

NATIONAL ACTION PLAN FOR ORGAN DONATION AND TRANSPLANTATION 2023–2033



Table of contents

1. Introduction	3
2. Measures taken on the basis of the action plan 2015-2018 and achievement of the objectives.....	4
3. Objectives of organ donation and transplantation activities for 2023–2033.....	12
4. Description of the organisation	14
5. National steering group for organ donation	18
6. National donor coordinator	19
7. Supervision of organ donation and transplantation and support from authorities.....	21
8. Tasks of the donor hospitals	24
9. Job descriptions and tasks of the donor team, physician in charge, donor coordinator and nurse in charge	26
10. Monitoring the quality and operation of own organ donation and transplantation work.....	32
11. A uniform operating model to all donor hospitals	34
12. Development targets for organ transplantation activities	37
13. Child as an organ donor and pediatric organ transplantations	39
14. Kidney transplant from a living donor.....	41
15. Training and orientation	44
16. Communication	47
17. Budget.....	49
18. Bibliography and references	51

1. Introduction

In 2008, the European Commission published an action plan on organ donation and transplantation with the aim of increasing the availability, quality and safety of organ transplants and improving the efficiency and functionality of organ transplantation systems. On this basis, the Ministry of Social Affairs and Health appointed an expert group in spring 2013, which prepared a National Action Plan for organ donation and transplantation for 2015-2018. The objective of the action plan was that all patients who, based on their illness and medical assessment, benefit from organ transplantation will receive a well-functioning transplant in a timely and equal manner, and that organ donation is a part of the normal activities of the hospital.

Based on the action plan, a national staggered organ donation organisation has been created. Each donor hospital has a donor team and a physician and coordinator responsible for organ donation. Instructions for organ donation have been harmonised, all donor hospitals have operating instructions, and all donor hospitals monitor their operations. The training has been intensified, and based on a national audit of the data of the deceased, we know that only 3.6% of potential organ donors remain unidentified, but treatment is still limited in the case of 6.1% of potential donors without considering the possibility of organ donation (2021).

Organ transplantations have established themselves in health care and their need has increased. In Finland, there are still too few organ transplantations compared to the need, as there is a continuous shortage of organs suitable for organ transplantation. It is estimated that at least 30 brain dead organ donors per million inhabitants (PMP, per million population) will be needed in Finland to achieve the quantitative target for organ transplantations. At the national level, this objective has not been achieved. The number of organ donors varies significantly from year to year and by region.

Optimal organ transplantation requires the functionality of the entire organ donation and transplantation chain and multi-professional co-operation. The possibility of organ donation is part of the good care of a dying patient at the end of their life and respect for the patient's will. Organ donation activities require continuous development, as some patients waiting for organ transplantation will still die because no suitable organ can be found for them.

In accordance with the action plan of the Ministry of Social Affairs and Health, organ donation activities have been developed, and this has led to a need for a new action plan for organ donation and transplantation, which takes into account the changed operating methods and creates new objectives and plans to achieve them.

2. Measures taken on the basis of the action plan 2015-2018 and achievement of the objectives

The main objective of the National Action Plan was to ensure that all patients who, based on their illness and medical assessment, benefit from organ transplantation receive a transplant in a timely and equal manner. Organ donation activities require continuous development, as some patients waiting for organ transplantation will still die because no suitable organ can be found for them in time.

The identification of organ donors has improved significantly. In 2021, based on an audit of data of the deceased carried out by donor hospitals, only 3.6% of potential organ donors remain unidentified and treatment is restricted in the case of 6.1% of potential donors without considering the possibility of organ donation. In the early 2000s, almost 50% of organ donors remained unidentified.

The Transplantation Center has created more detailed criteria for hospitals for sending patients to receive treatment, with the aim of improving regional equality of referral to treatment. The qualification criteria of organ donors have been adapted to meet the need for transplantation, which has led to an increase in the number of organ transplantation.

Organ donation as part of normal hospital activities

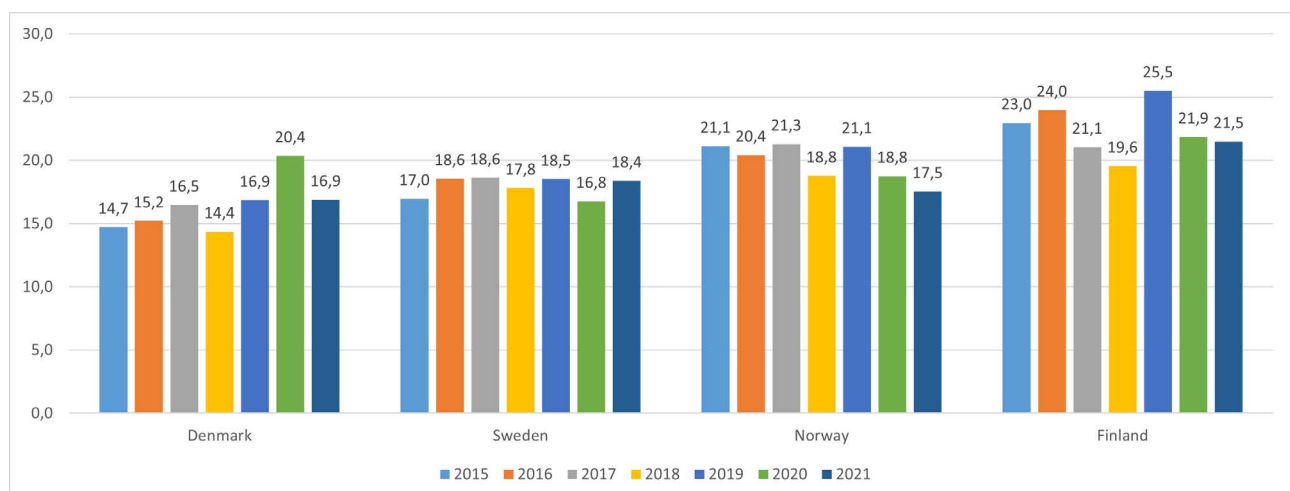
The possibility of organ donation is increasingly remembered in every stage of the treatment chain of a patient with a critical neurological illness, starting with emergency care. Assessing the possibility of organ donation is highlighted in several instructions from the Chief Medical Officers concerning the restriction of treatment and end-of-life care.

Organ donation has been generally accepted as an indication for intensive care throughout Finland. This enables high-quality treatment of potential organ donors and treatment whose sole objective is organ donation. In recent years, only individual donors have been lost because no intensive care bed has been found for them.

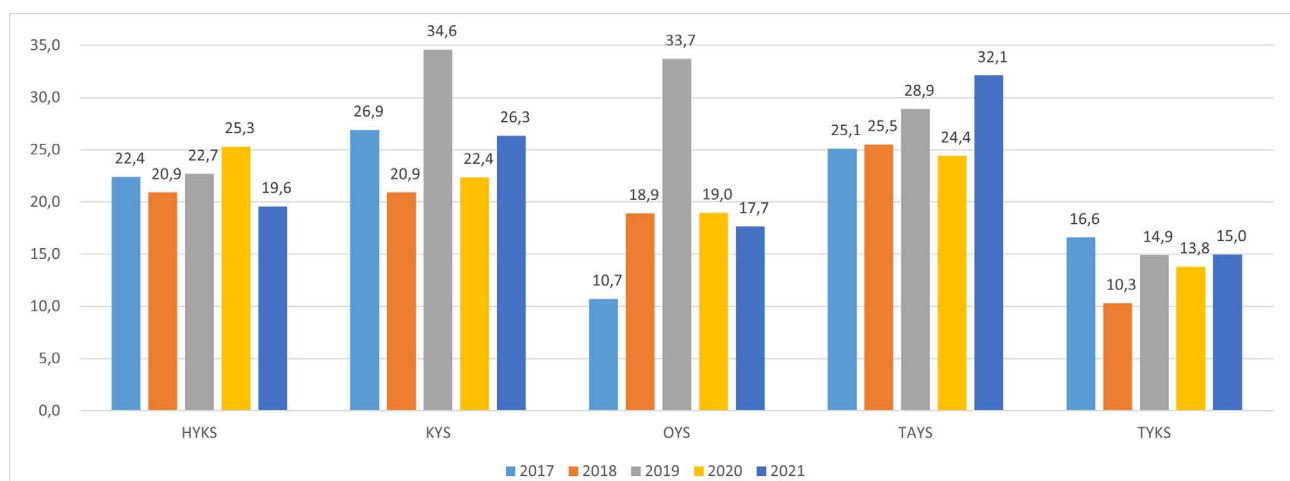
The number of organ donors per year should be 30 donors per million inhabitants (PMP)

Each organ donor is a potential multi-organ donor, a donor who donates more than one type of organ. In 2015, 67.5% of all donors were multi-organ donors, while in 2021, this number was 74%.

The number of organ donors varies significantly from year to year and by region. The target of 30 organ donors PMP has been achieved only a few times in the divisions of different university hospitals. However, in comparison with other Nordic countries, there are more deceased organ donors in Finland than average. For living organ donors, other Nordic countries are ahead of Finland (see figure on page 41).



Organ donors in Finland and other Nordic countries in 2015-2021 per million population (PMP).



Organ donors by divisions of the university hospitals in 2017-2021 (PMP).

HYKS: HUS, Päijät-Häme, Kymenlaakso, South Karelia
 KYS: KYS, North Karelia, South Savo, Central Finland, Savonlinna
 OYS: OYS, Kainuu, Länsi-Pohja, Central Ostrobothnia, Lapland
 TAYS: TAYS, South Ostrobothnia, Kanta-Häme
 TYKS: TYKS, Vaasa, Satakunta

In order to increase the number of organ donors, the preparation and piloting of the “Organ donation after circulatory confirmation of death” activities in university hospitals has been started. After the piloting, the results will be evaluated and the continuation and the expansion of activities to all donor hospitals will be planned.

During the Action Plan 2015-2018, the number of people waiting for organ transplantation has increased, so the estimate of an adequate number of organ donors should be updated in this Action Plan.

Supervision of organ donation and transplantation

Organ donation and transplantation are strictly regulated, supervised and instructed by law. The objective is to ensure the transparency of the activities, the prevention of misconduct and economic gain, traceability of organs and tissues, the provision of quality and equal treatment, the quality and safety of organ transplantations and to guarantee the availability of transplants.

The Finnish Medicines Agency Fimea has carried out regular inspections of donor hospitals since 2013 in accordance with the so-called Tissue Act (Act on the Medical Use of Human Organs and Tissues, 101/ 2001). No serious deficiencies have been identified and all donor hospitals have been inspected successfully. The shortcomings observed have been due to the lack of time available to complete the tasks, as there has been no dedicated resource for organ donation activities.

Organisation of organ donation activities

The Ministry of Social Affairs and Health’s National Action Plan on organ donation and transplantation stated that there has been no national body steering organ donation activities in Finland.

