**WP2 Information about the project for therapists and supervisors**

**Project title: Mental health in children with epilepsy trial**

We work at Great Ormond Street Hospital and the Institute of Child Health. We would like to invite you to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve for you.

Please read through the following information carefully. Take your time to decide whether or not you wish to take part. Please ask us if there is anything that is not clear or if you would like more information.

**What is this project and why are we doing it?**

We know that children and young people who have neurological problems like epilepsy are more likely to have other difficulties like anxiety, low mood or behavioural problems. We want to find the best way of treating such problems, which can impact so much on all areas of life including family, friendships and education.

At the moment, there is an unmet need for mental health services in children and young people with epilepsy. Additionally, mental health treatments are not specific to children and young people with epilepsy and these treatments are delivered face-to-face**,** necessitating travel costs, time and absence from school (and work for carers) for appointments. Additionally, mental health services are separate from epilepsy services.

This study is part of the second stage of a larger research project on this topic. In the first stage of this larger research project, a psychological treatment for children and young people was developed. This was done by using an existing treatment – the Modular Approach to Therapy for Children (“MATCH”) – that has been shown to work in children and young people (but not those with epilepsy specifically) and adding some epilepsy-specific materials to it to make it more relevant to children and young people with epilepsy and their families. This is the treatment that you have received training on, in what has been the initial part of the second stage of the larger research project.

Now, in the remaining part of this second stage, we would like to find out what you think of the training. We also want to find out what you and families think of the therapy.

**Why have I been asked to take part?**

We are contacting individuals who attended the training on MATCH to see if they might be eligible and willing to take part in our study.

**Do I have to take part?**

No. It is up to you whether you want to join the study. We will describe the study and go through this information sheet and if you agree to take part, we will then ask you to sign a consent form.

**What will happen if I don’t want to carry on with the study?**

You are free to withdraw at any time, without giving a reason. This would not affect your rights.

If you do withdraw from the study, the information that you have completed up to that point will be used in the analysis of the study results. If you prefer for this data not to be used, please let a member of the research team know.

**What will happen to me if I take part?**

Before you start delivering the treatment to families, you will be interviewed about your views on the training you have received. Then, you will be interviewed both during and after you deliver MATCH to families. The interviews will take place in person, or over the telephone/skype, and will take about 45 minutes. The purpose of these interviews is for us to learn about your experiences of the therapy, and to use your feedback to modify it further. For example, we may ask you for your opinion on improvements that could be made to the therapy.

All interviews will be audio/video recorded to allow us to consider your feedback in detail. All recordings made during the study will be transcribed by a transcription service and any information that would make you identifiable from the transcriptions would be removed. The recordings and the transcriptions will be kept confidential and will be stored and accessed as described in the ‘*Will my taking part in the study be kept confidential?*’ section below. All recordings and transcriptions will be stored and accessed for less than 3 months after the study has ended, after which they will be destroyed confidentially in keeping with University College London and Great Ormond Street data protection policies.

We will cover travel expenses of participants who make additional visits to sites to take part in the research.

**What are the benefits of taking part and is there anything to be worried about if I take part?**

The information we get from this study will help improve the treatment of children with anxiety, low mood or behavioural problems in the context of a neurological illness like epilepsy.

There are no risks from taking part in the study.

**Will my taking part in the study be kept confidential?**

If you join the study, your data collected for the study will be looked at by authorised persons from research or clinical team at the UCL Institute of Child Health and Great Ormond Street Hospital. This information will be transferred securely and entered onto a confidential database stored in the UCL data safe haven and a Great Ormond Street Hospital confidential database. It may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and will do their best to meet this duty, Please note that in the event that you disclose any information that suggests a risk of harm to you or others, we have a legal duty to disclose this information to the relevant bodies.

All your personal data will be stored and accessed for less than 3 months after the study has ended, after which time it will be destroyed. Your personal data – which includes your audio and video recordings – will only be accessible to the research team, although in the event of a sponsor-led audit or inspection, the individual carrying out this audit or inspection would also require access to your personal data in the course of their duties.

**What will happen to the results of the study?**

We will write to you to let you know the overall findings of the study. We hope to publish the findings of the study. No names or other identifiable information will be used in any reports or publications. Direct quotes will be anonymised, however confidentiality cannot be guaranteed.

**Who has organised the research?**

All research in the NHS is looked at by a Research Ethics Committee. This project has been checked by the South Central – Oxford A Research Ethics Committee.

**Who do I speak to if I have more questions or worries?**

If you would like further information please contact:

Contact: Professor Roz Shafran

Address: UCL Great Ormond Street Institute of Child Health, 30 Guilford Street, London, WC1N 1EH

Email: gos-tr.mice@nhs.net

Telephone: 020 7905 2232

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) Office at Enter Site PALS details (telephone: or email: ).

If you suffer an injury and you suspect that itis the result of the Sponsor’s (Great Ormond Street Hospital) negligence then you may be able to claim compensation, please discuss this further with the research team. Cover for negligent harm will be provided by the Great Ormond Street Hospital for Children NHS Foundation Trust through the Clinical Negligent Scheme for Trusts (CNST) and University College London.

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