

# **National Action Plan on Organ Donation and Transplantation**

2015–2018



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# SUMMARY

## National Action Plan on Organ Donation and Transplantation 2015–2018

■ The National Action Plan on Organ Donation and Transplantation for the years 2015–2018 was prepared on the basis of a proposal that was developed by an expert group appointed by the Ministry of Social Affairs and Health.

Organ transplantation is the best, and in many cases the only available treatment for end-stage organ failure. Due to a chronic shortage of organs, however, every year between 5 and 10 per cent of persons waiting for transplantation die before receiving a transplant. On the other hand, some studies suggest that donor hospitals fail to identify a significant number of deceased potential organ donors.

The main objective of the Action Plan is to ensure that all patients in need of organ transplantation have timely and fair access to transplants. Achieving this objective will require identifying every potential donor. Another aim of the Action Plan is to increase the number of kidney transplantations by enhancing living donation.

In order to improve the efficiency of the transplantation system, it is necessary to establish a national steering group for organ donation that will be responsible for developing, coordinating and monitoring activities at the national level. In addition, there is a need for a national coordinator for organ donation. The Ministry of Social Affairs and Health and the specific catchment areas (the future social welfare and health care regions) will work together to create the post of national coordinator. Catchment areas are responsible for providing guidance and support to donor hospitals and for monitoring activities within their areas. Additionally, every donor hospital will need to set up a donor coordination team that will be in charge of organ donation and related training activities within the hospital.

Both patients waiting for organ transplantation as well as the municipalities that finance the health services stand to gain from a more efficient transplantation system. Kidney transplantation is one of the most cost-effective treatments. It has been estimated that a functioning kidney transplant delivers a benefit to society of €500,000 compared to dialysis.

Key words:

**living donor, organ donor, organ transplant, organ transplantation, transplant**

# TIIVISTELMÄ

## Elinluovutusta ja elinsiirtoja koskeva kansallinen toimintasuunnitelma vuosille 2015–2018

■ Elinluovutusta ja elinsiirtoja koskeva kansallinen toimintasuunnitelma on laadittu vuosille 2015–2018 sosiaali- ja terveysministeriön (STM) asettaman asiantuntijaryhmän esityksen pohjalta.

Elinsiirto on vakiintunut hoitomuoto henkeäuhkaavassa elimen vajaatoiminnassa. Pitkälle edenneessä elinten vajaatoiminnassa elinsiirto on myös enusteen ja elämänlaadun kannalta paras hoito. Sopivista elinsiirteistä on kuitenkin jatkuva pula. Joka vuosi 5–10 % elinsiirtoa odottavista kuolee, koska sopivaa siirrännäistä ei löydy ajoissa. Toisaalta tutkimuksissa on todettu, että elinluovutussairaaloissa mahdollisia elinluovuttajia jää tunnistamatta.

Toimintasuunnitelman päätavoitteena on, että kaikki potilaat, jotka tarvitsevat elinsiirron, saavat elinsiirteen oikea-aikaisesti ja yhdenvertaisesti. Tavoitteeseen pääseminen edellyttää, että jokainen mahdollinen elinluovuttaja tunnistetaan. Tämän ohella munuaissiirtojen kokonaismäärää pyritään kasvattamaan lisäämällä elävältä luovuttajalta tehtäviä munuaissiirtoja.

Optimaalinen elinsiirtotoiminta edellyttää koko elinluovutus- ja elinsiirtoketjun toimivuutta ja moniammatillista yhteistyötä. Elinluovutustoiminnan tehostamiseksi on tarpeen perustaa valtakunnallinen elinluovutustoiminnan ohjausryhmä vastaamaan toiminnan kansallisesta kehittämisestä, ohjauksesta ja seurannasta. Ohjausryhmän ohella tarvitaan elinluovutustoiminnan kansallinen koordinaattori. Kyse on kansallisesta tehtävästä, jonka toteutuksesta STM ja erityisvastuualueet (tulevat sosiaali- ja terveysalueet) neuvottelevat. Erityisvastuualueet (tulevat sote-alueet) vastaavat toiminnan ohjauksesta ja seurannasta alueellaan. Jokaiseen elinluovutussairaalaan on lisäksi tarpeen perustaa elinluovutustyöryhmä, joka vastaa sairaalansa elinluovutustoiminnasta ja koulutuksesta.

Elinluovutustoiminnan tehostamisesta hyötyvät sekä elinsiirtoa odottavat potilaat että toimintaa rahoittavat kunnat. Munuaissiirto on yksi kustannusvaikuttavimmista hoidoista. Hyvin toimiva munuaissiirre säästää yhteiskunnan varoja puoli miljoonaa euroa dialyysihoidon kustannuksiin verrattuna.

Asiasanat:

**elinluovuttaja, elinsiirre, elinsiirto, elävä luovuttaja, siirrännäinen**

# SAMMANDRAG

## Nationell handlingsplan för organdonation och organtransplantation 2015–2018

■ Den nationella handlingsplanen för organdonation och organtransplantation har utarbetats för åren 2015–2018 utgående från förslaget från en expertgrupp som tillsatts av social- och hälsovårdsministeriet.

Organtransplantation är en etablerad behandlingsform vid livshotande organsvikt. Organtransplantation är också den bästa behandlingen för en långt framskriden organsvikt samt med tanke på prognosen och livskvaliteten. Det finns dock jämt brist på lämpliga organ för transplantation. Varje år dör 5–10 % av dem som väntar på organtransplantation, eftersom man inte i tid kan få tag på ett lämpligt transplantat. Å andra sida har man konstaterat i studier att donatorssjukhusen inte identifierat alla möjliga organdonatorer.

Huvudmålet för handlingsplanen är att samtliga patienter i behov av en organtransplantation ska få ett transplantat i rätt tid och på jämlik basis. För att man ska kunna nå detta mål behöver varje möjlig organdonator identifieras. Därutöver försöker man öka det totala antalet njurtransplantationer genom att öka transplantationerna från levande donatorer.

En optimal organtransplantationsverksamhet förutsätter en väl fungerande organdonations- och transplantationskedja och multiprofessionellt samarbete igenom hela kedjan. Det är behövligt att tillsätta en nationell styrgrupp för organdonationsverksamhet för att effektivisera verksamheten. Styrgruppen ska ansvara för nationell utveckling, styrning och uppföljning av verksamheten. Vid sidan av styrgruppen behövs en nationell koordinator för organdonationsverksamheten. Det är fråga om en nationell uppgift, och social- och hälsovårdsministeriet och specialupptagningsområdena (i framtiden social- och hälsovårdsområdena) ska förhandla om genomförandet av detta. Specialupptagningsområdena (de framtida social- och hälsovårdsområdena) kommer att ansvara för styrningen och uppföljningen av verksamheten inom sina områden. Det är också behövligt att varje donatorssjukhus ska tillsätta en arbetsgrupp för att ansvara för organdonationsverksamheten på sjukhuset och därmed förknippad utbildning.

