

2019

European Kidney Forum

Summary
Report

Organ Donation and Transplantation in Europe

Are We Meeting the Needs of Patients?

A POLICY ROUNDTABLE

Hosted by the MEP Group for Kidney Health

Tuesday, 25 June 2019
Brussels, Belgium



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Executive Summary

European Kidney Forum 2019 – Organ Donation and Transplantation in Europe: Are We Meeting the Needs of Patients? A Policy Roundtable



On 25 June 2019, the European Kidney Health Alliance (EKHA) held its 6th Annual European Kidney Forum in Brussels. With a focus on Organ Donation and Transplantation, stakeholders including policymakers from the European Commission, national competent authorities, patient associations, medical professionals, and representatives from the private sector tackled the fundamental question “Are we meeting the needs of patients?”

The Forum was opened with a video address by Mrs Hilde Vautmans MEP, Chair of the MEP Group for Kidney Health, who delivered a strong message signalling the commitment of the European Parliament to the cause

of organ donation and transplantation. MEP Vautmans emphasised the value of the European Kidney Forum and similar events as platforms for sharing ideas and experiences crucial to improve outcomes in the field. EKHA Chairman Professor Raymond Vanholder thanked the event’s sponsors **Astellas, Amgen, Baxter, B Braun, CSL Behring** and **Vifor Pharma** for their generous support in the form of unrestricted educational grants, and talked about the value of transplantation and the rationale for multi-stakeholder action in the face of the challenges inherent in organ donation and transplantation. He introduced the EKHA-led EU Thematic Network on Organ Donation and Transplantation as a powerful vehicle to shape future policy for organ donation and transplantation in Europe. Robert van der Wolk, a combined kidney and pancreas transplant patient, brought the patient’s viewpoint to the fore by sharing his very touching experience and providing a compelling argument for putting the patients’ needs at the heart of policy conversations around Organ Donation and Transplantation.

A panel discussion followed, moderated by Professor Wim Van Biesen, the Chief of the Department of Nephrology at the Ghent University Hospital. In addition to Prof Vanholder and Robert van der Wolk, the panel featured the following speakers:

- Dr Stefaan Van Der Spiegel, DG SANTE
- Dr Elisabeth Coll, Spanish National Transplant Organization (ONT)
- Professor Uwe Heemann, Technical University of Munich
- Dr Gabriel C. Oniscu, European Society for Organ Transplantation (ESOT)
- Dr Stela Živčić Ćosić, University of Rijeka

Recurrent topics in the discussion included the factors determining national differences; particularly organisational measures, training, the role of transplant coordinators, leadership and communication; challenges of increasing donation and transplantation activity; patient empowerment and raising public awareness; the role of registries and improving data availability and quality; the mandate of the EU and governance and cooperation at different levels.

The panel discussion made for a candid solution-oriented dialogue on Organ Donation and Transplantation. Experiences and good practices were shared in order to help move the dial in Europe, and to enable success stories and functioning models to be discussed and debated with a view to help raising the bar in other settings.



Audience participation made for a lively debate which culminated in voting on priority actions to improve organ donation and transplantation in Europe. In the live poll, 94% of the Forum participants declared a need to launch a second EU Action Plan on Organ Donation and Transplantation following the last Action Plan which covered the period 2009 to 2015. Furthermore, the audience considered the five most important elements in increasing organ availability to be (ranked in priority order):

the five most important elements in increasing organ availability to be (ranked in priority order):

1. Increasing public awareness and trust,
2. Each Member State having a dedicated strategy/action plan for organ donation and transplantation,
3. Appointing and maximising the role of transplant donor coordinators,
4. Promoting quality improvement programmes in hospitals, hence optimising deceased organ donation,
5. Training to improve knowledge and communications skills of healthcare professionals.

The poll results and discussions of the Forum will inform the Joint Statement of the EU Thematic Network on Organ Donation and Transplantation, the multi-stakeholder political declaration to be submitted to the European Commission on 3 October 2019 with a view to provide recommendations to shape the future of organ donation and transplantation in Europe.



