

The fairness chameleon



'De beloning van rechtvaardigheid' (the reward of justice) museum Boijmans van Beuningen Rotterdam the Netherlands

'Values and valuation in action'

Master Thesis HEPL

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“The world is not a solid continent of facts sprinkled by a few lakes of uncertainties, but a vast ocean of uncertainties speckled by a few islands of calibrated and stabilized forms” (Latour, 2005)

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Preface

The integration of sciences in one masterprogram to study health care was the reason for me to choose the master HEPL. It gave me the opportunity to learn more about each science, her theories and approaches. The integrated classes during the HEPL were helpful to debate and analyse questions compromising different aspects of health care by using approaches from health, economics, policy and law sciences. Questions relating the allocation of health care were often subject of debate and they intrigued me.

During integrated classes I was questioned why I considered certain measures to be either fair or unfair. Subsequently I would be looking for words to provide solid arguments. Thanks to my fellow HEPL students and the supervisors, often forcefully arguing from their disciplines, these debates were a challenge to participate in. Debates, literature and the essays I had to write, gave me more insight in approaching and analysing questions on fairness of allocation.

The master thesis gave me the opportunity to further understand how to treat the concept of distributive justice and fairness of allocation in practice. I chose a governance approach for my research, mainly because I felt this would challenge me most. It would give me the possibility not only to use a theory to argue on distributive fairness, but also to think about the consequences for governance.

Although I was enthusiastic about this subject, the question raised: how to approach such a complex and vague concept? To my great pleasure Teun Zuiderent-Jerak agreed to be my supervisor. He supported me throughout the process of writing my thesis. Here I express my gratitude for his support and especially for learning so much from our talks about performing research and trying to think out of the box. Also I hereby would like to thank Kor Grit and Roland Bal, for being co-evaluators of my thesis.

To be able to perform the case study for my research I would like to thank all the respondents that have participated in the interviews, with a special thanks to Jan de Boer of Eurotransplant.

For the joy I had in- and outside class, I want to thank all my fellow HEPL students and especially Guido. I think our mutual study started a friendship for life. To my family and friends, many thanks to your interest in my thesis. A special thanks to Hans, for your support and wise words throughout my master and my thesis. Dear Patrick, thank you for your support, enthusiasm and creating the best environment to study in.

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Abstract

Scarce public resources in health care can be valued in a certain manner and by different means to create fairness in their allocation. By using economical and philosophical theories on the concept of fairness arguments can be put forward whether a system of allocation is (un)fair.

Optimal use of scarce resources may be identified to be the leading principle of allocation and valuation of resources is assumed to go in accordance to create an optimal result. Third parties, legislation, protocols and rules are examples of instruments that are used to ensure for this (pre)intended valuation to allocate scarce public resources.

A constructivist view in research on values and valuation, used by Latour in his essays on policy processes, is that they are embedded within practice. This view challenges the assumption that valuation is a matter of design and implementation. Valuation, once translated into practice, may cause a dynamic that creates both intended and unintended effects. The implication for research on a valuation system is that a detailed study on valuation in practice is needed to get an understanding of the actual valuing of resources that is taking place.

For the thesis at hand a case study was performed on the valuation system to allocate post mortem donor kidneys in the Netherlands. Together with six other countries, the Netherlands participate in Eurotransplant to carry out the responsibility of allocation. Eurotransplant allocates post mortem donor kidneys by the use of different programs, but the ETKAS computer driven system is the main program to allocate. By interviewing some of the key members in Dutch donor kidney allocation an understanding is created in the valuation and allocation of post mortem donor kidneys in the Netherlands.

The findings of the case study are in line with constructivist theories and Latour's approach in research on values and valuation. Values and valuation are embedded within practice. The interaction of multiple variables in one system creates a complex dynamic that causes both intended and unintended effects in valuation. Next to the system itself, beliefs and behaviours of actors, political pressure, institutions and institutional arrangements influence the valuation and hence composition of fairness in allocation.

For research on a valuation system this implies that detailed research in practice is needed to understand the valuation and composition of different notions of fairness that is taking place by the system itself, the actors, the institutions and the institutional arrangements. Not only does research have to focus on effects that are created by single variables in the valuation system, but also what these effects implicate for the eventual outcome of valuation. For governance this implies that governing a valuation system needs redefining to decide what counts and what matters, which urges awareness and alertness in the actual valuing that is taking place in practice. To be able to redefine valuation detailed research in practice is needed.

Introduction

How to allocate scarce public resources?

Many scientists from different life sciences perform research on the concept of distributive fairness in health care (Helgesson et al. 2014, Starfield 2001, Braveman 2006, Wagstaff & Van Doorslaer 1998:4, Anand et al. 2006).

One important feature of research in relation to fairness of allocation in health care is to create a moral understanding by relating to classical philosophical theories and to political philosophical theories. Egalitarianism, libertarianism and utilitarianism are examples of these political philosophical theories (Rawls 1971, Roemer 1998, Marchand et al. 1998, Den Exter & Buijsen 2012:124).

By using theories and their associated frameworks for research on fairness of allocation arguments can be provided in judging whether a certain healthcare policy or measure should be considered (un)fair (Le Grand 1987, Wagstaff & Van Doorslaer 1998, Roemer 1998, Peter 2001, Marchand et al. 1998). Efforts in research are also performed in the question of how distributive fairness or equity could or should be measured (Roemer 1998, Wagstaff & van Doorslaer 1998, Culyer & Wagstaff 1993, Culyer et al. 1992).

Creating a moral understanding by relating to philosophical theories shows how definitions of the concept of (distributive) fairness seem to remain constant over time. Swierstra (2011:14), in his inaugural lecture on moral and technique, makes this point as follows “many ethics are staying heirs of Plato ,who equalised absolute to true and changeable to fiction.” Swierstra (2011:8) seems to question this liaison between absolute and true by arguing that “everyday technique can change people’s judgement of what they first considered to be fair, because of the information these techniques provide them with.” The first challenge of the thesis at hand is to research a question of allocation, aimed to be fair, and to understand what fairness entails once it is translated and functioning in practice.

Health care-, and/or health care related policies can be aimed to create fairness of allocation and distribution. Fairness of allocation might be expressed by politicians, health advisory committees, NGO’s, in health policy programs, legislation and attached memoires of memorandum (Evaluatie Orgaanontatie , Van der Geest 2005, 2008). The identification of fairness to be the aim of a certain health care policy or measure might be to use this in public policy analysis to explain actor’s behaviour, institutions, and institutional arrangements. However, the expression or identification of fairness does not give information on the concept itself.

What happens if instead of treating fairness as a given entity, used to explain actor's behaviour, institutions and institutional arrangements, the concept itself is treated as the one to be explored? The second challenge for the thesis at hand is to provoke a different starting-point in public policy research. Instead of regarding fairness to be a static and explanatory variable, to treat it as being an outcome that has to be explained.

An example on this approach on values in research is given in the forthcoming volume 'value practices in life sciences' (Helgesson et al. 2014). In chapter 7 of this forthcoming volume, Philip Roscoe (2014) examines the allocation of post mortem donor- kidneys and livers in the UK. Roscoe performs research on the development of a national valuation system to allocate post mortem donor kidneys to possible recipients on the waiting list. The system provides an outcome to make the decision which person on the waiting list will receive an available kidney.

Roscoe's research (2014) is an example of a case study that shows how a scarce public resource aimed to be allocated on principles of equity, is valued in and by practice. Roscoe's findings show that not only actors, institutions and institutional arrangements, but also the system itself influences the eventual outcome (Roscoe 2014).

Regarding the shortage of post mortem donor kidneys available in the Netherlands compared to the amount of people on the waiting list to receive a kidney the presence of the question *who receives a kidney and why* is evident [figures 1-4 index]. The Dutch Transplantation Foundation, responsible to implement the Law on Organ donation, declares she aims for a fair allocation of donor organs (NTS).

For the thesis at hand, the study on the allocation of post mortem donor kidneys in the Netherlands seems suitable to create an understanding of what fairness entails once it is translated into practice. Due to the complexity of a computer driven system this system can be used to further understand how this may create its own effects in allocation and in shaping fairness in practice. Furthermore, the governmental responsibility in relation to allocating post mortem donor kidneys, provides a suitable research case in what findings of research entail for governing a valuation system.

The eventual challenge of this thesis will be to answer the following central question:

How is fairness enacted in a valuation system to allocate?

Sub question 1: A valuation system: a matter of design and implementation?

The first sub question relates to chapter 2, which makes up the theoretical framework.

Sub question 2: How is a valuation system shaped in and through practice?

The second sub question will be central in chapter 3, the case study.

Sub question 3: What are the implications for policy instrumentation?

The possible implications for policy instrumentation will be enlightened in chapter 4, the discussion.

Chapter 2 Theoretical framework

A valuation system to allocate: a question of design and implementation?

2.1 Introduction

The theoretical framework of this thesis will explore whether a valuation system for a scarce public resource with a governmental duty to allocate is a matter of design and implementation. Next to theories on analysing public policy, Roscoe's research (2014) on the UK's post mortem kidney allocation system will be used to answer this question.

2.2 Governmental responsibility and policy instrumentation

In the Netherlands the responsibility to implement public values is often delegated to third parties beside government (Zuiderent-Jerak et al. 2014, Van der Grinten & Kasdorp 1999). Executive agencies, often made up by policymakers, scientists and economists in the field of health care, are one example of such third parties functioning besides government, who have a delegated governmental responsibility to establish and implement healthcare related policy programs and legislation. Third parties and legislation are frequently used policy instruments by Dutch government to realize the allocation of scarce public resources (WRR 2012, SER 2010).

The aim to base allocation of scarce public resources on certain values and principles might be expressed in debates, (health) policy programs, legislation, and attached memoires of memorandum. Policy instruments, legislation and the use of third parties, are used and are apparently considered capable, to ensure values and principles of an allocation system (Zuiderent-Jerak et al. 2014:2, WRR 2012, SER 2010).