Responsibility for the planning and coordination of the national entity of organ donation activities was given to the Hospital District of Helsinki and Uusimaa in the so-called centralisation decree (Government Decree on the division of labour in specialised medical care and the centralisation of certain tasks, 582/2017). Organ transplantations are also centralised nationally at HUS. Organ donation and transplantation organisations are completely separate activities of HUS.

The development and coordination of organ donation activities is the responsibility of the national steering group for organ donation established in HUS (HUS Chief Medical Officer’s decision 117/2019). The post of a national donor coordinator has been established to implement the steering group’s decisions. Donor hospitals have felt that the activities and support of the national donor coordinator are necessary: Guidelines have been developed and harmonised, and the minimum requirements for operations have been met throughout the country.

Organ donation activities are organised and staggered. All central hospitals in Finland serve as donor hospitals. University hospitals are responsible for steering, monitoring and training in their own area. Organ donation working groups have been set up at each donor hospital and they are responsible for the activities. The activities are led by a physician, and the working group includes a donor coordinator and representatives of the units central for the operations.

Each donor hospital has instructions for organ donation that cover the entire treatment chain of a critically ill neurological patient from the initial stage active treatment to organ removal surgery. Fimea checks that the instructions comply with the regulations and that they are complied with.

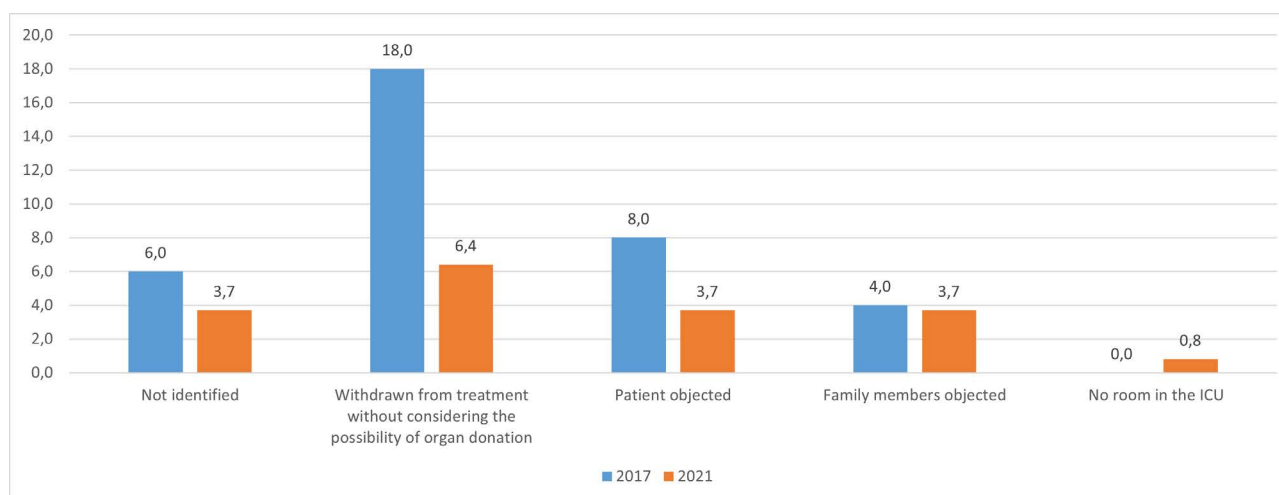
Each donor hospital's instructions include job descriptions for the hospital's working groups and physicians responsible for organ donation and the donor coordinators based on the Operating Plan of the Ministry of Social Affairs and Health. The aim is to comply with these specified instructions, but there are not enough resources available in donor hospitals, and organ donation activities are usually managed alongside employees' own activities without allocated working hours. With the organisation of the activities and the implementation of the Action Plan, the job description of donor coordinators and working groups has also changed significantly. In particular, the job description of donor coordinators at university hospitals has expanded. Today, in addition to their own region, they participate in the development and support of organ donation activities in the entire country, contrary to what is defined in the Ministry of Social Affairs and Health Action Plan 2015-2018. They are the most important partners of the national donor coordinator.

Reporting and quality assurance of organ donation activities

Professionals in organ donation and transplantation have jointly prepared uniform national guidelines and guides for organ donation activities in order to harmonise organ donation activities and ensure uniform quality.

In accordance with the National Action Plan, each donor hospital monitors its own activities (auditing the data of the deceased). The database created by the Oulu University Hospital has been used to monitor the reasons why organ donation has not been carried out for a potential organ donor. The data obtained has been compiled nationally (2017-2021), so it has been possible to compare the results of hospitals. It has been possible to provide feedback in a targeted manner, and training has been planned on the basis of audit results.

Based on the audit results of the data of the deceased (2021), we know that training has enabled us to improve the identification of organ donors and that treatments are no longer significantly restricted without considering the possibility of organ donation.



Development of operational key figures in 2017-2021. The figures are presented as a percentage of the potential organ donors identified on the basis of the deceased data audit programme.

In 2021, the audit programme was transferred from the hospitals' own registers to one national quality register (HUS's national organ donor audit register). The register is maintained by HUS. This will enable more detailed analysis of results, real-time monitoring and national comparison of results. The audit system is continuously updated.

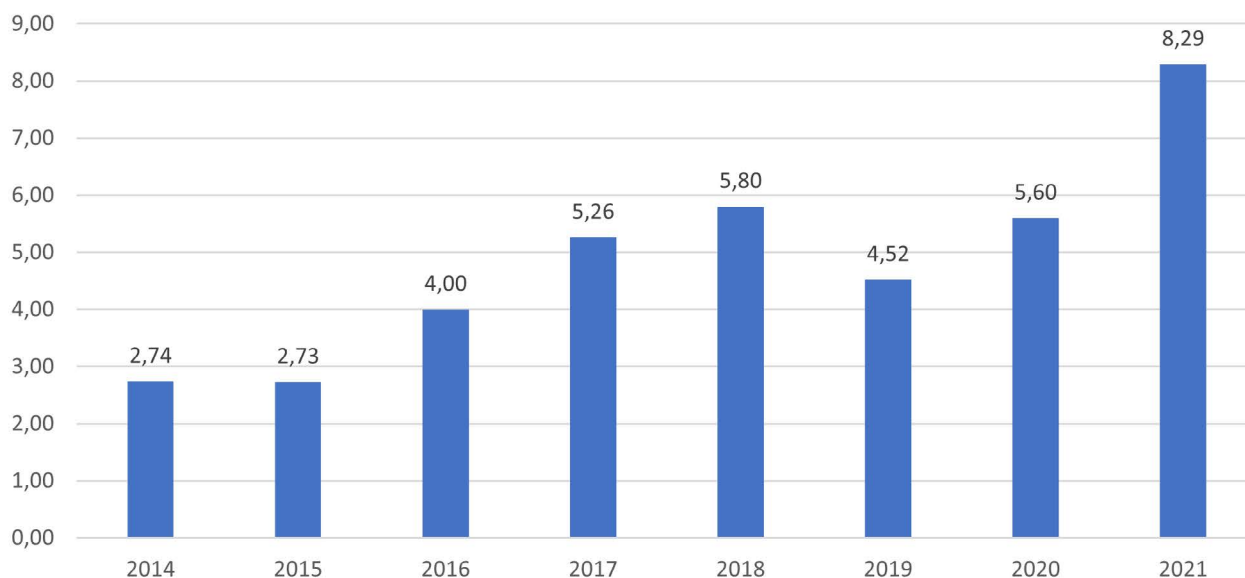
All patients in the transplantation queue, organ donors and those who have received an organ transplant are recorded in both the Scandiatransplant register and the HUS Organ Transplantation Register, which collect information on the period preceding the transplantation, organ donation surgery and organ transplantation surgery, data at the time of transplantation and follow-up data. All recipients and donors of organ transplants performed in Finland can be traced from the register. Information on the follow-up of living kidney donors required by law is also entered in the Organ Transplantation Register.

Kidney transplant from a living donor

The objective of the Action Plan was to increase kidney transplants from living donors to 10 transplants per million population (PMP) by 2020, but this objective has not been achieved. Additional resources and the amendment to the so-called Tissue Act were only obtained in 2019, and this has slowed down the achievement of the target.

In order to reach this goal, the post of a national coordinator for live donors was established in HUS at the beginning of 2019 to develop and instruct the activities. As the activities developed and transplants from living donors increased, a second coordinator post was established at HUS at the beginning of 2021.

Amendment to the so-called Tissue Act, which entered into force in March 2019, made it possible for other people than first stage relatives or the spouse of the patient to act as a donor as well as for so-called non-targeted living donation. In practice, anonymous altruistic donation and so-called cross-donation became possible. Of the 46 kidney transplants from living donors carried out in 2021, 11 organ donations were carried out from persons other than the patient's nearest family members. The impact of these measures is expected to be visible within a few years.



Living kidney donors in 2014–2021 per million population (PMP).

The costs of organ donation to the donor have been charted. The donor continues to suffer both loss of earnings and costs from renal donation. The legislative amendment involving the reimbursement of these costs has not been able to be promoted.

Training and staff orientation

Good treatment of organ donors throughout the treatment chain has been one of the objectives of the Action Plan, and based on this, all professional groups starting from emergency care have been taken into account in the training programmes. The training has emphasised the identification of organ donors, good encounters with family members and understanding the concept of brain death.

In accordance with the Action Plan, the annual national training event for donor hospitals has been established. The training provided by the university hospital for its region and the annual training events of each donor hospital have been able to be organised in some of the divisions of university hospitals.

An effort has been made to prepare orientation programmes and job descriptions for different professional groups and responsible persons hospital-specifically. The identification of an organ donor is part of the orientation programme in some units

where a potential organ donor can be encountered.

Regular national surveys of personnel attitudes and awareness in donor hospitals were launched in 2020. 88% of those who responded to the survey would donate their organs after their death, but only 59% knew whether their family members were willing to donate organs. The main reasons why professionals do not want to donate their organs are personal reasons, the fear that the organs are unsuitable or go to someone who does not deserve them. 28% of professionals did not understand the concept of brain death, and 41% of respondents thought that the decision on the organ's eligibility for removal was made by someone other than a transplant surgeon. These results show that there is still a need for continuous training.

Increasing citizens' awareness and knowledge about organ donation and transplantation

In practice, the responsibility for increasing citizens' awareness has remained with the Finnish Kidney and Liver Association, even though not enough resources have been allocated to it. In order to increase citizens' awareness, the Finnish Kidney and Liver Association organises an annual Transplant Week at the same time as other European countries.

The organ donation card and its mobile application are in use and maintained by the Finnish Kidney and Liver Association. They order a citizens' attitudes survey every two years (most recently in 2021). 31% of the respondents believed that they knew what the will of their family members was regarding organ donation. The aim of the previous Action Plan was that 70% would have told their loved ones about their willingness to donate organs.

In addition to the Finnish Kidney and Liver Association, HUS has also provided information on organ transplantations and donations through media releases and social media publications.

