

European Society for Organ Transplantation (ESOT)

Tackling Inequalities in Organ Transplantation: A Pathway Forward



Manifesto
2024-2029



ESOT'S POLITICAL MISSION

It is ESOT's aim to eliminate inequalities in organ transplantation across Europe.

To achieve this, **ESOT is calling on policymakers, health authorities and medical professionals** to join forces in setting stronger objectives for equitable access and sustainability in organ transplantation.

ESOT is an influential international organisation dedicated to its primary aim of improving patient outcomes in organ transplantation. With over 1700 active members and a wider community of 8000 individuals from all sectors related to transplantation, ESOT collaborates with leading transplant experts to support scientific advancements, promote education and drive political change.

The current landscape of transplantation in Europe

Across Europe, widespread inequalities exist across the organ transplantation pathway in several core areas, including:

ACCESS TO TREATMENT



Access to transplantation faces two major hurdles: limited organ availability and inefficient referral networks.^{1,2} Together, these barriers can lead to avoidable excess mortality among individuals with end-stage organ disease. Yearly, up to 4% of those actively on the waiting list die before being transplanted, representing 11 patient deaths daily across Europe.³

HEALTHCARE PROFESSIONAL (HCP) KNOWLEDGE



Disparities in HCP perception, driven by a lack of consensus, contribute to wide variations in process across the organ transplantation pathway.¹ In the Intensive Care Unit (ICU) setting, for example, inadequate training and standardisation of knowledge among HCPs may result in missed organ donation opportunities, impacting the number of available organs for transplantation.³

REPORTING AND DATA COLLECTION



Throughout Europe, the ability to collect robust data on organ transplantation procedures and outcomes varies considerably due to resource constraints.¹ As a result, significant data gaps persist, hindering critical aspects of the transplantation process including equitable organ allocation, timely patient referral and evaluation, efficient resource management and the ability to conduct effective transplant follow-up.

PATIENT AWARENESS



Limited information and health literacy among the general public can negatively affect transplantation rates. It is commonly seen that patients and/or families refuse transplantation or donation due to misunderstandings and uncertainty regarding the unknown.¹

While the EU Action Plan on Organ Donation and Transplantation (2009–2015) made strides to address these inequalities, the initial rise in transplantation rates observed after its initiation has plateaued in recent years, with some countries even experiencing a decrease.^{1,3} **Renewed action is therefore urgently needed** to drive fair and sustainable improvements in organ transplantation throughout Europe.

ESOT's vision for transforming the organ transplantation landscape between 2024–2029

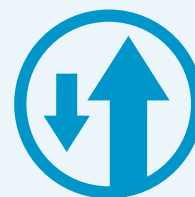
From 2024 to 2029, ESOT is dedicated to a collaborative partnership with Members of the European Parliament (MEPs) in prioritising actions that advance equitable access to transplantation across Europe. While ESOT spearheads initiatives to elevate healthcare professional and patient knowledge on organ transplantation, we seek MEP support for targeted actions related to data collection and fostering cooperation among EU member states.

Prioritise the collection of data regarding procedures and outcomes

The optimisation of transplant programmes necessitates the continuous collection of data to assess their effectiveness and identify specific areas for development.

Recommendations

- Sufficient funding opportunities and supportive regulatory frameworks need to be implemented to favour data collection initiatives, such as the ESOT pan-European registry platform, which promote the exchange of data and sharing of best practices across Europe
- Data collection should extend beyond the scope of clinical data, encompassing biomedical and biomarker data, alongside patient-reported outcomes (PROs), to gain a deeper understanding of the patient transplantation journey



Strengthen collaboration among EU member states

Collaborative efforts among EU member states are essential in establishing a cohesive and universally applicable standard that supports HCPs and EU transplant centres in delivering consistent, high-quality transplantation services.

Recommendations

- Emphasis should be placed on initiatives that support cross-centre collaboration and enable comparisons of organ donation and transplantation rates between countries. This can help drive consensus on patient criteria for transplant eligibility and illuminate best-practices that can be implemented elsewhere
- Consensus should be reached on specific frameworks and policies that facilitate organ exchange across the EU. It is imperative that these policies are carefully considered to maintain an optimal balance between self-sufficiency, where possible, and organ exchange to meet the needs of patients across the EU



Optimise the role of HCPs

At present, the level and quality of education and training of HCPs involved in the transplantation process is uneven across Europe.¹ Combined with robust data collection to inform evidence-based decisions, a more comprehensive and standardised approach to HCP education and training is required.

Recommendations

- Continuous education should be provided to HCPs involved in the transplantation process. Specific attention should be focused on optimising the role of donor coordinators and intensive care professionals to ensure they have a well-informed approach to identifying donor opportunities and in engaging with the families of potential donors
- The creation of consistent and widely available guidelines on patient eligibility and treatment decision processes across Europe is needed to alleviate issues seen within the referral process



Enhance patient awareness and knowledge

Overcoming misconceptions and fear surrounding organ transplantation is key to increasing transplantation rates.

Recommendations

- Support should be provided for awareness initiatives, both at a national and cross-country level, utilising mass and social media to highlight the benefits and processes of transplantation. Moreover, individuals should be encouraged to not only consider themselves as potential donors but also as potential recipients who may, one day, rely on a life-saving transplantation. If this mindset shift, which emphasises the personal benefit, is adopted collectively, it could act as a significant motivator for people to register as donors, thus expanding the donor pool
- Among broader awareness initiatives, tailored approaches are necessary for minority communities to ensure messaging effectively reaches affected individuals



Elevate the role of patient advocacy groups and patients in the policymaking process

Through their direct experiences, patient advocacy groups and patients themselves can offer valuable insights to address and alleviate the current inequalities in the organ transplantation process.

Recommendation

- Patient advocacy groups and patients, as well as living donors, should be included and consulted on the development of national initiatives and legislation. This will ensure policies are insight-driven and address the active needs of both donors and those receiving transplantations



Click [here](#) to read ESOT's full report.

For further information, please contact: askme@esot.org

REFERENCES

1. The European Society for Organ Transplantation (ESOT). *Tackling Inequalities in Organ Transplantation: A Pathway Forward*. April 2022. Available at: https://esot.org/wp-content/uploads/2022/10/EM012518_ESOT_ActionDay_ThinkTankReport_2201005_v0-8_FH.pdf (Accessed: May 2022); 2. Rudge C, et al. *British Journal of Anaesthesia*. 2012;108(S1):i48-i55; 3. Vanholder R, et al. *Nat Rev Nephrol*. 2021;17(8):554-568.