It may vary on which level, local, regional, national and cross-border, allocation takes place and by which means. A computer driven system to allocate may considered to create objectivity in allocation (Hippen 2009). The question that rises is whether the creation of a system to valuate resources to allocate them ensures for the principles and values that are aimed for?

2.3 Public policy research, theories and the role of values

Current research on public policy does not, generally, assume that policies are implemented in line with how they were or are intended (Buse et al. 2005:121). Although it can be intended that valuation takes place on certain notions of fairness, in practice valuation might be different. Sociologists and public policy analysts often explain for this discrepancy by relating to actors and their behaviours and to the role of institutions and institutional structures and arrangements (ibid:120). Economists have developed their own theories, which may focus on the relationship between principal and agent

(ibid:127-130). All of these theories have in common that they try to explain the gap between intention- and eventual outcome of a public policy (ibid:123-130).

A research perspective to analyse public policies can have a retrospective or prospective look. A specific focus on the actors surrounding the policy process consists of identifying the range of stakeholders, assessing their political resources, power and interests (Buse et al. 2005:176-179). The focus of research might also be on institutions and institutional structures to analyse a gap between policy intentions and outcomes and changes in policy (Lascoumes & Le Gales 2007:4).

Identifying which meanings of distributive fairness underlie a certain (health) policy program can bring understanding in the behaviour of actors (Buse e.o. 2005, Lascoumes & Le Gales 2007).

Reasoning from a network approach, identifying notions of fairness might be important because they can explain why actors are in a network or why the network is threatened to remain constant (Sabatier 2007:142-143).

The assumption that once notions of (distributive) fairness and the means by how to accomplish distributive fairness are (pre)defined will remain static and constant and can be ensured for, by third parties, is challenged by the results of multiple studies (MacKenzie, Muniesa, and Siu 2007; Sjögren and Helgesson 2007; MacKenzie and Millo 2003; Zuiderent-Jerak and van der Grinten 2009; Callon, Millo, and Muniesa 2007 in Zuiderent-Jerak et al. 2014:2-3). Results show that notions of fairness are composed in governmental arrangements, ensuring and shaping them in practice. Therefore the focus of governance and research needs to be based on the composition of these notions of fairness in governance arrangements' (Callon 1987; Latour 2007; Zuiderent-Jerak and van der Grinten 2009 in Zuiderent-Jerak et al. 2014:3).

Values may be predefined, but arguing from a constructivist point of view, are embedded within (technical) practice (Latour 1987, Helgesson et al. 2014). Latour addresses the question whether values and knowledge can assumed to be separated or left untouched from their practical setting and argues that, in accordance with the view of constructivism, because knowledge and values are embedded in- and are shaped by practice they cannot be separated from their practical setting (Latour 1987 & 2002). Values in practice are not parted from each other, they intertwine as well as they might conflict with each other (Helgesson et al 2014).

Latour's approach regards to 'how technology itself becomes a manner of moral exploration and translation' (Latour 2002 en Roscoe 2014:16&26). Creating room in research for the technical apparatus of the system itself seems to overlap with the public policy instrumentation approach (Lascoumes & Le Gales 2007 & Sabatier 2007). Instruments themselves can be producers of values and create their own effects, which shows the need to study on how the technical apparatus works in practice, to study on effects that are produced (Lascoumes & le Gales 2007:4-10).

For research this would mean that a system of valuation that is designed in a certain matter, for example with the intention to have ‘need or urgency’ to be a prior factor in allocation, is influenced in its functioning in practice by the ‘actors’, the institutions, the arrangements and by the system itself.

2.4 valuing in practice

Roscoe, in his research on the NHS’s system of donor organ allocation in the U.K, takes on a constructivist view on values by exploring how value is enacted in practice. In his research, Roscoe turns to Latour by declaring, ‘Valuing, in the case of transplantation, is inseparable from knowing: value depends upon the epistemic – what is known and what is worth knowing’ (Roscoe 2014: 3, Latour 1987).

In his research on the UK’s donor kidney allocation system, Roscoe pays attention to behaviour of actor’s, dealing with kidney transplantation and allocation in their daily practice. Statements from interviews in Roscoe’s research suggest that, although one of the reasons behind developing one national system for kidney allocation was to create unity, objectivity and transparency, doctors operating in the field of donor transplantation and allocation do not always follow the rules of the system (Roscoe 2014: 23). Moral and clinical considerations of doctors may influence the eventual valuation of a kidney available.

In the UK’s system the concept of ‘equity’ is expressed to be the leading principle. Roscoe shows how value is enacted in the computer-driven allocation system for kidneys by models, simulations in an algorithmic formula. By this system, or technical apparatus as Roscoe refers to it, the decision is made who gets an available kidney and how this reveals ‘what matters and what counts’ in the valuation of donor organ kidneys (Roscoe 2014).

Roscoe interviewed members of the UK’s NHS advisory committee on kidney allocation and quotes one of the surgeons, who explains that the intention behind systemising the allocation of kidneys was to ensure equity of access across the UK (Roscoe 2014:10). It becomes clear in Roscoe’s research from interviews as well as from his examination of the protocols, models and the algorithm used in the allocation of kidneys, how the main principle of valuing an available kidney is by how the donor’s HLA (human leucocyte antigens) matches with the HLA of a potential recipient on the waiting list (Roscoe 2014:11&15).

In line with a constructivist view, Roscoe shows the possible intertwinement and conflict between variables, for example how the factor of waiting time conflicts with the factor of HLA matching. Although both variables are taken into account in the algorithm due to a difference in weights and point scores attached, the one has a prior influence over the other and in this example constitutes equity (Helgesson et al. 2014, Roscoe 2014:11).

Roscoe shows that the eventual outcome is partly intended, reflected by the weights attached to the variables, and partly unintended. Waiting time was expressed to be an important variable, in practice it turned out to not really influence the eventual outcome. The interaction of variables in practice also led to negative effects for ethnic minorities on the waiting list (Roscoe 2014:25). By the time these unintended effects became visible, an adjustment was made to some extent to create a higher probability for ethnic minorities to receive a kidney (Roscoe 2014:11).

What the negative effects and the adjustment actually entail is not part of Roscoe's research. But the example does show how valuation of a scarce resource, in this case donor kidneys, in practice is enacted, which urges redefinition of what constitutes fairness and readjustment of the system to create this.

2.5 creating a valuation system; a matter of design?

Roscoe's research is an example that can be used to understand how a valuation system might work out differently in practice compared to how it was designed to function. It shows how in practice, the actors and institutions involved, the technical apparatus of the system and the arrangements in which the system is governed influence the valuation of a scarce resource. In line with a constructivist perspective towards values and valuation in research and with a focus on instruments provided by the public policy approach, practice and technology itself are central for moral exploration and translation. In practice values, both intentional and unintentional, are enacted. Also the presence of different notions of fairness, translated in different variables that are all part of one system, raises the question whether arguing that a valuation system is a matter of composition of notions of fairness sufficiently takes account of the tension and conflict these different notions cause and how they affect each other in defining fairness of allocation.

The next chapters will be used to further analyse the shaping of a valuation system in and through practice.

Chapter 3 Case Study

In what way is a valuation system shaped in and through practice?

3.1 Type of research

The central question of this chapter ‘In what way is a valuation system shaped in and through practice?’ is based on the assumption that a valuation system *is actually* shaped in and through practice. The theoretical framework, chapter 2, provides several starting-points for research.

A constructivist view on values considers values to be embedded within (technical) practice. The system to value available post mortem donor kidneys in the Netherlands seems to be an appropriate case to understand how valuation is shaped in and through practice. The scarcity of post mortem donor kidneys shows that a decision has to be made who gets a kidney and on what basis this decision is made. The allocation is part of a governmental responsibility and is performed by the use of a computer driven system to create fairness in allocation. Figure 1-4 in the appendix provide a more detailed look in mortality-, dialysis-, and waitinglist figures.

The possible gap between intentions to value and the outcomes of the allocation system might be explained for by the behaviour of actors, by institutions, institutional structures and arrangements and by the technical apparatus of the system itself. Therefore attention will be paid in research on actors, institutions, institutional arrangements and the technical apparatus.

3.2 Methods

To understand how, next to actors, institutions and institutional arrangements, the complexity of the technical apparatus itself creates, transforms and shapes valuation research methods are used that seem best capable to capture not only the organisational setting, but also the technical setting of valuation. Assuming valuation to happen in and through practice creates a need to closely observe how, by who and by which means and techniques valuation happens in practice and hence what fairness of allocation is composed of.

Therefore central settings in which valuation and debates on valuation take place are closely observed. Observations are performed at (HLA)tissuetypings meetings, Eurotransplant’s annual meeting, patientgroup meetings and the allocation desk of Eurotransplant. Guidelines, protocols and research on valuation and allocation are closely examined. Face-to-face interviews with the key members in Dutch donor kidney allocation are performed. To be able to create a further understanding a semi-structured interview method is employed. Table 1 provides an overview of the respondents.

In summary, close observations on central settings and interviews with key actors are used as qualitative research methods to create a detailed understanding of the organizational and technical setting to capture the dynamic practice of valuation.

Paragraph 3.3 will provide information on the organisational setting of Dutch post mortem donor kidney allocation and how the system is governed. Paragraph 3.4. will explain the technical setting, the allocation system.

Table 1: Respondents

Nephrologist	Professor Internal medicine, Nephrology and Transplant Head of Nephrology department Erasmus MC
Policy worker	Senior Policy worker NTS
Research scientist	Research scientist NTS
ET secretary kidney committee	Secretary general Eurotransplant kidney advisory committee
ET coordinator Education	Coordinator Eurotransplant Education and Training

3.3. Organisation of post mortem donor kidney allocation

3.3.1 Introduction

In 1996 Dutch legislation on organ transplantation was revised in a new Law On Organ donation (WOD). By law the Dutch Transplantation Foundation, the NTS, is responsible to act as an agent in the allocation of organs (art. 24 WOD). The implementation and accomplishment of the WOD is part of a governmental responsibility of the Dutch Minister of Health, Welfare and Sport (art. 1 WOD). This governmental responsibility is delegated to the NTS (art. 24 WOD). The policy worker declares that the NTS presents her performances to the Minister of Health by yearly reports.

