National Plan for Solid Organ Donation and Transplantation

Summary of the main report

LSE THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

Imperial College London

ONASSIS FOUNDATION

"An ambitious venture"

KATERINA SAKELLAROPOULOU
President of the Hellenic Republic

According to data from the Hellenic Transplant Organisation (EOM), Greece is at a disadvantage in the organ transplantation sector. The lack of information, coupled with fear about this sensitive issue, the lack of infrastructure and chronic problems in the organisation of the state operate as barriers to organs being voluntarily donated by members of society and to the spread of this medical achievement in Greece.

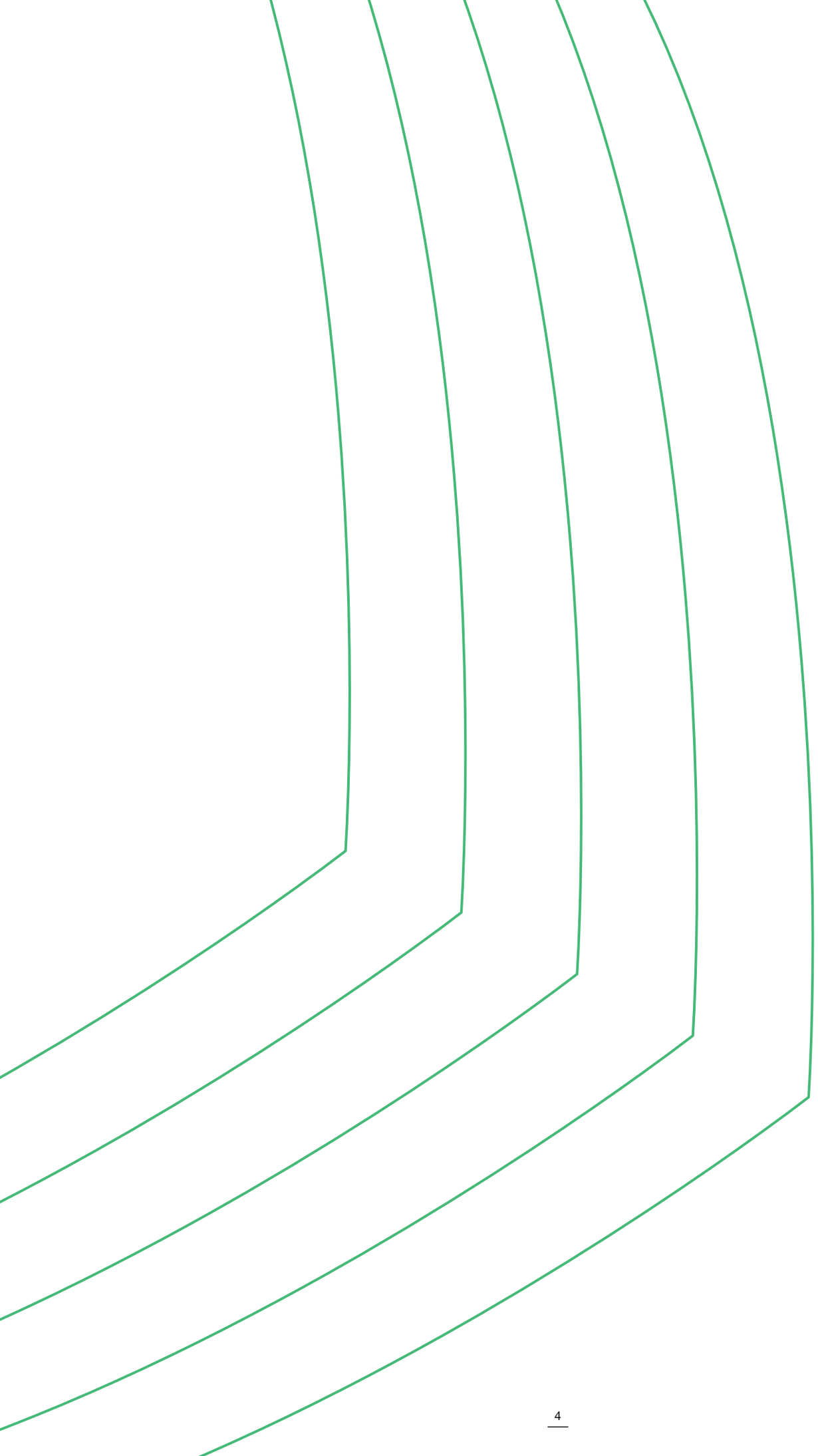
However, as the EOM annual report states, during the pandemic the number of transplants did not drop, and in some cases actually increased. Perhaps because, faced with the risk of loss, we realised how deeply our lives are in fact interconnected. This optimistic realisation once again demonstrates that where there is a vision and willingness to work in concert with each other, even the most difficult barriers can be overcome. However, the need for transplants remains vital, is ongoing and is on the rise. Much still needs to be done.

That is why the report carried out by an international team of scientists from the London School of Economics on the National Plan for Organ Donation and Transplantation for the years to come, prepared under the supervision of Professor of Health Policy Elias Mossialos and the Professor of Transplantation Surgery at Imperial College London and President of the European Society of Organ Transplantation Vassilios Papalois, is of particular importance.

This top-class scientific study carried out by Greek and international experts offers a sustainable, holistic organisational framework, helping to: improve the legislation and overall strategy of the State; bolster the role of the EOM and other transplant centers; and improve infrastructure and training methods for skilled staff, while also changing the culture among the general public, as well as much else besides.

The ambitious venture, which this exceptional initiative represents – an initiative undertaken by the Onassis Foundation to rebuild the system of organ donations and transplants in Greece, with cross-party support – fills us with optimism for the future. Besides, this is not the Foundation's only contribution in this sector. In parallel with the National Plan for Organ Donation and Transplantation, construction work on the Onassis National Transplant Center is also under way. It – along with the Onassis Cardiac Surgery Center – is expected to dramatically improve the health system and bolster the dissemination of scientific knowledge.

The President of the Onassis Foundation, Anthony Papadimitriou, and the people behind this outstanding project deserve heartfelt congratulations. They have made a tireless contribution to developing the organ transplantation sector in Greece. This is such an important issue for society; the love, altruism and generosity it reflects signal the high value that life has and showcase the greatness of human existence.



"The National Transplantation Plan will soon make its way to the Parliament"

KYRIAKOS MITSOTAKIS
Prime Minister of Greece

For the first time in its history, Greece now has a National Plan for Organ Donation and Transplantation. This will serve as a Charter for this pioneering medical achievement, as it is high time for our country to put it in the service of our fellow citizens' life and health.

This comprehensive programme is set to become the new modern foundation for the institutional framework on transplantations, setting and defining all relevant processes. It will also serve as a constant and valuable compass for the Onassis National Transplant Center, which will also put it into action.

The National Plan for Organ Donation and Transplantation has come to life thanks to the efforts of a team of distinguished experts. It was prepared by the London School of Economics, with the cooperation of the Imperial College, under the supervision of two leading Greek scientists, Elias Mossialos and Vassilios Papalois. It is thus a prestigious venture, integrating vast international experience.

In a comprehensive, clear approach, it sets even the slightest details for all transplantation-related issues, for both the State and patients. It completely reforms the National Transplant Organisation, which now becomes an Independent Authority. It provides compelling answers to sensitive bioethics issues that arise in the various and complex organ transplantation cases, following the loss of a life, while also putting in motion processes to increase the number of available grafts. Moreover, the National Plan for Organ Donation and Transplantation deals thoroughly with all aspects of transplantation: from the funding of the system, the modernisation of existing facilities and the establishment of new ones to digital data keeping; from physician training to the ongoing update of protocols, on the basis of global developments, know-how and practices.

Finally, it introduces follow-up and care practices for organ recipients following transplantation. Focus is now also on prevention, to minimise the need for transplants. At the same time, the concept of organ donation is promoted, building trust and raising citizen awareness through information.

The National Plan for Organ Donation and Transplantation will soon make its way to the Parliament to be voted for implementation. Undoubtedly, this is yet another cornerstone donation by the Onassis Foundation. But turning this investment into a law expresses the clear political will of the Government, as I deeply believe that collective prosperity and the overall progress of society are achieved when the public and the private sector join forces towards the same goal, under a joint plan.

This conclusion is in line with our history. As we now celebrate 200 years of independence, let us not forget that, amongst all difficulties and troubles, our country rose and moved forward thanks to the patriotism of Greeks who put their wealth at the service of their homeland. This tradition is continued by the Onassis Foundation with the creation of the Onassis National Transplant Center and the preparation of this Strategic Plan. This is why congratulations are in order from all of us.

ANTHONY S. PAPADIMITRIOU

President of the Onassis Foundation

In very difficult times for public health, the Onassis Foundation took a nation-wide initiative in cooperation with the Ministry of Health, the National Transplant Organisation, the Onassis Cardiac Surgery Center and other hospitals, to rebuild the solid organ donation and transplantation system in our country.

Even though transplantation is considered the most modern therapeutic practice of the 21st century worldwide, since it is the only option in end-stage heart, liver and lung failure and the most effective treatment for renal failure, unfortunately Greece ranks last in Europe and finds itself among the last ten countries in the Western world.

The waiting list of patients in need for a transplant is long and the chances of finding this longed-for transplant are very slim. Ignorance, bias and our hostile health system are the key inhibitors obstructing the progress of transplantations in our country.

Almost 30 years ago, the creation of the Onassis Cardiac Surgery Center by the Onassis Foundation transformed the healthcare landscape in our country. Today, the Onassis Foundation aims at transforming the healthcare landscape in Greece once again, adopting a holistic approach and leaving its mark in the field of solid organ donation and transplantation. The Onassis Foundation builds new infrastructure for transplantations, invests in innovation, boosts the National Health System structures, helps develop scientific research and carries out citizen information and awareness-raising actions.

Of course, our efforts focus on the creation of the Onassis National Transplant Center a cutting-edge transplant center that is open to everybody. Its construction by the Onassis Foundation is underway and its delivery to the Greek State is expected to happen in 2024. However, infrastructure alone is not enough to elicit change in the transplantation landscape in our country. Further actions are required; actions that will provide a solid foundation for the rebuilding of this sector. First of all, an institutional framework for an integrated national transplant policy is necessary for the operation not only of this specific hospital, but of the entire Greek donation and transplantation network.

Therefore, two years ago, having first ensured cross-party consent, we decided to support the elaboration of a National Transplantation Plan , by assigning the relevant report to the London School of Economics (LSE) headed by Professors Elias Mossialos and Vassilios Papalois, who are in charge of a team of distinguished Greek and foreign scientists.

The report on the National Transplantation Plan in our country is ready. Its summary is in front of you and the next step is to make it an official law of the State. It is a pioneering scientific piece of work at a global level, an outstanding and comprehensive report that can become the road map for transplantations in Greece in the following years. It is an important step forward and, at the same time, an answer to the long-standing demand raised by healthcare professionals, patients and all transplantation stakeholders.

Our vision is to forge an alliance in favour of life, within the context of which, no one is to spare. Nevertheless, besides infrastructure, works and the appropriate institutional framework, this alliance also requires to raise citizen awareness, build trust to the National Health System and fight unjustified fears based on rumours and unsubstantiated scenarios. More importantly, the concept of citizenship and its connection to organ donation and transplantation must be introduced into our educational system. This means that we should all realise that we are individuals who should act as members of a society, where everybody is there for the others. Through organ donation, we give life its due value.