KEY TAKEAWAYS OF THE EUROPEAN KIDNEY FORUM 2019

- The success of the national transplantation programme in **Spain** is underpinned by two main aspects: 1) the effective organisation of the donor coordination network and 2) the training provided to improve healthcare professionals' communication skills.
- In **Germany**, staff shortages and reduced ICU facilities are major problems resulting in inadequate resources for the provision of care to potential donors, in addition to cultural perceptions and lack of trust of the public which culminate in low levels of organ donation.
- Remarkable progress in **Croatia** is mainly a result of: 1) nationally-coordinated measures aimed at strengthening capacities and competencies in deceased organ donation, and 2) political and financial support provided to ensure the effective implementation of organisational measures (donor coordinator, training, system quality and hospital performance monitoring).
- While practices and outcomes are diverse, **similar challenges** prevail in organ donation and transplantation across Europe. Solutions lie in sharing good practices, tackling inequities in access, engaging the public as well as political leadership, and improving benchmarking.
- **Leadership** appears to be a decisive feature at all levels. Hospital and national transplant coordinators with good leadership and communication skills can make a real difference, but need to be supported by national authorities. Guidance and support from the EU is deemed equally important.
- While much can be achieved with organisation, education, motivation, leadership, and communication; **funding** is essential for sustainable outcomes as it remains a key issue for improving national transplantation programmes, research, registries, and data.
- Rather than focusing exclusively on increasing the transplantation rate, greater attention should be placed on fostering **quality and enduring outcomes**, which entails a multi-level and multi-stakeholder effort.
- Assessing transplantation outcomes requires longer term observational data. There is evident consensus around the benefits of setting up **registries** that could collect such data at the EU level. However, to establish trust, further consideration should be given to the governance of the data.
- It is important to seize the **opportunities at EU level** through the Thematic Network on Organ Donation and Transplantation and its Joint Statement, the Croatian Presidency of the Council and its political agenda, as well as forthcoming funding programmes of Horizon Europe.
- Given its limited mandate in health, **EU's role** in organ donation and transplantation is one of support and guidance, essentially complementary to national efforts.
- The **EU Action Plan on Organ Donation and Transplantation 2009-2015** is seen as successful as it encouraged a valuable exchange of good practices and inspired several national action plans. In view of this success and changing circumstances, the need for a new Action Plan to meet today's challenges is widely considered as necessary.
- **Meeting patients' needs** requires aligning patients' needs and expectations with that of the medical professionals, building trust, finding common ground, and taking concerted action.

Increasing organ availability and dialogue between stakeholders is key to improving outcomes



MEP Hilde Vautmans
MEP Group for Kidney Health Chair

MEP Hilde Vautmans
MEP Group for Kidney Health Chair

In her video message, MEP Hilde Vautmans welcomed the participants and underlined the importance of organising the European Kidney Forum and similar events regularly to foster dialogue and further achievements in Europe. Vautmans also highlighted the significance of this year’s theme of ‘Organ Donation and Transplantation in Europe’ for broadening the scope of EKHA’s annual kidney health-focused policy roundtable.

“Nowadays inside the European Union, organ transplantations are carried out every single day. We could still perform...more transplants if we had a sufficient amount of available organs ...At the end of 2017, more than 60,000 patients were still on the waiting list for transplantation ...[an intervention] that could possibly save their lives. Different guidelines, directives and action plans can be drawn up, but there’s always room for improvement, and it’s only by organising such events, by talking to each other and by sharing ideas with each other that these improvements can be achieved.”

MEP Vautmans ended her address by wishing the participants a fruitful meeting and adding that she looks forward to taking the participants’ recommendations forward in the next parliamentary legislature.

Thematic Network on Organ Donation and Transplantation

The high added value of transplantation underpins the Thematic Network



Prof Raymond Vanholder
EKHA Chairman

Professor Raymond Vanholder
EKHA Chairman

Professor Raymond Vanholder thanked the event’s sponsors **Astellas, Amgen, Baxter, B Braun, CSL Behring** and **Vifor Pharma** for their generous support provided through unrestricted educational grants. He highlighted the significance of organ donation and transplantation, and provided insight into the work being conducted under the umbrella of the EKHA-led Thematic Network on Organ Donation and Transplantation.

Prof Vanholder made a case for **transplantation as one of the highest added-value treatments in medicine, both for patients and healthcare systems**, being as it is both a life-saving and cost-effective intervention. Accordingly, even for kidney disease, virtually the only organ disease for which there exists a large-scale, long-term alternative treatment with hemodialysis, transplantation constitutes a better option with remarkable gains in life expectancy, quality of life, and cost efficiency. Despite these positive outcomes,

however, Prof Vanholder highlighted the sizeable divergences that remain in transplantation rates among European countries.