In their turn, the NTS has passed the actual carrying out of allocation of donor organs to Eurotransplant. Historical participation of the Netherlands in Eurotransplant is explained to be the reason why actual realization of allocation is Eurotransplant's task.

The organizational structures of Eurotransplant existed before the start of the NTS, as well as the collaboration with other countries in organ allocation...the NTS is primarily responsible, and we participate and can have our say, if Eurotransplant introduces rules that would conflict with Dutch legislation this would not be possible or if there would be arrears in for example the algorithm we would inform them. (Policy worker)

Eurotransplant has a policy in which it allows country specific rules. The Netherlands almost does not have any country-specific rules. "The Netherlands cooperates in most of the rules that are introduced" (Policy worker). Eurotransplant and the NTS are situated in the same building. "Our experiences in working together with Eurotransplant are positive, the current director of the NTS used to work at

Eurotransplant...we used to work together with Eurotransplant in the same office rooms, but now we are more autonomous and our collaboration has become more formal” (Policy worker).

The NTS declares she is responsible for implementing legislation in relation to organ donor legislation and she is, among others, responsible for a *fair allocation* of available organs in the Netherlands and for monitoring her performance in doing so (website NTS). Eurotransplant’s ethical charter declares “Eurotransplant shall ensure that the allocation of organs under its responsibility be guided by clinical and ethical criteria, and allocation rules are defined by appropriately constituted committees, based on principles of fairness, equity and transparency, and in accordance with domestic regulations of the member countries” (Eurotransplant ethical charter:3).

Having a closer look at rules from legislation to allocate donor organs creates the understanding that by law “no factors are accounted for in the allocation of donor organs except for blood- and tissue matching between donor and recipient, the recipient’s medical urgency and need, factors surrounding the condition of the organ, and in case none of the before mentioned factors give exclusion, the waiting time of the recipient” (Art.18 WOD).

The NTS clarifies that the amount of time on the waiting list for each potential recipient depends on the availability of a suitable organ by Eurotransplant (NTS). And she further explains that by delegating the allocation of post mortem donor organs to Eurotransplant, the Netherlands is part of a collaboration of seven countries together participating within Eurotransplant, which increases the amount of potential matches between a donor and a recipient. The NTS maintains its responsibility for a fair allocation and for monitoring this (NTS).

Above statements on donor allocation give some insights in values and principles, like fairness, need, urgency and waiting time, that may surround allocation and the role of more clinical factors in allocation, like blood- and tissuematching and condition of an organ. Together with information on the means by which it is believed how more potential matches can be found. The NTS and Eurotransplant are apparently assumed to ensure for these values and principles, which shows an example of how third parties are believed to be efficient and capable in doing so (Zuiderent-Jerak et al. 2013:2). Subparagraph 3.3.3 will provide more information on the involvement of countries, parties and committees in allocation policy.

Looking at Eurotransplant’s ethical charter shows that the aim to reach fairness of allocation is optimal use of a kidney. Eurotransplant expresses the need and well-being of the patient as her core principle (Ethical charter:1&2). Allocation of available organs is argued to be based on:

Eurotransplant shall ensure that the allocation of organs under its responsibility be guided by clinical and ethical criteria, and allocation rules that are defined by appropriately constituted committees, based on principles of fairness, equity and transparency, and in accordance with domestic regulations of the member countries... primarily on clinical criteria (need, urgency, match, other aspects related to both the donor organ and the recipient) and accrued waiting time,taking into account ethical principles, and without regard for personal, social or financial background...

As Eurotransplant operates on the basis of international cross-border collaboration and exchange of organs, its procedures for allocation across participating countries must take into account the principle of solidarity within each country (to be implemented through a mutually agreed balancing system). (Ethical charter:3)

Values and principles are translated in a system by the use of input-variables with different weights attached in a, for each organ developed, protocol for allocation by Eurotransplant (ETKAS). Each time a kidney becomes available the computer driven system provides an outcome, based on an algorithm in which all variables are accounted for and this outcome shows who on the waiting list has the highest score for the particular kidney available. To create fairness of allocation it is assumed that the means by how to reach this is by having a system that is based on transparency and objectivity.

Eurotransplant expresses that one of her main aims in donor allocation is to secure for a transparent and objective allocation system (ethical charter:1). ETKAS can be referred to as being Eurotransplant's computer driven- and main program in relation to allocation of organs.

Before the start of Eurotransplant in 1967, allocation of post mortem donor kidneys in the Netherlands took place on a local level. Patients were both depending on whether a donor was available at the centre where they were treated as well as whether their blood group matched with the donor's blood group (website Eurotransplant). Looking at system's used by other countries not every country allocates post mortem donor kidneys by the use of a computer driven system. Not having a system might cause allocation to be the responsibility of a doctor or centre.

Although for looking at any effects, whether they come from a change of policy, a difference in system based either on permission or on objection or the amount of money to spend, it all does not really seem to matter if one looks at the graphics on waiting lists, inflow and outflow and transplantation performed over a longer period of time, it pretty much stays the same...But to avoid doctors to allocate for themselves it is important there is a system for allocation. Due to scarcity we have a waiting list...one has to keep in mind that changing the system would eventually only cause shifts on the waiting list. Compared to a country like Sweden at least we have a system, in Sweden the doctor decides who will receive an available kidney. (Nephrologist)

Not having a transparent and objective system will enlarge the chance of allocation being too much part of the judgement of doctors, which is undesired in terms of fairness of allocation.

Allocation of donor organs in the Netherlands has not always taken place by collaboration between countries. Subparagraph 3.3.2 shows the main reason to collaborate in donor allocation between countries and why this collaboration is not European wide.

3.3.2 Eurotransplant

In 1965 Jean Dusset was the first to describe a group of human leucocyte antigens, which can be referred to as the HLA-system. Being aware of the development of HLA matching Prof. Dr. Jon J. van Rood in the Netherlands started a new system for donor allocation (Eurotransplant).

In 1967 Eurotransplant was founded by Van Rood to create a central database. Experiments with HLA matching made Van Rood believe in the influence of HLA matching between donor and recipient in kidney transplantation. To create a system in which chances to find best possible matches would increase he founded Eurotransplant (Eurotransplant).

Eurotransplant expresses the optimal use of available donor organs to be one of her main aims in allocation (ethical charter:1). This aim reveals that fairness of allocation is intended to be based on utilitarian notions of fairness. The best match is supposed to create most utility in terms of survival time of the kidney.

In the current situation seven European countries together participate in Eurotransplant (Eurotransplant). Figure 1 provides an overview of European organ allocation and the different organisations to allocate that exist

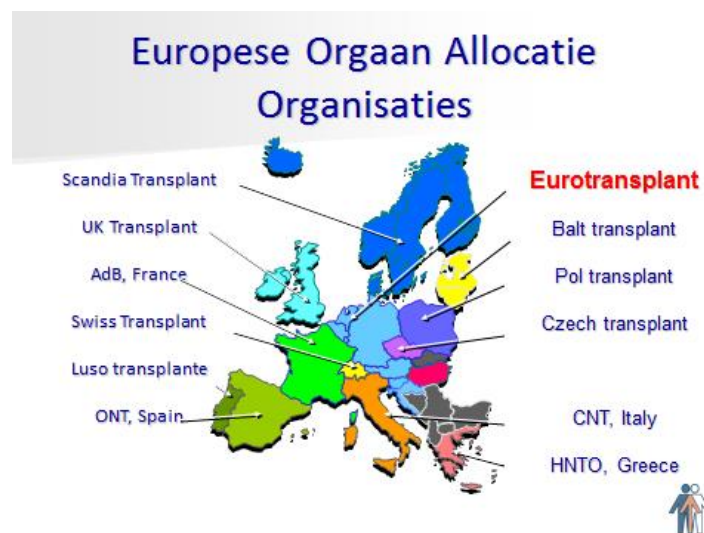


Figure 1 Source: master class introduction allocation September 2012

The initial idea of Eurotransplant was to create an European allocation system.

Differences in insight, for example relating to HLA matching, in particular with France turned out too great. Or countries, like the UK and Spain, did not feel the need to work together. At least Eurotransplant managed to create a beginning in collaboration with six countries, although at the start the intention to create one European system was more present, there are still new countries joining us, mostly from the East of Europe. For very difficult groups, highly immunized people in the AM program [anti mismatch program see par. 3.4.7], we are trying to work together with other partners in Europe. (ET secretary kidney committee)

These differences in insight regarding HLA matching will be further discussed in paragraph 3.4.3.

3.3.3 Responsibilities, involved organisations and committees

Eurotransplant is divided in committees that are ordered by types of organs. In case of kidney allocation Eurotransplant has a 'kidney advisory committee'. New ideas are designed in concrete plans

within the kidney advisory committee, these plans are submitted in the form of a recommendation to Eurotransplant's Board. The Board will give her agreement or disagreement, and once agreed will submit the recommendation as a proposal to countries participating in Eurotransplant. In the Netherlands the Dutch Minister of Health has to agree officially, but this governmental responsibility is delegated to the NTS. In complex cases, it is decided in the Netherlands to first forward the new plan to the Dutch Health council, de Nederlandse Gezondheidsraad (ET secretary kidney committee).

In case the Netherlands would want to introduce new ideas to Eurotransplant two members from the Dutch LONT (national meeting for kidney transplantation), take part in Eurotransplant's kidney advisory committee and may present these new ideas in the Eurotransplant kidney advisory committee. The LONT is specifically focused on kidney transplantation in the Netherlands. Next to members from the NTS, Dutch nephrologists are part of the LONT (ET secretary kidney committee & policy worker).

