

The steering group of the ESOT patients' inclusion initiative invites European transplant patient organizations to endorse and spread the call:

Monitoring health after transplantation: A call for a European effort to collect follow up data on transplant recipients and living donors

This call urges organizations dealing with transplantation to work together to achieve the following objectives:

1. to establish follow up registries;
2. to promote participation of low-volume transplantation countries;
3. to communicate scientific output in lay terms;
4. to monitor and improve quality of life after transplantation.

By endorsing this initiative, patient organizations call on:

*...hospital management, policy makers, scientific societies, industry and other organizations dealing with transplantation **to enhance scrutiny of transplant recipients and living donors** with the goal to gain knowledge and ultimately improve their quality of life.*

*...international medical and scientific societies **to establish registries to monitor follow up** of transplant recipients and living donors. Beside their function as repository of data and instrument for research, these registries should allow setting indicators to improve patients quality of life.*

*...transplantation centres and national authorities **to collect data and to share them with the international community**, enabling researchers to analyse large cohorts of transplant recipients and living donors, which may not be achievable at the level of a single country. Anonymised data should be made available to patients organizations that wish to carry out their own research.*

*...physicians **to adopt standardized questionnaires** developed in the context of international registries to report follow up data on transplant recipients and living donors.*

*...companies active in the life sciences **to support the effort to establish and maintain international registries.***

*the European Union, the European Council and the Parliaments of all European countries **to support and facilitate the establishment or the consolidation of local registries** and their participation in international initiatives. All transplanted patients and living donors have an equal right to access high-standard healthcare.*

*...international registries **to make data available broadly and openly** to the scientific, medical and patients communities in agreement with the applicable data protection laws.*

...researchers **to expand their studies to data from large cohorts** collected by international registries.

...researchers **to communicate the outcome of their research in lay terms** in collaboration with patients organizations when possible. It is extremely important for patients to feel involved and to be able to access medical information.

....scientific societies **to collaborate with patients representatives** in order to develop platforms dedicated to the collection of data directly from patients, in addition to medical registries. A multi-language native or web-based health app may be the perfect tool.

By endorsing this call, signatories commit to encourage patients participation in local and international registries.

Monitoring health after transplantation: A call for a European effort to collect follow up data on transplant recipients and living donors

The life of transplant recipients is a long journey, from the aggravation of a potentially fatal disease and the hope for a compatible organ to post-transplantation recovery and continue monitoring. Donation is the central switch that makes this journey possible, obviously attracting the attention of policy makers, legislators, and all of us as potential donors: the number of donations is, and must remain, scrutinized as well as the distribution to patients in waiting lists. This is ensured by national competent authorities or international donation programs affiliated to or delegated by the ministers of health. When living donation is an option, legal, ethical and health aspects are thoroughly assessed.

In their post-transplantation journey, people living with a transplant need constant medical care: they regularly go to the hospital and take medications, despite the transplanted organ fulfilling expectations. Recipients need to prevent organ rejection with the help of immunosuppressive treatments; with the support of their doctors, they monitor the functioning of the transplanted organ: the need for re-transplantation at a given point is a possibility; third, recipients deal with the short and long-term side effects of the treatments they undergo, cancer being the most feared complication.

How is the quality of life of transplant recipients and living donors? How to improve it? Which treatments work better? How to suppress or reduce side effects?

Here, we call on hospital management, policy makers, scientific societies, industry and other organizations dealing with transplantation to enhance scrutiny of transplant recipients and living donors with the goal to gain knowledge and ultimately improve their quality of life.

<p>Objective 1: to establish follow up registries</p>	<p>Objective 2: to promote participation of low-volume transplantation countries</p>
<p>Objective 3: to communicate scientific output in lay terms</p>	<p>Objective 4: to monitor and improve quality of life</p>

Objective 1: to establish follow up registries

Medical registries enable systematic collection of real-life patients data and assessment of practices and therapies. They can also contribute to the monitoring of access to donation and support policies to fight inequity in terms of age, gender, ethnicity, socioeconomic status, social networks and religion. In the field of transplantation, organ-specific registries such as the ELTR have been extremely successful in feeding the research community with solid evidence. We strongly believe that this approach should be followed for every transplantation type, including experimental therapies such as injections of cells or organoids.

We call on international medical and scientific societies to establish registries to monitor follow up of transplant recipients and living donors. Beside their function as repository of data and instrument for research, these registries should allow setting indicators to improve patients quality of life.