Having thus laid out the motivations for EKHA's proposal for a Thematic Network on Organ Donation and Transplantation and the Commission's decision to select it as one of the four Thematic Networks to be carried out in 2019, Prof Vanholder expressed his gratitude to the Thematic Network partners, comprising organisations involved in the transplantation of different organs as well as National Competent Authorities. The input and advice received from the partners has been indispensable for the development of the Joint Statement on Organ Donation and Transplantation, an output of the Thematic Network in the form of a political declaration uniting stakeholders around key actions to improve organ donation and transplantation in Europe. Prof Vanholder concluded his presentation with an overview of the topics of the Joint Statement, the final version of which will be informed also by the insights given by speakers and participants of the Forum, and submitted to the European Commission on 3 October 2019.

THE THEMATIC NETWORK ON ORGAN DONATION AND TRANSPLANTATION

- EKHA-led initiative selected by the European Commission as one of the Thematic Networks of the EU Health Policy Platform in the 2019 Cycle.
- Brings together a variety of stakeholders involved in Organ Donation and Transplantation across Europe to advance good practices and address the challenges faced by Member States.
- Will deliver a Joint Statement in the form of a political declaration to the European Commission on 3 October 2019.

Patient's perspective

'Nothing is impossible'



Robert van der Wolk
Transplant patient

A type-1 diabetes patient since childhood, who lost his eyesight overnight at the age of 21 and who has undergone over 60 operations and treatments including dialysis and a combined kidney-pancreas transplant, Robert van der Wolk shared his inspiring journey and his vision on life after kidney disease, which is encompassed in his mantra 'nothing is impossible'.

Starting with an interactive exercise showing the audience that one's limits are closely related to the limits of their imagination, van der Wolk talked about his lifelong struggle with diabetes, loss of eyesight and organ failure, and how none of these challenges stopped him from pushing his limits to run a marathon, author books, and found an international training institute for cultivating personal and professional leadership skills. Sharing his experience to support other chronic disease patients and educate medical professionals, Robert van der Wolk gave a message of hope; that regardless of the physical challenges life may bring, it is our responses to them—including our readiness to adapt to change—that determine the real outcome of living with chronic disease.

Panel discussion

Towards improved organ donation and transplantation in Europe: Sharing knowledge and exchanging best practices



Prof Wim Van Biesen
Ghent University

The panel discussion, moderated by Professor Wim Van Biesen, Chief of the Department of Nephrology at the Ghent University Hospital, featured speakers from the Spanish National Transplant Organization (ONT), Technical University of Munich, European Society for Organ Transplantation (ESOT), University of Rijeka in Croatia, and DG SANTE. Prof Van Biesen opened the panel session by introducing the interactive polling tool made available for all participants, thereby encouraging the audience to actively join the discussion by asking questions, answering polls and “upvoting” (i.e. endorsing) other submitted questions.

Prof Van Biesen gave the floor to the first speaker, Dr Elisabeth Coll from the Spanish National Transplant Organization. Asked about the main factors contributing to the remarkable success of the Spanish transplant programme, Dr Coll shared the following insights:

Spain is currently the leader in organ donation and transplantation in Europe, and not only for kidney. This means that many patients can get transplanted, but the approach in the country is that there is always room for improvement so long as there are patients suffering on waiting lists.

Spain’s success in the field is not by chance. Any improvement in transplantation essentially means an improvement in donation, so efforts have been focused on that front. The per million population (pmp) donation rate in Spain has been increasing steadily every year, as a result of the hard work put into growing the number of deceased donors.

The high donation rate in Spain cannot simply be explained by the generosity of the Spanish population; nor is it necessarily about an exceptional legal framework—in Europe, more or less similar laws on organ donation and transplantation exist. The success of the Spanish model, according to Dr Coll, is foremost related to organisational measures.



