

ORCHID RESEARCH PARTICIPANT PRIVACY NOTICE FOR the OPTimising Treatment for Mild Systolic hypertension in the Elderly (OPTiMISE) trial extension study

1. **Data protection** –The ORCHID database (“ORCHID”) is administered as a resource for conducting research. We, University of Oxford (“University”), will conduct research in ORCHID using information that we receive from your General Practitioner (GP). You can check with your GP to confirm whether it is a part of the Oxford -Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC). Wellbeing Software and EMIS provides this data from RCGP affiliated GPs (including TPP practices).

We will use data from ORCHID to examine if antihypertensive medication reduction is associated with an increased risk of cardiovascular disease and adverse events (including hospitalisation, dementia and other conditions affecting quality of life).

The data will only be processed by University.

Participants volunteered to take part in the trial have provided informed consent to sharing their personal data with the administrators of the ORCHID database. However, the legal basis from which the University process data under UK GDPR is Article 6(1)(e): “processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller”. Additionally, personal data will be processed under Article 9 (2)(j): “processing is necessary for the archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89 (1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject”

2. **How we use your data** - We will use your data only for the purpose of the mentioned research project with an agreement between the University and NHS Digital. We are processing your information because we are undertaking a project which is in the public interest and is only possible through linkage of study data to hospital and death data. The study is of public interest because it will be the first to determine whether stopping antihypertensive medication is associated with hospitalisation and death. This is in keeping with the studies’ aims to examine the safety and effectiveness of antihypertensive withdrawal. This important information could inform the care of millions of older people taking antihypertensive therapy across the country. To determine this association accurately, we need to access hospital and civil registration death data specifically for participants recruited to the original medication reduction trial. Accessing these data through NHS Digital is the only way to achieve this linkage. You can opt out from sharing your information at any time by contacting your General Practitioner. In this event, we will stop the processing as soon as we can. However, for opts out which NHS processes, we will continue processing de-identified data on these subjects. This will not affect the lawfulness of any processing carried out before your withdrawal of consent. We will only use your data for the purposes for which we collected it (research), unless we reasonably consider that we need to use it for another related reason and that reason is compatible with the original purposes. If we need to use your data for an unrelated purpose (non-research), we will seek your consent to use it for that new purpose.
3. **Who has access to your data?** Access to your data within the University’s secure environment will be provided to only those individuals approved to conduct research as described above. These include researchers from within the University only. They are required to take appropriate security measures to protect your data in line with our policies We do not allow them to use your data for their own purposes, particularly in situations where there is not a compliant agreement in place. We permit them to process your data only for the specified purpose and in accordance with our instructions. Staff from University and in particular members of the Clinical Informatics and Health Outcomes Research Group are not able to reverse pseudonymised NHS numbers to re-identify any individuals.

This notice is posted and available on demand: <https://www.phctrials.ox.ac.uk/studies/optimize>

4. **Retaining your data** - The data from NHS Digital will be retained for the duration of the agreement between the University and NHS Digital. Data collected from GP's for research purposes will be retained in line with the University's data retention policy. We will only retain your information for 10 years after concluding the OPTiMISE study.
5. **Security** - Your data will be held securely in accordance with the University's policies and procedures. Further information is available on the University's Information Security website: www.infosec.ox.ac.uk.
6. **Where we store and use your data** - We store and use your data electronically on University of Oxford's systems in the UK.
7. **Your rights** - Information on your rights in relation to your personal data are explained [here](#).
8. **Contact** - If you have any questions about how we will use your data, please contact the OPTiMISE Team at optimise@phc.ox.ac.uk. If you would like to exercise your rights as mentioned above or if, for any reason, you are not happy with the way that we have handled your data, please contact the University's Information Compliance Team. Please use the same address to contact the University's Data Protection Officer (data.protection@admin.ox.ac.uk). You also have the right to make a complaint to the Information Commission's Office.
9. University of Oxford will link primary care data they hold with the following datasets obtained from NHS Digital:
 - Hospital Episode Statistics Admitted Patient Care
 - Hospital Episode Statistics Accident and Emergency
 - Emergency Care Data Set
 - Civil Registration – Deaths