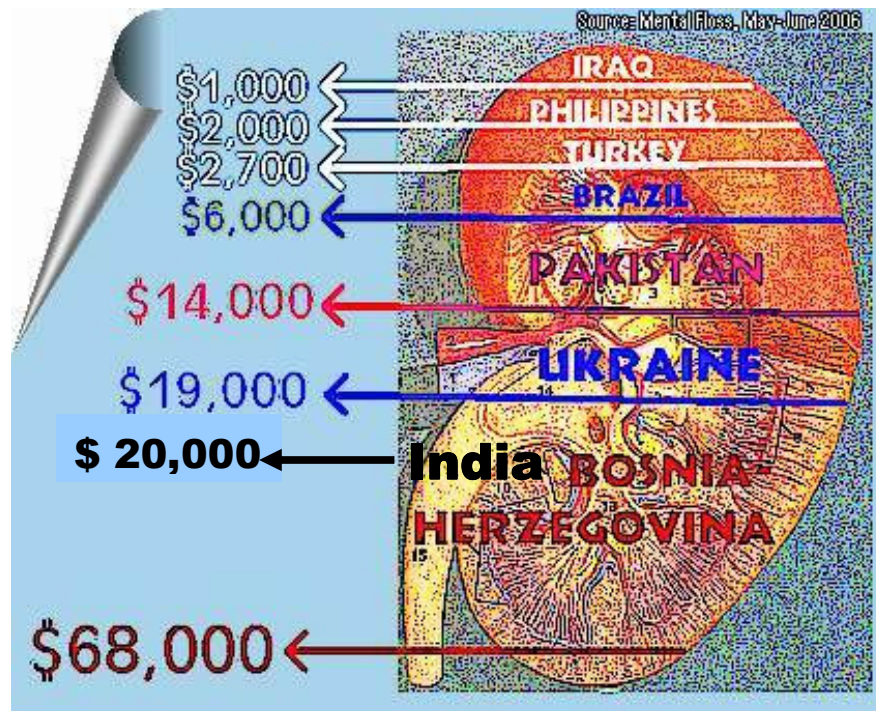


Master thesis:
“Wanna buy a kidney?”
Transplantation tourism towards India
How can countries deal with it?
A comparison of the Netherlands and the United Kingdom



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Prologue

This master thesis is final piece of work for completing the Master International Public Management and Policy at the Faculty of Social Sciences at the Erasmus University Rotterdam. Since the beginning of the study Public Administration that I started almost five years ago I was always searching for subjects that triggered my attention. In the end of the study I was caught by human rights and international public law. The course Human Rights and Fundamental Rights the first paper with an ethical dilemma was born: female genital mutilation. With this paper I discovered the interest in ethical sensitive subjects such as abortion. It was clear that I would like to write my master thesis about a subject that is ethical sensitive.

The idea for transplantation tourism was born after a documentary about Chinese prisoners who were executed and then their organs were removed. Rich (also Western) people bought the organs. After some research I discovered the problem of transplantation tourism. Transplantation tourism is a development that already occurred during the 1980s. It is well known by international organisations such as the World Health Organisations. But clear figures and action to prevent it do not exist yet. I was triggered by the fact that it is well known and that it exists already for more than twenty years that I wanted to research this further. Nine months later this master thesis was finished. I have learned a lot not only about the complexity of the subject but also about doing research in practice. Sometimes it was difficult but the whole time I was caught by the subject and I am happy that I choose this subject.

This master thesis is not only created by me but a lot of people give advice and helped me during the process of writing. First of all I would like to thank my supervisor Dr. J. Hakvoort for supervise me during the whole process. Second I would like to thank to Dr. K. Puffers for being my second reader. Also thanks to all the respondents who were willing to cooperate in this research. At last special thanks for a close friend Brenda Kramer who was willing to read this master thesis and to check the English.

Last but not least I would like to thank my family and friends. Without their continue support, not only during the study but in all aspects of life, this master thesis was not written.

I would like to dedicate this master thesis to my parents and brother because they taught me the perseverance to go on even when things get rough. I am sure that they are proud on what I achieved and will achieve.

The last thing to do is to wish you a pleasant reading.

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Summary

Transplantation tourism is a phenomenon that occurred since the 1980s. Especially India was worldwide famous for its illegal organ bazars where poor people sold their kidneys for a few dollars and where middle men earned capitals for selling the kidneys. Although India, and other countries, changed their legislation in order to stop the organ bazars transplantation tourism does still occur nowadays. Western patients travel to less developed countries where they buy a kidney and get transplanted there. They are attracted by the fact that there are no waiting lists over there. This situation is completely different with the long waiting lists for a post mortal kidney. Sometimes a patient has to wait for years before he or she can be transplanted. The post mortal kidney shortage and the possibilities to buy a kidney in a very easy way causes transplantation tourism. According to the World Health Organization is transplantation tourism a phenomenon that occurs in all regions and countries in the world.

This master thesis aims to analyse the problem of transplantation tourism from the Netherlands and the United Kingdom towards India with the following determinants:

- 1) Ethical analysis
- 2) Social
- 3) Economic
- 4) Medical
- 5) Current status of the policy
- 6) Political
- 7) Policy solutions

It will be proved that transplantation tourism is a development that is not only dangerous for the donors but also for patients. Research showed that most donors are poor, some live even below the poverty line, and after the donation their situation decreases. At the other side the patients have higher risks for complications after the transplantation but also higher risks on infectious diseases such as HIV/AIDS and Hepatitis compared to patients whom had transplantation in their home country.

This research argues that kidney transplantation is the best solution for patients with kidney failure. Other treatments such as dialysis have negative side effects and constrain the freedom of movement of the patient. The main problem is that there are not enough post mortal kidneys. Therefore it is allowed in both the Netherlands and the United Kingdom to donate a kidney to a relative or a friend voluntarily. It is clear that although the risks for the donors in both the Netherlands and the United Kingdom are low it is more favourable to use post mortal kidneys. Living kidney donation is presented as a temporary solution.

In both the Netherlands and the United Kingdom there is not yet current policy to stop and prevent transplantation tourism. There are also no reliable figures about the amount of patients who travel abroad for unrelated paid kidney transplantation. It is therefore difficult to say how big the problem is but it is very clear that it does exist in both countries. Also political parties are aware of transplantation tourism; they also link it automatically to the kidney shortage. Although it is clear with political parties it is not a political issue yet. In both countries there is not enough attention to the problem perhaps because there are no reliable data yet.

The conclusion in this master thesis is that transplantation tourism is unethical and that it needs to be prevented. What are the solutions to stop it? In this research the following solutions were presented in order to prevent and stop transplantation tourism:

- A different donor registration system
- Prevention of kidney failure
- Registration requirement of doctors
- Medical code

- Living kidney donation
- Cooperation in organ allocation in the European Union
- Allowing kidney sales by the market or by the government (Iranian model)

Not all of these solutions have the chance to be implemented. For instance, in both the Netherlands and the United Kingdom the subject of allowing kidney sales is undiscussable. It is seen as unethical and it is never been mentioned by politicians, transplantation doctors or others in the field.

The solutions which have the best changes to be implemented are:

- A different donor registration system
- Prevention of kidney failure
- Registration requirement of doctors
- Medical code
- Living kidney donation

It is very clear that most attention goes to a different donor registration system. Also in this research most of the respondents saw this as the best solution. Although a different donor registration system can increase the amount of post mortal donors there are also doubts about the effect of the system and how much the amount of donors will increase.

Remarkable is that the solution of preventing kidney failure does not get a lot of attention. When people talking about organ shortage and kidney disease everybody talks right away about registration systems and so on. Nobody is realizing that instead of increasing the supply of kidneys it is also, in some degree, possible to decrease the demand. There are some risks groups which have higher risks to develop kidney failure for instance diabetes patients. If those risks groups are monitored frequently it is possible to discover kidney failure in an early state and medical treatment can prevent that patients need to dialysis or to be transplant. More attention for preventing kidney failure can lead to less demand and therefore the kidney shortage will decrease.

One of the solutions will not lead to stop or prevent transplantation tourism but it will lead to reliable data about the scope of the problem. A registration requirement of doctors is a good method to collect data about the amount of patients who travel abroad. In both the Netherlands and the United Kingdom such a registration requirement does not exist yet. With such a registration requirement doctors are obligated to report how many patients travelled abroad for transplantation tourism. Doctors are aware of the fact that a patient goes abroad while patients need to get their follow-up treatment in their home country. Further, patients need to get their medical record to send that to India. Doctors only register the amount of patients, no names or other patient information, so such a registration requirement is in line with the confidential code which doctors have towards their patients. At the moment there is already a registration requirement for certain infection diseases.

This research shows that there is not one best solution to solve transplantation tourism or the organ shortage. It does show that there are enough alternatives available which can contribute to the decrease of the organ shortage and transplantation tourism.

Transplantation tourism is a very complex dilemma and it is very hard to judge about patients and donors who conduct it. This master thesis is not about judging if something is wrong or right although the ethical analysis shows that it is unethical. This research tries to analyse the complex matter of transplantation tourism not in a paternalistic way but in such a way that people understand the different dilemmas around this subject. At last the aim of this research is to present solutions which can contribute to decrease transplantation tourism and the kidney shortage in a human way.

Chapter 1 Background and research questions

1.1 Analysing the problem

In this paragraph the problem of transplantation tourism is analysed.

Since 30 years it is possible to save people's lives by organ transplantations. Due to medical developments survival rate is around 85-90% in Western Europe. Since the beginning the demand of organs has been much higher than the supply. The demand of organs was always higher than the supply but the organ shortage has increased because the demand increased but the supply was stable. This stable supply is partially caused by improved medical care; people are living relatively longer than 50 years ago. In 1950 the life-expectancy in Europe was 65 years; today this is approximately 75 years.¹

Ageing increases the chances that people will get kidney failure which increases the chances on kidney transplantation.²

Organ shortage is a global trend. Some figures from the countries which are researched in this master thesis:

- In the Netherlands there are in total 1440 people on the waiting list for an organ.³
- In the United Kingdom there are 6700 people on the waiting list for an organ donation.⁴

For kidneys the following figures are available for the Netherlands and the United Kingdom:

- In the Netherlands there are 1053 people waiting for a kidney.⁵ In 2005 of all the kidney transplantations 44% was from a living donor.⁶
- In the United Kingdom there are 5863 people waiting for a kidney.⁷ In the period 2005-2006 the amount of living kidney donations was 31% of the total amount of kidney transplantations.⁸

In India it is estimated that only 2,5% of the people with kidney failure can afford treatment; nor transplantation nor other treatments are covered by health insurance.⁹

India has not a national registration system but there are estimations that in India around 3000 kidney transplantations are conducted every year.¹⁰

The shortage of supply is even worse in cultures where religious or inhibit considerations prohibit organ donation. This plays also a role in the Western countries. For instance, in the United States 53% of the family doesn't allow their deceased to become an organ donor.¹¹

Due to the continuing and growing shortage of organs people are searching for other options. People are willing to travel and are willing to pay a lot of money to save their own life or that of a relative. Countries are not isolated and because of modern communications such as

¹ Trends in Europe and North America; the statistical yearbook of the Economic Commission for Europe 2003, at: <http://www.unecp.org/stats/trends/>, United Nations Economic Commission for Europe, 23-1-2007.

² http://www.henryfordhealth.org/body.cfm?id=39639&action=articleDetail&AEProductID=Adam2004_1&AEArticleID=004010, 1-10-2006.

³ Wachttijst in Nederland voor orgaantransplantatie (voorlopige cijfers), at: http://www.transplantatiestichting.nl/index.php?id=cijfers_organen_wachttijst_actueel, 31-12-2006.

⁴ This are only patients who wait for sole a kidney. Patients who wait for a kidney in combination with another organ are not included; this is a marginal. Wachttijst in Nederland voor orgaantransplantatie (voorlopige cijfers), at: http://www.transplantatiestichting.nl/index.php?id=cijfers_organen_wachttijst_actueel, 31-12-2006.

⁵ Orgaan transplantaties in Nederland (voorlopige cijfers), at: http://www.transplantatiestichting.nl/index.php?id=cijfers_organen_transplantaties_actueel, 31-12-2006.

⁶ Orgaan transplantaties in Nederland (voorlopige cijfers), at: http://www.transplantatiestichting.nl/index.php?id=cijfers_organen_transplantaties_actueel, 31-12-2006.

⁷ NHS Blood and Transplant, Transplant activity in the UK, UK Transplant August 2006, page 9.

⁸ NHS Blood and Transplant, Transplant activity in the UK, UK Transplant August 2006, page 17.

⁹ Kennedy, K., Organ Donation and Transplantation in India: An Inquiry in Kerala, in: *Journal of Social Distress and the Homeless*, Vol. 11, No. 1, January 2002, page 44.

¹⁰ Parvathi Menon, Against organ trade, in: *India's National Magazine*, Volume 19-issue 10, 24-5-2002.

¹¹ The Bellagio Task Force Report on Transplantation, and the International Traffic in Organs Bodily Integrity, D.J. Rothman, E. Rose, T. Awaya, G. Cohen, A. Daar, S.L. Dzemeshevich, C.J. Lee, R. Munro, H. Reyes, S.M. Rothman, K.F. Schoen, N. Scheper-Hughes, Z. Shapira, and H. Smit. Elsevier, 1997.

internet it is possible to get your needs on the other side of the world. Medical tourism is a new phenomenon and includes a wide range of treatments. Unfortunately, this development of globalisation has also negative side affects. In their search for organs people are willing to buy organs and to travel to get the surgery. The organs they buy come from unrelated living donors. Unrelated living donors get money to cede one kidney. In economic view you could say that it's a normal working private market. But in the case of organ trafficking a lot of difficult ethical dilemmas occur; negative side affects for both donor and receiver. Several 'victims' of paid living organ donation wouldn't do it again if they knew what the consequences were.¹²

In some countries like the Netherlands and the United Kingdom legislation forbid paid living organ donations because of different ethical reasons. Nowadays citizens of these countries travel to other countries where paid unrelated living organ donation is not forbidden or not controlled. India is a country where a big black market of paid unrelated living organ donation emerged. Mostly very poor people cede their organs for money.

The problem of transplantation tourism is not new. It is already mentioned in the eighties and nineties when it became clear that unrelated living donation was possible. In 1994 the World Health Organisation made clear that paid living organ donation is a violation of its own constitution as well as of the Universal Declaration of Human Rights.¹³ In 2004 the World Health Organisation speaks of "transplant tourism".¹⁴ The phenomenon occurs in all WHO regions and it affects especially the poorest people. Active steps are needed to prevent transplantation tourism. Unfortunately, solutions for preventing transplantation tourism are not given and after 2004 no resolutions or statements are made by the WHO on this matter. Until the moment that the international community does has sufficient agreements to prevent transplantation tourism; countries themselves are responsible for the behaviour of their citizens abroad. Especially, Western countries must take action on this matter not only to prevent their own citizens but also because of the international obligation to promote and protect human rights. The big question is how countries should react on this phenomenon because it is something across their border but affecting their domestic organ donation policy. For European countries one of the options is to cooperate with each other in the European Union.

Globalisation is a development which can't be denied anymore. Borders are fading and people are travelling around the world. Globalisation has also negative side affects. Domestic policies of countries are affected by developments across their borders. In the beginning of the globalisation this was mostly a matter in the economic sector but nowadays it plays also a role in the medical sector. Ethics play an important role in the case of medical issues and countries have different ethical views. When there are, unexpected, cross-boarder developments which affect the domestic health policies countries should react on it. These matters will become more and more important in the future and countries should be prepared. In this master thesis the research topic is transplant tourism but this is not the only example. Other examples are:

- IVF vacation or eye laser in Istanbul¹⁵
- Cosmetic surgery in Eastern Europe¹⁶

With internet you can find much different kind of options. People are attracted by lower prices and the fact that there are no waiting lists. People are not aware of the different standards and legislation in other countries. This can result in lower quality and negative side affects such as higher risks for complications. It seems to be an irreversible and growing

¹² Goyal, Mehta, Schneiderman, Sehgal; 2002.

¹³ For a compendium on relevant declarations, see the World Health Organisation, *Legislative Responses to Organ Transplantation* (Martinus Nijhoff and Kluwer Academic: Dordrecht, Amsterdam and Notwell, Massachusetts, 1994). The WHO declaration is at 467 ff

¹⁴ Human organ and tissue transplantation, 57th World Health Assembly, report by the Secretariat, 8 April 2004.

¹⁵ www.adortravel.nl, 30-8-2006

¹⁶ http://www.escapeartist.com/efam10/plastic_surgery.html, 30-8-2006

development. These examples are the most extreme ones but also in countries itself is cross border medical care getting normal. Dutch hospitals near a border are cooperating with foreign hospitals in Belgium and Germany. In some cases health insurance companies compensate treatments and surgeries which are conducted in another country.¹⁷ In the case of the Netherlands it is mostly Belgium and Germany; for some treatments the waiting list are there shorter.

All these developments show that national governments should be aware of foreign developments which can affect their domestic medical policy. As a result of these developments they must react effectively.

1.2 Main question & sub questions

The main question of this master thesis is:

“If and in what way do European countries react on the phenomenon of transplantation tourism for kidneys to India and what are the available policy solutions?”

To answer the main question sub questions are needed. The following sub questions, which can be divided in four parts, are defined:

1. Transplant tourism

- 1.1 What is transplantation tourism for kidneys to India?
- 1.2 What are the ethical dilemmas/problems with transplantation tourism for kidneys?
- 1.3 What is the international point of view in the case of transplantation tourism for kidneys?
- 1.4 In what degree does the Netherlands and the United Kingdom cope with it?

2. Organ donation policy

- 2.1 What is the currently the organ donation policy in the Netherlands?
- 2.2 What are the ethical points of view behind this policy in the Netherlands?
- 2.3 What is the current organ donation policy in the United Kingdom?
- 2.4 What are the ethical points of view behind this policy in the United Kingdom?
- 2.5 What is currently the organ donation policy in India?
- 2.6 What are the ethical points of view behind this policy in India?
- 2.7 Does transplant tourism for kidneys affect the organ donation policy/transplantation policy of the Netherlands and the United Kingdom and in what degree?

3. Reactions and solutions for preventing transplantation tourism

- 3.1 Do the countries react on transplantation tourism for kidneys and how?
- 3.2 How can a country deal with developments outside his border which affects its own policy (especially with ethical sensitive subjects)?
- 3.3 What are the solutions to react on transplantation tourism for kidneys?
- 3.4 Are the solutions to react on transplantation tourism for kidneys realistic and ethically acceptable?
- 3.5 Can these solutions be brought into practice into the Netherlands and/or the United Kingdom?

4. European policy on transplantation tourism

- 4.1 Is there at the moment a European policy to prevent and respond on transplantation tourism for kidneys?
- 4.2 Is there at the moment a general European organ transplantation and donation policy?
- 4.3 How can a European policy for preventing transplantation for kidneys be formulated?

¹⁷ <http://www.vzwgo.be/buitenlanders/nederland.htm>, 30-8-2006. OZ, CZ and Achmea have a cooperation agreement with a hospital in Knokke (Belgium).

With these sub questions it will be possible to answer the main question in the end of this master thesis.

1.3 Goal of research

- Descriptive; describing transplantation tourism and describing how the Netherlands and the United Kingdom respond on it.
- Explanative; it will give an insight of the process of transplantation tourism and why it occurs.
- Prescribe; possible solutions that European countries have to respond on transplant tourism.

This master thesis will show that even policy area's, which are mainly domestic, are influenced by cross-broader developments. Policymakers should react on this and this research looks if this happens with the problem of transplantation tourism. In order to do this an insight in the process of transplantation tourism is necessary; what is it and how does it occur. Next, this master thesis researches the possible solutions for European countries to react on developments abroad which influence the domestic policy.

Why the Netherlands, the United Kingdom, India and the European Union?

Although in the main question the focus is on European countries there are two countries chosen to do further research on. The European Union has at the moment 27 member states and it is impossible to research all these countries. Therefore the Netherlands and the United Kingdom are chosen to examine if these countries react on transplantation tourism and if they have policy on it.

Before starting this master thesis some research was been done about the subject. One finding was that there was a lot to find about transplantation tourism in India. Further it is interesting to see that there is in India major support for paid unrelated living donation. Transplantation tourism is not seen as unethical.

The United Kingdom is interesting because it has, because of the colonial past, strong ties with India. Last, during the research was discovered that the subject was under some attention of British politicians and doctors. This seems to be less in the Netherlands.

At last there is also the focus on the European Union. The reason is that both the Netherlands and the United Kingdom members are of the European Union. It is possible that at the European Union the subject of transplantation tourism is discussed and that at that level policies are developed which influence the policy solutions at the national level.

Academic relevance

The academic relevance of this master thesis is that it gives possible solutions for European countries to react on transplant tourism. At the moment it is well known that it exists but there is little material on how governments could react on it. There has been a lot of writing about the phenomenon of transplantation tourism but this is more the ethical and medical discussion if it is the matter. There is little written about the subject of policy solutions by governments and international organisations. In this master thesis possible proper policy solutions for European countries are examined. Transplantation tourism is seen as unethical by countries but also by large international organizations. Although there is written a lot about it there is not much specific information or research about it. The goal of this research is to bring the problem of transplantation tourism under the attention while it is a development which is unethical and violate the basic human rights.

Social relevance

The subject of transplantation tourism affects a lot of people; receivers, donors, their families, doctors but also institutions like governments, patients associations, health insurance companies and hospitals. They all are, direct or indirect, affected by the phenomenon. What is even more important is that the issue is heavily weighted by ethical choices, which have a big influence on the lives of these peoples. This master thesis deals with the complexity of

these dilemmas and searching for proper solutions. This is not easy and perhaps even impossible. Hopefully this master thesis can achieve a little step in the right direction in this complexity dilemma. Especially, because it is expected that in the future more complex dilemmas occur by the ongoing process of globalisation.

1.4 Concepts

In this master thesis some specific concepts are used. In this paragraph the most important concept are defined. These definitions are specific for this master thesis; it is possible that there are other definitions and views. Other concepts are defined later in this master thesis. The following concepts are important:

- Transplantation tourism
- Paid unrelated living donation
- Paid unrelated organ donation
- Cadaver organ donation
- Organ donation policy
- Domestic organ donation
- European policy

One of the most important concepts in this master thesis is transplantation tourism. The WHO defines transplant tourism as follows: "*Patients from countries where waiting lists are long or where organs from deceased donors are not available travel abroad in order to purchase a transplant.*"¹⁸ This definition is broad and for this master thesis it is modified. Transplant tourism is the phenomenon where patients from countries where waiting lists are long and where organs from deceased donors are not sufficient available travel abroad and pay money for organs in order to purchase a transplant. Transplantation tourism is a form of unrelated paid organ transplantation this is a transplantation where a person, who is not a near relative of the receiver, gets paid to donate a kidney by life (most common) or part of the liver and which is transplanted in the receiver. This master thesis deals with the donation of one kidney by life.

In the case of transplantation tourism the donor is a paid unrelated living donor. This is a living donor who is not a near relative of the receiver. For some organs it is possible to donate by life; the kidney and part of the liver. The donor can donate voluntary or get paid. It is important to note that organ donation by brain death is not part of this master thesis. A person who is brain death dies when the organs are removed. More organs can be used from a brain death person because this person is alive. This master thesis focuses on people who are living before and after they donate an organ. Next to living donations there is also cadaver organ donation possible. Cadaver organ donation is the donation of organs by a deceased person.

Also important to explain is organ donation policy. This is the policy of a country to regulate the donation of organs by persons. These persons can be deceased or alive. It also includes regulation of the institutions and organisations, such as hospitals and transplantation centres, which are (in)direct involved in the transplantation process. For instance; keep up the waiting list, the allocation of available organs and the care after organ transplantation.

It includes also the institutions which administer licenses, control and supervise whether the regulations are implemented correctly by the several participants. More narrow is domestic organ donation policy; the organ donation policy which arranges the matter within the border of a country.

At last the concept of European policy needs to be explained. This is a very broad concept because within the European Union (EU) several types of policies exist. These types are

¹⁸ World Health Organization, 57th World Health Assembly, Human organ and tissue transplantation: report by the Secretariat, A57/17, 2004, page 2.

caused by the different levels of competences within the European Union. These can be divided in four types:¹⁹

- 1) Market-building policy; the European Union has nearly exclusive. Examples are the EMU (European Monetary Union) and the internal market policies.
- 2) Market-correcting policy; in limited areas the European Union has often exclusive competence. For example, Common Agricultural Policy, Cohesion Policy and Fisheries.
- 3) Market-cushioning; the competence of the European Union is shared with the member states. Examples are: occupational health care and safety and environmental protection.
- 4) Non-market policies; these policies are subordinated to member states. Police cooperation and foreign policy are examples.

European policy is defined as one of these four policy types. In this master thesis the main focus is probably on the third pillar. It is examined if there is European policy concerning transplantation tourism. This can influence the available policy solutions at the country level.

1.5 Theory

This master thesis can, theoretical, be divided in seven parts which apply on transplantation tourism:

- 1) Ethical analysis
- 2) Social determinants
- 3) Economic determinants
- 4) Medical aspects
- 5) Current status of the policy
- 6) Political aspects
- 7) Policy solutions

This separation is necessary because this is much clearer although there is overlap and relations between the seven parts.

The first step is to analyze transplantation tourism and to decide whether it is ethically responsible behavior. In this master thesis the utilitarian approach is used. This approach is common used for analyzing medical ethical dilemmas which transplantation is one of. The utilitarian approach focuses on the outcome of an ethical decision. An ethical "good" decision is the outcome of a decision which maximizes the amount of welfare or happiness of the most. The utilitarian approach is not the only theory which can be used for analyzing an ethical dilemma. The reason to choose this approach is because the analysis is step by step and the criteria are clearer formulated and certain.

After analyzing the ethical side of transplantation tourism the social determinants of transplantation tourism are examined. This paragraph examines the people who buy and organ and people who sell one. The level of education, the income and the social status of people is examined. Perhaps there are certain social groups that conduct these practices.

Then the economic determinants of transplantation tourism are examined. Those are the different allocation systems that are possible. Transplantation tourism is a real market allocation system; people buy and sell organs and the price is set by the demand and supply. What are the advantages and disadvantages of such a system compared with other systems where for instance, the government arranges the allocation?

In the paragraph of medical aspects the current medical treatments which are available when you have kidney failure are described. Next, to organ transplantation there are other treatments such as dialysis possible. An overview of the medical treatments is been made by different questions, their advantages and disadvantages.

In the following paragraph the current status of policy on transplantation tourism is described.

¹⁹ Alberta Sbragia, 'Chapter 6: Key policies', In: *The European Union: how does it work?*, Edited by: E. Bomberg, A. Stubb, (Oxford University Press, Oxford: 2005), Page 131.

Do countries already have a policy to deal with transplantation tourism? If this answer is yes then research of what kind of policy this is and if this policy is effective is possible. If countries do not have a policy at this moment research needs to be conducted to discover why there is no policy. This paragraph is interrelated with the political aspects of transplantation tourism. It is in first instance a political decision if there will be a policy to deal with transplantation tourism. If politicians agree that there is not a problem then a policy will not be developed. It would be very interesting to look at the different views of politicians on transplantation tourism.

The last part of the theoretical framework is the theory on policy solutions. A distinction can be made between tamed and untamed problems. The way of the development of policy solutions differ between the two kinds of problems.

The different theories are further explained and described in the theoretical framework in chapter 3.

1.6 Methods

In public policy research different methods of research are possible. The choice of the methods is important because it affects the validity of your research but also the outcome. Not all methods can be used in this master thesis. There are boundaries that limited the use of certain methods. For instance, it is not possible to go to India and to have interviews with people who have sold a kidney to a foreigner.

Information about people who sold their kidney relies on secondary information and this is less favourable than doing the research yourself. But that is the reality and you should adapt to it. This master thesis is limited by time, available knowledge and distance.

The risk of doing a comparative research is that one country, for instance the Netherlands, is researched better than the other one. Although awareness about this fact is necessary this doesn't mean that this master thesis can not be valid. The goal is to build up a research that, with the available resources and boundaries, is as much as possible valid and reliable.

The empirical information in this master thesis is collected from two sources: documents and interviews.

The major sources for the empirical material are documents. The amount of documents is because of the internet eternal. The used documents are: books, articles in scientific journals, articles of new papers, information on several websites. The second source is interviews. Face to face interviews, interviews by e-mail and telephonic interviews are held. The methods and techniques are further described in chapter 5.

1.7 Notation

In chapter 1 the analysis of the problem of transplantation tourism was presented and the main- and sub questions were formulated. In the next chapter a more detailed sketch of transplantation tourism is given. The (international) organ shortage, transplantation tourism in India the process of buying a kidney in India, the different organ donation policies of the Netherlands, the United Kingdom, India and the EU are described.

Chapter 3 is the theoretical framework. Here the theories which are used to answer the research questions are described. The following chapter is about the conceptualisation and operationalisation. In this chapter the concepts which are used in this master thesis are defined and these concepts are made measurable. In chapter 5 the research methods are described. In the next chapter the empirical information which is collected with the documents and the interviews are presented.

In chapter 7 the analysis on the empirical information is conducted. This master thesis ends with conclusions and recommendations which are described in chapter 8.

Chapter 2 Sketch of transplantation tourism

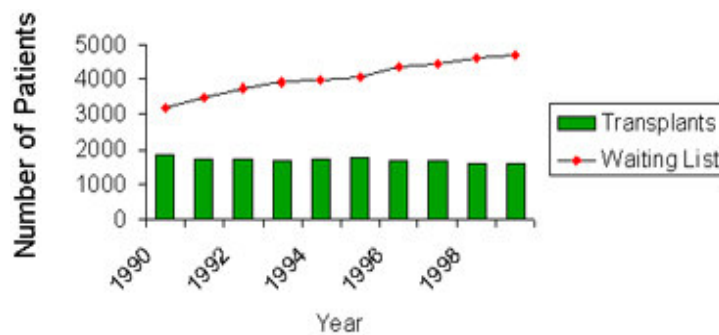
In this chapter the knowledge on the policy problem of transplantation tourism is described. First the international organ shortage is discussed and transplantation tourism in India. Then the principal of unrelated paid living organ donation is discussed. Next, the organ donation policy in the Netherlands, the United Kingdom, India and the EU are described. In this way the policy problem described in chapter 1 is more clarified and outlined.

2.1 International organ shortage

The organ shortage is a world wide problem. Most countries don't have enough supply to help all the people who need organ transplantation. The organ shortage is such a problem that 15-30% of the people on waiting list die because they don't receive a transplantation on time.²⁰ In Europe there are 120.000 kidney dialysis patients and more than 40.000 people are waiting for kidney transplantation.²¹ It is expected that the waiting time for an organ is 10 years in 2010.²² At the moment the waiting time is 3 years.²³ In 2003 247 people died in the United Kingdom while they were on the waiting list.²⁴ These figures show that there is a chronically organ shortage in Europe.

In the United Kingdom the number of patients on the waiting list for kidney in the period 1998-2000 increased but the amount of transplants was stable.

Figure 1 The number of patients on the active kidney waiting list and the number of patients who have had kidney transplants (cadaver and live) in the UK



Source: British Medical Association, in "Organ donation in the 21st century: time for a consolidated approach".

Eurotransplant²⁵ reports every year statistics about organ donors, organ transplantations and waiting lists for different organs. The transplantations only include post mortem organs.

²⁰ Council of Europe, Parliamentary Assembly, Recommendation 1611 (2003)1 "Trafficking in organs in Europe", 2003. <http://assembly.coe.int/Main.asp?link=/Documents/AdoptedText/ta03/EREC1611.htm>

²¹ Council of Europe, Parliamentary Assembly, Recommendation 1611 (2003)1 "Trafficking in organs in Europe", 2003.

²² Council of Europe, Parliamentary Assembly, Recommendation 1611 (2003)1 "Trafficking in organs in Europe", 2003.

²³ Council of Europe, Parliamentary Assembly, Recommendation 1611 (2003)1 "Trafficking in organs in Europe", 2003.

²⁴ The transplant trade, at: http://www.channel4.com/health/microsites/T/transplant_trade/, 7-11-2006.

²⁵ "It is responsible for the mediation and allocation of organ donation procedures in Austria, Belgium, Germany, Luxemburg, the Netherlands, Slovenia and Croatia (candidate member). In this international collaborative framework, the participants include all transplant hospitals, tissue-typing laboratories and hospitals where organ donations take place. The Eurotransplant region numbers well over 122 million.", at: <http://www.transplant.org/?id=about>, 7-11-2006.

Figure 2 Waiting list for kidneys²⁶

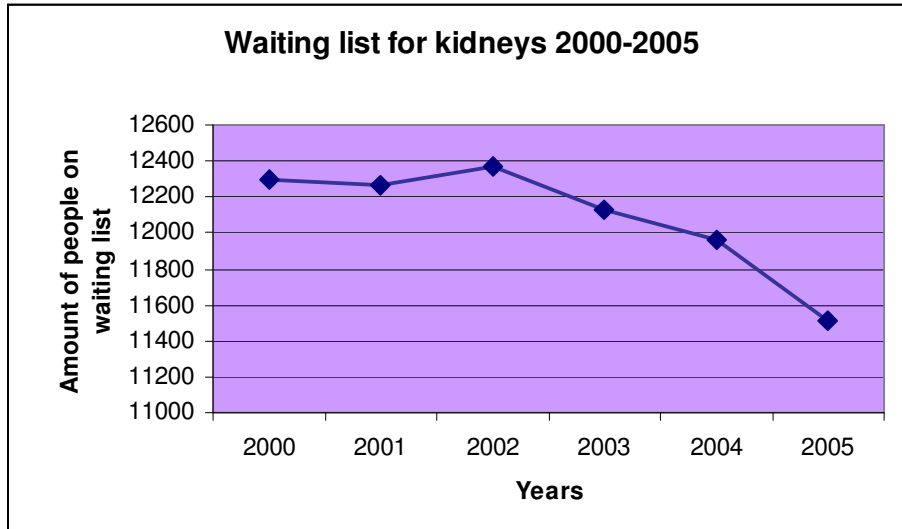
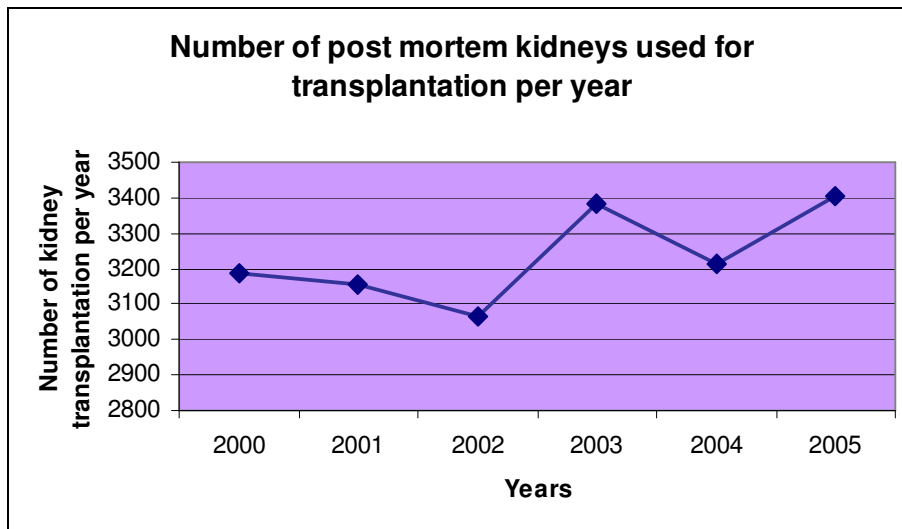


Figure 3 Number of post mortem kidneys used for transplantation²⁷



Figures of Eurotransplant show a more diverged picture. We see that there is a very slight decrease of the waiting list for a kidney.

The amount of kidneys from deceased donors which were used in transplantation is very divergent: in 2003 there was a increase, compared with 2002, of almost 10,5% but in 2004 there was a decline of 5% compared with 2003. It is hard to say something about these figures. But it shows that the amount of patients on the waiting list is slightly declining but the amount of kidneys is diffuse. How is the relationship between the waiting list and the amount of kidneys? Are there people dying while they are on the waiting list, are people going abroad for a kidney or are there other factors that play a role? These are interesting questions which can hopefully be answered during this research.

These figures show one thing: that the decline of the waiting list can not be totally be caused by the amount of kidneys of deceased donors (that is not increasing in line). It is possible that more people die before they get a kidney transplantation or people get in other ways a

²⁶ Statistics of Eurotransplant, at: http://www.transplant.org/?id=pereyear_public, 7-11-2006.

²⁷ Statistics of Eurotransplant, at: http://www.transplant.org/?id=pereyear_public, 7-11-2006.

kidney transplantation for instance by (un)related living donation. This can not be analysed by these figures.

Also in other countries there is an organ shortage. For example in the period 1995-2006 in the United States:

- The the waiting list of kidney patients grew from 31.045 till 72.374.²⁸ This is an increase of almost 133%.
- The supply of kidneys grew from 8.853 till 14.492.²⁹
- The amount of living kidney donations increased with 98%.
- The amount of deceased donations increased with 42%.

In some years the amount of living kidney donation was even higher than the amount of deceased donations. An overview of the kidney waiting list and the kidney donor list can be found in annex 1.

An explanation for the great increase of living kidney donations could be the development of medical techniques to conduct living kidney donation. But this increase shows that there is a need for organs; people will not donate their organs by life when this is not necessary. Also in the United States people are dying while they are waiting for a kidney. In 2005 4.039 Americans died while they were waiting for a kidney transplantation.³⁰

The different figures from the different countries show that there is an international organ shortage. Some future estimates are even worse.

This makes the problem of transplantation tourism even more complex because it occurs because of the organ shortage. The organ shortage and transplantation tourism are international problems. In practice international problems aren't easy to solve because of the amount of different actors such as states, international organisations, NGO's etc.

2.2 Transplantation tourism in India

In paragraph 1.4 the concept of transplantation tourism was defined and explained. In this paragraph transplantation tourism in India is examined.

The WHO stated that there is transplantation tourism but exact figures are not known: *"There are no reliable data on organ trafficking, or indeed transplantation activity in general, but it is widely believed to be on the increase, with brokers reportedly charging between \$ 100 000 and \$ 200 000 to organize a transplant for wealthy patients. Donors, frequently impoverished and ill-educated, may receive as little as \$ 1000 for a kidney although the going price is more likely to be about \$ 5000".*³¹

Although there are no reliable data available, there are some figures that give an indication that it does happen. For instance in the United Kingdom between 1974 and the half of 2002 it is known that 90 citizens had an overseas kidney transplantation.³² Of them 36 went to India this is 40% of the total.

In Canada is estimated that every year between the 30 and 50 people travel overseas to get kidney transplantation.³³ These people pay between \$50,000 and \$145,000 for their transplantation.³⁴

²⁸ National Transplant Waiting List: at 31-12-1995 and 31-10-2006. Note: some people are registered by more transplant centres so the actual amount of patient can be lower than the actual registrations. Source: United Network of Organ Sharing, United States, data request provided on 1-12-2006.

²⁹ Sources: United Network of Organ Sharing, United States, data request provided on 1-12-2006.

³⁰ Organ transplants: psst, wanna buy a kidney?, in: *The Economist*, 18th November 2006.

³¹ WHO, Organ trafficking and transplantation pose new challenges, at: <http://www.who.int/bulletin/volumes/82/9/feature0904/en/index.html>, 31-12-2006.

³² NHS & UK Transplant, Bid for European legislation to stop "transplant tourism", in: *Bulletin Autumn 2003*, page 11.

³³ The Rich Pay To Get to Front of the Line for Organ Transplants Rich Can Get Transplants Quickly, at: <http://www.commondreams.org/headlines01/0601-04.htm>, November 2006.

³⁴ The Rich Pay To Get to Front of the Line for Organ Transplants Rich Can Get Transplants Quickly, at: <http://www.commondreams.org/headlines01/0601-04.htm>, November 2006.

In several cases the receivers got negative side effects after the surgery. Some receivers did not receive a medical record; it is unclear what happened and what kind of medication they received.³⁵ There is also a case known where a man did not get a kidney at all; he had a scar but an ultrasound showed that he did not had received a new kidney at all.³⁶

2.3 How to buy a kidney in India?

The main subject of this master thesis is transplantation tourism. More specific: transplantation tourism from the Netherlands and the United Kingdom to India. But how do people in the Netherlands and the United Kingdom get a kidney in India?

How does the whole process go?

The research started on the internet with typing in: "buy + kidney + organ + India". It gives 168.000 hits but these are mainly articles over the phenomenon of transplant tourism. But at the pages there are also some sponsored links. One of them is an advertisement of a transplantation centre in India which offers kidney transplantations³⁷. The hospital has some preliminary requirements for the patient. These are requirements on the medical status of the patients. For example, the patient must have a '*case of irreversible renal failure and must already be seeing a Nephrologists*'.³⁸ Next, the patient must send its medical history with reports of some medical investigations. The patient's doctor needs to cooperate to give the medical history; he is legally bound to do that.

The patient stays in India for 20 days. The costs are not available but it is a package deal for the whole stay in India. The flights are not included.

On the website there are statistics of where the patients come from. Over the period 2002-2005:³⁹

- 26% of the patients where Indian
- 22% of the patients where European
- 1% of the patients where Canadian and American

In the hospital 1342 kidney transplantations where conducted.⁴⁰ The age group that underwent most kidney transplantations was the group between 55-60 years; 40% of all the patients who had kidney transplantation in this hospital felt in this age group.

The hospital claims to have better scores than a British hospital. Especially the rejection rate is lower. The hospital claims that this is because they have a wide range of living donors; the result is narrower matches.

On the website are copies of donor referrals forms and recipient referrals forms available. It becomes clear that they work with living donors. There is no information about the donors: how they are found, what they get paid, the procedures, requirements and after care.

The conclusion of the website is that it seems to be a professional hospital. It gives quite some information over kidney transplantation and what patients can aspects. There are even some nice pictures of the hospital and the city. What is missing is information about the purchase of the kidneys. Next, there is no information about the risks of the operation and about the after care when the patient returns to the home country.

2.4 Paid unrelated living organ donation

The first commercial organ market originates in 1983: the International Kidney Exchange established by an American physician. Estimated is that in the early 1990s every year 2000 unrelated paid living transplantations were conduct in India. Probably this amount is much higher because a lot of these transplantations were not registered.

³⁵ The Rich Pay To Get to Front of the Line for Organ Transplants Rich Can Get Transplants Quickly, at: <http://www.commondreams.org/headlines01/0601-04.htm>, November 2006.