Både de patienter som väntar på organtransplantation och kommuner som finansierar verksamheten kommer att ha nytta av en effektiviserad organdonationsverksamhet. Njurtransplantation är en av de kostnadseffektivaste behandlingarna. Ett väl fungerande njurtransplantat sparar samhället en halv miljon euro jämfört med kostnaderna för dialysbehandling.

Nyckelord:

**levande donator, organdonator, organtransplantat, organtransplantation, transplantat**

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# INTRODUCTION

Several years ago, the European Commission published an Action Plan on Organ Donation and Transplantation for the years 2009–2015, the objectives of which include increasing organ availability, improving quality and safety, and enhancing the efficiency and accessibility of transplantation systems (Commission of the European Communities 2008). In order to achieve these objectives, Member States were urged to draw up “sets of national priority actions” specifically tailored to the situation in each Member State.

In Finland, fewer organ transplantations are performed than needed due to a continuous shortage of suitable transplants. The main factor restricting transplant availability is a failure to identify all potential donors.

In order to develop the organ transplantation system, the Ministry of Social Affairs and Health appointed in February 2013 an expert group to prepare a national action plan on organ donation and transplantation and to estimate the resource needs for implementing such a plan. The expert group was also tasked with initiating the implementation of the action plan.

The main objective of the National Action Plan is to ensure that all patients in need of organ transplantation on medical grounds have timely and equitable access to a transplant.

To achieve this target, an estimated 30 donors after brain death per million inhabitants would need to be identified annually in Finland. The preconditions for reaching the target include identifying all potential organ donors and referring them to an intensive care unit, while paying particular attention to approaching donors’ families in an appropriate manner and ensuring that adequate skills and resources to care for organ donors are available.

Ensuring that the organ transplantation system functions in an optimal manner requires efficiency throughout the organ donation and transplantation chain and multi-professional cooperation. All patients needing an organ transplant on medical grounds should be referred to the Transplantation Centre at the Helsinki University Hospital for assessment, and patients should move up on the transplant waiting list fairly and without any unnecessary delays.

# BACKGROUND

## ORGAN TRANSPLANTATION IN FINLAND

Organ transplantation is an established treatment for end-stage organ failure or a cost-effective substitute treatment in cases where, for example, dialysis can be replaced by kidney transplantation.

### Shortage of transplants

The greatest problem affecting organ transplantation is a continuous shortage of suitable transplants. Currently, there are more than 350 people on the transplant waiting list in Finland. The need for organ transplantation is increasing more rapidly than the number of donations. Every year, 5–10% of patients on the waiting list die because a suitable transplant cannot be found in time.

### Number of transplantations

In 2013, a total of 285 organ transplantations were performed in Finland, with the majority of patients being adults. Annually, 15–20 transplantations are performed in children. Kidney transplantations account for 65% of the total number of such operations. In order of frequency, the next most common procedures are liver, heart, lung and pancreas transplants. Only a few small intestine transplantations have been carried out in Finland so far.

More than 8 000 organ transplantations have been performed in Finland over the last 50 years. Nearly 4 000 patients who have received a transplant are currently alive, and the majority of them are leading relatively normal lives.

### Outcomes

Organ transplantation outcomes in Finland are excellent by international comparison. Acute rejection is no longer a problem. For instance, 94% of transplanted kidneys remain functional one year after the operation, and one out of every two is still functioning 20 years later. The ten-year survival rate is 80% for liver transplant patients and better than 75% for heart transplant patients. For all organ transplant patients, the five-year survival rate is 80%.

Kidney transplantation is the best treatment option for end-stage kidney disease, both in terms of the prognosis and the patient's quality of life. Consequently, one European recommendation states that in the absence of



strict contraindications, kidney transplantation should be considered for every dialysis patient. Research has shown that kidney transplantation improves the prognosis regardless of a patient's age. In the majority of cases, transplantation improves a patient's physical, psychological and social well-being, and some patients are able to return to work.

## Cost-effectiveness

Kidney transplantation is also one of the most cost-effective treatments. Compared to the costs of dialysis treatment, a well-functioning kidney transplant produces savings amounting to half a million euros for society. In 2004, it was estimated that a kidney transplant pays for itself within two years of the operation. Heart transplantation is also more cost-effective than mechanical circulatory support when treating end-stage heart failure.

## ORGAN DONATION

### Organ procurement organisation

All university hospitals, central hospitals and some smaller hospitals take part in organ donation. Organ transplantations have been centralised at the Helsinki University Hospital (HUCH). A HUCH surgical team also carries out the removal of organs at procurement hospitals. HUCH is a member of the Nordic organ exchange organisation Scandiatransplant ([www.scandiatransplant.org](http://www.scandiatransplant.org)), which coordinates organ transplantation in the Nordic countries in accordance with jointly agreed upon rules. The organisation provides assistance with finding suitable transplants in urgent or otherwise problematic cases. As a general rule, each country relies on organs from donors in that particular country.

### Organ donors

Nearly all organ transplantations in Finland are performed using organs from donors after brain death. The typical cause of brain death is bleeding in the brain or a brain injury. In 2013, transplants were obtained from 95 donors after brain death. While the organs obtained from a single donor are, on average, used to treat three people, up to six patients may receive an organ from a single donor.

Under certain conditions, a kidney may be donated by one of the patient's living family members. Currently, in one out of every two kidney transplantations performed on children the donor is one of the child's parents.

# Comparison of donor figures

There are major differences between the various EU Member States in the numbers of organ donations (Figure 1). In 2012, the countries reporting the highest numbers of organ donors after brain death were Croatia and Spain, with more than 30 donors per million population. The number of donors after brain death in Finland in 2013 was, on average, 17.5 per million population.

Regional differences in population-adjusted organ donation rates are also significant in Finland. The number of organ donors in the specific catchments areas in the years 2009–2013 varied from 14.3 to 23.0 donors per million population (Figure 2). The differences in the figures between individual hospitals were considerably larger, ranging from 0 to more than 40 donors per million population. Such major differences cannot be explained by morbidity rates alone.

