



ORIGINAL ARTICLE

Building a bridge between patients and transplant healthcare professionals – a descriptive study



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SUMMARY

This article describes a pathway for collaboration between transplant healthcare professionals and organ recipients. Under the umbrella of the European Society for Organ Transplantation (ESOT) a joint initiative started from three Sections and Committees of ESOT: EDTCO (European Donation and Transplant Coordination Organisation), ETHAP (European Transplant Allied Healthcare Professionals) and ELPAT (Ethical, Legal and Psycho-social Aspects of Transplantation). The formal 'kick-off' of the Advisory Board Meeting of the European Transplant Patient Organisation (ETPO) was during the ESOT congress in 2019. The aim was to produce a series of statements to serve as a path to dialogue between patients and transplant professionals and to define the next steps towards giving a voice to the patient network. To include the patients' perspectives, two surveys have been performed. The results identified the unmet needs and lead to a proposal for future plans. Educational activities have since started leading to a patient learning workstream. All initiatives taken have one purpose: to include patients, give them a voice and build a foundation for collaboration between patients and transplant professionals. ESOT has created a platform for mutual understanding, learning and a collaborative partnership between ETPO and European donation and transplant professionals.

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Introduction

Joint efforts are more efficient than single initiatives. Patient participation has been growing in many different clinical activities, particularly in hospitals, with a focus on shared decision making [1–3]. Patient involvement is much more prevalent amongst research networks [e.g. Canadian SOLVE Chronic Kidney Disease (Can SOLVE CKD)], in medical societies [e.g. the Transplant Society of Australia and New Zealand (TSANZ)], and in academic medicine (e.g. Stanford Medicine X). However, there are few initiatives to incorporate patients within scientific organisations. The rationale behind this article is to describe a pathway for collaboration between transplant professionals and solid organ recipients in Europe. The first initiative to include patients at various stages of the donation or transplantation process was launched in 2016 at the European Donation and Transplant Coordination Organisation (EDTCO) Congress in Barcelona, held under the umbrella of the European Society for Organ Transplantation (ESOT): an organisation which strives to be pioneering and incorporate patients within their scientific activities. Collaboration enables mutual understanding, learning and creative solutions to unmet needs. For patients on the waiting list, there is only one sustainable option and that is a successful organ transplant. After transplantation, self-management is challenging because of the need to self-monitor, deal with symptoms and side-effects, as well as managing emotions and adapting to new roles. To informally kick-off the collaboration between patients and professionals, the first meeting was held in Barcelona 2017 during the ESOT congress. Patient needs were assessed and tentative goals were formulated, for example, to create a platform to support the voice of patients, their priorities and to escalate the debate to a European level. A promise was made to the patients to create more initiatives to give patients a real effective voice.

Joint initiative within ESOT

To keep the promise to the patients, a joint initiative started from three Sections and Committees of ESOT; EDTCO (European Donation and Transplant Coordination Organisation), ETHAP (European Transplant Allied Healthcare Professionals) and ELPAT (Ethical, Legal and Psycho-social Aspects of Transplantation). The first formal kick-off of the Advisory Board Meeting of the European Transplant Patient Organisation (ETPO) was organised during the ESOT congress in Copenhagen in 2019. Attendees included patients, patient association representatives and active members, representatives of EDTCO, ETHAP and ELPAT and a representative from Stanford University (Amy Price from Medicine X) [4]. The aim of this meeting was to produce a series of statements to serve as a path to dialogue between patients and transplant professionals and to define the next steps towards giving a voice to the patient network and help shaping the dialogue with the stakeholders.

Methods to include the patients' perspective

Two surveys have been conducted to elicit patient perspectives and understanding of their priorities within transplantation. Both surveys were prepared by EDTCO, ELPAT and ETHAP together with representatives from patient associations based in Denmark, Spain, Ireland and the United Kingdom. The first survey was conducted in preparation for the first ETPO Advisory Board Meeting in Copenhagen. Before the survey being distributed, all patient societies and associations received an invitational email about the upcoming meeting. The online survey was administered through Survey Monkey in July 2019 through the ESOT office to the email contacts of all 135 European and National transplant patient organisations. One representative from each patient organisation was requested to answer

the survey, either individually or following discussions with their board members. The deadline for response was set for 2nd of September 2019.