Dr Elisabeth Coll
Spanish National Transplant Organisation

In the Spanish experience, **the difference is attributed to two main aspects. The first is the donor coordination network**, whereby there are coordinators in every region in addition to the central office of the Spanish National Transplant Organisation. This structure replicates the healthcare system of the country, in which competence is transferred to local authorities. A crucial figure here is the hospital coordinator, which in most cases is a team rather than a single person, led by a critical care physician. **The second is the training**

of healthcare professionals on how to communicate with and support patients and families. When Prof Van Biesen asked Dr Coll whether she believes that opt-in and opt-out frameworks have a significant impact on donation rates, Dr Coll maintained that this policy choice does not determine the outcomes in itself, as the decision whether to donate is ultimately made by individuals and families. She therefore concluded by emphasising the importance of investing in the communication skills of healthcare professionals, who help patients and families make these critical decisions at a difficult time.

Prof Van Biesen then invited **Prof Uwe Heemann** from the Department of Nephrology of the Technical University of Munich, to explain the reasons for the dwindling transplantation rates in Germany.

Prof Heemann highlighted that Germany has never really been among the leading countries in organ donation and transplantation, and identified the root cause as limited ICU capacity due to a shortage of nurses and physicians. This has been a long-standing issue which German authorities have tried to counter by importing staff members from abroad. However, structural shortcomings, such as inadequate and gender-biased provision of work-life reconciliation measures which fail to accommodate the needs of the predominantly female healthcare workforce, remain unaddressed. **To solve the problem of reduced ICU capacities which gives rise to a competition between standard care and donor care in the ICU, Prof Heemann advocated for the financing of an ICU bed in all major hospitals dedicated solely to donors**, under the guidance of the transplant coordinator.

BASIC PRINCIPLES OF THE SPANISH MODEL

- Adequate legal and technical framework
- Donor coordination network
- The special profile of donor coordinators
- Donor coordinators inside the hospitals
- Central office (ONT) as a supporting agency
- Continuous potential donor audit
- Emphasis on professional training
- Hospital reimbursement
- Continuous attention to the mass media
- Flexibility and innovation
- Involvement of professional societies



Prof Uwe Heemann
Technical University of Munich

Prof Heemann mentioned other issues exacerbating the insufficient number of donations in the country, such as the ethical and historical debate surrounding the concept of brain death in the population as well as the “Transplantation Scandal” of 2012, whereby waiting lists were manipulated to push some candidates for transplantation to the top, causing a major loss of trust.

Prof Heemann proposed that European legislation on brain death and donation could help tackle these problems. However, Dr Stefaan Van Der Spiegel from DG SANTE, explained that the EU has limited competence in this particular field and that the distinctive ethics underpinning Member States’ practices and legal frameworks must be respected. Dr Van Der Spiegel argued that the focus should be instead on building domestic capacity in order to increase donations. Although

the challenges of a uniform EU-level legislation are recognised, Prof Heemann maintained that **recommendations coming from the EU would be highly valuable for achieving improvements at the national level.**

Summarising the points raised thus far in the discussion on organisation, communication, education, and motivations, Prof Van Biesen gave the word to ESOT Secretary **Dr Gabriel Oniscu**, who made the following remarks:

Today's theme of "are we meeting the needs of the patients?" reminds us to align patients' needs and expectations with that of the medical society for better outcomes. **Divergent practices prevail in Europe, but the challenges remain rather similar: there is variation in clinical practice, inequity in access, variation in outcomes, lack of benchmarking, and variation in access to all types of donation; living or deceased.** ESOT sees opportunities to meet these challenges, regardless of differences in national frameworks or cultural perceptions. Variations in practices can be mitigated by sharing good practices, creating guidelines, and benchmarking. In this regard, European registries can benefit all stakeholders in that they help compare national performances, evaluate practices and results, improve equity in access, and better inform patients. On the other hand, **education should not be limited to healthcare professionals—patients need to know what their treatment options are and the public needs to be educated about organ donation.** Fostering dialogue empowers both patients and professionals, but the wider public and the political establishment should also be engaged through campaigns and lobbying to influence transplantation policies. ESOT works to establish connections, for instance, a network has been created by ESOT as an online hub where people can reach out to professionals and ask questions. It is ultimately education, exchange of experiences and access to Europe-wide data that will take us forward, and help change practices, perceptions, and knowledge.