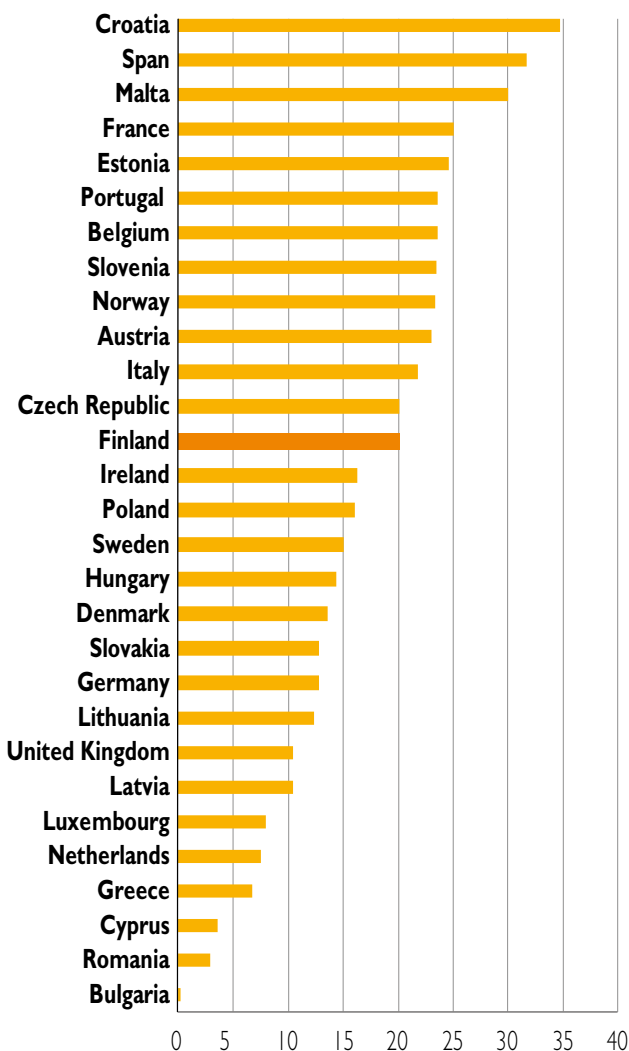


Figure 1. Donors after brain death per million population in the EU Member States and Norway in 2012 (Source: Newsletter Transplant 2013).

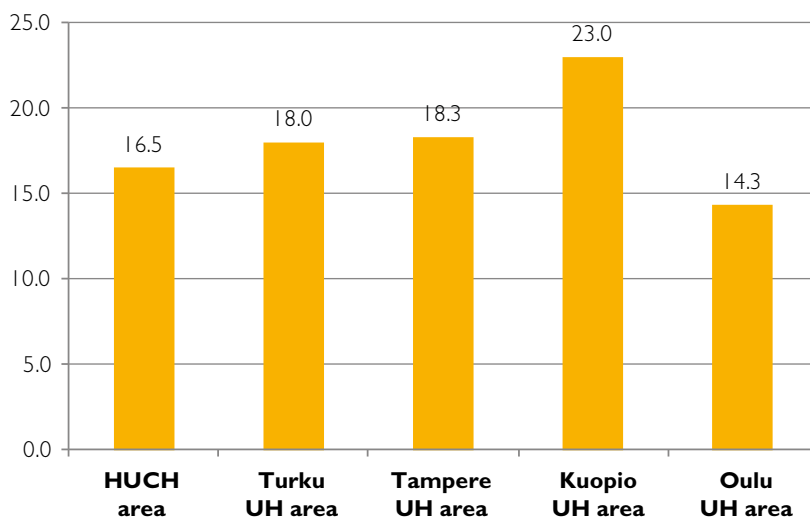


Figure 2. Organ donors after brain death per million population in specific catchment areas (UH area), annual average for the period 2009–2013 (Source: Transplantation Centre at Helsinki University Hospital).

## Presumed consent

A provision on presumed consent was included in the Tissues Act in 2010 (Act on the Medical Use of Human Organs and Tissues, 101/2001). This means that the organs of a deceased person may be removed unless it is known or there is reason to suspect that the person would have objected to it while alive. The act thus precludes the possibility of family members refusing donation. Also included in the Act is a duty to provide appropriate information to the deceased person's family or other close persons on the removal of organs, tissues and cells and on the significance of the removal. The objective of the amendments was to increase the number of organ transplantations and to stress the donor's personal views on the removal of organs and tissues for the purpose of treating another person.

Organ transplantation rates are highest in countries where the principle of presumed consent is applied. The introduction of presumed consent will not on its own eliminate the shortage of transplants, however, as Finnish attitudes towards organ donation have traditionally been very positive. In a survey conducted in 2013, 88% of respondents said that they would be prepared to donate their organs after death (TNS Gallup Oy 2013).

## More efficient donor identification

The major differences in organ donor numbers between hospital districts indicate that more attention should be paid to identifying potential organ donors. According to an international study, between 2007 and 2009 only 51.4% of potential donors in Finnish intensive care units were identified

and became actual donors. The single biggest problem was a failure to identify potential donors (Roels et al. 2012). Emergency medical service and emergency care units play a key role in identifying potential organ donors. Initiating care immediately after identifying a potential donor will ensure that the organs remain in an optimal condition for transplantation.

Large numbers of potential donors also remain unidentified among patients with critical neurological illnesses who die outside intensive care units. A study of brain haemorrhage patient data in Helsinki between the years 2005 and 2010 found that only 24% of potential donors had been identified and referred to an intensive care unit (Sairanen et al. 2014).

## Organisation of activities

Several examples from abroad (Spain, Norway) and Finland (HUCH, Oulu University Hospital) show that the availability of organs can be increased by focusing attention on how the organ donation process is organised. Identifying potential organ donors requires seamless multi-professional cooperation and improving the capabilities of the entire staff in procurement hospitals.

In order for the organ donation system to operate efficiently, stronger national steering is needed. Good internal organisation at procurement hospitals is also crucial.

# LEGISLATION ON ORGAN TRANSPLANTATION

Organ transplantation is part of specialised medical care and, as such, the general medical legislation, including the Health Care Act (1326/2010), the Act on Specialised Medical Care (1062/1989), the Act on the Status and Rights of Patients (785/1992) and the Act on Health Care Professionals (559/1994), applies.

In addition, provisions on organ transplantation are specified in the Tissues Act which covers the preconditions for organ donation and the donor's consent. The certification of death must be impartial and carried out exclusively on medical grounds. The doctors certifying the death of a person may not be involved in organ transplantation.

As required in Directive 2010/53/EU of the European Parliament and of the Council on the standards regarding the quality and safety of human organs intended for transplantation, the Tissues Act also contains provisions on the quality and safety requirements applicable to organ transplantation: the duties of organ procurement hospitals and the Transplantation Centre, good practices with respect to quality and safety, the requirements placed on personnel, the quality requirements for organ procurement, how to characterise organs and donors, the traceability of the organs and how to notify persons of adverse events and reactions. Moreover, the Act specifies the means for providing guidance and supervision and conducting inspections. The provisions of the current Tissues Act have been taken into account in the following sections of this document, and reference is made to the Act where applicable.

# SUPERVISION OF ORGAN TRANSPLANTATION

## NATIONAL SUPERVISORY AUTHORITY FOR HEALTH AND WELFARE AND THE REGIONAL STATE ADMINISTRATIVE AGENCIES

The prime responsibility for the general guidance and supervision of procurement hospitals and the Transplantation Centre rests with the Regional State Administrative Agencies within their mandate. However, the National Supervisory Authority for Health and Welfare (Valvira) directs and supervises specialised medical care, especially in the case of vital or wide-reaching issues or issues relevant to the operating areas of several Regional State Administrative Agencies or the entire country; issues related to a supervision matter concerning a health care professional that is handled by Valvira and issues that the Regional State Administrative Agency is not qualified to process. Valvira's duties further include authorising the removal of an organ from a living donor for transplantation purposes.