³⁶ The Rich Pay To Get to Front of the Line for Organ Transplants Rich Can Get Transplants Quickly, at: <http://www.commondreams.org/headlines01/0601-04.htm>, November 2006.

³⁷ <http://www.aadilhospital.com/renal.html>, October 2006.

³⁸ <http://www.aadilhospital.com/renal.html>, October 2006.

³⁹ <http://www.aadilhospital.com/renal.html>, October 2006.

⁴⁰ Website was checked on 24 October 2006.

Arguments of advocates of unrelated paid living organ donation are:

- The risks for the donor are low.
- Short-term survival rates are better than with cadaver transplants.
- The shortage on organs will decline.
- Regulation of living paid organ donation will band out the thousands of black markets of organ sales. Trade can be regulated but the illegal practice conduct at the moment not.⁴¹
- It is a paternalistic view of us to judge over norms, values and motivations of other people and cultures whose views are not like ours.⁴²
- Both donor and receiver are getting better of the transactions.⁴³ The donor gets money for it and overcomes extreme poverty. The donor has the right to choose if he/she sells an organ. The receiver will have a better life.
- In some countries the donation of hair, blood, sperm, and egg and surrogate pregnancy is also compensated by money.⁴⁴ What is the difference?

Arguments of opponents of unrelated paid living organ donation are:

- Health of donor declines. Research under 300 sellers' shows that 50% of the participants had complained of persistent pain at the side where the kidney was removed and 33% complained of long-term back pain.⁴⁵
- High risks for receiver. Australian research under patients who had commercial organ transplantation abroad were more likely to develop infections such as HIV, Hepatitis B, cytomegalovirus and fungal infections.⁴⁶ The patient survival rate was 81,5% after one year. The most cause of death where infections 56%.⁴⁷ Other researches shown same results.⁴⁸ There is a concern that the results are even "*worse because the majority of results have neither been followed up nor published.*" (Hoyer, 2006;1366)
- Exploitation of the donor.⁴⁹ The poor donor does not overcome poverty as a result of the sale. In some cases income declines and the donor stays in debt.⁵⁰
- Unequal allocation system of organs because poor recipients who are unable to pay for it are dismissed from the market.
- Paid organ donation prevents a national cadaver transplant program from being established or decreases the amount of cadaver donations⁵¹.
- Could have a negative impact on the availability of organs not suitable for living donation like heart and lung.⁵²
- Regional differences in financial rewards can lead to 'donor tourism'.

⁴¹ Friedländer, M.M., The right to sell or buy a kidney: are we failing our patients?, in: *Lancet*, 359, 2002, pages 971-973.

⁴² Friedländer, M.M., The right to sell or buy a kidney: are we failing our patients?, in: *Lancet*, 359, 2002, pages 971-973.

⁴³ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *Journal of American Medical Association*, Volume 288 13, 2002, pages 1589-1593.

⁴⁴ Friedländer, A., Controversy: Payment for living organ donation should be legalised, in: *BMJ*, Volume 333, 2006, pages 746-748.

⁴⁵ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *Journal of American Medical Association*, Volume 288 13, 2002, pages 1589-1593.

& Hoyer, P., Commercial living non-related organ transplantation: a viewpoint from a developed country, in: *Pediatric Nephrol*, 21, 2006, page 1366.

⁴⁶ Kennedy, S., Shen, Y., Charlesworth, J., Mackie, J., Mahony, J., Kelly, J., Pussell, B., Outcome of overseas commercial kidney transplantation: an Australian perspective, in: *MJA*, Volume 182:5, 2005, pages 224-226.

⁴⁷ Kennedy, S., Shen, Y., Charlesworth, J., Mackie, J., Mahony, J., Kelly, J., Pussell, B., Outcome of overseas commercial kidney transplantation: an Australian perspective, in: *MJA*, Volume 182:5, 2005, pages 224-226.

⁴⁸ See research of: Sever, M.S., Kaxancioglu, R., Yildiz, A., Turkmen, A., Ecder, T., Kayacan, S.M., Celik, V., Sahin, S., Aydin, A.E., Eldegez, U., Ark, E., Outcome of living unrelated (commercial) renal transplantation, in: *Kidney International*, Volume 60, 2001, pages 1477-1483. & Higgins, R., West, N., Fletcher, S., Stein, A., Lam, F., Kashi, H., Kidney transplantation in patients travelling from the UK to India or Pakistan, letter in: *Nephrol Dial Transplant*, 18, 2003, pages 851-852.

⁴⁹ Hoyer, P., Commercial living non-related organ transplantation: a viewpoint from a developed country, in: *Pediatric Nephrol*, 21, 2006, page 1366.

⁵⁰ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *Journal of American Medical Association*, Volume 288 13, 2002, pages 1589-1593.

⁵¹ Hoyer, P., Commercial living non-related organ transplantation: a viewpoint from a developed country, in: *Pediatric Nephrol*, 21, 2006, page 1366. & Phadke, K., Anandh, U., Ethics of paid organ donation, in: *Pediatr Nephrol*, Volume 17, 2002, page 310.

⁵² Hoyer, P., Commercial living non-related organ transplantation: a viewpoint from a developed country, in: *Pediatric Nephrol*, 21, 2006, page 1366.

The arguments that are used above are quite diverse. Perhaps most important is that research does not prove what is better. The fact is that there are in some countries, for instance India, illegal markets. For those countries this can give reasons to examine the possibilities to legalize and regulate paid unrelated living donation.

There are important questions that can be asked with a legalized kidney sales system such as:

- In what way can such a system be justified? People are selling vital parts of themselves.
- Are there other effective solutions to decrease the organ shortage?
- Do the prices of a kidney also include after care and the lost of income? Research shows that in India a lot of kidney donors had to pay for their own medication which is for especially poor people expensive.
- What are the effects of a free market on the cadaver transplant program?
- How must such a market be regulated and arranged?
- Can prices be calculated in theory? How would a market operate in practice? This is something that can not be calculated or assessed. The perfect market does not exist and in practice unexpected market failures do occur.
- What is the effect of such a system on receivers and donors? Research of donors who got paid and who donated voluntary showed that the latter were more happy and satisfied after the donation than the first group.

An open and non-medical discussion between experts of national and international regulations on this task is urgent needed. Next, national healthcare organisations should improve infrastructures instead of promoting organ selling. But developed countries do not have the right to paternalize less-developed countries in their pursuit of legal and controlled solutions. Because of paternalistic attitude towards less-developed countries will only have a negative impact on the process of problem solving. There is a big dilemma: how can developed countries respond on unrelated paid living organ donation without paternalizing developing countries.

Transplant tourism makes it even more complex because here people from developed countries travel to less-developed countries to buy organs. After a short recovery period they return to their home country for the after care. How can you protect your own citizens without harming people in another country?

You would think that international regulations would be the solution. Unfortunately, it is unlikely that all countries agree on standardized regulations especially with the absence of global governance transplant practices.⁵³ Until that moment countries should take self steps to deal with these problems. They also must address it at the international level. The World Health Organisation (WHO) seems to be the best solution. It will be difficult to get consensus among the different countries. The WHO has already taken some steps but it goes very slow. The last official sign of action was in 2004 after this there are no documents or actions which were made public by the WHO.

2.5 The organ donation policy in the Netherlands

In the Netherlands the organ donation is arranged by the Organ Donation Act⁵⁴ of 1996.

The most important articles in this act are:⁵⁵

- It is not allowed to get a compensation which is higher than the costs made by the donation (Article 1).

⁵³ Daar, 2004; 1877.

⁵⁴ In Dutch: Wet op de Orgaandonatie.

⁵⁵ Wet op de Orgaandonatie, into force at: 1996, Nederland, <http://wetten.overheid.nl/cgi-bin/sessioned/browsercheck/continuation=24539-002/session=045778622702810/action=javascript-result/javascript=yes>

- A person of age, which is capable in judging the situation, is allowed to donate organs by life for the purpose of transplantation by another person (Article 3.1).
- With persons under age of 18 but above 12 living organ donation is only allowed when it concerns a regenerate organ for the purpose of saving the life a family member until second degree and the transplantation will not dangerous affect the life of the donor and approval by the legal guardian is obligated (Article 5.1).
- Adults and under age from 12 can approve or object to donate organs after they die (Article 9). This will be done by filling in and signing the donor form (Article 9.2). When a person is under the age of 16 the parents will decide of organ removal will take place despite that the person has given his approval to it (Article 12).
- When there is no form than under article 11.1 it is possible that other persons have the authority to decide. But when the partner and/or relatives can't agree over it than approval can not be given (Article 11.3).
- Organs can only be removed when someone is death or brain death (Article 14.1 &2). The doctor who will determine the death is independent and not part of the transplantation team (Article 14.1).
- When there is suspicious if some has died an unnatural death removal of organs is not allowed (Article 17).
- The Minister authorizes organ centres. These organ centurms are the only institutions which can type, transfer and allocate organs (Article 24).
- A license to an organ centre can only by authorized to institutions which are non-profit and no donor banks (Article 25). There are specific conditions for these organ centres (Article 26).
- Article 32 gives the penalties by violating the law.

From this act it is clear that the Netherlands has a policy of unpaid organ donation. The registration system which is used is a non-active registration system. This means that if you want to become a donor you need to fill in a donor form. If you not fill in a donor form you will be automatically become a non-donor; it is then not allowed to remove organs after you died or your family or partner decides different. In 2005 there was a discussion about this system because in the Netherlands there is a donor shortage. The Parliament has eventually decided that the current non-active registration system will remain.

At the moment 2.861.172 persons in the Netherlands are registered to become a donor and/or donate organs for scientific purpose.⁵⁶ This is a percentage of 17,5% on a total population of 16.335.998. The amount of people that doesn't give permission for organ donation is 1.571.765.⁵⁷ This is 9,6% of the total Dutch population. In total 5.066.921 persons have filled in a registration form and in percentage of the total Dutch population this is 31,0%.⁵⁸

2.6 The organ donation policy in the United Kingdom

The United Kingdom has changed legislation on organ donation in 2004 with implementing the Human Tissue Act. This law came into force on 1 September 2006.

The biggest change in this Human Tissue Act is that the family can't overrule the decision of the deceased person. Before this law 1 out of 10 overruled the wishes of their deceased. The new law makes it impossible to do this: if someone is registered as a donor than this person has the right to become a donor even if the family is against.

Relevant articles in the Human Tissue Act are:⁵⁹

- Commercial dealing in human materials for transplantation is forbidden (Article 32). There are different penalties on breaking these rules.

⁵⁶ <http://www.donorregister.nl/>, 2-9-2006

⁵⁷ <http://www.donorregister.nl/>, 2-9-2006

⁵⁸ <http://www.donorregister.nl/>, 2-9-2006

⁵⁹ Human Tissue Act 2004, Crown Copyright 2004, act into force at: 01-09-2006, <http://www.opsi.gov.uk/acts/acts2004/20040030.htm>

- It is forbidden to remove human material from a living person (Article 33.1 & 33.2). The Secretary of State may by regulations provide that articles 33.1 & 33.2 shall not apply in some cases (Article 33.3). There are different penalties on breaking these rules.
- Removing of organs and transplantation after the death of a person is lawful with consent of the person (Article 1).
- Transplantation, and other actions involving human tissue, can only be done with consent of the person (Article 1).
- Appropriate consent of children defines when a child gives permission for certain practices when he is alive and when he is death (Article 2). In practice this will mean that who has the paternal responsibility will decide.
- Appropriate consent of adults defines how and when a person gives permission for using human tissue when he is alive and after his death (Article 3). When the person has not given permission or made clear what he wants than the family (in order of family ties) will decide.
- A Human Tissue Authority shall be installed (Article 13.1). To do his job the Human Tissue Authority has several remits (Article 14).
- The general functions of the Human Tissue Authority are formed in Article 14 and are for instance: giving information and advice, monitoring, guidance and oversight.
- The United Kingdom Transplant Authority leads and provides the national framework for successful and solid organ and cornea transplantation.⁶⁰ Next, it will lead the developments of standards, the criteria for waiting lists, determines the rules for organ allocation, and increases the awareness of importance of organ donation toward the public. The United Kingdom Transplant Authority has been established in 2005 together with the National Blood Authority.

The system of the United Kingdom is a non-paid voluntary one. If you are not registered you will not become a donor. It has a quite similar policy system as the Netherlands although the laws and management of the system are different.

In the United Kingdom there are at the moment 13.572.920 people registered as a donor this 22% of the population.⁶¹ In 2005 there were 6543 people on de national waiting list. In 2005 2195 transplantation with organs of deceased persons were conducted. The amount of transplantations with living donors was in 2005 551 people.

2.7 The organ donation policy in India

The problem with India was and is the lack of law and control. India was since the eighties the country with the biggest commercialized market in living organs.⁶² The result was that especially poor people sold one kidney in questionable circumstances for economic reasons. After a lot of media criticism and international pressure the Transplantation of Human Organ Act 1994 was approved by the Indian Parliament in 1994. In this act paid organ donation is prohibited.

The relevant articles of the Transplantation of Human Organ Act 1994 are:⁶³

- Any donor may, in such manner and subject to such conditions as may be prescribed, authorize the removal before his death of any human organ of his body for therapeutic purposes (Article 1.1).
- When there was no such authorizing as subscribe in article 1.1 than the person lawfully in possession of the death body can decide if organ removal will be conduct (Article 1.3)

⁶⁰ Remits of the NSH Blood and Transplant Authority, <http://www.dh.gov.uk/assetRoot/04/10/23/30/04102330.pdf>, 6-9-2006

⁶¹ at: <http://www.uktransplant.org.uk/ukt/default.jsp>, 7-9-2006

⁶² Jha, V., Paid transplants in India: the grim reality, in: *Nephrol Dial Transplant*, Volume 19, 2004, pages 541-543.

⁶³ Transplantation Human Organ Act 1994, at:<http://www.medindia.net/>, 2-9-2006.

- Removal of organ of people with brain death is allowed when certain conditions and requirements which are prescribed by the Board of medical experts is met (Article 1.6).
- When a death body lies in a hospital or prison and is not claimed by near family within 48 hours the authority can be given to the person in charge of the time being or the management of the institution (Article 5.1).
- No human organ removed from the body of a donor before his death shall be transplanted into a recipient unless the donor is a near relative of the recipient (Article 9.1).
- If any donor authorizes the removal of any of his human organs before his death under sub-section (9.1) of section 3 for transplantation into the body of such recipient, not being a near relative as is specified by the donor, by reason of affection or attachment towards the recipient or for any other special reasons, such human organ shall not be removed and transplanted without the prior approval of the Authorisation Committee (Article 9.3).
- No hospital, unless registered under this Act, shall conduct or associate with, or help in the removal, storage or transplantation of any human organ (Article 10.1)
- The Central Government shall appoint, by notification, one or more officers as Appropriate Authorities for each of the Union territories for the purposes of this Act (Article 13.1).
- Under article 14 the functions of the Appropriate Authorities is described. For instance organizing the registrations of hospitals and authorize hospitals.
- Payment for organ donation is illegal and certain punishments are on it (Article 19).

The Authorized Committees, which are installed by the central government as Appropriate Authorities, have the task to decide if unrelated living donor transplantation is possible. The Committees have to judge if there is a case of non-paying organ donation. Only in the case of altruistic organ donation unrelated living organ donation is legal. It is important to note that this Act is not implemented by all 15 Indian states; “*which allows for interstate paid transplantation.*”⁶⁴ It is the state responsibility to take care of the health care system within the state; it is the state’s decision if it implements the Act.⁶⁵

As we can see in the Act paid human organ donation is illegal in India by law and punishments are on it. In practice there is still paid human organ donation. There is a gap between the law and the practice. How can this happen? In some states the Authorized Committees have approved thousands of paid donor applications “*after getting affidavits from donors stating that the donations were being made on the grounds of ‘love and affection’ for the recipients.*”⁶⁶ In 2003 the head of an Authorized Committee was arrested because he was accused of bribing to approve paid organ transplantation.⁶⁷ The investigator estimated that it was about 30 million dollar in kidney deals. Estimated is that more than 60% of the kidney donations are paid.⁶⁸

In India there is not a good functioning cadaver donor program. In the period 1999-2001 only 426 cadaver organ transplantations took place. This is an average of almost 61 transplantations per year. Of this cadaver organ transplantations there were 377 non-living kidney transplantations. Compared with the amount of almost 3500 living kidney transplantation only in the year 1999 the percentages of cadaver transplantations is way behind.⁶⁹ India is suffering with a big organ shortage.

⁶⁴ Kennedy, K., Organ Donation and Transplantation in India: An Inquiry in Kerala, in: *Journal of Social Distress and the Homeless*, Vol. 11, No. 1, January 2002, page 43.

⁶⁵ Kennedy, K., Organ Donation and Transplantation in India: An Inquiry in Kerala, in: *Journal of Social Distress and the Homeless*, Vol. 11, No. 1, January 2002, page 43.

⁶⁶ Jha, V., Paid transplants in India: the grim reality, in: *Nephrol Dial Transplant*, Volume 19, 2004.

⁶⁷ Biosafety news no. 38, “Human kidney trade now thrives in India”, 2003.

⁶⁸ Phadke, K., Anandh, U., Ethics of paid organ donation, in: *Pediatr Nephrol*, Volume 17, 2002, pages 309-311.

⁶⁹ Shroff, S., Presentation, Organ Donation: Story of life after death, at: <http://www.mohanfoundation.org/slides/6.pps>

India is a very large country with different administrative units. It is interesting to see that when one administrative authority takes action to prevent paid organ donations the amount of paid organ donations in other areas rises.⁷⁰ A good legal framework does not exist. Next, a lot of medical professionals are in favour of paid unrelated organ donation. In their eyes there is nothing wrong with selling your kidney to a stranger for saving someone's live. The Indian Medical Association justified the kidney sales as life saving and supported doctors who were conducted unrelated paid organ transplantations.⁷¹ This combined with the huge shortage of organs in India makes it possible that there is a big market for unrelated paid living organ donation. Further, the prices of the organs are increased after the illegalizing of paid unrelated organ donation.

2.8 One European organ donation policy?

At the moment there is not one European Union organ donation policy. But there was action on this field partly due to the developments such as transplantation tourism. The Committee on Citizens' Freedoms and Rights, Justice and Home Affairs has published a report called Trafficking in human beings: prevention and control of trafficking in human organs and tissues on 3 October 2003. The reason that this Committee made the report and not the Committee concerning health is due to the fact that trade in human organs and tissue (where transplantation tourism is part of) is a transnational crime; it is seen as trafficking of human beings.⁷² Therefore the Committee sees it as a priority issue.

The report came after an initiative of the Hellenic Republic to a draft view on a Council⁷³ Framework Decision concerning the prevention and control of trafficking in human organs and tissues.⁷⁴ This draft of the Hellenic Republic was published on 28 March 2003. The Hellenic Republic based its initiative on articles 29, 31e and 34.2b of the Treaty on European Union; therefore this initiative falls within pillar 3. The Committee made some amendments on the draft proposal of the Hellenic Republic. The Committee on the Environment, Public Health and Consumer Policy gave also an opinion on the draft.

The report and amendments of the Committee on Citizens' Freedoms and Rights, Justice and Home Affairs was a consultative procedure. The European Parliament adopted the draft with the amendments with 425 votes in favour and 25 abstentions. A consultative procedure means that the European Parliament is "*allowed to give a nonbinding opinion to the Council of Ministers before the latter adopted new law in selected areas, such as aspects of transport policy, citizenship issues, the EC budget, and amendments to treaties*". (McCormick, 2002; 108) It is possible that the Council could ask the European Commission to amend the draft⁷⁵. The European Commission is not obligatory to do that.⁷⁶

The draft view on a Council Framework Decision was sent to the Council in 2003. The matter was discussed in the Council but eventually it ended on the table; the member states could not unanimously agree on a decision which is necessary due to the fact that the subject which is a non-market policy. Police cooperation but also transnational crimes are subjects which fall in the third pillar. The member states have the last word in this case. Transplantation tourism is not a matter of priority in the Council and therefore nothing happens. In practice there is already a draft but here the countries could not unanimously agree on it. It would be perhaps different as this matter, human organs and tissues, was a

⁷⁰ Jha, V., Paid transplants in India: the grim reality, in: *Nephrol Dial Transplant*, Volume 19, 2004, pages 541-543.

⁷¹ Biosafety news no. 38, "Human kidney trade now thrives in India", 2003.

⁷² European Parliament, Committee on Citizens' Freedoms and Rights, Justice and Home Affairs, rapporteur: R. Evans, Report A5-0326/2003, 3 October 2003, Amendment 3, Recital 2, page 7.

⁷³ With Council is meant the Council of Ministers of the European Union. Which Ministers attends depends on the subject. In this case the Ministers of Justice and Home Affairs are responsible.

⁷⁴ European Parliament, Committee on Citizens' Freedoms and Rights, Justice and Home Affairs, rapporteur: R. Evans, Report A5-0326/2003, 3 October 2003, page 5.

⁷⁵ McCormick, J., *Understanding the European Union; a concise introduction*, Palgrave, New York, 2002, page 108.

⁷⁶ McCormick, J., *Understanding the European Union; a concise introduction*, Palgrave, New York, 2002, page 108.

health care matter then it would be a pillar three subject and the procedures are here different but that is just guessing.

In June 2006 the Directorate-General Health and Consumer Protection (DG SANCO) of the European Commission organized an open consultative on organ donation and transplantation. The different contributions from countries, patient and donor associations, professional and scientific associations, organ exchanges and national authorities were summarized in the report on open consultative: *“Policy options for organ donation and transplantation at the EU level”*. This report is published in December 2006. The DG SANCO gave three options for future EU actions where the different contributors could react on:⁷⁷

- 1) *“To continue the work under existing Community programmes, without further coordination.”*
- 2) *“To promote active coordination between Member States on organ quality, safety and availability.”*
- 3) *“To strengthen coordination between Member States, consider minimum harmonisation on quality and safety to complement and reinforce these actions through a directive, and in addition an initiative on organ trafficking.”*

The majority of the contributors gave their preference to the third option. Although also a large amount of contributors did not give their opinion and only give some activities that the EU could undertake.⁷⁸ It is perhaps useful to note that the patients and donors associations and the professional and scientific associations preferred the third option.⁷⁹

The organ exchange organisations and national authorities preferred the second option although there was also quite some support for the third option. These organisations and authorities had some agreement on the following points:⁸⁰

1) *“the content of a possible future directive should be limited to establishing a basic quality and safety framework for Europe and, at the same time, it should respect clinical practice. Binding requirements should not create any barriers for organ donation, including the use of the so-called “expanded criteria donors” under specific circumstances.”*⁸¹

2) The contributors agreed that the main problem with organ donation and transplantation policy is the organ shortage. Interestingly they were not supporters for a centralised European donor pool. But they pointed out that there are activities possible: benchmark between Member States, coordination and training of professional, development of guidelines and promotion of donation.

3) Also the access to transplantation was seen as a problem not only between Member States but also within Member States. Cooperation between Member States was partly mentioned as a solution but also human and financial resources must be available.

4) Some participants mentioned the problem of transplantation tourism but also the increasing growing number of non-EU citizens on the EU waiting lists. In the case of combating organ trafficking there was great support to explore the possibilities.

The main conclusion of the report was that there are specific problems in the case of organ donation and transplantation. The three main problems are:⁸²

- 1) Quality and safety aspects of organ transplantation
- 2) Organ shortage
- 3) Organ trafficking

⁷⁷ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, pages 4.

⁷⁸ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, pages 4.

⁷⁹ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, pages 4.

⁸⁰ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, pages 6-7.

⁸¹ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, page 6.

⁸² European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, page 7.

The European Commission come to the final conclusion that these problems “*should be addressed in the context of Community competence in order to propose the best alternatives for EU action.*”⁸³

At European level there are some initiatives although there are no concrete actions yet. It is interesting to see both the European Parliament as the European Commission have taken some actions. The EU is aware of the fact that there is an organ shortage and that there is organ trafficking (were transplantation tourism is part of it). But perhaps most interestingly is that it within different areas. The European Parliament discussed it in the light of transnational crime while the European Commission discussed in from the health perspective. Further research on this is necessary and it comes probably back in chapter 6 about the empirical information.

This chapter makes it clear that transplantation tourism is a complex matter. In this master thesis this will be examined further. Next, I will conduct research for policy solutions for the Netherlands and the United Kingdom.

⁸³ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, page 7.

Chapter 3 Theoretical framework

3.1 Introduction

The dilemma of transplant tourism is not a problem standing alone. The whole discussion begins with views on organ transplantation. In some religions is organ transplantation forbidden. Next, there is the ethical discussion about the right or wrongness of paid unrelated organ donation. Besides this there is also a discussion about how far people can go to get health care: is someone allowed to get medical health in another country where the practice conduct is contradictory with the legislation in his home country. These are important questions which have a big influence on the policy decision makers. Different actors are participating in different arenas for instances: politicians, doctors, (medical) researchers, ethics, patients & relatives, donors & relatives, interest organisations a.o. The last important issue that involves transplant tourism is the normative aspect within these different discussions. The problem perception is very normative. A kidney patient who needs a kidney urgently will look different at the transplant tourism than a doctor especially in a global discussion. Doctors in the Netherlands have a different opinion on transplantation tourism than doctors in India. This makes analyzing the problem and finding policy solutions not easy. In this theoretical framework theories are formulated which help to peel of the different layers behind the problem of transplant tourism. The theoretical framework helps to research available policy solutions. Different theories are used because that is the best way to research a complex ethical issue. A policy problem can be divided in different rationalities. Rationalities are “*in it self closed schemes of criteria for responsible acting.*”⁸⁴ Snellen concludes that there are four rationalities which are always applicable for policy: political rationality, the legal rationality, economic rationality and the scientific rationality.⁸⁵ He states that the rationalities are subjective.⁸⁶ Although his rationalities are logical these will not be used in this form. For this subject rationalities are developed which are suitable for this research. Next, some of the rationalities of Snellen, such as the scientific and the legal rationalities will come back in all rationalities that are used.

In the case of transplantation tourism the following rationalities are formulated:

- 1) Ethical
- 2) Social
- 3) Economic
- 4) Medical
- 5) Political
- 6) Policy

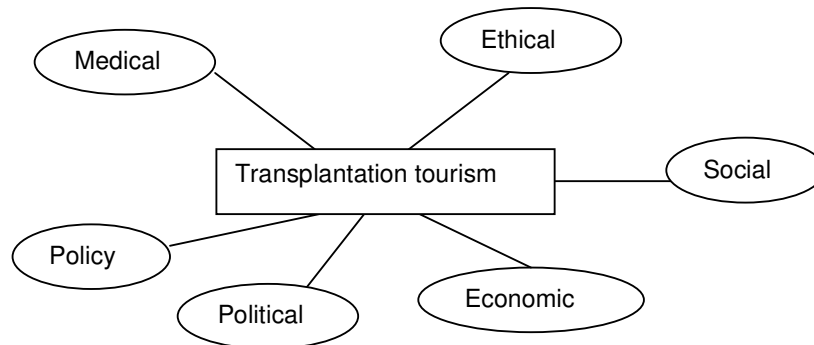


Figure 4 Rationalities of transplantation tourism

⁸⁴ Snellen, I.Th.M., Boeiend geboeid; ambivalenties en ambities in de bestuurskunde, Samsom H.D. Tjeenk Willink, Alphen aan den Rijn, 1987, page 1.

⁸⁵ Snellen, I.Th.M., Boeiend geboeid; ambivalenties en ambities in de bestuurskunde, Samsom H.D. Tjeenk Willink, Alphen aan den Rijn, 1987, pages 3-4.

⁸⁶ Snellen, I.Th.M., Boeiend geboeid; ambivalenties en ambities in de bestuurskunde, Samsom H.D. Tjeenk Willink, Alphen aan den Rijn, 1987, page 2.

These rationalities are chosen because this combination of rationalities embrace the complexity of transplantation tourism the most. Other rationalities are perhaps possible but for this research and the goal of the research these rationalities are the best. It will be showed that transplantation tourism is a complex problem and that these rationalities analyse this problem in a sufficient way. The rationalities are, in some way or another, interrelated to each other. For instance, the medical aspects influence the policy because the government reacts on new developed technologies. But also the medical aspects are influenced by the policy. Law and policy decides what the boundaries are in doing medical research. This is important in stem cell research or xenotransplantation. It shows that legal and scientific rationalities also play a role in the used rationalities.

3.2 Analyzing ethical issues

There are different theories which can be used to analyze ethical issues. The theory used is important because this explains why you have a specific view on an ethical issue; it are your glasses through which you see the ethical issue and these glasses have different colours. For discussing transplant tourism the utilitarian approach is used.⁸⁷ In this paragraph the approach is described and discussed.

The utilitarian approach has three elements: consequentialism, welfarism and aggregationism. Consequentialism can be defined as *"the view that the consequences of an act are what make it right or wrong."*⁸⁸ A consequentialist looks at the consequences of an action and decides if this action is wrong or right. An action is something that makes a difference in what happens. If you did or did not take action has influence on what happens. For actions that did make a difference you should take responsibility for what you did or not.

The second element is welfarism. Utilitarians believe that the consequences of our actions influence our welfare. Welfare is *"the obtaining to a high or at least reasonable degree of a quality of life which on the whole a person wants, or prefers to have."*⁸⁹ This is a quite vague definition especially with defining 'prefers' and rises a lot of questions.

What is "prefer" exactly? Is it necessary to take all preferences you have? Are external preferences also important? What time line do you use? Do you take 'now-for-now', 'then-for-then' or 'now-for-then' preferences? To avoid these questions a different approach is been taken. The concept of happiness is used for this analyse. Welfare is a much broader concept then happiness. Happiness is part of welfare. The concept of happiness fits well in the approach because the founder of the utilitarian approach, Bentham, his base was the "Greatest Happiness Principle". The Greatest Happiness Principle holds that *"actions are right in proportion as they tend to promote happiness, wrong as they tend to produce reverse of happiness."*⁹⁰ In order to apply the Greatest Happiness Principle first the concept of happiness needs to be defined or else it can't be measured. It is not simple to define the concept of happiness and there is not one general definition. A lot of researchers stay constraint to the question "are you happy or not" but this doesn't explain what happiness is. The definition of Veenhoven is used. Veenhoven defined happiness as *"a relative constant situation of predominating satisfaction with living as a whole."*⁹¹ So in general you are satisfied with the life you live and the situation you are in. In the operationalisation the concept of happiness will be made measurable.

⁸⁷ Kuhse, H., Singer, P. (ed.), *A companion to bioethics*, Blackwell Publishers Ltd., Oxford and Malden, 1998, pages 61-113.

⁸⁸ Hare, R.M., *A Utilitarian approach*, in: Kuhse, H., Singer, P. (ed.), *"A companion to bioethics"*, Blackwell Publishers Ltd., Oxford and Malden, 1998, page 80.

⁸⁹ Hare, R.M., *A Utilitarian approach*, in: Kuhse, H., Singer, P. (ed.), *"A companion to bioethics"*, Blackwell Publishers Ltd., Oxford and Malden, 1998, page 81.

⁹⁰ Mill, J.S., *Utilitarianism*, in J.S. Mill, *Utilitarianism, on liberty, Essay on Bentham*. Ed. Warnock, M., Glasgow, Fontana 1861, page 257.

⁹¹ Veenhoven, R. Geluk als onderwerp van wetenschappelijk onderzoek, in: *Sociologische Gids*, volume 17, 1970, page 116.

The last element is about the distributing of happiness: aggregationism. In distributing welfare there are a lot of different people whose welfare will be affected by a decision. We should choose those actions that maximize the welfare of all in sum. Aggregationism implies that we ignore the distribution of welfare and simply maximize its total sum in aggregate. The basic thought behind this reasoning is that in making moral judgments we have to be impartial between the interests of the people affected by our judgments. This means that *“everybody to count for one, nobody for more than one.”*⁹² We need to respect the interest of the different people equally and therefore we shall give the same weight to the equal interests of each of them. This reasoning leads directly to aggregationism. To secure impartially we should treat the interests of others like they are our own interests. It does not ignore the difference between people but it is used to give equal weight to the interests of different people.

There are different objections on the utilitarian view:

- An objection made by egalitarians is that equality of distribution is a matter in itself; it is an independent value. Their opinion is that equality *“must not be sacrificed to the maximization of the total welfare.”*⁹³
- This objection is the opponent of the first objection. There are matters that give us special duties to certain people and not to other people. For instance, a doctor has duties to his patient but not to other people which are not directly involved in this matter. Therefore, the opponents agree, you don’t have to look at the welfare of the total.
- Utilitarians *“do not take seriously the distinction between people.”*⁹⁴ An example to make this more clear: one patient has severe pain, five other patients have less pain; helping five patients with less severe pain adds more aggregate than helping one patient with severe pain. These outcome derives from the equality principle. Utilitarians are aware of the fact that people are different. All they try to do is to do justice between the interests of different people.
- The utilitarian approach clashes with intuition of people. It seems counter-intuitive to help five less injured patients over one severe injured patient. This can be explained by the recognition that moral based think appears on two levels: the critical (utilitarian level) and intuitive level. Those two operate in such a way that they do not conflict. We have simple general rules in approaching an ethical decision. These rules functioning on the intuitive level of moral thinking. It is possible that these rules clash with each other. In practice it seems to be that we than can reconcile our intuitions with utilitarianism by the additional information available.⁹⁵

In summary the utilitarian approach has a three steps ladder which helps us to judge about a moral dilemma.

Steps	Definition
1) Consequentialism ↓	The consequence of an action makes the action right or wrong.
2) Happiness ↓	An action should gain the total sum of happiness.
3) Aggregationism ↓	All people are equal and the interests of the people are weighted equally.

⁹²Mill, J.S., Utilitarianism, in J.S. Mill, *Utilitarianism, on liberty, Essay on Bentham*. Ed. Warnock, M., Glasgow, Fontana 1861, last chapter.

⁹³ Hare, R.M., A Utilitarian approach, in: Kuhse, H., Singer, P. (ed.), *“A companion to bioethics”*, Blackwell Publishers Ltd., Oxford and Malden, 1998, page 82.

⁹⁴ Hare, R.M., A Utilitarian approach, in: Kuhse, H., Singer, P. (ed.), *“A companion to bioethics”*, Blackwell Publishers Ltd., Oxford and Malden, 1998, page 82.

⁹⁵ Kuhse, H., Singer, P. (ed.), *A companion to bioethics*, Blackwell Publishers Ltd., Oxford and Malden, 1998, page 84.

Judgment on moral dilemma	An action is morally right when the consequence of the action rises the welfare/happiness of the total sum when the interests of people where taken equally.
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Table 1 Utilitarian approach

Transplantation tourism is not only an ethical dilemma but there are more factors that play a role in it. That will be described in the following paragraphs. First, the social determinants are examined.

3.3 Social determinants

Since recently there is, in the field of health policy, a shift from a 'disease-focused solutions' towards solutions which also includes social determinants. This disease-focused view has also a part in the growing inequality in health care.⁹⁶ Although the life expectancy, as mentioned before, has grown there are inequalities in it between countries but also within populations.⁹⁷ Generally health inequalities within societies are seen as unfair and unjustifiable. This position is not a rational or medical one; it is a political position made on the base that health care should be equally available for all the members of the society.⁹⁸ These inequalities are caused by different factors: personal, social, economic and environmental factors. Not only inequality plays an important role but also the fact that social determinants and health are interrelated. There is a two way path: social and economic determinants influence health and health influences the social and economic position.⁹⁹ Academic research has shown that social determinants have a big influence on the health and life expectancy of individuals.¹⁰⁰ To improve the health of people you must take social factors into account.

When health policy is developed the social determinants must be taken into account. For this master thesis the social determinants are discussed and how they influence the different policy solutions. There are quite some different social determinants which can be used in this master thesis. Only the social determinants which are most useful for this research are discussed.

The following social determinants have an impact on the health of individuals:

- *Social environment*

Social environment can be defined as *"encompass the immediate physical surroundings, social relationships, and cultural milieus within which defined groups of people function and interact."*¹⁰¹ Social environment exists out of a different kind of infrastructures which are interrelated and interconnected to each other such as: labour markets, social and economic processes, social, human and health services, social inequality, cultural practices, power relations and beliefs about place and community and so on.¹⁰² It is a complex structure of relations between people in different social networks. These social networks are dynamic and they can change by internal and external factors over time.¹⁰³ The social environment is important in influencing people's health. There are conditions in the social environment that influence the health of people negatively. In this research poverty, social exclusion and social support are examined.

⁹⁶ Questions and answers about the Commission on Social Determinants of Health http://www.who.int/social_determinants/strategy/QandAs/en/index.html, 8 November 2006 & Marmot, M., Wilkinson, G., editors, Social determinants of health, Oxford University Press, Oxford, 1999, pages 4-5.

⁹⁷ I. Crombie, L.Irvine, L. Elliot, H. Wallace, Closing the health inequalities gap: an international perspective, WHO, 2005, Page 6. & J. Mackenbach, Health inequalities: Europe in profile, 2006, page 4.

⁹⁸ M. Kelly, J. Bonnefoy, A. Morgan, F. Florenzano, The development of the evidence base about the social determinants of health, WHO Commission on social determinants of health measurement and evidence knowledge network, 2006, page 4.

⁹⁹ Marmot, M., Wilkinson, G., editors, Social determinants of health, Oxford University Press, Oxford, 1999, page 12.

¹⁰⁰ Marmot, M., Wilkinson, G., editors, Social determinants of health, Oxford University Press, Oxford, 1999, page 3.

¹⁰¹ Barnett, E., Casper, M., in: *American Journal of Public Health*, Volume 91, No. 3, 2001, page 465.

¹⁰² Barnett, E., Casper, M., in: *American Journal of Public Health*, Volume 91, No. 3, 2001, page 465.

¹⁰³ Barnett, E., Casper, M., in: *American Journal of Public Health*, Volume 91, No. 3, 2001, page 465.

Wilkinson et al. (2003) distinguish two forms of poverty:

- 1) Absolute poverty: *"a lack of the basic material necessities of life."*¹⁰⁴
- 2) Relatively poverty: *"living on less than 60% of the national median income."*¹⁰⁵

This paragraph about poverty and social exclusion is partly based on the conclusions made by Wilkinson et al. (2003). Poverty is not something for developing countries also in the developed world there are people living in great poverty. The life expectancy of people in poverty is lower than that of other people.

Poverty leads to social exclusion. This is when people are denied from access to education, decent housing, transport, health care and other aspects of a social life for instance sport clubs etc. Social exclusion leads to more stress and this is especially harmful during pregnancy.¹⁰⁶ Poverty is not the only cause of social exclusion there are also other circumstances that can cause it:

- Racism
- Unemployment
- Discrimination
- Hostility
- Stigmatization

Poverty and social exclusion increases the risk on:

- Divorce and separation
- Disability illness
- Addiction
- Social isolation

Social support has a positive contribution to people's health. As part of social support is social cohesion. Social cohesion is *"as the quality of social relationships and the existence of trust, mutual obligations and respect in communities or in the wider society."*¹⁰⁷ Social cohesion negatively correlates with high income inequality: in societies with a high income inequality the social cohesion is low. A study has shown that in a community with high social cohesion the rates of coronary heart disease were low. In societies with low social cohesion the affect was opposite. Social support is affected by the economic and social status; this is connected to the bigger social environment and also to the social class where people belong to.

It has a positive protective affect on health when people are feeling a strong social support from their environment. Interestingly is to look at both the kidney patients as for the donors, if this is possible, to look in what kind of social environment they live and if this can explain their decisions.

- Social class

The social class is one of the elements which form the social environment. Social class is defined as a hierarchical distinction between people in a culture or society. This distinction can be made on base of different factors but mostly by income, education and ownership.

The social class is explicitly examined because research has shown that there is a clear relationship between health and social class.

The amount of health problems is lower by the higher social classes.¹⁰⁸ This can be seen as a general tendency although there are few exceptions to this rule.¹⁰⁹ The life expectancy of people with in a higher social class is higher than people in a lower social class.¹¹⁰

¹⁰⁴ Edited by Wilkison and Marmot, Social determinants of health: the solid facts, World Health Organization, 2002, page 16.

¹⁰⁵ Edited by Wilkison and Marmot, Social determinants of health: the solid facts, World Health Organization, 2002, page 16.

¹⁰⁶ Edited by Wilkinson, R., Marmot, M., Social determinants of health: the solid facts, 2nd edition, World Health Organisation, 2003, page 16.

¹⁰⁷ Edited by Wilkinson, R., Marmot, M., Social determinants of health: the solid facts, 2nd edition, World Health Organisation, 2003, page 22.

¹⁰⁸ Borg, V., Kristensen, T., Social class and self-rated health: can the gradient be explained by differences in life style or work environment?, in: *Social Science & Medicine*, 51, 2000, page 1019. & Contoyannis, P., Jones, A., Socio-economic status, health

Cornwell (1995) showed that beliefs about health and illness are shaped by how people live and of their working conditions.¹¹¹ People who work in good circumstances and have good housing appear to rate their health better than people who live in lesser conditions.

Next, research about middle class and working class women and food showed that the middle class women looked for a 'balanced diet' and 'everything in moderation'.¹¹² The working class women wanted meals which were 'substantial' and 'fulfilling'. Thus, there is a relationship between health and social class. There is discussion about how this relationship is built: does health affect the social class or vice versa? Probably there is an interaction between the two.

The working conditions of people in a higher social class are better than those of lower social class. This is logical: working in a fabric is different than working at an office. Next, when you are in higher social class you are able to have better housing and better access to other primary life needs. Further more it is more difficult to climb up the social ladder when your health is less good because this needs much energy and effort. It seems to be a vicious circle which is difficult to break through.

For this research it is not necessary to look deeper on the relationship between health and social class; the research of Cornwell described in this paragraph shows this relationship. It is although interesting to look if the social class of a person changes after receiving or donating a kidney.

In the case of transplantation tourism we can assume that the patients who undergo kidney transplantation abroad will come from a higher social class. The argumentation is simple and also connected with other social determinants presented here: people from higher social classes are better informed and have better access to different treatments and are able to pay themselves the costs when health insurance companies not compensate them.

The donors will probably come from lower social classes. They have less knowledge about the consequences and risks of the donation. The collected empirical data must show if these assumptions are correct.

- Income

Income plays also a role in the rate of health of a person.¹¹³ When a person has a better income the status of health is also better compared with people who have less income.

