



European Liver Transplant registry

# ELTR Patient Information Security Policy

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The ELTR is a service of the European Liver and Intestine Transplant Association (ELITA). It therefore includes the ELITA members who provide data to the ELTR. The ELTR collects data on adult and pediatric LT performed in all of Europe to evaluate the results and outcomes of LT in Europe

There are two reasons the ELTR is doing this privacy notice for patients:

- First, it prevents any confusion about the way personal data is being used and ensures a level of trust between the ELTR and the individuals (liver transplant patients and living liver donors).
- Second, it gives patients more control on the ELTR collection of their personal data. If there's something they aren't happy with, they can query it and ask the ELTR to suspend that processing activity.

The ELTR patient information security policy include the following details according to Article 30 of the GDPR:

## 1) Contact details

Organisation: General Manager: Prof. René Adam, MD, PhD.  
European Liver Transplant Registry  
Centre Hépatobiliaire – Hôpital Paul Brousse  
12 Avenue Paul Vaillant Couturier  
94804 Villejuif – France  
Email. [rene.adam@aphp.fr](mailto:rene.adam@aphp.fr)  
Tel. +33145593828

ELTR DPO: Vincent Karam, PhD.  
Email. [vincent.karam-ext@aphp.fr](mailto:vincent.karam-ext@aphp.fr)  
Tel. +33145593437

## 2) The types of personal data the ELTR processes

ELTR's protected data includes information about individual transplant patients and living donors, considered as personal health information. The information is provided to ELTR by the liver transplant centre directly or via a national or international organ sharing organisation. The ELTR patients' data are pseudo-anonymised all along their process.

## 3) Lawful basis for processing personal data

The ELTR is relying on patient consent, that can be withdrawn at any time.

ELTR processes data exclusively for scientific studies in line with RGPD Article 9.2 (i) and (j) - Article 89 and Recitals 157 and 159, consent being the legal basis of data processing. Consent must be freely given, specific, informed, and unambiguous. To obtain freely given



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consent, it must be given on a voluntary basis. The element “free” implies a real choice by the data subject. The ELTR informed consent form is available to the transplant centers at this [link](#).

### 4) How ELTR processes personal data

ELTR does not share raw data with third parties without the agreement of the ELTR/ELITA scientific board committee. There are two situations where raw data are shared with third parties:

- Registry’s studies that use only available data: in that case patients and centers are anonymized.
- Registry’s studies that need to request to centers supplementary data necessary to conduct the study: in this case, the centers' ID is provided to the study leader who takes care of the survey by contacting centers and collecting the required supplementary data.

In any situation, third parties must be from an ELTR contributing center. In case third parties submit a proposal to perform a registry study, the ELTR/ELITA board examines the project according to the [regulations for the ELITA /ELTR studies](#) and carefully select eligible parties. Thus, ELTR/ELITA and the study leader conclude a [Data Processing Agreement \(DPA\)](#) in which the party is obliged to keep ELTR data confidential and to only process data on behalf of ELTR/ELITA, for the authorized purpose and in compliance with GDPR.

### 5) How long ELTR keep the data

ELTR does not store data for any longer than is necessary for the purpose for which they are being processed or to fulfil legal requirements or the registry’s scientific needs.

### 6) Data subject rights

The GDPR gives patients the following subject rights, which are:

- **Right to be informed:** ELTR informs patients what data of theirs is being collected, how it’s being used, how long it will be kept and whether it will be shared with any third parties.
- **Right of access:** patients have the right to request a copy of the information that the ELTR holds on them.
- **Right of rectification:** patients have the right to correct data that is inaccurate or incomplete.
- **Right to be forgotten:** in certain circumstances, patients can ask ELTR to erase any personal data that is stored on them.
- **Right of portability:** patients can request that ELTR transfers any data that it holds on them to another company.
- **Right to restrict processing:** patients can request that ELTR limits the way it uses personal data.
- **Right to object:** Patients have the right to challenge certain types of processing, such as direct marketing.
- **Rights related to automated decision making, including profiling:** patients can ask ELTR to provide a copy of its automated processing activities if they believe the data is being processed unlawfully. The ELTR reminds patients that they are free to exercise their rights simply by contacting the ELTR organisation (contact details in (1))