Valvira is not aware of any complaints relating to organ donation or transplantation.

## FINNISH MEDICINES AGENCY

The Finnish Medicines Agency (Fimea) is responsible for the direction and supervision of procurement hospitals and the Transplantation Centre concerning the quality, safety and traceability requirements applicable to transplants. This includes steering and guidance related to the following matters: requirements applicable to the testing, preservation, storage, packaging, transport and other handling of organs and the relevant quality and safety requirements; reporting and managing serious adverse events and reactions; and traceability.

An administrative regulation (2/2014) has been issued by Fimea on quality and safety requirements that concern organ donation and transplantation. Fimea actively monitors organ donation and transplantation and keeps an updated record of procurement hospitals and the Transplantation Centre. Every year, it publishes a review based on the Transplantation Centre's annual report. Fimea also coordinates the processing of serious adverse events and reactions observed and reported by the Transplantation Centre.

Fimea carries out regular inspections of procurement hospitals and the Transplantation Centre. The purpose of these inspections is to ensure compliance with the statutes and evaluate the way in which the National Action Plan is implemented at each hospital.

# TRANSPLANTATION CENTRE AND THE TRANSPLANTATION OFFICE

Helsinki University Hospital (HUCH) serves as the Transplantation Centre to which all organ transplantations in Finland have been centralised under Government Decree on the provision and centralisation of highly specialised medical care (336/2011). The Transplantation Centre approves donors, carries out the actual removal of organs, is responsible for packaging and transporting them, selects the recipients and performs the transplantation surgery. Before initiating a transplantation process, the Transplantation Centre must ensure that the quality and safety of the organ and the description of the organ's and the donor's characteristics are appropriate.

Up until now, the Transplantation Centre and the Transplantation Office at HUCH have issued national guidelines and provided training related to both organ transplantation and organ donation. It has maintained guidelines for donor care and organ removal and provided training at both procurement hospitals and at the national level.

HUCH's Transplantation Office coordinates organ transplantation throughout the entire country and collaborates with procurement hospitals. Each hospital that has facilities for at least intensive monitoring as part of donor care may and also should serve as a procurement hospital.



# ORGANISATION OF THE ORGAN DONATION SYSTEM

## NATIONAL STEERING OF THE ORGAN DONATION SYSTEM

Many countries, including the United Kingdom, Spain and Norway, have prepared national guidelines to increase the availability of transplants. The organisation of the donation system has played a key role in these guidelines.

In Finland, there has been no national-level institutional actor to direct the organ donation system. However, such an actor is needed to manage and coordinate organ donation in this country and to level out regional differences in the population-adjusted organ donation rates.

A national steering group for organ donation that is separate from the Transplantation Centre needs to be established to develop, guide and monitor organ donation. The steering group will also be tasked with coordinating training related to organ donation. The Transplantation Centre will continue to perform its statutory duties relating to organ donation.

The Ministry of Social Affairs and Health plans to appoint such a steering group. The group will be composed of the physicians responsible for organ donation and the donor coordinators of the university hospitals as well as representatives of the Transplantation Centre. The steering group for organ donation would meet at least twice a year. Representatives from Fimea and Valvira as well as representatives from patient organisations would take part in the meetings in an expert role when necessary. The parties responsible for organ donation and transplantation and the bodies supervising these activities are depicted in Figure 3. The tasks of the different actors are listed in Table 1.

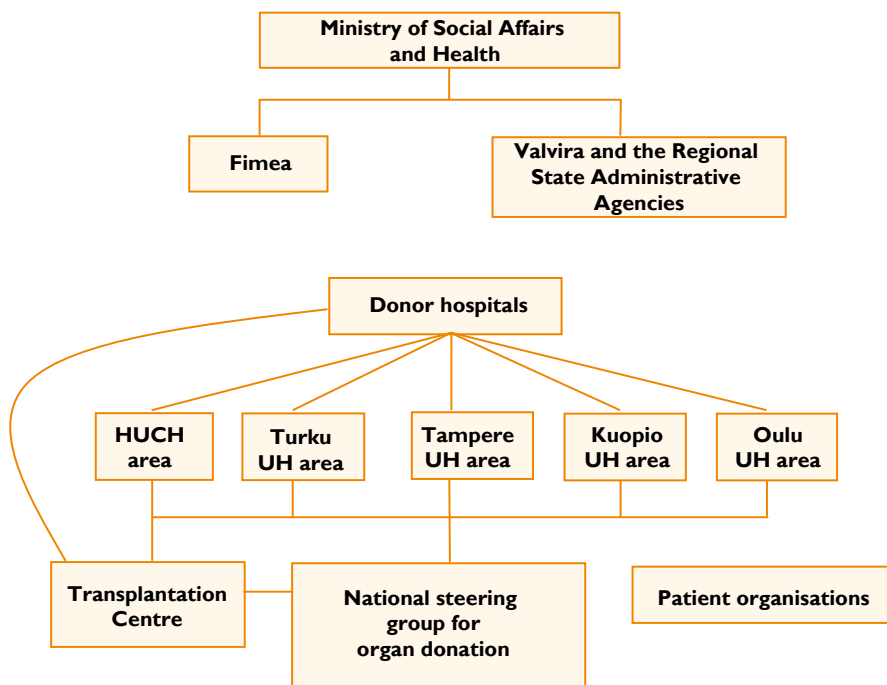


Figure 3. Parties responsible for organ donation and transplantation, the parties supervising these activities and the patient organisations. For a more detailed description of the actors' duties, see Table I.

A national coordinator will be needed to coordinate and develop the organ donation system. He or she would be a member of the steering group. The coordinator's role would be a national one and initially it would be a full-time position. The Ministry of Social Affairs and Health and the specific catchment areas will negotiate the establishment of the new position.

## DIRECTING ACTIVITIES IN THE SPECIFIC CATCHMENT AREAS

The following proposal for the regional organisation of the organ donation system was prepared in compliance with the current legislation. In the future, decisions on the proposed allocation of duties will be included in the decisions on service provision that the social welfare and health care regions will make every four years.

The structure of the organ donation system must be based on the specific catchments areas, and the arrangements concerning organ donation must be specified in their regional agreements on the provision of specialised medical care. University hospitals will be responsible for directing and monitoring the activities and for providing training within their specific catchment areas.

Donor coordination teams will be set up at university hospitals to coordinate organ donation within their specific catchment area and to assume responsibility for regional training related to organ donation activities. These working groups will be composed of the physician responsible for organ donation, the donor coordinator and representatives from units that play a key role in organ donation. Central hospitals in the area should also be represented in the working group.

