

INFORMED CONSENT FORM

Dr. Zarine Mogal and Dr. Hiba Mahmud, under supervision of Prof. Hasan Aziz, are conducting a pilot study in collaboration with the "EpiNet Study Group" to create a secure Internet-based platform that can be used to run a multi-centre epilepsy database.

EpiNet Study Group is a group of doctors and associated research assistants who have an interest in epilepsy, and who have come together to undertake research into the optimal management of patients with epilepsy.

In this multi-centred pilot study, we along with neurologists and paediatric neurologists from several different countries will test the website and database by entering data on patients who would be in future suitable for randomized controlled trials. In this study, we will not actually be performing any randomized controlled trials, but will be focusing on developing the platform as a tool for rapid and easy recruitment.

You have been selected because you are diagnosed with epilepsy. We invite you to participate in this pilot study. For this study you will be given a unique study number which will be used for identification purposes. We require your personal data, detailed seizure history, types of seizures /seizure syndrome, cause of epilepsy, investigations, anti-epileptic drugs being used or those used in past. This information will be entered on a secure Internet-based epilepsy database. Access to the database will be restricted to members of the study group.

Transmission of your data will not be permitted without the approval of the Jinnah Postgraduate Medical Centre ethics committee, and your consent. You are not obligated to participate and maintain the right to voluntarily accept or decline this invitation.

Your participation will be totally free of cost and requires no participation or registration fee. Even if you do not wish to participate in this project your treatment at the National Epilepsy Centre will not be affected in any way. You will still continue to get optimal epilepsy care as you would otherwise at the centre.

For adult patients who can read/write:

I have read the foregoing information. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I voluntarily give consent to participate and be recruited for this research.

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

For guardians (who can read/write) of patients below 18 years or those who are unfit to give consent

I have read the foregoing information. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I voluntarily give consent for the participation of my child / relative to participate in this research.

Name of Guardian _____

Relation with the Patient _____

Signature of Guardian _____

Date _____

Day/month/year

For adult patients OR guardians who cannot read/write:

I have witnessed the accurate reading of the consent form to the potential participant / guardian of potential participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness _____

AND

Rt Thumb print of Patient

Signature of witness _____

OR Guardian

Date _____

Day/month/year



Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the above mentioned will be done.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year