

Randomized, Embedded, Multifactorial, Adaptive Platform trial for Community-Acquired Pneumonia

REMAP-CAP

Privacy Notice

This is a large global trial, and we will follow the law by making sure your information is kept private and secure. The sponsor for this study is University Medical Centre (UMC) Utrecht, based in the Netherlands. We will be using information from you and your medical records to run this study, and UMC Utrecht will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. UMC Utrecht will be storing study data, as outlined below, on servers based in Sydney, Australia. This information will be kept for 25 years after the study has finished.

Some (anonymous) data about safety of specific medications tested and your clinical situation at the end of study follow-up (e.g., whether you are still in hospital or you were discharged) may be shared with companies making the treatments, if they are involved in the trial (for example they provide the treatments). These data can never be traced back to you. The companies need these data to know if their treatment worked and if it was safe.

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 collected. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting privacy@umcutrecht.nl.

Your hospital will collect information from you and your medical records for this research study in accordance with the sponsor's instructions.

Your hospital will keep your name and contact details confidential and will not pass this information to UMC Utrecht (sponsor). Your hospital will use this information as needed, to contact you about the research study, make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UMC Utrecht (sponsor) and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

Randomisation, clinical and follow up data will be collected on the study database which is stored on servers in Sydney, Australia, this will have some personal information about you for this global study, which includes year of birth, sex at birth, and basic study eligibility health information. The data collected will be pseudonymised, which means that your data will be given a reference number (code), so you cannot be directly personally identified by this. The information will be held securely with strict arrangements about who can access it.

With your permission, in order to contact you in 6 months, your hospital will provide your name and telephone number to the ICNARC trial team (based in the UK). Your hospital will also provide some additional clinical data including NHS number. This will allow the trial team to identify you on the Case Mix Program database (a health database for critically ill patients) and share your name, postcode, year of birth and NHS number, with NHS Digital (a UK national health database). This will enable NHS Digital to provide us with information about your long-term health situation after the study follow up has finished and help us learn whether the treatment worked. These data may also be shared with the study database team in Australia mentioned earlier.

Study data will be analysed in the UK, Australia and the USA. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Your hospital will keep identifiable information about you from this study for 25 years after the study has finished. This will be securely kept either as paper files or electronic files. If files are electronic, these will be filed on a tested/approved system called Florence which complies with research regulations and provides the appropriate level of security during the time the files are stored. Florence is a cloud-based storage system and the server/data centre is located in Germany.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations, or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance. It is necessary for us to process your data as described to allow us to perform a task in the public interest (by law).