VASSILIOS PAPALOIS

Professor of Transplantation Surgery at Imperial College London, President of the European Society of Organ Transplantation

ELIAS MOSSIALOS

Professor of Health Policy at London School of Economics and Political Science (LSE), Head of LSE Health

Co-Chairs, Commission for a New National Donation and Transplantation Plan in Greece

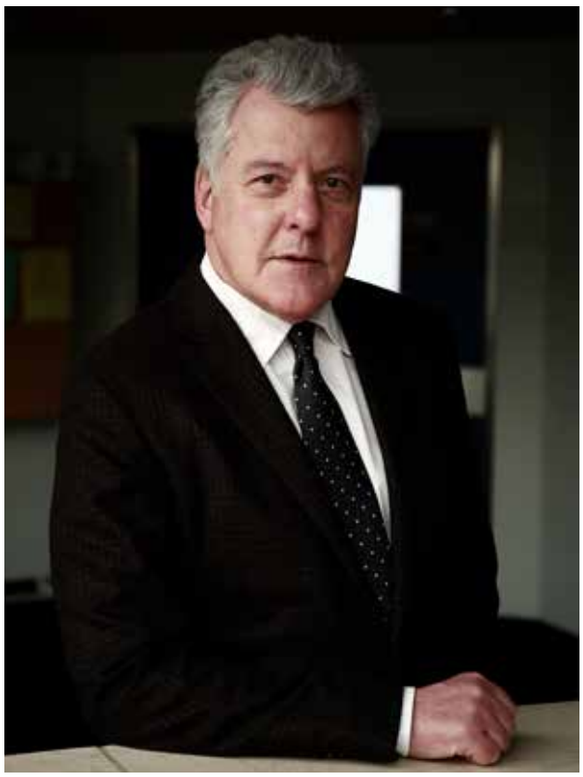
The COVID-19 pandemic is a catastrophe, which has cost countless lives, devastated livelihoods, and tested many health systems to their very limits. But amid the crisis there is opportunity: a chance to reflect on how we want to change ourselves and our societies. It has brought health systems into focus as never before, and revealed the fault lines and underlying challenges they face. While the immediate focus is on the pandemic, now is the time to take stock and consider what needs to be done to build health systems that better meet the populations needs, both during and beyond the crisis. Health systems are enormously complex, and can only be transformed for the better through carefully planned, strategic reforms, requiring sustained commitment, investment and collective effort.

The Greek organ donation and transplantation system is a powerful example of this. A miracle of modern medicine, organ transplantation should be equitably available to as many people as possible who would benefit from it. In recent years, our European partners have made great strides in building systems that make this life-saving, and life-changing treatment available to ever greater numbers of people suffering from late-stage organ failure, whether that be of the kidney, liver, pancreas, lung or heart. But Greece stands in stark comparison: our transplantation rates are among the lowest in the developed world, despite having relatively high levels of need. The statistics, in terms of lives lost, and those who face an uncertain future while waiting for a transplant, paint a tragic picture, the human cost of which cannot be quantified.

Despite the efforts and commitment of hospitals and health care professionals and the National Transplant Organisation, Greece has never had a coherent national strategy or system for organ donation and transplantation. However, with the right set of reforms, investment and long-term commitment, Greece has the potential to become a leader in solid organ donation and transplantation. The Onassis Foundation's investment in the development of the Onassis National Transplantation Center (ONTRC) represents an important step forward. This will be a world-class clinical facility, significantly improving the national infrastructure available for donation and transplantation activities. While no single hospital can transform a system, the ONTRC can act as a catalyst for wider change, spanning from how services are organised, funded and delivered, to public attitudes and awareness of the benefits of donation and transplantation.

In recognition of this, since late 2019, following the initiative of the Onassis Foundation, we have been working with a team of Greek and international experts as well as with a dedicated research team from the London School of Economics and Imperial College London, on a detailed review to identify the steps necessary to transform the Greek organ donation and transplantation system. Informed by extensive research and engagement with stakeholders across and beyond the health system, the report presents a comprehensive set of evidence-based recommendations, which are summarised in this document.

Our vision is for Greece to establish an organ donation and transplantation system capable of attaining and sustaining world-class levels of performance within 10 years. This will be a major undertaking requiring wide-ranging reform, sustained commitment, investment and collaboration across the system, but dramatic improvements can be achieved in a much shorter time-frame. The story of one transplant recipient, Katerina, who tells her story in our report, shows just how transformative organ transplantation can be. It is our hope that the adoption of these recommendations will bring the same benefits and give a new life to thousands of Greek patients and their families



Professor I. N. BOLETIS

President of the Onassis Cardiac Surgery Center
President of the Greek Transplantation Society

Solid organ transplantations have been carried out in Greece for about 50 years now. However, if we are to face the truth, our performance has been quite poor. We must do better.

The infrastructure of Transplantation Units, their human resources and their overall operation in our country could qualify as average to good. The National Transplant Organisation, given its scarce financial resources and despite its institutional complexity, can luckily carry through with what is absolutely necessary; nevertheless, there is minimum capacity for the promotion of donations.

Important groups for transplantations, such as physicians and other healthcare professionals, lack in information and training. The State has passed legislation which complies with the decisions of the Council of Europe and the European Union, but, unfortunately, this is where all its efforts are exhausted.

By contrast, two important organisations, Orama Elpidas (Vision of Hope) in Athens and KEDMOP (Center of Awareness Raising and Attraction of Bone Marrow Donors) at the University of Patras, have engaged in the donation of haematopoietic stem cells. As a result, our country has a National Registry with about 200,000 haematopoietic stem cells donors. On the contrary, the number of organ donors in Greece over the last years equals to 1/4 of the European average, that is 5 instead of 20 per million population.

Why is that? In brief, we have not replicated in a complete and integrated manner everything the other countries have actually achieved. All efforts undertaken have been fragmented, while healthcare professionals and the society have definitely not been involved to the necessary extent.

Are we optimistic for the future? The answer is yes. Because what has changed is the State's commitment, at the Prime Minister's level, for the implementation of an integrated - this time - plan. This National Transplantation Plan has been prepared by the London School of Economics, with the participation of distinguished Greek and foreign experts, and sponsored by the Onassis Foundation.

The Onassis Foundation, at the same time with its generous sponsorship for the creation of the Onassis National Transplant Center under the same standards and further to the creation of the Onassis Cardiac Surgery Center identified the gaps and the needs of transplantation. Therefore, it undertook the effort to tackle this multidimensional problem, having realised that even its sponsorship would not mean much if the number of donations did not increase.

The National Transplant Organisation and the entire Greek transplantation community has been standing by our side and cooperating closely.

It is with great joy and hope that we welcome the National Transplantation Plan. We hope that it will be soon implemented, so that Greek citizens can enjoy the benefits of transplantation at the same level as the other European citizens.

GEORGIOS V. PAPATHEORIDIS

President Of The National Transplant Organization

Organ transplantation is an invaluable “gift of life”, which can save patients suffering from advanced organ failure.

Unfortunately, organs cannot be manufactured in vitro; they come from volunteers who make the decision, either when living or after their death, to save another suffering patient, known or unknown to them. There is no such thing as a transplantation without donor; this is why the development of relevant programmes and the self-sufficiency of each country in terms of organ donors and transplantation is a national obligation and should be a national priority.

It is known that Greece lags significantly behind in terms of deceased donation rates per million population, even though organ donation and transplantation rank high in most Greeks’ value system. The causes for the low number of deceased donors are manifold and careful, multilateral and coordinated efforts are required to tackle this problem.

Other than the main effort to increase donations, it is equally useful to undertake actions aiming at reducing potential donor losses, as well as losses of the existing donors’ organs, and maximising the supply of organs perhaps from abroad through international partnerships.

The development of active solid organ transplantation programmes begins with the increase of donor supply but, at the same time, a strong National Transplant Organisation is needed for effective and prompt coordination and, more importantly, strong, highly organised transplantation units and hospitals and specialised professionals offering high quality medical services.
In our country, despite the highly skilled personnel in the existing Transplantation Units, much more effort is needed to further staff the Units and, above all, to generally improve the support and organisation of all involved bodies and departments.

The National Transplantation Plan is a valuable tool which is expected to significantly boost and breathe new life into the field of solid organ transplantations in our country, since it provides evidence-based recommendations for the increase of organ donation and the improvement of the organisation of our Transplantation Units.

In light of the above, on behalf of the National Transplant Organisation, I would like to warmly thank the international team of experts headed by Professors Mossialos and Papalois, who worked thoroughly and, in the midst of the unprecedentedly difficult pandemic, managed to complete such a complex project, as well as the Onassis Foundation for its support in the elaboration of the Plan.

We hope that the State will gradually implement the National Plan recommendations to achieve an increase in the number of transplantations and offer hope for life to the many patients who have been anxiously waiting for a longed-for transplant.

Background to the report for a new national donation and transplantation plan in Greece

Commissioned by the Onassis Foundation and undertaken by London School of Economics (LSE) in collaboration with Imperial College London, the Report for a New National Donation and Transplantation Plan in Greece presents recommendations to enable Greece to transform its organ donation and transplantation system in order to achieve rates of transplantation in line with the leading countries in Europe. This document provides an introduction to the report, and a summary of its recommendations.

Transplantation is a miracle of modern medicine: it is the best treatment for organ failure, and offers significant benefits to patients in terms of both survival and quality of life. It offers recipients the chance of returning to enjoying full lives, to participate more in society and to return to work. While transplantation is a complex and expensive procedure, it is also significantly cost-saving compared to alternatives such as kidney dialysis. The complexity of transplantation as a surgical procedure is mirrored by the degree of coordination needed across the health system in order to deliver a successful transplantation programme. However, just as with surgery, the vital steps in implementing such a programme are increasingly well understood.

The moral and economic case for investing in a comprehensive organ donation and transplantation service in Greece is undeniable. Despite a disproportionally high level of need, Greece lags behind European countries in rates of organ donation and transplantation. Chronic kidney disease (CKD) accounts for the majority of cases of organ failure requiring transplantation, and Greece has one of the highest incidence rates of end-stage renal disease among high income countries, yet Greece performs 75% fewer kidney transplants compared to the European average per million people, and has the lowest rates of transplantation in the OECD, with rates stagnating in recent years. The average waiting time for a kidney transplant in Greece is 8.8 years, whereas the average period of survival for patients starting dialysis is three years, and one quarter of dialysis patients will die within a year. Unless action is taken to improve the availability and quality of transplantation services in Greece, it is inevitable that many lives will continue to be unnecessarily cut short.

Previous efforts to improve the Greek programme and increase rates of organ donation and transplantation have been hampered by many systemic problems, which have proven resistant to change. There is no doubt that the challenges faced by Greece in building a world-class organ donation and transplantation programme are substantial. The economic crisis in Greece has certainly contributed to the recent decline in transplantation rates, which reached a low of 3.5 per million people (pmp) in 2015. However, other countries, such as Portugal, which were likewise severely impacted by the economic crisis of the late 2000s and early 2010s, have nonetheless been able to sustain significant performance improvements in their organ donation and transplantation systems. A comprehensive service capable of meeting the needs of the population is possible within existing economic limitations, if underlying factors of poor performance are identified and tackled in a national reform effort with consistent support and collaborative engagement from all stakeholders.

In recognition of this, the Onassis Foundation contacted LSE Health in October 2019 to undertake a review of the system and make recommendations for its reform. LSE established a research team led by Professor Elias Mossialos and Professor Vassilios Papalois (Imperial College, London) to undertake this work, advised by a panel of eminent international and Greek experts in organ donation and transplantation. The resultant report is the product of many months of careful research and multiple interviews with experts and stakeholders which, due to the constraints of the COVID-19 pandemic, were mainly conducted remotely. The key output is a set of recommendations for changes required to improve the Greek organ donation and transplantation system, supported by evidence, which are summarised in this document and presented in full in the main report.

Methodology and structure of the report

Framework for best practice

Based on the findings of a literature review, the report presents a framework, with a detailed accompanying narrative, which encapsulates best practice in the design, operation and management of a national organ donation and transplantation system. The framework is comprehensive, providing a breakdown of the elements of a successful national programme against which the Greek system can be assessed.

Lessons from international experience

In order to derive further lessons on best practice in national organ donation and transplantation systems, the report presents a summary of five case studies of successful systems in Croatia, Italy, Portugal, Spain and the United Kingdom. The countries were selected because of distinctive features of their transplantation systems and wider health systems, which are likely to yield valuable insights for Greece. The case studies provide detailed information on the organisation and performance of the health systems in those countries, and highlight specific organisational principles, policies and initiatives from which Greece can learn.

Analysis of the greek organ donation and transplantation system

Guided by the framework, the report includes a detailed review of literature on the organ donation and transplantation system in Greece, including both Greek and English language sources, to capture relevant details relating to each of the domains of the framework. The review team undertook a series of semi-structured interviews with key stakeholders in the Greek transplantation system. These enabled a detailed situational analysis of the system, and provided the basis for the generation of recommendations.