The university hospital's donor coordinator will collaborate with the donor coordinators and physicians responsible for organ donation in the hospitals of the specific catchment area and provide guidance to them. With the assistance and support of the university hospital's donor coordination team, the donor coordinator will organise annually a regional meeting of officials responsible for organ donation. The donor coordination team will be responsible for monitoring the achievement of set targets.

In each specific catchment area, the care pathway of a potential donor will be defined from primary care to the university hospital. The possibility of organ transplantation should be accounted for in regional care pathways, in particular in the case of critically ill neurologic patients who are not transferred to the university hospital for treatment. The place of care of these potential organ donors should be agreed upon regionally. To care for an organ donor, at minimum a unit with intensive monitoring facilities is needed that has equipment for mechanical ventilation, invasive arterial monitoring and the administration of vasoactive drugs. The specific catchment areas should also make arrangements for providing consultative support at the regional level.

## PROCUREMENT HOSPITALS

At each hospital where organ donation is possible, organ donation is part of the normal specialised medical care activities. The organ procurement hospitals in each region will be listed in the agreements on the provision of specialised medical care in the specific catchment areas, and adequate resources for organising organ donation will be secured for these hospitals. Under the Tissues Act, the procurement hospital must identify a potential donor of an organ, establish brain death, find out and record the deceased person's possible view, while living, on removing of his or her organs, see to it that an adequate explanation is given to a near relative or other individual close to the deceased person, assume responsibility for the care of the donor and perform the necessary further examinations regarding the organ's suitability for transplantation.

A procurement hospital must have jointly agreed upon written organ donation instructions that cover the entire care pathway. The most critical parts of the care pathway consist of the active treatment of a critically ill neurologic patient in the acute phase, taking the possibility of organ donation

into account and approving potential organ donation as an indication of the need to place a patient in intensive care.

## DONOR COORDINATION TEAM

A donor coordination team will be established at each hospital caring for organ donors. The team will be responsible for directing and monitoring organ donation activities, for reporting them and for providing training and induction training related to organ donation for the personnel within the hospital. Team members will include the donor coordinator and the physician responsible for organ donation, who will act as the team leader. In addition, team members will include representatives from the joint emergency services and units that treat neurological, neurosurgical and trauma patients. The team may also include representatives from other key units, including emergency medical care units, intensive care units and intensive monitoring units as well as neurological and neurosurgical inpatient wards and monitoring units. Hospitals may decide on the composition of the donor coordination team based on the availability of resources.

Table I. The duties of actors responsible for organ donation and transplantation and of the entities supervising these activities, and the role of patient organisations.

Actors	Duties/Role
<b>Parties responsible for organ donation</b>	
<b>Procurement hospitals</b>  Hospitals in Fimea's record of procurement hospitals having at least a high dependency unit	<ul style="list-style-type: none"> <li>■ Identify potential organ donors</li> <li>■ Find out and record the views the deceased person may have held about the removal of their organs</li> <li>■ Discuss organ donation with family members</li> <li>■ Care for the donor</li> <li>■ Perform the requisite additional examinations to confirm that the organs are suitable for transplantation</li> <li>■ Provide guidelines for and monitor organ donation in their hospital</li> <li>■ Regularly provide appropriate training for the hospital personnel</li> <li>■ Collaborate with other procurement hospitals in the specific catchment area, the donor coordination team at the university hospital and the national steering group</li> <li>■ Immediately notify the Transplantation Centre of any serious adverse events and reactions</li> </ul>
<b>Donor coordination teams at university hospitals</b>  Central hospital representatives	<ul style="list-style-type: none"> <li>■ Coordinate organ donation in the specific catchment area and monitor performance</li> <li>■ Responsible for regional training related to organ donation</li> <li>■ Provide consultancy support for procurement hospitals in the specific catchment area</li> </ul>
<b>National steering group for organ donation</b>  Representatives of all university hospitals and the Transplantation Centre  Representatives of Fimea, Valvira and patient organisations take part in meetings in an expert capacity when necessary	<ul style="list-style-type: none"> <li>■ Responsible at the national level for development, guidance and monitoring of organ donation</li> <li>■ Coordinates training related to organ donation</li> <li>■ Engages in broad-based cooperation with other actors involved in organ donation and transplantation</li> </ul>
<b>Party responsible for organ transplantation</b>	
<b>Transplantation Centre at HUCH</b>	<ul style="list-style-type: none"> <li>■ Ensures the quality and safety of transplants</li> <li>■ Responsible for removing and transporting transplants</li> <li>■ Approves organ donors and selects recipients</li> <li>■ Keeps an organ transplantation register</li> <li>■ Provides instructions on the care of organ donors</li> <li>■ Takes part in organising national-level training</li> <li>■ Provides expert assistance</li> <li>■ Notifies Fimea of serious adverse events and reactions</li> <li>■ Submits annual reports on organ transplantation to Fimea</li> </ul>

Actors	Duties/Role
<b>Supervisory authorities</b>	
<b>Fimea</b>	<ul style="list-style-type: none"> <li>■ Issues guidance to procurement hospitals and the Transplantation Centre on the quality, safety and traceability of organs and supervises compliance with these requirements</li> <li>■ Evaluates the implementation of the National Action Plan</li> <li>■ Keeps an up-to-date record of procurement hospitals and the Transplantation Centre</li> <li>■ Coordinates the management of serious adverse events and reactions observed and reported by the Transplantation Centre</li> <li>■ Inspects the facilities and operations of procurement hospitals and the Transplantation Centre within its mandate</li> <li>■ Publishes an annual report based on the Transplantation Centre's annual report</li> </ul>
<b>National Supervisory Authority for Health and Welfare and the Regional State Administrative Agencies</b>	<ul style="list-style-type: none"> <li>■ Provide general direction for and supervise procurement hospitals and the Transplantation Centre</li> <li>■ Inspect the facilities and operations of the procurement hospitals and the Transplantation Centre within their mandates</li> <li>■ Valvira authorises the removal of organs from living donors for transplantation purposes</li> </ul>
<b>Other authorities</b>	
<b>Ministry of Social Affairs and Health</b>	<ul style="list-style-type: none"> <li>■ Drafts legislation and provides general direction for and supervises organ transplantation</li> </ul>
<b>Patient organisations</b>	
<b>Finnish Kidney and Liver Association</b>  <b>Finnish Heart and Lung Transplant Federation SYKE</b>	<ul style="list-style-type: none"> <li>■ Support patients and transplant recipients as well as their families</li> <li>■ Organise rehabilitation and peer support activities</li> <li>■ Oversee patients' interests</li> <li>■ Disseminate information about organ donation and transplantation</li> <li>■ Work together with other actors to improve the operating conditions of the organ transplantation system</li> </ul>

# DUTIES OF DONOR COORDINATION TEAMS AT HOSPITALS

The physician responsible for organ donation directs the activities of the donor coordination team and provides instructions concerning organ donation at the hospital. He or she and the donor coordinator work closely together and with the other members of the donor coordination team.