Dr Gabriel C. Oniscu
European Society for Organ Transplantation (ESOT)



As regards addressing inequities, Dr Oniscu talked about living donation figures which show that the white middle class gets transplanted while others don't. He maintained that there is a need to overcome the inequity between patients who can get a transplantation and those who cannot, and aim instead for a point where patients are differentiated simply on the basis of whether they would benefit from a transplantation or not. Following from this remark, from the audience, Kidney Care UK Policy Director **Fiona Loud** put forth **the role that patient support charities can play as the voice of patients**: accordingly, by sharing unheard stories, these organisations can raise awareness while serving to mitigate inequities.

Dr Oniscu added that **improving health literacy, preferably through EU programmes, would be another key aspect in fighting inequity.** To Prof Van Biesen's question of whether the EU could ensure that education on organ donation is a part of school curricula, Dr Van Der Spiegel explained that this cannot be required given the absence of EU mandate to directly regulate national education policies, but added that education ministers could be advised and supported by the EU's education programme to incorporate this subject into national curricula. Dr Stela Živčić Ćosić noted that in Croatian universities, medical students receive courses specifically on organ donation and transplantation as part of the national strategy.

Prof van Biesen then invited **Dr Stela Živčić Ćosić** to present the key elements in the remarkable success of Croatia's national transplant programme in recent years. Dr Živčić Ćosić explained that prior to 2000, patients' needs were not met and all stakeholders involved in organ donation and transplantation were largely dissatisfied with the functioning of the system. The change was initiated with a Ministry of Health strategic plan aimed principally at enhancing the governing capacities of the Ministry as well as hospitals' capacity for organ donation. The regulatory framework based on presumed consent was complemented with proper organisational settings for deceased organ donation, such as: coordinators' network, training, funding, system quality and donor hospital performance monitoring, public awareness campaigns, and international organ exchange and collaboration. In particular, Eurotransplant membership has further boosted trust in the system as a result of fair and transparent allocation rules and criteria. According to Dr Živčić Ćosić, **in addition to political support and financial investment enhanced national and clinical leadership in deceased organ donation has also been decisive in the Croatian experience.**

Moderator Wim Van Biesen addressed Dr Živčić Ćosić's point on leadership, and asked whether the EU could play such a role to drive national action on organ donation and transplantation. Dr Van Der Spiegel agreed that the EU can support, set a common direction and provide leadership as has been undertaken over the last ten years, particularly through the Action Plan on Organ Donation and Transplantation. However, he stressed that healthcare is a national policy area and all transplants are organised at national level. The initiative, therefore, needs to come first from the national level. Where such national initiative and interest exists, the Commission can play a supportive role, in particular to build national political interest in organ transplantation and to develop and exchange national know-how at administrative and professional level. To this, **Helena Zakharova** from the Russian Dialysis Society added that **lack of support from national governments can hinder improvement even where there is solid training and good leadership at the local level**, and so emphasised the importance of supplementing these endeavours at the national level.



Dr Stela Živčić Ćosić
University of Rijeka

The discussion then moved on to issues of funding and whether these can preclude progress in organ donation and transplantation in a country. **Mark Murphy** from the Irish Kidney Association noted that in most EU countries, because dialysis budgets and transplant budgets are not covered by the same body, the long-term cost-effectiveness of increasing transplantation by spending more on ICU facilities is often overlooked. Prof Uwe Heemann mentioned the difficulties arising from donation not being a part of the hospital budget in Germany unlike in Spain. On the other hand, Dr Stela Živčić Ćosić highlighted that funding for transplantation activities was not provided in Croatia until 2006, but the first improvements started in 2000, illustrating the value of a motivated healthcare personnel in overcoming financial shortcomings. Prof Heemann acknowledged the importance of motivation, leadership, and training; but pointed out the need to complement these with resources in the face of increasing pressure on healthcare systems with more hospitals yet inadequate staff, coupled with a growing number of patients in need of transplants and consistently low levels of donation particularly in the case of Germany. Dr Van Der Spiegel maintained that funding is essential for sustainable



achievements and mentioned that the **positive cost-benefit outcome of investing in organ transplantation**, due to savings compared to dialyses, is supported by multiple studies, including the upcoming report of the EU-funded EDITH project. It is important to compensate healthcare professionals for their efforts, but living donations should also be incentivised with fair compensation, considering the process following donation before donors can go back to their work and usual activities. Here, Prof Van Biesen stressed the ethical aspect, saying that the incentives should be provided strictly with a view to compensate efforts and empower stakeholders, so as not to create other problems.