Recommendations for reform

The recommendations are comprehensive and take a whole-system approach. Each overarching recommendation is accompanied by a number of sub-recommendations, specification of the main responsible bodies and a brief text which explains the underlying reasoning. The recommendations were carefully constructed through a gap analysis of the current Greek situation set against the conceptual framework and the key lessons of the five successful countries from the case studies. An iterative approach was taken by which feedback was gathered in a series of interviews from the panel of international and Greek experts and incorporated into the final version. Due to the complex nature of organ donation and transplantation and the high degree of professional and organisational cooperation which is required for a successful programme, the recommendations cover many diverse aspects of health care delivery such as public health programmes, professional training, health information technology systems, and funding and reimbursement mechanisms.

The need to improve the organ donation and transplantation services in Greece, through the story of Katerina Katsori, a liver and kidney transplant recipient.

My name is Katerina, four and a half years ago I received a liver transplant and two and half years ago I also received a kidney transplant.

At just 13 years of age, I was admitted to hospital with kidney stones. I was subsequently diagnosed with a serious and aggressive disease which had started in my liver and then caused severe damage to my kidneys. My family and I were told that the only effective treatment for my condition would be a liver transplant followed by a kidney transplant. Without these transplants my illness would inevitably progress and be fatal.

For a number of years, medication kept my problem stable. I had a normal childhood, I went to school, learnt foreign languages, socialised with my friends and even managed to go to my university of choice. However, by the time I was 20 years old my kidneys were failing, and I had to start dialysis. My whole life came to a standstill. Due to the severity of my illness, I had to undergo dialysis five days a week, for five hours on each occasion. This is more than most dialysis patients, but it was necessary to keep me alive. Due to the time that I had to spend on dialysis it was impossible to attend university, and I was so weak and tired that I seldom saw my friends.
The strain caused by my illness and the dialysis sessions changed the atmosphere in our home. My parents and siblings were profoundly affected; I was constantly tired and crying about how bad I felt. I felt anxious all the time about the toxins building up in my body, and my family had to put up with constant changes in my mood. Despite my desperate state, my parents were a source of constant support. I feel very lucky and proud to have such a wonderful family, they gave me great strength and courage, and never treated me like a sick person. Without them I would have struggled to stay positive. In this difficult journey I also met many wonderful people who helped me with my health problems, and they also have a very special place in my heart.

I am also extremely fortunate that from the outset my parents were willing to become my organ donors. If they had not offered to donate their organs, I would have had to go on the waiting list for the two transplants I needed. I might have died waiting for a suitable donor. As my liver was failing it was especially urgent to find a donor, as there is no alternative to transplant in liver failure. Although it is very detrimental to quality of life, dialysis does at least offer an alternative for kidney failure and buys time until a donor is found.
In June 2016 my mother donated a lobe of her liver to me, and the liver transplant was performed. The liver had to be transplanted first, as the disease which had caused my illness originated in my liver, and there would have been no point in performing the kidney transplant before replacing my liver; the transplanted kidney would have become damaged again. Although the operation was not easy, and I took several months to recover, I felt much better than before the surgery. Although I remained on dialysis, I had more colour in my face and some of my strength returned.

After a further two years, in June 2018, my father donated a kidney to me and I underwent a kidney transplant. This was also a difficult operation, but I recovered more easily this time. From the moment that my recovery was complete, and I no longer needed dialysis, I became stronger day by day. I realised that my troubles were over, and that a new life was starting for me.

My life, and my family's life is now back to normal. My parents both recovered very well from the donation operations, and lead full lives. They are full of joy to see their children in good health and pursuing their dreams. I am now strong and resilient. I exercise regularly and can walk for hours without having to sit down every ten minutes. I have started my studies again, and hope to finish soon. I have travelled abroad and visited countries I always wanted to see. Prior to my transplants I couldn't travel unless I could find a dialysis unit. Now I can follow my dreams and make plans without restrictions. This was impossible before, I had to constantly think about my health problems and plan everything around them. I am now the master of my life, and no longer limited by the difficulties with my health. I am recovered, I can finish my studies, move abroad, and maybe even fulfil my ambition to travel the world.

Finally, I would like to highlight the importance of transplantation. Transplantation is the gift of life; it is a second chance to live life and realise dreams. Organ donation is the only way in which this can be achieved.

My name is Katerina, and I am the recipient of two organ transplants. Thanks to these transplants, and my donor parents, I am able to follow my dreams again.

Credit Nikos Kokkas

Onassis National Transplant Center:

Building the “home” of solid organ transplantation.

A longtime vision of the Management of the Onassis Foundation is coming to life through the Onassis National Transplant Center (ONTC): to offer Greek society an organ transplantation hospital that will also serve as a transplantation research and innovation center.

The ONTC is expected to act as a catalyst in developing the country’s transplantation activities, offering support to existing units by creating a nationwide transplant network.

Under the State’s coordination and supervision, through the NTO, it will conclude partnerships with physicians abroad, who will operate in the ONTC.

The state-of-the-art construction project, with a total budget of € 100,000,000, will boast cutting-edge technology worth € 30,000.000.

The independent paediatric transplantation clinic, the Onassis Children Hospital, will provide specialised high-level pediatric cardiology and surgery services, reducing the need to go abroad for transplants.

With state-of-the-art infrastructure, cutting-edge technology, specialised staff and in cooperation with other transplant centers, it will create an integrated framework for each and every patient, even those with no health insurance.

A hospital for all.

Its main principles:

- Respect and care for patients and their families
- Quality and innovation in healthcare
- Health for all
- Care even for non-insured patients
- Accountability and integrity in the performance of medical duties
- Cooperation towards achieving a joint vision

The premises:

7.000 sq. m.

4 floors

48 new beds

12 ICU beds for children, of which

5 exclusively for infants.

National Plan for Solid Organ Donation and Transplantation

A detailed overview of the recommendations for the fundamental change and development of the Greek national program.

Government: Political Support and long-term commitment

Recommendation:

To achieve a comprehensive, high-quality and safe national programme, long-term governmental commitment and support is necessary.

Sub-Recommendations:

- The planning, coordination and implementation of the national donation and transplantation programme should be the responsibility of an independent national donation and transplantation organisation (NTO) which answers directly to Parliament (see recommendation: NTO).
- The government should make available targeted and sustainable funding to enable the planning and delivery of the national donation and transplantation programme.

Responsible bodies:

- **The Ministry of Health • The NTO**

Rationale:

Achieving a successful and high-quality system for organ donation and transplantation is a challenging but worthwhile endeavour that saves individual lives and saves the health system precious funds. Substantial improvement in donation rates in a reasonable time frame is possible, but only when the government wholeheartedly supports reform. The realisation of the Onassis National Transplant Center provides a window of opportunity for the government to renew commitment to provide life-saving organ transplant solutions. Other countries in Europe have undertaken and succeeded in national transplantation reforms, some under even less favourable economic conditions than those faced by Greece. Italy, Portugal, Spain and the UK all delegate national transplant reform to an independent authority (the National Transplantation Organisation – NTO) which answers directly to its respective parliament and works in collaboration with its ministry of health. These countries have shown that the long-term success of a national transplant programme will require longitudinal governmental support and targeted, sustainable funding mechanisms. When governmental support wanes, as was the case in Portugal following the 2008 recession, the productivity of the transplantation system declines. In order for Greece to develop and sustain a world-class organ transplantation programme there must be adequate resources available, excellent governance structures in place, and the NTO must have the authority to enact reform. These goals are achievable only with continuous political and financial commitment.

Diagnosis of brain death (DBD)

Recommendation:

A culture must be fostered where brain death is routinely diagnosed according to international guidelines.

Sub-Recommendations:

- There should be strengthening of training programmes for intensive care unit (ICU) physicians, neurologists, neurosurgeons and anaesthetists in the diagnosis of brain death in collaboration with scientific societies. These could follow international examples of simulation-based training.
- Organ donor coordinators (ODCs)[1] should be responsible for monitoring and facilitating the diagnosis of brain death in patients with catastrophic and irreversible brain damage.
- Legislation on the definition and diagnosis of brain death should be distinct from legislation on transplantation.
- ODCs should educate local staff regarding the national legislation and international best practice in the diagnosis of brain death.
  - Brain death diagnosis should be based on clinical criteria and performed by two experienced physicians trained in conducting a neurological examination in the context of brain stem death and who are independent from the organ donation process.
  - Ancillary testing, such as brain blood flow imaging, should only be conducted under certain circumstances (for example, where comprehensive neurological examination is not possible).
- Medical training and public educational campaigns should include the concept of brain death.

Responsible bodies:

- **The Ministry of Health • The NTO, in an advisory capacity • The Ministry of Education**

Rationale:

Identification of all possible organ donors with a devastating and irreversible cerebral injury in the ICU is critical to achieving a good donation rate, and the diagnosis of brain death is a critical step in this process. There is a need for clear, comprehensive, and transparent national legislation, guidance and protocols regarding the diagnosis of death by neurological criteria which must be drawn up in accordance with internationally accepted best practice. Key criteria for diagnosing neurological death are an established aetiology resulting in irreversible loss of consciousness and breathing, exclusion of reversible conditions and a clinical examination demonstrating profound coma, apnoea and absence of brain stem reflexes. Without specific training and support, clinicians may lack confidence in the diagnosis of brain death, and in conveying this information to families and loved ones. International examples show that training, in particular simulation training, can greatly help improve clinical knowledge and skills (including communication skills) in this challenging and emotive area of medical practice. There are a range of ancillary tests available which can be used to confirm the clinical diagnosis of brain death. In broad terms these tests examine blood flow and electrical activity in the brain. However, as these tests are time-consuming, not always available locally, and may cause false hope or distress to families, they should only be used under specific circumstances – for example, when a full clinical examination is not possible. These circumstances should be clearly laid out in national guidelines in accordance with international best practice. In Greece, national legislation includes a definition of brain death and there is an official diagnosis proforma. This definition is currently a part of the legislation on transplantation, which may create the false impression that diagnosis of brain death is performed primarily to facilitate transplantation. There remains ambiguity in practice, and there is a lack of clarity as to when to initiate and apply the process of diagnosing death by neurological criteria. The role of ancillary testing is poorly defined, and this contributes to the lack of confidence of clinicians in relying on their expertise and clinical judgement. The resultant hesitancy in performing and interpreting the necessary assessments impedes the prompt diagnosis of brain death, and the ability to convey information to families and loved ones in a timely and appropriate fashion.

[1]ODC = Organ Donation Coordinator, Συντονιστές Δωρεάς Οργάνων

Reducing the need for transplantation: Primary and secondary prevention

Recommendation:

Expansion of comprehensive primary and secondary prevention strategies targeting the general population and high-risk individuals.

Sub-Recommendations:

- Primary and secondary prevention programmes must target the most important modifiable risk factors linked to end-stage kidney and liver disease. These include obesity, diabetes, hypertension, alcohol consumption and smoking.
- The type and content of prevention activities should be the responsibility of a special committee under the Ministry of Health and regional health authorities.
- The implementation of primary and secondary prevention strategies should be considered the remit of public health and primary care, taking into account recommendations made by the NTO.
- There should be national consensus on, and adoption of, a single national guideline for the modification of risk factors of end-stage renal disease (ESRD)[2] and end-stage liver disease (ESLD)[3].
- There must be national consensus on, and adoption of, a single national guideline on the screening and early diagnosis of kidney and liver disease.
- Guidelines and prevention programmes should be created in collaboration with the relevant specialist scientific societies as well as general practitioners.
- Prevention programmes should be linked to key performance indicators (see recommendation: Quality Standards and Quality Improvement).

