



ESOT presents

**The European Pancreas
and Islet Transplant
Registry**

esot.org

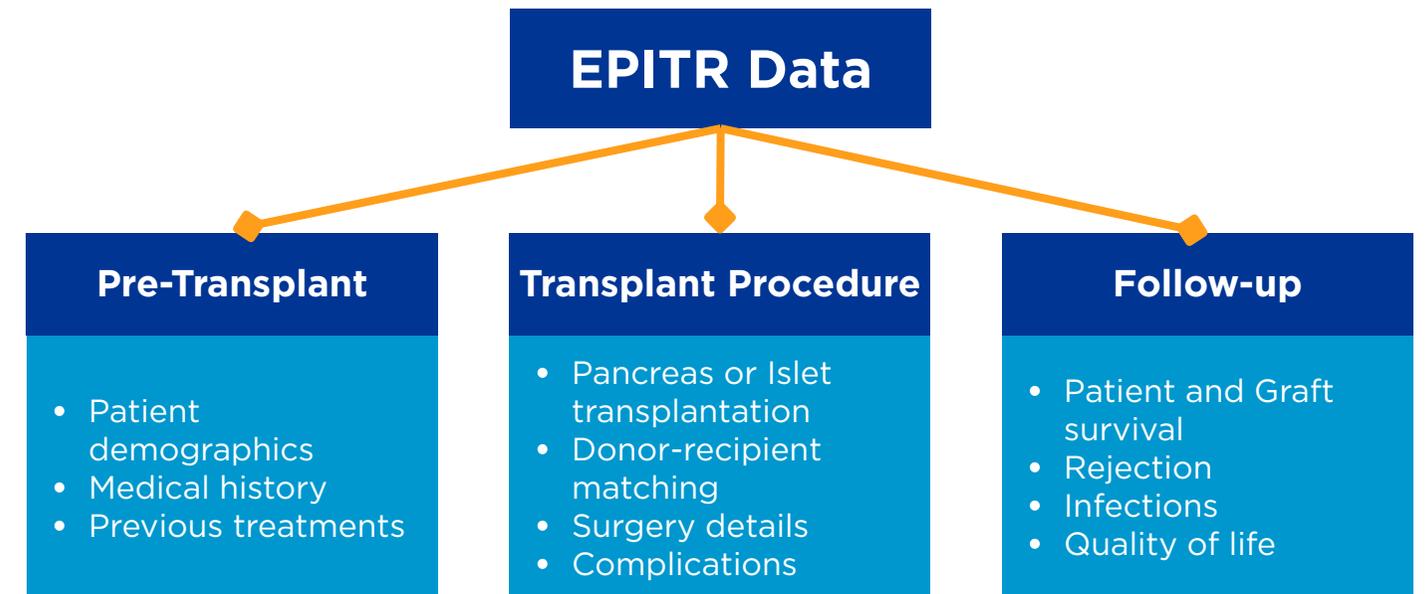
About ESOT Registries

With its pan-European Registries Platform, ESOT offers the transplant community a tool to gain and increase knowledge about solid organ transplantation and living donation outcomes. International data sharing is essential to acquire this knowledge and enable clinicians, scientists, and policymakers to improve practice, address unanswered questions and base recommendations on solid evidence. This modular and scalable platform represents a long-term investment in collecting information on organ transplantation. It offers a one-stop solution to contribute data and share practice with the community. The Registries Platform will ultimately lead to enhanced care and improved quality of life for recipients and living donors.

The European Pancreas and Islet Transplant Registry

EPITR unites Europe's transplant centres under one secure, harmonised data platform. Its goal: to improve patient outcomes, advance research, and inform policy through transparent, standardised data collection on pancreas and islet transplantation.

“EPITR turns data into knowledge — and knowledge into better lives for patients.”



Why EPITR matters?

Pancreas and islet transplantation saves lives and offers a vital treatment option for patients across Europe. To support continued progress, EPITR brings together fragmented national and regional data into one coordinated, GDPR-compliant registry — enabling shared insight, stronger collaboration, and better outcomes.

Key Benefits:

- A harmonised registry across Europe
- Transparent, standardised data sharing
- Real-time analytics to guide research and policy
- Secure, ethical, and scalable by design

Scientific Committee

EPITR brings together surgeons, researchers, data scientists, coordinators, and clinicians from across Europe, supported by ESOT's strong governance and operational framework.



Diego Cantarovich
EPITR Chair
Nantes, France



John J. Casey
EPITR Vice Chair
Edinburgh, UK



Helmut Arbogast
Munich, Germany



Thierry Berney
Geneva, Switzerland



Eelco De Koning
Leiden, Netherlands



Joana Ferrer
Barcelona, Spain



Torbjörn Lundgren
Solna, Sweden



Vassilios Papalois
London, UK



Lorenzo Piemonti
Milan, Italy



František Saudek
Prague, Czechia



Steve White
Newcastle, UK

Benefit to...

TRANSPLANT PROFESSIONALS

Access to pan-European data, facilitated international collaboration, and opportunities for professional development and advocacy

TRANSPLANT RECIPIENTS, LIVING DONORS AND FUTURE CANDIDATES

Improved organ allocation, broader donor inclusion, increased organ availability and quality, enhanced transplant outcomes, and opportunities to contribute to research and innovation

PHARMACEUTICAL AND MEDICAL DEVICE COMPANIES

Opportunities for real-world data, post-market surveillance, evidence generation, research collaboration, market insights, and collaboration with key stakeholders

PATIENTS' ASSOCIATIONS

Access to comprehensive data, evidence for advocacy and fundraising, collaboration opportunities, support for research and innovation, new educational resources, and patient empowerment

Which audience?