Research has shown that the life-expectancy of poor people is shorter than people with a higher income. In Britain the gap between the life expectancy between poor people and richer people is even widening.¹¹⁴ Similar trends are found in other (industrialized) countries. The relationship between income and health is that when you have a higher income you are better capable to take care of your self. For poor people this is difficult to achieve: poor nutrition and poor housing are common and these factors have a negatively affect on your health. This has not only an affect on the people themselves but also on their children. A low income makes it difficult to control the family health: it is often that parents put their health at risk to contain or improve the health of their children.¹¹⁵ These patterns do not only apply to

and lifestyle, in: *Journal of Health Economics* 23, 2004, page 979. & Williams, S., Theorizing class, health and lifestyles: can Bourdieu help us?, in: *Sociology of Health & Illness* Volume 17 No. 5, 1995, page 578.

¹⁰⁹ Borg, V., Kristensen, T., Social class and self-rated health: can the gradient be explained by differences in life style or work environment? in: *Social Science & Medicine*, 51, 2000, pages 1019-1030.

¹¹⁰ Edited by Wilkinson, R., Marmot, M., Social determinants of health: the solid facts, 2nd edition, World Health Organisation, 2003, page 10.

¹¹¹ Cornwell, J. Hard Earned Lives: Accounts of Health and Illness from East London, Tavistock, London, in: Williams, S., Theorizing class, health and lifestyles: can Bourdieu help us?, in: *Sociology of Health & Illness* Volume 17 No. 5 (1995), page 579.

¹¹² Calnan, M. Food and health, in: *Readings in Medical Sociology*, Cunningham-Burley, S., McKegney, N., Routledge, London, in: Williams, S., Theorizing class, health and lifestyles: can Bourdieu help us?, in: *Sociology of Health & Illness* Volume 17 No. 5, 1995, page 579.

¹¹³ Ettner, S., New evidence on the relationship between income and health, in: *Journal of Health Economics* 15, 1996, pages 67-68&82.

¹¹⁴ Marmot, M., Wilkinson, G., editors, Social determinants of health, Oxford University Press, Oxford, 1999, page 211.

¹¹⁵ Marmot, M., Wilkinson, G., editors, Social determinants of health, Oxford University Press, Oxford, 1999, page 216.

the poorest people but there is an overall gradient between the rate of income and the rate of health.¹¹⁶

In this paragraph different social determinants of health were discussed. It should be mentioned that although there is evidence between the relationships of the determinants with health there is more research needed to give an exact weight between the determinants and health; that is currently not known.¹¹⁷

In this research the social determinants of patients and receivers are examined. Four hypotheses are formulated:

- 1) Patients who buy organs are wealthy, middle/high class people with employment and high level of education.
- 2) The position of the patient after transplantation will improve on all levels of social determinants.
- 3) Donors are people from the lower social classes with low income. It are meanly poor people how will sell their kidney.
- 4) The income position of the donor after ceding a kidney doesn't necessary have to increase.

3.4 Economic determinants

Not only is health influenced by social determinants also economics plays a role. Economics *"is the systematic study of resource allocation mechanisms."*¹¹⁸ Economics goes about the allocation of resources, which the demand of is infinite. Infinite means that there *"is no end to consumption aspirations."*¹¹⁹ Also in the health sector choices must be made to allocate the limited resources over the demands of people. The discipline of health economics focuses on:¹²⁰

- *"how to allocate whatever resources are available to the production of health services."*
- *"how to distribute those health services produced between those who want them."*

In the case of health there are two ways to organize the allocation of resources in the health sector:¹²¹

- 1) Society can leave that to the market
- 2) Society plans the distribution. The government has the mandate of society to collect resources of health and to distribute them over the population. These are public health systems.

3.4.1 The market

The information in this paragraph is mostly based on research by Wonderling, Gruen and Black (2005). Within the market system there are different systems possible. The most ideal market system is when there with perfect competition. This is an ideal market because in practice this does not exists because of market failures and government intervention. In the perfect competition system there are four features:

- 1) The same product is sold to many purchasers by many producers.
- 2) There are no restrictions for entering the market for potential producers.

¹¹⁶ Marmot, M., Wilkinson, G., editors, Social determinants of health, Oxford University Press, Oxford, 1999, page 212.

¹¹⁷ Kickbusch, I., Health literacy: addressing the health and education divide, in: *Health Promotion International*, Volume 16 no. 3, 2001, page 290.

¹¹⁸ Wonderling et al., Introduction to health economics, Open University Press, Berkshire, 2005 page 9.

¹¹⁹ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 3.

¹²⁰ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 5.

¹²¹ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 5.

- 3) The existing producers do not have an advantage over the new producers.
- 4) Both the producers as the purchasers are well informed about the prices.

In practise such a perfect market does not exist in all areas of health care. For a perfect market the patients, purchasers of health care, must have the following possibilities in making a decision out of the different health suppliers:

- 1) Judge the costs and benefits of health care.
- 2) Bear the costs and receive the benefits.
- 3) Purchase those treatments where benefits exceed costs.

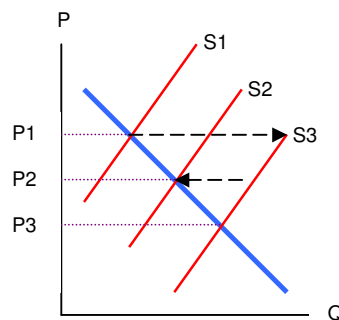
It is for patients difficult to judge the costs and benefits of health care. In the decisionmaking process patients rely on the knowledge of medical professionals. Those professionals are part of the supply chain and provide the health care; they may not act in the best interest of the patient. Next, patients do not always have the time to collect information on different medical treatments or providers. Another problem is that patients can not, when they received a treatment, be sure if the improvement of the health is caused by the treatment or that other factors were involved.

In some situations it is possible for patients to collect information. This can occur when there is a gap between the diagnosis and the treatment. For instance pregnant women are able to collect information about where and how they want to give birth to their child.

It is also difficult for patients to bear the costs of health care when there is health insurance. Taxes and premiums diffuse the image of the real costs of the treatment. This can also be true for the receiver of the benefits. In some cases, such as infectious disease, not only the patient will benefit of the treatment but a greater community.

The last condition that is described above is the condition that a patient can make its own decision on which treatment it will undergo. Some patients are not capable of making these decisions and sometimes relatives are authorised to do that.

Based on findings of McPake, Kumaranayake and Normand (2002) the following graph can be drawn of the situation of a perfect market from the supply side.



Source: McPake, B., et al (2002) page 43.

Figure 5 Market system

The price starts with P1 and the supply S1: in this market situation firms expect to have 'normal' profits. This attracts new firms and the price goes to P3 and the supply to S3; there is more supply so prices drop. At this point the firms which do not produce effectively step out; there are not able to produce the health services at this price and quit after a while. The supply decreases towards S2 and the price will rise towards P2.

There are some conditions which are needed to create a perfect health care market both on the supply as the demand side. In practise this there is not a country that has a perfect market system; in every country there is at least some government support in some areas of

the health care sector. Next, to the market system there is also a public health system which works differently; here there is government intervening.

3.4.2. Public health system

In the public health system there is, contrary to the ideal market system, intervention by the government. Differently to the market system the extreme of a public health system completely ran by the government did exist; an example was the health system in the German Democratic Republic.¹²² In the German Democratic Republic the financing and providing of health care was totally public and almost all services were free for all patients.¹²³

But most countries do have both elements of a market sector as a public health system in arranging health care.

McPake, Kumaranayake and Normand (2002) identify different actors in a health system: users, payers, providers and regulators. In such a system the government can play different roles:

- financier
- regulator
- provider of services

One of the typically characteristics of a health system is “insurance”. This can be defined as *“the mean that users pay regularly towards health system expenses in order to avoid bills that would make an unacceptable hole in the household budget at the time of use, and in order to share risk between larger population groups so that no one family faces completely unaffordable catastrophic costs.”*¹²⁴

Within health systems there are three forms of insurance possible:¹²⁵

- Health insurance; *“this is restricted to arrangements where separate premiums and a separate ‘earmarked’ fund for health services is created.”*
- Social insurance; *“this implies compulsory membership and usually a public or quasi public insurance agent.”*
- Private insurance; this is offered by private insurance companies and most of the time voluntary.

In a public health system the funding of the costs of health care are provided by general taxation. The system is characterised by:¹²⁶

- Public ownership
- Fixed annual budgets for care providers
- Health workers are direct employees

When users need health services these are provided free of charge. The costs of health care in such a public system are much more difficult to distinguish than in the previously described market system. In the market system the patients of health services have a clear overview of the different providers, treatments and costs of health care. In a public system the patients only pay general taxation and perhaps additional social or private insurance. The actual costs of the health services are not clear to the patients because the payment of these services goes by taxation and insurance(s) and are not, in all cases, done by the patients themselves. This is also valid for the prices of the health services. In a public system the

¹²² McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 191.

¹²³ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 192.

¹²⁴ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 191.

¹²⁵ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 191.

¹²⁶ McPake, B., Kumaranayake, L., Normand, C., Health economics; an international perspective, Routledge, London, 2002, page 201.

government contracts health providers and set a price with them for the health services. These prices can be higher than they would be in an open market where different providers must compete for providing health care services.

In the case of organ transplantation there are also different allocation models possible. At the moment most of the allocation systems are based on voluntary and non-paying organ donation where the government or an organisation which has a (governmental) mandate arranges the distribution and allocation of organs. There are also models which are more market focussed and where people get paid for organ donation. An example is the Iranian model where living paid kidney donation is allowed. This model is described in paragraph 6.4. Different models are discussed and latter a discussion follows about which model would be most suitable for in the case of preventing transplantation tourism.

A hypothesis is that a market model, which is favoured by some scholars, where people can sell their kidney, will not be the most suitable model because selling a kidney is something that must be well considered. Next, it is very difficult to see how such a market system will work and if “real” prices are set or that those prices will rise by different circumstances. It is although possible that some market needs to be created because at the moment people are travelling abroad because there is in their own country an organ shortage. The question is: “is allowing the sale of kidney by living kidney donors the ultimate solution for the (international) organ shortage or are other solutions better?”

3.5 Medical aspects

Medical aspects are very important in developing policy solutions. New technologies in medicine influence the health solutions. Before kidney transplantation was possible most people were condemned to dialyses but this new technique improved the life’s of many people. So, when we want to develop policy solutions we must take the medical aspects into account. In the case of transplantation tourism we must examine the different medical treatments which are possible in the case of kidney disease. Kidney failure is that the productivity is less than 10%.¹²⁷ In this case dialyses or perhaps transplantation is needed.

In following table summarizes the possible treatments which are medical available at this moment:

Kind of treatment	Short description of treatment
Hemodialysis	This <i>“is a procedure that cleans and filters your blood. It rids your body of harmful wastes and extra salt and fluids. It also controls blood pressure and helps your body keep the proper balance of chemicals such as potassium, sodium, and chloride”</i> ¹²⁸ .
Peritoneal dialysis	<i>Peritoneal dialysis “removes extra water, wastes, and chemicals from your body. This type of dialysis uses the lining of your abdomen to filter your blood. This lining is called the peritoneal membrane”</i> ¹²⁹ .
Cadaver kidney transplantation	This is transplantation of a kidney of a deceased person.
Related living kidney transplantation	The donor is a near relative of the patient. A near relative is a person who has a blood band with the patient. This can be a parent, brother, sister or an adult child ¹³⁰ .
Unrelated living kidney transplantation	The donor is not a near relative of the patient.

Table 2 Description of medical treatments

¹²⁷ Behandelingen, Nierstichting, at: <http://www.nierstichting.nl/patient/behandelingen>, 10-11-2006.

¹²⁸ Kidney failure, at: http://www.medicinenet.com/kidney_failure/article.htm, 10-11-2006.

¹²⁹ Kidney failure, at: http://www.medicinenet.com/kidney_failure/article.htm, 10-11-2006.

¹³⁰ The donor, The kidney donation guide; a person’s guide to kidney transplantation surgery, at: <http://www.kidneytransplant.org/patientguide/donor.html>, 11-11-2006.

That are the treatments for patients with kidney failure which are medical possible at the moment. To compare the different treatments several factors are defined:

Factors	Questions
Availability of the treatment	Is the treatment available for every patient or are the specific requirements or limitations like health condition, age or weight?
Risks for patient	Are there risks for the patient of the treatment? What are side affects of the treatment and can these side affects is compromised?
Survival rate of patient in the short and long term	When the patient gets the treatment what is than the survival rate of the patient on the short and long term?
Long term consequences for the patient	Is the treatment once a time or do the patient have to come back? Are there special medications that the patient must take? What are the consequences of the treatment on the daily life of the patient; can the patient go working again or are there limitations?
Costs of the treatment	What are the costs of the treatment? Are those costs sole or are there costs which will continue for the patient rest of his life for instance medication.
Risks for the donor (only in a case of living donation)	In the case of donation we must also the risks of the donor into account. Are there risks during the donation? What is the survival rate of donors? Is there are greater risk for kidney disease in the future comparing with non donors?
Consequences for the donor (only in a case of living donation)	After the donation what are the consequences for the donor? Is the donor able to do the things he/she did before the donation or are there limitations for instance more tired and less capable to work? Does the donor need to take medication?

Table 3 Factors and questions about medical treatments

In the chapter 7 the different factors are applied on the different treatments and a comparison is been made.

3.6 Political factors

This is in the extension of the next paragraph. Political support is needed to achieve policy change. It is a political decision which issues are seen as important to focus on. Politicians are contacted every day by persons and organisations with different issues and interests. Politicians have to choose which problems will be discussed at the political agenda. When a majority of political parties agree that action is necessary a debate will start on how the problem needs to be solved.

It is therefore important to examine the political views in a country on organ donation policy and transplantation tourism. If there is political agreement that there is not a problem than it is not possible to develop policy changes in order to prevent transplantation tourism. Therefore the different positions on organ donation policy and transplantation tourism in the United Kingdom and the Netherlands in the Parliament are discussed.

Next, examined is if both are an issue on the political agenda of political parties in the Parliament. This gives a good indication how far the problem of transplantation tourism is an issue in the country. For the United Kingdom this will be easier to research because the United Kingdom has a two party Parliament system. The Netherlands has a multiple party Parliament system and so more parties need to be contacted then in the United Kingdom.

3.7 Current status of policy

A last feature which influences the development of policy solutions in the case of transplantation tourism is the current status of policy. As mentioned before examined specific is if the Netherlands and the United Kingdom already have policy to prevent and stop transplantation tourism. If a country already has a policy then it is more difficult to formulate a whole new different policy. On the other hand, when transplantation tourism is not seen as a problem by the policy makers it is more difficult to achieve any action at all; they don't think that policy needs to be formulated.

3.8 Policy solutions

When the conclusion is that transplantation tourism occurs and that it is not a desirable phenomenon then policy must be developed to reduce transplantation tourism. Policy is *“intensions, choices and actions of one of more governmental institutions focused on steering of a certain social development.”*¹³¹ Policy is *“the concreting of steering of specific social areas.”*¹³²

Policy on transplantation tourism has two goals:

- 1) Preventing that people go abroad to buy a kidney and have the transplantation there.
- 2) Measures when citizens did go abroad and bought a kidney.

Before policy can be implemented it must be made; this is called policymaking. There are two forms of policymaking to distinguish:¹³³

- Policy design; this is the process of inventing a solution for a policy problem.
- Exhorting and fighting over the solutions that are made; this is the process to reach consensus on a certain solution of a policy problem or closing compromise between different solutions.

The two are interconnected; it is not possible to use one without the other.

This master thesis mainly focuses on the policy design because the main target of this master thesis is to develop policy solutions for transplantation tourism. The target is not to judge if these solutions could be implemented in practice because this is a whole different and complex matter. This does not fall within the subject of this master thesis. This does not mean that the importance of the second step is neglected but it simply does not fit in this master thesis. Of course it is not possible to ignore it completely; during the development of policy you will continue keep in mind how solutions are received by the different actors. For this reason only shortly the policy solutions that are formulated are discussed if they have a change to be implemented.

The first step in the policymaking process is problem shaping. With problem shaping you examine if different features are existing in order to find a policy solution. There are three criteria to conduct problem shaping¹³⁴:

- 1) The problem is an unsatisfied situation
- 2) There is a gap between “is” and “must”
- 3) There is a chance that the situation can be improved

When a problem meets these criteria it is possible to go a step further: to look what kind of problem it is.

Transplantation tourism meets all three criterias:

- 1) In both the Netherland and the United Kingdom is paid unrelated living kidney donation forbidden. Transplantation tourism is in these countries unethical.
- 2) There is a gap between “is” and “must”. The current situation is that transplantation tourism exists in the Netherlands and the United Kingdom. It is seen as unethical and the situation must be changed. There is not yet policy developed to stop and prevent transplantation tourism.
- 3) There is a good chance that the situation can be improved. It is naïve to think that transplantation tourism can be prevent completely but this research shows that there are good solutions available to reduce transplantation tourism.

There are two different sorts of problems to distinguish¹³⁵:

¹³¹ Bovens et al., Openbaar bestuur: beleid, organisatie en politiek, Kluwer, Alphen aan den Rijn, 2001, page 82.

¹³² Bovens et al., Openbaar bestuur: beleid, organisatie en politiek, Kluwer, Alphen aan den Rijn, 2001, page 82.

¹³³ Van de Graaf, H., Hoppe, R., Beleid en politiek: een inleiding tot de beleidswetenschap en de beleidskunde, Coutinho, Muiderberg, 2^{de} druk, 1992, page 427.

¹³⁴ Van de Graaf, H., Hoppe, R., Beleid en politiek: een inleiding tot de beleidswetenschap en de beleidskunde, Coutinho, Muiderberg, 2^{de} druk, 1992, page 436.

- 1) Tamed problems
- 2) Untamed problems

Before the policymaking process can start first there need to be decided what kind of problem it is. For both problems different policymaking processes are necessary.

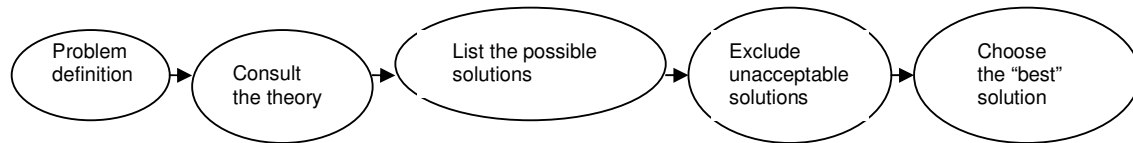
Tamed problems

Tamed problems have three characteristics¹³⁶:

- The problem can be exhaustive formulated
- The possibility that the problem can be formulated in a total univocal manner as a gap between “is” and “must”
- The possibility for the gap an in every respect sufficient of giving declaration

In summary is this means that for every tamed problem we can specify an adequate policy theory.

With tamed problems the following scheme can be used in order to develop policy:



Source: Van de Graaf, H., Hoppe, R., *Beleid en politiek: een inleiding tot de beleidswetenschap en de beleidskunde*, Coutinho, Muiderberg, 2^{de} druk, 1992, page 437.

Figure 6 Tamed problem

With this scheme it is possible to develop possible solutions. In this case the last step “choose the best solution” is not necessary to take because it is not necessary to take a decision. Only the different acceptable solutions are presented.

In the second step of this scheme the theory is consult. In the case of transplantation tourism the theories which where described in the paragraphs 3.1 till 3.6 are used in order to come to acceptable policy solutions.

Untamed problems

Policymaking for untamed problems is a bit more complex. Untamed problems can not be solved with the same scheme as presented above. Two complications occur:¹³⁷

- 1) An untamed problem can only be defined with an unacceptable reduction. As a result that it is also not possible to formulate one univocal policy theory.
- 2) There is not one plausible definition of the problem. There will be also discussion and dispute about the question of the core of the problem.

In this case the first step is to define the problem. Then you divide this into different parts of whined problems. Prove the solubility of a couple of parts of the problems. The last step is to weigh the costs between the problem reduction by the part of whined problems and the costs of doing nothing. In the case of untamed problems it is not possible to come with “one solution”. The problem needs to be stripped of in different parts of whined problems. The problem will not be solved entirely; only a problem reduction can be achieved.

¹³⁵ Van de Graaf, H., Hoppe, R., *Beleid en politiek: een inleiding tot de beleidswetenschap en de beleidskunde*, Coutinho, Muiderberg, 2^{de} druk, 1992, pages 436-443.

¹³⁶ Van de Graaf, H., Hoppe, R., *Beleid en politiek: een inleiding tot de beleidswetenschap en de beleidskunde*, Coutinho, Muiderberg, 2^{de} druk, 1992, pages 436.

¹³⁷ Van de Graaf, H., Hoppe, R., *Beleid en politiek: een inleiding tot de beleidswetenschap en de beleidskunde*, Coutinho, Muiderberg, 2^{de} druk, 1992, pages 438-439.

First there needs to be decided whether transplantation tourism is a tamed problem or an untamed problem. The problem of transplantation tourism can be defined exhaustively. Transplantation tourism of kidney exists when:

- A receiver buys a kidney in another country
- The donor gets money for donating one kidney by life
- The receiver travels abroad to get the kidney transplantation
- The receiver will return, after a short period of recovery, to his own country

This definition of transplantation tourism of kidneys is quite bound. It is difficult to have discussion about this definition. The definition does not imply whether it is ethical correct or not; it only describes what happens. The second step is decided whether there is a gap between “is” and “must”. Previously is described that there is a gap between “is” and “must” in the case of transplantation tourism. In both the Netherlands and the United Kingdom it is defined as unethical. The third step is to give a clear declaration for why there is a gap between “is” and “must”. In the case of transplantation tourism two clear declarations can be given:

- 1) There is an international organ shortage. Paragraph 2.1 shows that there is an international organ shortage and that people at the moment die because they did not receive a kidney transplantation on time. There is also stated that the number of people that will need kidney transplantation in the future will rise and that the international organ shortage will grow.
- 2) There is at the moment little action by national governments but also within international organisations to take action against transplantation tourism. There are some statements by the international organisations such as the WHO that they condemn transplantation tourism and trade in organs but at the moment there are not concrete actions to stop it.

With the information that at the moment is available the conclusion is that transplantation tourism of kidneys is a tamed problem. Therefore the scheme of figure 3.7.1 to develop policy is used.

3.9 Hypotheses

In this chapter the different theories that are used in order to answer the main question were described. From these theories the following hypotheses are formulated:

- One hypothesis is that, based on the utilitarian approach, transplantation tourism is not accepted. The argumentation is that the happiness of people must not decrease. In the case of transplantation tourism is that kidneys that go to foreign people can not go to Indian people. In India there is an organ shortage and other treatments such as dialysis are for most people too expensive. Kidney transplantation is the only solution for them and this is made even harder if foreign people pay a lot of money to buy a kidney. Second, it is not convinced that the donor’s happiness will always increase. On the other hand, also from the patient’s side this is not guaranteed; risks of complications exist.
- Another hypothesis is that the people who sell their kidney are poor, low income people with a low education level. People who earn enough and are able to afford their primary life needs will not sell their kidney fast. People how do sell their kidney is to overcome poverty or other related factors.
- It is hard to get figures about the patients who go abroad. This is caused because transplantation tourism is not something ethical accepted and people will not be open about that. It is therefore also difficult to say something about the patients. Suspected that the patients will have a quite good income because the transplantation is expensive if you have to pay it for yourself.
- A hypothesis is that a market model, which is favoured by some scholars, where people can sell their kidney, will not be the most suitable model because selling a kidney is something that must be well considered.

- Living kidney donation will not be the solution to solve the organ shortage. It is only a short time solution. For the donors there are negative side affects and although we can live with one kidney it is better to have two.
- At the moment there is not current policy in Netherlands or the United Kingdom in order to stop transplantation tourism. The reason is that politicians are not informed about it and that they not seen it as a problem.

At the end of this master thesis these hypothesis are tested.

Chapter 4 Conceptualisation and operationalisation

In this chapter the research is conceptualised and operationalised. This is the next step towards the research design which is further described in chapter 5.

4.1 Conceptualisation

Conceptualisation is “*the process of specifying observations and measurements that give concepts definite meaning for the purposes of a research study*”. (Babbie, 2001; 112&146)

In chapter 1 several concepts which are used frequently in this master thesis were defined. But there are more concepts used which need to be specified for the reader. Concepts are constructed by people they are not fixed and concepts can have different interpretations by different people.¹³⁸ To avoid that the readers have a different view of the concepts they are described here. The definitions here used are based on a certain view and other definitions are possible. Also the relationship between the concepts and transplantation tourism are given.

The following concepts are defined:

- Globalisation
- International community
- Medical tourism
- Ethical dilemma
- Domestic policy
- Policy
- Policy solutions

At the beginning the reason for the choice of transplantation tourism as a subject was described. One of the reasons is that health care; traditionally a primary domestic state matter is also affected by globalisation. But what is globalisation exactly? There is not a common definition. Globalisation in this master thesis is defined “*as a process leading to greater interdependence and mutual awareness (reflexivity) among economic, political and social units in the world, and among actors in genera.*”¹³⁹ The definition embraces the research; people who cross borders to conduct economic and medical actions. This is nowadays possible because of the awareness and interdependence between countries and people. Coherent to globalisation is the concept of international community. This is the composition of countries, international organisations (such as United Nations and WHO), non-governmental organisations and even individuals who participate at the international level. The international community is regulated by international law.

Transplantation tourism is not something exceptional in health care. Since several years, as one of the results of globalisation, medical tourism occurs. Medical tourism is defined “*as provision of cost-effective private medical care in collaboration with the tourism industry for patients needing surgical and other forms of specialized treatment.*”¹⁴⁰ It is facilitated by both the medical as the tourism sector. Transplantation tourism is a form of medical tourism. In chapter 1 other examples were described.

Earlier transplantation tourism was described as an ethical dilemma. An ethical dilemma can be defined “*as situations in which, on moral grounds, persons ought both to do and not to do*

¹³⁸ E. Babbie, *The practice of social research*, 9th edition, Wadsworth, Belmont, 2001, page 121-122.

¹³⁹ Guillén, M.F., *The Limits of Convergence: Globalization and Organizational Change in Argentina, South Korea, and Spain*, Princeton University Press, Princeton, 2001. & Held, D., McGrew, A., Goldblatt, D., Perraton, J., *Global Transformations*, Stanford University Press, Stanford, 1999, pages 429-431. & Petrella, R., *Globalization and Internationalization*, in: *States against Markets: The Limits of Globalization*, editor Boyer, R., Drache, D., Routledge, London, 1996, pages 63-68 & Waters, M., *Globalization*, Routledge, New York, 1995, page 63.

¹⁴⁰ ‘Medical tourism is becoming a common form of vacationing’, At: <http://www.expresshealthcaregmt.com/20050315/medicaltourism02.shtml>, October 2006.

something.”¹⁴¹ It implies that “issues of conflict and choice are centra.”¹⁴² In the case of transplant tourism there are some dilemmas. The difficulty of an ethical dilemma is, in my view, that there is not one fixed and good solution. The way someone sees an ethical dilemma validates certain decisions.

Examined is whether the Netherlands and the United Kingdom have reacted on transplantation tourism; do they have formulated policy? Before research can be done the concept of policy needs to be clarified.

There are a lot of definitions of this concept. In this master thesis the definition of Bovens, ‘t Hart, Van Twist and Rosenthal (2001) is used. Policy is “intentions, choices and actions of one of more governmental institutions focused on steering of a certain social development.”¹⁴³ Policy is “the concreting of steering of specific social areas.”¹⁴⁴ In the case of the Netherlands and the United Kingdom the domestic policy is examined. This is policy made by a state that applies within the borders of the state.

In the end there will be a search for policy solutions at the European level in order to try to prevent and to stop transplantation tourism. Policy solutions are “means on tackling policy problems.”¹⁴⁵ Policy solutions are out-comes of the policy decision-process but need to get approval of the politics. They are created by policy-makers and other actors but this doesn’t mean that all of these solutions will be implemented; this is a political decision. Policy solutions are not “permanent mechanical fixes.”¹⁴⁶ It is an ongoing process in which policy solutions evolve and change over time by several different developments. Developments could be: scientific research, economic change, change of society etc.

4.2 Operationalisation

Operationalisation is “the process of developing operational definitions, or specifying the exact operations involved measuring a variable.”¹⁴⁷ The used concepts are defined and now they need to be made measurable.

The following research methods are used to collect the data that is necessary to answer the main question:

1) Documents

There are different document sources possible and the focus is on: books, articles in scientific journals, articles in new papers, information on website. The content analysis and the secondary analysis are used for analyzing the documents. These techniques will be further explained in paragraph 5.2.

2) Interviews

The interviews are held as additional information for the specific cases. Chosen is to held semi-structured interviews; this gives me some guidelines during the interview but gives me also freedom to interact during the conversation. This is explained further in paragraph 5.3. Whom and how are interviewed is also explained in this paragraph.

The following table is an overview of the different concepts defined in the previous paragraph and the level of measurement, what will be measured and how this will be measured. The following levels are measurements distinguished: the international level, European level and country level. The international level is what happens within international organisations such as the UN and the WHO. European level is concerning the European institutions such as

¹⁴¹ Braunack-Mayer, A.J., What makes a problem an ethical problem? An empirical perspective on the nature of ethical problems in general practice, In: *Journal of medical ethics*, 2001, page 99.

¹⁴² Braunack-Mayer, A.J., What makes a problem an ethical problem? An empirical perspective on the nature of ethical problems in general practice, In: *Journal of medical ethics*, 2001, page 99.

¹⁴³ Bovens et al., Openbaar bestuur: beleid, organisatie en politiek, Kluwer, Alphen aan den Rijn, 2001, page 82.

¹⁴⁴ Bovens et al., Openbaar bestuur: beleid, organisatie en politiek, Kluwer, Alphen aan den Rijn, 2001, page 82.

¹⁴⁵ Stone, Policy paradox: the art of political decision making, W.W. Norton & Company, New York, 2002, page 261.

¹⁴⁶ Stone, Policy paradox: the art of political decision making, W.W. Norton & Company, New York, 2002, page 261.

¹⁴⁷ E. Babbie, The practice of social research, 11th edition, Wadsworth, Belmont, 2007, page 44.

the Commission, the European Parliament etc. Country level is constraint to the three countries in this research: the Netherlands, United Kingdom and India. Some concepts are not measured because they are only defined so it would be clear what they mean.

Measured concept	Level of measurement	What to measure	How to measure
Cadaver organ donation	Netherlands, United Kingdom & India	- How many kidney transplantations are conducted with a cadaver kidney? - What is the proportion between the amount of cadaver kidney donations and living kidney donations?	Documents
Domestic policy	Not of application	Not of application	Not of application
Domestic organ donation policy	Netherlands, United Kingdom & India	- What is the organ donation policy of the Netherlands? Is unrelated paid kidney donation forbidden by law? - What is the organ donation policy of the United Kingdom? Is unrelated paid kidney donation forbidden by law? - What is the organ donation policy of India? Is unrelated paid kidney donation forbidden by law?	Documents
Ethical dilemma	Netherlands, United Kingdom & India	- Is transplantation tourism seen as an ethical dilemma in the Netherlands, United Kingdom and India?	Documents + Interviews
European policy	EU level	- Is there an EU policy in the case of organ transplantation? If no, is there one in development? - What is the content of this policy? - Is transplantation tourism something that the EU concerns? - What is the opinion of the EU on transplantation tourism?	Documents + Interviews
Globalisation	Not of application	Not of application	Not of application
International community	International level	- Does the international community, by international organisations such as the WHO, react on transplantation tourism? - What is the opinion of the international community on transplantation tourism?	Documents
Medical tourism	Netherlands, United Kingdom & India	- How big is the medical tourism industry in India? - How many people in the Netherlands go abroad for a medical treatment? What kinds of treatments are most common? Are these treatments covered by medical insurance? Which countries are most common to go? - How many people in the United Kingdom go abroad for a medical treatment? What kinds of treatments are most common? Are these treatments covered by medical insurance? Which countries are most common to go?	Documents
Organ donation policy	Netherlands, United Kingdom & India	See domestic organ donation policy.	See domestic organ donation policy.
Policy	Netherlands & United Kingdom	See policy solutions	See policy solutions
Policy solutions	Netherlands & United Kingdom	- What are the policy solutions to stop transplantation tourism in the Netherlands and United Kingdom?	Documents + Interviews
Transplantation tourism	Netherlands, United Kingdom & India	- How many people in the Netherlands went abroad to get an unrelated paid organ transplantation? How many people in the Netherlands travelled abroad to get an	Documents + Interviews

		<p>unrelated paid living kidney transplantation? What is the proportion of the costs of this unrelated paid kidney transplantation compared with such transplantation in the Netherlands?</p> <p>- How many people in the United Kingdom went abroad to get an unrelated paid organ transplantation? How many people in the United Kingdom travelled abroad to get an unrelated paid living kidney transplantation? What is the proportion of the costs of this unrelated paid kidney transplantation compared with such transplantation in the United Kingdom?</p> <p>- How many people travelled to India each year to get unrelated paid organ transplantation? How many people travelled to India to get unrelated paid living kidney transplantation?</p>	
Paid unrelated living donor	Netherlands, United Kingdom & India	<p>- What are the health consequences for an unrelated paid living donor?</p> <p>- What are the social consequences for an unrelated paid living donor?</p> <p>- What are the economic consequences for an unrelated paid living donor</p> <p>- Is paid unrelated living donation allowed in the Netherlands, the United Kingdom and India?</p> <p>- How many paid unrelated living donations are conducted in the Netherlands, the United Kingdom and India?</p> <p>- What is the proportion with other kidney donations (cadaver and related)?</p>	Documents + Interviews
Paid unrelated organ transplantation	Netherlands, United Kingdom & India	<p>- What are the health consequences for the receiver of unrelated paid organ transplantation?</p> <p>- What are the economic consequences for the receiver of unrelated paid organ transplantation?</p> <p>- What are the social consequences for the receiver of unrelated paid organ transplantation?</p>	Documents + Interviews

Table 4 Operationalisation

The second step in the operationalisation is defining variables and attributes. Variables are *“logical groups of attributes.”*¹⁴⁸ Attributes are *“characteristics or qualities of something.”*¹⁴⁹ A variable must have two important features:¹⁵⁰

- 1) The attributes that composing the variable must be exhaustive.
- 2) The attributes that composing the variable must be at the same time be mutually exclusive.

The different concepts that are measured, as presented in the previous table, need to be specified in variables. These concepts are already described in chapter 3 of this research: it is the determinants which are used to analyse transplantation tourism. The following variables are discussed:

- Transplantation tourism
- Ethical determinants
- Social determinants
- Economic determinants
- Medical aspects
- Political aspects
- Current status of the policy
- Policy solutions

Transplantation tourism is the only dependent variable in this research. All the other variables are independent while they do not necessary influence each other although interrelations are discussed. This latter is not the goal of the research and therefore it is not discussed. All the independent variables influence transplantation tourism. Therefore transplantation tourism is the dependent variable. The following table can be made with the variables.

The variable of ethical determinant is measured, as described in paragraph 3.2, by the utilitarian approach. To measure if a decision is ethical or unethical the following concepts are measured:

- Consequentialism. The consequence of an action makes the action right or wrong. So, the consequences of transplantation tourism need to be measured. Here the consequences for both patient and donor are discussed.
- Happiness. An action should gain the total sum of happiness. The consequences of the action do they increase the total sum of happiness of both the patient and the donor? This is measured by different data which researched the positions of both donor and patient before and after the transplantation.
- Aggregationism. Both the interests of the patient and the donor are equal. No distinction will be made. This is not something that is measured specific but this influences the previous steps.

Transplantation tourism is ethical right when the happiness of both the patient and the donor clearly and certainly increase after the paid unrelated living kidney donation. This is the indicator for this variable.

The second independent variable is social determinants. The social determinant gives a better picture of the social life of the patient and donor; what kind of people are it?

As described in paragraph 3.3 the social determinants of social environment, social class and income are measured. In the case of the social environment it is examined in what kind of social environment both the patient and donor are part of. As described in paragraph 3.3 this influence health status of a person. This can contribute to explain why transplantation tourism exists and how it can be prevented.

¹⁴⁸ E. Babbie, *The practice of social research*, 11th edition, Wadsworth, Belmont, 2007, G-12.

¹⁴⁹ E. Babbie, *The practice of social research*, 11th edition, Wadsworth, Belmont, 2007, page 136.

¹⁵⁰ E. Babbie, *The practice of social research*, 11th edition, Wadsworth, Belmont, 2007, page 136.

The market system and a public health system are the economic determinants. Both are discussed in the light of a system which legalizes kidney sales. What is measured is what the system is most suitable to arrange a legalise kidney sales. Both systems are described and discussed in paragraph 3.4. The starting point is a market system while there are some conditions necessary in order to set up a market system. These conditions are the indicators:

- 1) The same product is sold to many purchasers by many producers.
- 2) There are no restrictions for entering the market for potential producers.
- 3) The existing producers do not have an advantage over the new producers.
- 4) Both the producers as the purchasers are well informed about the prices.

If these conditions are not met then some short of governmental intervention is necessary or market failures will occur. It is not measured how and in what degree governmental intervention is necessary. This is a very complex subject and does not fit in this research. It will be only measured if a free market sytem is possible or some governmental intervention is necessary.

The medical determinant discusses the different medical treatments which are at the moment available for kidney failure. Treatments have a big influence on the patient's happiness. Next, costs play also a big role while medical treatments are very expensive and are, in the Netherlands and the United Kingdom, paid in a whole or partly by the government. Also the medical consequences for potential donors are measured (only when it is living donation).

Indicators are formulated which measure which treatment is the best for the patient:

- Availability of the treatment
- Risks for patient
- Survival rate of patient in the short and long term
- Long term consequences for the patient
- Risks for the donor (only in a case of living donation)
- Consequences for the donor (only in a case of living donation)

With these indicators it is possible to measure which medical treatment is the best for the patient but also the medical consequences for the donor (living donation).

The following variable is the political aspects. This determinant is necessary in order to analyse if transplantation tourism is a problem which is under the attention of politicians and if it is on the political agenda. The indicators that are used are:

- Political views on organ donation in both countries.
- Transplantation tourism is a policital issue or not.
- Transplantation tourism is on the political agenda or not.

The variable of the current status on policy measures if the Netherlands and the United Kingodm have already policy to prevent transplantation tourism or not. If they have this policy will be described and discussed.

The last varaible are the policy solutions. First there need to be measured if there is a problem. In paragraph 3.8 it is already described that transplantation tourism is a problem. This was measured by the following indicators:

- The problem is an unsatisfied situation.
- There is a gap between "is" and "must".
- There is a chance that the situation can be improved.

The second step is to mearue if transplantation tourism is a tamed problem. Also this is already measured in paragraph 3.8 with the following indicators:

- The problem can be exhaustive formulated.
- The possibility that the problem can be formulated in a total univocal manner as a gap between "is" and "must".
- The possibility for the gap an in every respect sufficient of giving declaration.

Then the policy solutions can be searched with the steps drafted in figure 6 in paragraph 3.8 In annex 3 an overview of this paragraph is presented.

Chapter 5 Research methods

In this chapter the different research methods which are used to gather and analyze the empirical information are described. The used information sources are: interviews and documents. Both sources are different in set up, the way of the analysis and the validity and reliability.

5.1 Research design

This is a research design that design evolves during the research and several methods are possible.¹⁵¹ The main reason is that only qualitative methods such as interviews and documents can be used. The subject doesn't allow using quantitative methods such as experiment or survey.

This research design is not completely flexible; it has also an element from a fixed design. This element is that the main question and the sub questions are pinned down from the start.¹⁵² The main- and sub questions are the base on which this master thesis is built and formulated it at the beginning of this master thesis. The research methods follow out of them.

Within the flexible design different strategies are possible. The type of strategy used is the case study. A case study is *"development of detailed, intensive knowledge about a single 'case', or of a small number of 'cases'."*¹⁵³

The two cases are:

- 1) Transplantation tourism from the Netherlands towards India.
- 2) Transplantation tourism from the United Kingdom towards India.

Within these two cases both countries are examined on how they react on the transplantation tourism. When the research is finished a detailed and extensive knowledge about these two cases is developed. A negative side affect of a case study is that it can not be applied broader; the research findings can not be generalized to more countries because only two countries are studied.

There are different levels on which a case study can be conduct. The level in this master thesis is a study of events, roles and relationships. In this type of case study *"the focus is on a specific event."*¹⁵⁴ What kind an event is very varied. The specific event in this master thesis is transplantation tourism. Within this specific event the different groups which are involved: doctors, receivers, donors, insurance companies, governments and organisations are examined. With the information collected the policy solutions are formulated.

The other levels of case study are more focused on the social relationships and interactions between different individuals, groups and institutions. This is not the focus of this master thesis.

To collect data in a case study they use multiple sources:¹⁵⁵

- Documents
- Archival records
- Interviews
- Observations
- Physical artefacts

Documents and interviews are used. These are the two main sources for data collection. Observations, archival records and physical artefacts are not suitable or useful for this research.

¹⁵¹ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 4.

¹⁵² C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 82.

¹⁵³ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 163.

¹⁵⁴ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 191.

¹⁵⁵ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 165.

This research has also an element of a grounded theory strategy. This is “*developing a theory grounded in data from the field.*”¹⁵⁶ With grounded theory strategy the researcher formulates a theory based on the collected empirical information. The researcher goes out into the field to collect the data. One of the most used methods within the grounded theory strategy is interviews.¹⁵⁷ In this research is not a specific theory formulated but policy solutions are formulated based on the empirical information that is collected during the research.

So, this master thesis has an element of grounded theory: Formulating policy solutions which are not specific theories but which do not exist before this master thesis and which are formulated by the empirical research.

5.2 Documents

As mentioned in chapter 1 the major source for the empirical information for this master thesis will be documents. Documents fall under the category of unobtrusive measure which is “*ways of studying social behavior without affecting it in the process.*”¹⁵⁸ They do not “*embody truth any more than other measures; they are merely steps, albeit sometimes sizable ones, along the way to it.*”¹⁵⁹

The following documents are mainly used:

- Books
- Articles from scientific journals
- Articles in new papers
- Information from websites

There are different methods available for analyzing these documents. But in this case the content analysis and the secondary analysis are chosen.

5.2.1 Content analysis

Content analysis is an unobtrusive measure which is nonreactive.¹⁶⁰ This means that the document you analyze is not affected by it. Content analysis is the quantitative analysis of what is in a document.¹⁶¹ It is a research technique “*for making replicable and valid inferences from data to their context.*”¹⁶² Content analysis is most suitable when you study communications: who says what, to whom, how and with what effect?¹⁶³ The content analysis exists out of four steps:

- 1) During searching for documents sampling the documents
- 2) Determining the unit of analysis
- 3) Coding
- 4) Qualitative data analysis

The first step is to sample documents before starting the analysis. There are a lot of documents suitable but some more than others. Therefore it is necessary to sample during the search for documents which documents are used or not. Sampling starts during the search for documents.

