 0121 200 1900
	Email: H9130@accor.com
Dean House 38 Upper Dean Street Birmingham West Midlands B5 4SG Reservations: 0121 666 4444 Email: gm@premierapartmentsbirmingham. com	Email: reservations@birmingham.staybridge. com IBIS Styles Birmingham Centre (Hotel) 65 Lionel Street Birmingham B3 1JE Reservations: 0121 200 1900 Email: H9130@accor.com

We have updated our Privacy Notices in line with the data protection legislation (General Data Protection Regulation (GDPR)/Data Protection Act 2018. For more information about how we use your personal data please visit our website at:

https://bwc.nhs.uk/privacy-policy

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