

THE HEART HIVE PRIVACY NOTICE

What is the purpose of this document?

Imperial College of Science, Technology and Medicine (the “**College**” or “**Imperial**”) is committed to protecting the privacy and security of your personal 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 Data Protection Act 2018 and the General Data Protection Regulations (the “**GDPR**”) and the College’s *Data Protection Policy*.

The College is a “data controller”. This means that we are 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 applies to participants registered with the Heart Hive registry. This notice does not form part of any 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.

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. Relevant to the purposes we have told you about and limited only 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.

We may collect, store, and use the following categories of personal information about you:

- Personal contact details such as name,

- addresses, telephone numbers, and personal email addresses.
- Date of birth.
- Gender.
- Marital status and dependants.

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

- Information about your race or ethnicity
- Information about your health, including any medical condition, health records.
- Information about your clinical care team
- Genetic information (i.e. any genetic mutations or variations that you have told us has been identified as a possible cause/predisposes you to heart muscle disease)

How is your personal information collected?

We collect most of the personal information about you through our registration forms and online surveys. We may sometimes collect additional information from third parties including NHS digital and other national databases where you agree to join one of our research studies or activities. However, this will be collected using an identifier key and removing your personal details. Data gathered from online databases will not be uploaded to the Heart Hive web portal. We will not gather other data from national databases if you do not consent for us to do so.

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. Most commonly, we will use your personal information in the following circumstances:

Where we need to comply with a legal obligation.*

Where it is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in us.**

Where it is necessary for our legitimate interests (or those of a third party) and your interests and fundamental rights do not override those interests.***

Where you have consented / requested us do something for you.****

Situations in which we will use your personal information

We need all the categories of information in the list above (see The kind of information we hold about you) primarily to determine your eligibility for studies and surveys, and to contact you in the event that you are eligible to join research opportunities. In some cases we may use your personal information to pursue legitimate interests of our own or those of third parties[***], provided your interests and fundamental rights do not override those interests. The situations in which we will process your personal information are listed below. We have

indicated by [asterisks] the purpose or purposes for which we are processing or will process your personal information, as well as indicating which categories of data are involved.

- To contact you in relation to a research or participant feedback opportunity which has opened to you (this can be opted out if you change your mind at a later date)^{***}/^{****}
- To provide you with the information and services that you request from us (for example feeding back genetics results if you asked to receive them)^{****}.
- To identify which studies you may be eligible to join^{***}/^{****}
- To ensure we meet any and all legal obligations with regards to the service we provide to you for the duration of any research study^{*}
- To monitor participation and administer research studies which you consent to join^{***}/^{****}
- To notify you about changes to our service^{*/}^{***}.
- To ensure the information we hold about you is up to date and accurate^{*}.
- To ensure that content from our site is presented in the most effective manner for you and your computer or mobile device^{****}.
- To contact your clinical care team to confirm your suitability to join research studies that you express an interest in^{*/}^{***}.

Some of the above grounds for processing will overlap and there may be several grounds which justify our use of your personal information.

If you fail to provide personal information

If you fail to provide certain information when requested, we may not be able to perform the agreement / activity with you and we may be prevented from complying with our legal obligations.

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 without your knowledge or consent, 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 archiving purposes in the public interest, for historical, scientific, research or statistical purposes, subject to appropriate safeguards.

Our obligations

We will use your particularly sensitive personal information in the following ways:

- Use your medical history and/or your genetic status to identify which studies you may be eligible to join
- Focus group/patient surveys used to help us inform future research protocols may use sensitive information in a deidentified manner. You will be asked if you would like to opt in, and are informed how your data will be processed for individual surveys.

Do we need your consent?

We do not need your consent to process sensitive personal information if we use special categories of your personal information to carry out the functions of the Heart Hive research registry and administer any research that you express interest an/or sign up to. In limited circumstances, we may approach you for your written consent to allow us to process certain particularly sensitive data. If we do so, we will provide you with full details of the information that we would like and the reason we need it, so that you can carefully consider whether you wish to consent. You should be aware that it is not a condition of your contract with us that you agree to any request for consent from us.

Automated decision-making

You will not be subject to decisions that will have a significant impact on you based solely on automated decision-making, unless we have a lawful basis for doing so and we have notified you.

We do not envisage that any decisions will be taken about you using automated means, however we will notify you in writing if this position changes.

Data sharing

We may have to share your data with third parties, including third-party service providers and other entities in the College group.

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

We may transfer your personal information outside the UK though if we do, you can expect a similar degree of protection in respect of your personal information.

Why might you share my personal information with third parties?

We may share your personal information with third parties where required by law, where it is necessary to administer the relationship with you or where we have another legitimate interest in doing so.

Which third-party service providers process my personal information?

"Third parties" includes third-party service providers (including contractors and designated agents) and other entities within the College group. [The following activities are carried out by third-party service providers: The following third-party service providers process personal information about you for the following purposes:

- The Broad Institute of M.I.T. and Harvard a US based not-for-profit research institute provide the software for the Heart Hive portal and store data on their secure servers.

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

All our third-party service providers and other entities in the College group are required to take appropriate security measures to protect your personal information in line with our policies. We do not allow our 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 may share your personal information with other third parties, for example in the context of the possible sale or restructuring of the business and operations of the College. We may also need to share your personal information with a regulator or to otherwise comply with the law.

Transferring information outside the UK

We may transfer the personal information we collect about you to the USA which is outside the UK and does not have an adequacy decision by the UK nor European Commission in respect of that country. This means that the country to which we transfer your data are not automatically deemed to provide an adequate level of protection for your personal information.

However, to ensure that your personal information does receive an adequate level of protection we have put in place the following appropriate measure[s] to ensure that your personal information is treated by those third parties in a way that is consistent with and which respects the EU and UK laws on data protection:

- Data processing agreement has been signed between The Broad Institute and Imperial College London which includes Standard Contract Clause and additional processes that assess the company and countries data protection legislation in terms of it risks to data subjects.

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, where they have agreed to treat the information confidentially and to keep it secure.
- All activities pertaining to personal data have been recorded to ensure compliance with the listed terms and activities.
- All activities have been reviewed to align to College requirements regarding digital and physical security relating to data

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 business 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 only retain your personal information for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements. Details of retention periods for different records the College holds are available in our retention policy which is available on this website: <http://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf>. To determine the appropriate retention period for personal data, we consider the amount, nature, and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of your personal data, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements. In this case, we expect to retain your personal information for 10 years

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).

- **Object to processing** of your personal information where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your personal information for direct marketing purposes.
- **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 the College's Data Protection Officer in writing.

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

In the limited circumstances where you may have provided your consent to the collection, processing and transfer of your personal information for a specific purpose, you have the right to withdraw your consent for that specific processing at any time. To withdraw your consent, please contact the College's Data Protection Officer. Once we have received notification that you have withdrawn your consent, we will no longer process your information for the purpose or purposes you originally agreed to, unless we have another legitimate basis for doing so in law.

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 at:

Imperial College London
Data Protection Officer
Exhibition Road

Version: 2.0

Date: November 2023

Faculty Building Level 4

London SW7 2AZ

e-mail: dpo@imperial.ac.uk

You have the right to make a complaint at any time to the Information Commissioner's Office (**ICO**), the UK supervisory authority for data protection issues.

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.