Next, **Professor Raymond Vanholder** discussed the issue of lasting impact of organ donation and transplantation. He emphasised that having a high rate of transplantation is one goal, but what matters ultimately is that the transplanted organ lasts, serving the patient for many years and improving their quality of life. He explained that despite progress, many transplanted patients are lost due to progressive graft failure, fibrosis, and rejection; or complications such as cancer, diabetes mellitus, cardiovascular disease, and infections. For kidney recipients, going back to dialysis may also be needed, creating an additional mortality risk during the transition period.

To improve the quality of transplantation and for enduring outcomes, the EU, national stakeholder societies, and national competent authorities all have a role to play. The Thematic Network on Organ Donation and Transplantation is a notable example of concerted stakeholder effort in this regard. Furthermore, research projects on transplantation should be facilitated with adequate funding. Lastly, the creation of registries that include complications and long-term outcomes could help go beyond the mere comparison of transplantation rates and lead to a better understanding of the real impact on patients' lives. Here, Prof Vanholder referred to the European Commission co-funded pilot project **EDITH**, which aims to assess the effects of differing kidney disease treatment modalities and the impact of organ donation and transplantation practices on health expenditure and patient outcomes. EDITH's support for the establishment of follow-up registries underscores the need for reinforced efforts in collecting much-needed evidence to ultimately improve the quality and safety of living donors as well as transplant recipients.

Prof Van Biesen then brought up the difficulties arising from the fact that available evidence in the field is often limited to one- or two-year trials, whereas assessing transplantation outcomes requires longer-term observational data that can reveal the real impact on a transplanted patient's life. On whether the EU can support with the creation of registries to collect such data at the EU level, Dr Stefaan Van Der Spiegel was positive, adding the increasing value of **having all transplantation outcomes well registered, analysed, and acted upon, also to improve safety and quality of transplant therapies.** He cited the established registries in bone marrow transplantation as a good example for the field of solid organ transplantation, with over 30,000 bone marrow transplants registered annually, enabling long-term follow-up.

Addressing this, Prof Van Biesen said that while patients treated in the fields of haematology, oncology, and particularly in bone marrow transplantation are often part of a study, this is not the case for solid organ transplantation, and asked whether this could be due to issues with funding. Prof Heemann said that there are indeed more EU funding opportunities for research in these areas than for solid organ transplantation. Dr Van Der Spiegel, however, underscored that limitations in funding could not be a decisive impediment, and that data collection is not necessarily as costly as it is often thought to be. He said that creative models can be devised to provide quality and long term statistics, and pointed out the fact that the whole initiative in bone marrow transplantation was developed by physicians who did not receive funding for this activity, but were eager to share and learn from each other's data. He therefore stressed that such initiatives require mutual trust and cooperation among professionals, which can be achieved through a good governance model. Only then would it be more appropriate to support this with a binding requirement set at the EU level, as opposed to a top-down approach. Dr Oniscu expressed ESOT's supportive position on the issue, agreeing that the initiative should come from the professionals and be supported with legislation to ensure the availability and quality of the data. Dr Van Der Spiegel also invited **transplant professionals to be more proactive in building a strategic agenda for research in their field at a time when new research budgets are being determined as part of Horizon Europe**, in order to secure funding that could make a great impact in the sector.



For improved registries in the field of organ donation and transplantation, Prof Van Biesen suggested the prospects of harnessing Artificial Intelligence (AI) and big data, while **Peter Wubbe** from the European Digital Peer Patient Alliance raised the issues associated with the collection and use of patients' data under the EU General Data Protection Regulation (GDPR). Dr Stefaan Van Der Spiegel acknowledged that the governance of data, that is, with whom it is shared, whether it is anonymised or pseudonymised, and how it is reviewed and made public, constitutes a fundamental aspect in setting up registries. Here, Dr Oniscu revisited the importance of establishing trust in the system, and held that the data should be owned and governed by the professionals and registry centres themselves.



