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A LEVEL-PLAYING FIELD FOR TRANSPLANT PATIENTS – SPURRING ACTION ACROSS EUROPE

Introduction

The following meeting report is the summary of the session “A level-playing field for transplant patients – spurring action across Europe” at the European Health Forum Gastein, Austria, on 27 September 2022, organised by the European Society for Organ Transplantation (ESOT) and Takeda.

In line with the Forum’s 2022 theme “A moonshot for a true European Health Union: if not now when?”, the session explored what needs to be done at the EU, national and local levels to improve organ donation, access transplantation and post-transplant care. In addition, the session provided the chance for EHFG’s validation of the [ESOT Manifesto](#) ‘Tackling Inequalities in Organ Transplantation: A Pathway Forward’ prior to its launch.

LINK TO SESSION:



[A level playing field for transplant patients: Spurring action across Europe - YouTube](#)

Meeting summary report

Penilla Gunther, 58, celebrates two birthdays. Her actual birthday is on 13 August and then there is 1 April, the day when 15 years ago she obtained a new heart. “Until then, it had felt right to me to have a donor pass, so my organs could help other people if I was dead. But never did I think of myself as a recipient of a life-saving organ”, Penilla, a former Member of the Swedish Parliament and moderator of this session, stresses. Life happens while you are busy making other plans...



Still, organ donation and transplantation are frequently considered a niche topic and at times misunderstood or even stigmatised in the public but also amongst experts in public health and those responsible at the

political and policy level. This perception could not be more flawed: Organ transplantation is an incremental part of successful treatment for many patients with end-stage organ disease, be their underlying condition cardiovascular, gastroenterological, hepatological, or renal. Clearly, awareness, prevention, swift diagnosis, and linkage to the appropriate medical care are important in the earlier stages of the journey of a patient with such diseases. However, patients can also enjoy a good quality of life also at a later stage, when organ failure is imminent, provided they have successful organ transplantation.

Unfortunately, this is frequently not the case: the demand for organs is much greater than the supply and patients do not always receive the best possible treatment and care. This situation is unsustainable.

The European Society of Organ Transplantation (ESOT) is on a mission to pull not only the speciality of its members

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out of this niche but also change politics, policies, and the organisation of care for the better – with the goal that all those in need have the chance of a new life thanks to successful organ transplantation.

ESOT has identified three main areas in their Manifesto which need to be worked on to make this a reality: (1) Organ availability, (2) Equity in access, (3) Quality and Safety of Performance in Organ Transplantation along the Patient Journey.

The session in EHFG 2022 was an opportunity to discuss these issues with an expert panel.

For instance, we used the model of Spain which has the highest rate of patients receiving a transplant per million population in Europe from 2019 to 2020 (114.8 per one million inhabitants), 15 times higher than Bulgaria, where transplantation is at its lowest in the EU with the lowest rate (7.6 p.m. inhabitants).



Alicia Perez Blanco, a leading physician at the Spanish National Transplant Organisation, outlines why: Organ deceased donation and transplantation have always been a priority of the public health

system, irrespective of the makeup of the government, and as such, it has become ingrained in the Spanish culture. There is a solid legal framework and supporting regulation which addresses the diagnosis of both death by neurological and circulatory criteria. There is part of the government budget invested in the training of healthcare professionals and other professionals indirectly working in the field of donation and transplantation. As a result, Alicia highlights, there is trust in the system, both from people living in Spain as potential or actual donors and from healthcare professionals. The latter recognise

transplantation as the best treatment option in case of organ failure and enlist patients because they are confident their patients will receive a transplant timely.



Hélène Viatge is the COO of Cibiltech, a data service provider which supports medical professionals in their treatment decisions for transplant patients through telemonitoring and predictive

medicines using AI and helps researchers in their clinical trial designs. Hélène highlights the importance of transplant patients as a data source, for both improved management of transplant care but also for the better management of highly prevalent co-morbidities, severe chronic conditions such as diabetes or cardiovascular disease. At this stage, there is little public impetus to generate data from transplant patients across Europe. Hélène compliments the EU on its proposal for a European Health Data Space, which sets the framework to accelerate research on organ transplantation and other diseases. However, she stresses, this mission will not set off and exploit its whole potential unless Europe invests significantly in the digitalisation of its healthcare systems. Currently, there is very limited communication and exchange of data in

primary and secondary care and significant differences across Europe.