Eurotransplant's Board is composed by one member from every committee and one member from each Eurotransplant nation. Besides these members, there are certain selected members that are part of the board based on their qualities. The organizational structures imply that the Netherlands cannot make any decisions in kidney allocation, influence on policy can be realized by proposition (ET secretary kidney committee). A mutual dependency between the countries participating in Eurotransplant exists. "We are depended on the countries we work together with and they are depending on us" (policy worker).

Considering responsibilities to change or correct the system differences of opinion seem to exist. Eurotransplant is argued to be responsible for changing the system in case negative effects are created by the system. "An average doctor only has its own patients to care for and does not notice the effects of certain variables on the total waiting list... This is why Eurotransplant is and should be responsible for monitoring and changing such negative effects" (Nephrologist). It is also argued that the responsibility for changing the system is part of the role of nephrologists and research scientists.

By law it is decided which factors should be taken into account in allocating post mortem donor kidneys. We (note: the NTS) have to monitor whether allocation takes place on these grounds. Of course we want the sickest person to be helped, but sometimes this conflicts with optimal use of the kidney. This relates to a question of fairness, but this should be seen as business-like-objectiveness of the system... It is not our role, only in case nephrologists or our own researchers will come with a proposition in line with legislation and agreed upon in the LONT this proposition can be forwarded in the Eurotransplant committee... In case negative effects are created the nephrologists will supports their patients, they will see it once a trend is visible, to give their patients an equal chance they will point this out. Eurotransplant facilitates, but they do not make up the rules, they can deliver data and be alert, but we, the NTS or Eurotransplant, cannot just make that up, this responsibility is on the level of the nephrologists. (Policy worker)

Due to criticism from certain countries Eurotransplant has introduced a council to discuss matters, relating for example the amount of kidneys that stay in a country or go abroad.

There is contact between ministries of Health and Eurotransplant. This is why we recently have introduced a council, criticism from governments and for example media on the scarce amount of

influence that governments have on Eurotransplant’s policy...although they are represented in committees already once this criticism comes you must do something, so we have an initiated a council. Now we have representatives from all countries in a council. (ET Secretary kidney committee)

3.4 System for post mortem donor kidney allocation

3.4.1 ETKAS: Input-variables, algorithm and point scores

Figure 2 shows Eurotransplant’s scheme of allocation. The bottom of this figure shows Eurotransplant’s main allocation program, ETKAS. Subparagraphs 3.4.1 – 3.4.6. will explain the main program that is used by Eurotransplant to allocate, the ETKAS system. Also including 0 HLA mismatches and pediatric status, in the middle of the scheme. The program for highly immunized (AM) and the ESP/ESDP program, at the top of the scheme, are part of subparagraph 3.4.7.

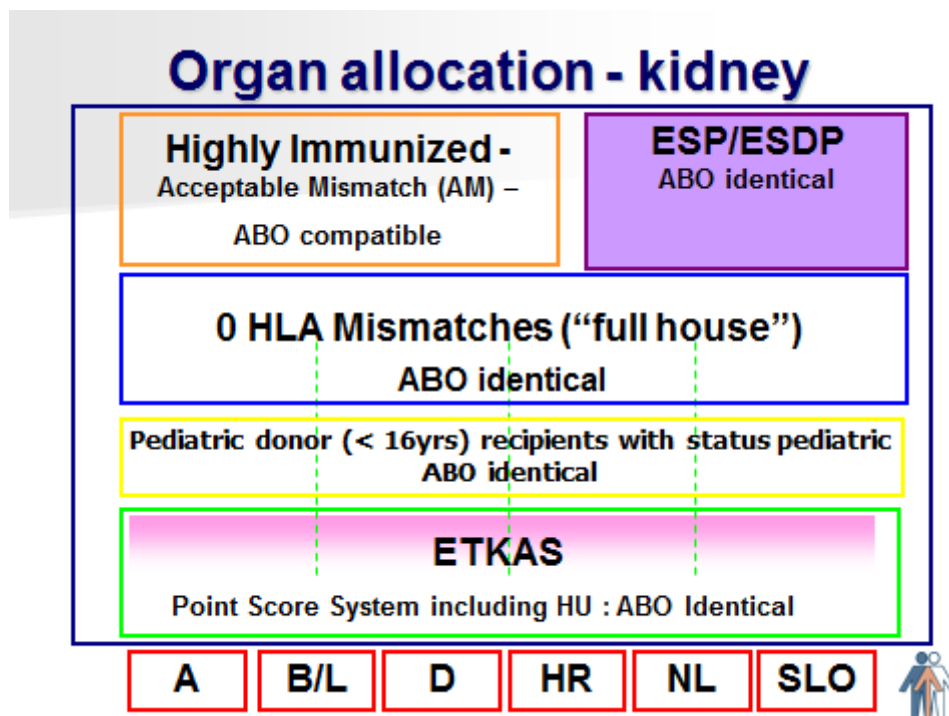


Figure 2 Source: Eurotransplant organ allocation kidney 2011

The ETKAS system consists of variables that are part of one algorithm. Every time a kidney is offered the algorithm will give points to each person on the waiting list. The person with the highest amount of points will be on top of the list. Multiple variables are included in the algorithm.

“A good HLA match will lead to more points, as well as a close distance between donor and recipient, and a high urgency status of a recipient...this is in short how the algorithm works” (Research scientist). “Waiting time, HLA matching, the probability of receiving a kidney and region are the four main factors of the system” (Nephrologist).

Eurotransplant's guideline on the ETKAS system provides an overview of the procedure of allocation, a description of factors that are translated in input-variables, the algorithm and on how much weight is attached to each input-variable in this algorithm (ETKAS). The guide line shows that potential recipients on the waiting list are selected by the system on the following factors: medical urgency, %PRA level, HLA-A, -B, -DR matching between donor and recipient, ABO blood group rules, waiting time and donor region (ETKAS). The kidney available is offered to the centre of the recipient with the highest score (ETKAS).

Considering the variety of variables used it seems intentioned to have different notions of fairness operating in one algorithm. The importance of HLA matching reveals utilitarian considerations. The variable of waiting time shows egalitarian notions of fairness. At first sight some variables seem to be of medical importance, while others do not. The description of the variables used and the formulas of how they are calculated is provided in the guideline. Understanding the influence of each variable in total valuation is a complex, each variable is calculated in formulas, has its own 'weight' attached and either has a limited or unlimited amount of points.

3.4.2 A National Kidney

- Country balance

An important variable in the ETKAS system is named 'country balance factor', due to the high points attached to this factor. "It kind of overrules the algorithm, unless a kidney is available that can be used in the AM program [see subparagraph 3.4.7] or is HLA identical [see subparagraph 3.4.3] to a potential recipient" (Nephrologist). To create a better understanding of this factor, the reason behind having this variable is further explained:

Countries within Eurotransplant have different systems regarding to how they acquire post mortem donor kidneys, the Netherlands and Germany have a system based on permission, while other countries have a system that is based on objection. Although in both systems there is scarcity in the amount of post mortem donor kidneys available, countries with an on objection based system, although no hard proof of a causal relationship exists, have more post mortem donor kidneys available. If there would be no correction factor in the ETKAS system the risk will be that post mortem donor kidneys from countries with an on objection based system will mostly go to Germany... This is because the chances of finding a good match in a big country with relatively more people on the waiting list and with a system based on permission will be high. (ET Secretary kidney committee)

The points for this 'country balance factor' variable are not maximized and are counted by a formula for each country:

If Germany, the country that imports the most post mortem donor kidneys, would have a country balance of 20, compared to Belgium with a negative balance of -10, the result if a kidney would be available: (Germany's score) 20 minus (Belgium's score) -10, would result in: $20 - (-10) = 30$. The outcome of 30 has to be multiplied by 10 which will give a score of 300 points to Belgium, or to a person with a Belgian nationality on the waiting list. (ET Secretary kidney committee)

The arguments for having a country balance factor seem partly medical and partly political.

In medical terms the period of a kidney outside a body, the cold ischemic time, should be as short as possible to maintain a good quality of the kidney. But also, no country will want all the available kidneys to go to the biggest country, especially not in the case of Germany. The waiting list of Germany, also considered in a relative perspective, is larger compared to most countries...so the impression is now that people on the waiting list in Germany have to wait longer. (Nephrologist)

Because multiple variables are part of one algorithm the question is which effect this country balance variable has. Apparently a counter-effect is created by the country balance variable on the waiting list variable.

In short one might say that having a country balance factor in the allocation system this compromises for the factor of waiting time. They both have a counter-effect on each other...Because countries with lower country balance points generally have a longer waiting list, this entails that with more people on the waiting list these countries receive more points for waiting time...What we see at Eurotransplant is a constant skewed growth between the two, currently that is at a disadvantage for country's like Belgium and Austria, with more country points, while it is more of an advantage for the Netherlands, with less country points. (ET Secretary kidney committee)

Different notions of fairness of allocation exist, but also create a tension. The importance of waiting time reveals egalitarian notions of fairness to be desired, while it is also considered fair to take national considerations into account in allocation. The effect is a tension between the existence of both these notions of fairness. The intention is to balance between them. Though, in practice the effect of having these two notions of fairness is that the system does not balance this tension but favours the one notion of fairness more compared to the other. There is a new idea how national considerations should be taken into account in the system.

The idea entails direct refund. Suppose a kidney from Belgium goes to Germany for a person from a specific group, the ETKAS system should make sure a kidney from Germany that comes from someone from the same type of group goes to Belgium, the group might relate to age and blood group. So in case a new kidney comes available somebody from the country that has a negative balance due to giving kidneys to another country should be on top of the list. (ET Secretary kidney committee)

Political pressure seems to be the main reason to initiate the idea of direct refund and for national considerations to have an increasing influence in the composition of fairness of allocation. The country balance factor is a matter that is discussed upon by the council, which was introduced because governments of countries wanted to have more influence on allocation policy (ET secretary kidney committee).