Some examples of the tasks of the physician responsible for organ donation and the donor coordinator are provided below for reference purposes. The hospitals may agree on the detailed division of duties locally.

## **DUTIES OF THE PHYSICIAN RESPONSIBLE FOR ORGAN DONATION**

1. Leading the donor coordination team within the hospital and developing the team's activities
2. Providing guidance on organ donation
  - maintaining and updating local care guidelines together with the donor coordination team
  - incorporating the instructions issued by the Transplantation Centre and Fimea in the hospital's care guidelines
  - creating a care pathway for organ donors at the hospital
  - informing the hospital's personnel about the care guidelines
3. Responding to consultation requests concerning organ donation
4. Maintaining the personnel's capabilities for approaching family members
5. Notifying the Transplantation Centre of serious adverse events and reactions that may influence the quality and safety of organs
6. Monitoring organ donations and providing feedback
7. Reporting on the performance of the organ donation system
  - to hospital management and key units
  - to the donor coordination team of the university hospital
8. Planning and developing organ donation activities
9. Providing training for the various types of health care professionals who participate in donor identification and management
10. Providing induction training related to organ donation to new employees
11. Maintaining his or her own professional competence related to organ donation by taking part in training

## **DUTIES OF THE DONOR COORDINATOR**

1. Assisting in the provision of instructions on organ donation
  - assisting the physician responsible for organ donation in maintaining and updating local care guidelines (instruction folders, websites)
  - informing hospital personnel about the care guidelines
2. Responding to consultation requests concerning organ donation
3. Supporting the organ donation process and, if necessary, taking part in it
4. Maintaining the personnel's capabilities for approaching family members
5. Serving as the hospital's contact person in organ donation matters (hospital personnel, donor coordinators at other procurement hospitals, donor coordinator at the university hospital, Transplantation Office)
6. Notifying the Transplantation Centre of serious adverse events and reactions that may influence the quality and safety of organs
7. Monitoring organ donation activities
  - keeping a register of the hospital's organ donations
8. Auditing organ donation activities (analysing the data of the deceased) at regular intervals
9. Conducting surveys of personnel attitudes and giving feedback on the results
10. Planning and developing the activities in collaboration with the physician responsible for organ donation and other members of the donor coordination team
  - participating in studies and projects
11. With the support of the physician responsible for organ donation and other members of the donor coordination team, provides training for the various types of health care professionals who participate in donor identification and management
  - personnel training at the ward and doctors' meetings
  - organising annual training days for the entire personnel
  - helping organise regional training
  - lecturing at educational institutions on request
  - maintaining a calendar on training related to organ donation and monitoring the implementation of scheduled activities
12. Maintaining his or her own professional competence by participating in training



## Objectives

- Organ donation will be part of a hospital's normal activities.
- The possibility of organ donation will be assessed in the case of each critical patient with a neurological illness.
- In 2015, a national steering group for organ donation will be set up to assume responsibility for the stewardship and development of organ donation activities.
- In 2016, a full-time national coordinator for organ donation will be appointed.
- Beginning in 2015, a donor coordination team will work at each organ procurement hospital. The teams will consist of the physician responsible for organ donation, the donor coordinator and other experts, depending on the hospital's operations.
- By the end of 2015, each university hospital will have appointed a donor coordination team to support the donor coordination teams at hospitals in the specific catchment area and to monitor and provide guidance on organ donation in its specific catchment area.

# REPORTING AND QUALITY ASSURANCE IN ORGAN DONATION

Good quality assurance practices in organ donation include the objective monitoring of donation activities and benchmarking. Procurement hospitals will monitor the number of potential donors and the reasons for a donation not going ahead in the case of some potential donors. The physicians responsible for organ donation at central hospitals will report on the performance of organ donation activities to hospital management and the donor coordinator at the university hospital. The donor coordinators at university hospitals will report on organ donation in the specific catchment area to the national steering group for organ donation.

The monitoring of performance, regular death audits and benchmarking will help to maintain and improve the quality of organ donation. The analysis of benchmarking data by the national steering group will be a key tool for developing the activities in question.

# KIDNEY TRANSPLANTATION FROM LIVING DONORS

## BACKGROUND

### Legislative requirements for living organ donation

Under the Tissues Act (101/2001), organs may be removed from a living donor who has given his or her consent in order to treat human disease or injury. Organs may only be removed for the treatment of a recipient if this does not cause the donor any major health hazard or serious harm and if no alternative therapeutic method of comparable effectiveness is available. Organs from a living donor may only be used in cases where no suitable organ from a deceased donor is available, or if the results are expected to be significantly better than the results of transplantation from a deceased donor.

Adults who are able to decide on their treatment may donate non-regenerative organs to treat disease or injury only to a near relative or other person close to them. Authorisation from the National Supervisory Authority for Welfare and Health is required for such organ donation.

Donors must give their informed written consent for the removal of an organ. Before giving their written consent, donors must be given appropriate information as to the purpose and nature of the organ removal as well as its consequences and risks to themselves. Donors have the right to withdraw their consent at any time before the removal of the organ without being required to state a reason.

Doctors treating recipients may not be involved in decisions concerning the removal of organs. It is important that the donor's decision to donate is voluntary, and that decisions on removing organs are made independently and appropriately in compliance with ethical principles. The donor is thoroughly examined by doctors from several fields of specialisation to ensure that the donation is safe for him or her. The examination and test results are submitted to the Transplantation Centre, where the transplant surgeon makes a decision on the donation, after which the Centre submits the requisite information to Valvira. At the Transplantation Centre, a surgeon who will not take part in operating on the donor or the recipient confirms that the donation is voluntary and that the donor has understood the significance and possible consequences of the operation. The surgeon evaluates the risk to the donor and weighs it against the expected benefit for the recipient before making a decision.

The Tissues Act also contains provisions on the long-term follow-up of a living donor after an organ donation.

## Waiting time for kidney transplantation

The waiting time for kidney transplantation in Finland has become longer in recent years as the gap between the number of patients needing transplants and the number of available transplants has widened further. Kidney transplantation from living donors can help increase the number of transplantations and address this imbalance.

## International comparison

In many countries, increasing the number of transplantations from living donors has made it possible to boost the total number of kidney transplantations. There is a clear difference between Finland and other Nordic countries in terms of the number of kidney transplantations using organs from living donors. The share of these operations in relation to all kidney transplantations in adults is only a few percentage points in Finland, whereas in Sweden and Norway, for example, their share is 30–40% (Figure 4). In Finland, only a dozen kidney transplantations from live donors have been performed annually in recent years, which is the equivalent of approximately two transplants per million population. Internationally, this figure varies between 0 and 26 per million population.