In the theoretical framework different rationalities which are already specific were distinguished. With searching for documents it is examined whether a document is suitable for one of the formulated rationalities; if it is it is used for further research. This method is only possible when the amount of documents is not infinite.

¹⁵⁶ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 163.

¹⁵⁷ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 191.

¹⁵⁸ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 328.

¹⁵⁹ Webb et al., Nonreactive Measures in the Social Sciences, 2nd edition, Houghton Mifflin Company, Boston, 1981, page 34.

¹⁶⁰ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 349.

¹⁶¹ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 349.

¹⁶² Krippendorff, A content analysis: an introduction to its methodology, Newbury Park California, Sage, 1981, page 21.

¹⁶³ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 305.

After selecting different documents the second step is sampling within these documents. For instance, when a book is useful for this research it is probably parts of the book and not the whole book. This can be done with determining the unit of analysis; these are the individual units which make descriptive and explanatory statements.¹⁶⁴ Determining the unit of analysis is not an easy task. In this master thesis different resources are used and different information is necessary to answer the main question. Four possible units of analysis are distinguished for the documents:

- 1) Chapters
- 2) Pages
- 3) Paragraphs
- 4) Lines

For each document the most suitable unit of analysis is used:

Sort of document	Unit of analysis	Reason
Books	Chapters and pages	Books are very large and the best way to analyze them is to look up the appropriate information in chapters and pages.
Articles from scientific journals	Paragraphs and lines	The information in these kind of articles are very specific and mostly the length makes it possible to read the whole article.
Articles in new papers	Paragraphs	Information in new papers will be to collect more general information about the subject and to see if there is information in it that can help me for further research.
Information from websites	Paragraphs	Information on website will be used to collect general information about the subject and as a starting point for further research.

Table 5 Unit of analysis

The third step in the content analysis is coding. This is the process where “*raw data is transformed into a standardized form.*”¹⁶⁵ During coding the different documents the latent content of the information is used. Latent content is a coding method where you look at the underlying meaning of the content of the document. It is not important how many times a certain word is used in a document; this is the case in the second coding method which is manifest content.¹⁶⁶ In this master thesis the (underlying) content is more important. The latent content method has a negative side effect on the reliability and specificity. This is especially true when the coding is been done by different persons¹⁶⁷; that is not the case.

The fourth and last step is the data analysis. In this case qualitative data analysis is used. This is “*the nonnumerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships.*”¹⁶⁸ With qualitative data analysis different methods are possible to analyze the collected data.

With data analysis we can discover several patterns.¹⁶⁹

- 1) Frequencies
How many times did transplantation tourism from the Netherlands and the United Kingdom towards occur under this study?
- 2) Magnitudes

¹⁶⁴ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 306.

¹⁶⁵ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 309.

¹⁶⁶ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 310.

¹⁶⁷ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 310.

¹⁶⁸ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 378.

¹⁶⁹ E. Babbie, The practice of social research, 11th edition, Wadsworth, Belmont, 2007, pages 378-379.

- What is the magnitude of the problem of transplantation tourism? Is it a global problem or in some countries?
- 3) Structures
Who is transplantation tourism structured; who does it work? How is involved?
 - 4) Processes
Are governments reacting on the development of transplantation tourism?
 - 5) Causes
What is the cause that people go abroad to buy a kidney from a stranger? Why are people selling one kidney?
 - 6) Consequences
What are the: health, economic and social consequences of unrelated paid kidney transplantation for both receivers as donors?

The Netherlands and the United Kingdom are examined separately and therefore it is not necessary to conduct data analysis across both studies. When during the research is discovered that there are some elements the same or totally different it will be mentioned but the goal is not to mix up both cases because then it is not possible to development proper policy solutions for both countries.

5.2.2 Secondary analysis

Secondary analysis is “any further analysis of an existing data set which presents interpretations, conclusions or knowledge additional to, or different from those presented in the first report.”¹⁷⁰ In this form already existing data and results are reanalysed by another researcher. The main advantage is that the costs and time for doing survey research is avoided.

For instance, there is research be done about Indian people who sold one kidney. The research focuses on the economic and health consequences after this paid kidney donation.¹⁷¹ This research is necessary for this master thesis but it is not possible to go to India to conduct the research there. In this case the secondary analysis of the already existing research is the solution.

The main advantage of secondary analysis is that it is cheaper and faster than doing an original survey.¹⁷² In this master thesis data need to be collect which can not collect by the researcher due to lack of resources and knowledge. Then secondary analysis is the best way to collect the data. A second advantage is to benefit from the knowledge and expertise from other researchers. For instance, in this master thesis there is research about the different medical treatments that are possible for patients with kidney failure. This research is specific and medical. The study of public administration does not give this information and therefore data of medical professionals is used.

But secondary analysis has also a major disadvantage. The key problem of secondary analysis is the validity.¹⁷³ The question is to what extent the existing research is suitable for answering the main question.¹⁷⁴ In practice the data can come close to measuring what you are interesting but it will never fit it completely.

But when you weigh the pro’s and contra’s in doing a secondary analysis this method is suitable although it is necessary to take the validity of the results into account.

¹⁷⁰ Hakim, Secondary analysis in social research: a guide to data sources and methods with examples, Allen & Unwin, London, 1982 page 1.

¹⁷¹ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *JAMA (2002) Volume 288 13: 1589-1593*.

¹⁷² E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 270.

¹⁷³ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 270.

¹⁷⁴ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 270.

5.3 Interviews

The second source is interviews. These methods are used as a complementary source to get under build or to tackle other information. Interviews can be held in different ways: face-to-face, by telephone, by e-mail. There are also various ways to conduct an interview: structured, un-structured, fixed and open. All approaches have advantages- and disadvantages. You must choose that way of interviewing that is possible in amount of time and distance and available sources. Next, you are depended on the cooperation of other persons where you don't have control over. It is possible that some people refuse or don't respond at all.

5.3.1. Forms of interviews

In this master thesis different forms of interviews are used:

- Face-to-face interview. This is only possible for the interviews held in the Netherlands. The United Kingdom and India are too far away. Next, it will be impossible to plan all interviews in those countries in for instance a week.
- Telephone interview. This will be applied for the possible contacts in the United Kingdom and India. In this it will be able to respond on answers the conversation can be steered.
- E-mail interview. When it is not possible to have a phone interview I will try to set up an e-mail interview. This has not my preference because you can't anticipate and steer.

5.3.2 Semi-structured interview

For the interviews the semi-structured method is chosen. This means that the interviews are formulated but that there is a possibility open so during the conversation there is room to steer the conversation and act in the moment.

The main reason for formulating the question is that different people are interviewed and these people are differently involved in transplantation tourism. Because of this diversity structure is important. For instance, an interview with a transplantation doctor will be more focused on the medical aspects of transplantation tourism. But when you talk with some one from the kidney patient association the character of the conversation will be much more on what a kidney disease holds in for the daily life of a patient and in what way transplant tourism can relieve that. To get not confused by the different conversations it is wise to structure the base of the interview.

It is important to note that the interviews with Dutch people are held in Dutch and also be added at the end of this research in Dutch. The main reason is simple: not everybody is capable to be interviewed in English. The quality of the interviews is higher when they are held in Dutch. This has one problem because the whole master thesis is written in English; in formulating questions it is necessary that this is be done with much care in order to prevent language errors. A language error is defined as faults in translating the questions and answers into other languages. For instance, the word policy in English is much broader than the translation in Dutch ("beleid"). So, when these words are used it needs to be known in which context they are placed. Probably the translation problem will not lead to big problems but it is something that you must consider and take into account when taking off the interviews.

For the Netherlands the following actors where interviewed:

- Eurotransplant
- Nederlandse Transplantatie Stichting¹⁷⁵
- Dutch health insurance company VGZ/IZA
- Dutch association "Transplantatie Nu"¹⁷⁶

¹⁷⁵ In English: Dutch Transplantation Foundation.

¹⁷⁶ In English: Transplantation Now.

Extra contact was made with the Nierstichting Nederland¹⁷⁷ and health insurance company CZ. Both provided extra information by e-mail.

For the United Kingdom a British European Member of Parliament is been interviewed. Next, there has been contact with the National Kidney Federation and the British Medical Association. They provided extra information.

For the United Kingdom this will be more difficult to achieve but efforts are made to get also some representatives of organisations who want to cooperate in this research.

With permission of the respondents the conversations are recorded. Also notes are taken for the certainty. When respondents not agree then only written notes are possible although this has not the preference because it is difficult to listen and to write at the same time and valuable information can be lost.

The interviews are written out in detail; this to make sure that not valuable information will be loosed. After writing out the interview it is send to the respondent who can make comments on it. This gives the respondent the chance to check whether the content is correct. The interviews are added in the annexes of this master thesis. The respondents are anonymous although organisations they are represented are mentioned.

5.4 Reliability and validity of the research

Not one social research is perfect; there are always biases which affect the outcomes of a research. In order to judge the value of the founded data the reliability and the validity of the research methods which are used in this master thesis must be examined. Only then the researcher is capable to judge if the analysed data are useful and reliable for answering the main question.

5.4.1 Reliability

Reliability is *"getting consist results from the same measures."*¹⁷⁸ One method to measure the reliability of a research is by doing a retest.¹⁷⁹ This is not common in social science because you can not reconstruct a real life situation again; then it would be an experiment which has different purposes.

A retest can be done with the founded documents. The analysis of the document can be done two times with a certain amount of time between them. In this way it is prevented that important information is overlooked; this is a check. There are some limitations to this method but due the time and resources it is not possible to retest the document analysis by a third person which would increase the reliability.

It is not possible to retest the interviews. Even if it would be possible to do the interviews over this would make not a lot of differences because the interviewed have already heard the questions; there is a great chance that they know the answers of the first time and that they just would reproduce them. One way to check the reliability of an interviewed is to check if the interviewed have given their opinion in other documents and if that is in line with what they have said in the interview with me. For example, if some says that he is against transplantation tourism but in another interview he or she said to be in favour of commercial organ donation then you can draw the answer in doubt. Transplantation tourism is in fact ordinary commercial organ donation.

The main conclusion is that, outside the two given methods to check the reliability, it is difficult to say something about the overall reliability of the used documents and interviews in this master thesis.

¹⁷⁷ In English: Kidney Foundation Netherlands.

¹⁷⁸ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 146.

¹⁷⁹ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, pages 141-142.

5.4.2. Validity

Validity refers to “getting results that accurately reflect the concept being measured.”¹⁸⁰

There are four different forms of validity used for a fixed research design:¹⁸¹

- 1) Face validity
- 2) Criterion-related validity
- 3) Construct validity
- 4) Content validity

This master thesis is not merely a fixed research design but a flexible design with some elements of a fixed research design. A consequence is that it is not possible to use all different forms of validity described above. It is not possible to use the criterion-related validity in this research. Face validity, construct validity and content validity can be measured in this master thesis.

For flexible research designs there are different threats which affect the validity of the research.¹⁸²

- Description; it is important that to get a valid description of what you have heard or seen. The biggest threat lies in the incompleteness or inaccuracy of the data. You must always try to record conversations or when this is not possible you need to make accurate notes.
- Interpretation; to come to a valid interpretation of the research you must not draw findings and results as being self-evident but you must always justify and explain the steps that you took during your research.
- Theory; within the theory there are three threats of validity:
 - Reactivity; this refers to “the way in which the researcher’s presence may interfere in some way with the setting which forms the focus of the study, and in particular with the behaviour of the people involved.”¹⁸³
 - Respondent biases can have different forms and biases are caused by the behaviour of the respondent. For instance the researcher is seen as a threat or the respondent gives socially justified answers instead of his or hers own opinion.
 - Researcher biases refers to “what the researcher brings to the situation in terms of assumptions and preconceptions, which may in some way affect the way in which they behave in the research settings, perhaps in terms of persons selected for observation or interview, the kinds of questions asked, or the selection of data for reporting and analysis.”¹⁸⁴

There are different strategies to reduce the threat of the researcher bias and/or respondent bias. The table below shows an overview of the different strategies, which bias they affect, how they affect the bias and if this strategy is useful in this research.

Strategy	Threat	How?	Applicable in this research?	Used in this research?
Prolonged involvement	Reduces respondent bias but increases researcher bias.	The researcher goes into the field and becomes involved with the respondents. A trusty relationship is developed between the researcher and the respondents.	No.	-

¹⁸⁰ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 146.

¹⁸¹ E. Babbie, The practice of social research, 9th edition, Wadsworth, Belmont, 2001, page 146.

¹⁸² C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, pages 171-176.

¹⁸³ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 172.

¹⁸⁴ C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, page 172.

Triangulation	Reduces researcher and respondent bias.	<i>Data triangulation</i> ; use more than one method of data collection. <i>Observer triangulation</i> ; using more than one observer. <i>Methodological triangulation</i> ; combining quantitative and qualitative methods. <i>Theory triangulation</i> ; using multiple theories.	Yes. No, there is one interviewer. Yes. Yes.	Yes. - Partly. The interviews were qualitative but existed research is used which were in many cases quantitative methods were used. Different theories are used. See chapter 3 theoretical framework.
Member checking	Reduces researcher and respondent bias.	Return to your respondents and ask their opinion about your findings and results.	The concept drawing of the interviews will be send to the respondents. They can react on that.	Yes. All respondents reacted and give comments on their interview
Peer debriefing and support	Reduces researcher bias.	Can help to guard against the research bias and can have a therapeutic function.	Only contact with the supervisor.	Regular meetings with my supervisor where the drafts were discussed.
Negative case analysis	Reduces researcher bias.	It helps to elaborate a stronger theory.	If negative cases can be find.	-
Audit trail	Reduces researcher bias.	During the research you keep a full record of all the activities conduct during the research.	As much as possible.	Did this as much as possible.

Source: C. Robson, Real world research, 2nd edition, Blackwell Publishing, Oxford, 2004, pages 172-176.

Table 6 Threat reducing strategies

With these strategies the validity of this master thesis within the existing boundaries is hopefully guarantee. Now the research design is finished the next step is to go into the empirical world to collect the data that is necessary to answer the main question.

Chapter 6 Empirical information

6.1 Introduction

In this chapter the empirical information collected with documents and interviews is presented.

Transplantation tourism is a phenomenon with many ethical aspects. There are different opinions about the question whether it is ethical or not. The difficulty with transplantation tourism is that it consists out of different layers. The first layer is if living related transplantation is ethically right. Although the fact can't be neglect that people are against living related transplantation or transplantation in general it is not discussed in this research. Given the reason that living kidney transplantation is something practiced more and more and is legal in the countries which are researched. The second layer is unrelated living transplantation. This is something more disputable. But that is not the main dispute in the discussion. There are three points that give much of discussion:

- The fact that someone is paid for a living kidney donation
- The fact that the organ goes to a foreigner
- The fact that it is possible to get other surgeries abroad. So, why not a kidney transplantation

These are the three main characteristics which stipulate if transplantation tourism is ethically right. If something is ethically right is partly stipulated by culture but also by individual believes. It is therefore difficult to generalize the outcome of the ethical analysis conducted.

It could be stated that the purpose of laws in a democratic society is to protect ourselves from harming ourselves.¹⁸⁵ For instance there are laws protecting children from child labor. So, we do not allow a child to get out of poverty by exploiting itself. The same could be said about paid kidney donation; the poor will donate sooner in order to improve their circumstances.¹⁸⁶ You protect the poor for making a decision that will harm them.¹⁸⁷

Mani (2006) states two factors in the case of transplantation tourism towards India:¹⁸⁸

- *"poverty in the developing world is associated with extreme ignorance and gullibility."*¹⁸⁹ This causes that the easy victims are the poor.
- In practice the Indian government is not capable to control the regulations of the Human Organ Act. The Authorized Committees are open for bribes and payments in order to allow paid unrelated kidney transplantation. When paid unrelated transplantation is regulated it is probably the reality that these regulations are not be controlled and that the poor are the victims. Even when the government sets fixed market prices the poor never receive their promised amount of money.

The last factor is founded by the fact that India is a country that scores lowest on the (30th place) Bribe Payers Index 2006 and it scores 70th place from the 163 countries in the Corruption Perceptions Index 2006.¹⁹⁰ In paragraph 2.7 it is already mentioned that there are doubts about how the Indian government could protect the poor people for exploiting their body.

¹⁸⁵ Cohen, R., Organ sales: Compromising ethics, letter to editor in: *Kidney International*, Volume 70, 2006, page 608.

¹⁸⁶ Mani, M., Payment for donor kidneys, in: *Kidney International*, Volume 60, 2006, page 603.

¹⁸⁷ Cohen, R., Organ sales: Compromising ethics, letter to editor in: *Kidney International*, Volume 70, 2006, page 608.

¹⁸⁸ Mani, M., Payment for donor kidneys, in: *Kidney International*, Volume 60, 2006, page 603.

¹⁸⁹ Mani, M., Payment for donor kidneys, in: *Kidney International*, Volume 60, 2006, page 603.

¹⁹⁰ Transparency International, Bribe Payers Index 2006, Germany, page 4. & Transparency International, Corruption Perceptions Index 2006, Germany, page 6.

6.2 Medical treatments by kidney failure

In the theoretical framework was described the different possible treatments for patients with kidney failure. Kidney failure is when the kidneys function for less than 10%; then there is a life-threatening situation and the patient needs treatment.

In this paragraph the different treatments, their advantages and disadvantages and possible consequences for the donor (in the case of living donation) are described. In annex 3 a more extended description of the treatments is presented.

The following treatments are medical available at the moment:

- Hemodialysis
- Peritoneal dialysis
- Cadaver kidney transplantation
- Living kidney transplantation
 - Related living
 - Unrelated living

6.2.1 Hemodialysis

The first treatment described is hemodialysis. Information in this paragraph is mostly from the Kidney Association Netherlands and the National Kidney Foundation from the United States.¹⁹¹ As mentioned in paragraph 3.4 hemodialysis *“is a procedure that cleans and filters your blood. It rids your body of harmful wastes and extra salt and fluids. It also controls blood pressure and helps your body keep the proper balance of chemicals such as potassium, sodium, and chloride.”*¹⁹² With hemodialysis the kidney function can be around 20%. With this treatment the waste of the blood is removed by an artificial kidney.

There are negative side effects with hemodialysis:¹⁹³

- Most common are vascular access problems. These are problems with the shunt which can silt up or get infected.
- Common negative side effects are muscle cramps and hypotension. Hypotension is a sudden drop in blood pressure. These problems are caused by the rapid changes of the body's water and chemical balance in the body.
- Hemodialysis takes a lot time and it constraints the freedom of movement. For instance, vacancies must always be near by a dialysis centre or hospital. The life of the patient is arranged around the dialysis.

6.2.2 Peritoneal dialysis

The second form a dialysis is peritoneal dialysis. This form of dialysis *“removes extra water, wastes, and chemicals from your body. This type of dialysis uses the lining of your abdomen to filter your blood. This lining is called the peritoneal membrane.”*¹⁹⁴

Peritoneal dialysis has also negative side effects:¹⁹⁵

- The most serious side effect is the risk for peritonitis. This is an abdominal infection occurs *“if the opening where the catheter enters your body becomes infected or if contamination occurs as the catheter is connected or disconnected from the bags.”*¹⁹⁶ The infection can be treated with antibiotics.
- The patient can gain weight.
- The patient can get a larger abdomen scope.
- The patient has during the dialysis little freedom of movement.

¹⁹¹ National Kidney Foundation (United States), Hemodialysis, 2001, 3th edition.

¹⁹² Kidney failure, at: http://www.medicinenet.com/kidney_failure/article.htm, 10-11-2006.

¹⁹³ <http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/index.htm>, 05-02-2007.

¹⁹⁴ Kidney failure, at: http://www.medicinenet.com/kidney_failure/article.htm, 10-11-2006.

¹⁹⁵ Nierpatienten Vereniging LVD & Nierstichting Nederland, Is dialyse uw toekomst?, 2^{de} druk 2003, page 18 & 19. & Kidney Failure: Choosing a Treatment That's Right for You, at:

<http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/index.htm#peritoneal>, 07-02-2007.

¹⁹⁶ Kidney Failure: Choosing a Treatment That's Right for You, at:

<http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/index.htm#peritoneal>, 07-02-2007.

- The CAPD treatment takes a lot of time because it must be done several times per day, seven days per week.
- A negative side affect of APD is that the patient needs a machine and that the patient has little freedom of movement while sleeping. This could be a problem if the patient moves a lot during sleep.

In this part kidney transplantation in general was described from the patient's point of view. Next, the different donors are described: cadaver, related living and unrelated living.

6.2.3 Cadaver kidney transplantation

A general description of the procedure of kidney transplantation is described in annex 3. Cadaver kidney transplantation is well known. The donor who provides the kidney is deceased. The kidney is removed after a person is death or, not in all countries, when the donor is brain death.

For the donor itself there are no disadvantages because the donor is deceased. But in practice not all people wish to donate their organs after their death. They have religious or other reasons for that. In many cases the family is against it. This leads to the biggest disadvantages of cadaver kidney transplantation: there are not enough cadaver kidneys. This is previously described in the paragraph 2.1 about the international organ shortage. That there are not enough cadaver donors is only partly caused by the fact that people are not willing to donate their organs. In fact, not all deceased donors can be used. A person needs to die in certain circumstances so the kidney can be used. Not all death circumstances are suitable for organ donation. Mostly traffic victims or brain death patients are used for donation because those people die in a hospital and transplantation can be conduct. So, although someone is registered as a donor the changes are big that there will be no organ donation.

The survival rate of a cadaver kidney one year after the transplantation increased from 75,7% in 1988 to 87.7% in 1996.¹⁹⁷ Survival rate is the percentage of kidneys that still function one year after the transplantation. These results came from a big American research were 93.934 kidney transplantations both cadaver as living were studied with a regression analysis.¹⁹⁸ The "projected half-life for transplants from cadaveric donors was 7.9 years in 1988 and 13.8 years in 1995."¹⁹⁹ These figures include the patients who died with functioning kidneys; the cause of death is something else. When these patients are excluded from these data then it is 11,0 and 19,5 years respectively in 1988 and 1996²⁰⁰.

6.2.4 Living kidney transplantation

In 1954 the first successful kidney transplantation was conduct by Joeseph Murray and his colleagues at Peter Bent Brigham Hospital in Boston.²⁰¹ This was living kidney transplantation between twins. After this successful surgery more living kidney transplantation between (identical) twins were conducted. Since several years more living kidney transplantations are conduct due to the increasing organ shortage.

¹⁹⁷ Hariharan, S., Johnson, C., Bresnahan, B., Taranto, S., McIntosh, M. & Stablein, D. Improved graft survival after renal transplantation in the United States, 1988-1996, in: *The New England Journal of Medicine*, Volume 342, 2000, page 609.

¹⁹⁸ Hariharan, S., Johnson, C., Bresnahan, B., Taranto, S., McIntosh, M. & Stablein, D. Improved graft survival after renal transplantation in the United States, 1988-1996, in: *The New England Journal of Medicine*, Volume 342, 2000, pages 605-612.

¹⁹⁹ Hariharan, S., Johnson, C., Bresnahan, B., Taranto, S., McIntosh, M. & Stablein, D. Improved graft survival after renal transplantation in the United States, 1988-1996, in: *The New England Journal of Medicine*, Volume 342, 2000, page 609.

²⁰⁰ Hariharan, S., Johnson, C., Bresnahan, B., Taranto, S., McIntosh, M. & Stablein, D. Improved graft survival after renal transplantation in the United States, 1988-1996, in: *The New England Journal of Medicine*, Volume 342, 2000, page 609.

²⁰¹ Kidney transplantation: past, present, and future. History, at: <http://www.stanford.edu/dept/HPS/transplant/html/history.html>, 08-02-2007.

In the case of living kidney transplantation a kidney from a healthy donor is surgically removed and transplanted in the recipient's body. Living kidney donation is only possible, like other forms of kidney transplantation, when there is a match between the donor and the patient. Second the donor must be in a healthy condition and is also examined.

There are two forms of living kidney donation to distinguish:

- Related living kidney donation; the donor is a near relative of the receiver.
- Unrelated living kidney donation; the donor is not a near relative. In the case of transplantation tourism it is paid unrelated living kidney donation.

The survival rate after one year after a living kidney transplantation increased from 88,8% in 1988 to 93,9% in 1996.²⁰² The "projected half-life for transplants from living donors was 12.7 years in 1988 and 21.6 years in 1995."²⁰³ These figures include the patients who died with kidney function; the cause of death is something else. When these patients are excluded from these data then the years are 16,9 in 1988 and 35,9 years in 1996.

Because the donor is a living person and this donor needs to undergo surgery there are also disadvantages and risks for the donor. There has been done research to examine the risks for the donors. The perioperative mortality rate is 0,03%.²⁰⁴ Perioperative mortality is mortality caused by complications which occurred during or short after the surgery. Complications in the long term for the donor are < 10%.²⁰⁵ Next, to the risks of having a surgery there are also risks in the long-term of living with a single kidney.

Living kidney donation is more practised and therefore more data can be collected for research. A Swedish research from 1997 showed that of the living kidney donors, after a 20 year of follow-up, 85% were still alive.²⁰⁶ The survival rate for the general population was 66%. Also a Nordic research showed similar results.²⁰⁷ These better survival rates of living kidney donors can be explained by the fact that donors must have a good health in order to become a donor and because of better medical treatment and follow-up after the transplantation. People with certain health histories or some diseases are excluded to be a donor.²⁰⁸

These figures do not show the potential risks of living with a single kidney. On average after living kidney donation the blood pressure will rise.²⁰⁹ For related living donors it is possible that they have a higher risk to develop kidney failure than other donors because of the genetic match with the patients. Some kidney diseases are genetically related and if you are family of the patients you have higher risks that you also have these genes. This risk is highest for first degree relatives.²¹⁰

The long-term risks are more difficult to describe because this depends on the donor.²¹¹ It is clear that the kidney function declines during the process of ageing. This is a normal process; it happens also by people who have two kidneys. Only a small amount of donors

²⁰² Hariharan, S., Johnson, C., Bresnahan, B., Taranto, S., McIntosh, M. & Stablein, D. Improved graft survival after renal transplantation in the United States, 1988-1996, in: *The New England Journal of Medicine*, Volume 342, 2000, page 609.

²⁰³ Hariharan, S., Johnson, C., Bresnahan, B., Taranto, S., McIntosh, M. & Stablein, D. Improved graft survival after renal transplantation in the United States, 1988-1996, in: *The New England Journal of Medicine*, Volume 342, 2000, page 609.

²⁰⁴ Matas, J., et al., Morbidity and mortality after living kidney donation, 1999-2001: survey of United States Transplant centres, in: *American Journal of Transplantation*, 2003, Volume 3,830-834, page 833.

²⁰⁵ Matas, J., et al., Morbidity and mortality after living kidney donation, 1999-2001: survey of United States Transplant centres, in: *American Journal of Transplantation*, 2003, Volume 3,830-834, page 833.

²⁰⁶ Weitz, J., Koch, M., Mehrabi, A., Schemmer, P., Zeier, M., Beimler, J., Buchler, M., Schmidt, J., Living-kidney transplantation: risks of the donor – benefits of the recipient, in: *Clinical Transplantation*, Volume 20, Supplement 17, 2006, pages 13-16

²⁰⁷ Weitz, J., Koch, M., Mehrabi, A., Schemmer, P., Zeier, M., Beimler, J., Buchler, M., Schmidt, J., Living-kidney transplantation: risks of the donor – benefits of the recipient, in: *Clinical Transplantation*, Volume 20, Supplement 17, 2006, page 14.

²⁰⁸ Ingelfinger, J., Risks and benefits to the living donor, in: *The New England Journal of Medicine*, Volume 353, Number 5, 2005, page 448.

²⁰⁹ Weitz, J., Koch, M., Mehrabi, A., Schemmer, P., Zeier, M., Beimler, J., Buchler, M., Schmidt, J., Living-kidney transplantation: risks of the donor – benefits of the recipient, in: *Clinical Transplantation*, Volume 20, Supplement 17, 2006, page 14.

²¹⁰ Weitz, J., Koch, M., Mehrabi, A., Schemmer, P., Zeier, M., Beimler, J., Buchler, M., Schmidt, J., Living-kidney transplantation: risks of the donor – benefits of the recipient, in: *Clinical Transplantation*, Volume 20, Supplement 17, 2006, pages 14-15.

²¹¹ Ingelfinger, J., Risks and benefits to the living donor, in: *The New England Journal of Medicine*, Volume 353, Number 5, 2005, pages 447-449.

will get kidney failure themselves. Occasionally the donor develops microalbuminuria.²¹² This is when there is a high amount of protein in the urine. In the case of microalbuminuria the amount of protein is 30-150mg during a 24 hours test.²¹³ In the case of kidney failure the amount of protein is more than 3500mg.²¹⁴

Not only medical factors must be taken into account but also psychological factors. Most studies reported a better quality of life of living donors compared with the general population.²¹⁵ These are cases of voluntary kidney donation. The better quality of life can have two causes. The first one is that the donors are in general happier. For living kidney donation donors have a good state of health. Health has an effect on happiness and quality of life.²¹⁶ The second reason is that donors after the donation have a good feeling because they contribute, voluntarily, to improve another's life. Although it is possible to live with one kidney the risks of donating a kidney should be taken into account when someone is examined to become a living kidney donor.

6.2.5 Cadaver versus living

On average the graft function of a cadaver kidney is lower than the graft function of living kidney donation.²¹⁷ Also the survival rate of cadaver kidney donation is lower than in the case of living kidney donation.²¹⁸

The difference in the graft function and survival rate between cadaver kidneys and living kidneys can be explained by the conditions of the kidneys. The usage of living kidneys is done under better circumstances and with healthier donors than with cadaver kidneys.²¹⁹

Secondly, the cadaver kidney is not directly transplanted into the recipients' body but most of the time the kidney is conserved for a while and this affects the quality of the kidney. Thirdly, the cadaver kidney can have traumatic events "*such as intensive care management, cause of death and psychological states which can be associated with brain death.*"²²⁰

From the patient's point of view a living kidney donation is better. In the case of living kidney donation there must be also serious attention to the risks and disadvantages for the donor.

6.3 Transplantation tourism

As mentioned before there are two forms of living kidney transplantation. In the case of transplantation tourism it is unrelated living kidney transplantation. Now, the consequences for both the patient and the donor in the case of transplantation tourism are examined. This is necessary because donors in this case do not voluntarily donate their kidney; they get paid for it. It is possible that this influence the reason to donate one kidney but also their health and economic conditions and their overall happiness afterwards.

The donors

In 2002 Goyal et al. published a research in the Journal of the American Medical Association with the title "*The economic and health consequences of selling a kidney in India.*"²²¹ In this research 305 donors were interviewed after they had sold a kidney in Chennai, India.

²¹² Ingelfinger, J., Risks and benefits to the living donor, in: *The New England Journal of Medicine*, Volume 353, Number 5, 2005, page 448.

²¹³ Proteinuria & microalbuminuria, at: <http://www.nephrologychannel.com/proteinuria/>, 11-02-2007.

²¹⁴ Proteinuria & microalbuminuria, at: <http://www.nephrologychannel.com/proteinuria/>, 11-02-2007.

²¹⁵ Hartmann, A., et al., The risk of living kidney donation, in: *Nephrol Dial Transplant*, Volume 18, 2003, pages 872-873.

²¹⁶ Nordenfelt, L., Quality of life, health and happiness, Avebury, Aldershot, 1993, pages 167-168.

²¹⁷ Koo, D., Welsh, K., McLaren, A., Roake, J., Morris, P., Fuggle, S., Cadaver versus living donor kidneys: impact of donor factors on antigen induction before transplantation, in: *Kidney International*, Volume 56, 1999, page 1551.

²¹⁸ Koo, D., Welsh, K., McLaren, A., Roake, J., Morris, P., Fuggle, S., Cadaver versus living donor kidneys: impact of donor factors on antigen induction before transplantation, in: *Kidney International*, Volume 56, 1999, page 1551.

²¹⁹ Koo, D., Welsh, K., McLaren, A., Roake, J., Morris, P., Fuggle, S., Cadaver versus living donor kidneys: impact of donor factors on antigen induction before transplantation, in: *Kidney International*, Volume 56, 1999, page 1556.

²²⁰ Koo, D., Welsh, K., McLaren, A., Roake, J., Morris, P., Fuggle, S., Cadaver versus living donor kidneys: impact of donor factors on antigen induction before transplantation, in: *Kidney International*, Volume 56, 1999, page 1556.

²²¹ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *Journal of American Medical Association*, (2002) Volume 288 13, pages 1589-1593.

Of these donors 70% sold their kidney through a middleman and the remaining 30% sold their kidney directly to a clinic. The major group of donors (96%) sold their kidney to pay of their debts. The most common sources of debts were: food and household expenses (55%), rent (24%), marriage expenses (22%) and medical expenses (18%). On the question if helping a sick person was also a reason to sell one kidney 95% of the donors said that was not a major factor.

The donors were promised to receive an average of \$1.410. In the end they actually received \$1.070. They got less then they were promised.²²² The money the donors received was with 60% mostly spent on paying of debts. 22% had been spent on food and clothing. Of the total amount of money donors received only 11% was cash equivalents.

The economic status of the donors decreased after they sold their kidney. Before the donation the annual family income was \$660. After the surgery the annual family income was, during the research, \$420. Also the amount of participators below the poverty line increased from 54% to 71%. From the donors who sold their kidney to pay of debts 74% was still in debt after the sale. It is unclear if the decrease of income was caused by the kidney donation. Although the economic development of the area the donors lived increased during the survey; it can not be said that a back lash in the economic development in the area the donors lived has caused the decrease of the economic status of the donors. This can be a sign that the donation of the kidney played a role. This is also confirmed by the decrease in health which could cause the decrease in income while people are less able to work.

The research not only focused on the economic status of the donors but also the health status. 13% of the donors stated that there were no changes in health status. 38% reported a decline of health between 1 to 2 point and 48% reported a decline of 3 to 4 points in health. Next, 50% of all the donors in the research had consistent pain at the side where the kidney was removed and 33% had long-term back pain. On the question if they would advise others to sell one kidney 79% said "no" and 21% said "yes".

Although this research has some limitations it gives an indication about the situation of donors before and after they sold their kidney.²²³ It is possible that other sellers are more positive after selling one kidney. But based on the research which was available this can't be confirmed.

The patients

Although there seems to be a general agreement that living donation is good for a patient in this master thesis the case of paid unrelated living kidney transplantation is examined. The reason is that there is a difference between the quality and treatment of patients in countries. Especially when patients travel to a developing country to get a serious surgery it is interesting examine the results of that. It must be said that it is quite difficult to find empirical information about patients who underwent kidney surgery in India. One of the reasons is that patients are not open about it. The British Kidney Foundation tried several times to find kidney patients who underwent paid kidney transplantation outside Europe but no patient was willing to talk about it.²²⁴ It is therefore difficult to get a clear picture on the consequences of travelling abroad for paid living kidney transplantation.

In the period 1996-2001 9 patients from the kidney transplant unit of University Hospitals of Coventry and Warwicksire Walsgrave hospital travelled to China (1), India (5) and Pakistan

²²² See also: Salahudeen, A., Woods, H., Pingle, A. Nur-El-Huda Suleyman, M., Shakuntala, K., Nandakumar, M., Yahya, T., Daar, A., High mortality among recipients of bought living-unrelated donor kidneys, in: the Lancet, Volume 336, 1990, pages 727-728. & Marshall, P, Thomasa, C., Daar, A, Marketing human organs: the autonomy paradox, in: *Theoretical medicine*, Volume 17, 1996, page 9.

²²³ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *Journal of American Medical Association*, (2002) Volume 288 13, page 1592.

²²⁴ Stated by the British Kidney Federation in an e-mail on 31-01-2007.

(3) to get kidney transplantation.²²⁵ In the same period 30 living kidney transplantations were conducted in that hospital. The survival rate in India was 68% compared with 92% in Coventry.²²⁶ The 8 patients who went to India and Pakistan got 11 complications. Of those complications were hepatitis B or C and one patient died of a bacterial infection. Compared with the figures of Coventry the patients who travelled abroad had a higher complication rate. Two patients who went abroad were removed from the transplantation waiting list in the United Kingdom because their health condition was not good enough to have kidney transplantation.

The different researchers do not tell anything about the social or economic status of the patients. It can be assumed that patients who can abroad will not be poor because such transplantations are not covered by health insurance. For instance, in the Netherlands kidney transplantation is reimbursed by health insurance. But health insurance does not reimburse paid kidney transplantation abroad because this is forbidden by law in the Netherlands. There are conditions which allow a patient to go abroad to get kidney transplantation:²²⁷

- The patient must meet the Dutch conditions to apply for kidney transplantation.
- The patient must in minimal have a referral of a Dutch specialist which underlines the transplantation abroad.
- There must be clarity about the costs of the transplantation and the follow-up treatment.
- The costs of the transplantation may not exceed the costs of transplantation in the Netherlands. These are, at the moment, at least € 50.000-, these costs are included the costs of the different specialist who are involved in the process.
- In the Eurotransplant countries it is only possible to be in one country on the waiting list. Although Eurotransplant is allowed to have a limited patients that are on more waiting lists.²²⁸ Eurotransplant stated that this limit is not crossed yet.

It is also very difficult to estimate how many people from Europe go to India or other countries to get paid unrelated kidney transplantation. For instance the National Kidney Federation in the United Kingdom stated in an e-mail that they have tried several times to get into contact with patients who went abroad for kidney transplantation. Unfortunately the National Kidney Federation didn't find patients who were willing to talk about it. The National Kidney Federation thinks that this is caused by the fact that they are principally against it and the patients don't want to be open about it. The National Kidney Federation also stated that transplantation tourism is something that does occur in the United Kingdom but that the government has not taken any action.

Conclusion

Although these researches are all conduct in different countries and in different periods they have quite the same results. In all cases there are patients travelling abroad for kidney transplantation while their doctors advised not to because their health condition does not allowed that. Further, in most cases patients returned with hardly any medical information which is necessary for follow-up treatment. Thirdly, the survival and graft rates are lower compared with patients who were treated in the own hospital. With this last conclusion there needs to be taken into account that some patients that received a kidney abroad were not healthy enough to undergo such transplantation. At last the different researchers show that

²²⁵ Higgins, R., West, N., Fletcher, S., Stein, A., Lam, F., Kashi, H., Kidney transplantation in patients travelling from the UK to India or Pakistan, in: *Nephrology Dialysis Transplantation*, Volume 18, 2003, pages 851-852.

²²⁶ Higgins, R., West, N., Fletcher, S., Stein, A., Lam, F., Kashi, H., Kidney transplantation in patients travelling from the UK to India or Pakistan, in: *Nephrology Dialysis Transplantation*, Volume 18, 2003, pages 851-852.

²²⁷ Electronic interview with medical advisor specialized in foreign policy of health insurance company VGZ/IZA and Trias, the Netherlands.

²²⁸ Telephonic interview with the general director of Eurotransplant, 31-01-2007.

patients who travelled to India had more infections and bacterial diseases such as hepatitis B or C or HIV/AIDS. These researches show that the risks for the patient in the case of unrelated paid living kidney transplantation abroad are higher than in the case of non paid kidney transplantation in Western countries.

6.4 The health care system in India

As mentioned before transplantation tourism towards India has also affected the amount of available kidney donors in India. The kidneys that go to foreign people are not available for Indian people. What the consequences are depends on the availability of other treatments for Indian patients with kidney failure.

6.4.1 Introduction

Most information in this paragraph about the health care system in India comes from the following researchers: Chugh and Jha (1995 & 1996), Sakhuja & Sud (2003), Jha (2004), Agarwal (2005).

India has, just like other developing countries, a two-tier or dual health care system. This means that there is public- and private healthcare. The last one is only available for the richer Indian people.

Within India there are 31 states and unions which are the administrative units. Health is one of the responsibilities of the state government. The central government formulates broad guidelines for health but the state governments decide over the health priorities and budget. As a result there are differences in the way people receive health care. The public healthcare sector is organized in the shape of a pyramid. At the bottom there are the primary health centres. The second level are the block and district level hospitals and university hospitals. The top exists from 3 tertiary care referral institutions. Healthcare for patients with kidney failure are only available in a few university hospitals or higher-level hospitals.

The waiting lists in the public hospitals for dialysis and transplantations are long; hospitals are overloaded with patients. It is not possible to accept patients for maintenance dialysis. In public hospitals the consultations are mostly free. Dialysis treatments and transplantations are subsidized. In the private hospitals there is an opposite situation. Here they accept patients for maintenance dialysis programs and the waiting lists for transplantation are shorter. The quality of private hospitals differs but in general it can be stated that the quality in bigger private hospitals is in general better than in public hospitals. This is caused by the fact that the private hospitals have better and modern equipment than public hospitals. The big difference in quality between the public and private hospitals can be explained by the amount of money spent on public health care. A public primary healthcare centre spends approximately every year about \$0,75 per patient on medicines and equipment. India has no state-funded or insurance system to cover medical expenses. In the case of kidney failure patients have to find other resources to collect the money. Most people get help of their employer or charity organisations. Others take a loan to pay the costs of the treatments.

There are no national or regional registration systems and it is therefore hard to give precise numbers of the amount of patients that have kidney failure in India. Conservative estimations are that there are every year between 80.000- 100.000 new patients with kidney failure in India. It is important to note that a lot of people live in rural areas and these people are never reached and are excluded in these estimations. The actual amount of people could be higher.

6.4.2 Dialysis in India

It is estimated that there are in India about 400 dialysis units; they have 1.000 dialysis stations. Of this total 2/3, respectively 267 units and 667 stations, are in the private sector. In the public sector there are around 133 units and 333 stations. There is no equal distribution of dialysis centres over the country. The least developed states in the eastern part have

fewest centres per million population compared with the more industrialized southern and western states. Although most people live in rural areas most facilities are in the more metropolitan cities; some patients travel 2.500 kilometres for a treatment. There are two forms of dialysis: hemodialysis and peritoneal dialysis. The capacity of the dialysis treatments is 5.000 for hemodialysis and 300 for peritoneal dialysis.

Hemodialysis programs are not available on large scale in India. Only richer patients can afford to have hemodialysis for a longer period. Other patients have it depending on their economic situation. The costs of hemodialysis are between \$10-40 per session; this can be done in a public hospital or a private one. The costs for a treatment twice per week are between \$1.040- 4.160 per year. The costs for a treatment thrice per week are between \$1.560- 6.420 per year. The medicines are between \$150-200 per month (\$1.800- 2.400 per year).

In a private hospital hemodialysis is on average \$2.500 per year for twice per week and on average \$3500 for third times per week per year. The costs of the medicine are the same.