Public opinion leads to political influence...we have to inform governments and therefore it is for example known that Belgium exports a lot of kidneys, so they can see how many kidneys are leaving their country. This causes them to ask questions like 'why do we have to export that much?', this is the reason why we are thinking about this idea of direct refund. (ET Secretary kidney committee)

A correction of the system, changing the country balance variable, might affect countries in unforeseen ways. The Netherlands, compared to the other countries in Eurotransplant, realizes more transplants by the living donor program, especially in case of children.

Indeed a counter effect could appear between the living donor program and the idea for direct refund, but I do not think we have thought about this, actually we would have to correct for this...for example by keeping post mortal kidneys from donor children in the Netherlands, which will cause the living donor program not to create negative effects, but I have to think further about this. (ET Secretary kidney committee)

- Regional Bonus

Next to the country balance factor, potential recipients on the waiting list from a certain region will receive 300 points in case a kidney is available in the same region. Only in countries with more than one region, people on the waiting list will receive 100 points extra if a kidney is available in the neighbouring region in the same country. The Netherlands is defined to be one region, while for example Germany is divided in seven regions (ETKAS).

The differences in amount of regions creates undesired effects. “There are plans to change this variable, because the effect for countries with more regions to create more points is unwanted. We want to handle that differently” (ET Secretary kidney committee). The idea to correct the variable of regional bonus points is to leave out the country border points in case of a neighbouring region.

We are thinking about some kind of circles around regions, instead of only giving points to neighbouring regions which are in the same country, extra points will go to potential recipients on the waiting list that are from all regions that are next to the region in which a kidney is available. But this is complex, imagine a country like Estonia would become an Eurotransplant member, no neighbouring country or region would exist. In this case we could for example look at the distance in amounts of flight hours, but the problem is maybe it will be a two hour flight, in reality it will be eight hours due the flight schedule. (ET secretary kidney committee)

This example of the new idea for regional bonus shows the complexity that might occur in practice in case changes are desired to create more fairness of allocation. Eurotransplant expresses in her ethical charter the aim to achieve an optimal use of available donor organs, based upon medical and ethical criteria (Ethical charter:1). The medical aspect to keep cold ischaemic time as short as possible to remain a good quality of a kidney can assumed to be a medical criterium. Though it seems apparent that in case a donor and a potential recipient are from a different region or country this does not automatically have to mean that distance between donor and recipient or the time of a kidney outside a body would increase and hence would harm the quality of the kidney.

- Solidarity within each country

Looking at the criteria for allocation Eurotransplant “operates on the basis of international cross-border collaboration and exchange of organs, its procedures for allocation across participating countries must take into account the principle of solidarity within each country (to be implemented

through a mutually agreed balancing system)” (Ethical charter:3). The intention to take account of ‘solidarity within each country’ in practice implicates that fairness of allocation is strongly defined by national considerations. Apparently most of the kidneys do not cross border. “It is due to the country balance factor and regional bonus points that the Netherlands keeps around 80% of its post mortem donor kidneys inside the Netherlands” (Nephrologist).

The country balance variable and regional points create quite some impact on outcome as a whole. “It is not strange at all that due to these factors you might be offered the most wildly mismatched kidney, because there will always be someone on the waiting list in your country that at least is half similar to the kidney’s donor from the same country” (Nephrologist). The consequence of this intention to create solidarity within each country is that it conflicts with other considerations that are intentioned to create a fair allocation.

Eurotransplant declares that allocation should primarily be based on clinical criteria, one of these criteria is HLA matching and that the aim of allocation is to create optimal use of the kidney (Ethical charter:1&3). In practice more mismatches are allowed and in terms of survival time no optimal use is reached, in favour of national considerations in allocating kidneys. Fairness of allocation seems to be constituted in the rise of a national kidney.

The next subparagraph will be used to get a better understanding of HLA matching in the allocation system.

3.4.3 HLA Matching

- HLA matching in the ETKAS system

HLA typing relates to the calculation of mismatches. HLA-A,-B and –DR are taken into account (Chapter 4 Etkas:7). This means that not all HLA antigens are taken into account. Mismatches are defined to be: “donor HLA-antigens that are different from the recipient's own HLA-antigens” (Chapter 4 Etkas:8). The reason for matching on HLA is to lower the probability the body of the recipient will reject the kidney. “The more similar matches on A, B and DR between donor and recipient, the lower the chance will become that the body will reject a kidney” (Research scientist).

The number of mismatches is added according to a formula, which leads to a point score: $= 400 \times [1 - (\sum \text{broad HLA-A, -B, split HLA-DR mismatches} / 6)]$ The maximum score of 400 points resembles zero mismatches. HLA identical reflects 0 HLA mismatches and is called a ‘full house’. As each following mismatch will subtract 66,67 points of the maximum of 400 points, no score is given from the point of six mismatches. HLA matching has a maximum point score (Chapter 4 Etkas:8).

- Understanding HLA matching

All of the respondents mention the complexity of understanding HLA matching and the need to look at the historical background to create more insights in HLA and the role of HLA matching in kidney transplantation.

HLA was only discovered in the 1960's, compared to the scientific ideas and beliefs surrounding HLA in the 1960's and the 1980's, the current understanding of HLA is much different. The ETKAS system only counts for 'broad matches' on A and B and 'splits' for DR. Imagining HLA types to be families, HLA A1 types can be considered close family, but A1 and A28 are also related. These relationships are complex and are being discovered over time. HLA was discovered by matching blood cells of persons, which either 'attacked' each other or not. Any different reaction was labelled a different A type. If one keeps on doing this, the family becomes greater and greater. In the system broads are equal for different family members and are important to recognize antibodies, if antibodies occur on broads this will lead to a mismatch in the system. (Research scientist)

HLA matching, according to the nephrologist, is based on old definitions of HLA. "It is now commonly known between scientists that current research on HLA matching shows HLA matching is much more complex. Current HLA matching is based on old definitions of HLA" (Nephrologist). The first ever successful kidney transplantation ever performed was between twins. "This was already based on a belief that the more related donor and recipient are the better effects on survival would be and also research shows that a better HLA match between donor and recipient will positively affect survival" (ET Secretary kidney committee).

- Mismatch probability

One of the variables in the algorithm, 'mismatch probability', represents points for the probability of receiving a kidney when 1000 kidneys would be offered, taking into account HLA-A, -B, or -DR mismatch, ABO blood groups rules and PRA screening. The maximum score attached is 100 points (ET Secretary kidney committee & ETKAS:8).

The influence on the outcome as a whole is small according to the nephrologist. "It reflects an individual's chance of having a good match, based on HLA matching, this depends on the individual's HLA type and antibodies against other HLA parts...but it does not really influence the outcome because to my belief it does not create a lot of points" (Nephrologist). The intention of having this variable is to somewhat correct the inequality in chances on having a good match. This shows that although matching is desired in valuing, the inequality it creates does not seem to be desired. But the solution to correct for this does not take away these notions of inequality. An understanding of the effects of HLA and what this implies in the composition of fairness now follows.

- Effects of HLA matching

The statistical significance of HLA matching on survival is recognized by the nephrologist, but the relevance for survival is assumed to be small. “A couple of years of survival time between the worst and the best match is not that much when you look at the survival rate without having a new kidney” (Nephrologist).

Optimal use of donor organs is declared to be the aim in donor allocation (Policy worker & ethical charter:1). According to the NTS optimal use relates to compatibility between donor and recipient. “We mean that you have to use the potential, in donor allocation you have to look for the best match possible, this is what the system is focused on, you want the donor to be as much compatible with a receiver as possible, you can never avoid rejection of the receiver’s body to a new kidney, but you have to make the chances on rejection to be as small as possible” (Policy worker). Apparently Eurotransplant intentions to allocate on the basis of utilitarian notions of fairness, creating an optimal in surviving time. HLA matching is expressed to be part of clinical criteria, but on the significance of the effects it creates there is no shared consensus.

The implication of these utilitarian notions of fairness in the system, translated by the use of HLA matching, is that a kidney offered does not automatically go to the next person on the waiting list. Besides this, certain groups of people on the waiting list have lower chances to receive a kidney.

Although HLA is important, it gives reason for concern as well, because of the importance of HLA matching equality of chances in getting an available kidney becomes less... Certain HLA types are more frequently present, while other types are more rare, the latter is causing a much lower chance for groups of people having a rare HLA profile in finding a reasonable match... People who originally are from other countries have lower chances, this is a clear problem for people who have a Turkish background and in particular people with a Moroccan background. They have less similarities with Europeans on a HLA level. The problem is they are with less, so the chances for finding a good match become smaller... generally they do have a disadvantage because in the country they are originally from they would not have this problem or at least it would be less of a problem... next to this certain HLA types are just rare, originally coming from a whole different area, for example a HLA profile that is more present in China. (Research scientist)

As a consequence of utilitarian notions of fairness a tension is created because these notions cause certain group to be discriminated. Earmarking certain groups would apparently go too far for Eurotransplant. “People from Mediterranean countries, the South of Europa or the North of Africa have different HLA profiles, so for these people you may assume they are part of a less favourable group, but to earmark them would go too far for me” (ET Secretary kidney committee).

- Developments in HLA matching

By having a look at other systems of allocation it becomes clear that the presence of HLA matching in the system is a choice. Regarding the use of HLA matching within other systems of allocation the example of the USA is brought up by the research scientist. HLA matching in the allocation system of the USA does not have a significant impact on valuing a kidney due to the use of medication.