Responsible bodies:

- **The Ministry of Health • The regional health authorities**

Rationale:

IAs it seems unlikely that the supply of organs is ever going to be sufficient to meet need, no organ donation and transplantation policy would be complete without including national strategies which attempt to reduce the incidence of chronic diseases leading to organ failure and the need for transplantation. Across Europe, 70–80% of the health care budget is spent treating these chronic diseases. Targeting the most important modifiable risk factors of obesity, diabetes, hypertension, alcohol consumption and smoking will lower levels of preventable chronic disease, decrease premature deaths and decrease disability in the population. In Greece, reducing ESRD and ESLD can be achieved by preventing the development of risk factors for these conditions (primary prevention). Reductions in dietary salt intake can decrease the incidence of hypertension. Achieving a 10% decrease in blood pressure in a hypertensive population has been shown to lead to a decrease of 0.7 to 5.8 CKD events per 100,000 person-years. Likewise, lifestyle modifications can reduce the incidence of diabetes and obesity, and so decrease the incidence of ESRD and ESLD. International best practice guidelines suggest that primary prevention programmes should promote healthy diets (lower consumption of salt, fat and sugar), increased physical activity and the cessation of excessive alcohol consumption and smoking. They should also focus on reducing risk factors for hepatitis (intra-venous drug use harm reduction, high-risk sexual behaviours, immunisation where possible) and improving health literacy. Secondary prevention strategies should focus on screening and detection of high-risk populations, routine monitoring, and prevention of early disease progression using pharmacological and non-pharmacological means. For those individuals at high risk for kidney disease, regular screening for markers of kidney damage is recommended. Certain populations (e.g. people with diabetes) also benefit from initiation of targeted therapies to prevent kidney disease. For liver disease detection, people with a significant alcohol history, history of intravenous drug use, metabolic syndrome, hepatitis or genetic liver disease should be screened at routine health visits.

[2]ESRD = End-Stage Renal Disease
[3]ESLD = End-Stage Liver Disease

Reducing the need for transplantation: Tertiary prevention

Recommendation:

A mandatory system should be established whereby those presenting with end-stage organ failure are referred for specialist supportive management and for consideration of suitability for transplant.

Sub-Recommendations:

- NTO must develop a compulsory and standardised procedure for the timely referral for specialised management and transplant eligibility evaluation for patients who meet the national diagnostic criteria for end-stage renal, liver, heart and pulmonary disease.
- Implementation of, and adherence to, this system of mandatory referral should be monitored by the NTO using key performance indicators.
- The development of these guidelines and referral processes should be undertaken in collaboration with the appropriate scientific societies. These include nephrology units, the Greek Society of Nephrology and the Greek Association for the Study of the Liver.
- Transplant centers should make preparations for an anticipated increase in demand for services.

Responsible bodies:

- **The Ministry of Health • The NTO • Relevant scientific societies**

Rationale:

Patients' survival and quality of life can improve through investments in healthcare for patients with existing renal, liver, heart or pulmonary disease. These tertiary prevention strategies include surveillance of disease progression, medical management of the complications of disease and referral to appropriate specialists to prepare for definitive management (i.e. transplantation). All successful European donation and transplantation programmes have a standardised, transparent and well-respected referral process for evaluation of candidacy for solid organ transplantation. Recommended guidelines and referral standards that are adaptable to the Greek context include: ERA-EDTA[4] Clinical Practice Guidelines, KDIGO[5] guidelines, NKF KDOQI[6] guidelines, and EASL[7] guidelines. Referrals for assessment of transplant candidacy are a gap in the current system despite renal transplantation being the international gold standard treatment for end-stage renal disease. Development and implementation of a referral process for transplant candidacy is one part of a comprehensive national transplant programme, and must be established with the development of waiting lists and registries to be successful.

[4]ERA-EDTA = European Renal Association – European Dialysis and Transplant Association,
[5]KDIGO = Kidney Disease: Improving Global Outcomes
[6]NKF KDOQI = National Kidney Foundation - Kidney Disease Outcomes Quality Initiative
[7]EASL = European Association for the Study of the Liver

Public Support: Addressing issues of trust

Recommendation:

The NTO must combat misinformation and misconceptions about organ donation and transplantation and foster a culture of altruism and social solidarity.

Sub-Recommendations:

- Correcting existing misconceptions should be a core element in all public relations activities and part of a comprehensive and continuous public relations strategy. This includes communications with the media, public awareness campaigns, educational campaigns, and training programmes.
- Strict adherence to fair, equitable and transparent processes and the establishment of good governance structures will build confidence in donation and transplantation standards and ethics.
- Confidence and trust established at the bedside and during the process of organ donation by the medical team and medical community is crucial, and aid in the transparency of end-of-life decision making.
- Periodic surveys monitoring attitudes and perspectives towards organ donation and transplantation will assist in monitoring and addressing issues of public trust.
- Establishment of partnerships and alliances with reputable organisations may aid the NTO with its communication strategies.

Responsible bodies:

- **The NTO • Transplant centers • Relevant scientific societies**

Rationale:

The Eurobarometer[1] on Organ Donation and Transplantation shows that Greece consistently stands out as having low support levels for organ donation. In comparison to 55% and 53% of Europeans, only 43% and 41% of Greeks would say yes to personal and family organ donation, respectively. Among all European countries Greece had the highest proportion (45%) of respondents who were not willing to donate organs and citing distrust in the system as the primary reason. Fear of manipulation of the human body and religion were two other reasons for refusal, also higher in proportion than the European average. As a result, over 70% of the Greek population have never had a discussion about organ donation. Without public trust, it is unlikely that any national transplant programme will succeed. Instilling trust requires strict adherence to fair, equitable and transparent organ transplant processes and governance. Over time, faithfulness to the highest ethical standards may result in cultural change where organ donation is seen as part of an altruistic society, and this will be reflected in an expanded pool of available donors and resources. Prior to national transplant reform in the 1990s, Italy had similar levels of mistrust in transplantation. Within two decades, Italy has managed to become a global leader in transplantation and is now said to possess a national consciousness in solidarity for organ donation, reflected in public attitudes and donation rates. Universally, organ donation is a sensitive issue as it is often at odds with human expectations of death, religious teachings and culturally accepted rituals around death and dying. These issues must be addressed with sensitivity in Greece, allowing for gradual reversal of misconceptions held by the population. Public trust will evolve with time and demonstration of a fair and equitable transplantation system in conjunction with providing education on the safety of altruistic donation. This is a highly complex and multifactorial issue and therefore benefits from a multi-faceted approach. It may be useful to periodically monitor public attitudes and perceptions as surrogate markers of public trust.

1. Directorate General Health and Consumers. Eurobarometer 72.3: Organ donation and transplantation. European Commission; 2010. [Internet] [cited 2020 Nov]. available from: https://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_333a_en.pdf

Public Support:
Building relations with the media

Recommendation:

The NTO should establish a dedicated NTO Media Office, hold regular conferences and provide regular progress updates to the press and media.

Sub-Recommendations:

- The media office of the NTO should establish a 24/7 hotline, whereby the press and media can obtain reliable, accurate and timely donation and transplantation information.
- Organ transplantation is the gold standard treatment in ESRD, and the only curative treatment available for ESLD. The NTO should aim to present this information in a transparent, ethical and favourable manner.
- The media office of the NTO, guided by experienced media professionals, should ensure that the press and media are made aware of all donation and transplantation conferences and any other events of national importance. Sufficient content must be made available to ensure transparency and encourage constant press and media support for the national organ donation and transplantation programme.
- The NTO must work in collaboration with the press and media to build public trust in organ donation and transplantation, and disseminate information to dispel misconceptions and foster cultural change.
- It may be helpful to assemble a repository of visual arts, literature, music and cinema favourable to organ donation and transplantation which can be used appropriately in public relations activities.

Responsible body:

- **The NTO**

Rationale:

The portrayal of transplantation in the media has a powerful influence in shaping public attitudes and perceptions. Positive media coverage can be harnessed to address issues of mistrust, show fairness in the transplant process and highlight the lives saved through transplant activities. Consistent positive media coverage is equally or more important than public campaigns to improve knowledge and awareness, and increase population donation rates. Portugal and Spain provide good examples of developing these links with the media. Both countries schedule regular meetings to share transplantation information, provide regular updates, and invite journalists to select educational and training events/conferences. Spain's NTO has a branch directly responsible for media relationships, which is available by telephone 24/7. Establishing good relations with journalists is crucial for public trust, and they can also be allies when there are errors in the transplant system that require clear and concise disclosure. The media remain one of the most important channels for spreading information in Greece. For organ donation, the media were the number one source of information used by adults to form their attitudes and behaviour towards organ donation according to a 2012 survey in Thessaloniki. Interviews identified a willingness on the part of the Greek media to disseminate information on organ donation and transplantation. However, better communication, professional materials and more frequent updates were requested from the NTO.

Public Support: Building awareness

Recommendation:

Investing in public education and national campaigns is necessary to raise public awareness of organ donation and transplantation, dispel misconceptions and stimulate collective reflection on end-of-life discussions

Sub-Recommendations:

- Public information and education campaigns should be undertaken in partnership with relevant organisations and aimed at a wide audience. The NTO should establish a dedicated Public Information and Education Office to oversee these efforts.
- Educational campaigns should be tailored to address the entirety of the population with special attention to age-appropriate messaging. These campaigns should be devised to target populations across age groups, including programmes for school-aged children, young adults and older adults.
- National campaigns should highlight successful stories that resonate with all age groups. Personal stories from the unique perspective of the transplant recipient, particularly paediatric stories, have been shown to be effective in presenting the benefits of organ donation and transplantation.
- Further, tailored educational campaigns for select groups should be considered, such as religious congregations and the armed forces, for whom targeted messages would be appropriate. These campaigns should be undertaken in partnership with community members, governmental organisations and the press and media.

Responsible bodies:

- **The Ministry of Health • The NTO • The Ministry of Education • Transplant centers • Scientific societies**

Rationale:

Public awareness campaigns are investments to achieve sustainable supplies of organs for transplant over the long term. There is often a natural reluctance to discuss death and end-of-life wishes, and national programmes play a key role in reaching a wide audience and dispelling commonly held myths and misconceptions. Awareness campaigns are associated with an overall 5% improvement in health outcomes, especially registry signing. However, the positive influences are only sustained when awareness campaigns are repeated or longitudinal. Such initiatives need to be thoughtfully planned and executed, and be respectful of local cultural norms and practices if unintended adverse consequences are to be avoided. Carefully constructed publicity and media programmes are thought to have a modest impact in increasing the number of people on registry lists and in the donation rate. Furthermore, culturally tailored and issue-targeted strategies undertaken in collaboration with community partners are more likely to lead to successful organ donor campaigns.
In some jurisdictions personal stories can be a very helpful strategy to increase support and drive change. Personal accounts are a potent mix of tragedy and joy, and tend to capture the hearts and minds of the population. Examples include ‘Effetto Nicholas’ (Italy) or ‘Max and Keira’s law’ (UK). Recipient stories are typically more effective than donor stories. Italy, Spain and Portugal run educational programmes in partnership with education ministries targeted at primary and secondary schools. Educational programmes directed at younger people play a role in stimulating family debate and reflections about end-of-life wishes and contribute to a culture of solidarity. Other transplant programmes organise educational activities in the community, in partnership with advocacy or religious organisations.

National Transplant Organisation (NTO)

Recommendation:

The NTO should be empowered to lead the national donation and transplantation programme, with independent authority to enact change, requiring changes to legislation, governance, organisation and funding, and its national and international responsibilities.

Sub-Recommendations:

- The government should introduce legislation to re-launch the NTO as an independent authority answering directly to parliament, with a relationship of close cooperation with the Ministry of Health.
- Reforms to the NTO should include:
  - Appointment of a board of directors by parliament to oversee the NTO and its strategy.
  - The creation of advisory committees to provide scientific, ethical and clinical advice.
  - Sustainable, long-term funding must be identified which is commensurate with the duties and expectations of the new, expanded NTO.
  - Appointment of a Chief Executive Officer and Chief Medical Officer via a transparent and open selection process.
  - In addition to the central (Athens) office, establishment of four regional offices with deputy lead roles.
  - A significant increase of staffing in line with the mission and functions of the NTO.
  - A central team must be available 24/7 to support all activities related to donation and transplantation.
  - The creation of advisory committees to provide scientific, ethical and clinical advice.
  - The establishment of a separate quality, safety and regulatory division.
  - The NTO to have a longer-term goal to join a European network of transplant organisations.