Peritoneal dialysis starts from \$400 per month (\$4.200 per year) and the medicine are compared with hemodialysis. At the moment less then 2.000 patients get peritoneal dialysis; the duration of the treatment depends also on their economic situation. The costs of peritoneal dialysis are even 2 till 4 times higher then for hemodialysis. This is paradoxical because in advanced nations this form of dialysis is cheaper then hemodialysis. Also with the lower salaries of the staff it is be expected that it would be even cheaper in India.

Of the patients who started dialysis between 69-71% dies or stops the treatment. The majority stops within three months after starting the dialysis treatment.

6.6.3 Kidney transplantation in India

From the new patients, 80.000 – 100.000 per year, only 5%, which is on average 4.500, receive kidney transplantation. India has approximately 600 nephrologists and 105 transplant centres. The public hospitals only conduct related kidney transplantations. The private hospitals also conduct paid unrelated kidney transplantations.

Of all the kidney transplantations between the 30-40% are living related kidney donations. There is a cadaver donor program and although the India government has promoted it only 2% of the total kidneys come from deceased donors. The amount of paid unrelated living kidney donation covers 60-70% of all kidney transplantations in India.

As mentioned in paragraph 2.7; it is illegal in the Transplantation of Human Organ Act 1994. But in practice even the Authorized Committees which decide if a living kidney donation is legal are not acting in line with the law and accept paid unrelated living kidney donations.

The costs of kidney transplantation vary strongly between the public hospitals and the private sector. In a public hospital a patient pays between \$700-800 for kidney transplantation. The costs in a private hospital are \$6 000. Kidney transplantation in a private hospital is almost 10 times more expensive then in a public hospital. The medicine after the surgery is around \$250 per month but it is possible that this decrease because sometimes patients buy different medicines which are cheaper. Although the prices of kidney transplantation, compared with the GNP per capita \$450, are high for most Indian people kidney transplantation is cheaper then dialysis.

6.5 Political factors

Political factors play an important role in developing policy solutions; without political support nothing happens. This is described in paragraph 3.6.

In the Netherlands the different respondents are well known by the phenomenon of transplantation tourism but this is different for the political parties. All the ten Dutch political parties were e-mailed. Five political parties (the SGP, PVV, GroenLinks, VVD and CDA) have answered the questions which be can found in the end of this research. Three Dutch

parties (D66, SP and Partij voor de Dieren) answered with the response that their members of Parliament were not able to answer the question because they were too busy. The other political parties were also contacted by telephone with the question if it was possible that the questions would be answered.

50% of the total amount of political parties answered the questions. One party, the SGP, was not familiar with transplantation tourism. The other parties heard about it. The political parties agreed that transplantation tourism is unethical. Only CDA was a bit milder; they agree that they can't prevent people going abroad and they would like to focus more on information about the risks of transplantation tourism. In order to prevent transplantation tourism most political parties focus on increasing the amount of potential donors in the Netherlands. Interesting to mention is the fact that the willingness of Dutch people to donate their organs is decreased²²⁹. The opinion of the family plays an important role.

Also the two major political parties in the United Kingdom were contacted to answer the questions. Although both parties contacted the information they gave was useless. The Labour Party gave another person to contact but due to lack of time this is not happened.

6.6 Current status on policy

Both in the Netherlands and the United Kingdom there is at the moment no specific policy to prevent and stop transplantation tourism.

6.6.1 The Netherlands and the United Kingdom

In the interview with the Nederlandse Transplantatie Stichting (NTS)²³⁰ it became clear that the government and other organisations which are involved in organ transplantation have no overview how big or small the problem is. The NTS is established in 1997 and has the following tasks which result from the Dutch law on organ donation:²³¹

- Organ centre
- Transplantation follow-up
- Consulting donor register
- Give medical information and answering questions
- Donor recruitment

The NTS has mandate of the Dutch government to carry out these tasks. The NTS states that at the moment there is no specific policy to prevent and stop transplantation tourism. In 2003 there were 3 patients, at a couple of hundred, that went abroad for a transplantation but it is unknown whether those patients had a paid unrelated living kidney transplantation. In that same year there were 84 patients removed from the waiting lists for other reasons; it is possible that in this group are patients that went abroad but there is no prove for that. The NTS thinks that the amount of Dutch patients who go abroad for paid unrelated kidney transplantation is very small. But they have no figures at all; it is guessing. Because there is no indication that Dutch patients go abroad the Dutch government don't think it is necessary to research these developments. The argumentation is that because there is not a lot known about it the problem would not be so big. So, it is not necessary to take any action.

Also the other Dutch respondents know about transplantation tourism. They know that it exists but they don't have any figures at all. It stays with guessing.

The same can be said for the United Kingdom. Although there are doctors who went public with the fact that their patient's went abroad the government has not taken action at all. This can be found in the interview with the British European Parliament Member. He states that transplantation tourism is not something of concern of the British government although he expects that the numbers of British people that go abroad are very big.

²²⁹ Nabestaande doorslaggevend bij orgaandonatie, <http://www.nivel.nl/>, 14-05-2007.

²³⁰ In English: the Dutch Transplantation Foundation.

²³¹ Nederlandse Transplantatie Stichting, at: <http://www.transplantatiestichting.nl/>, 28-03-2007.

The National Kidney Federation in the United Kingdom has tried to investigate the amount of patients that went abroad. Unfortunately they were not able to do this because the NKF is against transplantation tourism and the people they contacted didn't want to talk about it. The NKF suspects that it is very difficult to research the number of patients who went abroad because people are not proud of it and do not want to go public. The NKF also stated that the British government has not taken any action on this matter. According to the organisation also the government has no figures at all.

6.6.2 The European Union

At the European level there is not yet policy against transplantation tourism but there is some action to stop and prevent organ trafficking in general. Mr. Evans, one of the respondents, was rapporteur in the European Parliament Committee Citizen's Rights, Justice and Home Affairs. This Committee has written a consultative report that was sent to the European Council. The report was written after an initiative of the Hellenic Republic to stop organ trade. The starting point was that organ trade, transplantation tourism is part of that, is a transnational crime and has high priority in the Committee. As mentioned in paragraph 2.8 the report ended on the table of the Council. In the Council there was no agreement about the initiative and no decision has been made. It does not seem to be agreement will be reached in the near future. The European Union has enlarged from 15 to 25 to 27 member states and it is much more difficult to get unanimity about the plan. Unanimity is obligated because this matter falls in pillar four; non-market policies.

Countries could not agree when they were with less so it is not logical that they will agree now when they are with much more. The European Member of Parliament also stated that the initiative countries (the Hellenic Republic with support of the United Kingdom) did not give enough pressure to the other countries to reach unanimity. It seems that it is also for these countries not important enough to push it forward.

Interestingly is that in December 2004 an experts group on trafficking in human beings has presented a report on human trafficking.²³² The goal of this report was to contribute to the translation of the Brussels Declaration into concrete implementation proposals to the European Commission (Directorate-General Justice, Freedom and Security). The European Union used the definition of article 3 of the UN Trafficking Protocol as a base for the Brussels Declaration.²³³

"Trafficking in persons" shall mean the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs; (Article 3²³⁴)

The European Union decided to modify the definition and the Council Framework Decision of 2002 does not include the removal of organs into the definition of human trafficking.²³⁵ The European Union deviates from the UN Trafficking Protocol. Organ trafficking is not part of trafficking of human beings.

At the moment organ trafficking is not part of trafficking human beings in the European Union. At the same moment there is a proposal on the table of the European council to

²³² European Commission, Directorate-General Justice, Freedom and Security, Report of the Experts Group on Trafficking of Human Beings, Brussels, 22 December 2004.

²³³ Officially it is named: Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention Against Organized Crime.

²³⁴ United Nations, Secretary-General, Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention Against Organized Crime, 2000.

²³⁵ European Commission, Directorate-General Justice, Freedom and Security, Report of the Experts Group on Trafficking of Human Beings, Brussels, 22 December 2004, page 130.

define organ trafficking as part of human trafficking. It is possible that a shift will be made. This proposal is supported and approved by the European Parliament. So, actions have been made in order to change the current situation.

Interestingly this is not the only track in the European Union where there is movement in order to stop or prevent transplantation tourism. In paragraph 2.8 can be read that the DG SANCO has organised an open consultative on organ donation and transplantation. During these event professionals, academics and civil servants were asked their opinion on different issues. One of the main concerns was the organ shortage but also organ trafficking was mentioned. Both are seen one of the three biggest problems at the moment.

The contributors chose for further European Union action the option *“To strengthen coordination between Member States, consider minimum harmonisation on quality and safety to complement and reinforce these actions through a directive, and in addition an initiative on organ trafficking.”*²³⁶ (DG SANCO, 2006; 4)

The main problem within the European Union is the organ shortage. Interestingly they were not supporters for a centralised European donor pool. Also the problem of transplantation tourism was mentioned.

The main conclusion of the report, already described in paragraph 2.8, was that there are specific problems in the case of organ donation and transplantation. The three main problems are²³⁷:

- 1) Quality and safety aspects of organ transplantation
- 2) Organ shortage
- 3) Organ trafficking

The European Commission came to the final conclusion that these problems *“should be addressed in the context of Community competence in order to propose the best alternatives for EU action.”*²³⁸ At the moment no further action has been made public. This could be possible while the report was published in December 2006 and during the writing of this research it is March 2007. Most of the time there is quite some time necessary in order to propose further action especially at the European Union level where many actors are involved.

6.7 Policy solutions

The respondents of the interviews agree that transplantation tourism is caused by a kidney shortage. Some policy solutions that are given in the interviews are focused on reducing the kidney shortage:

- A different donor registration system
- Living kidney donation
- Cooperation in organ allocation in the European Union

Other solutions that respondents gave were focussed on preventing transplantation tourism:

- Registration requirement of doctors
- Medical code

There are also policy solutions which the respondents didn't mention but which are possible:

- Prevention of kidney failure
- Allowing kidney sales by the market or by the government (Iranian model)

In this paragraph these solutions are described.

²³⁶ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, page 7.

²³⁷ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, page 7.

²³⁸ European Commission, Directorate-General Health & Consumer Protection, Report on the open consultation: policy options for organ donation and transplantation at EU level, december 2006, page 7.

6.7.1 A different donor registration system

A solution that is mentioned by several respondents is implementing a new donor registration system. Stichting Transplantatie Nu, Eurotransplant and the European Member of Parliament all suggested changing the non-active registration to the presumed consent system. Both the Netherlands and the United Kingdom have a registration system whereby the donor must fill in a codicil only then he or she can become a donor. In practice a lot of people do not fill in anything. Stichting Transplantatie Nu said that 70-80% of the people are willing to donate their organs after their death but in practice only 40% of the Dutch people has filled in a donor codicil (not all of them want to be a donor). With a presumed consent system everybody is an organ donor unless you say different. So, you need to fill in a form to say that you don't want to be an organ donor.

In 2005 there was a voting in the Dutch Parliament to implement a presumed consent system. The Parliament voted against such a system with 78 votes against and 68 in favour.²³⁹ This proposal was initiated by a member of the opposition party SP. Minister Hoogervorst, of the VVD, was against such a proposal he wanted to use other methods in order to increase the amount of transplantations. VVD, CDA (both parties were in the government at that time), SGP, Wilders, 5 members of PvdA and 2 members of the LPF voted against.²⁴⁰

The main arguments or uncertainties against a presumed content system are:²⁴¹

- How would unregistered people react on the new system? It is possible that the amount of no registrations is much higher than with the current system due to the fact that there is no other choice than “yes” or “no”. The new system can give organ donation a negative image.
- With the new system the current registrations would expire and in this group there are already direct “yes” registrations.

After the voting against a presumed content system a pilot was held in 15 municipalities which would give citizens a donor form when they picked up their passport, identification card or drivers license.²⁴² In June of 2005 93% of the Dutch municipalities have indicated that they would cooperate with this initiative.

Belgium and Spain have a presumed consent system and there the amount of post-mortal donors is much higher but more factors play a role in the amount of post-mortal donors. The amount of people who died because of a traffic accident plays a role. It is possible that there are more traffic accidents in Spain and Belgium which could partly explain the higher amount of post-mortal donors.

Eurotransplant estimated that with a presumed consent system the amount of donors will grow with 10-20%.

The NIGZ²⁴³ (Nederlands Instituut voor Gezondheidsbevordering en Ziektepreventie) presented an alternative donor registration system: the active donor registration system. The principle of this system is that everybody at the age of 18 is positive over organ donation. But people can change this with three choices:²⁴⁴

- 1) I wish only to be donor of the organs and tissues that I agree to donate. (choice 1)
- 2) I don't want to be organ donor. (choice 2)
- 3) I wish that relatives or a specific relative decide if I become an organ donor or not. (choice 3 and 4)

²³⁹ Tweede Kamer, TK 56, 56-3627, Stemmingen, 8 maart 2005.

²⁴⁰ Tweede Kamer, TK 56, 56-3627, Stemmingen, 8 maart 2005.

²⁴¹ NIGZ, NIGZ stelt alternatief donorregistratiesysteem voor, Woerden, 02-02-2004.

²⁴² Minister van Volksgezondheid, Welzijn en Sport, GMT/IB 2738123, Stand van zaken orgaandonatie, 08-01-2007, page 1.

²⁴³ Nederlands Instituut voor Gezondheidsbevordering en Ziektepreventie, in English: Dutch Institute for Health Promotion and Disease Prevention.

²⁴⁴ NIGZ, NIGZ stelt alternatief donorregistratiesysteem voor, Woerden, 02-02-2004.

The base of this system is that everybody above the age of 18 is automatically donor. The difference is that this is explicitly asked. Second, the donor has more alternative choices than simply “yes” or “no” what is the case in the presumed content system. But the people themselves need to lay down this decision actively; no action means that they become a donor.

The NIGZ describes beside the advantages also the disadvantages of the system which are:²⁴⁵

- High implementation costs.
- Although the system change is less dramatic than with the presumed content the law needs to be changed and information about the new system is necessary.
- Certain groups of people have the danger that they are not reached (for instance analphabetic, people who stay for a longer time abroad and people who do speak enough Dutch). With developing the information these groups need to get special attention.
- The system is less synoptic compared to the presumed content system; it is not just “yes” or “no”.

Friele and Kerssens (2004) researched the possible effects of this proposal for NIGZ.²⁴⁶ The main conclusion was that this proposal has the potential to increase the amount of donors.²⁴⁷ But the second evaluation of the Dutch Organ Donation Act showed that different systems on paper are less different in practices²⁴⁸. The effect of this active donor registration system could be less in practice than it is on paper.

6.7.2 Living kidney donation

Both Stichting Transplantatie Nu and Nederlandse Transplantatie Stichting mentioned living kidney donation as a temporary solution. They agree that it is better to give patients a kidney transplantation and if post-mortal kidneys are not possible then from living donors. They both stated that this should be on a voluntary base. Although they both say that the risks of the living donor are low they prefer not to operate a healthy person. This argument is also stated in paragraph 6.2.4 were living kidney donation is discussed.

The Nederlandse Transplantatie Stichting has established a monitoring body that follows up living kidney donors to examine the effects and risks of living kidney donation. The kidney donors are examined 3 months, 1 year, 2, 5 and 10 years after the surgery. In this way the organisation wants to monitor if and in what degree the long term damages are of living kidney donation.

Stichting Transplantatie Nu mentioned a special program that Erasmus MC has developed: Living Donor Exchange List (LDEL). If there are people in your near surroundings who want to donate a kidney but the kidneys are not compatible. In this case it is possible that you come on the LDEL. The LDEL is a list with people who have a living kidney donor but which is not compatible. With the list, matches are made between the different living kidney donors and patients on the list. In this way the chances are higher that a suitable kidney is available. The Health Council of the Netherlands²⁴⁹, this is an independent scientific advisory body for Ministers and Parliament²⁵⁰, has stated that it appears that the LDEL is prohibited under the current law²⁵¹.

²⁴⁵ NIGZ, NIGZ stelt alternatief donorregistratiesysteem voor, Woerden, 02-02-2004.

²⁴⁶ Friele, R.D., Kerssens, J.J., Actieve donorregistratie? Een onderzoek naar de mogelijke reacties op de introductie van een actieve donorregistratie, NIVEL, 2004.

²⁴⁷ Friele, R.D., Kerssens, J.J., Actieve donorregistratie? Een onderzoek naar de mogelijke reacties op de introductie van een actieve donorregistratie, NIVEL, 2004, page 31.

²⁴⁸ Friele, R.D., Kerssens, J.J., Actieve donorregistratie? Een onderzoek naar de mogelijke reacties op de introductie van een actieve donorregistratie, NIVEL 2004, page 32.

²⁴⁹ In Dutch: Gezondheidsraad

²⁵⁰ Mission, at: <http://www.gr.nl/missie.php?phpLang=en>, 29-03-2007.

²⁵¹ Gezondheidsraad, Ruilen met de wachtlijst: een aanvulling op het programma voor nierdonatie-bij-leven?, 26 maart 2007, page 18.

The Nederlandse Transplantatie Stichting has made a policy proposal as a supplement on the current organ donation program in the Netherlands. In summary the proposal is as follows:²⁵²

Kidney patients with an incompatible living kidney donor, if they participate without success in a cross-over system that is established for such pairs, will be allowed to exchange with a compatible kidney on the post-mortal donor list. The patient with a living kidney is placed on top of the list while the living kidney of the patient will go to the first one on the waiting list. In this way per saldo more patients are helped although the amount of kidneys on the waiting list stays equally. The Nederlandse Transplantatie Stichting would like to set up a pilot in order to see how it will work in practise.

The council has judged this proposal and also the proposal to set up a pilot. The conclusion of the council is that under the current law LDEL is prohibited and even a pilot is not possible.²⁵³ It would be possible that the Organ Donation Act would be changed although this is up to political decision makers. The question is if these necessary legal changes are in line with constitutional principles such as equality and other instruments that are based on these principles.²⁵⁴ The council states that the emerging of LDEL is caused by a serious shortage of transplantable organs and that the current Organ Donation Act is not working sufficient.²⁵⁵ The LDEL is seen as a serious alarm signal; research to alternative solutions is necessary.

Living kidney donation is seen as a solution but only as a temporary one. The respondents agree that it is more favourable that kidneys would come from post-mortal donors although it is possible to live well without a kidney (see also paragraph 6.2.4).

6.7.3 Cooperation in organ allocation in the European Union

One of the possible solutions to expand the organ donation pool is to cooperate within the European Union. This suggestion has been made by the British Member of European Parliament. At the European level there are some actions in order to reduce the organ shortage this is already described in paragraphs 2.8 and 6.6. The Committee on Citizens' Freedoms and Rights, Justice and Home Affairs amended an initiative of the Hellenic Republic for a council framework decision. This proposal was adapted by the European Parliament but the Council could not reach agreement and it is officially still on the table although there are no intentions to come to agreement. Mr. Evans thinks that it is possible to cooperate within the European Union in the allocation of organs. At the moment Eurotransplant is doing this in 6 countries (the Netherlands, Belgium, Luxembourg, Germany, Austria and Slovakia). He suggests implementing the presumed consent system within the European Union. In this way the organ donation pool in the whole EU will expand. Second, the allocation of organs could also be arranged at a higher level; countries could exchange organs in order to provide more patients a compatible organ. But at the moment there is neither the pressure nor the initiative to set up such a system; without that nothing happen

6.7.4 Registration requirement of doctors

One of the problems with transplantation tourism, both in the Netherlands and the United Kingdom, is that there are no exact figures. To decide if action is necessary the government needs exact figures. The opinion in the Netherlands is that because there are no figures it will probably not exist. It is clear that patients who went abroad for paid kidney transplantation are not very open about it. A first step is to collect figures about the amount of patients that go abroad. In both the Netherlands and the United Kingdom this does not

²⁵² Gezondheidsraad, Ruilen met de wachtlijst: een aanvulling op het programma voor nierdonatie-bij-leven?, 26 maart 2007, page 3.

²⁵³ Gezondheidsraad, Ruilen met de wachtlijst: een aanvulling op het programma voor nierdonatie-bij-leven?, 26 maart 2007, page 21.

²⁵⁴ Gezondheidsraad, Ruilen met de wachtlijst: een aanvulling op het programma voor nierdonatie-bij-leven?, 26 maart 2007, page 21-22.

²⁵⁵ Gezondheidsraad, Ruilen met de wachtlijst: een aanvulling op het programma voor nierdonatie-bij-leven?, 26 maart 2007, page 22.

happen yet. Stichting Transplantatie Nu and the Nederlandse Transplantatie Stichting suggested that doctors can be obligated to report anonymously about the amount of patients per year that went abroad. So, doctors only report the number and don't have to give any names or other information. Perhaps it is possible to report where the patients travelled to.

A registration requirement is a good solution to evaluate how big the problem is and if there is a problem at all. After two or three years a decision, based on the figures, can be made if further action is necessary or not.

This registration requirement is not contrary with the confidential rule of a doctor while none of confidential information is given; it is not possible to trace back to the patient. In the Netherlands such a registration requirement already exists for certain infection diseases.

6.7.5 Medical code

A solution suggested by Eurotransplant was that transplantation doctors create a medical code. In such a code the doctors declare that they are against paid unrelated organ donation and against the practice of transplantation tourism. They declare that they inform their patients about the risks and complications and also that they inform the patients about other treatments for instance living kidney donation by a family member.

Such a medical code is more a symbolic solution because it will not actively contribute to preventing transplantation tourism. A code shows only that transplantation doctors are against transplantation tourism and that they make all efforts to prevent that patients go abroad. A medical code should come from the transplantation doctors themselves.

6.7.6 Prevention of kidney failure

One of the solution that none of the respondents mentioned, only shortly in the interview with Stichting Transplantatie NU, is the prevention of kidney failure.

There are two forms of kidney failure: acute kidney failure and chronic kidney failure.²⁵⁶ In first case the function of the kidney drops acute in the second case it is a longer process.

In the case of chronic kidney failure there is an amount of time between the first complaints and actual kidney failure in such a degree that dialysis or transplantation is necessary.

In most cases the patient was already having medical complaints. The problem is that some of the complaints are general and are also common with other diseases.

The Dutch Kidney Foundation has launched a campaign whereby people at home can use a self-test in order to test if they have a kidney disease. Stichting Transplantatie Nu warns that not all kidney diseases can be traced by this self-home test while the test measures the amount of protein in the blood. Higher amount of protein can be an indication for kidney failure. But the organisation thinks that it is a positive action to make people more aware of kidney disease especially because the complaints are general and are mostly in a late stage recognizable.

There are some groups of people who have higher risks to develop kidney failure. Persons with diabetes have higher risks; half of the dialyse patients in the Netherlands has diabetes. Kidney failure can be caused by diabetes when the diabetes is not controlled for several years.²⁵⁷

Other groups have indirect higher risks; groups which have greater risks on diabetes and high blood pressure. People with overweight are in this group.²⁵⁸ These people have higher risks on diabetes and high blood pressure and therefore it could be possible that they have indirect higher risks on kidney failure.

²⁵⁶ UMC Utrecht, Informatie Nierziekten, at: <http://195.109.25.12/afdeling/overzicht/overzicht.asp?dep=29&mmid=167, 07-04-2007>.

²⁵⁷ Diabetes Mellitus, at: http://www.astrazeneca.nl/patienten/hart_vaten/diabetes.asp, 01-04-2007.

²⁵⁸ Voedingscentrum, at: http://www.voedingscentrum.nl/voedingscentrum/Public/Dynamisch/gewicht+en+dieet/overgewicht/gezondheidsrisico___s/, 01-04-2007.

It is important that groups with higher risks are more preventative controlled if kidney failure develops. The Dutch Kidney Foundation has in November 2006 initiated to bring this problem under attention of the Dutch general practitioners. In practice only few people with diabetes and high blood pressure are annually controlled at kidney failure. At the moment only 40% of diabetic patients and 25% people with high blood pressure are controlled by the general practitioners.²⁵⁹

A good preventive solution is that patients with higher risks are annually controlled on kidney failure by general practitioners. This is important because half of the dialysis patients in the Netherlands are diabetic. That group, if they are controlled well, could be prevented. With early control of high risk groups the amount of people that get kidney failure could be decreased. At this moment there is less attention for preventing kidney failure although it could decrease the amount of patients that needs dialysis or transplantation.

6.7.7 Legalize kidney sales

Legalize kidney sales is the second solution that the respondents did not mention but that is discussed by scientific researchers. When kidney sales would be legal there are two possibilities to arrange this:

- The market
- The government

There is quite some research done for the possibilities of a legalized kidney market. Some researchers even calculated prices and supply of kidneys.

At the moment there is one government in the world that arranges paid unrelated living kidney donation and that is Iran. None of the respondents mentioned this as a solution and the respondents that were asked if they would favour this option were against it.

The prices for a kidney by a market

One of the suggestions to solve the (international) kidney shortage is to create a regulated kidney market; allow the sales of living kidneys. This kidney market should be regulated by the government. Different researchers proposed to allow kidney sales.

The prices that donors should receive for a kidney differ between \$7.663 till \$45.000. The \$45.000 is based on the following assumptions:²⁶⁰

- A donor has a life value of 3 million dollar based on an annually income of \$40.000.
- The risk of death by the surgery is 1%
- The quality of life will decrease with 5%
- The loss of income because of the recovery time from surgery will be \$7.000.

Becker & Ilias (2003) calculated the following kidney prices with different life values. These life values are calculated on base of income.

²⁵⁹ Nederlandse Nierstichting, Persbericht, Nierstichting ondersteunt huisartsen in preventie en behandeling nierziekten, Bussum, 30-11-2006.

²⁶⁰ Becker & Ilias, Introducing incentives in the market for live and cadaver organ donations, at: Conference on Organ Transplantation: Economic, Ethical and Policy Issues, University of Chicago, May 16, 2003.

Price of Organ	Value of Statistical Life	Risk of Death	Risk of Death Component	Quality of Life Component	Value of Time ⁽¹⁾	% Change in price ⁽²⁾	% Change in Total Number of Transplants ⁽³⁾
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
(c) + (d) + (e)	(a)	(b)	(e) = (a) * (b)	(d)	(e)		
Kidneys							
\$7,663	\$2,000,000	0.001	\$2,000	\$2,971	\$2,692	4.8%	52%
\$10,149	\$3,000,000	0.001	\$3,000	\$4,457	\$2,692	6.3%	49%
\$15,121	\$5,000,000	0.001	\$5,000	\$7,429	\$2,692	9.5%	44%
\$20,092	\$7,000,000	0.001	\$7,000	\$10,400	\$2,692	12.6%	39%
\$27,549	\$10,000,000	0.001	\$10,000	\$14,857	\$2,692	17.2%	32%

Source: table 3, page 42, Becker & Lias, Introducing incentives in the market for live and cadaver organ donations Conference on Organ Transplantation: Economic, Ethical and Policy Issues, University of Chicago, May 16, 2003.

Figure 7 Prices of a kidney

Based on their calculations the prices of kidneys will range between \$7.663 and \$27.549. The creation of kidney sales will increase the number of transplants between 52% and 32%.

It is also possible to regulate the market by a bidding system; a kidney auction.

There are different arguments that are in favour of (regulated) living kidney sale:

- It increases the number of available kidneys. An increase of kidneys will shorten the waiting time and will improve the patient's survival rate.²⁶¹
- Black organ markets do exist already and regulations to prevent it do not work. Therefore is it better to regulate it.²⁶² There seems to be a demand for kidneys and people are willing to pay for a living kidney. Next, people are willing to donate one kidney if they get paid a certain amount of money.
- The liberal claim of the individual over his own body.²⁶³ An individual has autonomy over his or hers body and therefore there should not be paternalistic measures to prevent the individual to act. The individual has the right to choose whether he or she wants to donate or sell organs.
- Other people involved in the transplantation process such as the surgeon but also the person who allocates the available organs does get paid for their job.²⁶⁴ So why not the donor should get paid while he is also contributing in the transplantation process?

There are also arguments against kidney sale which are partly mentioned in paragraph 2.4:

- Exploitation of the donor.²⁶⁵ The (poor) donor overcomes not poverty as a result of the sale. In some cases income declines and the donors stay in debt.²⁶⁶
- Unequal allocation system of organs because poor recipients who are unable to pay for it are dismissed from the market.
- Paid organ donation prevents a national cadaver transplant program from being established or decreases the amount of cadaver donations.²⁶⁷

²⁶¹ A. Matas, the case for living kidney sale: rationale, objections and concerns, in: *American Journal of Transplantation*, 2004;4: 2007-2017, page 2009.

²⁶² A. Matas, the case for living kidney sale: rationale, objections and concerns, in: *American Journal of Transplantation*, 2004;4: 2007-2017, page 2009.

²⁶³ A. Matas, the case for living kidney sale: rationale, objections and concerns, in: *American Journal of Transplantation*, 2004;4: 2007-2017, page 2009.

²⁶⁴ Delmonico, F., Schepers-Hughes, N., Why should we pay for human organs, in: *Zygon*, volume 38, number 3, September 2003, page 692-693.

²⁶⁵ Hoyer, P., Commercial living non-related organ transplantation: a viewpoint from a developed country, in: *Pediatric Nephrol*, 21, 2006, page 1366.

²⁶⁶ Goyal, M., Metha, L., Schneiderman, L., Seghal, L., Economic and health consequences of selling a kidney in India, in: *Journal of American Medical Association*, Volume 288 13, 2002, pages 1589-1593.

²⁶⁷ Hoyer, P., Commercial living non-related organ transplantation: a viewpoint from a developed country, in: *Pediatric Nephrol*, 21, 2006, page 1366. & Phadke, K., Anandh, U., Ethics of paid organ donation, in: *Pediatr Nephrol*, Volume 17, 2002, page 310.

At the moment the current view is that kidney sale or organ sale in general should not be allowed. For instance the World Medical Association, the WHO and the Transplantation Society have spoken against organ sale.²⁶⁸ But the discussion, especially in the United States, opened because of the growing shortage of organs.

The Iranian kidney sales model

At the moment only Iran has a regulated kidney sale model. In 1988 the Iranian government implemented “a government-funded, -regulated, and -compensated living-unrelated donor renal transplantation program.”²⁶⁹ The government decided this after that a lot of patients went, governmental-funded, abroad for a kidney transplantation. This was very expensive for the government because the amount of patients grew quickly. At that moment there was in Iran no cadaver organ transplantation program. And it did not seem to be an option for the near future. Living kidney donation was allowed in Iran. The amount of transplantation centres was expanded from 2 to 25 after implementing the kidney sale. The kidney waiting list is completely eliminated.²⁷⁰ Iran is the only country in the world which has eliminated the waiting list.²⁷¹ It should be mentioned that in a developing country as Iran not all people that have kidney failure are diagnosed or treated because they live in villages where such medical services are not available.²⁷²

Of the total amount of kidney transplantation 78% is by living kidney donation. The process of kidney transplantation in Iran is as followed:²⁷³

- 1) The doctor advises the patient to have living related donor instead of unrelated living donor. In Iran there is only one hospital, Shiraz University, which has an active cadaver donor program. This hospital advises his patients to wait for 6 months for a cadaver kidney donor.
- 2) When a living related donor is not available the patient needs to subscribe at Dialysis and Transplant Patients Association (DATPA).
- 3) Also potential donors can subscribe at DATPA and then a match will be made between donor and patient.
- 4) There is no broker or agency involved in the allocation of kidneys and the hospitals or patients do not receive any money to bring in potential donors.
- 5) In Iran only university hospitals conduct kidney transplantations and the government pays for the whole kidney transplantation including the fees of doctors etc.
- 6) The government provides the donor an award and health insurance after the kidney transplantation. It also pays partly for the medication.
- 7) The patient will pay the donor a reward which is determined by the DATPA. For patients who can not pay this reward is there different charity organisations which can help.
- 8) Medication for the patients is heavily subsidized by the government and charity organisations can pay for these medications for poor patients.
- 9) The whole system is monitored by the Iranian Society of Organ Transplantation.
- 10) It is not allowed for foreigners to get organ transplantation in Iran. It is only possible, with mandate, to have transplantation when both patient and donor have the same nationality.

²⁶⁸ A. Matas, the case for living kidney sale: rationale, objections and concerns, in: American Journal of Transplantation, 2004;4: 2007-2017, page Page 2007.

²⁶⁹ Ghods, A & Savaj, S, Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation in: *Clin J Am Soc Nephrol* 1: 2006, page 1137.

²⁷⁰ Ghods, A & Savaj, S, Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation in: *Clin J Am Soc Nephrol* 1: 2006, page 1137. & Daar, A., The case for a regulated system of living kidney sales, in: *Nature Clinical Practice Nephrology*, November 2006, Volume 11 number 2, page 600.

²⁷¹ Daar, A.S., The case for a regulated system of living kidney sales, in: *Nature Clinical Practice Nephrology*, Volume 2, Number 11, November 2006, page 600.

²⁷² Ghods, A & Savaj, S, Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation in: *Clin J Am Soc Nephrol* 1: 2006, page 1139.

²⁷³ Ghods, A & Savaj, S, Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation in: *Clin J Am Soc Nephrol* 1: 2006, pages 1137-1138.

Chapter 7 Analysing the empirical information

In this chapter the empirical information is analysed by the rationalities which were formulated in chapter 3.

In the case of transplantation tourism the following rationalities were formulated:

- 1) Ethical analysis
- 2) Social determinants
- 3) Economic determinants
- 4) Medical treatments
- 5) Political factors
- 6) Current status of policy
- 7) Policy solutions

The analysis described in this chapter is in order of the rationalities above.

7.1 Ethical analysis

For the ethical analysis the utilitarian approach is used. The following steps need to be followed:

Steps	Definition
1) Consequentialism ↓	The consequence of an action makes the action right or wrong.
2) Happiness ↓	An action should gain the total sum of happiness.
3) Aggregationism ↓	All people are equal and the interests of the people are weighted equally.
Judgment on moral dilemma	An action is morally right when the consequence of the action rises the welfare/happiness of the total sum when the interests of people where taken equally.

Table 1 Utilitarian approach

The basic idea is that of consequentialism; the consequence of the action makes it right or wrong. An action is right if the total sum of happiness gained. In the case of transplantation tourism it is difficult to distinguish the total sum due to the fact that people go abroad. In this case you can't speak of total sum as the Dutch population because a very large amount of the population is not involved in this matter. On the other hand, you can argue that everybody has the risk to develop kidney failure, especially some higher risk groups, and in that way the whole population is a potential patient. This analysis is not focussed on a philosophical discussion about whose happiness should be analysed.

The focus is on kidney patients and paid unrelated living kidney donors. It is a small and distinguished group which is examined.

The first step is to make an overview of the consequences of transplantation tourism. These were presented in paragraph 6.3. From the empirical information the following conclusions can be made:

Donors in India

- A large amount of paid unrelated living kidney donors does it only for the money. The biggest group used the money to pay of their debts.
- Helping a sick person is not the main reason to donate a kidney.
- The economic status of the donors decreased after they sold their kidney. Also the amount of donors below the poverty line increased after the surgery. A possible explanation could be that donors are not well informed about the consequences. Often they don't receive the money they are promised and

also the medication they need during the after care is on the bill of the donors. In this way the organ donation costs more than that it gains.

- The majority of the donors reported a declined health status after the surgery. This could be explained by the fact that donors are mostly not informed well about the surgery, risks and complications. Also the after care for donors is not sufficient; often they don't receive good medications.
- The majority of the donors wouldn't recommend paid unrelated living kidney donation.

Patients from United Kingdom

- There is no waiting list; sometimes patients can be helped within a couple of weeks. While in the Netherlands and the United Kingdom the waiting lists for kidney transplantations are long. Although it must be mentioned that this is only for cadaver kidneys for living kidneys there is not a waiting list; you need to find a compatible donor.
- The quality of life will be improved very much when the operation succeeds. Although dialysis is available in Western countries this treatment limits your freedom of movement and also complications can occur if you dialyse for a long time.
- The survival and graft rates were lower compared with patients who had surgery in Western Europe.
- The risks on complications and death are higher with patients who travelled abroad than patients that were operated in Western countries. This is partly caused by the fact that some of the patients were removed from the waiting list; their condition was too severe to undergo kidney transplantation. Next, the rate of infections or bacterial diseases such as Hepatitis B and C and HIV/AIDS in India must be higher than in Western countries.

Based on this information the second step is to judge whether the total sum of happiness increases. This overview shows that there are for both the donor and the patient high risks that the situation will deteriorate after the surgery. If donors are well informed they probably wouldn't do it that easily but in the case of the patient it is difficult to say. Most patients are for a long time on dialysis and their quality of life is lower compared with other people or people with kidney transplantation. If you are already waiting for years it is difficult to think clear about the consequences of such surgeries. In some cases it is even a matter of life or death; "*what would you do?*"

But examine the different researchers in most cases the both donors and patients' happiness will not increase and perhaps it can be said that it decreases. Therefore transplantation tourism is unethical. Although you can't blame desperate patients that they travel abroad to have kidney transplantation; governments have to make sure that patients don't even have to consider it.

Another issue that plays a role is the fact that paid organ donation is forbidden in the home countries of the patients. Is it justified to let patients travel abroad in order to pay donors while in the home countries paid organ donation can't be even discussed? What is the difference to have paid organ donation in India or in Europe? Also from this point of view transplantation tourism is unethical.

This analysis focussed only on donors and patients but there is another important fact to also mention. When Western patients travel to India to buy a kidney those kidneys can't go to Indian people. Also Western patients are capable to pay higher prices than Indian people; the average income in India is much lower than in Western Europe. So, the kidney prices increase and Indian people can't afford it anymore. In India dialysis treatments are even more expensive than kidney transplantation; see paragraph 7.4. Dialysis in the Netherlands and the United Kingdom is covered by insurance but in India there is not an

insurance system. Those people that couldn't afford dialysis but could afford kidney transplantation are disadvantaged while kidney prices could rise when more Western patients travel to India. Although this research does not focus on the situation in India it must be mentioned that the behaviour of Western people also influence the domestic supply of kidneys in India. These consequences make it clear that transplantation tourism is for even broader reasons unethical. Opponents could argue that perhaps in India the kidney supply for domestic use declines but that the kidney demand in Western countries would decline and in fact nothing change. The utilitarian approach would not agree with this because all people are equal and the total amount of happiness would not increase while the suffering would be much more.

7.2 Social determinants

In paragraph 3.3 following social determinants were described:

- Social environment
- Social class
- Income
- Education

It is for both donors and patients difficult to find data about their social environment, social class, income and education.

The empirical information shows that it is almost impossible to say anything about the social determinants of the patients. During the research it became clear that there is little known about patients who travel abroad for paid unrelated kidney transplantation. This was confirmed by the interviews. Even about the amount of patients that went abroad is big uncertainty. Also for the United Kingdom exact figures are unavailable; only from individual doctors.

An explanation for this information lack is that, and respondents confirmed that, transplantation tourism is something that occurs in a grey area. Patients who went abroad will not go public about that because the main opinion in Western Europe is that it is unethical. A second explanation could be, given by some Dutch respondents, is that there is not a problem. They stated that the amount of Dutch patients that go abroad is very low and can be neglected. But in this case it is guessing; no reliable figures are available.

There are no hard data about patients but some careful statements can be made. It is clear that health insurance companies do not compensate paid unrelated kidney transplantation. Both in the Netherlands and the United Kingdom paid organ donation is forbidden and health insurance companies can not compensate something that is forbidden by law.

Therefore patients must be capable for paying the whole trip by themselves. These prices, depends on different factors, are quite high. So, probably patients with quite some money can afford it or patients take a loan. This latter seems to be less logical but could be possible. It seems to be that this is the only thing that can be carefully said about patients.

The empirical information has more but not complete information for the donors. During one research donors were interviewed before and after the kidney donation. The average annual income was before the donation \$660 and after the surgery \$420. The average GDP in India is \$450 annually. So, the income of the donors was before the surgery above the average GDP income.

Before the donation 54% of the donors lived below the poverty line and after the surgery that was 71%. The donors were promised to receive an average of \$1.410. In the end they actually received \$1.070.

Although research does not specific mention social class and social environment it is expected that the donors are from lower social classes. India has still a caste scheme and it

is expected that most of the donors are in the lower castes. Especially the one's who live under the poverty line. The low income indicates that the donors live in lower social classes.

7.3 Economic determinants

In paragraph 3.4 two systems are described in order to allocate supply and demand in health:

- The market
- The government

One of the solutions of the kidney shortage that is mentioned by some researchers is legalizing kidney sale. This is a very discussable issue although there seems to be, in line with the growing organ shortage, more and more support to research these possibilities. If kidney sales would be legalized the allocation of kidneys can be arranged by a (free) market system or by the government. But in how must this be arranged and implemented? At the moment only Iran has a government funded kidney sale model. Perhaps kidney sale is not the right word while in Iran they call it compensation.

7.3.1 The market

Some authors suggest that kidney sale can be legalized and can be arranged by a free market. The government sets the legal framework in which kidney sales are allowed. An important element is control by a governmental institution or an organisation that is mandated by the government. For some people lack of control is the reason that they are against legalizing kidney sale. At the moment India can't control the implementation of the Transplantation of Human Organ Act while paid organ donation is forbidden it is a normal practice. How can poor donors be protected when kidney sales is allowed? In the latter it is even more important to control regulations in order to protect the donors. But when the circumstances exist it could be possible that kidney sale by a market might work. But how are prices formed? Becker & Ilias (2003) calculated, based on income and life value, the prices that people want to receive for their kidney. It is clear that there is a positive correlation between income and the price of a kidney. The supply of kidney is highest by people with a lower income (see the table in paragraph 6.7.7) and decreases when the income rises.

Another system could be that of bidding; the highest bid "gets the price". It would be something like a kidney auction.

In paragraph 3.4.1 conditions to establish a free market were described. This table presents in what degree a kidney sale market could apply to these conditions:

Condition	Case of kidney sale
Same product is sold by many producers.	True, everybody sells the same product: kidney. But a kidney must match with the receiver and some patients are difficult to match then others.
No restrictions for entering the market.	Partly true, not everybody can be a donor. If you have certain diseases it is not possible to donate. Also people with bad condition are not capable of donation. But this depends if there is control; if there is no control probably everybody would donate also people with diseases or bad condition (see in India were patients from abroad have higher infections and death rates.)
Existing producers do not have advantage over new producers.	Not true, you can only sell one kidney once. Once you sold your kidney you are out of the market.
Both producers as the purchasers are well informed about the prices.	This depends. It is very difficult to calculate what the right price is. Can it be calculated? It depends on what the donor wants to receive and what the purchaser is willing to pay.

Table 7 Kidney sale and market conditions

The kidney sale does not meet all the conditions that are necessary to establish a free market. If a market is possible it must be regulated by the government while it has not all necessary conditions of a free market.