Following this discussion, **Dr Stefaan Van Der Spiegel** from DG SANTE presented the EU's role in improving organ donation and transplantation in Europe. He outlined the 10 priority action points of the EU Action Plan on Organ Donation and Transplantation that ran between 2009 and 2015, with a view to promoting the objectives of increasing organ availability, enhancing the efficiency and accessibility of transplantation systems, and fostering quality and safety. According to Dr Van Der Spiegel, the Action Plan based on the experiences of different Member States provided a solid foundation for policymaking within countries and inspired several national action plans. Thus, **the value of the Action Plan stems from the fact that it initiated an exchange of knowledge and good practices at the EU-level, which accelerated progress at the national level** and ultimately, served all countries.

On the other hand, Dr Van Der Spiegel reiterated the large differences that prevail across the 28 Member States, and insisted that **Action Plans are intended to guide national efforts, but cannot be applied in the same way in different countries**. Therefore, having a good understanding of the local context is always important, with regard to different elements including the approach to ethics, consent laws, and education. Here, two vital elements remain, first, the overall awareness and views on donation in the public, and second, the capacity of the systems to organize, fund and sustain organ donation and transplantation activities.

In view of this success and changing circumstances, Dr Stefaan Van Der Spiegel agreed that **a new Action Plan to meet today's challenges could be useful**, and shared several points for the organ donation and transplantation community to consider going forward. Accordingly, **it is important to elicit more political support and engage more with the political level**. The fact that the forthcoming Croatian presidency of the Council, which will run from January to July 2020, has declared organ donation and transplantation a priority, presents a great opportunity to put issues on top of the political agenda. The stakeholders should be well prepared for the meetings of Ministers of Health that will be taking place within this framework, and bring important messages on the table. Among the most important of these messages is certainly the economics of organ transplantation, because funding remains a key aspect. In particular, it has to be conveyed clearly that kidney transplantation is the one therapy that is not only saving patients and improving their quality of life, but also, generating substantial savings to the healthcare system compared to dialysis. The realization of this fact can go a long way, as in the case of the UK, where the largest increases in organ transplantation have been recorded in the recent years thanks to a cost-efficiency analysis undertaken about 10 years ago. With the EDITH project, this analysis is currently being made at the European level, to assess how far-reaching the returns on investment in organ donation and transplantation are.

10 PRIORITY ACTIONS OF THE EU ACTION PLAN ON ORGAN DONATION AND TRANSPLANTATION (2009 – 2015)

A. Increasing organ availability

- 1- Transplant coordinators
- 2- Quality improvement programmes
- 3- Living donation programmes
- 4- Communication skills of professionals
- 5- Information on citizens rights

B. Enhance efficiency and accessibility of transplantation systems

- 6- Enhancing organisational models
- 7- EU-wide agreements
- 8- Interchange of organs

C. Quality and Safety

- 9- Evaluation of post-transplant results
- 10- Common accreditation system

Following this presentation, moderator Wim Van Biesen invited the audience to participate in the live poll, which yielded the following insights:

Do you think there is a need to launch a new Action Plan on Organ Donation and Transplantation following from the last action plan (2009-2015)?



Which of the following you consider to be the top 5 most important elements in increasing organ availability?



Accordingly, 94% of the Forum participants declared a need to launch a new Action Plan on Organ Donation and Transplantation following the last Action Plan of 2009-2015. Furthermore, the audience considered the five most important elements in increasing organ availability to be:

1. Increasing public awareness and trust,
2. Each member state having a dedicated strategy/action plan for organ donation and transplantation,
3. Appointing and maximising the role of transplant donor coordinators,
4. Promoting quality improvement programmes in hospitals, hence optimising deceased organ donation,
5. Training to improve knowledge and communications skills of healthcare professionals.

Wrapping up the discussion following the survey, Prof Van Biesen asked **Robert van der Wolk** for his views as a patient on the issues raised throughout the discussion. Van der Wolk concluded:

“The crux of the matter is people, beyond funding, regulations, strategies, and data. The desired outcome from a patient’s point of view would always be to have a transplanted organ that lasts a long and healthy lifetime. Hence meeting patients’ needs ultimately means joining efforts to make this possible, and finding common ground to create a vision for long-term outcomes in organ donation and transplantation in Europe.”

Prof Van Biesen then gave the final word to Prof Vanholder, who thanked the sponsors for making the event possible, and the moderator, the speakers and the audience for their contributions in what had been a very fruitful and interactive debate, and closed the 2019 European Kidney Forum.