Responsible bodies:

- **The Ministry of Health • Parliament • The NTO**

Rationale:

Current international guidance and experience from top-performing countries on national strategy recommend that an adequately funded and resourced National Transplant Organisation (NTO) should be established, with overarching responsibility for the entire process from donor selection to long-term follow-up. In countries with a system of regional government, the NTO often has regional branches to coordinate the organ retrieval and transplant processes (e.g. Spain). In other countries, a smaller population leads to a strong central organisation of the transplant organisation (e.g. Croatia). In Greece, consistent commentary from stakeholders revealed that a comprehensive NTO currently exists only on paper. In practice, the NTO is severely short staffed, under-resourced and lacks multi-representation. There is little trust in the NTO as the authority for organ donation and transplantation, and little faith in the process of transplantation overall. The NTO in its present form lacks the power to coordinate activities, to implement and enforce legislation and regulations, and to control quality standards. The NTO suffers as its decisions do not have immediate effect, and must first be approved by Parliament or the other relevant health committees/councils. For these reasons, it has had little success in enacting changes to the programme or realising improvements to the national donation/transplantation infrastructure. Resolving these difficulties is a crucial area for reform. An NTO's membership of an established international network of transplant organisations provides numerous benefits for a country developing its own transplant programme. There is a direct benefit for patients with end-stage organ failure by expanding the donor pool. Collaboration and an international waiting list are especially important for high-urgency or specialised populations for whom it takes considerable time to develop a suitable programme for transplantation. International collaborations also provide access to knowledge and information sharing between specialists and transplant organisations. This will help the national organ donation and transplantation programme remain up to date and in accordance with world standards. Finally, there are resources and monetary grants afforded to members of these organisations, whether for further development of the transplantation programme or to enhance research endeavours.

Infrastructure

Recommendation:

To achieve sustainable improvements in donation and transplantation activity, all the national transplant centers should be supported to meet the current European standards in terms of infrastructure and resources

Sub-Recommendations:

- Transplant theatre capacity should be doubled in order to reach the European average. This should include both elective and emergency theatre lists.
- Centers involved in organ donation must ensure that there is adequate theatre capacity to facilitate organ retrieval, and that this is given appropriate prioritisation.
- Rapid 24/7 access to computed tomography, ultrasound scanning, interventional radiology and endoscopy services should be established in all centers. There must be trained staff and equipment available at all times.
- Local arrangements must be in place for the regular maintenance of the above equipment and policies must be established for addressing equipment failures in a rapid and effective manner.
- ICU capacity must be sufficient to facilitate donation processes, and ICU staff must have access to the necessary equipment for donor maintenance.
- Laboratory capacity (general pathology, histocompatibility, immuno-genetics capacity) must be adequate and have rapid response times in order to support donation and transplantation processes.
- There must be sufficient space and equipment to conduct assessment and follow-up clinics, and to accommodate administrative support.
- All staff must have access to adequate IT and communications equipment.

Responsible bodies:

- **Donation and transplant centers • The NTO**

Rationale:

The Infrastructure supporting the donation and transplantation programme must be fit for purpose and regularly updated. Existing infrastructure varies significantly across Europe, and quantitative and qualitative data on the basic infrastructure requirements necessary for the donation and transplantation processes are lacking at an international level. In making decisions regarding infrastructure requirements, the current and the projected future demands should be taken into consideration. The geographical distribution of the organisations needs to be considered, particularly with regard to the time-limited nature of many processes and the travel times required for the transportation of organs and/or patients. Infrastructure considerations must take into account not only clinical processes, but also supporting functions such as administrative support, IT and communications (for IT infrastructure see recommendation: Databases and Information Technology). This recommendation is informed by two surveys of national and European transplant centers which were undertaken in order to conduct the gap analysis of the existing Greek organ donation and transplantation programme. In Greece, the national donation and transplantation centers' available resources are not systematically registered. However, the survey and the national situational analysis revealed an urgent need to expand operating theatre capacity (both for donation and transplantation procedures) and improve access to imaging and other diagnostic services such as endoscopy. Although ICU capacity in the transplant centers themselves is comparable to that in other European transplant centers, it is low overall, and there is a need to address this. It was also demonstrated that there is a need to improve access to pathology services and to histocompatibility testing, which at the moment often requires an off-site transfer. In view of the predicted increased demand, it will also be necessary to ensure that there is adequate clinical space and equipment available to conduct transplant assessments and follow-up. It must not be forgotten that clinical staff will need the support of an administrative team who will require office space and equipment to perform their tasks including up-to-date IT and communications technology. The expanded NTO will also need accommodation and equipment.

The Onassis National Transplant Center (ONTRC)

Recommendation:

The ONTRC should act as a part of a national network of excellence, with all transplant centers working in close collaboration, providing leadership and support to other centers. This is particularly the case in Athens, where the three centers are in close geographical proximity. The centers of Ioannina and Patras already work in alliance.

Sub-Recommendations:

- Working in partnership with the NTO, the ONTRC should help to facilitate the close collaboration of transplant centers and transformation of the wider system in the following areas:
  - Quality assurance of clinical outcomes
  - Pioneering innovative clinical pathways
  - Digitalisation of health care
  - Translational and clinical research in transplantation
  - Continuity of training in all transplant disciplines
  - Fostering international collaborations.
- The ONTRC should act as the national center for paediatric transplantation, ensuring ample infrastructure and health care staffing is available in a coherent unit.

Responsible bodies:

• The NTO • The ONTRC

Rationale:

The creation of the ONTRC will confer major benefits on the wider organ donation and transplantation system. Beyond extending the availability of infrastructure, service and training capacity for transplantation, the ONTRC should work in close collaboration with the NTO to foster greater connectivity and collaboration across the national organ donation and transplantation system. The benefits of close collaboration within clinical networks of transplant centers have been demonstrated by the success of the UK in maintaining transplantation services during COVID-19. The ONTRC can establish programmes in support of the enhancement of services across the nationwide network of centers involved in transplantation, pioneering innovative clinical pathways and supporting other centers to adopt them, providing support in the quality assurance of clinical outcomes, leading in the adoption of digital technologies, acting as a center for translational and clinical research, providing opportunities for training and continuous professional development, and fostering international collaborations in research, training and development. Strategic planning on how the future transplantation activity is going to be distributed among the national transplant centers is crucial in order to enable effective collaboration within the network. Reaching Portugal's transplantation performance would be a feasible mid-term objective for Greece.

Reimbursement

Recommendation:

All activities related to organ donation and transplantation must be adequately financially reimbursed; this includes payments to staff, participating units and supporting services.

Sub-Recommendations:

- A panel of experts should be convened to discuss and agree the exact details of appropriate reimbursement for all donation and transplantation activities.
- There must be a revision of the KEN-DRG hospital payment system to include reimbursement for donation activities. This must include all activities related to donor management including a per diem payment for the time spent on the ICU from the time of declaration as a donor.
- There must be a specific KEN-DRG for organ retrieval. As a minimum, this should be reimbursed at the rate of a major laparotomy and/or thoracotomy.
- All personnel must be adequately reimbursed for their activities related to donation and/or transplantation. This should include supplements to recompense them for the often-antisocial hours of work involved.
- There must be a review and reform of the current funding arrangements in place to reimburse transplant units and/or local providers for long-term follow-up care and treatment of any complications following discharge from hospital. This should include follow-up of live donors.
- There must be funding arrangements in place to reimburse all supporting services including laboratories, radiology services, transport and IT support.

Responsible bodies:

- **The Ministry of Health • Insurance funds**

Rationale:

Although organ transplantation is highly cost-effective in the long-run, the immediate costs and resource requirements are considerable. Without a sophisticated reimbursement system, there may be financial burdens which pose a barrier to the effective functioning of the organ donation and transplantation programme. Additionally, donation and transplantation activities often occur during, or extend into antisocial working hours in the middle of the night, at weekends and during national holidays. It is of great importance that all staff and facilities involved in the donation and transplantation programme are considered and adequately recompensed for their activities, taking into account the often-antisocial nature of the work. This must include all supporting services such as laboratories, radiology and transport. In countries with successful programmes, donation and transplantation do not incur any financial strain on institutions and that personnel are adequately paid for their efforts and rewarded for their willingness to regularly work during antisocial hours. Carefully designed incentives may be helpful, although they must be strictly monitored and honoured. In Spain, a system of variable reimbursement provides incentives for donation and transplantation activities and is thought to have helped to boost rates of activity. In Greece there are specified payments (via the KEN-DRG system) for transplantation, but not for activities related to donation, including maintenance of donors in ICU and organ retrieval. As a result, donation activities pose a considerable financial burden to participating hospitals. Donation coordinators receive no extra pay for their work related to donation, and there is no provision to recompense any staff members for the often-antisocial nature of their work, and the long hours which are frequently involved. There is a need to revise funding arrangements to ensure that all steps of the process are accounted for, from identification of potential donors to long-term follow-up. All supporting services must be taken into account when undertaking a review of funding, from laboratory support to the transportation of organs. As the Greek organ donation and transplantation programme evolves, cost-savings from reducing more expensive modalities of end-stage organ care should be re-invested in the programme, aiming for a self-sustaining system.

Donation:
Organ donor coordinators (ODCS)

Recommendation:

There is an urgent need to expand number of specially trained Organ Donor Coordinators (ODCs), and to train and appoint ODCs in every unit participating in organ donation.

Sub-Recommendations:

- Every hospital with an intensive care unit in Greece should appoint a minimum of two ODCs, with sufficient cover to guarantee round-the-clock coverage 365 days a year.
- Appropriately trained clinicians with additional training in the role of donation coordination should be recruited as ODCs.
- Physician ODCs should be supported by specialised nursing staff or nurses with appropriate training, and by ICU directors and hospital administrators.
- In larger centers the donation team should be available 24 hours a day, 365 days a year.
- ODCs should have a minimum of 10 hours per week dedicated to their responsibilities (including donation activities)
- ODCs should receive dedicated reimbursement for their role (including donation activities), taking into account the often-antisocial nature of their work.
- Basic training for ODCs should be provided by the NTO via an introductory module with further support from NTO as necessary.
- Introductory and advanced training should follow the curriculum of the European Union of Medical Specialists and the European Society of Organ Transplantation.
- ODCs should aim to achieve Certification of European Transplant Coordinator (CETC)[8].
- Adherence to the existing legal framework pertaining to ODCs must be monitored and enforced.

Responsible body:

- **The NTO**

Rationale:

ODCs are responsible for coordinating the process of organ donation at hospital level. It is essential that they have dedicated time to fulfil their role alongside competing clinical demands and that their pay reflects the arduous and often antisocial nature of their work. Their appointment should be subject to completion of basic training provided by the NTO and supported by their employer. They must be able to access and attend ongoing training updates and opportunities to achieve advanced qualifications (see recommendation: teaching, training and professional development). Communication skills must be a core component of their training. Experience shows that, if the above conditions are met, involvement of an ODC is one of the most important elements in the process of gaining consent for donation. Greece made an attempt to implement ODCs in 2003, and loosely defined their responsibilities in the PD 93/2002. However, in practice, implementation was not sustainable and the role of ODCs remained somewhat unclear. The lack of protected time, adequate reimbursement and dedicated training have been key barriers to recruiting and retaining sufficient numbers of ODCs. The pay of ODCs must be urgently reviewed, and funding streams identified to ensure that they are adequately reimbursed for the nature of their work. To ensure long-term commitment, reimbursement and minimum protected time dedicated to donation purposes should be defined in legislation. With the support of the NTO, all hospitals with a role in organ donation should initiate processes to train and deploy an appropriate number of ODCs, taking into consideration the size of their facility and levels of activity (in particular ICU capacity). Considering cultural factors in Greece and professional requirements, in the first instance it may be appropriate to recruit tenure-track physicians. These physicians should be supported by specialised nursing staff who must also be granted protected time, dedicated payment and tailored training for their role. It is unlikely that clinicians will dedicate their careers to the role of an ODC, and so it will be necessary to enable the role to be undertaken part-time with support of other professionals. The role of nurses should be progressively expanded, in order to move towards a primarily nurse-led model of donation coordination over time.

[8]CETC = Certificate of European Transplant Coordination,

Donation: processes involved in evaluation, retrieval and transport

Recommendation:

All steps of the donation process must be covered by nationally agreed protocols and guidelines in accordance with internationally recognised best practice. This includes the evaluation and management of donors, organ retrieval, organ preservation, packing and transportation.

Sub-Recommendations:

- Nationally approved guidelines for evaluation of potential donors in accordance with internationally recognised best-practice.
- Guidelines for 'expanded criteria donors' in accordance with international standards.
- Nationally approved guidelines for management of potential donors in accordance with internationally recognised best-practice.
- Every hospital involved in organ donation must ensure that staff trained in donor evaluation and maintenance are available 24/7, 365 days a year.
- Every region must be able to rapidly deploy an adequately staffed and specially trained organ retrieval team to donor hospitals 24/7, 365 days a year, supported and coordinated by the NTO.
- Staff involved in organ retrieval must be adequately reimbursed for this duty, and reimbursement should reflect the often-antisocial nature of the work.
- All hospitals involved in organ donation must ensure that there is adequate operating theatre time and equipment available for efficient and timely organ retrieval.
- The retrieval team must have rapid access to specialist advice and support including pathology, histopathology and microbiology.
- Nationally approved guidelines for the preservation, packing and labelling of retrieved organs, in accordance with internationally recognised best practice.
- The NTO should support the ODCs in arranging for organs to be transported to recipient hospitals safely and swiftly, meeting international standards.