A second survey was conducted in April 2020 to gain a better understanding of the main everyday concerns of transplant patients, both in relation to their transplant and their donor. The second survey was again sent through Survey Monkey to each of the 135 European and National transplant patient organisations within the ETPO network, who were asked to distribute the survey amongst their members. Affiliates of these organisations were then asked to complete the survey. The survey was closed on 30th April 2020.

Individual patient details were anonymised in both surveys. Only the name of the society or association was requested, plus the name of the city and country.

Survey I: accessibility to transplantation (File S1)

Topics assessed in the questionnaire were as follows:

1. Countries' donation and transplantation self-sufficiency

To obtain a larger appraisal of transplant accessibility in different countries, in terms of both organ donation and transplantation, the five A's of access were presented (https://eupatientaccess.eu/?page_id=58): availability, adequacy, accessibility, affordability and appropriateness. The question was related to the perception of the five A's within the participant's country when looking to achieve self-sufficiency in both deceased organ donation and transplantation (explicitly excluding living donation and living donor transplantation).

2. Patients and waiting list criteria

Organ availability for transplantation is a limited resource. There is a need to have clear and transparent inclusion criteria for entry onto the waiting list of the hospital transplant centre (locally), as well as regional and national waiting lists. Questions were asked about participation in meetings to discuss criteria to enter the waiting list, if the national criteria to access the waiting list for a specific organ were known, and if local, regional or national outcome data regarding graft and patient survival were known.

3. Informed consent

This includes information available to patients about the whole process, including being ready and prepared to receive an organ, being on the waiting list, the actual surgery and process of transplantation, the follow-up and self-care after transplantation. A list of 18 topics was presented with the question: What should be

included in the process and discussion about informed consent for recipients?

4. The empowered patient and patient empowerment

Patients need to be considered as the central focus of medical care in transplantation, but they are also responsible of their own health and active involvement in prevention, treatment, adherence and follow-up. What can patients do and which tools can be used to take care of their own well-being and physical condition before and after transplantation?

Survey II: main concerns of transplant patients

The survey contained several demographic questions on gender, type of organ received, type of donor (living or deceased) and the number of transplants the individual had had (see File S2). Participants were asked to identify five main concerns and issues of everyday life in relation to their transplant and five main concerns and issues regarding the donor, from the perspective of an organ recipient. Finally, additional questions focussing on the relationship between transplant patients and transplant professionals were asked, including topics such as: expressing concerns to healthcare professionals involved in your transplant follow-up, what is important for healthcare professionals to understand about your concerns and issues and how healthcare professionals could potentially anticipate these.

Findings of the surveys

Survey I

Forty-one surveys were completed by participants from 15 countries, with the majority from Spain ($n = 7$), Greece ($n = 5$) and the Netherlands ($n = 5$) (Fig. 1). The mean score (where the scale indicated 1 was poor and 5 was excellent) for 'self-sufficiency in organ donation' was 3.24. This was lower than the mean score of 'self-sufficiency in organ transplantation', which was 3.42. Eighty percent of respondents were aware of patients and waiting list criteria. Forty percent of the respondents participated in discussions about the medical criteria for a specific organ waiting list. One hundred percent of the respondents had access to figures on organ donation and transplantation activities and 85% stated that they knew figures on the survival rates of transplant centres at a regional or national level. When asked which subjects should be included within informed consent by recipients, 18 topics were listed, the most common of which were related to information: the procedure and what