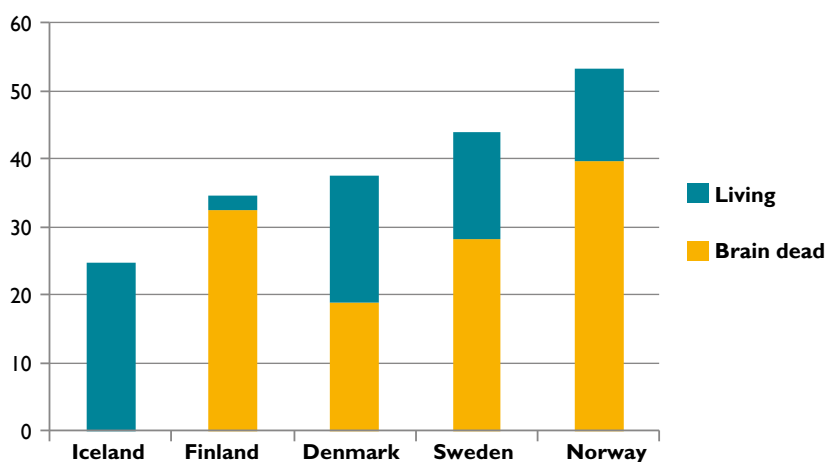


Figure 4. Kidney transplantations from brain dead and living donors per million population in the Nordic countries in 2013 (Source: Scandiatriplant).

## Transplantation outcomes

The prognosis of a patient who receives a transplant from a living donor is good regardless of whether the donor is genetically related to the recipient or not, for example a spouse.

Live kidney transplantation makes it possible to perform a so-called pre-

emptive organ transplantation. This means that the kidney transplantation is scheduled to take place before the patient starts dialysis, thus eliminating the need for dialysis treatment. The number of such transplantations is low in Finland, whereas in some countries their share is as much as 15% of all kidney transplantations.

## Kidney transplantations in children

In Finland, more than one half of all kidney transplantations in children are performed with organs from living donors. A child's illness and the associated dialysis treatment, which requires repeated hospital visits, affect the whole family. Kidney transplantation, on the other hand, makes it possible for both the child and his or her family to lead a relatively normal life. Kidney transplantation has been found to have a considerable positive impact on the quality of life in children with an incurable kidney disease. However, a kidney transplanted during childhood often ceases to function effectively when the person reaches adulthood, and the patient thus faces the need for a second transplantation.

## Ethical viewpoints

Kidney transplantation from a living donor is associated with significant ethical issues. The organ donation must always be voluntary and no pressure may be exerted on the donor. It is necessary to assess in each case whether donating a kidney could have significant short- or long-term negative effects on the donor. On the other hand, consideration has been given to the harm done to a person by denying her or him the possibility of a living donation.

The prognosis for a kidney donor is usually good. In cases where the donor selection process is handled in an appropriate manner, the donor's quality of life is no different from the reference population. A Finnish expert group that investigated kidney transplantation from living donors recently drew up national selection criteria for kidney donors and recipients.

## TARGETS

### Quantitative target

It is proposed that the annual rate of kidney transplantations from living donors be increased to 10 per million population by the year 2020. The long-term target is to achieve the same level of transplantations as in other Nordic countries, where the annual rate has varied between 13 and 20 living donors per million population.

## Directing and development

There is a need to set up a working group of nephrologists and transplant surgeons to direct and promote kidney transplantation from living donors.

A physician at the Transplantation Centre is responsible for advising and assisting as necessary care units at other hospitals in preparing living donors. Transplantation Office coordinators also help coordinate the examinations of the donor and the recipient when required.

## Follow-up of living donors

It is a legal requirement to conduct a long-term follow-up on living donors and to enter their data into a register. There is a need to agree on how the data will be recorded in the existing donor register kept by HUCH. The aim is to enable each health care unit monitoring the donors to regularly enter the donors' data into the register. Donors should be encouraged to take part in monitoring their own health.

## Costs incurred by a living donor

When presumed consent was introduced, a provision was included in the Act whereby the medical examinations and treatment of a living donor are free of charge to ensure that donations are not impeded for financial reasons. After the operation, the donor may receive a sickness allowance for 4–6 weeks.

In the future, the costs that a kidney donor incurs because of a donation should be investigated and a solution should be sought for compensating the donor for the expenses that are currently not reimbursed. Issues associated with a kidney donor's life and medical insurance would also have to be examined from the perspective of insurance companies.

## Attitudes

As only a few transplantations from living donors have so far been performed in Finland, more information on live kidney donation should be disseminated to health care professionals, patients and their families. Attention should also be drawn to the fact that the kidney donor does not always have to be genetically related to the recipient. The information will be directed at the following people:

- personnel: positive attitudes must be promoted, for example via training
- kidney disease patients: discussions at the doctor's surgery, patient education, information leaflets, etc.
- family members: with the patient's permission, information may be sent to a potential donor

- the media
- patient organisations, which play an important role in increasing public awareness

### **Targets**

- In 2016, a working group of Finnish nephrologists and transplant surgeons will be established to direct and promote kidney transplantation from living donors
- Possibilities for reimbursing the costs that kidney donors incur will be explored
- Kidney transplantations from living donors will be increased to 10 per million population a year by the year 2020

# PERSONNEL TRAINING

## OBJECTIVES OF TRAINING

The main objectives of training personnel at procurement hospitals are to ensure that all potential organ donors are identified and properly managed until organ removal and that the viability of the organs is maintained.

Achieving these objectives will require procurement hospitals to regularly provide appropriate training for their personnel. Organ donation must be included in induction training programmes for doctors working on duty at the hospital and also for doctors and nurses in key units.

The responsibility for training within the hospital will rest with the donor coordination team. The specific objectives of training related to organ donation are detailed below.

### **OBJECTIVES OF TRAINING AT PROCUREMENT HOSPITALS**

- Increasing awareness among the personnel about organ donation and transplantation and their significance
- Motivating the personnel and building their commitment to organ donation activities
- Identifying potential donors
- Understanding the significance of brain death
- Approaching potential donors' families in an appropriate manner
- Proper donor management along the entire donation pathway

## TRAINING AT NATIONAL, REGIONAL AND LOCAL LEVELS

### Training at the national level

Once a year, a national training event will be organised for the members of the donor coordination teams of all procurement hospitals. The objectives of the event will be to expand their knowledge about organ donation, to share experiences and to chart development needs. Team members will be encouraged to participate in the development of the organ donation process.



In addition, donor coordination team members will receive training in how to audit organ donation activities at the hospital and in surveying attitudes of the personnel.

Other important objectives of training at the national level will be to offer peer support and motivate the team members.

A national training network will be created to support local training, and training material will be prepared centrally. Currently, *National Guidelines for the Management of Organ Donors* are in use. One of the tasks of the national coordinator for organ donation will be to promote and develop training in collaboration with the members of the training network.

## Training at the regional level

University hospitals will provide support to procurement hospitals in their respective specific catchment areas in both the theoretical and practical aspects of organ donation. They are responsible for ensuring that all procurement hospitals in the area receive training. A regional meeting of officials responsible for organ donation should be organised annually in each specific catchment area.