Responsible bodies:

- **The NTO • Donation and transplantation centers**

Rationale:

Complex processes are involved following identification of a potential donor through to the transportation of organs to the recipient hospital. Nationally agreed criteria and protocols which cover donor evaluation and maintenance, organ retrieval, preservation, packing and transportation must be in place, and these should be in accordance with internationally approved best practice. Every hospital involved in organ donation must ensure that there is adequate infrastructure, equipment and appropriately trained staff available to cover all processes 24 hours a day, every day of the year. The NTO should be available at all times to provide support and advice. Spain has had notable success in the use of 'extended criteria' donors implementing programmes which age match older donors with older recipients. The UK has overcome difficulties in the coordination of organ retrieval procedures by instituting a National Organ Retrieval service, and Spain and Portugal regularly use their air force for the transportation of organs. In Greece, there is a need for harmonised national guidance and protocols to cover the steps of the donation process outlined above. There is an urgent need to ensure that the staff and facilities involved in donation are adequately reimbursed (see recommendation: Reimbursement), and that they have dedicated time for their duties and are in receipt of regular tailored training and appraisal (see recommendation: Teaching, training and professional development). Attention must also be paid to the interface with vital supporting services such as expert pathology or microbiology advice and specialist laboratory support.

Donation:
Living donation (ODCS)

Recommendation:

Living donation should become a cornerstone of the donation and transplantation programme, and pre-emptive renal transplantation from a living donor (LD) must become the treatment of choice for ESRD.

Sub-Recommendations:

- Appropriate legislation must safeguard against any form of coercion.
- There must be no perverse incentives to living donation. However, measures must be in place and enforced to remove any financial burden incurred as a direct result of donation.
- LDs should continue to receive prioritisation on the waiting list should they need a transplant in future.
- Education and publicity campaigns must be undertaken to raise awareness around the benefits of pre-emptive renal transplantation from a LD.
- The Greek Society of Transplantation will play an active role in promoting living donation, through their representation on the advisory committee of the NTO.
- All assessments for dialysis should include discussions around living donation, and explore whether there might be a potential willing donor in the patient's family or wider social circle.
- Partnerships and communication channels must be established between the donation and transplantation programme and physicians involved in referring patients for assessment.
- A LD registry must be created. This would facilitate the expansion of kidney exchange schemes and boost successful rates of transplantation.
- National organ-specific guidelines for the life-long follow-up of LDs must be devised. These should be drawn up in accordance with internationally recognised best practice.
- Outcome data must be collected and collated by the NTO for national monitoring purposes and for contribution to international research efforts.

Responsible bodies:

• The NTO • Transplant centers

Rationale:

While deceased donation remains the primary cornerstone of a transplantation programme, living donation plays a vital role in the development of a successful donation and transplantation system. In the case of renal failure, pre-emptive transplant (prior to the need for dialysis) from a living donor is the treatment of choice, and a wealth of international evidence is available which shows the excellent short- and long-term outcomes in LD, from both clinical and quality of life perspectives. Living donation has many advantages including reduced ischaemic time, better graft survival and a decreased incidence of delayed graft function. The patient is in better health when a transplant recipient and avoids the risks associated with dialysis. Additionally, in cases of fulminant liver failure, a living donation may be the only way in which to save the life of the patient, as death can occur within days, and there is little time available to wait for a good match from a deceased donor. In Greece in 2018 the rate of LD kidney transplantation was only 6.2 pmp. By comparison, in the same year, Turkey had one of the highest rates of LD kidney transplant in the world at 36.8 pmp. In Greece, poor levels of trust in the system and lack of awareness and education regarding LD are significant barriers. Unfounded fears concerning the possible risks prevent potential donors coming forward, and many patients are not even aware that this is a feasible treatment option. There is legislation regarding reimbursement of the expenses of LDs, but this is not enforced, and although LDs do have priority on the waiting list should they need a transplant in future, there are no other incentives in place. Patients are not automatically assessed for a transplant when referred for dialysis, and LD is not routinely discussed as an option. Nephrologists and other secondary and tertiary care physicians who might need to refer patients for a LD transplant are not actively involved in the donation and transplantation network. There is no LD registry or widespread participation in kidney exchange schemes. There is a lack of national harmonisation regarding the recording of outcome data.

[9]LD = Living Donor, Ζώντας Δότης

Transplantation

Recommendation:

There is a need to expand the existing workforce, infrastructure and IT capacity for transplantation, and ensure that all processes are subject to nationally agreed protocols, consistent with international best practice.

Sub-Recommendations:

- There should be nationally agreed organ-specific criteria and processes in place, in line with international best-practice, to enable the NTO to monitor adherence and hold units accountable for meeting standards in:
  - Inclusion of patients on the waiting list for transplant.
  - Criteria for re-transplant.
  - Transparency and communication of decisions regarding listing.
  - Inclusion of consent for transplant in the listing process, accounting for all eventualities.
  - Listing assessments to be performed by organ-specific multi-disciplinary teams (MDTs).
  - Processes for regular re-assessment of the fitness of those on the list for transplant.
  - Assessing patients for transplant listing when they are referred for kidney dialysis, and at agreed periods thereafter.
  - Physical and psychological support programmes for patients prior to surgery.
  - Organ allocation and prioritization.
  - 'Super-urgent' listing, which should only apply to liver, heart and lung transplants and when death is likely to occur in a short period of time should a transplant not be performed.
  - Perioperative and surgical care of transplant recipients.
  - Coordination of the process by specially trained Transplant Recipient Coordinators (TRCs) from the point of identification of a possible donor, with 24/7 NTO support.
  - Ensuring that those awaiting transplant can be alerted, transported safely and undergo any necessary perioperative checks or procedures at short notice.
  - Communication between the ODCs and the TRCs facilitated by the NTO.
- Continual availability of sufficient numbers of suitably trained staff to perform all steps necessary for the transplant operation and provide perioperative care.

Responsible bodies:

- **The NTO • Transplant centers (as part of advisory group) • Scientific societies (as part of advisory group)**

Rationale:

Achieving success at the transplantation end of the national programme involves a number of components. All successful systems have established and nationally harmonised protocols and pathways in place for transplantation, with clear designation of roles and responsibilities, and excellent lines of communication between professionals supported and facilitated by their NTO. Well-managed and regularly updated waiting lists and clear national guidelines regarding eligibility for inclusion on the waiting list and re-assessment at regular intervals to affirm fitness for transplant (or re-transplant) are essential. It is vital that dialysis patients are assessed for transplant at point of referral for dialysis, and that the option of living donation is considered. Waiting list assessment and management requires the employment of comprehensive organ-specific MDTs including psychosocial support, to ensure optimal medical and psychological fitness prior to the procedure. Ethical, fair and nationally agreed allocation and prioritisation rules which are in accordance with the guiding principles of the WHO, and the principles of equity, utility and benefit should be adhered to, and monitored by the NTO. As a minimum these include organ-matching criteria, time on the waiting list, the age of recipient (and donor) and distance. The NTO must have overall responsibility for the maintenance of the transplant waiting lists and should coordinate the allocation of organs to the most appropriate recipient. Excellent coordination of the components of the transplant process is vital. Due to organ viability these processes are time-limited and therefore need to be done swiftly and efficiently while maintaining the highest quality and safety standards. The role of the Transplant Recipient Coordinator (TRC) is crucial and there must be established and reliable means of communication between the TRCs and ODCs, facilitated by the NTO. Adequate workforce and infrastructure to deliver transplant surgery and perioperative care are needed. There must be sufficient numbers of transplant surgeons and staff to ensure availability 24 hours a day, every day of the year. This includes anaesthetists, nurses and other supporting staff. There must be rapid access to well-equipped operating theatres and ICU beds for post-operative recovery. There must be clear nationally approved organ-specific guidelines available covering the perioperative and surgical care of transplant recipients, and these should be drawn up in accordance with internationally recognised best practice.

Post-Transplant Follow-Up

Recommendation:

Transplant recipients should be offered life-long follow-up. The NTO, alongside a panel of experts with organ-specific expertise should draw up national guidance for the follow-up of transplant recipients in accordance with internationally accepted best practice.

Sub-Recommendations:

- Multidisciplinary organ-specific follow-up teams must be established in every transplant unit.
- Nationally agreed organ-specific protocols for the frequency of post-transplant reviews in uncomplicated patients should be agreed.
- Nationally agreed organ-specific protocols must be drawn up regarding all relevant issues including monitoring of post-transplant complications, immunosuppressive therapy optimisation, monitoring of complications of immunosuppressive therapy, prevention of recurrence of primary disease and treatment of comorbid conditions.
- Follow-up care should include access to psychosocial support and lifestyle advice with a focus on enabling patients to return to a normal family and everyday life.
- Protocols should be established for shared-care arrangements for those recipients who live far from the transplant center, and whose routine reviews could be conducted by a suitable identified local physician.
- The implementation of telemedicine technology and electronic health records would facilitate the follow-up of those patients who live in more remote locations.
- Nationally agreed outcome data should be recorded at every follow-up visit, periodically collated and sent to the NTO for the purpose of monitoring, quality improvement and research.

Responsible bodies:

• The NTO • Transplant centers • Scientific societies

Rationale:

National guidelines for the follow-up of transplant recipients should be drawn up in accordance with international best practice. A multidisciplinary, holistic and patient-centered approach is required in order to maximise long-term outcomes, minimise possible complications and optimise graft function and survival. The finer details will vary according to the organ transplanted, and there are a number of internationally recognised documents which give detailed guidance. These provide specific recommendations regarding renal), liver, and heart/heart-lung transplantation. It is crucial that transplant follow-up is conducted by comprehensive MDTs including psychosocial support. Follow-up should initially be provided by the transplant center, but in the longer-term, and if it is more convenient, can be delivered by approved providers in the patient's locality. In this eventuality support and advice should be provided by the transplant center when needed. The follow-up team must have sufficient clinical space to carry out their duties and rapid access to supporting services such as laboratories and radiology. Systems should be in place to swiftly address any concerns or complications. Observing the principles of patient-centeredcare (see recommendation: Patient-centered care) will aid in communication, enhance safety and improve overall outcomes. Internationally, countries with good outcomes in organ donation and transplantation offer comprehensive long-term follow-up, provided by multidisciplinary teams. In addition to surgical and medical follow-up, the care provided incorporates support with psychological and social issues and promotes a return to normal family and vocational life. Once the immediate post-surgical period has passed, and in cases where patients live too far from the transplant units to travel for regular checks, shared-care protocols have been adopted with local providers. Locally arranged follow-up under a shared-care protocol will also facilitate better overall engagement of local services with the donation and transplantation network. In Greece, there is no consensus on the follow-up of transplant recipients. Follow-up is currently planned according to the protocols of individual transplant units, with no national harmonisation. There is no established system of shared care with local providers in place, necessitating some patients to travel long distances for routine check-ups. Electronic health records and telemedicine, both of which would be helpful in this respect, have not been developed. There is no system for recording of outcome data which would help inform future quality or research initiatives.

Patient-Centered Care

Recommendation:

Patients, their families and loved ones, and live donors must be at the heart of the national donation and transplantation programme, with collaborative engagement with patients, families and carers in all aspects of system planning and development.

Sub-Recommendations:

- The principles of patient-centered care must become a core component of the curriculum for all donation and transplantation personnel from the outset of training, and reinforced in ongoing professional development.
- The donation and transplantation programme must be attentive to the needs of patients and their carers, and responsive to any issues which they see as important, including proposed benefits or assistance programmes.
- Patient and carer representatives should be involved in the planning of professional curricula to ensure that the focus of training accurately represents their needs.
- Personal electronic health records and telemedicine must be developed to promote the involvement of patients in their own care, and improve access for those who live in more remote locations.
- Service planning and development must be informed by regular surveys of patient and carer experience, devised with input from patient and carer organisations.
- Patient and carer representation should be established at all levels of the system, including the boards of individual hospitals and national and regional branches of the NTO.

