

Tackling Inequalities in Organ Transplantation: A Pathway Forward



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Foreward:

Luciano Potena, President of the European Society for Organ Transplantation (ESOT):

“For the last four decades, with greater challenges in recent times due to the Covid-19 pandemic, our community has been at the forefront of global health issues.

The COVID-19 pandemic has reiterated widespread disparities in healthcare relating to gender, ethnicity, socioeconomic status and place of residency. These inequities have long been recognised as a reflection of social fault lines within our society. As we celebrate ESOT’s 40th anniversary, we need to reflect as a community on what we can do over the next 40 years to build a future together as an inclusive organisation.

When discussing how to celebrate ESOT’s 40th anniversary, our first thought was, *‘How can we ensure sustainability? How can we continue to build on the foundation that we are already blessed with?’*. We felt that the only way that we could truly celebrate our society was to launch an action day as a formal commitment to our community. To move effectively in this direction, we held an EU Think Tank as part of the action day to address inequalities in access to transplantation and appropriate post-transplant care.

During the Think Tank, we recalled the past and looked to the future of this initiative, not only the future of clinical transplantation practice, education and science, but also, most importantly, the future of our patients. Awareness is the first step to identifying and defining the barriers to equity at country, ethnic, cultural and socioeconomic levels to implement concrete evidence and action evidence-based policies.

We are delighted to launch this report immediately following the European Health Forum Gastein (EHFG), the leading pan-European health policy event. Many of the key issues addressed in this report were discussed at EHFG during a dedicated session organised by ESOT and Takeda: *‘A level playing field for transplant patients: Spurring action across Europe’*.

We hope that the outcome of our Think Tank, the EHFG session and this report will inspire our community to work collectively in addressing the burden of inequalities in organ transplantation and finding innovative solutions to improve access to treatment, awareness and education for healthcare professionals (HCPs) and patients.





INTRODUCTION

Across Europe, widespread inequities exist in organ transplantation, particularly in access to treatment and healthcare professional (HCP) and patient awareness and education.¹

Despite large- and small-scale efforts to improve these disparities, inequities remain in terms of accessing waiting lists, the allocation and receipt of deceased and living donor transplants, and attainment of pre-emptive transplantation.

Key factors, such as age, sex, gender, socioeconomic status, ethnicity, place of residency and level of health literacy, continue to exert undue impact on equity of access to transplantation, as do HCP and patient awareness and training.¹⁻⁴

Despite the efforts of the EU Action Plan, which was in place until 2015, less than half of the 28 European countries assessed achieved a greater than 20% increase in organ transplantation between 2010 and 2019, whilst others showed a decrease.¹ This reflects the marked differences between countries and demonstrates that there is ample room for improving transplantation rates across Europe.¹

It is imperative that further action is taken to address these varying figures.¹ The education of patients, HCPs and the general public also plays a vital role in reaching this goal.¹

In view of this, the ESOT Think Tank was specifically designed to discuss and address inequalities in organ transplantation across Europe, primarily associated with access to treatment and HCP and patient education. The ultimate aim of the session was to attain a consensus on a set of recommendations and actions aimed at improving equitable access to service delivery and sustainability in organ transplantation.

ESOT will then take the points identified in the discussions and devise a series of calls to action that, together with our partners, networks and wider stakeholder groups (i.e. policymakers), we must adopt to drive and implement change.

This report outlines the key challenges that the European transplant landscape currently faces and emphasises innovative solutions to bridge the inequality gap.



ACCESS TO TREATMENT

Inequities in access to transplantation can be seen at multiple points in the transplantation pathway and across many parameters, including age, gender, ethnicity, socioeconomic status, social networks and religion.

