



A study of Standard and New Antiepileptic Drugs – SANAD-II

GDPR Leaflet

The laws about how personal data can be used have recently changed. You are being given this leaflet as you are a **SANAD2** participant and we need to explain to you what this means for the data you are contributing. Please take the time to read this leaflet – you can ask your **SANAD2** researcher if you have any questions.

The University of Liverpool, and the Walton Centre NHS Foundation Trust are the co-sponsors for this study based in the United Kingdom/ country. They have delegated the day-to-day management of the study to the Clinical Trials Research Centre (CTRC), which is part of the University of Liverpool and delegated data analysis to the CTRC and to the Centre for Health Economics and Medicines Evaluation at Bangor University. We will be using information from you and your medical records in order to undertake this study and will act as the data controllers for this study. This means that we are responsible for looking after your information and using it properly. The University of Liverpool, the Walton Centre NHS Foundation Trust, and Bangor will keep identifiable information about you for up to 25 years from the end of the study, until 2044.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information. You can find out more about how we use your information in the “**How we use your information**” section on the study website here: www.sanad2.org.uk

Your NHS site will collect information from you and your medical records for this research study in accordance with our instructions.

Your NHS Hospital and Clinical Trials Office at the University of Liverpool will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the Study co-sponsors

(University of Liverpool and the Walton Centre) and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your NHS site will pass these details to the co-sponsors (University of Liverpool and The Walton Centre) along with the information collected from you and/or your medical records. The only people in The University of Liverpool who will have access to information that identifies you will be people who need to contact you to provide you with Quality of Life Questionnaires or to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

Your NHS Hospital /other site will keep identifiable information about you from this study for up to 25 years after the study has finished.