The following arguments are used in the discussion about kidney sales arranged by a market:

Arguments in favour	Arguments against
Increasing the number of kidneys.	Exploitation of the donor.
Regulation of black market failed; better to regulate a market because there seems to be need for kidneys and people are willing to pay.	Unequal allocation system of organs because poor people are not able to pay the price.
The liberal claim of the individual over their body.	Paid organ donation prevents the establishment of a nation cadaver transplant program.
Other people involved in transplantation process also get paid so why not the donor?	

Table 8 Arguments kidney sale

The main arguments in favour are quite clear. These arguments are formulated from a liberal market point of view. The most important argument they use is that the number of kidneys increase but this is also the case in voluntary living kidney donation. Would it even increase more with paid living kidney donation?

The main arguments against are exploitation of the donor. The calculations of Becker & Ilias show that people with a lower income are more willing to donate a kidney for money. It can be expected that in a free kidney market people with low incomes are more willing to donate a kidney for only the money. The question is: *“are these people capable in judging the consequences of selling a kidney?”* The research in India showed that people who sold their kidney were less healthy and in lesser economic circumstances afterward. By legalizing kidney sale the poorer people can't be protect.

The second main argument is that a kidney sale is an unequal allocation system while not everybody is capable in paying the price. This is especially true for an auction system were the highest bid gets the kidney.

It is very difficult to assess the consequences of a free market of kidney sales. Although within the free market the variant of auction seems less favourable here the highest bidder wins and poorer people that need a kidney are not capable to bid high and the changes that they bid high enough is small. An auction system is therefore an unequal system and not ethical because every kidney patient should have the same changes to buy a kidney. Perhaps a free market system with fixed prices and governmental regulation is possible. Then the poorest people would not be capable to pay the prices. In such a system it could be possible that health insurance companies compensate the kidney sale. In the Netherlands and the United Kingdom the laws need to be revised. It is quite clear that this will not happen because the countries are against organ sale.

At the moment the current international view is that kidney sales is unethical. For instance the World Medical Association, the WHO and the Transplantation Society have spoken against organ sale. But in some countries, for instance the United States, the discussion is opened by the growing organ shortage.

7.3.2 The government

In paragraph 6.7.7 the Iranian kidney sales model was described. In this model the government compensates the kidney donor and receiver can pay the donor extra. This model is constructed in such a way that also poor people are capable to compensate the donor because charity organisations help. In Iran there is no kidney shortage although it must be mentioned that people in rural areas are not included; it is possible that a group of people with kidney failure are excluded.

The process of kidney transplantation in Iran is as followed and was previously described in paragraph 6.7.7. This model is constructed well and the government has an organisation that controls it. It is not strange to compensate the donor in a certain way. In most countries the donation is completely voluntary. The operation and medication of the living donor is for the health insurance company of the patient but most of the times a donor work. The lost income is not compensated and donors have to discuss this matter with their boss. Donors are not able to work for a couple of weeks and the lost income is perhaps compensated by employee insurance but the boss will lose a valuable employee. Most people would say that a boss should help his employee for doing such a noble thing but another way is to compensate the living donor for lost income. This is even more important with people who run their own (small) business. Most of the case those people are not insured and for them is one day not worked no money.

In the Netherlands and the United Kingdom such a model has not been discussed. The overall view is that any compensation with money that goes direct to the donor is unethical. People should donate their organs completely voluntary. There is something to say about this but on the other hand it is strange that a citizen has to pay (the donors does not receive income) indirect for another citizen because of goodwill.

7.4 Medical treatments

In paragraph 3.5 different questions were formulated in order to judge which treatments are the best for the patient. In paragraph 6.2 the medical treatments were described. With this information the table in annex 4 can be made. Analysing this table the conclusion is that kidney transplantation is, when the patients can have surgery (in some cases this is not possible), the best solution. The quality of life of patients that had a surgery in Western country increases after the operation and when the kidney is not rejected patients do not have to bother for almost 20 years although after care and control is needed. Within kidney transplantation the best results are made with a living kidney donor. For the patient this would be the best option. But during the interview all the respondents made it clear that they see living kidney donation as a temporary or last solution. They rather see that there are enough cadaver kidneys. Although the risks for a living kidney donor are quite low the respondents all agree that a healthy person needs to undergo surgery and it is better not to. Therefore cadaver kidney transplantation is the best option also because the survival rate of kidneys and the years a kidney functions are improved and perhaps more improvement can be expected in the future with better medical techniques. The quality of life of patients that had paid unrelated living kidney donation in India decreased. This is discussed later.

Dialysis is also a treatment but in the long term it is quite a burden for the patient. It takes a lot of time to do. Patients are constraint in time and freedom of movement. Next, how longer the period of dialysis takes how higher the risks on negative side affects such as infections. The last negative side affect is that although a dialysis machine filters the blood it can't take over the function of the kidney. A lot of dialysis patients feel tired because of this.

The overview in annex 4 shows that kidney transplantation is the best solution for patients with kidney failure. This is in the case when Dutch or British patients are helped in their home country. Within kidney transplantation the preference is for cadaver kidneys although the results of living kidneys are better. But in the availability of cadaver kidneys the figures show

that there is a long waiting list; other treatments do not have such a long waiting list. Here the problem of the cadaver kidney shortage is very clear; the best solution but not enough supply.

Treatment of kidney failure in India

In paragraph 6.6.2 the costs and availabilities of the two forms of dialysis: hemodialysis and peritoneal dialysis were described. The following table summarizes this information.

Short of dialysis	Capacity	How many patients are treated	Costs per year	How many times GNP per capita?
Hemodialysis	5.000	-	-	-
o public	1.667	-	\$ 1.040- 1.560	2,3 – 3,5
o private	3.333	-	\$ 2.500- 3.500	5,6 – 7,8
Peritoneal	300	Less then 2 000	\$ 4.200	9,3

Table 9 Dialysis in India

Paragraph 6.6.3 described that there are approximately between the 80.000 – 100.000 new patients with kidney failure per year in India; on average this is 90.000. Of them 5% receive kidney transplantation which is 4.500 people per year. Below is presented the average % of the two forms of kidney transplantation conduct in India: living related and unrelated. The amount of cadaver kidney transplantation can be neglected because only 2%, which is 90 per year, of the total kidney transplantations is with a cadaver kidney. The average GNP per capita is \$450 per year. The costs of the medicine after the surgery are around \$250 per month but it is possible that this decrease because of replacement by cheaper medicines.

Short of kidney transplantation	% total of kidney transplantations	Amount of treatments conduct	Costs of treatment	How many times GNP per capita?
-	100%	4.500	-	-
Living related	35%	1.575	\$700-800	1,6-1,8
Unrelated	65%	2.925	\$6.000	13,3

Table 10 Kidney transplantation in India

A comparison of the different treatments shows that kidney transplantation is the best option in India because of the lack of insurance or government funded medical treatment. Most patients with kidney failure can only afford dialysis for a short period and this is not a long term solution. Although the costs of dialysis in Western eyes are low compared with the GNP per capita of \$450 in India it is very high and most patients can not afford it. Most patients depend on the possibility of kidney transplantation.

7.5 Political factors

Both in the Netherlands and the United Kingdom political parties were contacted.

In the Netherlands five of the ten political parties responded and three political parties stated that they did not have time to respond. Only one of the five political parties did not know the phenomenon of transplantation tourism. The other parties did know it. They were all against it and the solutions they gave in order to prevent transplantation tourism focussed on increasing the amount of potential donors. Interestingly it became recently clear the less Dutch people are willing to donate their organs. It is important that it is researched why people are less willing to donate their organs in order to try to stop the decrease of the amount of potential donors. One political party stated that transplantation tourism is something that can not be stopped; you can't force people to stay in this country they are free to move. This political party initiated that it is better to start to inform people who want to go abroad about the risks of paid unrelated organ transplantation.

7.6 Current status of policy

In this paragraph the current status of policy on transplantation tourism in the Netherlands, the United Kingdom and at European level are described. Interestingly at the European level there is more awareness of the problem of organ trafficking and transplantation tourism than at country level.

The Netherlands

During the interviews in the Netherlands it became clear that there is no overview of the scope of the problem of transplantation tourism towards India. There is at the moment no policy developed to stop and prevent transplantation tourism. It is known that in 2003 3 patients went abroad for kidney transplantation; it is unknown if it was paid unrelated kidney transplantation. In that year 84 patients were removed from the waiting list for other reasons; it is possible that some of these patients also had kidney transplantation abroad by paid unrelated kidney transplantation. There is no hard data if transplantation tourism towards India by Dutch patients exists and how many patients it concerns. All the Dutch respondents are familiar with transplantation tourism and know the incidents but they can't give any concrete data.

The reason that there is no policy is because there are no figures. The Dutch government does not see any problems because there are no hard figures till that moment the government will not take any action to prevent it.

There are initiatives from the government to increase the amount of donor registrations but still this is quite low. The government is also aware of the organ shortage.

Here is a vicious circle; the government will not take action without figures but without government action figures will not be available. Research is necessary in order to examine if transplantation tourism in the Netherlands occurs and in what extent. Only then a good decision can be made; if action is necessary or not. At the moment it is just guessing.

One possibility is to introduce a registration requirement for transplantation doctors. With such a requirement doctor's report every year how many patients went abroad for paid unrelated kidney transplantation. Only the number is reported and in this way the secrecy a doctor is not be violated. For some infection diseases this already happens. In this way it is easily examined if there is a problem and in what extend.

The United Kingdom

The same situation exists in the United Kingdom. Here there is also no policy to stop and prevent transplantation tourism. There is a difference with the situation in the Netherlands; in the United Kingdom some doctors went public with the problem. A couple of doctors has published in scientific journals about the results of paid unrelated kidney transplantations that some of their patients had undergo. In the case of the United Kingdom it could be said that there is a problem. A reason that here more patients go to India is due to the fact that the United Kingdom and India have a historical relationship. In the United Kingdom a large amount of Indian people live and when those people get kidney failure it is understandable that they know the way to unrelated paid kidney transplantation in India. The research of the doctors did not mention anything about ethical background so this is an assumption.

European Union

At European Union level there is some action but no concrete decisions are made. At the moment there are two ways in which transplantation tourism can be placed. On one hand it can be seen as transnational crime although it is hard to say if that is true because it is conduct not in the European Union but outside its borders. The Framework Decision of 2003 does not include the removal of organs as trafficking of human beings. But the UN Trafficking Protocol does.

The European Parliament Committee Citizen's Rights, Justice and Home Affairs has written a report to stop organ trade. This was after an initiative of the Hellenic Republic for a Council Framework Decision. In this report organ trade is seen as transnational crime. The consultative report of the Committee was send to the European Council. In the Council

countries couldn't agree unanimous and nothing happened yet. So, at the European level there seems to be disagreement about the fact if organ trade is a transnational crime or not. At the moment the European Commission and Council don't see it this way.

It is very difficult to define organ trade while it can happen in the EU but also outside the EU were EU citizens buy an organ. There is also a difficult question to answer: *"how can you punish someone for a desperate action to save his or hers life?"* People wouldn't travel outside the EU when there are enough organs available. So, it is quite difficult to justify this.

The main reason why is it difficult to see transplantation tourism as organ trafficking and as a transnational crime is that it happened across the borders and most of the time (although this is difficult to prove) the donor itself is behind the decision to sell one kidney. As long as there are people voluntarily selling their kidney it is difficult to punish the patient. Perhaps this is legal not possible; this is a complex and different research and not examined in this master thesis.

A second trace at the European level which is active on organ donation is the European Commission. This is in a begin phase because the European Commission has only organised an open consultation with professionals, academics and others which are active in the field of organ transplantation. The main conclusion of the congress was that there are major worries about the organ shortage. Also the problem of transplantation tourism was highlighted. In order what kind of action the EU could take the contributors chose for: *"To strengthen coordination between Member States, consider minimum harmonisation on quality and safety to complement and reinforce these actions through a directive, and in addition an initiative on organ trafficking."*²⁷⁴

At the moment no further actions are made public. This is possible because the report of the open consultation was published in December 2006 and the writing of this research was in March 2007.

It is interesting to see that at the European level both Parliament and Commission are active but both in different areas. In the case of transplantation tourism it is probably wiser to arrange policy or regulations within the area of health. It seems to be much more difficult to arrange transplantation tourism in the area of transnational crime while there could be discussion if it is a transnational crime. In the UN Trafficking Protocol organ trafficking is a transnational crime but it is not in the EU Framework Decision of 2003 which used the definition in the UN Trafficking Protocol as starting point.

Second, transplantation tourism can't be seen as a problem on its own; it is connected to the organ shortage. Organ shortage is part of the organ donation policy which falls within the health area. Therefore it is better that transplantation tourism becomes part of concern in the field of the organ donation policy. Danger is that the European Commission or member states let it out but it is a good starting point that the problem of organ trafficking was mentioned by the contributors of the open consultation. It seems inevitable that organ trafficking and transplantation tourism are neglected in the further process. At the moment it is difficult to say anything in which direction this will go; it could be possible that it ends on the table likewise the Hellenic Republic initiative in order to stop organ trafficking.

7.7 Policy solutions

In chapter 6 different policy solutions were described here they are analysed and it is examined if the policy solutions could have political support.

The following solutions are discussed:

- A different donor registration system
- Living kidney donation
- Cooperation in organ allocation in the European Union

²⁷⁴ European Commission, Directorate-General Health & Consumer Protection, "Report on the open consultation: policy options for organ donation and transplantation at EU level", december 2006, page 4.

- Registration requirement of doctors
- Medical code
- Prevention of kidney failure
- Allowing kidney sales by the market or by the government (Iranian model)

A different registration system

This solution was most mentioned by the respondents in the interviews. Both the Netherlands and the United Kingdom have the non-active registration system; people have actively give permission to become a donor. Another donor registration system is the presumed consent hereby people are automatically donor or they said otherwise. This is the opposite of the non-active donor registration system. A third system that is possible is active donor registration system. Here people are automatically donor but they have three choices instead of two (“yes” or “no”) in the presumed consent system. Here an overview of the three described systems:

Donor system	Features	Advantages	Disadvantages
<i>Non-active</i>	<ul style="list-style-type: none"> - You are not donor or you decide otherwise (fill in a donor form) - You have three choices: <ol style="list-style-type: none"> 1) You become donor 2) You are not donor 3) You let your family or partner decide. - It is possible to decide which organs and tissue you exclude from the donation. 	<ul style="list-style-type: none"> - It is really a voluntary choice when people become a donor. - The donor system is major support for in the Netherlands and the United Kingdom. - Within the systems are perhaps changes possible. 	<ul style="list-style-type: none"> - Not enough donors. - People are dying while they are waiting for an organ. - People who wish to be a donor but who don't fill in a donor form are missed.
<i>Presumed consent</i>	<ul style="list-style-type: none"> - You are automatically donor or you decide otherwise (fill in a donor form) - You have the choice between “yes” or “no” 	<ul style="list-style-type: none"> - More potential donors. - Decrease of organ shortage. - Living kidney donation is less necessary. 	<ul style="list-style-type: none"> - Changes that people are not informed well and that they become donor without their consent. - System is more controversial; in the Netherlands this system didn't get enough votes in Parliament. - Costs of implementing a new system; public information about the new system etc.
<i>Active</i>	<ul style="list-style-type: none"> - You are automatically donor or you decide otherwise (fill in a donor form) - You have three choices: <ol style="list-style-type: none"> 1) You wish only to be donor of the organs and tissues that you agree to donate. 2) You don't want to be organ donor. 3) You wish that relatives or a specific relative decides if you become an organ donor or not. 	<ul style="list-style-type: none"> - More potential donors. - People are automatically donor but have more choices. - Decrease of organ shortage. 	<ul style="list-style-type: none"> - High implementation costs; public information about the new system etc. - Less black and white than other systems; can be confusing if there is no good public information campaign.

Table 11 Donor registration systems

Research shows that there is a lot of uncertainty about the effects of introducing a new donor system; it is difficult to calculate what their effects would be. It is clear that the system that exists at the moment in the Netherlands and the United Kingdom are not effective enough. Although there are some extra campaigns, which cost also money, there is not a significant

increase of donors. It is important that diverse organisations such as patient associations give information about organ donation especially with people who almost reach the age of 18 years.

It is considerable to research new possibilities within the current donor registration system and discuss the implementation of a new donor registration system. In 2005 there was in the Netherlands not enough support in Parliament but after the elections the Dutch political map has changed. Although the current Government has no plans to discuss the current organ registration system; it is not part of the coalition agreement but the Government parties.²⁷⁵ So the initiative should come from the opposition.

If a choice must be made between the new systems the system of the active donor registration has at the moment preference. This system is less controversial as the presumed content system but will increase the amount of post mortal donors. It is only important to keep in mind that implementing a new system must be done carefully and all different groups must be informed well; also groups which are difficult to reach such as analphabetic, people who don't speak Dutch or people who stay abroad for a longer time.

Living kidney donation

Allowing living kidney donation is mentioned as a temporary solution. All the respondents agreed that it is better that organs come for post mortal donors instead of living. Although in Western Europe the risks for the living kidney donors are low.

Within living kidney donation the system of the Living Donor Exchange List has been developed in the Netherlands. But a current publication of the Health Council of the Netherlands stated that this system is not in line with the current law and perhaps is even contradictory with the Dutch constitution (principle of equality). The development of the LDEL is an alarming signal that there are not enough kidneys available.

Both in the Netherlands and the United Kingdom living kidney donation is completely voluntary. The health insurance company does compensate the operation and after care of the living kidney donor but the loose of income is not compensated. Donors go then in the Sickness Benefits Act which obligates the employer to pay the loon during the sickness period. The boss of the donor must give his consent. In practice this will not give problems because almost everybody would agree that it is a noble thing to do but it is strange that a third person (a company) has to pay for the voluntary of another. It is not strange that the period of absent of the donor is also compensated in one way or another perhaps by the health insurance company or by the government.

It is unclear if this is in line with the current law in both countries and if such compensation is seen as paid organ donation which is illegal in both countries. More research must be conducted in order to examine this complex question if compensation in the loss of employment could be paid in another way then by a third party which is not involved in the living kidney donation. Such compensation could make it easier for people to decide to become of living kidney donor for their friend or relative while there is not a boundary where an employer could decide that it is not possible. Compensation of loss of income is even more important for people with their own (small) business while if they are not working they are not earning any money. It is unknown if such loss of income is been covered by insurance and which insurance.

Cooperation in organ allocation in the European Union

At the moment there is in different fields in the European Union action. In the case of transplantation tourism and the organ shortage it is logic that it falls within in the field of health. There was also action to stop organ trade which is defined by the European Parliament as a transnational crime but there was not unanimity in the Council. This track

²⁷⁵ CDA, PvdA & ChristenUnie, Coalitieakkoord tussen de Twee Kamerfracties van het CDA, PvdA en ChristenUnie, 2007, pages 39-43.

walks kind of death because formally it is still on the Council's table but in reality no action is expected in the near future. The European Commission has started with an open consultation in 2006; the report was published in December 2006. Professionals from the field of organ donation could give their opinion about organ donation policy in the European Union. The majority had the preference for strengthening the coordination between member states to develop a minimum requirement in the field of quality and safety and action to stop organ trafficking. At the moment there is no more information made public about the developments that will be made by the European Commission.

An overview of the different actions at the European level:

Level	Short of action	Stage of action
<i>European Parliament</i> Committee on Citizens' Freedoms and Rights, Justice and Home Affairs	Initiative for Council Framework decision.	Is on the table of the Council for some time; no further action expected in the near future.
<i>European Commission</i> Directorate-General Health and Consumer Protection	Open consultation over organ donation policy with different professionals from the field.	There is action but at the moment there is not more information made public.

Table 12 Action on the European level

It is considerable that member states would cooperate more with each other in order to stop organ trafficking, transplantation tourism and the organ shortage. At the moment Eurotransplant already arranges the allocation of organs in 6 countries and it should be possible that this would be extended to more countries are even the whole European Union. Probably the European Union is here not ready for but it is important that member states take action in order to stop transplantation tourism and the organ shortage. Most logical is that action is taken in the field of health in stead of the field of justice and home affairs while organ trafficking and transplantation tourism is linked to the organ shortage; it is not possible to see organ trafficking as just a transnational crime because the cause of organ trafficking is the organ shortage.

It is dangerous that at the European level different institutions in different fields are take different actions that in the end nothing can happen while there is no agreement or actions are taken which work contradictory. The best is that the problem of organ donation is arranged in the field of health but with consultation, coordination and cooperation with the field of justice and home affairs in the specific case of organ trafficking. The danger is that this makes the developing of a policy much more difficult because different fields need to cooperate but that is probably better then that at different fields actions are taken without being aware of the effects of the actions in other policy fields.

Registration requirement of doctors

In the Netherlands and the United Kingdom there is not a clear view how big or small the problem of transplantation tourism is. A good solution to evaluate the scope of transplantation tourism is a registration requirement of doctors. Hereby doctors report the amount of patients that underwent paid unrelated kidney transplantation abroad and they also report the amount of patients who had the plans to do that. With such are registration requirement the code of secrecy which a doctor has is not violated while only the amount is reported and no further information about the patients is given. Such a registration requirement is the first step to examine the scope of the problem and to monitor how it develops in the future.

Medical code

A medical code is more a symbolic solution while it does not take any action to stop transplantation tourism. Such a code only shows that transplantation doctors are against transplantation tourism and that they make all efforts to prevent that patients go abroad.

A medical code can be made by transplantation doctors. In such a code they declare that they are against transplantation tourism and that they will inform patients with plans do it on the risks of transplantation tourism. Transplantation doctors will inform patients on other possible treatments in order to prevent that patients go abroad for paid unrelated kidney transplantation.

The initiative of such a medical code must come for the transplantation doctors because they are the ones how can develop such a code; this is not a thing that the government can do for instance.

Prevention of kidney failure

One of the solutions to decrease the organ shortage is to decrease the demand of kidneys. Mostly the focus is on increasing the supply but there are also possibilities to decrease the demand. It is in the case of chronic kidney failure possible to discover it sooner then now happens. Of a patient has acute kidney failure this is not possible although it is possible that it is a temporary kidney failure.

It is very difficult to discover chronic kidney failure because the first complaints are general and are also common with other diseases. The Dutch Kidney Foundation has introduced a pre-test to examine the kidney function. People can order the test at the website of the foundation. The disadvantage of such a test is that not all kidney diseases are measured because the test measures the amount of protein; high level of protein can indicate kidney disease. But it is a start and people can do it at home and if people have doubts they can contact their general practitioner.

There are also risk groups which have higher changes to develop kidney failure. Two groups are diabetes and people with high blood pressure. It is important that those groups are monitored annual if there is change in their kidney function. At the moment this is not done enough; research has showed that not all general practitioners do this. It is important that risk groups are monitored annual because of lot of misery can be prevent if chronic kidney failure is discovered in an early stage. Another group that must be monitored is the group of overweighted people this group has higher risks on diabetes and high blood pressure and therefore indirect on kidney failure. In Western countries the amount of people that are overweighted or even obese is increasing rapidly and not only adults have it but also children. Also in public information the risks of being overweighted and risks on kidney failure must be highlighted more; at the moment there is not enough attention on that and probably most people don't know how kidney failure is caused and what the complaints are.

If there is not awareness that these groups have higher risks on kidney failure the amount of people that need kidney transplantation will even increase more in the future.

Governments must invest more in prevention and also in research that focus on the early discovering of kidney failure. In the Netherlands the prevention of kidney failure fits in the plan of the Government of the next years. In the coalition plan of the Government prevention in the field of public health is one of the pillars; although kidney failure is not explicitly mentioned.²⁷⁶ The prevention of kidney failure must be included and more awareness must be created under the public not only on the cause and risks of kidney failure but also on the consequences of it.

Legalize kidney sales

The last policy solution discussed in this master thesis is the most controversial one: legalize kidney sales. In Western countries legalizing kidney sales is not discussed and seems to be a non discussion issue. It can't be neglect that the last couple of years in the transplantation world a discussion have opened about this issue and especially in the United States there seems to be some advocates for it.

It seems to be that these described models of paid unrelated kidney donation are not received positive by the different actors. In the Western world there seems to be on one hand

²⁷⁶ CDA, PvdA & ChristenUnie, Coalitieakkoord tussen de Twee Kamerfracties van het CDA, PvdA en ChristenUnie, 2007, pages 40.

a hesitating attitude towards drastic measure in order to increase the organ supply but on the other hand everybody agrees that something should be done. One of the solutions could be legalizing kidney sales. Even in the Netherlands and the United Kingdom there are case known were citizens put advertisings on the internet to sell one kidney. But the question is: *“is kidney sales desirable and ethical correct?”* In the light of this master thesis the answer would be no while both the Netherlands, the United Kingdom and the European Union forbid it. Also within the different transplanted organisations the opinion is that kidney sales is unethical. Perhaps the first step is to discuss it within the transplanted world in order to see what the general opinion is. It is not recommended that Western countries themselves start this discuss while there are other policy solutions, several are described in this master thesis, which are possible and less controversial to decrease the organ shortage. Further, it is unclear what the effect of the legalization is on the cadaver organ donation programs that the different countries have. First, everything must be done in order to increase the amount of post mortal organ donors as long is not all the possibilities are implemented kidney sales should not be allowed. While it is so controversial and it has such a deep impact on how society looks at organ donation it must be discussed as the last solution. But it is the reality that there are academic researchers who are advocates of legalize kidney sales and this shows that there is a hurry for effective solutions to decrease the organ shortage.

If kidney sales would be discussable the model whereby the government regulates it seems to be most favourable. The government can then control and regulate the market this is important to protect the potential living kidney donors. It is expected that people with lesser income sell their kidneys sooner then people with more money; it must be prevented that poor people are exploited by other people because they live in less favourable circumstances. This task can be better conduct by the government then by the free market while the market has too often unexpected market failures and when people's life are at stake all risks should be excluded.

Discussion of the policy solutions

The next two pages is an overview of the different policy solutions with their features, the opinions and the changes on implementation.

The overview shows that there are different opinions about the solutions. The most important factor for a policy solution to be implemented is that there must be enough political support. In the case of transplantation tourism it is clear that there is not a lot of political support or even political awareness. There is more attention for the organ shortage. Policy solutions linked to the organ shortage have more changes get political attention and support. Based on this knowledge the following solutions seem to have the biggest change:

- New organ registration system; the changes for the active system are higher then for the presumed content system while the latter one is more controversial.
- Prevention of kidney failure
- Registration requirement
- Medical code; although it is a symbolic solution it can have some effect on patients who want to go abroad.
- Living kidney donation; although more attention must be on increasing the amount of post mortal donors. This is a temporary solution.

More cooperation at the European level is also a good solution but it is difficult to estimate what the changes are while some many factors are involved. Even if there is political support then that is no guarantee that something happen; see the initiative of the European Parliament in order to stop organ trafficking. But this is also a preferable solution because there is already a successful example that proves that cooperation between countries is possible; Eurotransplant.

The changes for the solution of legalize kidney sales are minimal. In Western Europe there is no support for such a system. Next, there are too many uncertainties of the effect of such a

system. Further it is important that first other solutions are examined and implemented before the legalization of kidney sales is discussed. At the moment there are enough other solutions which are less controversial and drastic. Legalize kidney sale must be seen as a last resort; if nothing else works. At last, this solution and the fact that this solution is mentioned by academics shows that there are big concerns about the organ shortage and that governments must take action or else patients will find other ways which are less ethical or unethical.

Solution	Feature	Opinion	Changes of implementation
<i>A different registration system</i>	<p>Presumed consent system: you are automatically donor unless you fill in a donor form. Only “yes” or “no” is possible.</p> <p>Active system: you are automatically donor unless you fill in a donor form and you have then three choices.</p>	<p>In both the Netherlands as the United Kingdom the presumed consent system does not enough support.</p> <p>The active system is not been discussed in both the Netherlands and the United Kingdom</p>	<p>Small while there is in both countries no support or enough attention for the matter.</p> <p>Unknown. Probably this system is less controversial then the presumed content system. Although there are disadvantages.</p>
<i>Cooperation in the organ allocation in the European Union</i>	<p>More cooperation at the European level in the allocation of organs; example is Eurotransplant.</p> <p>The same donor registration system in the European Union; presumed content</p>	<p>Professionals from the field are positive for more European cooperation. It is unknown what the opinion of the member states are. Probably they are hesitating for letting Europe arrange the organ allocation.</p> <p>This is probably not discussable at the European level because it is quite for going solution.</p>	<p>It is difficult to estimate the changes but most will agree that more cooperation is necessary. It will take probably quite some years before there is agreement about how this cooperation is arranged.</p> <p>It is expected that one donor registration system is something for in the far future.</p>
<i>Living kidney donation</i>	<p>Living Donor Exchange List (LDEL)</p> <p>Compensate the loss of income of living kidney donors</p>	<p>In the Netherlands it seems to be not in line with the law and even in controversy with the constitution. For the United Kingdom this is unknown.</p> <p>It could be in controversy with the laws of the both countries but that is unknown.</p>	<p>In the Netherlands is one hospital conducted such a list. The Minister has the report and it is uncertain what happens next. But if it is in controversy with the current law and the constitution the LDEL will not be implemented. In the United Kingdom is this not an option.</p> <p>There seems to be no action take implement such a solution. It is unclear at the moment if it is in controversy the laws of the countries.</p>
<i>Registration requirement</i>	Transplantation doctors report the amount of patients who go abroad for paid unrelated kidney transplantation	This is a good first step to evaluate how big the problem of transplantation tourism is.	This solution can be implemented with not a lot of problems.
<i>Medical code</i>	Transplantation doctors make a	It is a symbolic solution but can give a	It must be an initiative of the

	code were in they speak against transplantation tourism and they claim to inform their patients on the risks of it and to inform them about other possibilities.	clear picture of how transplantation doctors see transplantation tourism.	transplantation doctors themselves. In the United Kingdom the transplantation doctors seem to be more worried then in the Netherlands.
<i>Prevention of kidney failure</i>	Risks groups are monitored annual. Special attention for: diabetes, people with high blood pressure and overweighed people.	There is less attention for although it is a good solution which can prevent a lot of misery and money.	More attention and focus must be on this solution. It is a good solution while it is always better to prevent for both the patient and society as whole while treatments cost a lot of money.
<i>Legalize kidney sale</i>	Kidney sale is legalized. It can be arranged by the market or by the government.	In Western countries it is very controversial. When it would be discussable the governmental system is preferable. But at the moment there is only some discussion about it in the transplantation world itself.	None; it is better to examine and implement other solutions this is more a last solution; when nothing else helps.

Table 13 Policy solutions

Chapter 8 Conclusion and recommendations

This is the last chapter of this master thesis. The research and analysis has been done and now it is time to answer the main question formulated in the first chapter and to test the hypothesis formulated in the end of chapter 3.

8.1 Conclusion

In this paragraph the sub questions are answered in order to answer the main question:

“If and in what way do European countries react on the phenomenon of transplantation tourism for kidneys to India and what are the available policy solutions?”

1. Transplantation tourism

Transplantation tourism towards India is the phenomenon where people from Western countries, in this master thesis the Netherlands and the United Kingdom, travel to India to get paid unrelated living kidney transplantation. In this case the donor is unrelated and gets paid to donate one kidney by life. In Western countries this is forbidden by law.

Hereby different ethical dilemmas exist:

- The dilemma of paid unrelated organ donation.
- The right of the patient on treatment.
- Risks for both donor and receiver.
- The dilemma of the availability of organs for Indian people.

The main discussion is the part of paying someone for donating organs by life. Especially in less developed countries poor people are donating their organs by life for a very low price. The main reason is to get out of debts but research showed that most of the time they stay in debt and their financial situation gets even worse while the living donors don't receive the promised money, they can work less or not at all after the surgery and they have to pay themselves for the after care. The worry for exploiting poor people is one of the main arguments and ethical dilemmas in the case of transplantation tourism. The question is also: *“is the ethically correct that people travel abroad for paid unrelated kidney donation while it is in the home country forbidden and a non discussable issue?”* In Western countries paid unrelated kidney donation is a non discussable issue but is it then fair to let people travel from Western countries towards countries where it is more common?

Another dilemma is the right of a patient to receive a treatment. If there are not enough organs available in his or hers own country but they are abroad how can you deny someone to go abroad to improve their quality of life or even to save their life? A lot of kidney patients are on dialysis and this constraint the freedom of movement and the quality of life. If someone is waiting for four, five or six years it is logical that someone is searching for other possibilities to improve their life. The people who travel abroad can't be blame for that.

A third dilemma is the risks on complications for both donor and receiver. Research proves that for donors the risks are low but this is different in developed countries where medical treatments are less developed. In a lot of cases the condition of the donors decreased with the consequence that the donor was less able to work. Also for the patient there are risks; the risks on complications and infection diseases are higher with people who went abroad for paid unrelated kidney transplantation than for people who had surgery in Western countries. It is therefore important that patients are aware of the higher risks but also in this case; some people rather take that risk than that they die and in some cases that is the hard reality.

A last dilemma described in this research is the dilemma that kidneys which go to foreigners can't go to Indian people. In India the health care system is less developed and health insurance doesn't exist. Dialysis is for the average Indian people not affordable; they depend on kidney transplantation and most of the time they have to take a loan to afford it. If rich foreign people go to India and buy the kidneys those kidneys are not available anymore for Indian people. Next, there is a major change that prices raise because foreigner people can afford much more money and especially brokers will take advantage out of that. It is thus

no argument that the living kidney donors will benefit for it; research shows otherwise. The argument that more Indian people will sell their kidney and therefore there are enough kidneys available is probably not valid while these people will only sell their kidney for the higher prices which only foreigners or very rich Indian people can afford. So, transplantation tourism does not only affect donor and receive but also indirect Indian people.

Transplantation tourism is from a Western point of view unethical although you can't blame desperate patients that they travel abroad to improve their quality of life or in some case save their lives. The Western government must take such action that people don't have to travel abroad for organs. International organisations such as the WHO and the International Transplantation Society have spoken against kidney transplantation.

In both the Netherlands and the United Kingdom the phenomenon of transplantation tourism is known although no action has taken yet. It seems to be that it has not the attention to be on the political agenda. Further, transplantation tourism plays in a grey area and therefore there are no reliable figures. This gives governments the idea that there is not a problem although that has not been proven yet. There are simply no exact figures known. Organisations in the Netherlands and the United Kingdom in the field of organ transplantation are well aware of transplantation tourism and they know some incidents but also they don't have any reliable figures.

2. Organ donation policy

Both the Netherlands and the United Kingdom have a voluntary donor registration system. This is a system whereby people have to give their consent to donate organs after their death or else it will not happen (or the family has to decide otherwise). In practice not all the people above the age of 18 have filled in a donor form so there are a lot of potential donors who are not registered yet. In both countries there are not enough post mortal donors. In both the Netherlands and the United Kingdom living donation is allowed but only voluntary and there must be a clear relationship between donor and receiver. Paid organ donation or compensation is forbidden by law in both countries and there are penalties on it.

The ethical view in both countries is the same; organ donation must be voluntary in order to prevent exploitation. The choice for the voluntary registration system is also the same; people really need to donate their organs voluntarily and with a presumed consent system this can't be guaranteed. Although there are more people in both countries who wish to have a presumed consent system in order to increase the amount of post mortal donors.

It is difficult to say if transplantation tourism does affect the organ donation policy in both countries while there are no reliable and exact figures of it. But it is expected that the amount of people who go abroad is relatively small and that there is at the moment no huge effect on the organ donation policy. It is of course possible that when transplantation tourism more occurs or that the amount of people is high that there is an effect on the organ donation policy but it is difficult to say anything about what this effect could be and in what degree.

Since 1994 has India a new organ transplantation act. Before that paid unrelated living organ donation was allowed but by pressure of the international community India changed its law. Now paid organ donation is forbidden but in practice it does occur on a large scale. Corruption of the Authorize Committee which decided if unrelated living kidney donation is allowed makes it possible that paid organ donation still occurs. In India there are not enough control mechanisms which can prevent that the organ transplantation act is violated. Second, the implementation of the organ transplantation act is something of the states. States can decide if paid organ donation is forbidden or not in some states it is therefore not illegal at all. A third and important reason that paid living organ donation still occurs in India is that fact that a lot of professionals in the field of organ transplantation have the opinion that paid living organ donation is not unethical. In their eyes it is a possibility for poor people to get out of poverty and for patients to improve their life or even save their life. In practice research shows that poor people don't benefit in all cases.

Also India has a voluntary donor registration system but the amount of post mortal donors is very small comparing to the amount of living donors. In India a good cadaver transplantation program has never been established and some researchers agree that this will not happen because paid unrelated living kidney donation occurs.

3. Reactions and solutions for preventing transplantation tourism.

This research shows that at the moment no countries have developed a policy to prevent transplantation tourism. There is not enough attention for the problem while there are no exact and reliable figures. There seems to be the opinion of the governments and political parties that while there are no exact figures it probably will not occur in huge amounts. This is somehow comprehensive but on the other side the indication that people do go abroad is an alarm signal that there is something wrong in the countries. It is clear that transplantation tourism is an effect of the increasing organ shortage in the home countries and it is expected that this will increase in the future. At the moment there is not enough awareness of governments and political parties for the problem and effects of the organ shortage. It is even possible that in the near future the amount of people with kidney failure increase while more people are overweighted, even children, and those people have higher risks on diabetes and high blood pressure which are two causes of kidney failure.

Although there none of the countries have policy to prevent transplantation tourism there are some policy solutions possible:

- A different donor registration system
- Prevention of kidney failure
- Registration requirement of doctors
- Medical code
- Living kidney donation
- Cooperation in organ allocation in the European Union
- Allowing kidney sales by the market or by the government (Iranian model)

The solutions which have the best changes to be implemented are:

- A different donor registration system
- Prevention of kidney failure
- Registration requirement of doctors
- Medical code
- Living kidney donation

There is in a lot of countries discussion about a different donor registration system. Most countries have the voluntary system but this does not provide enough donors. The presumed content system is an automatically system but has some controversies. Another system is the active donor registration system which is a system that is automatically but where people have more choices then “yes” or “no”. Although this system has some disadvantages it seems to be the best solution to attract more donors.

A second solution, which seems to be the best one, is more attention and action in the field of prevention of kidney failure. At the moment most of the action is in the field of raising the amount of donors. It does not seem to be very effective and perhaps it is better to have more attention on the prevention of kidney failure. It is always better to prevent something then to cure it. More attention must be raised on the complaints and effects of kidney failure. Also high risks groups such as diabetes, people with high blood pressure and overweighted people must be controlled annual. In campaigns to warn people for overweigh not only the risks on diabetes, high blood pressure and heart- and vain diseases but also on the higher, indirect, risk on kidney failure. At last more research is needed to develop better research methods in order to discover kidney failure in an earlier stage and in order to find other treatments.

A good solution to collect reliable figures about transplantation tourism is a registration requirement of doctors. Hereby doctors report how many people went abroad for paid unrelated living kidney transplantation. In this way with a quite simple method reliable data can be collect. With a registration requirement only the amount of people are reported so in this way the privacy law and the confidential relationship between doctor and patient are respected.

A medical code is more a symbolic solution and is a solution of the transplantation doctors themselves. With such a code the transplantation doctors give a signal towards the world that they are against transplantation tourism and that they will try to prevent that patients will go abroad. Transplantation doctors inform their patients on the risks of paid unrelated living kidney donations and give other solutions to the patients.

Living kidney donation is a solution that already exists but it is seen as a temporary solution. In both the Netherlands and the United Kingdom living kidney donation is allowed but only when there is a relationship between the donor and patient this to guarantee that the living kidney donor is donating the kidney on a completely voluntary base. In the Netherlands an new system is developed the Living Donor Exchange List hereby patients who have a living kidney donor but which is not compatible can exchange their living kidney donor with somebody else or they get higher on the post mortal donor list. The Health Council of the Netherlands has examined this LDEL but it is in controversy with the current organ donation act and possibly with the Dutch constitution.

The risks for both donor and patient are in the case of living kidney donation low. The survival rate of the kidney and the amount of years that a kidney functions well after the transplantation are higher for living kidney donors. For the patient living kidney transplantation is better but there is overall agreement that kidneys should be provided by post mortal donors. You rather have that not a healthy person has to undergo surgery although the risks are low.

Within living kidney donation it could be an idea to compensate the donor for the loss of income. Now donors have to get permission of their employer to undergo the surgery while the employer has to pay the salary during the left of the employee. This is not a strange thought especially in the case when donors have a small business. It is not clear if such compensation is a violation of the current law.

The last solution described is to legalize kidney sales. This solution is controversial in Western countries but there are researchers who are in favour of it. In the previous chapter this solution was described as one of last resort; it is such a far going and controversial solution that it is something that should be discussed when other solutions are not effective. In some parts of the world there is already discussion about legalizing the kidney sales for instance the United States but also in India there are advocates of paid unrelated living kidney donation. When legalize kidney sales is discussed the best model to arrange it is a model whereby the government arranges and regulates the kidney sale. The Iranian model is here the world's only example of. Of course there is also discussion about the effect of the Iranian model but it is better that the government arranges and regulates it then the free market. A free market is possible but probably this will not give enough protection to both donors and receivers. Next, it is possible that prices raise that high that some people can't afford it and are excluded from the market. Also the changes on unexpected market failures give too much uncertainty about how the market system would work in the case of legalize kidney sales.

But this research shows that there are many other possible solutions which are less controversial and were the outcome is less uncertain which should be tried first before legalize kidney sales would even be discussed.

4. European policy on transplantation tourism

There seems to be more awareness for the problems of transplantation tourism and organ trafficking at the European level than within the member states.

At the European level there is some action to prevent organ trafficking but initiatives to stop that stranded on the table of the European Council. In this initiative organ trafficking would be defined and prosecuted as a transnational crime but in the Council there is no agreement about that.

A second track at the European level where there is action is by the European Commission but this is just started. The European Commission, the Directorate-General Health and Consumers Protection, organised an open consultation with professionals out of the field of organ transplantation. Transplantation tourism and organ trafficking were two major points of concern. Next, the professionals recommended that there would be more cooperation between member states at the European level in organ donation policy. At the moment it is uncertain what further steps are and in which direction this will go. Although it seems to be that countries are hesitating integration at the European level in the case of organ donation policy. It is unclear if this will lead towards one European organ donation policy but at the moment such a policy does not exist.

