

NIHR Imperial Clinical Research Facility Privacy Notice for Healthy Volunteers and Contributors to Patient & Public Involvement Activities

What is the purpose of this document?

NIHR Imperial Clinical Research Facility (ICRF)

The NIHR Imperial Clinical Research Facility (ICRF) is part of Imperial College Healthcare NHS Trust. The facility is located at Hammersmith Hospital in West London and specialises in early phase clinical trials, metabolic research and experimental medicine. Imperial College Healthcare NHS Trust is part of the Imperial Academic Health Science Centre, which is a university-NHS partnership to accelerate the translation of research into better patient outcomes and population health. The ICRF therefore works with staff and researchers from all institutions within the Imperial Academic Health Science Centre.

This notice applies to anyone that has contributed to **Patient and Public Involvement (PPI) activities** with the ICRF or anyone that has registered onto our **Healthy Volunteer Database**. With your consent, we will keep and process limited personal information about you as described below.

Note that this privacy notice **does not** apply to data collected for research studies. Participants in clinical research studies at the ICRF should refer to the information provided in our FAQs at: <https://www.imperial.ac.uk/nihr-crf/ppi/faq/> and in the study-specific participant information sheets. We need to keep more detailed information about study participants and your rights to access, change or move such data is limited.

Imperial College Healthcare NHS Trust

Imperial College Healthcare NHS Trust is the "data controller", meaning that the Trust is responsible for deciding how we hold and use personal information about you. We are required under data protection legislation to notify you of the information contained in this privacy notice.

This notice does not form part of any contract of employment or other contract to provide services. We may update this notice at any time.

It is important that you read this notice, together with any other privacy notice we may provide on specific occasions when we are collecting or processing personal information about you, so that you are aware of how and why we are using such information.

This privacy notice describes how we collect and use personal information about you during and after your relationship with us, in accordance with the applicable data protection legislation (the UK GDPR and Data Protection Act 2018).

Under data protection law, Imperial College Healthcare NHS Trust is the 'data controller' of the information we hold about you and we are responsible for determining how it will be used to perform our legal duty. We are registered with the Information Commissioner's Office as a data controller with the reference Z1152836.

Data protection principles

We will comply with data protection law. This says that the personal information we hold about you must be:

1. Used lawfully, fairly and in a transparent way.
2. Collected only for valid purposes that we have clearly explained to you and not used in

any way that is incompatible with those purposes.

3. Adequate, relevant and limited to what is necessary in relation to those purposes.

4. Accurate and kept up to date.

5. Kept only as long as necessary for the purposes we have told you about.

6. Kept securely.

The kind of information we hold about you

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

There are "special categories" of more sensitive personal data which require a higher level of protection.

Depending on whether you are involved in PPI, or registered on the Healthy Volunteer Database, we may collect, store, and use the following categories of personal information about you:

- Personal contact details such as name, title, addresses, telephone numbers, and personal email addresses
- Date of birth
- Sex
- Height and weight (Healthy Volunteer database only)
- Smoking status (Healthy Volunteer database only)
- Bank account details (PPI contributors only)
- Availability and preferences for study / event types
- Dates of last study participation (Healthy Volunteer database only)
- Details of employment or workplace (PPI contributors only)

We may also collect, store and use the following "special categories" of more sensitive personal information:

- Information about your ethnicity
- Limited information relating to your health conditions or medical history; e.g., use of long-term medications, pregnancy status, allergies or other diagnoses. We may use this information to review your potential suitability for studies and for monitoring inclusivity, diversity and equality.
- Additional information to help us monitor inclusivity, diversity and equality, e.g:
 - Gender, including transgender identity
 - Disability status
 - Carer status
 - Sexuality
 - Religion

These additional data will not be used to review suitability for study participation or involvement in PPI/E opportunities.

How is your personal information collected?

We will have obtained personal information from you when you registered on our website or when you completed Healthy Volunteer Database or Patient and Public Involvement forms. We may cross reference data you have provided to us for other reasons, such as for research study participation.