The Action Plan of the Ministry of Social Affairs and Health proposed the establishment of a communications division to coordinate communication with the population, but for resource reasons it could not be established. Efforts have been made to intensify cooperation between HUS Communications and the Finnish Kidney and Liver Association. Increasing awareness about organ donation increases the number of donors (Organ donation and Transplantation, Facts, figures and European Union Action, European Parliamentary Research Service, 2021).

Child as an organ donor and pediatric organ transplantations

The previous Action Plan addressed pediatric organ transplantations rather than organ donation of children. Following the preparation of the Action Plan, national guidelines have been drawn up on child organ donors and on the diagnosis of brain death.

There are very few child organ donors, and even professionals working in pediatric intensive care units do not meet child organ donors annually. It is very important that all potential minor organ donors are identified in all units in our country that treat neurologically critically ill pediatric patients.

Organ transplantation is also a generally accepted form of treatment for severe organ damage in children. Pediatric organ transplantation activities in Finland are concentrated in the New Children's Hospital. By 2022, more than 500 children or adolescents have received an organ transplant.

Compared internationally, the results of pediatric organ transplantations are excellent in Finland, and 70-95% of patients survive. After the transplant, the growth and development of children and adolescents is mainly normal and the quality of life is good.

3. Objectives of organ donation and transplantation activities for 2023–2033

Organ donation and transplantation activities require continuous development, as some patients waiting for organ transplantation will still die because no suitable organ can be found for them. In order to further develop organ donation and transplantation, concrete development targets are presented at the end of each section.

1. **The main objective of the National Action Plan is to ensure that all patients who, based on their illness and medical assessment, benefit from organ transplantation receive a transplant in a timely and equal manner.**
2. Organ and tissue donation is part of the hospital's normal operations
 - a. A uniform organ donor care path in to all donor hospitals
 - b. Organ donation is part of good end-of-life care
 - c. Care restrictions should not be made without considering the possibility of organ donation
 - d. Organ donation after circulatory determination of death activities are part of organ donation activities.
3. Increasing the awareness of citizens, professionals and decision-makers about the importance of organ and tissue donation
 - a. More and more people inform their family members about their willingness to donate organs and tissue
 - b. More and more people are aware of the possibility of living kidney donation
 - c. Adequate resources for staff training must be guaranteed
4. Sufficient multi-professional resources for national support provided by HUS
 - a. A uniform orientation and training material will be created for donor hospitals
 - b. Continuous maintenance of training and awareness at national level for donor hospitals

5. Sufficient resources must be created for each donor hospital to ensure high-quality development and monitoring of organ donation
 - a. Organ donation activities directly under hospital management
 - b. Each hospital has its own budget for organ donation to cover the hospital's needs
 - c. Family members do not have to pay for the care of an organ donor
 - d. Monitoring and developing own activities

6. Developing the encounters with the organ donor's family
 - a. Establishing an expert network
 - b. Launching expert by experience activities

7. Developing living kidney donation
 - a. A person in charge of operations into each hospital examining living kidney donors
 - b. Full reimbursement of costs incurred by a living kidney donor
 - c. Development of psychosocial support for kidney donors

8. Intensifying Nordic cooperation
 - a. Creating an organ donation group in connection with Scandiatransplant

9. Signing and ratifying the Convention against Trafficking in Human Organs, Council of Europe Treaty Series 216, 2015

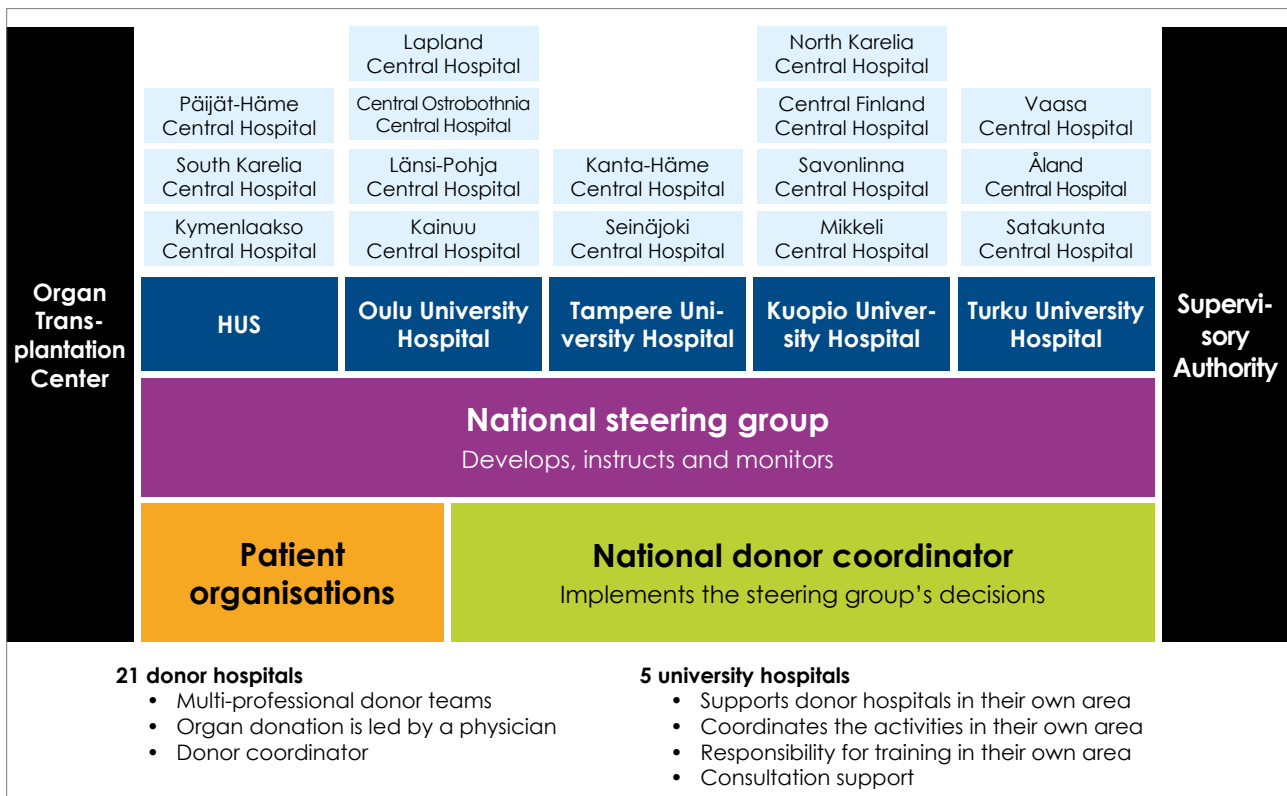
4. Description of the organisation

Organ donation organisation

The organisation of organ donation activities began by giving HUS the responsibility for the planning and coordination of the national entity of organ donation activities in the so-called centralisation decree. Based on this, a national steering group for organ donation activities has been established in HUS (HUS Chief Medical Officer's decision 117/2019) to be responsible for national development, steering and monitoring. University hospitals were given responsibility for steering, monitoring and training in their own cooperation area. All central hospitals in Finland serve as donor hospitals. The Transplantation Office coordinates all organ donations and transplantations.

Under the so-called Tissue Act, Fimea, that operates under the Ministry of Social Affairs and Health, is responsible for the steering and monitoring of organ donation and transplantation activities. Practical organ donation and transplantation work is carried out in cooperation with Scandiatransplant. Cooperation between Nordic organ donation organisations and persons responsible for organ donation should be developed.

Increasing the awareness of both professionals and citizens about organ donation has been found to be the most effective way to increase the number of donors (Organ donation and transplantation, Facts, figures and European Union action, EPRS | European Parliamentary Research Service, April 2020). Nowadays, communication and substance competence are decentralised between patient organisations, donor hospitals and the national organ donation steering group. The aim is to map the establishment of a separate support centre for organ donation activities, which would be responsible for communication to citizens, training of professionals and steering of organ donation activities (similar to Denmark and Australia).



Organ donation organisation 2022. From the beginning of 2023, the activities of hospital districts will cease and the wellbeing services counties will be responsible for the social welfare and health care services. Five cooperation areas will be established for regional integration, development and cooperation

Development areas

- Closer cooperation at national and regional level
- An effort will be made to create a joint Nordic organ donation working group in connection with Scandiatransplant
- The possibility of establishing a national multi-professional center supporting organ donation will be explored
 - The role of communication and awareness must be emphasised

Organ transplantation organisation

At the national level, organ transplantation activities are centralised in HUS by means of the so-called centralisation decree, and the Transplantation Center is responsible for the measures laid down in legislation. The Transplantation Center has three units: The Abdominal Center's organ transplantation unit is responsible for organ transplants in the abdominal area, the Heart and Lung Center's unit is responsible for organ transplants in the chest area and the Children and Adolescents department is responsible for pediatric organ transplantations. All transplantations in Finland are coordinated through the Transplantation Office of the Transplantation Center.

HUS is one of the owners of the Nordic organ donation and transplantation organisation ScandiTransplant, which coordinates organ transplantation activities in the Nordic countries in accordance with jointly agreed rules.

Description of organ transplantation activities

Organ transplantation and liver surgery unit

The unit's head physician is responsible for organ transplantations in the abdominal area, and the physicians and employees of the Transplantation Office, transplant coordinators and the systems secretary work under this person. The work of the Transplantation Office includes the practical implementation of organ donations. Transplant coordinators receive the organ donor's information and forward it to the abdominal and thoracic area transplant surgeons who decide which organs can be used. The coordinators organise transports, removal surgeries and transplantations, ensure possible transports of organs within the framework of Nordic cooperation, manage the register data of organ donors and transplant recipients and record the necessary data of the entire process in databases. The coordinators also maintain monitoring data and participate in staff training.

Abdominal area transplant surgeons decide on the preliminary examinations of recipients of kidney, pancreas, liver and intestinal transplants and on placing patients on waiting lists. They perform the removal surgeries as well as the actual organ transplantations and are responsible for the treatment of patients after the transplantation, initially with the physicians in the intensive care unit, during recovery in the inpatient wards and after discharge with doctors in the patients' own hospitals. Their tasks also include drafting instructions and training. Surgeons together with internal medicine specialists in each speciality define the data to be stored in the registers.

Heart and Lung Center organ transplantation unit

Heart and lung transplants are carried out by the chief physician of cardiac surgery together with cardiac surgeons, cardiologists, pulmonary specialists and heart and lung transplant coordinators involved in organ transplantations. The decision to place a patient on the transplant list is made in a multi-professional meeting, in which all team members participate. Perioperative treatment is mainly the responsibility of cardiac surgeons at the cardiac surgery intensive care unit in cooperation with cardiac anaesthesiologists, and cardiologists, pulmonary specialists and heart and lung transplant coordinators are responsible for post-transplantation monitoring. In addition, the coordinators monitor patients waiting for an organ transplant, organise heart and lung transplant removal and transplant surgery logistics, organ perfusion in removal surgery, manage the quality register for heart and lung transplantations, and participate in the heart and lung donation process and maintenance of the register in the Nordic umbrella organisation ScandiTransplant, if necessary.