Gabriel Oniscu, a surgeon at the Royal Edinburgh Infirmary, with specialisation in liver and kidney transplantation,

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concurr. We need better data also to identify variations in practice, not for a punitive approach but to take informed decisions on how to achieve the best patient outcomes. Beyond the data issue, Gabriel stresses the silos at different levels, which prevent the good practices from being shared and adapted to the local level. In many countries, transplantation as treatment option is not that well understood amongst medical specialties, and unlike in Spain, not embedded in treatment plans. Gabriel agrees on the importance of training for health professionals but points out that patient education is equally important. Patients must be informed of their rights, the criteria to be eligible for an organ, as well as the standards that must be met for the actual transplantation, as well as in post-transplant care.

Dr. Cristian-Silviu Busoi Member of the European Parliament (MEP) (European People's Party, Romania) highlights the importance of making sure that donated organs are not wasted and are used in the best way. If we fail in this regard, we will



both jeopardise patients' life and erode people's trust in our health systems.

There are significant inequalities across Europe, between Western countries and the East and South of Europe. Whilst we cannot

remedy all inequalities in view of different financial and human resources, and the limitations of EU competence, MEP Busoi outlines his view on what support the EU could provide, which is threefold:

(1) Highlight to Member States the benefits of improved transplant care to patients and health systems. Help Member States by identifying good practices with the help of experts and facilitating a discussion at the EU level on how these can be adapted and taken up at the national level. (2) Use the momentum of the European Health Data

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Space to improve data generation throughout Europe. The ESOT work of registries is very important but can only exploit its full potential if we achieve connectivity across Europe. EU4Health funding programme can be helpful for both.

(3) Include transplantation into the general discussion on chronic disease management, as well as in key EU-driven health research programmes, which currently focus on cancer and NCDs.



In the subsequent discussion, part of which was in breakout groups, participants largely agree that yet another EU Action Plan, was hardly going to move the needle but that actions must be taken throughout the EU to make sustainable changes to meet standards, improve transplant care for the benefit of patients, their families and European societies. Whilst culture is difficult to export, national governments have a responsibility to set the right rules to ensure that both patients and professionals can have trust in the system. In terms of the organisation of care, health boards should encourage multidisciplinary care to ensure that transplantation is embedded in the

management of chronic diseases. Furthermore, health professionals need support in the generation, management, and analysis of data.

This should also include a discussion on why such uptake and adherence to guidelines can be difficult nationally or locally, and which policies and measures could be undertaken to overcome such problems. Particular attention should be given to underserved communities who are discriminated against in access and whose health literacy is frequently low.



The EHFG-appointed caricaturist's take on the issue.

The European Reference Network for Child Transplants has been helpful in sharing medical expertise across the border using a dedicated

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IT platform and telemedicine tools to review a patient's diagnosis and treatment. The EU should build on this success and make it available for all transplant patients, for the benefit of patients and the dissemination of knowledge amongst all healthcare

professionals in transplant care. National governments should then ensure that healthcare professionals are reimbursed for the work they do across-country.

Identified challenges	Key insights from the discussion
<p><i>Increasing organ availability</i></p>	<ul style="list-style-type: none"> ○ <i>Clear legal framework and supportive legislation</i> ○ <i>Build trust in the healthcare system and professionals</i> ○ <i>Promote patient understanding in the process</i> ○ <i>Improve data registries and connectivity of data across the EU</i> ○ <i>Address inequalities in underserved communities, as well as discrimination in access to transplant availability and care</i>
<p><i>Enhancing the efficiency of and accessibility to transplantation systems</i></p>	<ul style="list-style-type: none"> ○ <i>Increase public investment in the training of healthcare professionals and other professionals involved in organ donation and transplantation</i> ○ <i>Significant investment in the digitalisation of healthcare systems</i> ○ <i>Integrate transplantation into treatment plans</i> ○ <i>Include organ transplantation in key EU-driven health and research programmes</i>
<p><i>Improving the quality and safety of organ transplants</i></p>	<ul style="list-style-type: none"> ○ <i>Include transplantation in the scope of chronic disease management in a multidisciplinary approach to care</i> ○ <i>Support healthcare professionals in the collection, management, and analysis of data on transplant patients for improved transplantation and post-transplant care</i> ○ <i>Improve communication and exchange of data along the patient pathway</i> ○ <i>Identify variations in practise that deviate from established standards and make evidence-based decisions for best patient outcomes</i> ○ <i>Identify good practices with the support of experts, facilitate their discussion at the EU level, and implementation at the national level, emulating and adapting the reference network for paediatric transplantation</i>

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Conclusion by ESOT President, Dr. Luciano Potena *(Left side, above)*

In his thank you to all participants, Luciano confirms ESOT's commitment to making a lasting improvement to patient outcomes, by breaking down silos and engaging with policymakers and stakeholders, and also informing them on the issues at stake. The Future ESOT Manifesto will propose solutions to make use of the opportunities that data technologies offer, as well as how to improve healthcare professional training, patient literacy, and transplant care throughout Europe.