How we will use information about you and the legal basis for processing your data under the GDPR

We will only use your personal information when the law allows us to. We will use your personal information in the following circumstances:

- Where you have consented to the processing

We need the information in the list above (see ‘

The kind of information we hold about you’) to carry out the following activities:

- To check your suitability for clinical research studies (only applicable if you are registered to the Healthy Volunteer database)
- To contact you in relation to PPI activities / participation feedback or volunteering for clinical research
- To notify you about any changes to the information we hold or the way we process it and to seek your consent for any changes.
- To pay you for clinical research or PPI activities
- To ensure that the information we hold about you is up to date and accurate.
- To provide you with relevant news, training opportunities and special offers by email, phone or post where you have consented to receive this information.
- Monitoring the make-up and diversity, in terms of sex, gender, age, disability, sexuality, religion, carer status, deprivation index (via postcode) and ethnicity of potential volunteers and PPI contributors.

If you fail to provide personal information

If you fail to provide certain information when requested, there is no detriment to you personally, unless we require information to deliver a benefit or a service to you. For example we may be unable to reimburse your participation if you withdrew consent for us to hold your bank details, but in that situation we would take reasonable steps to arrange an alternative method of payment with you.

Change of purpose

We will only use your personal information for the purposes for which we collected it, unless we reasonably consider that we need to use it for another reason and that reason is compatible with the original purpose. If we need to use your personal information for an

unrelated purpose, we will notify you and we will explain the legal basis which allows us to do so.

Please note that we may process your personal information in compliance with the above rules, where this is required or permitted by law.

How we use particularly sensitive personal information

"Special categories" of particularly sensitive personal information require higher levels of protection. We need to have further justification for collecting, storing and using this type of personal information. We may process special categories of personal information in the following circumstances:

In limited circumstances, with your explicit written consent.

- Where the processing is necessary for the establishment, exercise or defence of legal claims, or for courts acting in their judicial capacity.
- Where the processing is necessary for reasons of substantial public interest, and occurs on the basis of a law that is, inter alia, proportionate to the aim pursued and protects your rights as a data subject.
- Where the processing is required for the purpose of medical treatment undertaken by health professionals, including assessing the working capacity of employees and the management of health or social care systems and services.
- Where the processing is necessary for reasons of public interest in the area of public health (e.g. ensuring the safety of medicinal products).
- Where the processing is necessary for archiving purposes in the public interest, for historical, scientific, research or statistical purposes, subject to appropriate safeguards.

If you are registered to our Healthy Volunteer database, we will retain particularly sensitive personal information, and use it in the following ways:

- We will use information relating to your pregnancy status, health conditions or medications and race / ethnicity to assess your potential eligibility for participation in research studies, and to review the diversity / inclusivity of our Healthy Volunteer database and PPI group.
- If you decide to share with us your gender, disability status, carer status, sexuality and religion, we will only use this information to monitor the inclusivity, diversity and equality of our PPI panel and Healthy Volunteer database.

Do we need your consent?

By registering to the Healthy Volunteer Database or to the Patient and Public Involvement Panel, you provide consent for us to process your personal data as described in this privacy notice. This includes sensitive personal information, as described in the section above: **'How we use particularly sensitive personal information'**.

If we wish to collect further data from you, or process it in different ways, we will provide you with full details of the information that we would like and the reasons, so that you can carefully consider whether you wish to consent. This will usually be communicated to you via

an update to this privacy notice and a data collection form or email request to obtain additional information as relevant. If you withdraw your consent, we will delete your data.

Automated decision-making

Automated decision-making takes place when an electronic system uses personal information to make a decision without human intervention. We may use automated decision-making in the following circumstances:

In limited circumstances, with your explicit written consent and where appropriate measures are in place to safeguard your rights.

If we make an automated decision on the basis of any particularly sensitive personal information, we must have either your explicit written consent or it must be justified in the public interest, and we must also put in place appropriate measures to safeguard your rights.

Imperial College Healthcare NHS Trust does not make automated decisions about patients or carry out evaluations based on any automated processes (profiling).

Data sharing

We may have to share your data with third parties.

We require third parties to respect the security of your data and to treat it in accordance with the law.

Why might you share my personal information with third parties?

We may share your personal information with third parties where required by law or where it is necessary to administer the relationship with you (i.e. to fulfil the purposes described above, in '***How we will use information about you and the legal basis for processing your data under the GDPR***').

Which third-party service providers process my personal information?

We will not share your data directly with any third party, unless you authorise us to do so. For example, if you ask us to arrange a taxi for you, we may share your details with the taxi company.

How secure is my information with third-party service providers and other entities in our group?

