

Privacy statement

Introduction

The BRAVEST project is a cooperation between [different parties](#) with the purpose of researching the impact of the SARS-CoV-2 (COVID-19) pandemic on organ donation and transplantation. The project focuses on analysing the organisational and management procedures in organ donation and transplantation during and after the onset of the pandemic. For the BRAVEST project, organ transplantation data from different countries are analysed together, with a focus on specific clinical features of donors, outcomes of allocation procedures, and operational practices to ensure the safety and continuity of organ supply.

The European Society for Organ Transplantation (“**ESOT**”) is the coordinating party, overseeing the processing of personal data within the context of the BRAVEST project. The data is provided by different national consortium partners (“**data providers**”) and will be analysed by and under the supervision of ESOT.

This privacy statement serves to inform data subjects of the processing of personal data for the purposes of the BRAVEST project. If you were the recipient or donor of an organ transplant during the period covered by the study at one of the participating institutes, your personal data may have been included. More specific information can be found under 0. The statement does not apply to the other processing activities carried out by the parties mentioned.

Who is processing your data?

Joint controllers

The BRAVEST project is a cooperation between the following entities:

- [ESOT](#) (Project Leader)
- [Agence de la biomédecine \(ABM\)](#) (FR)
- [Centro Nazionali Trapianti \(CNT\)](#) (IT)
- [European Public Health Alliance \(EPHA\)](#)
- [Paris Transplant Group – PARCC INSERM](#) (Inserm) (FR)
- [The National Transplant Organization \(ONT\)](#) (ES)
- [Országos Vérellátó Szolgálat \(OVSZ\)](#) (HU)
- [Slovenija-transplant \(ST\)](#) (SI)

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- [Eurotransplant \(ET\)](#)

Eurotransplant provides data originating from the following countries:

- Croatia
- Germany
- Hungary
- The Netherlands
- Slovenia

When this Privacy Policy refers to “**we**”, that means all entities in the above list. If you would like to confirm whether your personal data is being processed for the purposes of the BRAVEST study, you can exercise your rights as a data subject, as explained under 0.

BRAVEST is a collaborative research project to which the individual data providers contribute personal data related to organ donors and recipients. Consequently, the entities mentioned above are joint controllers within the meaning of Article 26 of the General Data Protection Regulation (“**GDPR**”). All parties have signed a data sharing agreement, which serves to allocate responsibilities between the joint controllers and to make sure that your personal data is processed in a secure and responsible manner. The contents of this agreement are set out in this Privacy Statement.

Processors

We process data for the purposes of the BRAVEST study on a secure database hosted by [Dendrite Ltd.](#)

Which personal data do we process and for which purposes?

The BRAVEST study intends to study and analyse influential factors on organ transplantation before, during, and in the aftermath of the COVID-19 pandemic, in order to provide input to help improve resilience against crises in organ transplantation. To achieve this aim, we rely on the personal data of organ donors and recipients.

If you have been an organ recipient or donor between 2017 and 2022 at one of the hospitals or centres mentioned under 0, we may process your personal data for the purposes described above. We process a Unique Patient Identifier (“**UPI**”) used to differentiate you from other patients, as well as data linked to the transplant. It is important to note that each data provider uploads its data to the BRAVEST database in pseudonymised form. Patients can only be

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identified via the UPI by the data provider to which the patient belongs, and not by the other parties involved. As such, the UPI serves to protect your privacy.

This data has initially been obtained by the data providers participating in the BRAVEST project.

The personal data we use for this purpose includes the following categories:

- Unique Patient Identifier (UPI)
- Gender
- Geographical information
- Health data, such as:
 - Date of transplant
 - Blood type
 - Personal physical characteristics
 - Hospital information
 - Various recipient health variables, including COVID-related

As a consortium partner, [Inserm](#) will perform data analysis on the complete dataset used for BRAVEST.

After the study has been completed, results will only ever be published in aggregated form. This cannot be used to identify you.