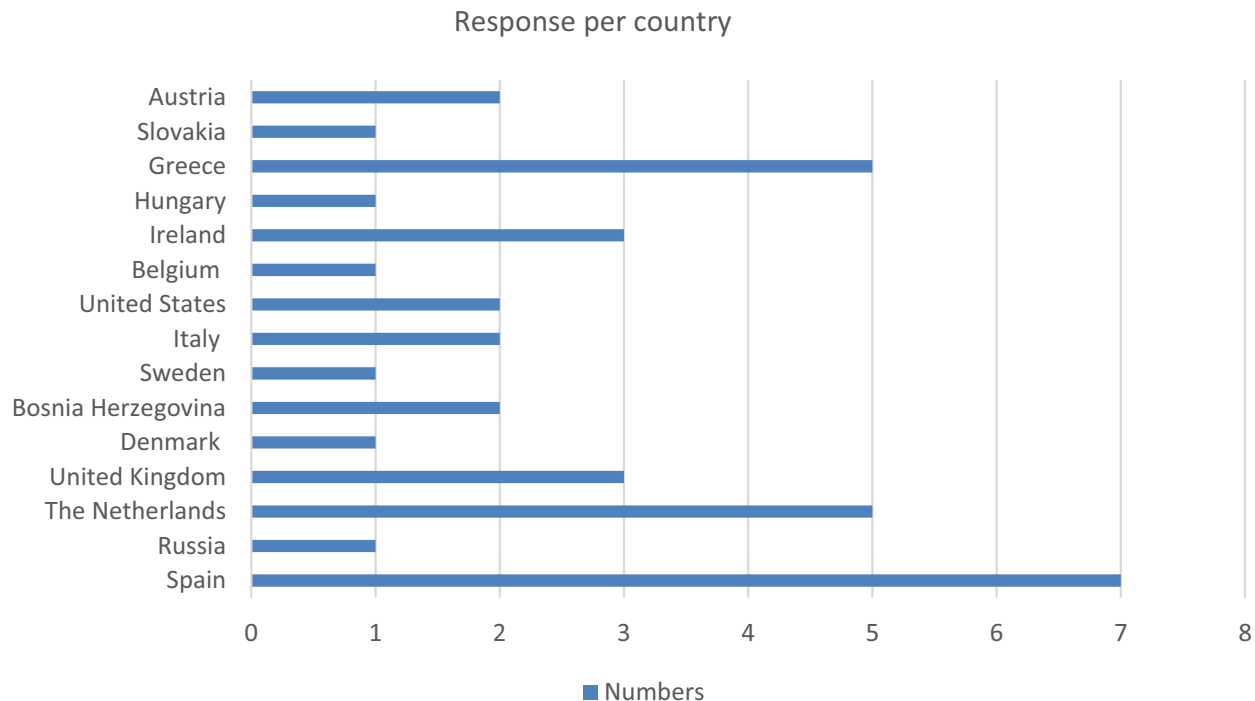


Figure 1 Survey I—accessibility to transplantation—response per country.

happens during the organ transplant, treatment adherence after transplantation and follow-up after an organ transplant. Answers from questions about patient empowerment highlighted a role for transplant patients to play in helping their fellow patients, both before and after transplantation, by sharing their experiences whilst on the waiting list and becoming ambassadors for the promotion and acceptance of organ donation within society.

Survey II

Three hundred and fifty-one responses were received from participants across a broad range of European countries, the majority being from Ireland, followed by United Kingdom and Belgium [5] (Fig. 2). Of the 351 responses, 54% were from women ($n = 177$). The majority had received a kidney transplant, followed by liver, heart, lungs and pancreas. Thirty-five responders had received two transplants and six had received three. Participants were mainly transplanted with organs from deceased donors ($n = 249$). Of the living donor recipients, the majority had received a kidney ($n = 81$) and only two had received a lobe of liver. The most prominent concerns were uncertainties related to the graft (i.e. graft rejection/graft failure) along with infections and side-effects of medication. Regarding the donor, the

main concerns were thoughts for the deceased donor's family, followed by the well-being of the living donor and then specific questions about the deceased donor. The best way for healthcare professionals to respond to patient concerns were to: pay attention to the psychological aspects of organ transplantation, take me seriously as a patient, give person-centered care, cluster all information and use digital solutions, plan a pretransplant evaluation to gain better knowledge of what will happen after transplantation and adopt a team approach, thereby acknowledging that a single professional cannot provide the same healthcare as a collaborative team.