Pediatric organ transplantations

The physicians responsible for organ transplantations in the Children and Adolescents department together with the transplant coordinator are responsible for pediatric transplantation activities. They are tasked with placing patients on transplant lists, monitoring before and after the transplantation, and taking care of the patients' transition to the adult department for monitoring together with the responsible transplant surgeons and special nurses. The organ removal of organs intended for children is carried out by adult surgeons, if necessary preparing the transplant for the child (mainly liver resection) and taking part in the transplantation itself if necessary. Pediatric organ transplantations are performed by pediatric cardiac surgeons and gastroenterological surgeons. In pediatric organ transplantations, cooperation is particularly important, as the selection of the transplant takes place between adult surgeons and doctors responsible for pediatric transplantations and the surgeons carrying out the transplantation. Quality factors at different stages of surgery and the details and stages of the procedures themselves must be carefully assessed for each transplantation.

Development areas

- Closer cooperation between different donor actors
- Improving cooperation between transplantation units
- Ensuring adequate training

5. National steering group for organ donation

The so-called centralisation decree gave HUS the responsibility for the planning and coordination of the national entity of organ donation activities. Based on the decree, a national steering group for organ donation activities has been established in HUS (HUS Chief Medical Officer's decision 117/2019).

The steering group must include representation from all university hospitals, two other donor hospitals, the Transplantation Center, the Finnish Institute for Health and Welfare, the Ministry of Social Affairs and Health and Fimea. Comprehensive representation provides a broad-based view of the challenges and development needs of organ donation activities and offers better opportunities for influence. If necessary, the group will consult experts from different areas. The steering group meets twice a year. The national donor coordinator chairs the steering group and implements its decisions.

The steering group is responsible for the development, guidance, instructions and monitoring of organ donation activities. Its task is also to coordinate training related to organ donation activities and to organise an annual training event for the responsible persons in donor hospitals. The steering group is responsible for creating and producing national uniform guidelines and training and orientation material.

On the basis of the authorisation granted by the so-called centralisation decree, the guidelines issued by the steering group must be followed. Donor hospitals must adapt their activities to these guidelines in order to ensure uniform organ donation activities at the national level.

Development areas

- The steering group assumes greater responsibility for guiding national organ donation activities
- The steering group prepares an annual report on its activities and the instructions it has produced. This will be delivered to all key persons in organ donation activities, the supervising authorities and to the meeting of the senior medical directors of all donor hospitals for information on the measures to be taken
- The steering group plans regional training and development needs based on the annual reports and audit results of donor hospitals

6. National donor coordinator

The task of the national donor coordinator is to steer, coordinate, harmonise, develop and monitor national organ donation activities based on observed development needs. Extensive cooperation with other parties involved in organ donation and transplantation is essential in order to develop organ donation activities. The national donor coordinator's main partners are the donor coordinators of university hospitals, and this cooperation has enabled the development of organ donation activities.

The tasks of the national donor coordinator include providing support to donor hospitals. Visits and cooperation meetings with local organ donation organizers each year lay the foundation for good organ donation activities. The national donor coordinator is a member of the steering groups of all university hospitals, thus receiving up-to-date information on the regional organisation and resourcing. This facilitates providing instructions for operations.

Together with the national steering group, the coordinator provides instructions on training related to organ donation activities and supports donor hospitals in organising internal training. The coordinator is responsible for organising an annual national training event for donor hospitals, together with the steering group.

The coordinator analyses the audits carried out by donor hospitals and distributes feedback to donor hospitals. The necessary measures will be planned based on the audit results to promote organ donation activities in cooperation with donor hospitals.

The coordinator advises the operators of donor hospitals on organisational and practical issues related to organ donation events. The coordinator monitors the inspection visits to donor hospitals carried out by Fimea and, if necessary, helps to complete the required measures.

The coordinator cooperates with parties involved in various organ donation and transplantation activities with regard to communication to the public.

The national donor coordinator cooperates with the authorities (Ministry of Social Affairs and Health, National Supervisory Authority for Welfare and Health, Finnish Institute for Health and Welfare and Finnish Medicines Agency Fimea) on matters such as law-drafting and instructions, and acts as a contact person for communicating important messages between the authorities and organ donation organizers.

Familiarisation with organ donation activities in different countries enables and creates new ideas for national development work. Networking improves international cooperation and consultation opportunities.

The coordinator participates in the preparation and implementation of new activities.

The activities of the national coordinator should be further developed and sufficient operating conditions and support should be created for it. The steering group creates a framework for the activities, but as a single actor, the national coordinator needs support for the practical implementation of matters in a high-quality manner.

Development areas

- The national donor coordinator needs a person who is familiar with organ donation activities, masters digital tools and is capable of multi-professional cooperation across hospital districts to assist them in their job
- Networking with organ donation actors in different countries
- Adequate funding must be obtained for national organ donation activities
- National support for donor hospitals should be increased
 - Training and orientation packages should be created in cooperation with the national steering group for organ donation
 - Annual cooperation meetings should be established with donor hospitals

7. Supervision of organ donation and transplantation and support from authorities

The Ministry of Social Affairs and Health has identified a diverse need to reform the tissue regulations both for the actual tissue legislation and, for example, for the regulation on determining the cause of death. The Government Programme should include provisions on the Tissue Act and on determining the cause of death. In 2022, the European Commission issued a proposal to reform the provisions on tissues, blood and cells. In this context, the need for national regulation will also be taken into account.

A valid Government Decree on the division of labour in specialised medical care and the centralisation of certain tasks (582/2017) has given HUS the task of national planning and coordination of organ donation activities. The implementation has not reached the actors nationally, so the Ministry of Social Affairs and Health will continue to support the steering group under HUS, for example by publishing the Action Plan at an event organised by the Ministry of Social Affairs and Health. The Ministry of Social Affairs and Health will continue to support the position of the steering group appointed by HUS in order to ensure that the donor hospitals commit to the instructions issued by the steering group.

The Finnish Medicines Agency Fimea has supervised the quality and safety of organ donation and transplantation activities since 2013, when the EU directive on the operations was adopted in Finland (Directive 2010/53/EU of the European Parliament and of the Council on standards of quality and safety of human organs intended for transplantation). The aim of the directive is to guarantee the quality and safety of organ transplantations and to ensure comprehensive traceability throughout the EU.

Fimea's supervision procedures include maintaining a register of hospitals participating in organ donation and transplantation activities and regularly inspecting their operations. It publishes an annual summary of organ donation and transplantation activities and their supervision.

Regular on-site inspections of donor hospitals and the Transplantation Center assess compliance with regulations. The inspections will focus on:

- The persons responsible for the activities and their tasks
- Introduction and training of personnel involved in the activities
- Adequacy of personnel for assigned tasks
- Instruction and quality system guiding the activities
- Procedures and documentation of operations throughout the organ donation and transplantation chain, from identification of the donor to monitoring of the transplant recipient.

Fimea will also actively assess the achievement of the objectives set out in this Action Plan in donor hospitals and the Transplantation Center. Inspection observations and any shortcomings in operations are reported in the inspection record, which must also be brought to the attention of the unit and hospital management.

Since 2020, Fimea has granted organ transplantation permits for kidney transplantations from living donors and stem cell transplantations from minors. For its part, Fimea aims to develop the permit process so that the application and permit procedure as a whole would be without delay, secure and comprehensively instructed. Providing guidelines for the donor's psychiatric assessment, checking the data from the Digital and Population Data Services Agency as a task of the authorities and examining the possibility of using electronic services have been set as development targets.

The Transplantation Center reports serious patient safety incidents and adverse events detected in Finland. Notifications concerning other Nordic countries arrive via the Scandiatransplant reporting system. When processing these adverse events, Fimea pays particular attention to investigating the root causes of the incidents and planning and implementing corrective and preventive measures.

Fimea and the Ministry of Social Affairs and Health actively participate in European Commission meetings of the Competent Authorities and strive to actively influence legislation on operations. Fimea transmits current information on organ donation and transplantation activities from the Commission and the European Centre for Disease Prevention and Control (ECDC) to organ donation and transplantation actors.

The national steering group for organ donation and the Finnish Institute for Health and Welfare (THL) have cooperated in, for example, legislative reforms related to the determination of the cause of death and confirmation of death.

The Forensic Medicine Unit of the Finnish Institute for Health and Welfare is responsible for directing and supervising the investigation of the cause of death and for carrying out the medicolegal autopsy ordered by the police. The Forensic Medicine Unit of the Finnish Institute for Health and Welfare has a consultation telephone number reserved for the authorities and health care, which serves in matters related to the cause of death determination on weekdays. The Forensic Medicine Unit also has a consultation telephone number reserved for the police for questions related to organ donation and other emergency determination of the cause of death. When planning the removal of organs from a deceased person who must undergo a medicolegal death investigation and possibly an autopsy, the police and, if necessary, the forensic pathologist must be consulted regarding organ donation. Organ removal can be carried out when the police have determined that it does not interfere with the death investigation.

After a medicolegal autopsy, the Finnish Institute for Health and Welfare submits a preliminary summary of the autopsy findings to the police. Once the death investigation has been completed, all documents will be submitted to the police. The doctor who treated the patient during his or her lifetime has the opportunity to request these documents from the police responsible for the death investigation, who can hand them over at their discretion.

The Finnish Institute for Health and Welfare provides feedback to tissue establishments on findings observed after the medicolegal autopsy. In order to ensure up-to-date monitoring of hazardous situations in organ transplantation activities, feedback practices should also be included in organ transplantation activities.

In the future, a cooperation meeting will be held each year to develop cooperation between organ donation activities and the death investigation activities, in which mutual feedback and development suggestions can be given on cases that have taken place during the year (for example, a discussion on whether doctors have ignored the need for medicolegal examinations to determine the cause of death or whether separate instructions on medicine or drug poisoning are needed).

Development areas

- The Ministry of Social Affairs and Health will continue to support the position of the steering group appointed by HUS in order to ensure that the donor hospitals commit to the instructions issued by the steering group
- Hospital management will receive the feedback from Fimea's inspections for information
- In the case of a living kidney donor, providing instructions for the donor's psychiatric assessment, ignoring the family connection check from the Digital and Population Data Services Agency's data and establishing electronic services
- Annual joint meeting with the Finnish Institute for Health and Welfare on organ donation events from the perspective of forensic medicine
- Feedback from the medicolegal autopsy to the Transplantation Center

8. Tasks of the donor hospitals

The tasks of donor hospitals are defined in the so-called Tissue Act. Donor hospitals are hospitals in Fimea's donor hospital register that provide at least intensive care level treatment.

Their task is to participate in organ donation activities and national development tasks in their own area.