The USA is even considering on leaving HLA matching out of the allocation system or they have already done this. To reduce rejection of a new kidney you either choose to prioritize HLA matching or you have to give medication to reduce chances of rejection...the reason why Eurotransplant does not opt for medication used to be because it created a lot of negative side-effects. In short it ruins the state of the kidneys, without medication the kidneys will maintain a better quality and will likely last longer and create more quality of life for the recipient. Also it might negatively influence the chances of someone needing to have a second new kidney. It is quite common someone will need two kidneys during his or life, with a lot of antibodies due to medication finding a second kidney that will survive will be even more difficult. (Research scientist)

In contrast to Eurotransplant, the USA does opt for medication to reduce rejection although this will create other negative effects.

In the USA people on the waiting list have even more mixed HLA types due to the history of the country and how this has affected the mix in population. This almost creates new HLA types. Compared to native African Americans, 'white people' in the USA have much more chances to match, even in case a kidney comes from an African American donor. From the perspective of fairness, to have an equal chance, this would not be right. Next to this, medication is improved and it creates less side-effects. In Europe we seem to be more conservative and still believe medication and side-effects will harm the patient...so we are kind of in a 'two dance' between these options. (Research scientist)

The above statement shows that in deciding what is considered fair in an allocation system a choice is made between clinical considerations and notions of equal treatment. A difference in population between the USA and Eurotransplant countries is brought forward as a reason why the USA needs to prioritize on notions of equality in treatment. Hence medication is improved, which may provide an argument for Eurotransplant to also prioritize on notions of equality in treatment.

The USA has a more diverse population, so this leads to different problems. Compared to the USA, our population is more uniform. Medication for rejection is much more developed so this would be an argument to accept a worse match, but there are still side effects that suppress the immune system...maybe the acute emergency for matching is decreased, but I think that in the long term there is no research that really shows the opposite. Within our committees, for example the immunologists- or tissue types committee, we have already said matching on -DR is the most important...(ET Secretary kidney committee)

Undesired effects may also become less in case chances for disadvantaged groups are increased by creating a more diverse database. Though this is declared not to be a solution that is currently aimed for. "Expansion to Morocco or Turkey is not likely to happen. We do not go that far yet. If we would ever go to that direction I do not know, it seems too far distanced from us" (ET Secretary kidney committee).

Apparently there is an idea to change the current use of HLA matching in the Etkas system by only matching on HLA-DR.

Maybe we could make HLA matching more easy. Due to research we assume that it is mainly important to match on HLA -DR. Only looking at -DR would lower the chances of having mismatches and would still reduce the chances on rejection...research does give us reason to believe -DR is the most important. We have simulated on the waiting list what would happen in case we would only match for HLA-DR and it turned out that overall the waiting list became a bit more equal. People with a less frequent HLA type would have a better chance, but for the group of

people who have a more uncommon -DR type the chances of not finding a match did increase. This leads to the question what to do with the latter group? Maybe in that case you have to accept for this group to be left out of HLA -DR matching or in other words you would have to accept a -DR mismatch, for now no decision is made... I hear people talk about this, also within Eurotransplant, there does seem to be a kind of lobbying taking place to change the HLA matching factor in the ETKAS system. (Research scientist)

There does not seem to be consensus about the clinical significance of current HLA matching as well as only matching on HLA -DR.

You cannot say HLA matching is not important in allocation, because without it, it will cause problems in case someone is in need of a second or even third new kidney. But you have to look for which groups you find this important. Only matching on HLA -DR would already be a step in the right direction, because it will lead to a more equal allocation. (Research scientist)

Only matching on HLA-DR prioritizes clinical and utilitarian notions of fairness, but would reduce some of the undesired effects in terms of inequality of treatment and discrimination. Though it is also argued that waiting time would be more desired to define fairness of allocation.

There is no real understanding of what -DR is. This is only examined on 900 people and in that study it did not have any real influence at all. HLA matching is much more complex, with certain DNA techniques we can see that even in case of splits on -DR there are differences. What counts for HLA matching on broads also counts for HLA matching on -DR looking at the splits... we do not know the exact influence and it maybe only creates a 5 to 6 percent influence on very large groups, so on an individual level it does not create any real influence, the ideas are outdated. So comparing the effect to the amount of time you win, unless kidneys are identical, a couple of years between the worst and the best is not that much, so you should actually think waiting time is more important compared to HLA (Nephrologist)

The above statement, implicitly, mentions that HLA matching creates more points compared to waiting time. Although both are present in the allocation system to create a fair allocation, utilitarian and clinical notions of fairness prevail over egalitarian considerations. As waiting time increases, egalitarian notions become more important as no maximum amount of waiting time points is determined. "In case there is not that much difference in waiting time, HLA is a more important factor. The more this difference increases the more points waiting time will get, just like medical urgency" (Research scientist).

Compared to the USA HLA matching creates more impact in the Eurotransplant allocation system, however the significance of HLA matching in the UK's system seems to be higher. "In the UK, HLA matching is even more important, and also matching is combined with age categories. The Etkas system is not fully based on an utilitarian approach. Compared to the UK we only have differences for children under 16 and persons above 65, but not for the whole layer in between" (ET Secretary kidney committee). "Next to HLA matching the UK has a system with even more variables, it drives you mad. Generally their system is more based on utility. Looking at the system of the UK, it prioritizes on age... age should not be a criterion, it is not a medical factor" (Nephrologist).

- Influences on HLA matching

Changing the HLA matching variable, for example to only match on HLA-DR, creates effects on the interaction with other variables because they are part of one algorithm. “In case you would change HLA matching to only matching on HLA -DR we have to see how this works out with other factors, like waiting time, we did not include this in our simulation [note: research on matching people on HLA-DR on a simultaneous waiting list]” (Research scientist).

Research on the effects of the system in practice is retrospective. “The greatest problem is the fact that research on effects is always retrospective, only over time you know the outcomes, so you are constantly behind the clearing” (Nephrologist). Science may provide new ideas that influence the current use of variables.

Science shows matching might become less important, looking at the living donor program shows we are able to transplant without taking blood group into account, we are not this far yet in case of post mortem kidneys, due to cold ischemic time which increases chances for rejection...but maybe one day we will be able to do this or we need to find better medication to reduce rejection and maybe scientists in the future will come up with an idea how to influence the immune system locally in a human's body'. (Research scientist)

Science may provide solutions that will influence the use of certain variables like HLA matching. But also the role of HLA matching is influenced by the impact of immunologists in Eurotransplant and the historical significance of HLA matching at the start of Eurotransplant.

I do not think Eurotransplant will really let go off HLA matching. There are differences in insights about how to deal with HLA, but generally we are an organisation in which HLA still has a dominant impact...this is because Eurotransplant's policy, for a big part, is decided by immunologists and they have a big influence. This influence arises from Eurotransplant's establishment, especially in the Netherlands the influence of immunologists is big...also within Eurotransplant there are differences in insights, in general there is one line, and not so much in the Netherlands, but in other countries there are differences between centres often due to differences between internists and surgeons, the latter allow more neurological influences, while the first do not...this difference on a centre level also exist on a Eurotransplant level. (ET Secretary kidney committee)

Actors involved in the allocation system seem to point at each other in who is responsible to change the system. It is argued that changing current HLA matching is the task of Eurotransplant. “To my opinion still allocating on old definitions of HLA is old-fashioned silliness, apparently the system meets the expectation to allocate. So many think what would it matter to me if an A9 really is an A9 or not, we do not have to think about this because this is Eurotransplant's task, so this puts us off the task of deciding this, but still the grounds are wrong” (Nephrologist). While it is also argued that doctors “will see it once a trend is visible, to give their patients an equal chance they will point this out. Eurotransplant facilitates, but they do not make up the rules, they can deliver data and be alert, but we, the NTS or Eurotransplant, cannot just make that up, this responsibility is on the level of the nephrologists” (Policy worker).

3.4.4 Waiting time

The date of the patient's first dialysis is used to determine a recipient's starting point on the waiting list. Furthermore, dialysis should not be interrupted for more than three months and in case a recipient has had a transplantation before, the date of reinstatement of maintenance dialysis is used (ETKAS:9).

The ETKAS systems counts 33.3 points for every year of waiting time, resulting in 0,091 points for each day of waiting. No maximum amount of points for waiting time exist. "The role of waiting time is more important over time, because waiting time has no limitation in points score" (ET Secretary kidney committee). Although it is possible to be registered on the waiting list before the start of dialysis, there will be no points given to so called pre-emptive transplant candidates (ETKAS:10).

The factor of waiting time is important due to the results for survival on dialyses. "With an average waiting time of four years, half of the people will die between four to five years. Although the outflow on the waiting list seems equal to the inflow, one has to keep in mind that already every year around twenty percent has not survived" (Nephrologist).

In deciding what is considered fair in allocating donor kidneys egalitarian notions of fairness are taken into account. Though, utilitarian and clinical notions of what matters in donor kidney allocation are the reason why the system does not automatically give a kidney to the first person on the waiting list. As a consequence certain people have to wait longer and have to stay longer on dialysis.

"Waiting time seems to be the best parameter to give someone advantage who is getting more disadvantage, so this seems to be a good parameter to choose who really deserves a new kidney. HLA matching is causing most of the inequality, and next to this also the matching on blood group, because with both factors there are less frequent type" (Research scientist).

3.4.5 Blood group matching

There needs to be a blood group compatibility between the blood group of the donor and the potential recipients (ETKAS:13). The reason for matching on blood group, similar to HLA matching, is to lower the probability of rejection. "The match in blood group between donor and recipient is important in terms of the possibility the body might reject a new kidney. It is even more important compared to HLA matching, but in case of HLA matching there are many more types, which makes HLA matching more difficult compared to matching on blood group" (Research scientist).

In 2009 the ETKAS system was adapted due to the effects that were generated by the blood group variable on outcome as a whole.