All our third-party service providers and affiliated researchers are required to take appropriate security measures to protect your personal information in line with our policies. We do not allow third-party service providers to use your personal data for their own purposes. We only permit them to process your personal data for specified purposes and in accordance with our instructions.

What about other third parties?

We will not share your data in any circumstances other than as described above.

Data security

We have put in place measures to protect the security of your information.

Third parties will only process your personal information on our instructions and where they have agreed to treat the information confidentially and to keep it secure.

We have put in place appropriate security measures to prevent your personal information from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. In addition, we limit access to your personal information to those employees, agents, contractors and other third parties who have a legitimate need to know. They will only process your personal information on our instructions and they are subject to a duty of confidentiality.

We have put in place procedures to deal with any suspected data security breach and will notify you and any applicable regulator of a suspected breach where we are legally required to do so.

Data retention

How long will you use my information for?

We will retain your data for as long as you wish to remain on the Healthy Volunteer database or Patient and Public Involvement Panel. When contacting you, we will explain how you can request to withdraw consent and have your data removed. We will also review our records occasionally to monitor engagement. If you have not responded to emails on multiple occasions, we will contact you specifically to confirm whether you wish to remain on the Healthy Volunteer Database or remain a member of the ICRF Patient and Public Involvement Panel. We will delete the records of those who do not respond to this email.

In some circumstances we may anonymise your personal information so that it can no longer be associated with you, in which case we may use such information without further notice to you.

Rights of access, correction, erasure, and restriction

Your duty to inform us of changes

It is important that the personal information we hold about you is accurate and current. Please keep us informed if your personal information changes during your relationship with us.

Your rights in connection with personal information

Under certain circumstances, by law you have the right to:

- **Request access** to your personal information (commonly known as a "data subject access request"). This enables you to receive a copy of the personal information we hold about you and to check that we are lawfully processing it.
- **Request correction** of the personal information that we hold about you. This enables you to have any incomplete or inaccurate information we hold about you corrected.

- **Request erasure** of your personal information. This enables you to ask us to delete or remove personal information where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal information where you have exercised your right to object to processing (see below).
- **Request the restriction of processing** of your personal information. This enables you to ask us to suspend the processing of personal information about you, for example if you want us to establish its accuracy or the reason for processing it.
- **Request the transfer** of your personal information to another party.

If you want to review, verify, correct or request erasure of your personal information, object to the processing of your personal data, or request that we transfer a copy of your personal information to another party, please contact a member of ICRF staff or the Trust Data Protection Officer. Details of how to get in touch can be found in the sections entitled *Right to withdraw consent* and *Data Protection Officer* below.

No fee usually required

You will not have to pay a fee to access your personal information (or to exercise any of the other rights). However, we may charge a reasonable fee if your request for access is clearly unfounded or excessive. Alternatively, we may refuse to comply with the request in such circumstances.

What we may need from you

We may need to request specific information from you to help us confirm your identity and ensure your right to access the information (or to exercise any of your other rights). This is another appropriate security measure to ensure that personal information is not disclosed to any person who has no right to receive it.

Right to withdraw consent

You have the right to withdraw your consent for processing at any time.

To withdraw your consent to registration on the Healthy Volunteer Database, please contact imperial.recruitment.icrf@nhs.net.

To withdraw your consent to Patient & Public Involvement Activities, please contact imperial.icrfppi@nhs.net

You can also telephone the ICRF main reception on 0203 313 8070.

Once we have received notification that you have withdrawn your consent, we will delete your personal data and no longer process your information, unless we have another obligation in law for doing so.

Data Protection Officer

We have appointed a Data Protection Officer to oversee compliance with this privacy notice. If you have any questions about this privacy notice or how we handle your personal information, please contact the Data Protection Officer:

Philip Robinson

ICT Division, Charing Cross Hospital, London, W6 8RF

Email: imperial.dpo@nhs.net Telephone: 020 3311 7344

If you want to access the information that we hold about you, please email:

imperial.accesstohealthrecords@nhs.net

Imperial College Healthcare NHS Trust is a registered data controller under the Information Commissioner's Office.

You can contact the Information Commissioner's Office at:

Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Website: www.ico.org.uk/concerns Telephone: 0303 123 1113

Changes to this privacy notice

We reserve the right to update this privacy notice at any time, and we will provide you with a new privacy notice when we make any substantial updates. We may also notify you in other ways from time to time about the processing of your personal information.