Tasks of each donor hospital

1. Identify potential organ donors
2. Find out and record what the deceased person's possible opinion was regarding organ and tissue removal when they were still alive
3. Attend to the report on the organ and tissue donation process given to family members. Take care of supporting family members. Organise post-donation contact.
4. Be responsible for the care of the organ donor
5. Carry out the necessary additional examinations to establish the organs' eligibility for transplantation
6. Instruct and monitor organ and tissue donation activities in their own hospital
7. Arrange appropriate regular training for hospital staff
8. Cooperate with other donor hospitals in their own university hospital co-operation area, the donor group of the university hospital and the national steering group
9. Promptly notify the Transplantation Center of incidents and serious adverse events
10. Carry out an audit of the deceased person's data and report the key figures and operations of the hospital's organ donation activities annually to the hospital management, the organ donation steering group and the national organ donation steering group

Tasks of donor teams/steering group in university hospitals

1. Coordinate organ and tissue donation activities in their cooperation area and monitor the achievement of the objectives set for the activities
2. Be responsible for regional training of organ donation activities
3. Provide consultation support for donor hospitals in their area of cooperation

Development areas

- Every year, each donor hospital submits a report on its own organ donation activities to the national organ donation steering group. This report is prepared by the hospital's donor team and signed by the hospital's Chief Medical Officer
- Better identification of organ and tissue donors
 - Training in the organ donation process must be systematically added to the training and orientation of specializing physicians, especially those on call at the hospital, regardless of their speciality
 - Increasing the resources of persons responsible for organ and tissue donations
 - Promoting new operating models to increase the number of organ donors

9. Job descriptions and tasks of the donor team, physician in charge, donor coordinator and nurse in charge

The donor team of the donor hospital is responsible for the direction, monitoring and reporting of organ donation activities and for the hospital personnel's training and introduction related to organ donation activities. If the persons in charge change, they must be introduced to their job description.

The donor team is headed by the physician in charge whose working partner is the donor coordinator, both of whom must have deputies. Each donor hospital has its own organ donation instructions, which take into account each hospital's special characteristics.

Organ donation activities are organised by university hospitals' cooperation areas, and each university hospital is responsible for the steering, monitoring and training of operations in its own cooperation area.

The job descriptions of the donor team, the physician in charge of organ donation, the donor coordinator and the nurses in charge are described as examples. The donor hospitals agree internally on a more detailed division of labour and the description of tasks in their own hospital.

Donor team

Each donor hospital must have a donor team

Members of the team	<p>The multi-professional team includes representatives from each unit where a potential organ donor can be encountered</p> <p>The chair is the hospital's physician responsible for organ donation</p> <p>Donor coordinator</p>
The team meets at least once a year	<p>Local objectives and practices as well as national guidelines are taken into account in the activities</p> <p>The activities must be regular and continuous</p>
The tasks of the team	<p>Guides and monitors the organ donation activities of their hospital</p> <p>Is responsible for ensuring that the hospital has instructions for organ donation</p> <p>Reports to the hospital's Chief Medical Officer and the national organ donation steering group</p> <p>Plans the hospital's training and orientation</p> <p>Draws up an annual plan and ensures that it is implemented together with the donor coordinator and the physician in charge</p> <p>Develops activities based on feedback received from the hospital's units, the national donor coordinator and the Transplantation Center and the auditing of their own hospital</p> <p>Communicates and informs professionals in their own hospital about the significance of organ donation activities</p>

Physician in charge of organ donation

<p>Manages, plans and develops organ donation activities together with the donor coordinator</p>	<p>Leads and develops operations with the hospital's donor team</p> <p>Maintains and updates local care instructions on the basis of the national organ donation steering group and Transplantation Office instructions and Fimea regulations</p> <p>Maintains the donor's treatment path</p> <p>Participates in developing their own university hospital area and the national organ donation activities</p> <p>Participates in research and projects</p>
<p>Quality and safety</p>	<p>Reports incidents and serious adverse events affecting the quality and safety of organs to the Transplantation Center</p> <p>Audits, gives feedback on the basis of it in a targeted manner and prepares a report together with the donor coordinator</p> <p>Plans and implements the required measures to develop the activities and ensure their quality together with the donor team</p>
<p>Reports and monitors organ donation activities and gives feedback</p>	<p>Monitors and develops activities based on feedback received from the hospital's units, the national donor coordinator and the Transplantation Center and the auditing</p> <p>Reports on the progress of organ donation activities (so-called annual report to the Chief Medical Officer, the donor team and key units, the donor team of the university hospital and the national organ donation steering group)</p> <p>Responds to consultations related to organ donation</p>
<p>Education and training</p>	<p>Participates in the training of professional groups encountering organ donors and orientation of new employees, and monitors their implementation</p> <p>Ensures that care instructions and updates are communicated</p> <p>Maintains his or her professional skills</p>

Donor coordinator

Each donor hospital must have a donor coordinator

<p>Manages, plans and develops organ donation activities together with the physician in charge</p>	<p>Follows national guidelines and adapts them to their own hospital's practices together with the physician in charge of organ donation</p> <p>Maintains the hospital's instructions for organ donation</p> <p>Ensures that the instructions for organ donation activities are up-to-date and consistent in all units</p> <p>Convenes the donor team</p>
<p>Quality and safety</p>	<p>Audits, gives feedback based on the audit in a targeted manner and prepares a report together with the physician in charge as part of quality assurance and monitoring of their own activities</p> <p>Responds to consultations related to organ donation</p> <p>Participates in the identification and treatment of organ donors according to his or her own job description</p> <p>Ensures that incidents and serious adverse events affecting the quality and safety of organs are reported to the Transplantation Center</p> <p>Carries out a staff attitude survey and gives feedback on it</p>
<p>Reports and monitors organ donation activities and gives feedback</p>	<p>Monitors and develops activities based on feedback received from the hospital's units, the national donor coordinator and the Transplantation Center and the auditing of their own activities</p> <p>Reports on the implementation of organ donation activities (so-called annual report to the Chief Medical Officer, the donor team and key units, the donor team of the university hospital and the national organ donation steering group)</p>
<p>Education and training</p>	<p>Participates in the training of professional groups encountering organ donors and orientation of new employees, and monitors their implementation</p> <p>Supports and, if necessary, participates in the organ donation process</p> <p>Takes encountering and supporting family members into account in training</p> <p>Forms multi-professional networks</p> <p>Maintains his or her professional skills</p>
<p>Communication</p>	<p>Acts as the hospital's donor contact person</p> <p>Informs the donor team and hospital staff of the care instructions and their updates</p> <p>Raises the entire hospital staff's awareness of organ donation and transplantation activities, taking into account the multicultural perspective</p> <p>Pays attention to and supports family members and is responsible for postoperative contact according to the hospital's practices</p>
<p>General matters</p>	<p>Promotes defusing and work guidance practices that correspond to the hospital's activities</p> <p>Ensures that the hospital's internal practices related to organ donation are functional</p>

Person responsible for organ donation activities

Each unit in which an organ donor can be encountered must have a person responsible for organ donation activities

<p>Acts as the responsible person for the department</p>	<p>Acts as a contact person and messenger to their own unit</p> <p>Ensures that the care instructions of the unit are up to date</p> <p>Develops and monitors the operations of the unit</p> <p>Participates in meetings of the donor team and nursing networks according to hospital practice</p> <p>Informs the physician in charge and the donor coordinator of the adverse events related to organ donation in the ward</p>
<p>Education and training</p>	<p>Plans and organises the training of his or her own unit</p> <p>Takes care of the orientation of new employees in the unit and documentation in accordance with hospital practice</p> <p>Participates in organising local organ donation training</p> <p>Maintains his or her professional skills</p>

University hospital coordinator

In addition to the job description of the donor hospital coordinator, the university hospital coordinator's tasks include the following

<p>Coordinates, monitors, develops and trains the activities in their own university hospital area</p>	<p>Organises meetings and training in the cooperation area of their own university hospital</p> <p>Guides and supports the activities of their area</p>
<p>Cooperates with the national donor coordinator</p>	<p>Regularly participates in the development of national activities in cooperation with the donor coordinators of other university hospitals</p> <p>Participates in the organisation of the national training day for donor hospitals</p>
<p>As a member</p>	<p>In the national steering group for organ donation</p>
<p>Participates in research and projects</p>	

Development areas

- The persons responsible for organ donation must be guaranteed sufficient working hours to perform their duties.
 - The work input of the persons responsible for organ donation must be allocated from the hospital management budget. Organ donation activities have extensive impacts on hospital operations. By budgeting the operations under hospital management prevents costs from burdening an individual hospital unit.
- A university hospital is responsible for the smooth running of organ donation activities in its own cooperation area. In order to ensure that this responsibility is fulfilled, it is justified that each university hospital should have a full-time donor coordinator and each university hospital's physician in charge should be allocated 20% working time. The working time input of the donor hospital coordinator should be 10 per cent and that of the physician in charge, 5 per cent.
- When the person in charge changes, the new person must be introduced to the task
- A recommendation on the working hours allocated to the persons in charge

Job description	Working hour need of the job descriptions, minimum
Physician in charge at a university hospital	1 day/week = 20%
Donor coordinator at a university hospital	Full time = 100%
Physician in charge at a donor hospital	1 day/month = 5%
Donor coordinator of a donor hospital	1 day/2-3 weeks = 10%
Unit nurses in charge of organ donation	1 day/month = 5%
+ a deputy for each person in charge	Depending on the job description of the person to be replaced, 1 day /month
+ external training: Domestic and foreign	2-3/year

10. Monitoring the quality and operation of own organ donation and transplantation work

Ensuring the quality of organ donation activities includes objective monitoring of organ donation activities and national peer review. This is approved in the instructions of all organ donation hospitals. Organ donation hospitals follow the data of the deceased by auditing the number of potential donors and the reasons why organ donation has not taken place in the case of a potential donor.

The national quality register (HUS's national auditing register for organ donors) for auditing the data of the deceased enables the discovery of lost organ donors, long-term monitoring and comparison between different donor hospitals. Based on the audit results, training and corrective measures can be better targeted. The results of the audit are reported to the hospital management, the regional university central hospital and the national steering group for organ donation.

The personnel's attitude and awareness of organ donation and transplantation activities are monitored and mapped by means of a uniform national survey conducted every three years.

The Transplantation Center must ensure that the quality and safety of the organ is appropriate. The Transplantation Center is responsible for the removal and transplantation of the organ and approves the organ donor and selects the recipient.

Verification of the quality of organ transplantation activities is based on care instructions and established care practices as well as monitoring both living organ donors and patients who have received an organ transplant (HUS Organ Transplantation Register).

National guidelines on organ donor care and organ procurement (HUS Transplantation Center) harmonise the treatment of brain dead organ donors in donor hospitals. Transplant surgeons make decisions on the possibility of organ donation based on the donor's medical history and examination results collected at the donor hospitals.