These inequities influence access to all types of donors, waiting lists and the allocation of a deceased donor organ and/or achievement of pre-emptive transplantation.^{1,2,4}

Between 2009 and 2015, the EU Action Plan on Organ Donation and Transplantation was launched in the hope of rectifying these inequities and bridging the gaps in transplantation access.⁴

Three challenges were identified:⁴

- Increasing organ availability
- Enhancing the efficiency of and accessibility to transplantation systems
- Improving the quality and safety of organ transplants

Despite these efforts, an analysis in 2019 showed that only 43% of EU countries had achieved an increase greater than 20%, with some countries even seeing a decrease over time.¹

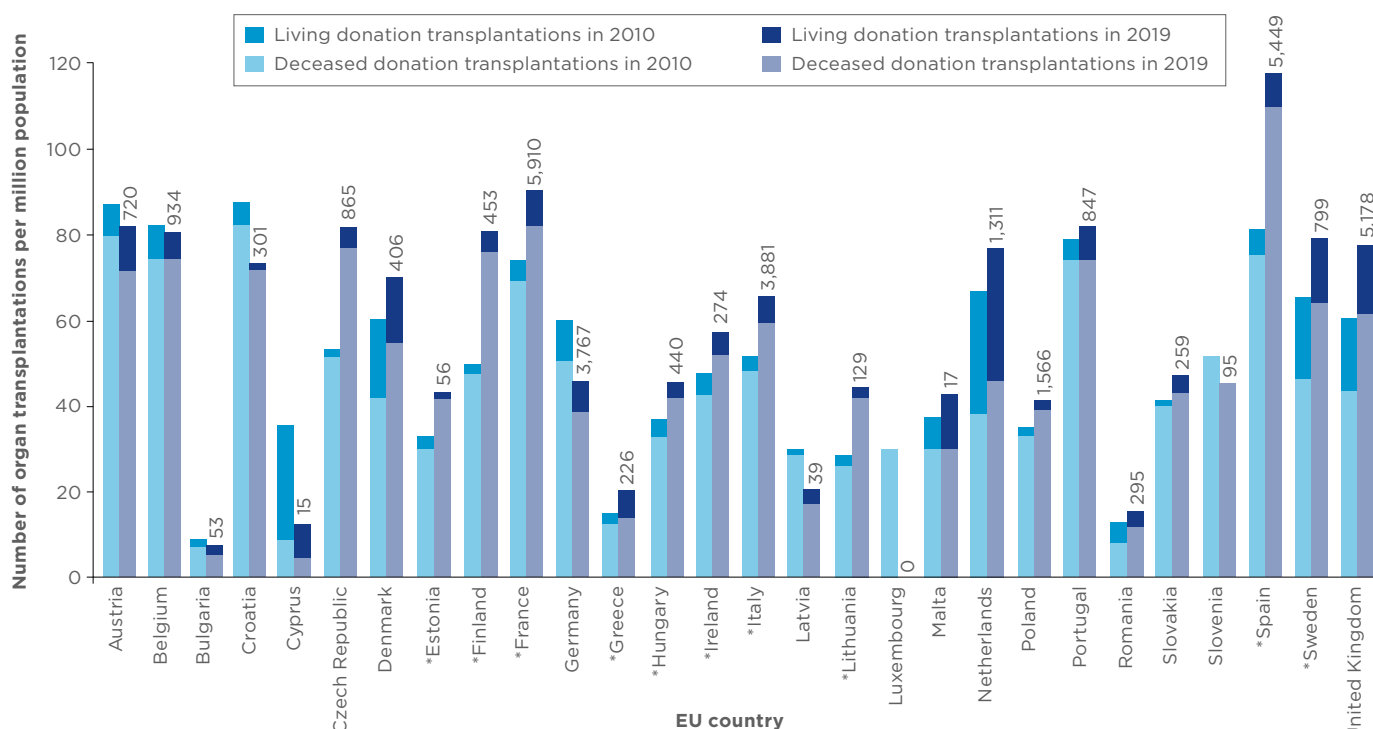


Figure from Vanholder R, et al. 2021.¹



Key challenges

One of the biggest hurdles faced in transplantation, and a possible explanation for the numbers shown above, is access to waiting lists. According to the Council of Europe, recent data show that, on average, 21 people die each day waiting for a transplant.⁵ In the eyes of patients, the lack of access may be the equivalent of a death sentence, with many candidates being at significant risk of not surviving the interval in which a transplant would become available, even if they make it to the list.^{5,6}

In addition to age, limited health literacy has been identified as a central factor affecting access to transplantation, independent of patient demographics, socioeconomic status and comorbidity.⁴ It has been noted that efforts to improve the effects of limited health literacy may, in turn, improve access to transplantation and, therefore, should be heavily considered in ESOT's future plans.⁴

