ESOT presents

The Registries Platform

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About

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.

Intro

ESOT started building a platform to host pan-European registries in January 2021, leveraging on the experience of its section ELITA, which had been successfully coordinating the European Liver Transplant Registry since 1985, and the work of the international consortium supporting the EU-funded EDITH project.

Despite the existence of some transplant registries, it was clear that a **multi-organ platform** would facilitate sharing expertise in registries building and management as well as liaising with national and international data providers.

With this aim in mind, the platform was conceived as modular, scalable, and able to receive information on different organ transplantations: a **one-stop solution** for European national and local authorities to contribute data and share practice with the community.

Moreover, the platform was designed to promote the **establishment of new national or local registries**: with a couple of clicks, it is possible for a centre or a country to start collecting data on their patients and sharing them with the international community.

Finally, the platform was conceived to host **short-term registries addressing specific questions** on top of those included in the standard datasets: scientific consortia can easily call for contributions from an existing community of data providers and patients.

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 ESOT Registries Platform 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 Registries Platform 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 Registries 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 Registries Platform.

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**.

How is this project governed?

In order to guarantee the success of this initiative, ESOT has engaged in discussions with representatives of data providers, in particular authorities competent for transplantation, as well as scientists involved in international registries. This effort has led to the establishment of a clearly-structured governance that allows easy implementation and smooth development.

GENERAL ASSEMBLY

represents data contributors and acts as an advisory board. It ensures that the registries can comply with the existing legal, scientific and ethical regulations, and it advises the Steering Committee on developing the strategy and establishing new registries

STEERING COMMITTEE

is responsible for developing the strategy of the Registries Platform and managing this initiative. It is composed of representatives of data providers selected by the General Assembly as well as renowned professionals and a patient representative selected by the ESOT council

SCIENTIFIC COMMITTEES

are established for each registry; they are composed of renowned professionals and a representative of data provider appointed by the General Assembly. Scientific committees define the set of variables to collect and the expected outcomes of the registry; they review proposals for short-term projects

How is data protection ensured?

The protection of data is at the core of the Registries Platform initiative.

As data controller, ESOT has taken all necessary measures to comply with the European General Data Protection Regulation, it has established a data processing agreement with the technical partner providing the infrastructure of the platform as well as data sharing agreements with data providers. An independent Data Protection Impact Assessment has been conducted, and a Data Protection Officer has been appointed.

Data collected on the Registries Platform will be stored in the EU (Ireland); they will be processed by Dendrite Clinical Systems, a UK-based company; data will be released in an aggregated form only. The risk of data breach is kept at the minimum possible.

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 the registries, 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.

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

What the Registries Platform can do for you

... in the context of AN EXISTING REGISTRY BY USING THE REGISTRY DATASET EXCLUSIVELY

Provided approval by the Steering Committee and agreement on publication policy, Registries Partners can request tailored reports produced by Dendrite Clinical Systems based on aggregated anonymised data. Fees may apply.

... in the context of AN EXISTING REGISTRY BY COLLECTING DATA ON ADDITIONAL VARIABLES

Partners may submit applications to collect new variables for specific purposes; ESOT invites the relevant committees 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.

... in the context of 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 transplant community; results must be published openly. Fees or unrestricted grants apply.

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ACKNOWLEDGEMENT
of your contribution in publications, when possible

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Become a Registries Platform Partner!

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