The system used to give kidneys from people with blood group O to not only potential recipients with blood group O, but also to recipients on the waiting list with blood group A, -B and -AB... We thought this would not create any problems, but eventually the system's results showed that by doing this over time a disadvantage became visible on the waiting list for potentials recipients with blood group O. It became apparent that we had to change the system. (Research scientist)

Before the adaption of the system this variable caused a longer waiting time for people with blood

group 0. The consequences of blood group matching seem similar to the effects created by HLA matching. The clinical consideration is that it is possible to get a kidney from a person with the same blood group or from a person with blood group 0. Matching on blood group creates more survival time, which shows the utilitarian consideration that is taken into account. As a consequence of clinical and utilitarian notions of fairness a tension is created between these notions of fairness and notions of equality of treatment, because the waiting time for people with blood group 0 increased

“By not earlier correcting for the effects of blood group O the waiting time for people with blood group O started to become one to two years longer compared to others. The priority was too much on HLA matching and acceptable mismatches instead of on the blood group factor” (Nephrologist). The way these consequences are recognized and acted upon differ in case of blood group matching compared to HLA matching. Eurotransplant has adopted a different rule for bloodgroup matching in the system. “The effects of blood group 0 caused unfair concurrence on the waiting list, Eurotransplant now follows a blood group identical rule in the ETKAS system” (ET Secretary kidney committee).

3.4.6 *Extra points*

- Paediatric status

Recipients with a *paediatric status* (figure 2) are part of the Etkas system, but create extra points due to a paediatric bonus of 100 points that is given to them. This counts for each potential recipient that either started dialysis under the age of sixteen, was registered as a pre-emptive candidate under the age of 16 and started dialysis before the seventeenth birthday, or is proven to be in maturation (ETKAS: 8&10). The points for HLA matching are double counted (ET Secretary kidney committee).

In the Netherlands most kidney transplants for children are performed by the use of the living donor program.

In general it is absurd to give post mortem donor kidneys to children in case both of their parents are alive...this is something doctors for children in Europe do not really want to face yet, while actually the living donor program should take care of this, in the Netherlands we have the best score for kidneys and transplants coming from the living donor program, so only in rare cases, due to medical circumstances, children in the Netherlands would be in need for a kidney coming from the ETKAS system. (Nephrologist)

The extra points for children show that what is considered to be fair takes into account notions of the age of the recipient. This notion of fairness causes a tension with the living donor program in the Netherlands, which is based on the idea that it is considered to be fair that in case a child needs a kidney this kidney should come from his or her parents or by participating in the living donor program.

- Donor Status

Another exception in points is made if someone during his or her life has given a kidney to someone, by the living kidney transplantation program, and in case this person would be in need of a kidney him- or herself. 500 bonus points will be given to this person, which reflects 15 years of kidney dialysis (Eurotransplant and secretary general ET committee). These extra points for getting points in return of giving a kidney show that meritocratic notions of fairness are intended to influence allocation. And regarding the amount of points it apparently is considered desired and fair that a person who has given a kidney does not have to wait as long. Though as a consequence people who did not give a kidney have to wait longer in case a kidney is available.

- High Urgency and Kidney after liver transplant

In case a person has a high urgency status 500 extra points are given. The following medical factors create a high urgency: imminent lack of access for both hemodialysis and peritoneal dialysis, inability to cope with dialysis with a high risk for suicide, severe uremic polyneuropathy, severe bladder problems (hematuria, cystitis etc.) due to kidney graft failure after simultaneous kidney + pancreas transplantation, provided that the pancreas graft is bladder-drained and functioning adequately (ETKAS:12).

Each person on the waiting list that has had a liver transplantation will get 500 extra points. The option for a kidney after liver transplant is possible in selected (clinical) cases. In particular a kidney after liver transplant is preferred in case of a hepatorenal syndrome. The medical need for a new kidney after a liver transplant causes a high medical urgency in terms of survival chances for the recipient (ETKAS:12).

Eurotransplant declares that allocation should, next to ethical considerations, be based on medical factors. The need and well-being of the potential recipient is the core principal of the ethical standards (Ethical charter: 1&3). The variable of medical urgency and the extra points in case a potential is on the waiting list that is need of a kidney after a liver transplant shows clinical and medical notions of fairness in the allocation system.

3.4.7 Different programs

- AM program

A special allocation program is developed for certain potential recipients, which is called the AM (anti-mismatch) program (figure 2 left on top). A converted HLA-typing of donor and recipients is taking place and is only accepted under specified circumstances. "In case a person has many antibodies for specific HLA molecules, which translates in a high PRA percentage, this means he or she has a highly immunized status and will be included in this special AM program" (Research scientist). This means an exception to Etkas allocation rules is made by the acceptable mismatch program.

The actual chance of being compensated, of having a suitable kidney, is small, but if there is one it will go this individual. This is only in case of an identical kidney... Imagine an individual has got a quite common HLA type but has got a lot of antibodies, 90%, this means the person only has a 10% chance, in this case the AM program will, instead of focussing on what would lower your chances, search on what your antibodies will not react on. For example this individual does not react on A66, this means an A66 will be searched for and if a donor kidney is found he or she will get it. The result will be, depending on the amount of mismatches, that an individual's chances of finding a kidney are still small, but become higher... this AM program is again based on historical beliefs of HLA matching. (Nephrologist)

The use of HLA matching in the system can either both or only be considered based on utilitarian and/or clinical notions of fairness [see subparagraph 3.4.3]. Matching negatively affects people that have a lot of antibodies due to medical circumstances. The existence of HLA matching in the algorithm is the cause for these people to have lower chances in case a kidney is available. For this reason one might argue that the variable of HLA matching shows that fairness of allocation in the system is defined by notions of utility: optimal use of a kidney in terms of survival time based on the HLA match between donor and recipient. Though, the negative effects this creates for highly immunized people are considered unfair. This tension between fairness based on utilitarian and clinical considerations and the negative effects this creates is acted upon by developing an AM program to somewhat correct for these undesired effects for highly immunized people.

- Eurotransplant senior program

Eurotransplant developed a special allocation program, *ESP*, for recipients who are 65 years of age and older, to receive a kidney from a person of 65 and older [figure 2]. Allocation takes place according to a national waiting list for each country. No HLA typing takes place in the *ESP* program. The primary focus is to keep the cold ischaemic period, the time a kidney is outside a body, to be as short as possible (ETKAS:14). To reach this aim kidneys are allocated locally, in the same centre or regionally in the Netherlands. In case no potential recipients are available within the senior program a donor kidney will be used in the regular Etkas system. Only in case the kidney would be used in the Etkas program HLA typing will take place (ETKAS:14).

Apparently it is becoming more common policy to use these kidneys in the Etkas system. "It used to be normal policy for a post mortem kidney received from a person of 65 or older to go to a person above 65, but due to scientific knowledge on survival of older kidneys and the amount of people on the waiting list who are younger it is becoming more normal and frequent that this kidney will be used in the ETKAS system and not in the *ESP* program" (Research scientist). The reason for having the *ESP* program is based on certain ideas about older kidneys and older people. These ideas might not correspond with the effects that are created.

Older kidneys should be for older people, which is based on the concept that older people will not live as long, so giving an older person a kidney with a probably lower quality due to its age is believed to be reasonable. But what you are actually doing is putting kidneys of lower quality in people with not such a good physical quality... So if some wonder why the survival rates are not that good, for me it is not that surprising... The age of the donor and the age of a recipient are two

independent factors. If you would put that same kidney from an older person in a younger person it would last longer. (Nephrologist)

The growing amount of older people and the hesitation by certain centres to transplant older people may create reason for concern.

It is a shame how little older people are being transplanted. If you have to wait for five years for a new kidney at the age of 65 you will not survive...looking from a distance at what you should do with kidneys from older people, you would say give it to the person it will most likely last the longest in, but this would mean that indeed it may not go to an older person...but what we are heading for is a growing group of people who will be 65 years of age or older and are waiting to receive a new kidney...but there are transplants centres that are not seeing this development and that are restrictive in transplanting older people, which is a misconception, because for older people we are able to create extra years of life as well'.

The above statements about the ESP program show that some doctors and centres consider it fair on the basis of their medical experiences that transplantation of older people or using kidneys from older people should be restrictive. The above statement shows that the clinical considerations that cause a hesitation to transplant older people and use kidneys from older people are not shared by all doctors and do not seem to be based on consensus between doctors and centres. This non-consensus creates a difference in acceptance policy. Which shows that an outcome provided by the system who should get an available kidney in practice does not mean that this person will get this kidney.

Besides this, no paper or protocol will inform you that transplantation centres have different policies in their acceptance of kidneys. The rules of the system might be changed, but this does not automatically mean a centre will act on this and I do not believe any legislation or policy can change this...for example, if a donor would die at the age of 69, due to severe heart failure, some centres will accept this donor's kidney and some will not. Or maybe you will only accept this kidney in case it is for someone that is from a particular group or only for a single patient. Of course everybody will want to have a kidney from a 29 year old that has died in a traffic accident. But between these two examples there is a whole grey area, which nobody, including the patient, knows. The eventual decision will be made by the nephrologist on duty, but this acceptance norm is part of the culture of the centre... No guideline will make this trade-off for you, while you are dealing with a 24 year old that is in real need for a kidney but the one that is offered to you is not the one you want...In my centre we are liberal in accepting, but you have to realize this influences your outcomes in terms of performance, if you are liberal and take risks your scores as a centre are less good compared to centres that are more reluctant in accepting...The implication is that survival rates do not necessarily give you the real information and besides this, the patient does not know...If you turn an offer down, Eurotransplant will just go the next person on the list of outcomes of the ETKAS computer system...The only solution is the experience and discovery that a kidney that beforehand was supposed not to be that good will eventually turn out to do very well. (Nephrologist)

Eurotransplant is aware of the differences in acceptance policy between transplantation centres.

Centres provide their acceptance norms per patient on a donor profile form. "We do not want to be involved in this [difference in acceptance norms], what we do experience is that an organ centre turns down a kidney due to age, while they earlier declared by their donor profile form, they would accept it" (ET Secretary Kidney Committee and ET Coordinator Education). Figure 3 shows the donor profile, on which centres fill in their acceptance norms per patient.

