

UK Aneurysm Growth Study (UKAGS)
Frequently Asked Questions (FAQs) for Participants

Thank you for taking the time to participate in our important research. Below is a list of common questions raised by participants, which we hope you find useful.

Why should I take part in this Study?

The aim of this Study is to find out why some men grow an abdominal aortic aneurysm and others don't. By giving us your blood and urine samples, and completing a short questionnaire, we can analyse the results and hopefully learn more about the condition to help future generations of men.

Will I be paid to take part in the study?

Participants in this particular study are not paid. There is little for the participants to do other than completing a short questionnaire and providing blood and urine samples initially and, for those who do have an aneurysm, annually. You are free to withdraw from the Study at any time.

I have received a Consent Pack, or a Sample Pack, and can't respond immediately for whatever reason, what should I do?

There is not a strict deadline for return of your signed Consent forms or blood and urine samples, so whenever you have time to sort either of these out is fine.

What should I do if my GP surgery won't take blood samples from me?

You can try your local hospital or ask the pharmacist at your local chemist if they would be willing to take them for you. If you do manage to get samples taken in a place other than at your GP surgery can you please let us know (or ask them to let us know) that they have taken the blood so that the correct person is reimbursed for this service.

However, if it will be inconvenient or you don't want to bother to go elsewhere to have blood samples please let us know. This does mean though that you will have to be withdrawn from the study.

Do I need to book a fasting blood test with my GP surgery?

No, our research does not require you to provide a fasting blood test so please arrange to have blood sampling done at a time of day to suit you.

Your letter asks me to get samples done at the beginning of the week if possible. However, I can't get them done until later in the week. Is this ok?

Yes, this is fine. We try and get patients to have sampling done at the beginning of the week to ensure that samples are not left lying around in the post room over the weekend. But if this is unavoidable, please don't worry. Just get the samples taken whenever is convenient and we will work around you.

What should I do if I need you to send me more sample bottles – for example if I have already filled the urine bottle but can't get bloods taken yet, or if my GP surgery needs more blood sample tubes?

Please contact the UKAGS office to obtain further sample pots. Your urine sample needs to be provided on the same day as you have blood samples taken, so if you have already filled the urine bottle and can't get blood samples done on the same day please destroy the urine sample and the bottle it is in. Please don't destroy the protective container as you will need this to return the urine sample once the new set of sample bottles is received.

I've moved house, do I need to tell you?

Yes please. Please notify the UKAGS office of your new address either by telephone, email or post so that follow-up questionnaires etc can be sent to you. Please always identify yourself using your unique UKAGS Study ID number, which can be found on all paperwork sent to you.

What should I do if I no longer wish to be part of the Study?

Please inform the UKAGS office either by telephone, email or post. Please always identify yourself using your unique UKAGS Study ID number, which can be found on all paperwork sent to you.

Will you let me know of any abnormality you may detect in the samples I send?

The samples you provide are purely for research into abdominal aortic aneurysm and we are not able to provide results of any testing to participants. If you think you need a blood test for any other medical reason please contact your GP surgery.

How many samples will you ask me to provide and when?

If you have an abdominal aortic aneurysm (a Case Participant for the purposes of our study) you will be asked to provide urine and blood samples yearly; if you do not have an abdominal aortic aneurysm (a Control Participant for the purposes of our study) you will not be asked to provide any further samples after the initial samples have been received.

What approvals has the study been given, particularly in relation to Item 6 on the Information Sheet?

Item 6 on the Information Sheet means the study has been given full Ethical Approval by the Leicestershire, Northamptonshire and Rutland Research Ethics Committee. We are bound by their strict rules and regulations and cannot deviate from them without first seeking further approval.

What controls are there on drug companies or individuals using the research or results of this Study?

The data and samples we collect for the study will be used for academic research. Whilst in the majority of cases this is purely academic work (i.e. no commercialization) in some circumstances we form partnerships with commercial enterprises/companies if this is beneficial to the academic partners. All Universities look to increase the financial benefits they gain from research activities so whilst it is not our (the University of Leicester's) aim to gain any financial benefit we cannot definitively say that, in the fullness of time, we will not. In our research to date we have not done this.

Our outputs have to be made known to colleagues around the world to move the field forward (particularly those relevant to clinical practice to ensure that patients get any benefit). These outputs will be presentations at conferences and publications in biomedical journals. Whilst our main outputs will likely be to answer questions such as 'What is the best blood pressure medication to prevent aneurysms develop and grow?' we will generate more scientific data such as a list of genes that are associated with disease. The NHS is investing heavily in methods to use genetic data to target treatment for individuals (personalized medicine) and by making our results publically available it is possible that the results will be used to develop new treatments by industry – and we would have no control over the treatments so produced.

Our approach is to do everything we can to ensure that patients benefit from the research without restriction.

Will you keep participants regularly updated with Research outcomes?

The study is still in the recruitment phase and samples and forms received are processed and logged onto our database, and then securely and safely stored. There isn't currently any research progress to update participants on as analysis and research will be done after the study recruitment phase ends. Participants will be sent a newsletter with a follow-up questionnaire on a yearly basis which contains information about the Study.

UKAGS
Vascular Surgery Group
PO Box 65
Leicester
LE2 7LX
T: 0116 252 3140
E: ukags@le.ac.uk