Implications of the surveys

The results of the first survey were used to promote further discussions during the Advisory Board Meeting of ETPO in Copenhagen. Out of the discussions, the following needs were defined:

- An alliance and a forum to facilitate discussions amongst patients and patient organisations
- Patient empowerment with a holistic, person-centred approach
- Promotion of self-care and self-management
- Accessibility of information and health literacy
- Dialogue with healthcare professionals and researchers

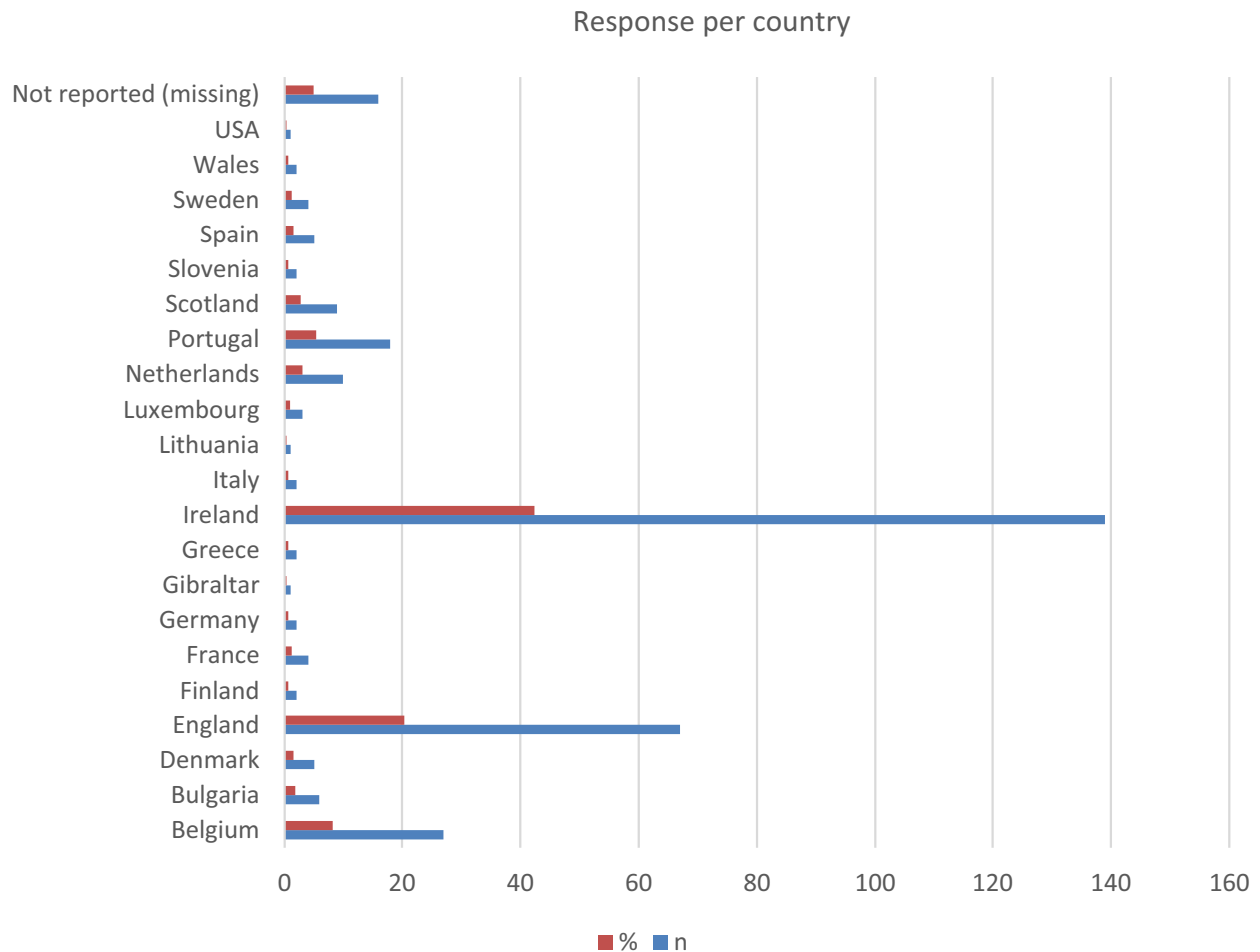


Figure 2 Survey II—main concerns of transplant patients—response per country.