The EPITR will serve a variety of stakeholders, including authorities competent for transplantation, transplant centres, researchers, industry, regulators, transplant recipients, living donors and patients' organisations.

Authorities or centres collecting data will use the EPITR to share data with the international community and **benchmark their own data** with aggregated pan-European data. Centres or countries that would like to establish new registries will be able to do so by using the EPITR infrastructure.

Patients and their families will participate in an international effort to improve practice and provide evidence for clinical guidelines by giving their consent to the use of data. In the long term, establishing registries based on patient-reported outcomes will contribute to the understanding and improvement of **recipients' and living donor quality of life.**

By accessing annual reports, researchers will be able to formulate their **hypotheses based on large, international datasets**; moreover, they will be able to submit requests for accessing the large community of providers contributing data to the EPITR.

By contributing unrestricted funding, the industry will support studies on the effect of treatments on a large **international cohort.**

The large amount of information released periodically by ESOT will enable policymakers to issue **recommendations based on solid evidence.**

Committed to Trust, Transparency & Data Protection

- EPITR is built in alignment with GDPR and evolving best practices.
- Upholding the highest standards of data protection, transparency, and accountability.
- Empowering science. Protecting patients.

How is data protection ensured?

The protection of data is at the core of the EPITR.

Governance and Oversight

- An External Data Protection Officer (DPO)
- A Privacy Officer (PO)

Together, they ensure governance, independence, and accountability.

Transparency and Accountability

- Privacy Policy: outlines ESOT's protection principles.
- Privacy Statement: informs participants about their data rights.
- Record of Processing Activities (RoPA): documents all data operations.

Risk Management and Security

- Data Protection Impact Assessment (DPIA): identifies and mitigates risks early.
- Pentest: ensures IT systems are secure and resilient.

Safe Collaboration

- Data Sharing Agreement (DSA): defines secure data sharing responsibilities.
- Research Transfer Agreement (RTA): regulates international data transfers.

Preparedness

- Data Breach Protocol (DBP): ensures swift response, containment, and communication in case of incidents.

How to support this international effort

ESOT invites sponsors such as industry partners, private funders, foundations and authorities to support this initiative and work in close collaboration to encourage greater sharing of best practices, address inequalities in organ transplantation and improve patient experience and outcomes. With your support, ESOT will be able to invest in enhancing EPITR and its registries platform, promoting scientific studies and ultimately improving transplant care and quality of life.

We call for unrestricted grants to support the infrastructure behind this huge effort and its long-term sustainability.

**More detailed information available upon request*



THE BENEFITS FOR SUPPORTERS OF THE REGISTRIES PLATFORM INCLUDE:

VISIBILITY

your logo will be listed on our [web pages](#) and in all presentations of the project by ESOT

REPORTS

you may request an annual tailored report based on the published annual report

EXPERTS

we will help you find the right expert in transplantation and liaise with them

RESEARCH*

you may submit research projects to our scientific committees

ACKNOWLEDGEMENT

of your contribution in publications, when possible

EPITR will allow you to

...USE THE REGISTRY DATASET

Registries partners can request tailored reports based on aggregated anonymised data. Fees may apply.

...COLLECT DATA ON ADDITIONAL VARIABLES

Partners may submit applications to collect new variables for specific purposes; ESOT invites the EPITR Scientific Committee to evaluate the application and call data providers to contribute. Data analysis should be realised by an academic research consortium; results must be published openly. Fees or unrestricted grants apply.

...CREATE A NEW, SHORT-LIVED REGISTRY

The Registries Platform allows creation of new registries easily. Partners may submit ideas to create a new registry, which should be formalised in a research plan by an academic research consortium. New registries are established considering relevance for the EPITR community; results must be published openly. Fees or unrestricted grants apply.


SILVER
partners

€30,000/year
4-year commitment
€120,000 total

VISIBILITY

your logo will be listed
on our web pages

EXPERTS

we will help you find the right
expert in transplantation and
liaise with them

ACKNOWLEDGEMENT

of your contribution in
publications, when possible


GOLD
partners

€60,000/year
4-year commitment
€240,000 total

VISIBILITY

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EXPERTS

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ACKNOWLEDGEMENT

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publications, when possible

REPORTS

you may request an annual
tailored report based on
the published annual report


PLATINUM
partners

€75,000/year
4-year commitment
€300,000 total

VISIBILITY

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EXPERTS

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ACKNOWLEDGEMENT

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REPORTS

you may request an annual
tailored report based on
the published annual report

RESEARCH

you may submit research
projects to our scientific
committees

We welcome
tailored partnerships
Let's connect!



Become our Partner!

DEVI MEY

Chief Executive Officer

M +39 393 164 58 05

M +41 78 234 14 40

E devi.mey@esot.org

VINCENT KARAM

Registries General Manager

M +33 648 371 273

E vincent.karam@esot.org

MATEUS WELNOWSKI

DPO

E dpo@esot.org



esot.org