Socioeconomic inequity persists as a major barrier to transplantation, even in public universal healthcare systems. A study by Pruthi R, *et al.* (2020), which investigated inter-centre variation in access to kidney transplantation, found that individuals with comorbidities, a body mass index (BMI) >35 kg/m², increased age and a lower socioeconomic status were less likely to be listed for a transplant.⁷ In addition, Asian and Black participants had reduced access to pre-emptive transplantation listings.⁷

While variations in patient cases and transplant centre practices predominantly account for inter-centre differences, further research is required to better understand the links between socioeconomic status and transplantation listing.⁷

With regard to transplantation centre factors, there is evidence that transplant centre infrastructure, whether a transplantation-first policy is in place, the structure of the multidisciplinary team and variations in centre processes (e.g. referrals) are some of the key factors affecting access to treatment. Addressing these challenges at the centre level can be more difficult, ultimately requiring the involvement of policymakers to break barriers and incentivise centres to increase transplantation activity.⁴

In addition to within-country geographical disparities, challenges in access to cross-border treatment for some European countries persist.⁵ Many patients still struggle to be accepted for cross-border treatment, especially those who are not members of a pan-European organisation promoting cross-border treatment (i.e. Scandiatransplant and Eurotransplant).

It has also been noted that some European hospitals no longer accept cross-border patients, despite substantial efforts from patient association campaigns.⁵ These difficulties persist and must be addressed.

Transplantation, like many other fields of medicine, will soon be driven by the inevitable progression and development of technology. However, this comes with its own challenges as it risks creating a new barrier – access to technology. Therefore, any newly adopted technology needs to be widely available throughout Europe and must not be restrictive due to financial constraints.⁴



Sex/gender of donors and recipients in organ transplantation³

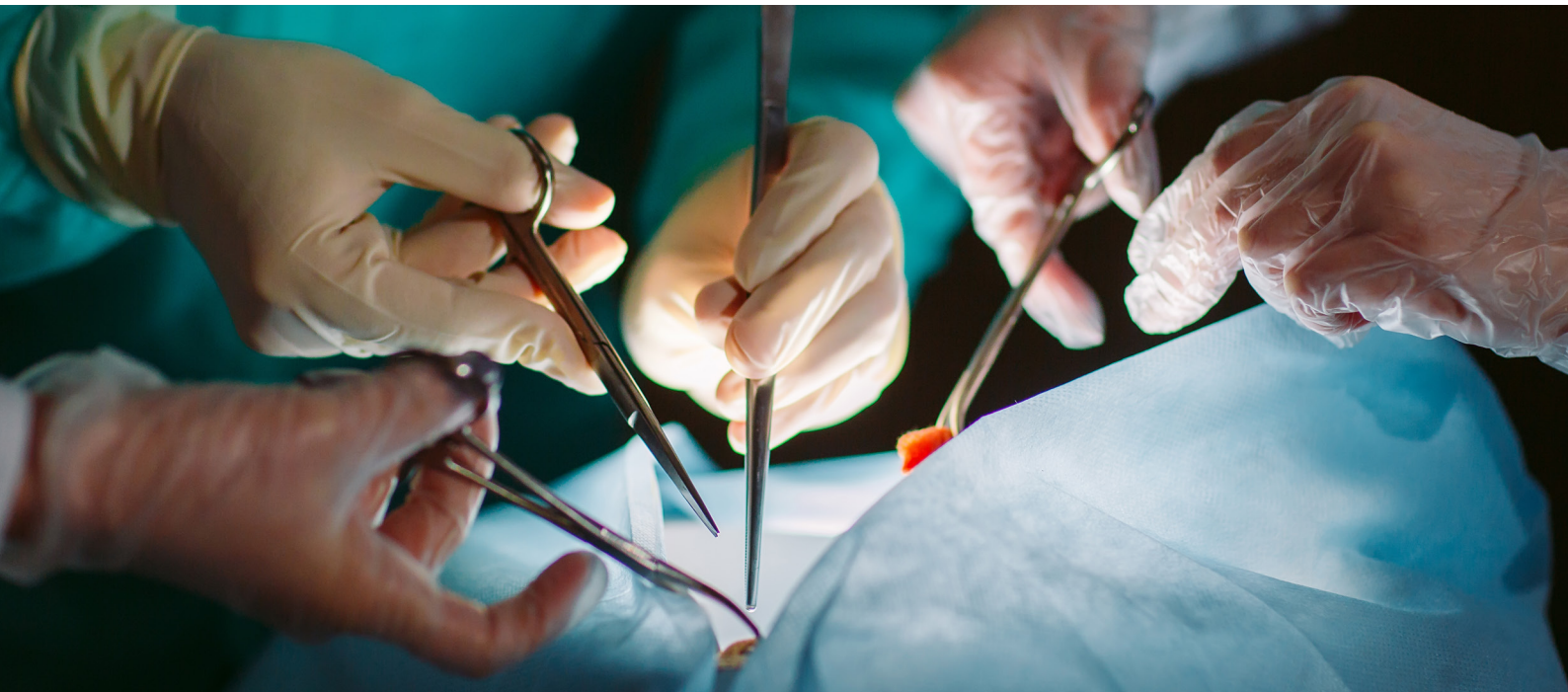
Sex and gender represent two fundamental variables that must be taken into due consideration to ensure that health policies are efficient and adapted to the current needs and circumstances of the global population. Sex and gender are often used interchangeably; however, they have specific definitions that must be understood.