- Patient representation in committees and policy-making bodies at the European and international levels

From the identified needs, a proposal for future plans was developed:

1. Establishing a European Transplant Patient Organisation (ETPO) Alliance
2. An online platform that will function as an online hub of the European patient organisations
3. Partnership with patient organisations promoting sport and physical activity in transplant patients
4. Organisation of workshops on communication with patients
5. Inclusion of patients and patient perspectives in all future ESOT events
6. Organisation of the meeting of the European Transplant Patient Organisation (ETPO) Alliance, to be held at the ESOT 2021 congress
7. Travel grants to support patient participation in ESOT events
8. Digital Outpatient initiative

Educational activities in collaboration with patients and professionals

In March 2020, Europe, like the rest of the world, had to deal with the COVID-19 pandemic; a new and threatening situation, especially for transplant patients. The COVID-19 pandemic had a significant impact on the capacity of healthcare systems and intensified the feeling of uncertainty that often characterises the life of transplant patients. To understand how transplant patients and transplant professionals dealt with this new and evolving situation, a webinar was organised in April 2020: 'Coping with uncertainty during the COVID-19 pandemic'. There were 240 participants, of which 37% were organ recipients, 26% were medical doctors, 9% were healthcare professionals (nurses, transplant coordinators) and 4% were patients on the waiting list. Participants were from 48 different countries. The eight panellists were a mixture of transplant professionals and patient representatives.

The webinar concentrated on patients' concerns both directly and indirectly related to COVID-19. Apart from fear of infection/death, patients were concerned that healthcare resources were limited in response to the crisis. They felt anxious about suboptimal follow-up (cancelled routine appointments, fewer tests and treatments) and whether this would mean that 'no one would notice' if their transplant failed. Further anxieties were related to transplant centres only performing essential and life-saving transplants, waiting lists getting longer and patients who may die waiting for a donor. Lockdown complicated the situation further by making it more difficult to attend appointments and had a negative impact on the well-being of patients and their carers. Participants were also concerned that non-specialist healthcare providers (who may have been drafted in to substitute for transplant healthcare providers) may be unaware of issues specific to organ recipients, such as viruses and the potential consequences of long-term immunosuppressive medication. A multidisciplinary approach that involves close liaison with patient representatives was deemed to be essential in such a situation [6].

The webinar was recorded leading to another 317 standalone views. Two question and answer (Q&A) sessions were also recorded addressing some of the recurring concerns raised by participants of the webinar. The main topics of the first Q&A session were: communication between patients and medical professionals during the pandemic, patient self-empowerment and reconnecting after the lockdown. This was viewed 175 times. The main topics of the second Q&A session were: organ donation during the COVID-19 pandemic, donor screening and donation after recovery from COVID-19. The number of standalone views was 162. The input gained from the webinars resulted in several recommended functional strategies to deal with the uncertainties arising from the COVID-19 pandemic [7].

Patient learning workstream

A patient learning workstream was developed as part of the Transplantation Learning Journey (TLJ 2.0) of ESOT: a comprehensive experience enabling participants to grow their knowledge and develop collaboration on a range of topics in transplantation. The Patient Learning Workstream featured a full stream of mutual understanding and learning dedicated to donor transplant coordinators, allied healthcare professionals, transplant professionals, together with patients. In preparation for the TLJ 2.0, a webinar was organised: 'How long will I wait, understanding uncertainty on the waiting list'. The webinar was a collaborative

between transplant professionals and patients, guided by EDTCO, ETHAP and ELPAT. In total, 59 participants from 23 countries joined the webinar, with representatives of patients and advocacy and transplant professionals. The countries with the highest attendance were: United Kingdom ($n = 15$), Netherlands ($n = 8$), Italy ($n = 6$) and United States of America ($n = 3$). The webinar was recorded, leading to another 142 standalone views.

This webinar was followed by a webinar on 'Uncertainty in offering and accepting an organ – sharing a decision'. The aim of this webinar was twofold: to get insight into the uncertainty of a transplant professional when offering a deceased donor organ to a patient on the waiting list and to get insight into the uncertainty of the transplant patient in accepting the organ offer. From both perspectives, the unknowns about an organ donor were the source of all kinds of uncertainty, resulting in both parties needing to make the right decision collaboratively. Sixty participants attended the webinar from 23 countries. The top countries with the highest attendance were: United Kingdom ($n = 15$), Italy & Netherlands ($n = 8$), Spain & Turkey ($n = 4$). The webinar was recorded, leading to another 123 standalone views.