European countries could cooperate in the field of organ allocation. At the moment Eurotransplant arranges the allocation of organs in 6 countries and this seems to go well. When countries cooperate in the allocation of organs the potential organ pool is bigger. The chances that there is a match between a patient and a post mortal donor are bigger in when there are 27 countries where the match can be made instead of 1 country. Such a larger European donor allocation system asks for a huge investment to arrange such a system in a good and effective way. Such a system does not mean that countries have nothing to say anymore in the case of organ donation. Only the allocation of the organs is arranged on a higher level. For instance in the Netherlands, which is member of Eurotransplant, there is a Dutch organisation the Nederlandse Transplantatie Stichting which has governmental mandate to implement and guard the Dutch law. So, it is possible that there is cooperation between member states without losing their mandate on organ donation policy. Such a plan is very huge and if member states agree about it will take some years to develop and implement it.

In conclusion, at the European level there is more action than on country level. It is only difficult at this moment to say at when and in which direction it will go.

8.2 Hypotheses

In paragraph 3.9 several hypotheses were formulated in this paragraph they are discussed.

The first hypothesis predicted that transplantation tourism is unethical. In the utilitarian approach a decision is ethically correct when the total sum of happiness increases. The prediction was that this is not always the case in transplantation tourism. This research showed that this is true. Both in the case of the donor and patient the happiness will not increase in all cases. Research even showed that there are also high risks for patients and that even after kidney transplantation their happiness decreases by higher risks on complications and even death.

This research showed that donors in India are poor and have a low income. The big majority of the donors sold their kidney to pay off their debts. This is in line with the second hypothesis. There was no information available about the level of education of the donors. This part of the hypothesis can't be confirmed or rejected.

There is a lack of information about the patients. In this master thesis researches are described about patients who went to India or another developing country for paid unrelated kidney transplantation but those researches only gave medical information. There is no

information about the income, social environment or level of education of the patients. This is in line with the hypothesis. During the research it became clear that transplantation tourism is a problem but that it is very difficult to indicate; patients are not open about it. This is in line with the hypothesis.

The allocation of kidneys can be arranged by many systems. In this master thesis the solution of legalize kidney sales was discussed. Such a legalize kidney sale system can be arranged by the market or by the government. Predicted was that a governmental arranged system was more favourable than a market system. The empirical information showed that a legalize kidney system does not meet all the necessary conditions to function as a market therefore it is better that such a system is arranged by the government. This was also the argumentation of the hypothesis and this hypothesis is confirmed.

This master thesis showed that living kidney donation is not the ultimate solution to decrease the organ shortage. This is also confirmed during the interview were the majority of the respondents stated that living kidney donation is only a temporary solution and that it is better to have more organ from deceased donors. Although the risks for a living kidney donor are low; especially in high developed countries with good medical treatments. This is in line with the formulated hypothesis.

The last hypothesis was that there is no policy in both the Netherlands and the United Kingdom to stop and prevent transplantation tourism. The research confirms this hypothesis.

8.3 Recommendations

In this last paragraph of this master thesis recommendations are made for different actors in the field of organ transplantation. These recommendations are not necessary based on the conclusion but can be formed by the experience during the research.

The following recommendations are described:

- Prevention of kidney failure.
- More political awareness for kidney failure and the consequences.
- European cooperation in the field of organ allocation.
- Stronger lobby by kidney organisations.

Prevention of kidney failure

One of the most important recommendations is that more attention is necessary in order to prevent kidney failure. It is well known that certain groups such as diabetes and people with high blood pressure have higher risks to get kidney failure. Such risk groups must be annually controlled if kidney failure is discovered in an earlier stage medication can prevent worsen. At the moment there is in politics not a lot of attention in the discussion to decrease the organ shortage. Only solutions which increase the amount of donors are discussed but it is of course also possible to decrease the supply. A shortage is caused by too much demand and too little demand. To solve the shortage you can increase the supply but you also decrease the demand. It seems to be that nobody has really thought about that because none of the empirical information shows this.

So, it is recommend that governments not only invest in increasing the amount of donors but also in preventing kidney failure by more public awareness of it and screening risk groups. The public is not aware of the impact of kidney failure on someone's life. They are also not aware what the general complaints are and which groups have higher risks on kidney failure. More information is important this can be provided by for instance the government but also by patient organisations.

Next, further research focussed on the early traceable of kidney failure must be stimulated. The general complaints of kidney failure are quite general and in most cases it is discovered in a later phase when there is irreparable damage is done. With better medical instruments it is possible that kidney failure to discover in an earlier stage.

At last more focus need to be at new treatments in order to treat kidney failure. Kidney transplantation and dialysis are good solutions but perhaps other, not yet discovered, treatments are even better. This should be stimulated by the government.

More political awareness for kidney failure and the consequences

During this research it became soon clear that transplantation tourism is caused by a shortage of deceased organs. This shortage is an international problem. The best way to prevent transplantation tourism is to decrease the organ shortage. It is an illusion that the problem of organ shortage could be solved entirely while there are always patients who are difficult to transplant or were it is difficult for to find a compatible match. But there are good solutions that could decrease the organ shortage. At the moment there is attention for decreasing the organ shortage although it seems to be very difficult to find good solutions. It seems to be that politicians are hesitating in making decisions. The question is if they realize how big the problem is for patients with kidney failure. Of course dialysis is possible in Western countries but the quality of life is lower then when kidney transplantation is possible. Dialysis patients are constraint in their freedom of movement and have to follow a strict diet. Although dialysis is a good solution it can't replace the function of the kidney; patients can't function for 100%. So, politicians should take these conditions into account while they are discussing solutions to decrease the organ shortage. They should ask themselves the question: "Could I do my current job and social life when I have to dialysis three times per week for four hours?" In this way politicians are more aware of what it is to be a kidney patient and what the effect is on their life. Perhaps here lies also a job for patients who are waiting for kidney transplantation. Let the people who decide know what the impact of kidney failure and waiting on a kidney is.

Not only are dialysis patients the victims but there are already people dying while they are on the waiting list. That is the reality and it is strange that rich Western countries a certain group of people can't help. Of course everyday there are people dying but it is hard that the government could decrease this amount of people with changing the donor registration system or with better prevention. It is also true that in the health sector there is always short on money and have to be made but certain solutions have a big impact but aren't that costly. In the case of kidney failure dialysis is much more expensive then kidney transplantation. Thus, the government profits if more donors are available. So, governments should consider solutions to increase the available amount of donors.

European cooperation in the field of organ allocation

This master thesis shows that in some fields there is more action at the European level then at the country level. In the case of transplantation tourism that is certainly true. At the European level there are several steps taken in order to develop policy. Unfortunately nothing happened concrete at this moment. European cooperation could contribute an increase in the amount of available post mortal donors. This is an important recommendation while it is important to increase the amount of post mortal organs. This master thesis shows that countries are not able to do this effectively at country level. One solution is that European countries cooperate together in the field of organ allocation. At the moment Eurotransplant is such a example of cooperation between 6 countries. When European countries cooperate the potential donor pool expands from 1 or 6 countries towards 27 countries. The chances that there is a compatible organ are higher when the donor pool consists out 490 million potential donors or 16 million (the Netherlands) or 60 million (the United Kingdom). Here there is a major opportunity for European countries to cooperate in order to solve a problem which all countries have. Cooperation in the field of organ allocation does not mean that countries will lose their sovereignty over organ donation policy while it only goes about the allocation. Also here a good example is Eurotransplant; all the Eurotransplant countries have their own rules, policies and systems but they do cooperate. This organisation could be a model for further discussion about the possibilities for such a European broad cooperation. In the case of the organ shortage the solution can be scale enlarging. At the moment the discussion about organ donation policy at the European level is

just started but it seems to be that countries are hesitating in discussion organ donation policy at the European level. The professionals in the field do see the opportunities in more cooperation in the field of organ donation and allocation.

Stronger lobby by kidney organisations

A last recommendation is one which was not part of this research but during this research it became clear that lobbying is very important in order to achieve goals. Starting this research it was not clear how big the organ shortage was and what the impact of kidney failure on people's life is. During this research it became clearer that there are people, probably unnecessary, dying because there is an organ shortage. It is very difficult to understand that there are people dying while this amount of people could decrease with other policies. Lobbying plays hereby a huge role; a good lobby can achieve a lot. When organisations lobby strong towards politicians the changes that they are heard are bigger and also the changes that something is done. It is not said that there is not a lobby by organisations but perhaps the focus could be more on the scope of the problem but also on solutions which have a change with politicians. In the Netherlands a donor registration system is very controversial but perhaps the changes are better for the prevention of kidney failure.

At the European level there is, based on the available empirical information in this master thesis, no active lobby while at the European action there is some action in order to prevent organ trafficking but also in the field of organ donation. Patient organisations in Europe could cooperate effectively in order to achieve their goals at European level.

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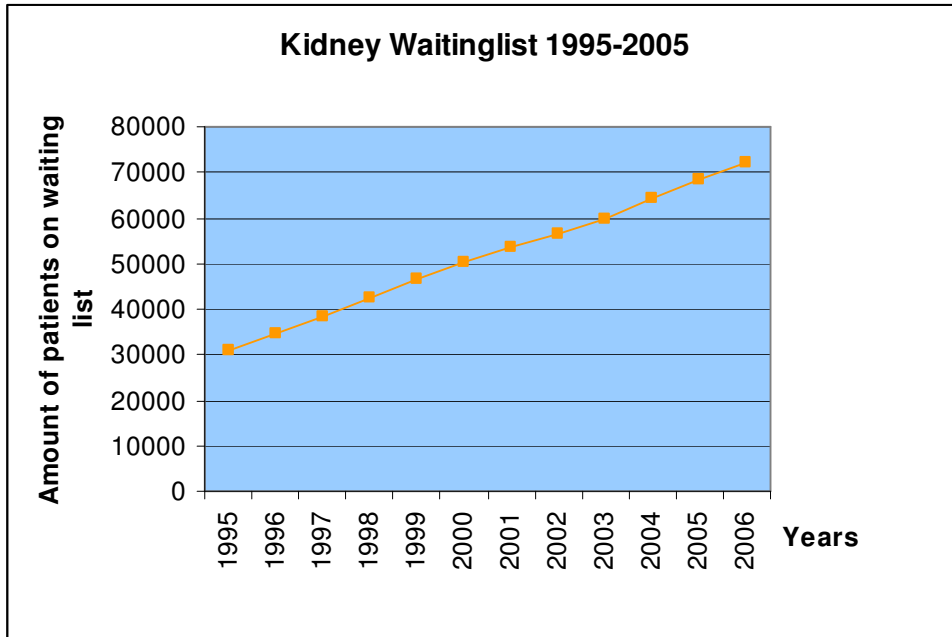
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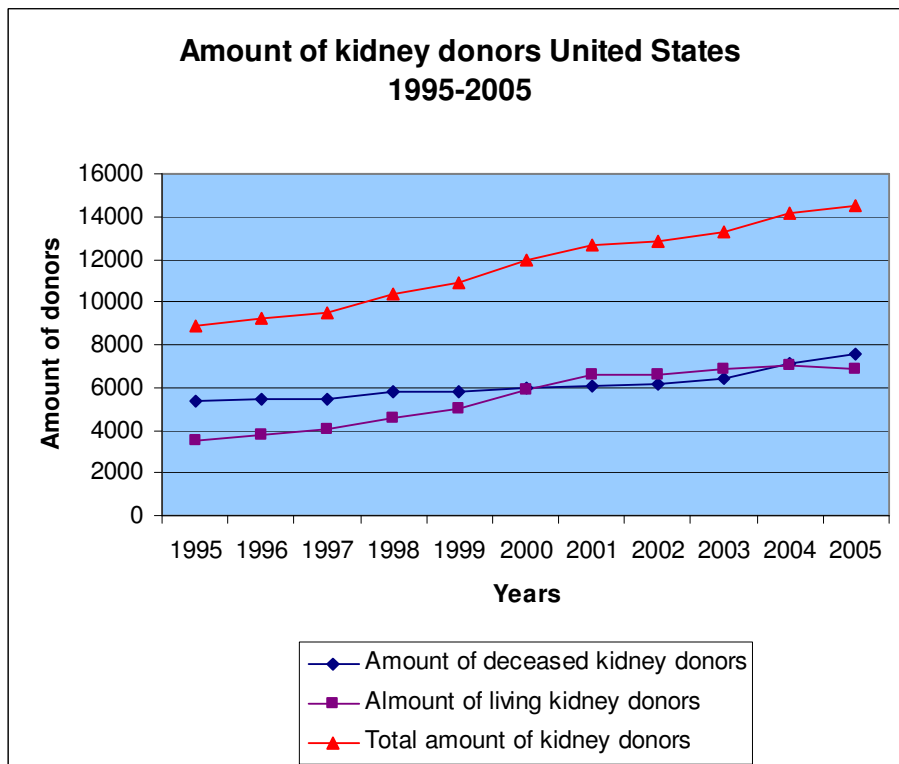
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Annex 1 Kidney waiting list and kidney donor list United States



Source: United Network of Organ Sharing, United States, data request provided on 1-12-2006.



Source: United Network of Organ Sharing, United States, data request provided on 1-12-2006.

Annex 2 Overview of the variables and indicators

<i>Variable</i>	<i>Short of variable</i>	<i>What is measured?</i>	<i>Indicators</i>
Transplantation tourism	Dependent	Ethical determinants Social determinants Economic determinants Medical aspects Current status of the policy Political aspects Policy solutions	See for each determinant below.
Ethical	Independent	The Utilitarian approach: - Consequentialism - Happiness - Aggregationism	Transplantation tourism is ethical right when the happiness of both patient and donor clearly and certainly increase after the paid unrelated living kidney transplantation.
Social	Independent	- Social environment - Social class - Income	- The social environment were both the patient and donor are part of. - The social class of both the patient and donor. - The income of both the patient and the donor before and after the donation.
Economic	Independent	- Market system - Public health system	The system that is most suitable in the case of legalize kidney sales. Measured conditions: - The same product is sold to many purchasers by many producers. - There are no restrictions for entering the market for potential producers. - The existing producers do not have an advantage over the new producers. - Both the producers as the purchasers are well informed about the prices.
Medical	Independent	- Hemodialysis - Peritoneal dialysis - Cadaver kidney transplantation - Related living kidney transplantation - Unrelated living kidney transplantation	For each treatment the following is measured: - Availability of the treatment - Risks for patient - Survival rate of patient in the short and long term - Long term consequences for the patient - Risks for the donor (only in a case of living donation) - Consequences for the donor (only in a case of living donation)
Political aspects	Independent	The opinion of Dutch and British political parties about transplantation tourism.	- Political views on organ donation in both countries. - Transplantation tourism is a political issue or not. - Transplantation tourism is on the political agenda or not.
Current status of the policy	Independent	If and in what degree the Netherlands and the United Kingdom a policy have to	- The Netherlands and the United Kingdom have policy or not. - If the Netherlands and the United

Annex 3 Medical treatments by kidney failure

In this annex the different medical treatments by kidney failure are extended described in order to understand better the quality of life of the patients and in the case of living kidney donation the donors. Further the costs and availability of the treatments are presented. These factors have also influence in the process of choosing a treatment.

Hemodialysis

Hemodialysis is a treatment where the waste is filtered out of the blood. The blood flows through the artificial kidney where it gets in contact with waste absorbing fluid²⁷⁷. The blood goes through the dialysis machine and goes, a bit cleaner, back into the body²⁷⁸. In the following picture the process of hemodialysis is showed.

Source: American National Kidney Foundation (2001), page 4.

Before a patient starts with hemodialysis a shunt must be surgically be placed in the patient's arm. A shunt is a link of a vein with an artery so more blood can flow through the vein and the vein is easier to prick. It takes about 6 weeks for a shunt to develop till a vein which is useful for dialysis²⁷⁹. With a shunt it is possible to do the daily things and it is also possible to practise sports²⁸⁰. Although certain sports, such as volleyball, are not possible because some sports can damage the shunt. It is possible that the shunt silts up and the patient needs to be careful with it. If this happens then the shunt needs to be surgically replaced.

Hemodialysis can be done in a hospital, a dialysis centre or at home. On average a patient needs to dialyze for four hours three times per week. This depends on different factors such as the weight of the patient, the kidney function, how much waste there is in the blood and what kind of dialyser is used. Next, to the dialysis the patient must follow a diet. Patients with kidney failure only make little amounts of urine; only a couple of drops of urine per day. The dialysis removes not a lot of fluid. Therefore a patient gets a fluid restriction. In generally a kidney patient is allowed to have 0,5 till 1,0 litre of fluid per day. Next, a patient who dialyzed must eat a lot of protein. The patient needs to be careful with sodium and potassium.

The Netherlands has 62 dialysis centres. In the Netherlands in 2005 there were 5.440 dialysis patients²⁸¹. Of those patients 4.124 were on hemodialysis. In the past there was a waiting list for hemodialysis but nowadays there is not.

The average costs for the first year of full care centre hemodialysis were in 2002 between €82.500 and €87.200²⁸². The costs of the following years for full care centre hemodialysis were in 2002 between €79.500 and €82.300 per year²⁸³.

The average costs for limited care centre hemodialysis for the first year were in 2002 between €72.400 and €77.100²⁸⁴. The costs of the following years for limited care centre hemodialysis were in 2002 between €65.500 and €72.300 per year.²⁸⁵

The average costs for the first year of home hemodialysis were in 2002 between €72.400 and €77.100²⁸⁶. The costs of the following years for home hemodialysis were in 2002 between €65.300 and €68.100 per year²⁸⁷.

Peritoneal dialysis

²⁷⁷ Nierpatiënten Vereniging LVD & Nierstichting Nederland, Is dialyse uw toekomst?, 2^{de} druk 2003, page 11.

²⁷⁸ Nierpatiënten Vereniging LVD & Nierstichting Nederland, Is dialyse uw toekomst?, 2^{de} druk 2003, page 11.

²⁷⁹ Nierpatiënten Vereniging LVD & Nierstichting Nederland, Is dialyse uw toekomst?, 2^{de} druk 2003, page 11.

²⁸⁰ Nierpatiënten Vereniging LVD & Nierstichting Nederland, Is dialyse uw toekomst?, 2^{de} druk 2003, page 11.

²⁸¹ Nierstichting Nederland, Feiten en cijfers, November 2006, page 2.

²⁸² Information provided by Hans Mak Insituut.

²⁸³ Information provided by Hans Mak Insituut.

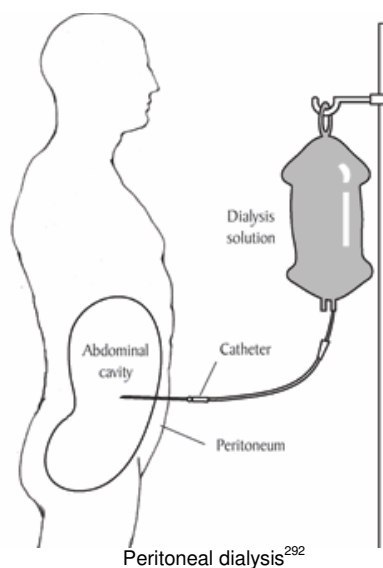
²⁸⁴ Information provided by Hans Mak Insituut.

²⁸⁵ Information provided by Hans Mak Insituut.

²⁸⁶ Information provided by Hans Mak Insituut.

²⁸⁷ Information provided by Hans Mak Insituut.

With peritoneal dialysis some ones peritoneal membrane is used as a dialyze filter. The peritoneal membrane wraps the abdomen cavity and it has a large blood circulation²⁸⁸. The waste-absorbing fluid is brought into the body through a catheter. The fluid absorbs the waste of the blood that flows through the veins in the abdomen membrane²⁸⁹. The blood gets cleaned and the waste is removed out of the blood. After a certain amount of time the fluids gets full with waste and the liquid needs to be changed; this is done by the catheter²⁹⁰. The catheter is surgically implemented through abdominal wall into the abdomen cavity. The catheter sticks a bit out of the abdomen and it is closed by a lid. With the catheter it is possible to do daily things²⁹¹. The picture below shows how peritoneal dialysis works.



There are two forms of peritoneal dialysis²⁹³:

- CAPD (continuous ambulatory peritoneal dialysis). Here the patient changes the waste-absorbing fluid four or five times per day with pauses between four and six hours. The patient can do this at home but also at work.
- APD (automated peritoneal dialysis). The filtering of the blood is done by night. Before the patients goes to bed he or she connects the catheter at machine. This machine conducts automatically four or five filtering during the night.

Also a peritoneal dialysis patient needs to look at what he or she eats²⁹⁴. A patient needs to take attention to that her or she eats enough proteins because proteins are removed out of the blood by the liquid. Next, a patient can't drink a lot; around 1,5 litre per day is the maximum. At last the patient should have a low calorie diet.

In the Netherlands in 2005 there were 1.316 peritoneal dialysis patients. This is low compared with the 4.124 hemodialysis patients²⁹⁵.

²⁸⁸ Nierpatiënten Vereniging LVD & Nierstichting Nederland, *Is dialyse uw toekomst?*, 2^{de} druk 2003, page 13.

²⁸⁹ Nierpatiënten Vereniging LVD & Nierstichting Nederland, *Is dialyse uw toekomst?*, 2^{de} druk 2003, page 13.

²⁹⁰ Nierpatiënten Vereniging LVD & Nierstichting Nederland, *Is dialyse uw toekomst?*, 2^{de} druk 2003, page 13.

²⁹¹ Nierpatiënten Vereniging LVD & Nierstichting Nederland, *Is dialyse uw toekomst?*, 2^{de} druk 2003, page 13.

²⁹² Source: *Kidney Failure: Choosing a Treatment That's Right for You*, at:

<http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/index.htm#peritoneal>, 07-02-2007.

²⁹³ Nierpatiënten Vereniging LVD & Nierstichting Nederland, *Is dialyse uw toekomst?*, 2^{de} druk 2003, page 14.

²⁹⁴ Nierpatiënten Vereniging LVD & Nierstichting Nederland, *Is dialyse uw toekomst?*, 2^{de} druk 2003, page 15.

²⁹⁵ Nierstichting Nederland, *Feiten en cijfers*, November 2006, page 2.

The average costs of peritoneal dialysis for the first year were in 2002 between €59.100 and €68.900²⁹⁶. The costs of the following years in 2002 were between €55.600 and €62.400 per year²⁹⁷. The costs depends on the age of the patient; the older the patient, the higher the costs. There is no waiting list for peritoneal dialyse although the patient needs first to get a catheter. This catheter must be surgical be placed and here an appointment is necessary. So, it can take sometime before the catheter is placed and then the dialysis can start. Most of the time there is enough time to place the catheter and when immediately dialysis is necessary hemodialysis is possible.

Kidney transplantation

The information about kidney transplantation is from the Kidney Foundation Netherlands (2005).

While a patient gets dialysis he or she is screened if they are qualified for kidney transplantation. In principal every dialysis patient can be qualified for kidney transplantation. One of the most important factors is the condition of the patient. If the condition of the patient is not sufficient then kidney transplantation can not be conducted. Also older patients can undergo transplantation but the changes that their condition is less or that they have other diseases increase. There are some diseases, which mostly coincide with kidney failure, which can cause that kidney transplantation is not possible:

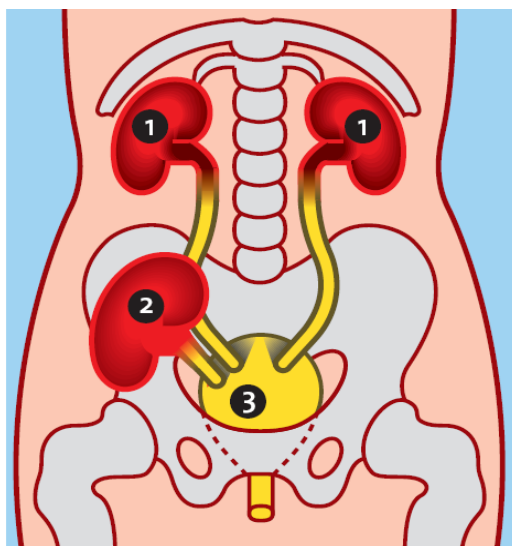
- Diabetes. This disease damages the heart- and blood veins. In some cases kidney transplantation is then not possible.
- Each time returning and chronic urinary tract infections are disorders which can prevent to have kidney transplantation.

The patient gets a health examine with special attention to the heart- and blood vessels. Also very important is an examine of the blood group and tissue characteristics because the most narrow match with that of the donor kidney decreases the changes of rejection. When the patient gets a call that there is a kidney available the patient goes to the hospitals. Again the patient must undergo some examines. The most important examine is the experimentum cruis. Here the blood of the donor and patient are mixed in order to see if there is rejection. If this test is positive and the other tests have also positive outcomes then the patient can receive the kidney.

During the operation the new kidney is placed under in the abdomen. The new kidney is connected to the bladder. In most circumstances the patient keep his or hers own kidneys. Only when they are very big or infected they will be removed. The picture below shows the situation after kidney transplantation.

²⁹⁶ Information provided by Hans Mak Insituut.

²⁹⁷ Information provided by Hans Mak Insituut.



Source: Kidney Foundation Netherlands, 2005; 2

Number 1: patient's kidneys

Number 2: new kidney

Number 3: bladder

After surgery the normal development is that:

- After 2-3 days most drips and tubes can be removed.
- After three weeks most patients can leave the hospital.
- The new kidney will, by 3 out of 4 patients, function after 2 or 3 days.

In 25% of the case the body rejects the new kidney. If rejection appears the new kidney's function will worsen and sometimes the new kidney is lost. When the new kidney is rejected the patient will have less urine production and high hypertension. There is medication to stop the rejection. In 80% of kidney transplantation the kidney functions well after 1 year. In 50% of the cases the kidney functions well after 5 years. To prevent that the new kidney will be rejected by the body the patient has to take medicines after the transplantation. The following medicines are used in general: prednison, ciclosporine, tacrolimus, azathioprine or mycophenolat mofetil. These medicines have negative side effects. Over time the medication can be decreased.

The costs of kidney transplantation differ from the different donor forms. The costs of cadaver kidney transplantation can differ between hospitals. But the average costs of a cadaver renal transplantation where in the Erasmus MC around €25.293 in the period of 1998-2001²⁹⁸. These costs are from the preparatory phase until one year after the transplantation.

The average costs of related living kidney transplantation where in Erasmus MC in the period 1998-2001 €31.367²⁹⁹. These costs are from the preparatory phase until one year after the transplantation.

²⁹⁸ Hemerik, D., Een nieuwe (ma)nier in het Erasmus MC, 2002, samenvatting.

²⁹⁹ Hemerik, D., Een nieuwe (ma)nier in het Erasmus MC, 2002, samenvatting.

Annex 4 Overview medical treatments

Factors	Hemodialysis	Peritoneal dialysis	Cadaver kidney transplantation	Living kidney transplantation
Availability of the treatment	No real waiting list.	No real waiting list. Although there is some certain amount of waiting time for the surgery to place the catheter.	Waiting list around 4 years.	Depends on availability of living kidney donor. Can't speak of a "real" waiting list.
Risks for patient	Surgery to place a shunt; risks on complications. Negative side affects are: - Vascular access problems. - Muscle cramps and hypotension.	- The risk for peritonitis; abdominal infection. - Patient can get a large a larger abdomen scope.	- Normal surgical risks. - Rejection risks; 25% of all kidney transplantation (cadaver and living) it occurs). - Risks that the donor kidney carries diseases (in Western countries is this very low).	- Normal surgical risks. - Rejection risks; 25% of all kidney transplantation (cadaver and living) it occurs). - Risks that the donor kidney carries diseases (in Western countries is this very low).
Survival rate of patient in the short and long term	Depends on different circumstances.	Depends on different circumstances.	- Survival rate of kidney after one year 87.7%. - Average amount of years a kidney functions 19,5 years	- Survival rate of kidney after one year 93,9%. - Average amount of years a kidney functions 35,9 years.
Long term consequences for the patient	- Takes a lot time (4 hours, 3 times per week). - It constraints your freedom of movement. - Patient needs to follow a strict diet.	- Takes a lot of time (several times per day, 7 days per week). - Patients needs t follow a strict low calorie diet and can't drink a lot. - Patient can gain weight. - During dialysis constraint freedom of movement.	- Patients need to take medication but this decrease over time. - When the transplantation fails the risk is that the kidney function decreases more. - Risks on rejection stays. - It is possible that a patients needs to have more kidney transplantation during life.	- Patients need to take medication but this decrease over time. - When the transplantation fails the risk is that the kidney function decreases more. - Risks on rejection stays. - It is possible that a patients needs to have more kidney transplantation during life.
Costs of the treatment	For full care centre hemodialysis the first year between €82.500 and €87.200. Following years between €79.500 and €82.300 per year	First year between €59.100 and €68.900. Following years between €55.600 and €62.400 per year	€25.293 for the hospital. The costs for health insurance company are higher.	€31.367 for the hospital. The costs for health insurance company are higher.
Risks for the donor	n.o.a.	n.o.a.	n.o.a.	- Normal surgical risks. - Perioperative mortality rate is

				0,03%. Complications in the long term for the donor are < 10%.
Consequences for the donor	n.o.a.	n.o.a.	n.o.a.	<ul style="list-style-type: none"> - Risks of living with one kidney. Although it seems to be that the risks are low. - Blood pressure can rise - Special attention for related living kidney donors while they can have higher risk on developing kidney failure because some are genetically stipulated.

Interview with Stichting Transplantatie Nu at 21-12-2006

Stichting Transplantatie Nu is een samenwerkingsverband van 5 patiëntenorganisaties. Het doel van de stichting is om meer transplantaties te krijgen (onderliggend hieraan is het verkorten van de wachtlijsten). De stichting probeert het doel te bereiken via de website en voorlichtingen. Deze voorlichtingen worden in kleinere groepen gegeven door ervaringsdeskundige door heel het land aan bijvoorbeeld scholen, vrouwengroepen etc. Daarnaast zit de stichting in een adviesgroep over orgaandonatie. Samen met andere organisaties die hierin zitten zullen zij reageren op de derde evaluatie op de wet orgaandonatie uitgevoerd door het kabinet. Deze evaluatie zal waarschijnlijk pas in april 2007 besproken worden als er een nieuw kabinet is. De werkgroep zal hier dan op reageren en de reactie wordt ook naar de Tweede Kamer gestuurd.

Is het fenomeen van transplantatie toerisme m.b.t. nieren bekend bij Transplantatie Nu?

Ja, dat is wel bekend bij de stichting en ook bij de Nierpatiëntenvereniging, maar bij beide zijn er geen persoonlijke gevallen bekend. Het fenomeen in elk geval wel bekend met name via de media zoals de televisie. Met nieren is het in feite echt handel. Mensen verkopen echt hun nieren. Vaak doen ze dit uit armoede; het gebeurt vooral dan ook in armere landen, maar ook in het Oostblok heb ik begrepen.

Heeft u data van hoeveel patiënten in een bepaalde periode naar het buitenland zijn gegaan voor een ongerelateerde betaalde niertransplantatie?

Nee, volgens mij is er in Nederland niet bekend op welke schaal dit plaatsvindt. Er zijn verhalen in de pers en de media erover. Je weet dat het gebeurt en voor komt. De verhalen in de media zijn ook geen Nederlandse verhalen; dit zijn verhalen uit het buitenland.

Bij niemand zijn er, volgens mij, Nederlanders bekend die dit gedaan hebben.

Het is zeker wel zeker dat het gebeurt, maar het is niet bewezen en er zijn geen cijfers of namen bekend.

In de wet staat dat het verboden is; in Nederland mag je niet handelen in organen. Dat is lange tijd een drempel geweest voor levende orgaandonatie in Nederland. Er is toen toch gedacht dat, zelfs bij familie en vrienden, mensen onder tafel iets konden gaan geven voor een levende orgaandonatie. Volgens mij is dit nog nooit gebeurd, maar het was wel een drempel om levende orgaandonatie toe te staan.

Wat is de positie van de Stichting Transplantatie Nu t.o.v. transplantatie toerisme? Wat is de argumentatie hiervoor?

In principe zijn wij daar op tegen alleen zouden we, denk ik, nooit ver weg gaan om mensen hierover te veroordelen omdat er veel schrijdende gevallen zijn. Nu heb je met nieren een tijdelijke uitvlucht mogelijkheid door te dialyseren, maar bij andere organen heb je die mogelijkheden niet. Jou vraag is specifiek op nieren en ook daarvan weet je dat het een beperkte tijd is dat je kunt dialyseren, sommige mensen kunnen dit heel lang volhouden maar het is slecht voor je lichaam en je hebt veel beperkingen. Het is voor te stellen dat een ouder het voor zijn kind zou willen als de ouder zelf geen geschikte donor is. Iedereen moet voor zichzelf kunnen uitmaken of iemand daarmee zou kunnen leven. Het gaat er ook om op wat voor manier het gaat. Er zijn gevallen bekend dat mensen een schrijntje krijgen en vaak nog armer worden omdat ze bijvoorbeeld arbeidsongeschikt raken.

Er rust een taboe op dus je het kunt niet goed regelen. In Nederland rust er ook een taboe op en waarschijnlijk speelt dit een rol dat er in Nederland geen cijfers over bekend zijn. In Nederland is er de heersende opvatting dat het niet mag en ethisch niet juist is. Er zijn landen waar het wel gebeurt, zoals Iran waar zelfs bedragen zijn vastgesteld. Het duikt iedere keer op in de media, maar er is in Nederland nog nooit met iemand gepraat die het gedaan heeft. Je weet absoluut niet wat de omvang en in principe zou daar wel achter te

komen zijn. Artsen zouden bijvoorbeeld het anoniem kunnen op geven. Hoeveel het er gedaan hebben omdat artsen heel goed weten dat het gebeurd, denk ik. Je kunt er als arts niet om heen als iemand het heeft laten doen. Vanuit de overheid zijn er, naar dat ik het weet, geen actie geweest om het te laten onderzoeken en tot op heden is dat niet gebeurd.

In mijn scriptie ben ik gericht op levende nierdonaties, maar is het bij u bekend dat er ook andere transplantaties voor komt?

In principe komt het bij alle organen voor. Een berucht verhaal, dat steeds opduikt in de media, zijn organen van (geëxecuteerde) Chinezen. Het speelt niet alleen bij levende donoren, maar ook bij overledenen. Bij de BBC was er een documentaire die ging over een Chinese sekte die gevangen worden genomen. Men houdt deze mensen zo gezond mogelijk met bijvoorbeeld oefeningen en allerlei onderzoeken. Zodra men een match heeft met een patiënt worden deze sekte leden geëxecuteerd; de gevangen worden als het ware geselecteerd. Er zijn Chinese sites waar je, via aanmelding, aan een orgaan kunt kopen. Echte bewijzen, op de verhalen na, zijn er niet, maar deze verhalen verschijnen wel iedere keer in de pers.

U bent een overkoepelende organisatie van vijf patiëntenorganisaties. Heeft u wel eens van deze patiëntenorganisaties gehoord dat zij te maken hebben gehad met transplantatie toerisme?

De voorzitter van het bestuur van Transplantatie Nu is ook voorzitter van de stichting Harten Twee en zij hebben wel hiermee te indirect te maken. Harten Twee is een stichting die de belangen behartigt voor mensen die een hart en/of longtransplantatie hebben ondergaan of hier voor in aanmerking komen. Het schijnt dat zodra mensen op de wachtlijst staan voor een long zij een e-mail krijgen waarin longen te koop worden aangeboden. Waar deze e-mail vandaan komt is onbekend en hoe diegene weet wanneer iemand op de wachtlijst staat ook. De stichting weet niet of er patiënten zijn die hierop hebben gereageerd. Zelf heb ik deze mail nog niet gezien, maar het schijnt echt zo te zijn. Volgens mij heeft de stichting zelf hier nooit iets mee gedaan.

De patiëntenorganisaties zelf hebben nog nooit gehad dat patiënten hun benaderd hebben met de vraag waar ze organen kunnen kopen in het buitenland en hoe dit gaat. In principe kun je tegenwoordig alles via Internet vinden.

Hoe denkt u dat het (internationale) orgaan tekort opgelost kan worden?

Ik vind het heel moeilijk om iets te zeggen over het international orgaan tekort, maar ik kan wel wat zeggen over het orgaan tekort in Nederland.

In Nederland is de eerste stap die gemaakt moet worden een ander registratiesysteem invoeren. In Nederland hebben we een toestemmingssysteem. Je moet kiezen of je geregistreerd wil worden. Aan de ene kant blijkt uit enquêtes dat 70-80% van de Nederlandse bevolking na overlijden organen zou willen donoren, maar in de praktijk blijkt maar 40% geregistreerd te zijn als donor. Daar zit een stukje laksheid en angst in, maar ook andere factoren spelen hierbij een rol. Wij zeggen maakt het die mensen makkelijk en registreer iedereen als donor. Wie geen donor wil zijn die kan dat aangeven. Dit is het zogenaamde geen bezwaar systeem; daar zou in de Nederlandse politiek geen draagvlak voor zijn.

NGIZ donorvoorlichting stelt het ADR (automatische donor registratie) voor als nieuw registratiesysteem. Daarbij blijf je dezelfde opties houden als die je nu hebt: ja, nee of overlaten aan nabestaanden, maar dit systeem draait het om. Je krijgt drie keer een schrijven waarbij aan wordt gegeven dat je donor bent en dat je kunt aangeven of je dat wilt óf niet óf dat je dat aan nabestaanden wilt overlaten. Waarschijnlijk houd je dan ook dat er een aantal mensen niet zullen reageren, maar hierdoor kun je wel meer aan donoren komen.

Het probleem bij orgaandonatie is dat je op een speciale manier moet overlijden. Je moet in feite in coma het ziekenhuis binnen komen; je moet op de intensive care komen te liggen. De kans is heel klein dat je op de manier overlijdt dat je donor kunt worden.

Je hebt heart-beating en non-heart beating donoren. Non-heart beating donoren komt vaker voor. Hier wordt onderzoek naar gedaan waarom dat is, maar waarschijnlijk komt dat doordat de donor dan al is overleden. Dit maakt het voor nabestaanden “makkelijker” om te beslissen donatie wel te laten doen omdat de persoon in kwestie al is overleden.

Bij heart-beating donor leeft de donor nog; de patiënt ligt nog aan machines, is nog warm en voor je gevoel ademt deze persoon nog. Het is dan voor familie veel moeilijker om donatie toe te laten. Maar bij heart-beating donoren kun je meer organen gebruiken zoals hart en longen die zijn van non-heart beating donoren onbruikbaar.

Internationaal gezien zijn er ook landen, zoals in Spanje, waar ze een geen bezwaar systeem hebben, maar waar ze ook organen tekort komen. Het probleem is misschien niet oplosbaar. Je kunt het in ieder geval verbeteren. Wij vinden dat de overheid er alles aan moet doen om het zo goed mogelijk te krijgen.

Is het bekend hoeveel extra donoren het geen bezwaar systeem zal opleveren?

Ja, er zijn wel cijfers bekend, maar het is moeilijk om deze te interpreteren.

Spanje heeft bijvoorbeeld een geen bezwaar systeem. Als je kijkt naar het aantal donoren daar dan ligt dat veel hoger. Dat soort cijfers zijn er wel. Er zijn mensen die stellen dat een hoog aantal donoren niet per se voortkomt uit het geen bezwaar systeem, maar dat het ook andere oorzaken kan hebben zoals een hoog aantal verkeersdoden. Het is moeilijk precies aan te geven welk aandeel toe te schrijven is aan het geen bezwaar systeem.

België heeft, volgens mij, ook een geen bezwaar systeem en daar ligt het aantal donoren niet veel hoger als in Nederland.

In de evaluatie staan daar ook cijfers over in. Die kun je vinden op de site www.nivel.nl

Zou een mogelijke oplossing voor het niertekort zijn dat men moet voorkomen dat mensen nier falen krijgen?

De Nierstichting houdt zich daar tegenwoordig mee bezig met bijvoorbeeld de Niercheck. Hiervoor richtte de stichting zich voornamelijk op het vergroten van het aantal donoren en transplantaties. Nu richt men zich ook op het in zo'n vroeg mogelijk stadium ontdekken van een nieraandoening. Hierbij moet wel gelet worden dat de Niercheck niet alle nieraandoeningen aangeeft. Het kan slechts het eiwit gehalte meten en dat is niet toepasbaar voor alle nierziekten.

Je kunt het veel langer uitstellen dat mensen nier falen krijgen en dus een nierdialyse of een niertransplantatie. Het hangt wel van de ziekte af, maar als het vroeg ontdekt wordt dan kun je het uitstellen en misschien wel voorkomen. Dat laatste is meer een medische vraag en dat weet ik niet precies.

Kan Transplantatie Nu bijdragen aan de oplossing van het orgaan tekort in Nederland?

Dat hoop ik. Wat wij nu doen is nu de evaluatie klaar is, is we samen met andere groepen een reactie schrijven. Met de commissie willen wij toch in de politiek lobbyen om de wet te veranderen. Toch weer een wetswijziging voorstellen. Vorig jaar waren er 6 stemmen te weinig om een wetswijziging er door te krijgen. Wij zetten er ons nu voor in om het nu te laten lukken. Dat is eigenlijk nu het enige wat wij kunnen doen. Daarnaast is voorlichting ook heel belangrijk omdat het ook niet veel helpt als mensen “nee” registeren. Voorlichting over orgaan donatie blijft dus altijd hard nodig.

Ik zelf denk dat ontwikkelingen zoals transplantatie toerisme mede voort komt uit het orgaan tekort. Hoe ziet Transplantatie Nu dit?

Dat is ons standpunt ook. Wij zeggen er altijd wel bij: kijk nu overheid het gebeurd gewoon en als je nu geen dingen gaat veranderen zoals een ander registratiesysteem dan zul je er op een gegeven moment echt tegen aan lopen dat het in Nederland ook gebeurd. In Nederland gebeurt al, maar dan zal het nog duidelijker worden dat het gebeurd en dat dit door het orgaan tekort komt. Bij hart, longen en levers moet je binnen een bepaalde tijd een orgaan krijgen anders overlijdt je gewoon; mensen zien op een gegeven moment een orgaan transplantatie in het buitenland als enige uitweg zien als ze het geld ervoor hebben.

Bij nieren is de wachtlijst korter geworden, maar het aantal donoren is niet toegenomen. Hoe is dit te verklaren?

Bij nieren is de wachtlijst aan het afnemen omdat er steeds meer levende donatie plaats vinden. Maar dat vinden wij in feite ook een noodoplossing. Dit is de eerste stap die mensen nemen. Heb ik iemand in mijn omgeving die mij een nier zou kunnen geven; familie of partner en soms een stapje verder zoals verdere familie of een kennis. Dan heb je in Nederland nog één andere mogelijkheid, dat is cross-over transplantatie. Dan kom je in een soort pool terecht en dan krijg je een kruis transplantatie. In Nederland zijn ze ook nog bezig met het systeem van LDLE (Living Donor List Exchange). Dat is weer een systeem waarbij ik bijvoorbeeld een nier nodig heb, maar de nier van bijvoorbeeld mijn broer past niet dan doe ik in feite de nier van mijn broer “aanbieden” en hierdoor stijgt ik een stukje op de wachtlijst. Je zou je kunnen voorstellen dat als dit ook niet zou lukken dat mensen dan gaan denken of ze op Internet niet een nier kunnen kopen. LDLE is met name iets waarmee het Erasmus MC zich mee bezig houdt.