Responsible bodies:

- **The NTO • Patient and carer organisations**

Rationale:

The success of a health care system is dependent on the benefits realised by patients and their families, and in order to maximise these benefits, they should be proactively involved in every aspect of health care. This involves building a collaborative culture not only around delivering individual clinical care, but also around the planning and delivery of services and the development of professional curricula. Changing from a paternalistic approach to one which is collaborative and holistic, and which encompasses the wider needs of the patient and their family requires a major culture-shift in the way in which health care is taught and delivered. However, it can bring many benefits to both patients and clinicians, enhancing relationships, improving services, and ultimately contributing to better outcomes for all. In addition to improving the experience of patients, their families and carers, this approach has been shown to improve overall outcomes, enhance quality and safety and build public trust and confidence in the system. It has also been demonstrated that staff working in patient-centered environments are happier and more productive. Various aspects of patient-centered care have been successfully implemented in many different jurisdictions and there are many good international examples of patient-centered care. For example, in the UK, patient-centered approaches are now an integral to the provision of clinical care, and to the training of all health care personnel. The UK NHS[10] also has well established mechanisms for involving patients and carers in the development and planning of services. Patient-reported outcome measures (PROMs)[11] and patient-reported experience measures (PREMs)[12] are regularly collected, the results disseminated and used to inform quality-improvement projects. Electronic health records have been developed in many jurisdictions (Estonia is a particularly good example, and telemedicine technology has been implemented for many years by NHS Scotland to facilitate access to health care for those living in remote regions. In early 2019 NHSBT[13] implemented a donor-reported outcome measure (DROM), a 20-point questionnaire survey to capture self-reported outcomes from living donors to complement the clinical information collected in the UK Living Donor Registry. Finally, and of key importance, patient-centered care has been shown to have a dramatic positive effect on donation rates, both living and deceased.

[10]NHS = National Health System, [11]PROM = Patient-Reported Outcome Measures
[12]PREM = Patient-Reported Experience Measures, [13]NHSBT = NHS Blood and Transplant,

Research and Development

Recommendation:

All units and staff involved in organ donation and transplantation must be actively supported and encouraged to participate in research activities at local, national or international levels.

Sub-Recommendations:

- A research advisory group should be established within the NTO.
- Research must become a core part of the professional development portfolio of all professionals involved in donation and transplantation.
- Sustainable funding streams must be identified for research activities, which might include partnerships with private collaborators or other innovative approaches.
- Grants and fellowships should be established for those training in the field.
- Clear processes must be in place at a national level for the ethical approval of all research activities.
- Mechanisms must be established to ensure that the results of research are published and disseminated nationally and internationally.
- Participation in international research projects should become an integral component of the organ donation and transplantation programme, and the NTO should support and encourage units to participate in such projects.

Responsible bodies:

• The NTO • All hospitals and centers participating in donation and transplantation

• Ministry of Development (National Research Council) • Scientific societies

Rationale:

Research is vital to the progress of organ donation and transplantation. The progress which has been made in this field of medicine over the past few decades has been dependent on the extraordinary and persistent research efforts of many individuals and organisations such as Thomas Starzl and Jean Dausset. Through their contributions to this field, and their collaboration and exchange of ideas, organ donation and transplantation have become the treatment of choice for end-stage organ failure. A diverse range of activities is involved in the construction, maintenance and continual improvement of a high-quality organ donation and transplantation system, and therefore research in this field encompasses a wide range of disciplines. These include the social and political sciences, basic medical sciences, translational research and clinical trials. Internationally, successful donation and transplantation systems have well-developed research programmes, operating at local, national and international levels. All the countries represented by our case studies actively promote and support research in all the aforementioned disciplines. Some NTOs have a dedicated research and development division, which works in close collaboration with the organ specific advisory groups. Additionally, there are clear, national arrangements in place for obtaining ethical approval. Funding streams for research are identified and innovative solutions for funding, including partnerships with the private sector, are pursued and realised. Grants and fellowships are awarded and participation in international schemes such as those provided by the European Society of Organ Transplantation (ESOT)[14] is encouraged. Additionally, these jurisdictions all have sophisticated systems for collecting and collating data on donation and transplantation which feeds into international research collaborations (see recommendation: Databases and IT). This enables participation in various studies of international importance, some of which are coordinated by organisations such as Eurotransplant. There are arrangements in place to ensure that the results of research are published, widely disseminated and used to inform future clinical practice, service planning and development. These mechanisms include local seminars and teaching
In contrast, in Greece, there is currently no high-level coordination or support of research activities in the field of organ donation and transplantation. Research efforts are hampered by insufficient organisational structure, inadequate IT systems and lack of funding. There is poor participation in the international collation of data or research efforts, and there is a need to improve the existing data collection systems in order to facilitate these activities.

[14]ESOT = European Society of Organ Transplantation

Quality standards and quality improvement

Recommendation:

The existing national system of quality assurance should be strengthened and expanded with regular performance audits based on comprehensive and up-to-date quality indicators.

Sub-Recommendations:

- The principle of using quality standards and performance indicators for evaluation is fundamental to a successful programme and should be enshrined in law.
- The NTO should establish a regulatory committee for quality improvement, consulting with advisory panels (see recommendation: NTO) to establish quality assurance standards.
- The committee should prioritise development of the existing auditing system, revise the list of currently collected indicators and ensure that it is regularly updated.
- Based on periodic inspections and performance measurements, NTO staff should audit local facilities and identify areas for improvement.
- The NTO authorities should provide feedback to local administration and offer support to units as required.
- The committee should set additional quality indicators to be collected in all pre-transplant care facilities.
- Donor coordinators should collect relevant data on organ donation in every hospital with an ICU unit.
- Pilot programmes for donation after circulatory death should report on the number of donations after circulatory death.
- Transplant centers should collect relevant quality indicators on transplantation and post-transplant follow-up.

Responsible bodies:

- **The NTO • Body of Inspectors for Health and Welfare Services (SEYYP)**
- **All centers participating in donation and transplantation • Scientific societies**

Rationale:

Measuring quality is at the heart of a successful organ donation system. Demonstrating high quality donation and transplantation processes will promote confidence in the transplant system. Quality assurance in donation achieves four objectives: (1) minimising risks to the donors and recipients, (2) guaranteeing the process is ethical, legal and medically safe, (3) ensuring good documentation and transparency, and (4) establishing a system of continuous improvement by increasing numbers of donors and improving quality and length of life for living donors and recipients. A commitment to excellence, to fulfil and exceed patient expectations and requirements, can succeed through the implementation of a quality assurance and management system. Systematic quality improvement and assurance should take a comprehensive approach and cover pre-transplant care, donation, transplantation, as well as follow-up. Indicators should be devised to provide information about the most critical components of the donation and transplantation process, and a standardised system established for documentation and regular collection of data. It is important that data is collected in the national organ and transplantation programme to be used in a constructive manner, to consider ways in which improvement may be achieved, and to celebrate excellence and examples of good practice and outstanding achievement. At present, only a limited number of quality indicators are collected in the field of organ donation and transplantation in Greece. The NTO attempts to pool national data but missing information and sporadic contributions are a problem. Important data points such as long-term graft survival and pre-transplant care information are either missing or not reported on a regular basis. The NTO does not currently have the capacity to inspect local centers, give feedback in the form of an audit or enforce much needed improvements. Thus, the NTO needs to develop a more comprehensive set of indicators and should be empowered to inspect and improve processes in local facilities. Finally, the NTO, through the regulatory committee, will ensure that quality is being upheld through a system of audits and inspections after hiring and training competent personnel equipped with authorisation and resources. The principles of this system of quality standards and improvement should be enshrined in legislation.

Databases and information technology

Recommendation:

The NTO should establish and maintain a national IT system and databases to facilitate communication and coordination, incorporating all information relevant to donation, organ matching and allocation, transplantation and long-term follow-up.

Sub-Recommendations:

- A Chief Digital and Information Officer should be appointed by the NTO, and an expert working group should be established to design, implement and maintain the new IT system and associated databases.
- Specific decisions regarding data recording should be informed by the data requirements of internationally respected organ exchange schemes.
- The databases will include pre-transplant data which is relevant to patients on organ-specific waiting lists and necessary for donor–recipient matching, and a living donor register, which could underpin a national kidney exchange network where recipients discover that their intended LD is not a good match.
- The database must be easily accessible for all personnel who need to access it, intuitive to use, real-time and easily updated. The IT systems of all participating units must be compatible.
- Data protection, patient confidentiality and information governance must be prioritised and compliant with General Data Protection Regulation (EU) 2016/679. There must be collaboration with individual hospitals or other units regarding any existing data they may hold, to ensure its preservation and security.
- Interconnectivity with international databases such as those of Eurotransplant and ESOT is recommended to facilitate exchange schemes and for research purposes.
- The NTO should evaluate the potential for the introduction of software into hospitals to support the early identification of potential donor patients in ICU at risk of brain death.

Responsible body:

- **The NTO**

Rationale:

Carefully designed, interoperable and easily accessible IT systems and databases are essential to the efficient and effective functioning of the entire system. In the context of organ donation and transplantation these systems have multiple functions, and the NTO must be responsible and accountable for their establishment and maintenance. Data recorded and held on the IT system must include the national donor and non-donor registries (see recommendation: Consent legislation), the national waiting lists and all information necessary for organ matching, prioritisation and allocation. All data related to donation (living and deceased) and transplantation activities must be recorded, including information on long-term outcomes. The database must also ensure traceability of individual organs, from the details of the retrieval procedure through to transplant at the recipient hospital. The IT system plays a vital role in organ matching and allocation, and in many jurisdictions advanced AI algorithms are used to aid swift and accurate matching and boost the rates of transplantation. In the case of living donation, it may facilitate the development of a LD exchange scheme, both nationally and internationally. In addition to facilitating clinical processes, IT systems and databases play a crucial role in the monitoring of quality, adherence to national standards, identifying areas in need of improvement and enhancing system vigilance and safety. They are also of vital importance in facilitating national and international research. If well designed, they can also help ODCs to collate regular reports and submit them when required to the NTO. In Greece, although donation and transplantation data is collected and collated by the NTO, there is no living donor register, and there is no national agreement on the exact details of the data to be collected. There is no comprehensive centralised IT system in place to facilitate the timely and efficient exchange of information between the component parts of the donation and transplantation system, or to record consistent data on outcomes. The current data collection falls short of the international standards which would be expected if Greece wishes to join an international collaboration such as Eurotransplant.

Teaching, training and professional development

Recommendation:

There is a need to develop a national strategy to continuously train health care professionals in all areas relevant for organ donation and transplantation.

Sub-Recommendations:

- Dedicated training modules should be developed and these should follow existing guidelines developed by the European Union of Medical Specialists (UEMS)[15].
- All professionals training in organ donation and transplantation should have a tailored CPD portfolio and a regular (at least annual) structured appraisal with an appropriate designated supervisor.
- The NTO should collaborate with medical schools to develop relevant training modules.
- Issues related to organ donation should be covered in all medical and nursing curricula.
- The NTO should design a mandatory introductory training module for ODCs:
  - This training module should be offered by the NTO on a regular basis.
  - The module should follow the training requirements set out by the European Organ Donation and Transplantation Coordination Organisation (EDTCO)[16].
- Following completion of the introductory training module there should be advanced training opportunities available to facilitate the achievement of the European Certification of Transplant Coordinators provided by the UEMS-ESOT.
- Existing short-term online courses on donor coordination and family consultation offered by the TPM-DTI[17] in Barcelona should be used to complement national training programmes.

