



INFORMATION SHEET

Quadram Institute Bioscience Participants Database

Information you need to know about the Participants Database

Thank you for your interest in our research studies.

To help you can decide whether you wish to have your details held on the Quadram Institute Bioscience (QIB) Participants Database please read this important information.

Who will manage the QIB database?

The database will be managed by QIB research scientist Jennifer Ahn-Jarvis. Appropriate technical measures and controls are applied to ensure the data held in the database are secure, kept confidential and only accessible by authorised members of QIB staff. Jennifer Ahn-Jarvis has extensive experience in conducting human studies, a long track record of successful study set up and extensive experience in human study recruitment.

What information will be held?

The database will hold the minimum information about you which will allow us to search the database and identify people who may be eligible for a specific study, based on the inclusion criteria. This information includes: name; postal address; email; contact telephone number; date of birth; gender; smoking status; allergies; and dietary requirements. We lawfully process your personal data under the current Data Protection legislation on the basis of a) informed consent and b) for scientific research purposes. You will be required to sign a consent form to enable us to retain the data described here.

How will my information be used?

Health and social care research should serve the public interest, which means that we must demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

Following successful review from an appropriate Ethics Committee the study scientist will contact the database manager and ask them to conduct a search of the participant database. The study inclusion criteria will be used to conduct the search to identify potentially eligible people. If you match the criteria for the study an information sheet will be sent to you from either the database manager or the study scientist. Only your name and address will be passed to the study scientist to enable them to send the information sheet. We will continue to post to you information sheets for any QIB research studies where your details held on the database indicate you may be eligible to take part. There is no obligation to take part in any study.

Please note: Depending on the number of studies being conducted and the study inclusion criteria it is possible there may be long periods where you may not be sent an information sheet.

Will my information be used/passed to others outside QIB?

No. The QIB participant database will only be used for research studies undertaken by QIB.

Where will the QIB studies take place?

QIB research studies will take place in the purpose-built Clinical Research Facility (CRF) within the Quadram Institute (QI). The CRF is an NHS-governed facility and will undertake clinical research in compliance with the International Conference on Harmonisation-Good Clinical Practice (ICH-GCP); the UK Policy Framework for Health and Social Care Research, the Medicines for Human Use (Clinical Trials) Regulations 2004, and the Human Tissue Act 2004.

What do I have to do if I don't want to stay on the QIB Participant Database?

Your information will remain on the QIB participant database until you decide otherwise. If you would like your details removed, you will need to let us know. We will ask you to fill in, sign and date a 'removal of information' form. This will be held by QIB for audit and archive purposes. Once we have removed your database record we will not contact you directly regarding future studies. However, we do use GP surgeries for recruitment, so you may receive information about a study at QIB through your GP surgery.

Returning completed forms

Completed forms can be sent to us using a FREEPOST address. (no stamp required).

Please send to

Jennifer Ahn-Jarvis, Quadram Institute FREEPOST NC252 Norwich Research Park, Norwich, NR4 7UQ

I have some questions who can I contact?

For questions about this information or the participant database, please contact:

Jennifer Ahn-Jarvis - QIB Research Scientist

Email: volunteer@quadram.ac.uk

Tel: 01603 255052

To exercise your rights under the Data Protection Regulations 2018 or any compliance related enquiries please contact:

Pete Andrews— Senior IT Security Specialist

Email: andrews@nbi.ac.uk

Tel: 01603 450067

Quadram Institute Bioscience (QIB) Participant Database Form

If you are interested in helping with our research and would like your information to be held on our Database, please complete the form below in BLOCK CAPITALS using black ink. Please also make sure you initial the box at the end of each clause and sign the form.

Please **initial** each box

I confirm that I have read the information provided and consent for my information to be retained on the QIB participant database

I understand that all information held on the QIB participant database is treated in the strictest confidence, used only for QIB research studies and will not be passed to any other organisation.

I understand that all information removed from the QIB Participant Database is treated in the strictest confidence and will not be passed to any other organisation

I understand that I can request that my information be removed from the database at any time without giving a reason and that I must provide this request in writing.

I understand that the QIB Participant Database is managed by QIB staff in compliance with EU General Data Protection Regulation (GDPR) and relevant UK regulations.

Name:

Address:

E-mail Address:

Preferred method for study information to be sent: Post/E-mail (circle as appropriate)

Contact phone numbers:

Date of Birth: (dd-mm-yyyy)

Smoker/Non-smoker: (circle as appropriate)

Known allergies: Yes/No (circle as appropriate)

Dietary requirements: Yes/No (circle as appropriate)

If yes to the above, please state

Signature:

Date:

(dd-mm-yyyy)

Please return the completed form using the following FREEPOST address:

Jennifer Ahn-Jarvis – confidential
Quadram Institute
FREEPOST NC252
Norwich Research Park
Norwich
NR4 7UQ