There are many central and regional hospitals in Finland where organ donation occurs infrequently. In order to ensure that potential donors are identified and properly managed in all procurement hospitals, networking between hospitals within the specific catchment areas is important. The activities will be coordinated by the donor coordination teams at the university hospitals.

## Training at the local level

To ensure that no donation is lost, it is necessary to provide training for all health care professionals attending to critically ill patients with severe brain injury and for those involved in the clinical management of organ donors. It is essential that all doctors working on duty assume responsibility for identifying potential donors, intensive care units for the management of potential donors, and operating theatre staff for the successful recovery of organs. A positive attitude towards organ donation within the hospital is critically important. It increases the likelihood of potential donors becoming actual donors.

The physician responsible for organ donation and the donor coordinator will regularly assess the training needs in all hospital units involved in the management of potential donors. Training will be offered, for example, at weekly meetings based on requests and feedback received from the units. Personnel should be required to attend the training sessions.

The donor coordination team may start by providing training in its own unit and gradually expand its activities to cover the entire hospital. Once the training programme is well established, training can also be offered to local educational institutions.

The experiences of the Hospital District of Helsinki and Uusimaa with simulation training have been quite positive. The approach has made it possible to mobilise the entire personnel to actively participate in the training. The training model covers all the steps of the donation pathway (see link on HUCH website: Donorpolku training model).

During the training, particular emphasis should be placed on how best to approach families of potential organ donors, as health care personnel typically find that this stage of the organ donation process, including the communication of brain death, is the most difficult. A family member of a donor could be invited to training events to recount how he or she experienced the donation discussion.

Each procurement hospital shall organise a training activity one afternoon at least once a year for the entire clinical staff. The training activity should be planned based on identified needs. At the local training events, the specific features of the hospital will be highlighted and the results of the personnel attitude survey and medical audits will be shared. It is also important to report on successful organ donations at the hospital. Depending on the topics to be covered, external lecturers may be invited to the training events (e.g. outcomes of transplantations, management of heart and lung donors).

### Targets

- In 2015, a national training network for organ donation will be established to support local training and to centralise the production of learning materials
- Beginning in 2015, an annual national training event will be organised for members of the donor coordination teams from all procurement hospitals
- Beginning in 2016, each university hospital will organise an annual meeting for persons responsible for organ donation in a specific catchment area
- Beginning in 2016, an annual training activity on organ donation will be organised for the entire clinical staff at each procurement hospital

## RESPONSIBILITIES

- Organising national training events: national coordinator for organ donation
- Regional meetings: donor coordinators at university hospitals
- Annual training events at procurement hospitals: donor coordinators at procurement hospitals

# INCREASING PUBLIC AWARENESS ABOUT ORGAN DONATION

## Importance of communication

There are great differences in attitudes towards organ donation between the various European countries. Positive attitudes among the population of a particular country can be reinforced by disseminating general information about organ donation and transplantation and about their significance. In its communication, the European Commission takes the view that continuing education should form an essential part of the Member States' Action Plans (Commission of the European Communities 2008).

Patient organisations have traditionally played a major role in information activities. In Finland, information about organ donation and transplantation directed at the general public is being systematically disseminated by the Finnish Kidney and Liver Association via *Lahja elämälle®* (a gift to life) activities. The Finnish Association of Transplant Surgeons and individual surgeons have provided expert information to the media. The Ministry of Social Affairs and Health has informed the public about organ donation in connection with legislative amendments.

## Organ donor cards

To increase the availability of transplants, the Finnish Kidney and Liver Association distributes organ donor cards titled "Say YES to organ donation". The surveys indicate that more than 90 per cent of Finns are familiar with the organ donor card. Signing an organ donor card is still considered important despite the legislative amendment of 2010 which introduced the presumed consent of a deceased donor. The card reminds people to inform their family members of the carrier's willingness to donate his or her organs, and it helps to ensure that his or her wishes will be carried out.

## General awareness and attitudes

The attitudes of Finnish people towards organ donation are highly positive. In a survey conducted in 2013, 88% of the respondents stated that they would be willing to donate an organ after their death to treat another person's illness. However, fewer than one out of two of the respondents had informed their family and friends of their intent to donate. The majority of the respondents

(63%) felt that there is insufficient public discussion on this theme (Survey 2013, Finnish Kidney and Liver Association).

## National coordination of communication

The national steering group may set up a communication division to coordinate communication about organ donation to the general public. In addition to its coordination task, the communication division could produce easily accessible, non-technical material on organ donation, transplantation and live donation by family members. Alternatively, it could reach an agreement with other actors on the production of such material.

In the future, communication targeted at the general public will continue to mainly rely on patient organisations and voluntary organisations.

## Communication objectives

The objective is that every adult will have up-to-date information about organ donation and the significance of organ transplantation.

Communication efforts will stress the fact that organ donation activities in Finland are strictly regulated and of a high ethical standard, and that trade in organs is prohibited under the Tissues Act.

Communication of factual and up-to-date information will reduce the possibilities of adverse publicity. Should any negative publicity arise, it will be responded to by rapid and open crisis communication.

The target is that by 2018, 70% of adults will have communicated to a relative their wishes regarding organ donation.

### Target

- By 2018, at least 70% of adults will have communicated to a relative their wishes regarding organ donation

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# APPENDIX I

## COMPOSITION OF THE EXPERT GROUP ON DEVELOPING ORGAN DONATION AND ORGAN TRANSPLANTATION, 15 FEBRUARY 2013 – 30 NOVEMBER 2014

### Chair:

Jaakko Yrjö-Koskinen, Ministerial Counsellor,  
Ministry of Social Affairs and Health

### Deputy Chair:

Timo Keistinen, Ministerial Counsellor,  
Ministry of Social Affairs and Health

### Members:

Riitta Burrell, Ministerial Adviser,  
Ministry of Social Affairs and  
Health (until 28 January 2014)  
Kirsi Ruuhonen, Ministerial Adviser,  
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Anne Tammiruusu, Senior Officer,  
Finnish Medicines Agency Fimea  
Pasi Peltoniemi, Senior Officer, Finnish  
Medicines Agency Fimea (Deputy Member)  
Eeva Leinonen, Unit Head, Finnish Medicines  
Agency Fimea (Deputy Member)  
Kirsi Liukkonen, Lawyer, National Supervisory  
Authority for Welfare and Health Valvira  
Päivi Tissari, Chief Physician, National  
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Health Valvira (Deputy Member)  
Helena Isoniemi, Chief Physician, HUCH  
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Rajja Malmström, Project Manager,  
HUCH, Joint Authority  
Karl Lemström, Head of Department,  
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Kirsi Rantanen, Acting Head of  
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Coordinator, HUCH Transplantation Office  
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Eero Honkanen, Chief Physician,  
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