Patients will be selected to wait for an organ transplant in multi-professional care meetings of organ transplantation units on the basis of a referral from specialised hospitals in the patient's own area. The assessment of suitability for organ transplantation is based on background information, examinations performed and expert opinions. Efforts have been made to harmonise the criteria for organ transplantation so that patients receive an organ transplant in a timely and equal manner.

Kidney removals from living donors are assessed by a multi-professional working group on the basis of referrals. The statutory monitoring of living donors and transplant patients is based on the HUS Transplantation Center instructions.

Organ transplantation units (HUS Abdominal Center, HUS Heart and Lung Center and HUS Children and Adolescents) monitor all patients who have received an organ transplant and provide treatment and consultation assistance. The treatment of complications is centralised at HUS.

The specialised medical care unit of the living donors' and transplant patients' municipality is responsible for the follow-up. At the organ transplantation unit, this information is registered in the HUS Organ Transplantation Register and further in the Nordic Scandiatransplant register.

The Transplantation Center reports any adverse events in donor hospitals to the supervisory authority (Finnish Medicines Agency, Fimea). Each year, the Transplantation Center submits its annual report to Fimea on organ donation and transplantation.

Development areas

- Ensuring the quality of the national audit of the data of the deceased
 - Cross-audits between hospitals will be developed to ensure consistency of the audit
 - Offering regular audit training
 - Reporting of audit results to the chief medical officers and steering group of donor hospitals
- National survey of personnel attitudes and awareness is carried out every three years
- The Transplantation Center monitors its operations
 - Updating the up-to-dateness and extent of monitoring and register data once a year
 - Monthly multi-professional monitoring of unrealised potential organ donors
 - Annual monitoring and reporting of transplantation results (e.g. to Fimea)
- New monitoring targets in the HUS Organ Transplantation Register
 - Organ-specific rejection criteria will be created
 - Feedback provided on each organ donation event to the donor hospital will be developed

11. A uniform operating model to all donor hospitals

In its final report, the Ministry of Social Affairs and Health working group 2015-2018 set the goal of achieving a level of 30 brain dead organ donors per million population (PMP) in Finland. Regional differences in morbidity or normal annual variations do not explain the current differences in organ donor numbers between the cooperation areas of different university hospitals (See Figure on page 5). As some hospital districts have reached the target in some years, it must be considered realistic.

As patients are still lost because a suitable transplant is not found for them in time and new patients are placed to wait for an organ transplant each year, there is a need to increase the number of transplantations. In order to avoid an increase in the number of people waiting for an organ transplant, 170 (31 PMP) dead donors per year are needed, and in addition, 70 kidney transplantations from living donors must be achieved. According to current knowledge, it is assumed that the need for organ transplantation will increase in the next 10 years, requiring 40 PMP dead donors and 80 transplantations per year from a living donor.

Identification of organ and tissue donors and cooperation with the patient's family play a key role in increasing the number of organ donors.

Directing a potential donor to the correct care location should be fast and flexible

Organ donation is an indication for intensive care, and potential organ donors should no longer be lost in monitoring because there is no intensive care bed available. It is possible that factors affecting the number of intensive care beds, such as pandemics or problems in the availability of personnel, also affect organ donation.

Once a probable organ donor has been identified, the correct place of treatment should be provided as soon as possible. Ensuring the patient's prognosis and opinion regarding organ and tissue donation should not be an obstacle to transferring the patient to the final care location.

Treatment should not be restricted without considering organ donation

The majority of potential organ donors are brought to the hospital by emergency medical care. The prognosis of a critically ill neurological patient may be found hopeless already at an early stage of treatment.

Treatment should never be restricted without considering the possibility of organ donation. A trigger should be created in the patient information systems that would remind the users of the possibility of organ donation whenever treatment restrictions are made.

Organ donation should be part of good care at the end of the patient's life, and this should be highlighted in the instructions of the hospital's chief medical officer concerning good care and restrictions of care at the end of life.

Length of monitoring in the intensive care unit

For an intensive care patient with no prognosis, the possibility of organ donation should always be considered. If the situation does not proceed to brain death, the possibility of organ donation must be assessed after the circulatory confirmation of death.

The practices of different hospitals regarding the monitoring period of a probable organ donor vary from one day to more than a week. If the likelihood of progressing to organ donation is high, the patient should be monitored for at least three days and even longer, if necessary. The Ethics Committee of the Duodecim Association has stated that there is no time limit for monitoring the potential donor. Good communication and cooperation with family members is important in this situation, and the treatment must not cause suffering to the patient.

Discussion with family members

A successful discussion with family members creates a positive image of the organ donation activities and is an important part of the organ donation process. It is important to reserve enough time for the discussion with family members. The aim of the discussion is to provide information on the significance of organ and tissue donation as required by law and to determine the patient's own will regarding organ donation.

83% of Finns have a positive attitude towards organ donation (Kansalaisten käsitykset, 2021). Only 22% of professionals find it natural to discuss organ and tissue donation with the patient's family members (Personnel attitude survey 2020). In many countries, the person conducting the discussion with the family members is an organ donor professional who has received training in the discussion with family members. In Finland, a physician on call usually conducts the discussion with the family members during on-call hours. During office hours this is done by a senior physician, while the specializing physician might follow the discussion. The nurse in charge of the patient's care should participate in the discussion to improve communication between the family members, the nurse and the physician.

A network of experts should be created to develop training for encounters with family members and to support professionals in their practical work.

Development areas

- National standardised and uniform guidelines for organ donation activities should be created
 - The organ donor's access to the right place of care as quickly as possible should be guaranteed
 - The treatment time in the intensive care unit should be long enough to assess the possibility of organ donation
- Creating triggers in patient information systems about keeping the possibility of organ donation in mind when treatment restrictions are made electronically
 - A medical history form for a potential donor should be attached to the form section of the electronic information systems of donor hospitals.
- Instructions from the chief medical officer should be included in the donor hospital's instructions
 - Instructions for end-of-life care: Considering organ donation is part of the good care of a dying patient and must always be done before treatment is restricted
 - Instructions on the appropriate organisation of organ and tissue donation activities in one's own area
- Encounters with the organ donor's family members are developed
 - Increasing training on organ donation discussions and encountering family members
 - Establishment of an expert network
 - Standardisation of support practices offered for family members
 - Launching expert by experience activities

12. Development targets for organ transplantation activities

The objective of quality assurance and development of operations is to increase the number of organ transplantations and ensure that the results remain at a high international level. A comprehensive register of the transplantations is kept, which, in addition to operating figures, shows the quality of operations. Transplant patients are monitored until they die and even the cause of death is registered.

In the last ten years, the number of transplantations has almost doubled, although the number of those waiting for a transplant is still increasing slightly. To correct this, "Donation after Circulatory Determination of Death (DCDD)" has been initiated. The piloting of the activities began in autumn 2021 and was completed on 1 August 2022. Thanks to good results, the activities will continue with kidney donations and transplantations as part of other organ transplantation activities. The activities will be established over the next few years and it is possible that DCDD donors will also be used for transplantation of other organs. As the number of those awaiting kidney transplantation increases, the activities involving living donors have also been significantly increased and efforts are being made to increase the activities further.

In Finland, resources for organ transplantation are scarce from an international perspective. The external audit of the HUS Transplantation Center was carried out in 2015 (External Audition of HUS Organ Transplantation Services 2015). Already at that time, serious shortcomings were found in the resourcing of operations. The increased number of organ transplantations has still not been taken into account in the resourcing of organ transplantation activities. The activities require more resources for all parts of the transplant patient's treatment chain, such as intensive care and operating room capacity, doctors, nurses and other personnel.

The average age of organ donors, as well as transplant patients, is rising and, in part, as a consequence of this, lower quality organs must also be accepted, as they have also been shown to improve the quality of life and life expectancy of the patient. With the help of new perfusion machines the functioning of such organs can be confirmed. Development has started with kidney transplantations in which these machines are used. The use of perfusion machines in liver transplantations is not yet necessary, but if the extension of indications brings more patients waiting for transplantation, this possibility must be enabled. Use of perfusion machines may be useful in ensuring the quality of heart-lung transplants.

In countries where the number of donors is lower than in Finland the use of these means has been established as part of the transplantation activities. Full body perfusion has also been introduced in donation, especially in DCDD activities, in which case oxygen supply to future transplant organs is kept normal for as long as possible. These methods can also increase the number of donors without compromising the quality of the transplants.

In liver transplantations, the possibility has been developed to distribute a single donor transplant to two recipients, such as the left side for a child and the right side for an adult (split liver), but so far this technology has not been needed in Finland.

The indications for transplantation have changed slightly throughout the activities, and new indications for a liver transplant will be the treatment of colorectal metastasis and chronic liver diseases that have become acute by transplantation. Correspondingly, the proportion of virus hepatitis is decreasing thanks to new treatment methods.

In order to ensure and develop the high quality of organ transplantation, continuous research and international cooperation are needed. Own work is monitored from Finnish and international quality registers, on the basis of which operating methods are assessed and the necessary changes are planned. Research is an integral part of organ transplantation, as it is a multi-professional sector that is continuously developing in diagnosing diseases, understanding their natural course and the factors associated with the transplantation itself.

International cooperation is a prerequisite for transplant operations both in ensuring its quality and in areas of development. It has been estimated that the appropriate population for one transplantation center is approximately 5 million, which means that there is only one transplantation center in Finland. The same principle applies in all Nordic countries. By expanding the cooperation with the Scandiatransplant organisation, it is possible to ensure that a transplant is found even in urgent cases or when it is difficult to find a suitable transplant. The importance of international connections is emphasised above all in training, research and the development of activities. The only way to ensure the operation of an individual center is to train staff carrying out transplantations also abroad.

Development areas

- Ensuring and developing the quality of organ transplantations
- Increasing the number of organ transplantations
- Accepting new indications
- Utilising new technologies
- Increasing resources
- Foreign cooperation in research and education

13. Child as an organ donor and pediatric organ transplantations

Child as an organ donor

There is no minimum age for organ donors; a small child and infant may also be organ donors. In the Nordic countries, the youngest children who have received an organ transplant have been under 6 months old. It is very important that all potential minor organ donors are identified in all units in our country that treat neurologically critically ill pediatric patients. There are very few child organ donors, and even professionals working in pediatric intensive care units do not meet child organ donors annually. From the point of view of organ transplantation, the training, communication and predetermined operating methods of the key units in Finland (intensive care units, emergency clinics and operating rooms) enable good and professional care of a child donor, encountering family members and staff coping.

The consent of both guardians must be obtained for the removal of organs from a minor. An acute critical illness and death of a child is a devastating crisis for the whole family. Sufficient time should be reserved for discussions with the child's family, and the aim should be to have multi-professional discussions led by a specialist during office hours. It is important for the nurse in charge of the patient's care to participate in all discussions with the family members. The discussions must provide sufficient information on organ donation and there should be no need to rush making the decision. The parents of a child organ donor need the support of professionals throughout the process, and they must be offered the opportunity to contact them afterwards.