We call on transplantation centres and national authorities to collect data and to share them with the international community, enabling researchers to analyse large cohorts of transplant recipients and living donors, which may not be achievable at the level of a single country. Anonymised data should be made available to patients organizations that wish to carry out their own research.

We call on physicians to adopt standardized questionnaires developed in the context of international registries to report follow up data on transplant recipients and living donors. We commit and call on patient organizations to encourage patients participation.

We call on companies active in the life sciences to support the effort to establish and maintain international registries.

Objective 2: to promote participation of low-volume transplantation countries

In addition to collecting data from countries that have already established national registries, international registries should promote the establishment of new local/national/regional registries. Ideally, international registries should offer the possibility for local/regional/national communities to create their own registry as part of the international one. This would be cost-effective for countries where the low number of transplants does not justify the investment in dedicated infrastructure. Any new transplantation programme should include the collection of follow up data and the provision of these data to an international registry.

We call on the European Union, the European Council and the Parliaments of all European countries to support and facilitate the establishment or the consolidation of local registries and their participation in international initiatives. All transplanted patients and living donors have an equal right to access high-standard healthcare.

Objective 3: to communicate scientific output in lay terms

International registries will be successful if collected data are made available openly.

We call on international registries to make data available broadly and openly to the scientific, medical and patients communities in agreement with the applicable data protection laws.

We call on researchers to expand their studies to data from large cohorts collected by international registries.

We call on researchers to communicate the outcome of their research in lay terms in collaboration with patients organizations when possible. It is extremely important for patients to feel involved and to be able to access medical information.

Objective 4: to monitor and improve quality of life

Medical registries focus on clinical and physiological parameters that measure the functioning of the transplanted organ and the health status of recipients and living donors. We believe that this information should be complemented by a thorough analysis of the recipient and living donors' quality of life. Because the severity of the condition as perceived by the clinicians does not always correspond to the patient experience, the evaluation of the quality of life must take into consideration the feelings of the patients. It is necessary to give voice to patients and to involve them in the development of indicators and tools to assess quality of life. Transplantation is experienced as a "*ritual of death and rebirth to a new life*". Return to physical activity, social relationships and work after transplantation may also be associated with psychopathological stress. Every person can answer the questions such as "*how are you?*", "*how do you feel?*", "*does this drug have any side effect on you?*", and this qualitative, subjective information is as much important as physiological data, when collected from a large number of subjects. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are excellent indicators of quality of life.

We call on scientific societies to collaborate with patients representatives in order to develop platforms dedicated to the collection of data directly from patients, in addition to medical registries. A multi-language native or web-based health app may be the perfect tool.

This call is endorsed by the steering group of the ESOT patients' inclusion initiative.

The following signatories support this call.

Name of the organization	Logo	Website
AIPI, Associazione Ipertensione Polmonare ODV (Italian Pulmonary Hypertension Association)		https://www.aipiitalia.it/site/
European Transplant & Dialysis Sports Federation (ETDSF)		http://www.etsdf.org/
FOKUS Patient®		https://fokuspatient.se/
Voice of VCA Patients		https://worldofvca.com
Federación Nacional de Enfermos y Trasplantados Hepáticos (FNETH) - National Federation of Liver Patients and Transplant Patients		https://fneth.org/
Hellenic Cystic Fibrosis Association		www.cysticfibrosis.gr/en/
Association of patients with respiratory failure and lung transplantation (APRFLT), Bulgaria		www.facebook.com/aprflt
Bulgarian Society of the patients with PH (BSPPH)		www.bspph.net
Association Française des Sportifs Transplantés et Dialysés – TRANS-FORME		www.trans-forme.org
Kidney Care UK		https://www.kidneycareuk.org/
Alliance for Pulmonary Hypertension		https://www.allianceforpulmonaryhypertension.com/
Fédération des Greffés Coeur et/ou Poumons		http://www.france-coeur-poumon.asso.fr/

Associação Portuguesa de Insuficientes Renais (APIR)		www.apir.org.pt
AITF, Associazione Italiana Trapiantati di Fegato ODV (Italian Association for Liver Transplant Patients)		https://aitfnazionale.it/
PHA Europe		www.phaeurope.org
Unione Trapiantati Polmone - Padova ODV (Lung Transplant Patients Union – Padova Italy)		https://oltremaalattia.it/
The Finnish Kidney and Liver Association		https://www.muma.fi/
Transplantoux		https://www.transplantoux.be/
Federación Nacional de Asociaciones ALCER (Spanish Kidney Patients' Federation)		https://alcer.org
European Kidney Patients' Federation (EKPF)		https://ekpf.eu