**PARTICIPANT PRIVACY INFORMATION**

**Research Study Title:** A secondary analysis of data from the STOPAH trial

**IRAS ID:** 286022

In this research study we will use information from you and your medical records. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it and for future research.   
We will make sure no-one can work out who you are from the reports we write.

This information pack tells you more about this.

**HOW WILL WE USE INFORMATION ABOUT YOU?**

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

* 15 years after the study has finished in relation to data subject consent forms.
* 15 years after the study has completed in relation to primary research data.

Further information on Imperial College London’s retention periods may be found at https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf.

A link to Imperial College London’s data protection webpage may be found at https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/ but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

We will need to use information from you and your medical records for this research project.

This information will include your

* NHS number
* STOPAH trial ID number
* Date of birth
* Sex

People within the College and study team will use this information to do the research or to check your records (see information to be collected) to make sure that the research is being done properly and the information held (such as contact details) is accurate.

We will keep all information about you safe and secure.

Some of your information will be sent outside of the EEA, including USA. They must follow our rules about keeping your information safe.

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.

**YOUR RIGHTS**

Your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

**LEGAL BASIS**

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research.  This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Our legal basis for using your information under General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:  
• Imperial College London - “performance of a task carried out in the public interest” (Article 6(1)(e) in the GDPR); Health and care research should serve the public interest, which means that we have to 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](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/)  
• Where special category personal information is involved, Imperial College London) relies on “scientific or historical research purposes or statistical purposes (Article 9(2)(j) in accordance with Article 89(1)in the GDPR)”.

**INTERNATIONAL TRANSFERS**

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner) either within the European Economic Area (EEA) or to other countries outside the EEA. Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates UK approved standard contractual clauses or utilise another transfer mechanism that safeguards how your personal data is processed.

**SHARING YOUR INFORMATION WITH OTHERS**

We will only share your personal data with certain third parties for the purposes referred to in this privacy notice and relying on the bases for processing your data as set out above.

* Other Imperial College London employees (including staff involved directly with the research study or as part of certain secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third-party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.
* the following Research Collaborators / Partners in the study;
* The University of Southampton – The University of Southampton ran the original STOPAH clinical trial and they will send your personal data directly to NHS Digital who will return further healthcare data to Imperial College London as Data Controller. Once The University of Southampton have shared the personal data with NHS Digital, they will destroy your personal data.

**POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH**   
When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study (such as contact details) may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation.  
This information will not identify you and will not be combined with other information in a way that could identify you. It will not be used to make decisions about you, such as for insurance policies.

**COMMERCIALISATION**

Samples (e.g. tissue or blood) and/or data from the study may also be provided to third parties e.g. commercial organisations or non-commercial organisations for the purposes of undertaking the current study, future research studies or commercial purposes such as development by a company of a new test, medication or treatment. The study will ensure your name and any identifying details will NOT be given to these third parties, instead you will be identified by a unique study number with any sample analysis having the potential to generate ‘personal data’.

Aggregated (combined) or anonymised data sets (all identifying information is removed) may also be created using your data (in a way which does not identify you individually) and be used for such research or commercial purposes where the purposes align to the legislation and wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes.

**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 because some research using your data may have already taken place and this cannot be undone.

* 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.

**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/](https://www.hra.nhs.uk/information-about-patients/)
* by asking one of the research team
* by sending an email to [m.thursz@imperial.ac.uk](mailto:m.thursz@imperial.ac.uk), or
* by ringing us on 020 3312 1903
* <https://www.mimah.org/>

**COMPLAINT**

If you wish to raise a complaint about how we have handled your personal data, please contact Imperial College London’s Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

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 (ICO).