The term 'sex' exclusively refers to biological traits and the term 'gender' refers to non-biological attributes that are socially constructed and are the result of an individual's culture and conventions. An analysis was conducted by the European Committee on Organ Transplantation (CD-P-TO) to investigate sex inequities in organ transplant donor and recipients and in an effort to address current data gaps.



The investigation drew the following conclusions:

- In most countries, men are the prevalent source of both donor/donation after brain death (DBD) and donor/donation after circulatory determination of death (DCDD) deceased donors
- Women are more likely to be a living kidney donor
- The majority of transplantation recipients are men
- Limited education and health literacy, as well as socioeconomic dependence, immunological sensitisation and donor-recipient size matching may be an explanation for the results of this observation.





Solutions

Actions to improve access to transplantation need to occur at three levels – patient, clinician and transplantation centre. To address the inequities in access highlighted above, tangible, modifiable patient factors and HCP/system factors must be clearly identified and addressed.⁴

ESOT has a joint road map, led by the European Kidney Forum and endorsed by ESOT (see figure on the right). This road map may assist in advancing organ donation through several approaches. Specifically, reducing barriers is underpinned by the need for education, equality and research.^{1,4}

In terms of research and data, a different approach must be taken, and it is important not to focus solely on clinical data. An integrated approach is required to influence clinicians and policymakers, whereby data are gathered across a variety of disciplines. Clinical, biomedical and biomarker data are needed in addition to patient-reported outcomes (PROs) to understand patient needs. To facilitate this need, ESOT is spearheading a fundamental development – the launch of pan-European registries.⁴

In addition, ESOT is setting up a collaboration framework with the Donation and Transplantation Institute (DTI) and World Health Organization (WHO) Europe to stimulate the development of transplantation programmes in countries with low transplant activity and high ‘transplantation tourism’ to improve access to education.

Moreover, thanks to BRAVEST – an EU4Health-funded project that ESOT will coordinate in collaboration with several national authorities – ESOT will promote the development of measures to improve the resilience of transplant and donor procurement networks when facing a crisis.

ESOT can also support less-developed countries across Europe, which may not have the means and/or resources to sufficiently collect the volume of data required, with the collection and transfer of data.⁸

Patient associations have a significant impact across Europe. For example, local charities and advocacy groups have raised funds for candidates to travel across borders and receive a life-saving transplant not available in their own countries. This is in addition to lobbying for new laws to be adopted in response to patient association campaigns.⁵ Patient associations have unique knowledge gained from the direct experiences of transplantation and the struggles to access treatment and, therefore, have a crucial insight to be able to contribute towards tackling inequities.

