

INVESTIGATOR SITE HEADED PAPER

SepTiC Privacy Notice

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 in the right way, appropriately. Imperial College London will keep your personal data for 10 years after the study has finished for information in relation to data subject consent forms and any information in relation to primary research data. The study is expected to finish in May 2027. For more information/confirmation regarding the end date please contact the study team, see 'Where can you find out more about how your information is used' for contact information.

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

This information will include your:

- Name
- Address
- NHS number
- Date of Birth
- Contact details

People within the College and study team (see the section below 'Sharing your information with others') will use this information to do the research or to check your records to make sure that research is being done properly and the information held (such as your contact details) is accurate. Anyone who does not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. 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.

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 the 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"); 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](#)

Where special category personal information is involved (most commonly health data, biometric data and genetic data, racial and ethnic data etc.), College London relies on "scientific or historical research purposes or statistical purposes.

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 UK adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient research partner 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 participant information sheet and by relying on the legal basis for processing your data as set out above.

- Other Imperial College London employees (including staff involved with the research study or as part of other 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 have data processing agreements with us to make sure they look after it safely. We only let them process your personal data for specified purposes and in accordance with our policies.
- Research Collaborators / Partners in the study.
 - In the analysis and writing-up of the results of the study some anonymised and de-identified data (so individual patients cannot be identified from it- it will not have a name or code on it) would be shared between research collaborators and partners. This would also be the case when assessing certain criteria, such as when they must decide if specific cases of an infection or illness meets a particular definition.

Potential use of SepTiC 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 your 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 including the GDPR and the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you. You will need to agree for your data to be used in this way, and there is a question about it on the consent form.

Combined or anonymised data sets (where all personal information is removed, so no individual patient can be identified) may also be created using your data such research which is in line with legal permission (including the General Data Protection Regulation) and the wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes (so no business will contact you after taking part in this research).

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. We will keep information about you that we already have because some research using your data may have already taken place.

- If you choose to stop taking part in the study, we would like to continue collecting information about your health from central NHS records, your hospital, your GP and NHS Digital. We will not contact you directly to ask any questions. If you do not want this to happen, tell us and we will not do it. This will not affect any healthcare or support you may be receiving separately.
- 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 medical data we hold about you if this could affect the wider study or the accuracy of data collected.

- If you agree to take part in this study, you will have the option to take part in future research using samples and de-identified data from this study, which will be added to the Imperial College Tissue Bank.

COMMERCIALISATION

Samples / data from the study may also be provided to organisations not named in this participant information sheet, 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, product or treatment. We 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 / data 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 relevant legislation (including the GDPR) 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.

If you choose to stop taking part in the study, we would like to continue collecting information about your health from central NHS records/ your hospital/ your GP. If you do not want this to happen, tell us and we will stop. This will not affect any healthcare or support you may be receiving separately.

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 this could affect the wider study or the accuracy of data collected. 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/
- by asking one of the research team
- by sending an email to septic@imperial.ac.uk
- by ringing us on 0207 5949725
- by visiting our site online: - septictrial.co.uk – **INSERT QR Code**

Complaint about how data has been handled

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to septic@imperial.ac.uk or by ringing us on 0207 5949725.

Following our response, if you are not satisfied, please contact Imperial College London's Data Protection Officer by :

- email at dpo@imperial.ac.uk,
- telephone on 020 7594 3502
- in writing at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you remain unhappy 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)- via www.ico.org.uk. Please note the ICO does say that you should try to sort out your concerns recommend that you seek to resolve matters with the Data Controller (us) first before involving them.