



## PHAST (Peripheral arterial disease, High Blood Pressure and Aneurysm Screening Test)

### Information you need to know:

The PHAST-F study is being sponsored by the University of Leicester and coordinated by the Leicester Clinical Trials Unit. Further information on the institution can be found here: <https://le.ac.uk/> The University of Leicester is the Data Controller for your information.

The University of Leicester's Data Protection Officer is: Parmjit Singh Gill, Data Protection Officer, University Of Leicester, University Road, Leicester, LE1 7RH. Email: [dpo@leicester.ac.uk](mailto:dpo@leicester.ac.uk)

This privacy notice explains how we use your personal information and your rights regarding that information.

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### What information are we collecting?

The data we collect from you will be dependent on the part of our study to which you are participating.

#### **For the Questionnaire research, from consent forms and questionnaires, we will collect personal information such as your:**

- Name, Date of Birth, NHS Number
- Your contact details and occupational status

#### **For the Questionnaire research, we are also collecting the following special categories of data:**

- Information relating to ethnicity
- Routinely collected Health information from NHS trusts/GP practices (we will contact your GP to notify them about your participation if we need to)
- Clinical information such as screening results, diagnoses, and medical procedures
- Healthcare information; such as medical history, physical health, quality of life and psychological wellbeing.

#### **For participants using our GENEActiv wrist device, we will collect:**

- Regularly updated information on your physical activity

#### **For the Interview research, we will collect personal information such as your:**

- Name

#### **For the Interview research, we are also collecting the following special categories of data:**

- Clinical information such as screening results, diagnoses, and medical procedures
- Any other medical or health data which you divulge may be recorded.

Please note: We will only collect and use your information for interviews if you have voluntarily agreed to participate in this part of the study and if you have completed the participant consent forms, this is in accordance with ethical requirements and to meet legal obligations relating to confidentiality.

### Why are we collecting your data?

Screening for Peripheral Arterial Disease (PAD) and high blood pressure (BP) is not currently offered by the NHS as a Screening Programme. This study aims to find out whether adding these additional screening tests is beneficial in improving the overall health of our participants. We specifically want to find out



whether it would be beneficial to change current screening programmes with the aim to improve the lives and wellbeing of people living with these conditions in the United Kingdom.

## How we will use this data?

### How we use your data from **consent forms**:

- Data provided within consent forms may be used to contact you, but only where you have indicated that you wish to be involved in future parts of this research study.

### How we use your data during the **Questionnaire research**:

- The information we collect from your questionnaires will be combined with information from your health records. The data will then be compared between male participants. Should the research indicate that the additional screening tests are beneficial, research funding has already been secured to test this theory on a larger scale.
- We will use the data collected from female participants to support the design a screening programme specifically for women. Should research indicate that further screening would be especially beneficial to women, additional research funding will then be applied for to test this theory on a larger scale.

### How we use your data at the **GENEactiv Wrist device research**:

- We will use health data from the GENEActiv device to analyse and assess any change in your physical activity in combination with your questionnaires and health records. The GENEActiv stage supports the Questionnaire research.

### How we use your data at the **interview research**:

- We will use interview data to determine how acceptable and beneficial the screening was to participants and screening staff.

Our research analysis does not involve any automated or other decision-making about individuals.

## What is the legal basis for processing the data?

The legal basis through which data will be processed is for the performance of a task in the public interest which is set out in the UK GDPR Article 6.1(e) and s8(c) of the Data Protection Act 2018.

*“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”*

Research is a task that the Universities of Leicester, Glasgow and Nottingham perform in the public interest, and is part of our core functions as Universities.

Our additional legal basis for processing special categories of personal information relating to health/healthcare and ethnicity is that it is necessary for reasons of public interest in the area of public health as set out in the Data Protection Act 2018 and UK GDPR Article 9.2 (i) and in relation to scientific research in the public interest Article 9.2 (j).

Please note: The official authority to carry out research is expressed in The University of Leicester’s Charter in section 13 (b). To find out more please visit our website

<https://le.ac.uk/about/governance-and-management/governance/documents/charter/>

## If we are sharing your data with others who are we sharing it with?

The University of Leicester research team; Trusted research team individuals from collaborating institutions (University of Glasgow and University of Nottingham); For participants involved in the interview stage, data may be shared with third party transcribers who will be working with the University of Leicester under strict contractual confidentiality.

## How long we will process your data for?

Personal data collected will be held for the following durations:



- Contact details provided for **Questionnaire research participants** will be kept for the duration of research activities.
- Contact details provided for participation in the **GENEActiv wrist device** and **interview stages** will be held for the duration of research activities.
- Consent forms and anonymised survey, interview and trial documentation data will be held for the duration of the research activities and for a total of 15 years after in accordance with the ethically approved research protocol and ICH-GCP guidelines.

## What are your rights and how to enforce them?

As a research Participant you have the following rights;

- right to access, if you wish to request copies of your personal data.
- right to rectification, if you think the data we hold about you is incorrect.
- right to restriction, if you believe we are over processing your data.
- right to objection, if you believe that any of the data we hold is incorrect.
- right to portability, should you want your information electronically transferred.

Please note: It is also important to understand that these rights will only apply to identifiable data. You may withdraw from the study at any point where we hold identifiable data, however where your information has been completely anonymised, your information is no longer accessible and is therefore not classed as personal data for the purposes of the Data Protection Legislation.

## How to complain to the Information Commissioner's Office?

The Information Commissioner can be contacted on:

Post:

Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK95AF.

Tel: 0303 123 1113.

Email contact can be made by accessing [www.ico.org.uk/](http://www.ico.org.uk/)