Moving forward, it is paramount that patient associations have a greater contribution in the decision-making processes and development of future strategies to tackle European variations in access to transplantation.⁵

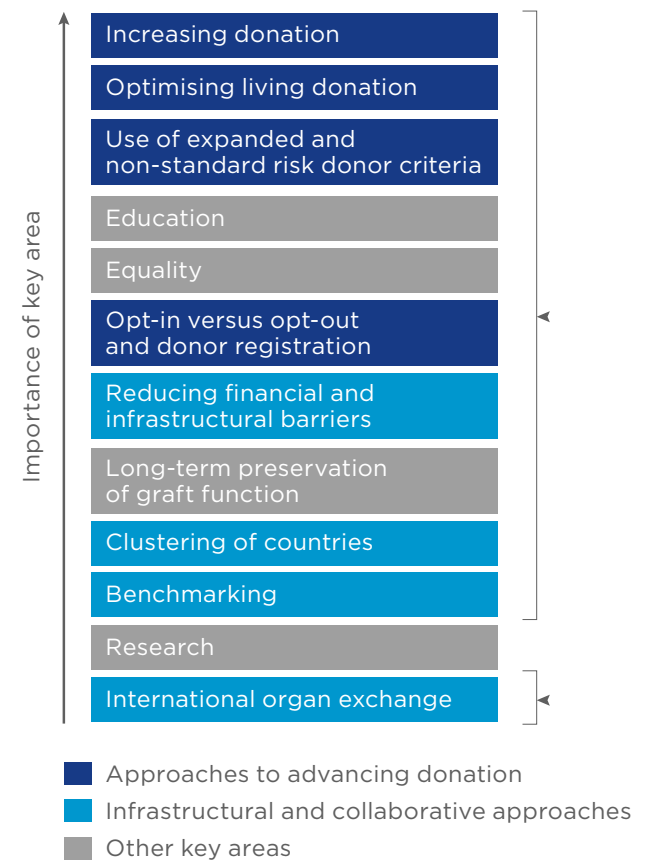


Figure from Vanholder R, *et al.* 2022.¹



HCP/PATIENT AWARENESS & KNOWLEDGE

It is evident that limited health literacy can have a profound impact on access to treatment; therefore, the need for education across all demographics is necessary.

Lack of education and awareness can promote fear of the unknown, which, understandably, can negatively affect transplantation rates.⁸ It has been recognised that there is substantial variation in the level and quality of education provided throughout the transplantation process, which needs to be consistently aligned in order to mitigate inequities due to lack of knowledge.⁴

There is a general lack of data to support the provision of education, whereby clinicians and patients require robust evidence to support a consistent transplantation process and understand the experiences of others.

In addition, the current means by which patients and HCPs are educated is insufficient; an alternative approach is required, both at a higher European level and local level, leveraging experiences from the patients themselves and local patient associations.⁸

Key challenges

The key challenges and themes identified for patients were the necessity to improve understanding of the transplant waiting list process and the fact that the provision of information about treatment options and listing is highly variable.⁴

A lack of adequate information and the limited health literacy of the general public and families can also feed into challenges around risk perception. It is commonly seen that patients and/or families refuse transplantation out of fear, and if this lack of awareness was to be addressed, transplantation rates may improve for this demographic.⁸

A major challenge in the transplantation process is the lack of dialogue between the clinician and the patient and the impact this has on the provision of knowledge. Patients currently meet with HCPs for around 10 minutes, which is insufficient for the provision of adequate information and clarity on the process and treatment options. Patient education needs to be delivered by an alternative means and not by the clinician during a brief consultation. This constant dialogue is, however, costly to healthcare systems, which is where ESOT can play a crucial role.⁸

Disparities in HCP perception, driven by a lack of consensus, are also evident. Currently, there are wide variations in the referral process across Europe, whereby eligible patients are not referred for transplantation. This stems from the interpretation of various factors, driven by lack of education and awareness and, in particular, a clinician's personal perception of risk.⁸

As previously outlined, there are a multitude of data gaps across Europe. Primary research is an essential source of education, as not only does this illustrate and contextualise the issues at stake, but also provides compelling evidence to raise awareness and improve knowledge. PROs – a measure reported directly by the patient with no external interpretation and pertaining to factors including health status and quality of life – are not collected often enough and would also drive patient education by reducing fear. In addition, the ability to collect robust data varies across Europe due to lack of resources and is, therefore, an inequity that needs addressing to improve overall training and knowledge.⁸



Solutions

Creating guidelines and sharing best practices are essential steps in challenging practice, changing behaviour and connecting professionals. Guidelines on patient eligibility and treatment decision processes may also alleviate issues seen within the referral process.⁸ In addition to this, ESOT are developing the 'ESOT Hub', an educational platform for a range of audiences, with the ultimate aim of bridging the knowledge gap and providing a reliable source where consistency in information quality is at the forefront.