During the TLJ 2.0, held between the 15th and 17th of November 2020, many initiatives were undertaken to include the voice of patients. The results of a European survey [1], launched in April 2020, were presented, followed by a live Q&A session. On the same day, there was a session on 'The fear of graft rejection: an open conversation', followed by a live Q&A. A full session was dedicated to the subject of 'Uncertainty in illness: impact on patient self-efficacy and self-management'. Topics as 'Managing uncertainty and expectations after organ transplantation', 'enabling adaptation' and 'self-efficacy and self-management' were discussed from a patient perspective. The session finished with the topic 'Fear of graft rejection- striving to control the uncontrollable', followed by a live Q&A.

Policy changes, position statement and future steps to giving a voice to the patient network

To further formalise the role of patients within ESOT, a draft ESOT-ETPO alliance was developed together with ETPO. This alliance was approved during the ESOT Council meeting last May 2021 and the position statement for the collaboration will be presented and signed during the ETPO advisory board meeting at the ESOT congress in Milan (August 2021). The members of the ESOT-ETPO alliance shall focus their efforts on the following objectives:

- Create an open and trusting environment that facilitates meaningful conversations between people with transplants and transplant professionals.
- Reduce unwarranted variation in healthcare and improve outcomes throughout Europe.
- Bring added value to the health and quality of life of the transplant population.
- Implement realistic medicine by ensuring that people with transplants are equal partners in the decision-making process through the appropriate provision of information and consideration of available treatment choices. In this sense, informed consent should be understood as an ongoing, dynamic process, commencing as early as possible in the transplant journey.
- Acknowledge that person-centred care and self-management support are essential to successful transplant care and that digital solutions that enhance these aspects safely should be developed and promoted.
- Ensure that research findings and data regarding health-related quality of life, self-management, adaptation and everyday life issues are rapidly disseminated to people with transplants in a transparent and easily accessible way, for example, by promoting and stimulating open-access publications and open events.
- Create partnerships with patient organisations to promote a healthy lifestyle in transplant recipients.

During the preparatory discussions to outline the ESOT–ETPO alliance, an agreement was made with patients' representatives not to use the term 'organ recipient' anymore, but to use 'people with transplants'.

The ESOT–ETPO alliance is visible at a special webpage for patients house on the ESOT website at: <https://esot.org/esot-patient-inclusion-initiative/>. The next steps for the alliance include focusing on valued-based care as an essential part of delivering improved treatment for people with transplants. There are special sessions during the ESOT congress in Milan on this topic, and additionally, a number of patient-centred sessions at the ESOT Congress will involve active participation of transplanted people. Furthermore, a pan-European registry on people with transplants will be launched by ESOT to gather further information after transplantation. It will feature a module for collecting information directly from people with transplants (patient-reported outcomes). Before the Milan congress, a webinar focusing on the importance of physical activity as an important lifestyle issue after solid organ transplantation is being organised with the aim of inspiring people with transplants to increase their physical activity and to provide easy and inspiring tools to

help facilitate this. Finally, there is an ESOT Hackathon project in place which is currently live (<https://esot.org/esot-events/hackathon/>), in which people with a transplant are active members of the team to design, develop and build digital solutions to help transplant patients in Europe and beyond.

Conclusions

Through the creation of ETPO, ESOT has provided a platform for mutual understanding, learning and collaborative partnership between patients and European donation and transplant professionals. All initiatives taken thus far have centred around one purpose; that is, to include patients, give them a real effective voice and build a strong foundation for collaboration between patients and transplant healthcare professionals. The activities conducted to date highlight the appetite within both transplant professionals and patient groups to engage with this initiative and strive to empower transplant patients now and in the future.

Authorship

All authors contributed substantially to the design of the article, its content and the reporting of the work as follows: NJ: designing the article and drafting the manuscript; HM: designing the article, critically reviewing the draft and making improvements; AF: designing the article, critically reviewing the draft and making improvements; FL: critically reviewing the draft; LMC: critically reviewing the draft; MM: critically reviewing the draft; JF: critically reviewing the draft; DG: critically reviewing the draft; DP: designing the article, critically reviewing the draft and making improvements.

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Conflicts of interest

There are no conflicts of interest to declare from any of the authors.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

File S1. Survey I: Accessibility to transplantation.

File S2. Survey II: Main concerns of Transplant Patients.

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