Legal basis

Under the GDPR, personal data may only be processed if one of the six legal bases applies. We rely on the following legal bases for the processing of personal data in the context of the BRAVEST study:

- For the data providers, the processing of personal data constitutes further processing for the purposes of scientific research in the public interest of advancing EU health policy objectives as expressed in the EU4Health Regulation. This further processing is compatible with the initial purpose for which the data was collected, such as the provision of medical care.
- ESOT relies on the performance of a task in the public interest for the data processing for the purposes of the BRAVEST study. Additionally, the processing of your health data relies on the exception for scientific research in the public interest provided for in Art. 9(2)(j) GDPR.

Data retention

The personal data used in the BRAVEST study will be retained in the secure database for up to two years after the conclusion of the research project. Afterwards, the data will be deleted. The reason for this two-year period is that it is good practice to keep raw research data for a time after conclusion of a study for research verification purposes.

Inserm, after it has completed the analysis, shall delete all data immediately upon completion.

Processing outside the EEA

We do not process any personal data outside the EEA. Personal data for the purposes of the BRAVEST study are stored on a secure server located in France.

Data sharing with third parties

We do not share your data with any parties outside of the controllers and processors mentioned in this privacy statement.

Technical and organisational security measures

We have taken appropriate technical and organisational security measures to keep the personal data in the BRAVEST database safe and secure. These measures include, but are not limited to:

- Data encryption;
- Pseudonymisation of personal data;
- Data partitioning;
- Access control;
- Non-disclosure agreements for persons authorised to access the data.

In the event of security incidents or personal data breaches, we will work together to make mitigating measures to mitigate potential adverse effects of these incidents.

Data subject rights

The GDPR affords data subjects certain rights:

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European Society for Organ Transplantation (ESOT) ESOT is registered as a charity (Algemeen Nut Beogende Instelling: ANBI) in the Netherlands. VAT Registration number NL820509498B01 - Chamber of Commerce Amsterdam Registration number 34329686. Stichting ESOT is the support foundation of the European Society for Organ Transplantation (ESOT) VAT Registration number NL822162313B01 - Chamber of Commerce Amsterdam Registration number 34385303 - Legal Seat: Westerdoksdiik 423, 1013 BX Amsterdam, The Netherlands.

- Right to access: you are entitled to receive information about whether your personal data was used in the BRAVEST study and if so, which personal data and for which purposes.
- Right to rectification: if the personal data we process is incorrect, you may ask us to rectify.
- Right to erasure: if we process your personal data unlawfully, or you have successfully objected to our processing of your personal data, you may ask us to delete it.
- Right to restriction of processing: under certain circumstances, such as while your objection to the processing of personal data is pending, you may ask us to temporarily stay the processing.
- Right to object: you may object to our processing of your personal data based on reasons related to your particular situation. This request shall be granted, unless we find the public interest served outweighs your interests, rights, and freedoms.

If you would like to exercise any of these rights, you can do so by contacting ESOT at askme@esot.org. Since the data used in the study is pseudonymised, ESOT is unable to independently grant your request. Therefore, when you contact us, please mention which data provider may have provided your data to the project. We will then make sure your request is fulfilled.

Alternatively, you may also contact the data provider directly. We have agreed on a coordinating mechanism to make sure all data subject requests are handled in a timely and adequate manner.

Complaints

It is important to us that you are satisfied with the way that we handle your privacy. If you have questions or concerns concerning our processing of your personal data, or if you are not satisfied or have a complaint, you can contact ESOT's Data Protection Officer at DPO@esot.org.

If we are unable to reach a solution together, you can submit a complaint to the Dutch Supervisory Authority ("Autoriteit Persoonsgegevens"). You can do so [here](#).

Changes to this privacy statement

This privacy statement is reviewed regularly, and we reserve the right to make changes at any time in response to changes in our operations and/or applicable laws and regulations. The most current version of our privacy statement is always available on our website. The last change was made on 9 September 2025.

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