This source of education plays a pivotal role in connecting the public, patients, researchers and professionals alike, as it provides an alternative approach to education in contrast to short clinician consultations and current practices.^{4,8}

It is also crucial that ESOT leverages the skills of its members. This wealth of knowledge is invaluable in sharing best practices, particularly when supporting less-developed countries in the initiation of transplant programmes.⁸ This mission is one of great importance, as it underpins the progression towards greater HCP knowledge and awareness whilst also addressing inequities to accessing transplantation resulting from geographical disparities.⁸

Collaboration at the local and national level is central to moving forward and increasing both HCP and patient awareness and knowledge. The specific education of HCPs on the referral process and patient eligibility is pivotal in progressing towards increased transplantation. This could be tackled by cross-centre collaboration, with a consensus on patient criteria for transplant eligibility and where personal beliefs and perceptions of risk can be avoided.⁸

Moreover, ESOT can leverage the experiences of others, for example, the Member State collaboration seen between Austria and Hungary following the formation of their cross-border bilateral lung transplant agreement. EU Member State collaboration is a crucial area of focus for ESOT, as it assists in the improvement of multiple aspects of transplantation activity.⁸ For example, cross-country educational campaigns would have a substantial impact in terms of consistent knowledge building and aligning perceptions of the general public, patients and HCPs.⁸

Patients and patient associations can provide real-world insight into the experiences of transplantation activity and can assist in educating HCPs and the general public. Awareness campaigns driven by patients would be particularly effective, as direct patient experience provides compelling information to influence, educate and engage a variety of audiences.⁵ In addition, ESOT can promote engagement of the public, patients, politicians and stakeholders through communications and campaigning, with the ultimate aim of changing perceptions and behaviours amongst stakeholders in the field of transplantation.⁸

The Directorate-General for Health and Food Safety (DG SANTE) is willing to provide EU support to ESOT for upcoming programmes, such as a global awareness initiative or the development of a multi-stakeholder council. These should be considered when planning future strategies.^{8,9}



SUMMARY

It is clear that organ transplantation is an extremely complex medical field, with inequalities relating to access to treatment and HCP and patient knowledge. Identifying these issues is pivotal to moving forward, with the hope of improving the transplantation landscape in Europe and, in turn, internationally.

European stakeholder actions:

Leveraging the outcomes of the EU Action Plan, ESOT is calling for a collective effort from policymakers, health authorities and medical professionals to set stronger objectives with greater impact and more tangible outcomes:

Governments and health authorities to include patient organisations and representatives in the development process of national initiatives and legislation on organ transplantation



Governments and health authorities to collaborate with key stakeholders, such as ESOT, to create a universal standard to support HCPs and European transplant centres in delivering consistent transplant services across the EU, ensuring equity of access to transplantation and improving HCP/patient awareness and training



ESOT actions:

ESOT is committed to ever improving the quality of and access to care for HCPs and patients alike. To ensure sustainability and to help drive a change agenda, ESOT has identified the following actions that aim to tackle inequalities associated with access to treatment, education and awareness in organ transplantation:

ESOT to launch data-driven registries and initiate an international call for data, specifically:

- Using new approaches in data gathering, such as the integration of data across various disciplines
- Attaining greater longitudinal data around inequities according to the sex of donors and recipients in organ transplantation
- Gathering patient-driven data (i.e. PROs) to inform patients on realistic experiences and reduce fear among patients and families/caregivers



ESOT to work with patient associations in establishing a multilingual and culturally competent transplant patient information portal aimed at improving patient education and awareness using real-world evidence



ESOT to develop a HCP communication guide promoting shared decision-making and bridging the inequality gap for access and education in organ transplantation between developed and less-developed countries within the EU



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