

PRIVACY NOTICE FOR PAiNTS STUDY VOLUNTEER EXPRESSIONS OF INTEREST

What is the purpose of this document?

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.

Under data protection law, Imperial College London 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.

This notice applies to anyone that expresses an interest in the PAiNTS study. With your consent, we will keep and process personal information about you as described below. If, when completing the questionnaire, you receive a message explaining you are ineligible for the study, no personal data will be collected about you.

Note that this privacy notice does not apply to data collected for research studies. If you enrol on the trial, further data will be collected, as described in the participant information sheet. We need to keep more detailed information about study participants and your rights to access, change or move such data is limited.

Imperial College London is data controller for the PAiNTS study. 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 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.

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 including your name, title, home address, telephone number, and personal email addresses

- Date of birth
- Sex at birth
- Gender
- Your GP details and your and NHS number
- Availability and preferences for a screening visit
- Information about your past health, including any medical conditions, medications, and your health and sickness record

If you fail to provide personal information

If you fail to provide certain information when requested, there is no detriment to you personally, but it may mean you cannot take part in the trial.

How is your personal information collected?

We will have obtained personal information from you when you registered on our website for the PAiNTS study.

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. For this processing activity we will use your personal information with the following legal bases: 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.

Situations in which we will use your personal information

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 the trial
- To contact you in relation to volunteering for the trial
- 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 ensure that the information we hold about you is up to date and accurate.

Note that data may be accessed, and the activities above may be carried out by staff employed at Imperial College and/or Imperial College Healthcare NHS Trust.

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:

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 public interest in the area of public health (e.g. ensuring the safety of medicinal products).

Where the processing is necessary for achieving purposes in the public interest, for historical, scientific, research or statistical purposes, subject to appropriate safeguards.

Our obligations

We will use the health-related information you provide in the expression of interest form and your medical records to assess whether you will be able to meet the criteria for this study. No additional sensitive personal information is collected unless you later decide to participate in the trial, in which case a separate privacy policy will apply.

Automated decision-making

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

1. Where we have notified you of the decision and given you 21 days to request a reconsideration.
2. Where it is necessary to perform the contract with you and appropriate measures are in place to safeguard your rights.
3. 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.

You will not be subject to decisions that will have a significant impact on you based solely on automated decision-making. We do not envisage that any decisions will be taken 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

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 EU.

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. We do not

intend to share your information with third parties for any other reason.

Which third-party service providers process my personal information?

"Third parties" also includes third-party service providers (including contractors and designated agents) and other entities within the Imperial College group. We do not intend to share your information with any third parties and will notify you if that position changes.

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 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?

Data collection is undertaken using Qualtrics, who have a separate privacy policy.

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 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. If you do not end up taking part in the PAiNTS study, your data will be deleted once the study is completed. If you are enrolled into the PAiNTS study, your data will be held securely for 10 years in line with Imperial College policy.

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.

Please note that these rights relate to your information in the registration of interest dataset. If enrolled onto the study you will be provided with separate privacy information covering your rights relating to the study dataset.

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 challenge-trial@imperial.ac.uk or the Data Protection Officer at Imperial College London. Details of how to get in touch can be found in the section entitled 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 object to processing

To use your right to object to us processing your information in relation to the CHANTS trial, please contact chants@imperial.ac.uk

Once we have received notification of your objection to processing, we will no longer process your information for the purpose or purposes you originally agreed to, 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: dpo@imperial.ac.uk or 020 7594 3502

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

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