Staff coping should be taken into account in all units that treat a potential child organ donor. The discussions with family members are difficult and the staff should be offered an opportunity to discuss the matter afterwards. Guardians prohibit individual organ donations each year.

The special characteristics of diagnosing brain death in children and infants and the main principles of care should be known in units treating children with critical neurological diseases nationwide. There are very few child organ donors in Finland and, if necessary, the intensive care unit of the New Children's Hospital will be consulted.

Pediatric organ transplantations

Organ transplantation is also a generally accepted form of treatment for severe, irreversible organ damage in children. The decision on organ transplantation is made on a patient-specific basis in a multi-professional meeting. The transplantation decision is influenced, among other things, by the nature of the underlying disease, the patient's prerequisites for coping with major surgery and subsequent antirejection

drugs affecting the body's defence system, and the assumption that the transplantation will improve the quality of life.

Pediatric organ transplantation activities in Finland are concentrated in the New Children's Hospital. Compared internationally, the results of pediatric organ transplantations are excellent in Finland, and 70-95% of patients survive. A child who has received a transplant needs lifelong antirejection medication, but otherwise everyday life may correspond to the child's age. After the transplant, the growth and development of children and adolescents is mainly normal and the quality of life is good.

The monitoring of patients who have received an organ transplant as a child is coordinated by the New Children's Hospital's renal and organ transplantation unit in cooperation with the patient's home hospital.

The transition to the monitoring of adult units takes place at the age of 18 to 20, patient-specifically. There is an increased risk of losing the transplant during and after the transition. The transition is preceded by systematic orientation of the patient and guardians in matters such as the patient's primary disease, the performed organ transplantation and antirejection medication. At HUS, the transition programme has been prepared in cooperation with units treating adult patients. In the patient's home hospital, the transition takes place according to local instructions.

Development targets for pediatric organ donation activities:

- Training for the identification and care of child organ donors
- Increasing staff capabilities, especially for encounters with family members
- Supporting the coping of staff (debriefing as part of the care of a child organ donor)

Development targets for pediatric organ transplantation activities:

- Sufficient resources must be ensured for high-quality implementation of the activities
- Promoting a smooth transition

14. Kidney transplant from a living donor

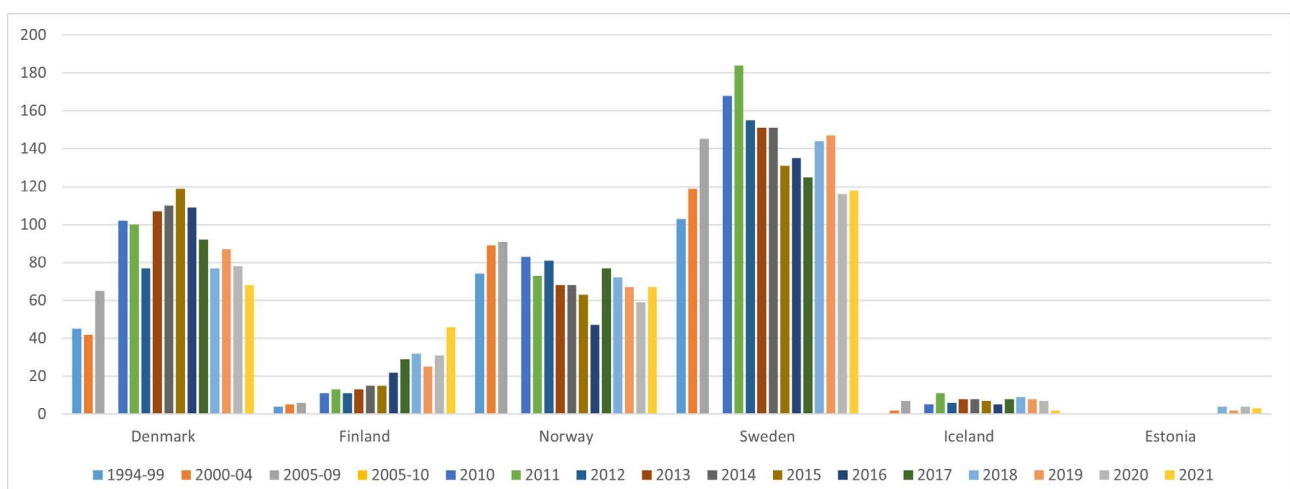
Under the so-called Tissue Act, an adult who is able to decide on his or her treatment may donate a non-renewable organ.

A permission from the Finnish Medicines Agency Fimea is required for the donation. Donation is subject to the condition that it does not cause the donor any major health hazard or serious harm and that no other treatment is available for the recipient that is equally effective. The donor must give written, informed consent for the procedure. They must be aware of the significance of the organ removal and the possible risks for themselves and the recipient. The donor has the right to withdraw the consent at any time without giving any reason. Potential donors are assessed very carefully. The purpose is to ensure the safety and voluntary nature of the donation and to ensure that the donation does not involve the acquisition or provision of financial advantage. The aforementioned voluntariness and financial advantage are assessed by an independent specialist in psychiatry. Examination results are sent to the Transplantation Center, where the transplant surgeon decides on organ donation.

Benefits of kidney transplantation from a living donor

A kidney transplantation from a living donor has many advantages for the patient. By increasing the number of living kidney donors, it is possible to significantly improve the timely implementation and cost-effectiveness of the treatment of patients awaiting kidney transplantation. If a suitable living donor is found, kidney transplantation is more likely to take place even before the start of dialysis (pre-emptively), the patient's possible time on dialysis is shorter and the prognosis after the transplant is better (Toolbox 2009–2015, Vanholder R 2019).

Current situation



Number of living kidney donors in the Nordic countries and Estonia.
Source Scandiarttransplant.org.

The job description of the national coordinators of living donors includes developing activities nationwide and building and maintaining a national cooperation network. In addition, Nordic cooperation within the framework of the cross-donation programme (STEP) is included in the job description of the coordinators of living donors.

Each hospital district must appoint persons responsible for living kidney donation (nephrologist and nurse) to help build a functioning cooperation network. The appointed responsible persons ensure that up-to-date instructions are put into practice and the equality of patient care is improved.

The possibility of a living kidney donor should be taken into account for each kidney transplant patient, and information on this should be provided to renal patients at an early stage. The criteria for suitable living donors should be nationally uniform and the examination process should proceed without delay.

Through a well-functioning national cooperation network, information on living kidney donation can be increased among health care professionals and patients and their families. Citizens' awareness of the possibilities of living kidney donation can be increased in cooperation with the Finnish Kidney and Liver Association. Sufficient resources should be allocated for the activities to ensure that citizens' positive perceptions of organ donation can be maintained and strengthened.

The law requires that kidney donors are regularly monitored and that their details are recorded in the register. The responsibility for the follow-up of kidney donors lies with the specialised medical care unit of their home municipality. These units also have an obligation to submit follow-up information to the Transplantation Center for it to be entered in the donor follow-up register.

Acting as a kidney donor should not affect the donor's health and social status and the donor should not suffer financial loss. In the current situation, some donors lose earnings in connection with pre-operative examinations and post-operative sick leave. Some donors incur costs for trips related to examinations and surgery. The situation should be rectified and it should be ensured that the costs incurred by the donors during the process are fully reimbursed.

Psychosocial support for living kidney donors, such as peer support, should be developed in cooperation with the Finnish Kidney and Liver Association.

Development areas

- Assigning nephrologist-nurse-teams to nephrological units
- Increasing the number of kidney transplantations from living donors to the Nordic level, approximately 70 kidney transplantations from living donors per year
- Awareness of living kidney donation among healthcare professionals and citizens should be increased
- The responsibility for the statutory follow-up of living kidney donors lies with the specialised medical care unit of the donor's home municipality
- Full reimbursement of costs incurred by kidney donors should be realised
- Psychosocial support offered to kidney donors should be developed
- Munuaisluovuttajille tarjottavaa psykososiaalista tukea tulee kehittää

15. Training and orientation

The key objective of personnel training has been to identify and care for a potential organ donor so that the usability of organs for organ transplantation remains as good as possible. A prerequisite for achieving the objectives is the appropriate training and orientation of the persons taking part in the care of the organ donor. Training and orientation are planned in a targeted manner based on information obtained from the audit, survey results on organ donation and transplantation activities and feedback.

The so-called Tissue Act (101/2001, section 20q) states that a donor hospital must regularly provide appropriate training for its personnel. The staggering of training is organised according to local, regional and national levels. Training materials are prepared centrally for use in education, taking into account different training methods (e.g. simulation and training videos), to be adapted to the needs of each hospital. In connection with the European Day for Organ Donation and Transplantation, hospitals organise an organ donation theme week at which time the activities will be made visible through various events, training and briefings.

The steering group is responsible for producing national teaching materials. Donor hospitals are responsible for producing their own training material.

In order to ensure uniform national training and orientation material, a training and orientation package will be created in HealthVillagePRO to cover the entire organ donation process. Up-to-date and consistent information will be collected in HealthVillagePRO that is accessible to all healthcare professionals, anytime, anywhere.

Orientation

The personnel's orientation to organ donation must be part of the normal orientation programme in units where organ donors can be encountered. In order to harmonise the orientation of the persons in charge, a national orientation template will be created for the donor coordinator, the physician in charge of organ donation and the persons responsible for organ donation. Orientation and training should be monitored and documented in accordance with hospital practice. If the persons in charge change, they must be introduced to their job description.

Local training

Identifying a potential organ donor is one of the most important factors in successful organ donation activities. In order for identification to be successful, all persons involved in the care of critically ill patients must be provided with regular, annual local training. The hospital's donor team is responsible for the internal training of the hospital.

Regional training

University hospitals offer support to donor hospitals in their own area of cooperation in different areas of organ donation. University hospitals organise regional organ donation training annually and ensure that all donor hospitals in the area receive training. In addition to maintaining practical skills related to organ donation activities, the training must also offer content on topical issues related to the activities. It is important that the persons responsible for organ donation in the cooperation areas of university hospitals network with each other to share best practices and expertise.

National training

Once a year, a national training event will be organised for the persons responsible for organ donation in donor hospitals. The national steering group for organ donation and transplantation and the national donor coordinator are responsible for planning and organising the training. HUS is responsible for the costs of the event.

The training must provide information on topical issues and an opportunity for networking, receiving peer support and motivating the responsible persons to promote organ donation activities.

