

**You are invited to take part in the PAFA study (Patterns of Adult Food Allergy) to find out how many people in the UK have food allergies or intolerances.**

**Please read the following information which will help you to decide whether or not to take part in the study**

### **Why are we doing the research?**

Many people in the UK suffer from food allergies and intolerances, which cause problems for them and their families when choosing what to eat. Although this is well recognised in children, it affects many adults too. We would like to find out how many adults in the UK aged 18-70 years have food allergies and intolerances, so we can help them to avoid the problem food and live a better life.

### **I don't have any problems with food, so do you still want me to take part?**

**Yes! We would still like to hear from you even if you don't have any problems with food.** We need information from people who don't have problems with food, so that we can accurately measure how common these problems are in the UK.

### **Do I have to take part?**

No. It is entirely up to you to decide. If you don't want to take part, that's OK. Your decision will not affect the quality of care you receive.

### **How do I take part?**

Please complete the short questionnaire. This will take less than 5 minutes. There are three ways to do it:

- **Online** (on your tablet, computer or smartphone) - please use your unique survey link [[unique survey link to be inserted here](#)]. If you have a mobile phone registered with your GP, you will receive a text message with the link in the next few days – so please look out for this.
- **On paper** - please fill out the attached questionnaire and return it to us by post; we have included a paid and addressed envelope.
- **On the phone** - ring one of our researchers on **07918 576 785** to answer questions over the phone.

If you participate in the study, we will need to convert your postcode to a geographic code used in the census. This will allow us to make sure those responding to the questionnaire are representative of the UK population.

Anyone who completes a questionnaire will be entered into our prize draw for £250 of vouchers (e.g. Amazon, or love-to-shop).

### **What happens next?**

Researchers would like to invite some of the people who have completed the questionnaire for an allergy assessment visit, which involves a longer questionnaire and allergy tests to see if they may have a food or other allergy. **Researchers will only be able to contact you if you tick 'Yes' to the last question** on the questionnaire, so that your GP can share your contact details (name, address, and telephone number). So whether or not you have problems with food, if you would consider taking part in the second stage of the study, please tick 'Yes'. If you don't want to be contacted again, tick 'No'.

## How will we use information about you?

We will need to use information from your GP for this research project. This information will include your contact details, which your GP will use to invite you to take part in the research study. People who do not need to know who you are, will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Some of your non-identifiable information will be sent to The Amsterdam University Medical Centre (AMC) in the Netherlands, a study partner. They must follow our rules about keeping your information safe. The AMC researchers will not be able to identify or contact you.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

## What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. Please see the "what happens next?" section above for more details on how to take part.

## Where can you find out more about how your information is used?

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- our leaflet available from <https://sites.manchester.ac.uk/pafa/>
- by emailing [dpo@mft.nhs.uk](mailto:dpo@mft.nhs.uk)
- by asking one of the study team. Please see the "how do I contact the study team?" section below.

## If you wish to make a complaint.

If you wish to make a complaint about the study you can do so through the NHS complaints procedure. Details can be obtained from the Patient Liaison Office on 0161 291 5600 or [pals@mft.nhs.uk](mailto:pals@mft.nhs.uk)

## Who is funding the research project?

The project is funded by:



## Who has reviewed the research project?

The project has been reviewed by **North West - Haydock Research Ethics Committee**. IRAS (Integrated Research Application System) project ID is 260430.

## Who is doing the research?

Researchers at the University of Manchester, Manchester University NHS Foundation Trust, the University of Southampton, the Isle of Wight NHS Trust, and Amsterdam University Medical Centre.

## How do I contact the study team?

By email: [pafastudy@manchester.ac.uk](mailto:pafastudy@manchester.ac.uk)

By phone: **07918 576 785**