Responsible bodies:

- **The NTO • The Ministry of Health • Scientific societies • Donation and transplantation centers • Medical and nursing schools**

Rationale:

Training of ODCs, especially in communication skills and sensitive family approaches, is essential to achieving improved rates of organ donation. International training institutions such as the TPM-DTI in Barcelona offer a variety of teaching activities from short-term online courses to master's degrees. Similarly, the European Society for Organ Transplantation (ESOT), in collaboration with the European Union of Medical Specialists (UEMS), offers a qualification for ODCs, the Certification of European Transplant Coordinators (CETC). Excellent training of donation and transplant professionals for their difficult tasks is essential. Dedicated training programmes for transplant surgeons, transplant physicians and immunologists are currently lacking. To date, individuals gain experience in transplantation during their core and higher overall specialty training (for example, general surgery) or during their independent practice (for example, by working in a European transplant center). Establishing a national fellowship with a structured training pathway would help to close this gap. ICU staff play a key role in achieving high rates of organ donation. At present, organ donation does not constitute a core training module for intensivists and their supporting staff. Consequently, these professionals lack confidence and feel uncertain about issues such as brain death criteria, consent legislation, and how to communicate these difficult matters to families and loved ones. Once properly trained and deployed, senior ODCs with a background in intensive care can commence local teaching initiatives to complement the regular training of ICU staff.

[15]UEMS = European Union of Medical Specialists, [16]EDTCO = European Organ Donation and Transplantation Coordination Organisation,
[17]TPM-DTI = Transplantation Procurement Management-Donation and Transplantation Institute, https://tpm-dti.com

Professional organisations and scientific societies

Recommendation:

Professional organisations and scientific societies must be consulted at all stages of the expansion of the donation and transplantation programme and should play a pivotal role in developing and ratifying guidelines, protocols, regulatory standards and training programmes.

Sub-Recommendations:

- The board of the NTO should include representatives of the relevant professional organisations and scientific societies.
- The development and implementation of the following items should be undertaken in consultation with the relevant professional organisations and scientific societies:
  - National policy regarding all aspects of organ donation and transplantation
  - National clinical guidance and protocols for all steps of the process
  - Professional portfolios and national standards for training
  - Regulatory standards for professionals and organisations
- The NTO should partner with the professional organisations and scientific societies to run educational meetings, conferences and other events which promote shared learning and a collegiate environment.
- Appointment of members to the specialist advisory groups of the NTO should be undertaken in consultation with the relevant professional organisations and scientific societies.

Responsible bodies:

• The NTO • Professional organisations and scientific societies

Rationale:

All fields of clinical practice are associated with a number of scientific societies and professional organisations. These bodies have many potentially important roles, and need to be recognised as an invaluable source of expert advice, opinion and support. They are also well placed to promote a collegiate environment, and can provide excellent opportunities for professionals from different disciplines and regions to meet regularly and exchange experience and ideas. There are a number of examples of collaboration with national and international bodies which have been central to the improvement of quality and training in the field of donation and transplantation. The Division of Transplantation of the UEMS works closely with ESOT to set standards of training and accreditation of professionals and transplant units, and run international education events. These excellent initiatives have been supported by more than 40 countries and their relevant scientific societies and medical associations. The Spanish TPM-DTI foundation runs numerous internationally acclaimed training and research projects, and facilitates communication and collaboration between a wide network of international experts.

In the context of Greece, there has been very little engagement with national professional organisations and scientific societies in attempts to reform the organ donation and transplant system. In particular, there is a need for collaboration in respect to drawing up national guidance regarding tricky ethical questions around deceased donation. There are a number of societies and associations which should be actively engaged in the development of the organ donation and transplantation system, including:

- The Greek Transplantation Society in collaboration with all transplantation-related medical societies.
- The Hellenic Society of Anaesthesiology
- The Hellenic Society of Intensive Care Medicine
- The Hellenic Medical Society

Implementation Task Force

Recommendation:

The implementation of the new national donation and transplantation programme should be overseen by an implementation task force under the remit of the Ministry of Health.

Sub-Recommendations:

- The implementation task force should be chaired by the permanent secretary of the Ministry of Health
- The implementation task force should be representative of the following interests: Ministry of Health, NTO, transplant centers, the ICU sector, relevant scientific societies and professional organisations, and medical schools. A seven-to-ten-person task force is recommended.
- The task force should produce an annual report detailing the progress made in the implementation of the recommendations in this document.

Responsible bodies:

• Government • The Ministry of Health

Rationale:

All too often there is a gap between policy plans and policy implementation. For this reason, it is crucial that a task force is appointed to oversee the implementation of the recommendations. This task force must be convened without delay, and the members must be representative of the key stakeholders in the donation and transplant programme. The task force must view its responsibilities as being long-term and ongoing; and publish and make publicly available an annual report detailing progress and identifying remaining gaps. The recommendations in this report are far-reaching and comprehensive, and achieving full implementation may seem a daunting task. It must be recognised that while some recommendations might seem more important than others, they are all interconnected and interdependent. Improvement to the organ donation and transplantation programme will not be realised unless there is system-wide change and close collaboration between all parties. All the areas outlined in the recommendations must be addressed, and timelines must be borne in mind so that every part of the process is ready to manage the anticipated increased demand. However, it is recognised that there are areas in which full implementation may not be possible without wider health system reform (for example in the area of prevention) and it will take time before the benefits are fully realised.

Improving Access and Quality in Organ Donation and Transplantation:

A Framework for a National Action Plan

Government: Political support, funding and long-term commitment

Key legislation:
Consent policy. Specific legislation addressing diagnosis of brain death, DBD, cDCD, uDCD, WLST, 'no-touch' time, donor maintenance, LD and altruistic donation. Prohibition of trafficking. Safeguards against coercion and for those lacking capacity. Minimum requirements for staffing and facilities.

Reducing the need for transplant. A whole system approach including:

Primary prevention of underlying causes of organ failure:
Comprehensive public health programmes eg:
smoking cessation/healthy eating/excercise promotion.

Secondary prevention: National screening and diagnostic guidelines. Regular health checks in primary care. Incentives to primary care clinicians. Access to health improving interventions.

Tertiary prevention: Optimal management of organ failure. Delaying and treating the long-term complications of chronic disease. Standardised referral processes for transplant assessment.

Building and maintaining public support and trust in the system:

Improving knowledge, awareness and attitudes
via campaigns and tailored educational programmes.
Conducting and acting upon the results of periodic surveys.

Building confidence in standards and ethics
via strict adherence to fair, equitable and transparent processes.

Building a supportive relationship with the media, religious and other community institutions
via a comprehensive and continuous public relations strategy.

Reimbursement mechanisms/incentives

- Cover all parts of the process, staff and facilities.
- Takes account of antisocial hours.
- Includes incentives for participating units and staff.

Infrastructure

- Distribution and capacity of transplant centers.
- ICU capacity and distribution.
- Clinical space and equipment.
- Laboratory, radiology and other supporting services.
- Operating theatre capacity and availability.
- Administrative support.
- IT and communications.
- Transport.

National Transplant Organisation (NTO)

An independent, adequately staffed and funded body with overarching responsibility and accountability for the entire process from donor selection to long term follow-up. Coordinates all processes, provides 24/7 support and advice. Maintains national registries, databases and waiting list. Ensures fair and ethical allocation of organs according to national criteria. Coordinates organ matching. Responsible for good governance of the system. Oversees workforce planning and training, regulation and inspection of facilities. Publishes national reports. Promotes organ donation and transplantation via educational and publicity programmes. Collaborates with the international organ donation and transplantation community. **Clear leadership and representation of all relevant interests is essential. The board must provide strategic vision and uphold the highest expectations in terms of quality and performance.**

Excellent communication and cooperation between all stakeholders and patients driven by shared vision, values and ideas.

Donation

Organ Donation Coordinators – available 24/7 – specifically trained with protected time for their duties. Potential sources of organs: DBD, cDCD, uDCD, living and altruistic donation.

- Involve all staff in every area where there may be potential donors, especially ICU.
- Continual scanning for potential donors.
- Donor identification, evaluation and management.
- Consent and family support.
- Incentives/recognition for deceased donor families.
- Organ retrieval - specialist teams available 24/7.
- Organ preservation, packing, transportation.
- Organ sharing schemes.

Transplantation

**Transplant personnel available 24/7.
Multidisciplinary assessment and follow-up teams.
All staff specifically trained with protected time for their duties.**

- Assessment of potential recipients according to nationally agreed organ- specific listing criteria.
- Preparation for transplant and regular re-assessment of those on the waiting list.
- Close collaboration with NTO and donation units to ensure compliance with national allocation criteria.
- Alerting and transporting recipients.
- Transplant surgery by specialist teams.
- Perioperative management, post-transplant hospitalisation.

Post-transplant follow-up

Multidisciplinary organ-specific teams provide long-term follow-up.

- National guidelines based on international best practice.
- Regular reviews and assessments.
- Shared-care arrangements for those living in remote locations facilitated by telemedicine technology.
- Immunosuppressive protocols and optimisation of immunosuppres -sive therapy.
- Preventing recurrence of disease. Eg; management of hypertension, diabetes, inflammatory disorders.
- Minimisation and management of post-transplant related complications.
- Optimising psychosocial outcomes.
- Recording and dissemination of nationally agreed outcome data.

Living donation

Pre-emptive renal transplant from a LD is the treatment of choice in ESRD.

- Safeguards in place to prevent coercion and protect the rights of LDs.
- Reimbursement of LDs for any costs or loss of earnings.
- All LDs assessed according to nationally approved guidance.
- All dialysis assessments include consideration of possible LDs.
- Close collaboration between medical specialists (especially nephrologists) and the donation/transplantation system.
- Establishment of kidney exchange schemes.
- Long-term follow-up must be offered to LDs and outcomes recorded.

Databases and Information Technology

- The NTO is responsible for; Organ donor registries (including the living donor register), waiting lists and waiting list management and the organ donation and transplantation database.
- Data collection in keeping with the data requirements of international organ exchange schemes.
- The databases must be easily accessible and intuitive to use.
- Information must be real-time and easily updated.
- Information governance, data protection and confidentiality are priorities.
- Connectivity with international databases.

Quality standards and quality improvement

- Regular inspection and accreditation of all establishments combined with processes to facilitate improvement.
- Protocols, standards and standardised documentation for every step of the process.
- Regular assessment of efficiency and effectiveness against carefully designed key performance indicators.
- Regular audit cycles and quality improvement initiatives
- Vigilance systems to respond rapidly to and learn from adverse events.
- Minimum annual, publicly available report of activity and outcomes to NTO from all participating units.

Research and Development

- Research advisory group within the NTO.
- Local and national audit and research activities.
- Collaboration with international research programmes.
- Approval by established research ethics committees.
- Funding of research, awarding grants and fellowships.
- Publication and dissemination of results to all stakeholders.

Teaching, training and professional development

- Tailored portfolios and regular appraisal.
- Clear supervision arrangements.
- Dedicated training modules and rotations.
- Incorporation to medical and nursing school curriculum.
- Education of the wider health community.
- Collaboration with international teaching and training schemes.

Scientific/ professional bodies

- Provide expert advice and support.
- Devise guidelines and protocols.
- Set standards for professional education, conduct and training.
- Coordinate educational events and facilitate exchange of ideas and experience.

Patient-centered care

- *Involvement of patient and carer organisations.*
- *Tailor-made multidisciplinary and holistic clinical care of all patients and families.*
- *Involvement of patients and carers in development of services and clinical curriculums.*
- *Regular patient and carer surveys.*
- *Development of electronic health records and telemedicine.*

**DBD – Donation after brain death, cDCD – controlled donation after circulatory death, uDCD – uncontrolled donation after circulatory death, LD – living donation, WLST – withdrawal of life-saving treatment, ESRD – end stage renal disease.*

International Expert Panel

Dr Mirela Bušić, Croatia
Ministry of Social Affairs and Health

Professor Daniel Casanova, Spain
University of Cantabria

Dr Ana Franca, Portugal
Instituto Português do Sangue e da Transplantação,

Dr Aliki Iniotaki, Greece
General Hospital of Athens "G. Gennimatas"

Professor Anastasia Kotanidou, Greece
National and Kapodistrian University of Athens

Professor Elias Mossialos, Greece
London School of Economics

Professor Vassilios Papalois, Greece
Imperial College London

Dr Jorge Paulino Pereira, Portugal
University of Lisbon

Professor Jacopo Romagnoli, Italy
Catholic University of Rome

Research Team

Dr Charlotte Johnston-Webber, United Kingdom
London School of Economics

Dr Jasmine Mah, Canada
London School of Economics

Dr Apostolos Prionas, Greece
Imperial College London

Dr Simon Streit, Germany
London School of Economics

George Wharton, United Kingdom
London School of Economics

For further information about the National Plan for Solid Organ Donation and Transplantation, send an e-mail to: mediaoffice-health@onassis.org.

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