Objectives of training and orientation

The objective of training the personnel of donor hospitals is that the personnel:

1. Identifies a potential organ donor
2. Knows how to follow the care path of an organ donor in their own hospital
3. Knows how to treat an organ donor in accordance with up-to-date organ donor care instructions so that the usability of organs for organ transplantation remains as good as possible
4. Understands the crisis affecting the donor's family members, supports them and is able to provide them with further support if necessary
5. Understands the significance of organ donation and transplantation for both individuals and society

Development areas

- The steering group is responsible for producing national, uniform training and orientation material
 - A training and orientation package covering the entire organ donation process will be created in HealthVillagePRO
- Organ donation as part of the orientation programme in units where an organ donor can be encountered
- The basics of organ donation and transplantation are included in the training of nurses, paramedics, doctors and practical nurses

16. Communication

Raising awareness of organ donation for both professionals and citizens has been found to be the most effective way to increase the number of donors and transplantations (Organ donation and transplantation, Facts, figures and European Union action, EPRS | European Parliamentary Research Service, April 2020).

57% of citizens feel that there is too little discussion about organ donation (Kansalaisten käsitykset elinluovutuksesta, Kantar/ Finnish Kidney and Liver Association, 2021). 42% of health care personnel feel that there is too little discussion in hospitals about organ donation, and 61% feel that there is too little public discussion (Personnel attitude survey, 2020).

Communication is targeted at citizens, professionals and health care personnel as well as decision-makers at the national and municipal level

Communication by target group

In communication aimed at citizens, the main message is “organ transplantation saves life”. The communication reminds people that it is more likely that you yourself will need a transplant than that you are an organ donor.

The aim of communication is to strengthen citizens' positive attitudes towards organ donation. They are encouraged to express their willingness to donate organs and discuss it with their family members. Only 31% of citizens know whether their family members are willing to donate organs. The Finnish Kidney and Liver Association conducts an attitude survey of citizens' perceptions of organ donation and transplantation every two years.

Communication aimed at citizens is carried out all year round online and in social media as well as through separate press releases, theme weeks and campaigns. The communication cooperation of organisations administered by the Finnish Kidney and Liver Association is responsible for the majority of communication directed at citizens.

In communication aimed at professionals, the main message is “more organ donations and transplantations are needed”, and the aim is to identify all potential donors. To achieve these goals, the hospitals' own homepages, social media, and the annual theme week of organ donation will be used for the entire hospital staff.

In communication aimed at decision-makers, the main message is that kidney transplantation is the most cost-effective treatment available and the only curative treatment in end-stage liver, heart and lung failure. In addition, organ transplantations are humane care. Awareness of the importance of organ donation and transplantation and the status of living kidney donors will be raised.

The aim is to increase the number of organ transplantations. In order to increase organ transplantation volumes, more resources are needed for organ donation work, as the factor limiting transplantation is the shortage of organ donors.

The parliamentary support group for kidney, liver and organ transplant patients in Parliament is doing significant work to raise awareness among decision-makers.

Communication objectives

- More and more people have informed others of their willingness to donate organs
- More and more people are ready to donate their organs
- Organ donation and transplantation activities are communicated openly
- Citizens' debate increases

Development areas

- Create an easily approachable and discoverable site that provides citizens with information about organ donation and transplantation
- Sufficient resources must be ensured to implement communication to citizens
- Social media communication on the importance of organ donation and transplantation should be increased
- Cooperation with decision-makers should be increased

17. Budget

Organ donation activities have not had an allocated appropriation, either regionally or nationally. In donor hospitals, funding has been received from the units in which the persons in charge work. As a rule, the intensive care and anaesthesia units have paid for the organ donation training and the necessary materials.

Kidney transplantation is the most cost-effective treatment provided by medical care. After the first year, one transplanted kidney saves €40,000 per year compared to dialysis, and the calculated half-life of a kidney is 20 years. Organ donation activities have extensive impacts on hospital operations. By budgeting the operations under hospital management prevents costs from burdening an individual hospital unit.

The budget of each donor hospital must take into account the recommendation on the working hours allocated to the persons responsible for organ donation activities ([see table on page 31](#)). Other costs arising from the activities are incurred from organising training, producing teaching material, communication and maintaining one's own vocational skills ([see table on page 50](#)).

Communication to citizens has traditionally been primarily the responsibility of the Finnish Kidney and Liver Association and the communication cooperation between the organisations administered by it. The activities have been funded by a decision of the Funding Centre for Social Welfare and Health Organisations. Should funding be transferred to the state budget in the coming years, its continuity and sufficient level should be taken into account. The current subsidy is considerably smaller than the funding for similar activities, for example in Sweden and Norway.

Development areas

- Activities directly under hospital management
- A separate budget for organ donation activities both nationally and at the level of the donor hospital
- Funding for the Finnish Kidney and Liver Association must be secured

The following should be taken into account in the costs of organ donation activities

Costs of the donor hospital

Physician in charge, senior ward physician 5%	
Donor coordinator 10%	
Donor nurse 3%	
Training and travel costs, maintaining your professional skills	
Materials	
Total estimated costs €/year	estimate 19 000 €

Costs of a university hospital

Physician in charge 20%	
Donor coordinator 100%	
Training and travel costs	
Materials	
Maintaining your professional skills	
Total estimated costs, university hospital €/year	estimate 98 000 €

The following should be taken into account in the costs of HUS's national responsibility

Donor coordinator 100%	100 000
Technical support person/senior planning officer 0% ->100%	65 000
Training and travel costs (donor coordinator)	8 000
Training and travel costs(senior planning officer)	4 000
National training of donor hospitals	15 000
Material costs, teaching videos	16 000
Other costs (audit of BCB data of the deceased)	30 000
Costs of communications (share of HUS communications)	50 000
Maintaining your professional skills	4 000
Total estimated costs €/year	estimate 292 000 €

18. Bibliography and references

National Action Plan on Organ Donation and Transplantation 2015–2018, Ministry of Social Affairs and Health publications 2014:14

Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine 24/2010

Directive 2010/53/EU of the **European Parliament and of the Council on standards of quality and safety of human organs intended for transplantation**, so-called EU directive

Commission Implementing Directive 2012/25/EU of 9 October 2012 laying down **information procedures for the exchange, between Member States, of human organs intended for transplantation**

Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin. Treaty 24/2010

Government Decree on the division of labour in specialised medical care and the centralisation of certain tasks (Valtioneuvoston asetus erikoissairaanhoidon työnjaoista ja eräiden tehtävien keskittämisestä, 582/2017), so-called centralisation decree

Administrative Regulation of the Finnish Medicines Agency 2/2014: **Quality and safety requirements applicable to organ donation and organ transplantation**

Administrative Regulation of the Finnish Medicines Agency 1/2016: **Information to be recorded on the donor and organ removal record**

National decision of establishing a steering group for organ donation, Decision of HUS Chief Medical Officer 117/2019

Database created by Oulu University Hospital for the auditing of the data of the deceased to find out the reasons why organ donors are lost, Tero Ala-Kokko and Sinikka Sälkiö, 2013

Act on the Medical Use of Human Organs and Tissues (101/ 2001), the so-called Tissue Act

Organ donation and Transplantation, Facts, figures and European Union Action, European Parliamentary Research Service, 2021

Toolbox Living Kidney Donation, Document developed by the Working Group on Living Donation under the European Union “**Action Plan on organ donation and transplantation** (2009-2015): Strengthened Cooperation between Member States”

R Vanholder, VS Stel, KJ Jager, N Lameire, F Lloud, et al. **How to increase kidney transplant activity throughout Europe**—an advocacy review by the European Kidney Health Alliance. *Nephrology Dialysis Transplantation*, 2019, 34: 1254–1261

Kansalaisten käsitykset elinluovutuksesta, 2021 Kantar, Ordered by the Finnish Kidney and Liver Association

19. Työryhmä

HUS

Eero Hartikka, Transplant Coordinator, Abdominal Center

Ilkka Helanterä, Nephrologist, Docent, Abdominal Center

Timo Jahnukainen, Pediatric Transplant Specialist, Docent, Children and Adolescents

Niina Kauppinen, Communications Manager, Communications

Jenni Kippola, Coordinator of Living Kidney Donors, Abdominal Center

Anna-Maria Koivusalo, National Donor Coordinator, Docent, Helsinki University Hospital Area Administration

Lotta Laine, Communications Specialist, Communications

Marko Lempinen, Transplant Surgeon, Docent, Abdominal Center

Karl Lemström, Chief Physician, Professor, Heart and Lung Center

Heikki Mäkisalo, Chief Physician, Professor, Abdominal Center

Arno Nordin, Head Physician, Docent, Abdominal Center

Kukka Nurmi, Donor Coordinator, Helsinki University Hospital Area Administration

Antti Nykänen, Specialist, Docent, Heart and Lung Center

Saija Näse-Stålhammar, Specialist, Intensive Care Unit, Children and Adolescents

Kirsi Rantanen, Neurologist, Neurocenter

Johanna Savikko, Specialist, Docent, Abdominal Center

Veli-Matti Ulander, Administrative Chief Medical Officer, Docent, Helsinki University Hospital Area Administration

Tuija Uosukainen, Donor Coordinator, Perioperative, Intensive Care and Pain Medicine

Eija Valin, Financial Manager, Abdominal Center

Elisa Ylinen, Pediatric Transplant Specialist, Docent, Children and Adolescents

OYS

Tero Ala-Kokko, Head Physician, Professor, Intensive Care Unit

Niina Keinänen, Specialist, Intensive Care Unit

Sinikka Sälkiö, Donor Coordinator, Intensive Care Unit

KYS

Maarit Lång, Specialist, Intensive Care Unit

Toni Matkaselkä, Donor Coordinator, Intensive Care Unit

Tiina Sirkka, Nurse, Kidney Center

Eija Vaskelainen, Donor Coordinator, Intensive Care Unit

TAYS

Jaakko Långsjö, Specialist, Docent, Intensive Care Unit, Acute Care Division

Satu Mäkelä, Nephrologist, Docent, Kidney Center

Jyrki Ollikainen, Neurologist, Neurocenter

Salla Salin, Donor Coordinator, B.Sc. (Health Science), Acute Care Division

TYKS

Juha Grönlund, Specialist, Intensive Care Unit, Totek

Tiina Hämäläinen, Donor Coordinator, Intensive Care Unit, Totek

Central Finland Hospital District

Anni Pulkkinen, Specialist, Intensive Care and Monitoring

Tiina-Mari Puumalainen, Donor Coordinator, Nurse (Master's Degree), Intensive Care and Monitoring

Kainuu Central Hospital

Thomas Riess, Head Physician, Surgical Department

Marja Tirronen, Donor Coordinator, Surgical Department

Ministry of Social Affairs and Health

Tuula Helander, PhD, Director

Sini Tervo, Master of Laws, Senior Officer, Legal Affairs

Finnish Medicines Agency Fimea

Minna Kymäläinen, Specialized Nurse, Officer

Anne Vaskunlahti, PhD, Head of Section

Finnish Institute for Health and Welfare

Antti Virtanen, Forensic Pathologist, Forensic Medicine Unit

Sirkka Goebeler, Senior Specialist, Docent, Forensic Medicine Unit

Finnish Kidney and Liver Association

Sari Högström, Master of Public Health, Executive Director

Petri Inomaa, Communications Manager