Op welke wijze denkt u dat transplantatie toerisme voorkomen kan worden?

Wij zeggen dat om het te voorkomen moet je het hier verbeteren. Zodra hier het aantal donoren omhoog gaat, zullen mensen minder snel naar het buitenland gaan. Zoals ik al eerder zei is een ander registratiesysteem van belang; het aantal donoren zal stijgen, maar de vraag is of je ook dan voldoende donoren krijgt. Als dat nog steeds niet zo is dan zul je het houden. Ik denk dat er in Nederland ethisch gezien er heel veel mensen zijn die niet over die drempel gaan. Dat is een moeilijk iets om het duidelijk te krijgen; het is namelijk een persoonlijke zaak. Als je een geliefde ziet die iets nodig heeft of anders overlijdt dan zul je er alles aan doen om diegene te redden. Als overheid moet je daarom er alles aan doen om te voorkomen dat mensen dit soort beslissingen moeten nemen. Wij zeggen dan dus moet je het systeem aanpassen want zolang je dat niet doet, doe je er niet alles aan. Je moet in Nederland zelf genoeg donoren krijgen.

Wij vinden dat ook voor levende orgaan donatie; dat is ook een nood optie. Wij keuren het niet af en je kunt er tegenwoordig niet om heen, want het gebeurt gewoon heel veel, maar ook hiervan zeggen wij doet de overheid er voldoende aan om ook dit te voorkomen.

Wij zien liever dat levende donatie ook niet nodig is. Voor de patiënt zitten er, denk ik, niet zoveel risico's aan. Voor patiënten is levende donatie soms beter omdat de nier warm wordt overgezet en dat heeft voordelen. Maar wij hebben nog steeds zoiets van eigenlijk snijdt je in een gezond lichaam. Een gezond mens heeft hierna risico's op complicaties. Tegenwoordig gebeurt dat ook met levers en daarbij zijn de risico's nog groter. Ook hierbij zeggen wij tegen de overheid dat zij meer moet doen om het aantal post-mortale donoren te verhogen. Je moet er alles aan doen om te voorkomen dat het nodig is dat mensen bij leven iets gaan geven.

Telephonic interview with Eurotransplant at 31-01-2007

Introduction by Eurotransplant

Eurotransplant is verantwoordelijk voor mediation en verdeling van orgaandonatie in Nederland, België, Luxemburg, Duitsland, Oostenrijk en Slovenië. Groot-Brittannië valt hier buiten.

Eurotransplant richt zich niet op publiekscampagne of voorlichting. Wij beheren een wachtlijst, call-centre en allocatie computer. Dag- en nacht kunnen we, als een donor binnenkomt, een match maken. Dit zijn alleen post-mortale donoren.

Door de taken van Eurotransplant staat de organisatie van het beleid van ministeries; omdat het niet onder een bepaalde overheid valt. Deze situatie is anders voor omdat zij zijn aangewezen door de minister om op nationaal niveau allocatieverantwoordelijkheid te nemen.

Verder is het een idee om patiëntenverenigingen zoals de Nierstichting te benaderen. Mensen vrij zijn om te reizen. Het is daarom erg moeilijk om het centraal te regelen; je kunt mensen niet tegenhouden te reizen.

Is binnen Eurotransplant het fenomeen van transplantatie toerisme m.b.t. nieren bekend?

Ja, maar wij hebben summiere cijfers (zie bijlage).

Er zijn wel geruchten dat bijvoorbeeld vanuit Israël agressief beleid wordt gevoerd om nierpatiënten te helpen. Hiermee wordt een link met China gelegd.

China is vaak negatief in het nieuws. Mensen betalen dan 50.000 euro om een orgaan te bemachtigen. Deze komen van geëxecuteerde Chinezen. Op onze website verklaren wij ons tegen dit soort praktijken.

Heeft u harde cijfers van hoeveel patiënten naar buiten Europa gaan voor een betaalde ongerelateerde nier transplantatie?

Er zijn hierover geen cijfers bekend. Niet plaatsgevonden dat men het weet.

Het enige wat wij kunnen zien is als mensen van de wachtlijst afgaan. Dit kan twee redenen hebben: één ze zijn overleden of twee ze hebben een orgaan elders gevonden. Wordt dit ons verteld? Nee, er zijn meerdere gevallen bekend dat mensen van de wachtlijst worden gehaald. In één geval is iemand weer terug op de wachtlijst geplaatst. Deze persoon had elders een transplantatie gekregen, maar het is ons niet bekend of de nier van een familielid kwam of dat hier sprake was van een commerciële niertransplantatie. Wel moet gezegd worden dat wij pas sinds september 2005 werken.

Dat een persoon van de lijst af gaat kan een indicatie zijn, maar wij krijgen hier geen informatie over. Waarschijnlijk weet een behandelde arts hier meer over.

Wat is de positie van Eurotransplant t.o.v. transplantatie toerisme? Wat is de argumentatie hiervoor?

Wij zijn er tegen. Wij vinden dat het leidt tot exploitatie van de lokale bevolking. In geval van China worden hierbij ook de mensenrechten geschonden.

Cijfers laten zien dat er een internationaal nier tekort is. Wat zijn de gevolgen van dit tekort?

Er is wel sprake van een niertekort. Door een aantal factoren neemt dit niertekort in de toekomst toe:

- de vergrijzing speelt mee.
- de indicatie die bepaalt of je in aanmerking komt voor een niertransplantatie is ruimer gesteld. Je kunt dus eerder in aanmerking komen voor een niertransplantatie dan voorheen.
- de uitname technieken zijn beter en er zijn betere medicijnen; hierdoor kan en durft men meer dan vroeger. Men ziet minder risico om een patiënt een niertransplantatie te geven.

Cijfers van Eurotransplantatie van 2000-2005 laten een daling van het aantal patiënten zien op de wachtlijst voor een donor nier. Het aantal donoren laat over de periode 2000-2002 een daling zien. Over de periode 2002-2003 een stijging. 2003-2004 een daling en 2004-2005 een stijging. Hoe wordt deze daling van het aantal patiënten veroorzaakt?

In onze ogen is dit niet echt een fluctuatie. Het is meer een bandbreedte waar tussen de cijfers schommelen. Wel kunnen we zeggen dat het aandeel van levende nierdonatie is toegenomen. Dat is het enige wat we kunnen zeggen en wat we kunnen laten zien.

Hoe denkt u dat het (internationale) nier tekort opgelost kan worden?

Dit is mijn persoonlijke mening; ik heb hierover geen overleg gehad met het bestuur van Eurotransplant. Er zijn een aantal mogelijke oplossingen:

- Beschikbaarheid van zorgfaciliteiten. Het peil van de gezondheidszorg is aan de ene kant een indicatie. Welstand van de bevolking speelt een rol. Landen die stuk armer zijn en waar mensen een moeilijke toekomst tegemoet gaan daarvoor is het verleidelijker om een nier af te staan. Het is goed te begrijpen dat mensen dit doen om bijvoorbeeld de toekomst van hun kinderen veilig te stellen. De economische kant is absoluut een factor.

- Een factor die zeker speelt in Europa is het bewustzijn te vergroten om organen te doneren. In bijvoorbeeld Spanje is de bereidheid om organen te doneren groter. Maar hierbij moet wel rekening worden gehouden dat het aantal verkeersdoden daar hoger ligt dan in Nederland. Bij een geen bezwaar systeem heeft de familie minder kans om een donatie tegen te houden; tegen de vaak (niet geëxpliciteerde) wens van de overledene is de kans kleiner dat één familielid een donatie weet te voorkomen. Hierdoor zullen er meer donoren beschikbaar komen; dat scheelt naar verwachting toch wel ongeveer 10-20%.

Hoe denkt u dat transplantatie toerisme m.b.t. nieren opgelost kan worden?

Een goede zaak is als medische beroepsgroepen een beroepscode op stellen om transplantatie toerisme te voorkomen. Ze kunnen het betitelen als slechte zorg en hier geen medewerking aan leveren. Ik denk niet dat mensen gestuurd worden door een dokter; dus dat de dokter ze aanraadt om in het buitenland een niertransplantatie te laten plegen d.m.v. kopen van een nier. Maar als de paar gevallen waarbij dit wel gebeurd kunnen worden voorkomen dan denk ik dat het een goede zaak is.

Het lijkt me geen goede zaak dat als iemand na een dergelijke transplantatie uit het buitenland terug komt in Nederland deze van de nodige nazorg of medicatie te ontzeggen. Ik denk dat dit ook juridisch onmogelijk is. Daarnaast moet er eerst bewezen worden dat de nier van elders komt en dat deze gekocht is. Dat is moeilijk te bewijzen.

Als arts mag je geen voorwaarden stellen of je wel of niet een patiënt behandelt. Bijvoorbeeld, een arts kan niet een bankovervaller met een kogel weigeren te helpen omdat hij net een bank heeft overvallen. Dit is in het geval van een commerciële niertransplantatie ook zo. Op dit vlak denk ik dat je niet verder kunt komen dan een ethische code, maar dat kan ook veel kracht hebben. Wellicht dat je kunt kijken of er al een dergelijk code is. Je kunt hiervoor contact opnemen met KNMG (Koninklijke Nederlandse Maatschappij tot Bevordering der Geneeskunst). Deze organisatie ontwikkelt medische beroepscode's.

Wat ook interessant is, maar misschien niet bij je scriptie past is te kijken naar hoeveel mensen van buiten Europa naar Europa toe komen. De druk op het gezondheidssysteem in Europa neemt juist toe door druk van buitenaf en niet zo zeer van druk van binnenuit. Er komen mensen uit arme landen hier naar Europa en vragen medisch asiel aan omdat de gezondheidszorg hier kwalitatief beter is dan in het thuisland. Dit geldt voor alle vormen van medische zorg; medisch toerisme. In Nederland, België en Duitsland komen vaak uit Arabische landen mensen met geld die hier behandeld willen worden. Ik denk dat het aantal mensen dat naar Europa komt voor een medische behandeling groter is dan dat er vertrekt.

In België is dit probleem heel zichtbaar; men probeert dit door middel van wetgeving te voorkomen. Het is een hot topic daar.

Ook binnen Europa is er sprake van stromen mensen. Zaak is te trachten te voorkomen dat mensen bijvoorbeeld dubbel op de wachtlijst staan; in verschillende landen. Ook binnen Eurotransplant staan er mensen van buiten onze regio op de wachtlijst. Hier is wel een limiet voor vastgesteld maar deze limiet halen we bij lange na niet.

Iran heeft bijvoorbeeld de zorg gereguleerd. Iran zet zich actief in om transplantatie toerisme te voorkomen. Je kunt als niet-Iraniër alleen aan een orgaan komen in Iran als je zelf daar een donor tegenover stelt bijvoorbeeld een familielid of vriend. Dit is geregeld door de wetgever. De heer Gohd heeft hier een aantal interessante artikelen over geschreven.

Interview per e-mail with health insurance company VGZ/IZA

Kunt u een korte introductie geven van uw functie en uw zorgverzekeraar?

Ik beoordeel individuele aanvragen voor alle soorten behandeling in buitenland, ondersteun de inkoop van de organisatie bij contractering van buitenlandse ziekenhuizen en adviseer op medisch inhoudelijk en juridisch beleidsnivo over keuze'n tav buitenlandbeleid. Dit gebeurt voor VGZ/IZZ en Trias.

Heeft de zorgverzekeraar al een verzoek gekregen van een nierpatiënt om een (betaalde) ongerelateerde niertransplantatie in het buitenland (of te wel: transplantatie toerisme) te vergoeden? Zo ja, hoe vaak? Hoe heeft de zorgverzekeraar dit verzoek behandeld?

Recent voor het eerst. Dit is uiteraard afgewezen omdat (aan donor) betaalde transplantaties in Nederland wettelijk niet zijn toegestaan en dan uiteraard ook niet in het buitenland voor vergoeding in aanmerking komen

In een eerdere mail stelt u vast dat er geen sprake is van transplantatie toerisme omdat voor de Zvw er ook incidentiele verzoeken werden ingediend. Kunt u dit verduidelijken?

Er werd incidenteel een verzoek tot toestemming (nier of lever)transplantatie in België of Spanje ingediend in het kader van de bestaande wachttijden in Nederland. Meestal werden deze gehonoreerd.

Onder de huidige Zvw is het mogelijk om een niertransplantatie uitgevoerd in het buitenland vergoed te krijgen. Er zijn hier wel medische en formele voorwaarden voor vastgesteld. Wat zijn deze voorwaarden? Waar liggen deze vastgelegd?

Het moet uiteraard duidelijk zijn dat de patient naar Nederlandse medische norm aangewezen is op transplantatie (per aandoening verschillend, afhankelijk van het soort transplantatie). Hij moet dus minimaal beschikken over een verwijzing door een Nederlands specialist die de transplantatie in het buitenland onderschrijft. Er moet ook duidelijkheid zijn over de nabehandeling en kosten. Je kunt binnen Europa maar in één land op de Eurotransplantlijst staan, dus op de wachtlijst in België betekent wel dat je van de Nederlandse lijst af gaat.

Uw zorgverzekeraar vergoedt alleen een niertransplantatie mits de kosten niet meer zijn dan als de kosten in Nederland. Wat bedragen de kosten voor een niertransplantatie in Nederland? Is dit voor alle zorgverzekeraars hetzelfde?

Hier zijn vaste DBC's voor. De kosten inclusief alle voorbereiding en nabehandeling gedurende het jaar waarin de transplantatie plaatsvindt bedragen ongeveer Euro 40.000,- Met de opslag die per ziekenhuis verschillend is kun je zeggen dat het om minimaal Euro 50.000,- gaat, want kosten van andere specialisten komen er ook nog bij.

De kosten gelden voor elke zorgverzekeraar want ze zijn door de overheid vastgesteld

Hoe denkt u dat het nier tekort in Nederland opgelost kan worden?

Geen idee, donor zijn van organen is een vrije keus en niet elke donor blijkt uiteindelijk ook geschikt voor transplantatie

Hoe kunnen zorgverzekeraars hier aan bijdragen?

In een dergelijke schaarste markt kan een zorgverzekeraar ook weinig. We kunnen er niet meer "kopen".

Op welke wijze denkt u dat transplantatie toerisme voorkomen kan worden? Ziet u hier een bijdrage van de zorgverzekeraars weggelegd?

Het wordt niet vergoed, dat kun je communiceren. Maar als u bereid bent om in Pakistan een nier te kopen en de kosten van plaatsing zelf te betalen is daar bitter weinig tegen te doen.

Interview with Nederlandse Transplantatie Stichting at 13-02-2007

Korte introductie door NTS

Er zijn een aantal trends en zaken die uit elkaar getrokken dienen te worden:

- Europees beleid. Dit wordt gemaakt door de EG
- Beleid voor orgaan transplantatie. In Nederland wordt dit uitgevoerd door de NTS
- Samenwerking met Eurotransplant

Dit zijn de drie belangrijkste actoren die actief zijn in dit veld.

In principe is er de regeling dat mensen op de wachtlijst komen in het land waar ze resideren. Een Nederlander kan in Duitsland op de wachtlijst staan als hij daar woont.

Er is een uitzondering voor Nederlanders in Zeeuws-Vlaanderen. Dit komt omdat het dichtstbijzijnde transplantatie centrum Antwerpen is. De dichtstbijzijnde transplantatie centra in Nederland zijn Rotterdam of Maastricht. 10 jaar geleden was er veel meer transplantatie toerisme. Patiënten ontdekten dat de wachtlijsten in België korter waren omdat ze daar meer donoren hadden. De wachttijd was de helft minder dan die in Nederland. Dit creëerde een transplantatie toerisme richting België. Nu zijn er afspraken gemaakt met Eurotransplant en wordt er gecontroleerd.

Is er in Nederland zicht op transplantatie toerisme?

Binnen Eurotransplant geldt in ieder geval dat je maar op een wachtlijst tegelijk mag staan. Hier hebben we zicht op. Bij transplantatie toerisme naar arme landen ligt dit anders. Daar is geen sprake van een wachtlijst omdat je daar een nier koopt. Daar hebben we geen zicht op. We hebben alleen toezicht op de wachtlijst in Nederland. Als de patiënt terugkomt uit het buitenland dan moet het ziekenhuis de patiënt helpen. De arts kan dit niet melden omdat de arts dan het beroepsgeheim schendt. Het is nogal moeilijk om inzichtelijk te maken hoe het loopt.

Heeft de NTS van artsen vernomen of gehoord dat transplantatie toerisme voor komt?

Ik weet dat het gebeurt. Ik ken van incidenten gehoord Ik weet dat er situaties zijn dat mensen uit India naar India gaan voor een transplantatie. Het probleem is dat het hier ook om een familie transplantatie kan gaan maar dat weet je niet.

We kunnen wel zien waarom mensen van de wachtlijst af gaan. Er staat aangegeven hoeveel patiënten bij Eurotransplant een transplantatie hebben gekregen. In 2005 waren er 3 gevallen waarbij de patiënt buiten Eurotransplant een transplantatie heeft gekregen. Ik weet niet of dit een sluitend getal is en we weten ook niet waar deze patiënten een transplantatie hebben gekregen. Daarnaast zijn er 84 gevallen waar de reden om van de wachtlijst gehaald te worden "overig" is. Het kan zijn dat de arts kiest om dit als reden te geven en niet aan te geven dat de transplantatie elders is uitgevoerd. Er zijn mogelijk ook cijfers bekend van Eurotransplant. Die getallen kun je ongetwijfeld in jaarverslag vinden. Je moet dan kijken bij de out-flow van patiënten.

Ik vermoed dat het aantal patiënten dat via transplantatie toerisme aan een nier komt op een hand te tellen is.

Wat is het NTS standpunt t.o.v. van transplantatie toerisme zoals ik dat beschrijf in mijn master thesis?

Het is duidelijk dat we transplantatie toerisme in die zin afkeuren.

Levende niertransplantatie is niet zonder gevaar. Ook niet voor de donoren; het kan de kwaliteit van leven aantasten. Zeker in arme landen leidt dit tot een zorgwekkende situatie. Bekend is dat bij niertransplantatie in China deze nieren afkomstig kunnen zijn van geëxecuteerde Chinezen. In Nederland wordt de levende donor zowel voor- als achteraf gecontroleerd. Daarnaast ontvangt de donor een goede verzorging, in arme landen is dit minder vaak het geval. Transplantatie toerisme is daarom duidelijk af te keuren.

Wat zijn de risico's voor de levende donoren?

- Het kan voor komen dat de nier op een later moment niet meer functioneert. Het gevolg is dat de levende donor zelf in aanmerking komt voor een transplantatie of aan de dialyse moet. Maar met de gegevens die we nu hebben is dit geen reëel risico.
- Daarnaast zijn er de normale risico's van een operatie. Rondom of tijdens de operatie kunnen er altijd complicaties optreden waaraan je kunt overlijden. Dit komt gelukkig vrijwel niet voor.

Zijn er negatieve effecten voor de levende donor? Bijvoorbeeld dat de levende donor minder kan of eerder moe is?

Dat zou kunnen. Ik heb daar geen directe cijfers voor maar de NTS heeft de Nederlandse Orgaan Transplantatie Registratie (NOTR) opgericht. De NOTR registreert de follow-up van getransplanteerde patiënten in Nederland. Hiermee volgen we niet alleen getransplanteerde maar ook levende donoren. De eerste keer is 3 maanden na de nierdonatie en daarna na 1, 2, 5 en 10 jaar. Door de levende donoren te blijven volgen kunnen we onderzoeken of er op de lange termijn schade is voor levende donoren.

Is er op dit moment beleid dat transplantatie toerisme probeert tegen te gaan/te voorkomen?

Nee, want we weten niet hoe groot het probleem is. Als onduidelijk is of er een probleem is dan is er misschien wel helemaal geen probleem. Zoals ik al liet zien zijn er in 2005 3 patiënten op de paar honderd levende donoren naar het buitenland gegaan voor een transplantatie. In deze 3 gevallen is het niet duidelijk of er echt sprake is van transplantatie toerisme.

Maar er zijn geen geluiden vanuit doktoren dat het er is of dat patiënten steeds vaker naar het buitenland gaan?

Die indruk hebben wij niet.

Zou het kunnen dat transplantatie toerisme hier niet voorkomt maar in Groot-Brittannië wel?

Ik verwacht dat het transplantatie toerisme in Nederland veel minder is. Dat heeft ook een duidelijke historische reden. Groot-Brittannië heeft nauwe banden met India. In Groot-Brittannië wonen ook heel veel Indiaanse mensen uit India. Ik weet dit niet zeker of mijn suggestie juist is. Maar ik het me goed voorstellen.

Ik denk dat transplantatie toerisme geen goede zet is, niet alleen voor de donor, maar ook voor de ontvanger. In Nederland worden zowel de ontvanger als donor goed gescreend. Bijvoorbeeld welke nier past bij de patiënt. In andere landen, zoals India, wordt daar minder goed opgelet. Daar zegt men dat er een nier is en men kijkt niet of de nier een goede is voor de patiënt. De kans op afstoting wordt dan groter. Dit vergroot ook het risico op achteruitgang naar een afstoting.

In principe zegt u vanuit praktijk niet zo'n sterke geluiden en daarom geen beleid nodig?

Ja, we weten niet de omvang van het probleem. Het lijkt te gaan om incidenten. Alle partijen die betrokken zijn bij niertransplantatie en nierdonatie zijn negatief over transplantatie toerisme dus wat dat betreft zien we geen directe aanleiding om een grote campagne te voeren. Dit kan natuurlijk veranderen als blijkt dat een structureel probleem is. Er wordt wel over het onderwerp gesproken. Als bijvoorbeeld een arts een patiënt binnen in het transplantatiecentrum krijgt die hiervoor plannen heeft of het heeft laten doen dan vindt een arts dit vervelend. Het is best lastig om het goed inzichtelijk te maken omdat het toch plaatsvindt in een grijs gebied.

Transplantatie toerisme wordt veroorzaakt door de toenemende wachtlijst. Hoe kan het niertekort worden opgelost?

Over de afgelopen vijf jaar is de wachtlijst gedaald. Het aantal postmortale nierdonoren is rond de 400 en dat is ongeveer gelijk gebleven. Het aantal levende nierdonoren is sterk gestegen.

De wachttijd voor een postmortale nier is 4 tot 4,5 jaar. Voor een levende donor is er niet echt een wachttijd; dit ligt aan de beschikbaarheid van een levende donor. Levende nierdonatie heeft een hele grote vlucht genomen. Het is zelfs zo dat meer dan 40% van alle niertransplantaties komt van een levende donor.

Voor postmortale nierdonoren is er wel wachtlijst hoe kan deze opgelost worden?

Ik denk dat het een illusie is dat de gehele wachtlijst opgelost kan worden. Er zijn bijvoorbeeld patiënten die heel moeilijk te transplanteren zijn. Sommige patiënten hebben sterke afweerstoffen waardoor het heel moeilijk is om een goede nier te vinden. Ik denk wel dat de wachtlijst een stuk verminderd kan worden. Dit vereist een goede registratie van alle Nederlanders in het Donorregister. Op het moment dat je jezelf geregistreerd hebt dan is de kans op donatie vele malen groter dan als je niet geregistreerd bent. Het maakt niet of je "ja" of "ik laat het aan familie over" registreert. Dus het is goed als iedereen geregistreerd is. Gelukkig zien we dat de jongere generatie zich vaker registreert dan oudere generaties.

Welke manieren zijn er om het aantal transplantaties te vergroten?

Een van de manieren is de levende transplantatie. Dit ziet de NTS als een alternatief. Het liefst zien we dat organen van overledenen gebruikt worden, maar als dit niet mogelijk dan van levende donoren. Het is in ieder geval zo dat het altijd beter is om zo snel mogelijk te transplanteren zodat mensen zo min mogelijk aan de dialyse moeten. De kwaliteit van leven met een niertransplantatie is vele malen beter dan als je aan de dialyse zit.

Kan transplantatie toerisme voorkomen worden? Ook al gaat het in Nederland mogelijk alleen om incidenten.

Het kan worden voorkomen of verder gereduceerd worden. Hiervoor zou een meldingsplicht voor de arts kunnen worden ingevoerd. Dit gebeurt nu al bij bepaalde infectieziekten. Je zou daar op vele manieren naar kunnen kijken. Op het gebied van sekstoerisme is ook van alles mogelijk.

Maar dat loont nu zich niet in Nederland?

Nee, dat denk ik niet. Je hebt altijd maar beperkt budget als Nederland. Ik denk dat je dit beter kunt inzetten op andere zaken.

Een meldingsplicht gaat dat samen met het beroepsgeheim van een arts?

Ja, dan zou dat kunnen. Dat is puur het melden van het aantal patiënten dat naar buitenland is gegaan voor een niertransplantatie. Deze meldingsplicht is niet met naam of toenaam. Een meldingsplicht heeft niet tot doel om over te gaan tot vervolging. Dit is meer om het aantal patiënten in kaart te brengen.

Zijn er bezwaren tegen een meldingsplicht?

Zelf zie ik daar geen bezwaren tegen. Mensen kunnen natuurlijk hun klacht doen dat het toch inbreuk op privacy is. Waarom mogen mensen wel naar buitenland voor cosmetische chirurgie maar waarom niet om kwaliteit van leven te verbeteren.

Ik vind dat persoonlijk geen valide argument. Ik kan me voorstellen dat hierover een discussie kan ontstaan.

Is een meldingsplicht een eerste stap om transplantatie toerisme in kaart te brengen?

Ja.

Interview with Robert Evans, MEP for labour party on 7-3-2007

Short introduction

I was vice-chair of the committee Citizens' Freedoms and Rights, Justice and Home Affairs in the European Parliament. I was chosen as the rapporteur of the report "*Trafficking in human beings: prevention and control of trafficking in human organs and tissues*" (CNS/2003/0812) but it was a response on an initiative of the Greek government. It was really to make transplantation tourism illegal within the European Union. The parallel was that it is illegal for European citizens to go to third countries for the purposes of child sex tourism. You can be prosecuted in your own country you committed crimes in third countries along these lines. So the issue was whether it would be legal or illegal for EU citizens to go to third countries whether it was India, Pakistan, Turkey or Latin America for the purposes to getting a new organ or to buying a new organ. We particularly talk about kidneys but it could have been other organs as well. The main purposes was to prevent that anybody would pay money because none of their family members, friends or other volunteers would donate a kidney but the concern was that these rich Europeans who exploiting poor people who donated their organ not for voluntary reasons or to save Europeans their lives but for the money.

Before this there were a lot of discussions, debates and evidence needed to be taken. I got sympathy with people whose kidneys were failing but I don't think that this gives them the right to exploit poor people in other countries. There is a shortage in Europe of organs for transplant and some countries have a system, Belgium is an example, where it is presumed consent. Unless you say otherwise after death your kidneys and other organs will be used for transplants. In the United Kingdom and most countries you have to give your consent by a donor card or through a website such that if you are killed your organs can be used. If there were the presumed consent then there would be not probably a shortage of organs for transplant in Europe. Everybody who will be killed in an accident or die in a way that organs could be used those organs would be used for transplantation. This would be a good solution and I think almost overnight would stop the trade in organs.

Against that there are people who say that you can sell your house and sell your car voluntarily so why could you not sell one of the kidneys. I argue that you can ask then the question of "why don't you sell your child?" Would you then put the same argument on? And nobody would offer their leg or eye for transplant and offering a kidney is all very well but it is a serious operation to have a kidney removed. And you can function with one kidney but when that one kidney is failing then you are in serious trouble. The operations taking place, I have taken a look at this, in India and Pakistan. Westerners get good treatments and they are paying a lot of money for that. Poorer South-Asian people get worse treatments they have big scars and their life-expectancy is certainly not improved but most be curtailed. So we had lengthy discussions and debates in the European Parliament and in the Committee and amendments. I had meetings with all sorts of people who are involved in it. And it went to the European Parliament with figures that we can find for you.

I don't know the exact result of the voting but it was about 6 people abstentions, 0 against and around 500 in favour. That was I think in 2003 but we can check the dates. But since then nothing has happened. After that the proposal was sent to the Council but some countries who didn't agree on it. I think it was Sweden or Denmark. And the pressure of the supported countries such as the British and Greek government was not enough; none of them saw it as a priority. I asked the Council what happened not long ago and I was told that it was on the table in the Council. Since then the EU has enlarged first to 25 countries and now to 27 so the changes that we will get an agreement are fewer or less.

It was under attention of the European Parliament but when it went to the Council it stopped? There was a not unanimous vote?

It was not a co-decision report but a consultation report. The European Parliament consulted the Council but the Council did not do anything with it. There was a unanimous vote necessary.

Is the phenomenon of transplantation tourism of kidneys known the United Kingdom respectively the European Union?

It is illegal in the United Kingdom to buy or sell kidneys. I don't think it happens in the United Kingdom. I think it is also illegal in the European Union. If it is illegal to buy in the European Union then I don't see why it is not illegal to buy a kidney outside the European Union.

Is transplantation tourism a subject that has the concern the government in the United Kingdom?

It is on the back burner as we say. It is not something that has the priority of the British government on the moment.

What is the reason that the British government has not taken any action?

It is just concerning a few hundred or thousand people and they will need support of the other European countries and that support does not exist at the moment.

They are focusing more on things that are more of significant important such as child sex tourism.

Within the United Kingdom the British government did not take action to prevent that people would go abroad. It is illegal within the United Kingdom but they did not taken any action further.

Do you have data of the amount of patients that went in a certain period abroad (especially towards India if available) for an unrelated paid living kidney transplantation?

No but that is because it is a bit secretive. But I suggest that the figure is between 1000 or 2000. It is not clear. The people that do it are not open about it because they are not doing it because they are proud of it. They are not coming back and saying "I exploited a poor Indian and taken his or hers kidney". I can see their motivation but it is a black market. There are one or two examples to went public. There is a famous Norwegian guy who I met several times and he was prepared to talk about it but not many people want to talk about it.

What is your party's opinion on transplantation tourism? What is the argumentation?

It is not really discussed at the party political level. The European Parliament did not split over political lines. But again the Labour Government in Britain has not considered it as a particular priority to push it forward. Of all the issues of which they are concerned this is not a major one and also they know that there is not support from the other European Countries so they are not prepared to bother.

Do you see an increase of transplantation tourism?

I don't see a decline but I think that there is less publicity for it. The numbers are probably static within the region.

There are signs that the organ shortage will increase can that affect that transplantation tourism?

If the organ shortage is on the increase as you say then it is reasonable to expect that more people who are desperate. And I do understand that desperate people do desperate things. That is why it is important to encourage that more people donate their organs voluntary.

Is there at the moment one EU organ transplantation policy in development? Could you tell me more about this for instance at which stage this development is? Who had the initiative? Are there already documents available?

No as I say it is in the bands of all the issues the European Union is bothered about organ transplant is not the key issue at the moment. So when there is not a majority for it in the Council. There was a clear majority in the European Parliament but when the European Parliament send its decision to the Council and the matter came in Council nothing really happened. That is about three or four years ago.

I think it is strange because the European Union could cooperate and expand the amount of potential donors. Especially in the light of the expected increasing organ shortage.

Yes, it could within the European Union be much easier to find a suitable organ with the compatible blood type and tissue type etc. I would prefer it rather that people from London go to Italy or from London to Rotterdam instead that they go to Deli or another country outside the European Union.

I don't know if you know the case about China. But there were prisoners at death row whose organs where removed just before they were hanged or executed. Sadly a lot of people thought that they were going to die anyway.

If there is no EU organ transplantation policy in development is it something that will be developed in the near future?

As the Council said back is that it is not being thrown away it is a sort of sitting and waiting. At the moment nothing will happen but it might in the future. My thoughts are that it is not a priority for them and they probably won't. I don't know but it might need that a big event must happen or a tragic accident to occur.

Do you think and in what way could one EU organ transplantation policy contribute to prevent and stop transplantation tourism?

If the European Union countries all agree on the same policy and all agree we would have a presumed consent donation within the EU. We could then easily set up a system where hospitals and governments cooperate with each other and organs would be available. Most people would get their transplant in their own country but now and then there would be someone is transplanted in another European Union country. It is quite possible that the European Union is capable to set up a system but at the moment there does not seem to be the pressure for it nor the initiative from the European governments.

In Iran there is, since 1988, a government-funded, -regulated, and -compensated living-unrelated donor kidney transplantation program is this something that should be considered?

I don't think that it is necessary in Europe to have such a system if there were enough voluntary donors. There would be enough volunteers in Europe. If we look at Belgium has the system of presumed consent and there it is not a problem. We need a better system and better implementation. I am not sure if it is necessary to pay people to develop a sort of trade as they do in Iran where I was not aware of but I am not sure that it is necessary. I am personally not in favour of something like in Iran. I don't think you should encourage people. And if we look at Iran then that is not a place of good practice.

In what way could transplantation tourism be preventing and how could the (international) kidney shortage be solved?

There are two ways to prevent it:

- 1) You make it illegal. I think that should happen with European action. But as I mentioned before this will not happen.
- 2) You take out the need. If there are enough organs than people do not have to go outside Europe to buy one.

It is very different from the child sex tourism because that can not be addressed along these lines. But in this case the need can be taken away by supplying more organs available in the European Union by voluntary. That may be controversy itself by presumed consent but I think that peoples attitudes has changed the last years. People should be encouraged to fill in donor forms or to register.

What could the European Union do in order to prevent transplantation tourism and the kidney shortage?

The European Parliament already has expressed it views when it was with 15 member states it is now back on the Council. It is not an issue in the Council at the moment but the opportunity is there. The Council could make it illegal and force 26 governments to come in line with Belgium.

Is it possible that a reason that it is not an issue at the moment is that there is not a strong lobby from for instance kidney federations or transplant centres?

There is not a lobby at all as far as I know. But it is possible for kidney federations and transplant centres and doctors to lobby. They could do that. I think that it would open doors because people are willing to listen and interesting in but it is not enough a priority.

E-mail to the Dutch political parties in the Parliament with questions about transplantation tourism send on 28 March 2007

The following parties were sent an e-mail:

CDA, PvdA, SP, PVV, VVD, GroenLinks, ChristenUnie, D66, Partij voor de Dieren and SGP

Geachte heer/mevrouw,

Op dit moment studeer ik bestuurskunde aan de Erasmus Universiteit. Met een scriptie over "transplantation tourism" zal ik mijn studie afsluiten mijn begeleider is dr. J. Hakvoort. Gericht wordt op transplantatie toerisme richting India voor een levende betaalde donor nier. In het onderzoek wordt gekeken hoe en in welke mate landen hierop kunnen reageren en als case studies zijn Nederland en United Kingdom gekozen.

Een belangrijk aspect in de scriptie is hoe politieke partijen tegen transplantatie toerisme aan kijken en of het een politiek issue is. Voor deze reden worden alle Nederlandse politieke partijen gemaild met daarin de vraag of de volgende vragen beantwoord kunnen worden:

- *Is transplantatie toerisme m.b.t. nieren naar het buitenland (in het bijzonder naar India) bekend bij de partij?*

SGP: Nee

PVV: We hebben diverse achtergrondstukken over transplantatietoerisme bestudeerd.

GroenLinks: -

VVD: Ja, die berichten zijn reeds lange tijd binnen de partij bekend.

CDA: Transplantatietoerisme is bekend. Het is niet mogelijk om mensen tegen te houden om medische behandelingen op eigen kosten in het buitenland te ondergaan. Een ander voorbeeld zijn de stamcelinjecties die sommigen als laatste redmiddel na een herseninfarct in het buitenland ondergaan. Er zijn grote risico's aan verbonden en daar moeten mensen met voorlichting op gewezen worden.

- *Wat is het standpunt over transplantatie toerisme en wat is de argumentatie hiervoor?*

SPG: Wij vinden dit onacceptabel; geld mag nooit de reden zijn een nier af te staan

PVV: Dat mensen die een donororgaan nodig hebben proberen dat op alle mogelijke manieren voor elkaar te krijgen valt te begrijpen, het mag echter nooit zo zijn dat arme en kwetsbare mensen uit andere landen de dupe worden van handel in organen en weefsel. Dit is verschrikkelijk en keuren wij ter zeerste af. Orgaandonatie moet op nationaal niveau geregeld worden en internationaal uitsluitend na het maken van goede afspraken met andere landen.

GroenLinks: GroenLinks vindt 'orgaan toerisme' een bijzonder slechte zaak. Dergelijke vormen van orgaandonatie zijn verwerpelijk en ethisch onverantwoord. Zeker wanneerin achterstandsposities (mensen die hun kinderen honger zien lijden) hiervoor worden beanderd. Er is maar een manier op deze vormen van toerisme te voorkomen en dat is door ervoor te zorgen dat er in Nederland voldoende donoren zijn.

VVD: Transplantatietoerisme is een kwalijke zaak om een aantal redenen. De manier waarop de organen verkregen worden is op zijn zachtst gezegd zeer dubieus. Kwetsbare mensen zijn ongewild slachtoffer van lugubere praktijken. Aan de verkrijgende kant worden hopeloze patiënten voor een duivels dilemma geplaatst. Er is geen controle op kwaliteit, manier van verkrijgen enzovoorts, voor alle partijen zeer riskant.

CDA: De CDA fractie is van mening dat goede voorlichting over risico's van transplantatietoerisme wenselijk is. Ook is toezicht van de Inspectie voor de Gezondheidszorg nodig op eventuele tussenpersonen die vanuit Nederland reizen met een medisch doel aanbieden.

- *Is transplantatie toerisme een onderwerp dat speelt binnen de partij? Waarom wel of niet?*

SGP: Nee; mocht het wel aan de orde gesteld worden in de politiek, dan zullen we onze bezwaren kenbaar maken

PVV: Het onderwerp speelt binnen de partij op dit moment nog niet. We vinden het wel een belangrijk onderwerp.

GroenLinks: -

VVD: Ja, transplantatietoerisme speelde en speelt met name binnen de partijcommissie Volksgezondheid een rol. Meerdere malen zijn er belangwekkende discussiebijeenkomsten geweest over de vraag of een systeemwijziging van ons donatiesysteem ertoe zou kunnen bijdragen een groter donatiepotentieel te creëren. Daarbij is het transplantatietoerisme uiteraard veelvuldig aan de orde geweest als zeer ongewenst effect van het te kleine potentieel.

CDA: -

- Is er beleid in ontwikkeling dat transplantatie toerisme kan voorkomen of stoppen?

SGP: Te weinig over bekend wat ons betreft.

PVV: Voor zover wij kunnen nagaan heeft de regering op dit moment nog geen beleid in ontwikkeling m.b.t. transplantatietoerisme.

GroenLinks: -

VVD: Er is binnen ons huidige donorsysteem ingezet op verhogen van het potentieel door betere en intensievere voorlichting, meer benutting van de expertise van donatiefunctionarissen, versterken van flankerend beleid, actievere registratie(pilots met paspoorten e.d.) en heel belangrijk: naleving laatste wil/wens door arts!

CDA: -

- Transplantatie toerisme is een ontwikkeling die mede veroorzaakt wordt door een nier tekort. Wat ziet de partij als een goede oplossing om het nier tekort te verkleinen? Is het nier tekort een belangrijk issue in de partij?

SGP: We steunen beleid van de regering om zoveel mogelijk donoren te werven, en mensen te stimuleren codicil in te vullen; verder steun aan onderzoek naar alternatieven

PVV: De kansen m.b.t. tot het tekort aan nieren ligt op drie terreinen. In de eerste plaats het werven van donors. Het beleid daarvoor willen wij niet wijzigen, het mag wel worden geïntensiveerd. Ten tweede moeten we zorgpasfraude (waardoor het mogelijk is dat mensen uit het buitenland op naam van een familielid of kennis in Nederland een donororgaan krijgen) effectief bestrijden. Het aankomende in te voeren Burger Service Nummer biedt daarvoor mogelijkheden en er moet er duidelijkheid zijn over dat niet-Nederlanders niet in aanmerking komen voor in Nederland beschikbaar gekomen organen (met uitzondering van organen waarvoor in Nederland geen geschikte patiënt gevonden kan worden en idem dito vanuit het buitenland) Ten derde is het goed mogelijk om te leven met één nier in plaats van twee, waardoor familie of vrienden kunnen overwegen een nier te schenken aan een patiënt. Dat deze mogelijkheden voldoende worden besproken lijkt aannemelijk. Dat er door de uitspraak van de Gezondheidsraad over dat het ruilprogramma voor nieren onwettig zou zijn minder nieren beschikbaar kunnen komen is een slechte zaak. In de aankomende vergadering op 4 april zal ik de regering met spoed om een kabinetsstandpunt vragen.

GroenLinks: GroenLinks betreurt het dat er geen kamermeerderheid is voor de invoering van het ADR-systeem. Bij dit systeem wordt je de keuze voorgelegd: niet reageren is ja ik word donor, wel reageren is nee ik word geen donor. GroenLinks is groot voorstander van dit systeem, omdat onderzoek heeft aangetoond dat het aantal orgaandonaties fors zal stijgen bij het ADR-systeem. Nederland heeft een groot tekort aan organen voor transplantaties. Invoering van het ADR-systeem was daarom de oplossing geweest. GroenLinks zal blijven pleiten voor het ADR-systeem en zal binnen het huidige systeem het maximale eruit proberen te halen. De minister zal geprikkeld moeten worden om fors te investeren in het opkrikken van het aantal donors. Geen ADR-systeem, dan maar in de buidel tasten en de creatieve geest laten werken. Want als we niets doen zullen duizenden mensen nog langer op een orgaan moeten wachten en misschien wel overlijden.

VVD: Om niertekorten tegen te gaan: naast bovenstaande middelen en maatregelen pleit de VVD voor onderzoek en ontwikkeling naar innovatieve vervangende mogelijkheden van dialyse. (denk aan kunstnieren etc.)

CDA: Het tekort aan nieren en andere organen is een grote zorg. Ik heb destijds een motie ingediend met een aantal voorstellen om te komen tot een verhoging van het aantal orgaantransplantaties in Nederland. U kunt deze motie en mijn inbrengen over orgaandonatie lezen op mijn website www.henkjanormel.nl onder standpunten/volksgezondheid.

Graag hoop ik dat u partij medewerking hieraan wilt verlenen zodat de informatie verwerkt kan worden in de master thesis en er een volledig beeld ontstaat.

Alvast bedankt,
Met vriendelijke groet,

Karin Dietvorst