Allocatiefactor: donorprofiel van ontvanger

Recipient Waiting List Heart

ET Nr	Recipient Name	Date of Birth	ABO	Rh	Sex	HE	LU	LV	PA	KI	Special	Reg. Ctr
267425	WIKERH, RALF	14.01.1971	B	Pos	M	T						GAKTP

General Donor Profile Listing Details

Min Age	18	0	HBsAg	Neg	Sepsis	No
Max Age	55		HBcAb	Neg	Meningitis	No
Min Height Female Donor (cm)	160		HCvAb	Any	Malignant Tumor	No
Max Height Female Donor (cm)	190		CMV	Any	Drug Abuse	No
Min Height Male Donor (cm)	160				Domino Donor	No
Max Height Male Donor (cm)	190				Rescue Allocation	Yes

Figure 3 Source: master class introduction allocation September 2012

The NTS shares this opinion on difference in acceptance norms with Eurotransplant. Showing which effects for people on the waiting list are created by these differences might help to start a discussion on the matter.

It is part of a nephrologist's autonomy, based on past experiences and on whether they are convinced by research, the NTS will not make any acceptance rules or interfere in a centre's policy, eventually the kidney will be offered to another centre so it will not get lost. Next to this, a centre needs to have the capacity to be able to operate at the moment a kidney is offered, because the time of a kidney to be outside a body needs to be as short as possible for quality reasons... If indeed there is a culture between centres in relation to acceptance norms this first would mean for nephrologists themselves, participating in the LONT, to have a responsibility in judging each other's acceptance policies... The only thing that might trigger a discussion would be if the NTS would be able to show the effects due to the differences in acceptance policy and present them to the chairman of the LONT committee. (Policy worker)

Considerations of autonomy currently seem to prevail over notions of equality in treatment.

Chapter 4 Discussion

Findings from chapter 2, the theoretical framework, and chapter 3, the case study, will be used for points of discussion to understand what the implications of these findings are for policy instrumentation.

4.1 Consequences for performing research on a valuation system

Information from the theoretical framework and the case study shows that to perform research on a valuation system a detailed observation on the functioning of the valuation system in practice is needed. The role of values in research on public policies, if taken into account, is often considered to have an explaining character. Identifying values can be an aspect of research to explain institutions, institutional arrangements and behaviour of actors. Identifying values that surround the allocation of donor kidneys might be based on legislation, juridical principles of legislation, statements expressed on the matter and guidelines and protocols used.

At first sight the juridical principles for post mortem donor kidney allocation mainly seem to relate to medical considerations. The NTS, the Dutch NGO with a governmental responsibility to allocate, expresses that one of her responsibilities is a fair allocation of donor organs (NTS). Eurotransplant declares in her ethical charter that she aims for an optimal use of kidneys and shall ensure that allocation rules are defined on the basis of principles of fairness, equity and transparency. Rules of allocation consist primarily on clinical criteria and on waiting time, taking into account ethical principles, without regard for personal, social or financial background (ethical charter:1&3).

Identification of the values and principles that are used to create fairness of allocation shows the versatility in notions of fairness, but does not reveal what the consequences for having these different notions of fairness are in valuing a kidney and how they interact in one valuation system. The weights or amount of points that are attached to variables in the algorithm reveal that the one variable is considered more important compared to the other. These points per variable are often the result of algorithmic formulas. Certain variables are having a maximum amount of points and some will create more points over time because no maximum is attached. For research this entails that understanding the algorithm is a (technical) complex and detailed undertaking, which requires some mathematical skills.

Assuming that closely observing the protocols and guidelines that are used will show which notion of fairness of allocation prevails over the other seems to be somewhat of a misconception. Close observation mainly results in what variable is considered more important in allocating a kidney compared to the other. For some variables identifying their presence and influence seems sufficient to get a better understanding of what fairness of allocation is desired to be. Looking at the example of waiting time, the protocol shows that more points are given to someone who is waiting longer. Also the definition of what medical urgency is becomes clear by understanding the protocol, which shows

the intention to have clinical arguments to decide who should get a kidney.

The case study shows that certain variables are defined to be clinical criteria. Observation on how the system is presented to for example patient groups in research creates the understanding that the use of HLA matching is presented as a medical necessity. As a consequence for research on fairness of allocation this would imply that by not going beyond the identifying of these variables and how they are defined these variables are assumed to create fairness of allocation due to clinical arguments. Although one would be free to argue whether or not these arguments create fairness of allocation, the case study shows that defining a variable clinical, although it is expressed to be clinical, is not always as straight forward as it seems to be.

To be able to get more understanding on variables, what they are, what notions of fairness they present and what their consequences in valuation are research needs to go deeper into the practice of valuing. This is in line with a constructivist view and Latour's approach on values and valuation, derived from the theoretical framework, which argues that what constitutes fairness is embedded within in practice.

Looking at the example of HLA matching in the case study shows that this factor is defined to be a clinical criterion. The clinical significance of HLA matching is not agreed upon. Although the belief is shared that matching influences chances of rejection or survival time of a kidney, there is no consensus about the significance of this influence. This finding is discovered by observing the central debates on HLA matching, by interviewing key members of the kidney transplantation community and by comparing the system to other allocation systems.

Defining HLA matching as a clinical factor is no subject of debate. If there would be no shortness in the availability of kidneys it would likely to be no point of discussion. The clinical significance of HLA matching becomes relevant in research on fairness of allocation because giving a kidney to a person based on a match means it does not go to another person on the waiting list. HLA matching will give more years of survival time in case of a good match, but this does not mean that this kidney will not give extra years of survival time to a recipient with more mismatches for the particular kidney. In other words, HLA matching can also be defined as creating utilitarian notions of fairness to allocate, it either gives more or less utility and it either favours or not favours people on the waiting list.

Prioritizing utilitarian considerations of fairness negatively impacts notions of equality in treatment. Research on the algorithm shows that waiting time has to increase by quite some years to be counted more heavenly than HLA matching, depending on the amount of mismatches. And people from certain ethnic groups have a less common HLA profile and eventually will have a lower chance of finding a good match.

Comparing a system to other systems in research on an allocation system shows that there is a possibility to choose how much and if HLA matching is influencing valuation. In the UK allocation system it turns out that the UK prioritizes more on utility in the trade-off between utilitarian and other

notions of fairness. While in the USA HLA matching has (almost) no impact on valuation.

The negative impact on equality of treatment is not random, certain ethnic groups have in common that they have a less common profile compared to donors and other people on the waiting list. This finding shows that research in practice by closely observing central settings and debates and interviewing key members can provide outcomes that are unexpected and surprisingly.

Comparing it to a system in which HLA matching does not create an impact in valuation shows that having HLA matching in or out a system is a choice between undesired effects in valuation. The choice that is made reveals what (un)desired effects are considered to define fairness in allocation. Either fairness of allocation is defined on having more equality and accepting lower chances for optimal survival time of a kidney or accepting less equality and having better chances for optimal survival time.

Having a close look on how these effects are acted upon shows that action is undertaken that will keep HLA matching in the system to decrease inequality, by the use of research on HLA matching and the waiting list. Also this shows that the ideas to improve the system are influenced by the institutional setting in which they are discussed. The historical role of HLA matching and the influence of certain actors in allocation policy seem to strongly influence the debate on HLA matching.

Although the allocation system is on an international cross-border level, attention in research on allocation on a hospital level provides some surprising outcomes. The case study shows that in practice the outcome of the system does not automatically have to lead to an allocation in line with this outcome. This finding was brought forward by a nephrologist who based it on experiences in practice by the actual allocation that takes place in transplantation centres. Individual doctor's behaviour and ideas on kidneys from older persons in particular explain for a difference in acceptance policies between centres. The reason not to use a kidney is brought forward as a clinical consideration, but the difference explains there is no consensus in the use of certain kidneys or in transplanting certain people. Trying to understand in research on how this is acted upon by interviewing key members in the allocation community shows that notions of autonomy of doctors are valued more compared to the negative effects this difference in acceptance policy may have for individual patients on the waiting list.

Reports of changes that are performed in the system might be provided, but they may not provide insight in why changes are made. In the case study, interviewing key members and observing debates on valuation reveals unintended and undesired effects that were corrected for. Giving kidneys from donors with blood group 0 to people on the waiting list regardless of their type of blood group over time created the effect that people on the waiting list with blood group 0 had to wait longer. Optimal use of a kidney because of the clinical possibility to do so might create tension due to the effects this generates on equality of treatment. The example of blood group also shows that in practice effects of valuation might be unintended. Only over time effects can become visible, practice may show these effects turn out different compared to how they were intended.

The examples above show that to just argue that different notions of fairness exist does not sufficiently cover the conglomeration of different notions of fairness in practice. These notions mainly relate to egalitarian, utilitarian and clinical considerations, but more notions of fairness are present. One example that relates to a different notion of fairness is defined in the ethical charter of Eurotransplant is 'solidarity within each country'. Because of the international cross-border collaboration allocation needs to take into account the solidarity within each country by a mutually agreed balancing system (Ethical charter:3).

Research on the guideline shows a country balance- and a regional bonus variable. Potential recipients on the waiting list from a country in which the import of donor kidneys is higher in relation to the export will get less 'country balance points' compared to potential recipients from countries with less import and more export of donor kidneys.

Interviewing key members of the kidney allocation committee provides the information that this country balance variable might be understood to be a clinical criterion, but that it is mainly based on national arguments. Although the aim of allocation is both optimal use of a kidney and waiting time, the influence of national notions of fairness in allocating a kidney seems to create a 'national kidney'. This 'national kidney' causes for more mismatches to be accepted and waiting time to increase for people from certain countries. Whether the impact of these national considerations are likely to increase because countries are getting more influence in allocation policy is unclear. Most countries have an objection based system and might therefore want to keep more kidneys inside their country, although the effects this generates may also turn out to be defined undesirable. Considering the expressed aims of allocation this finding of research of a 'national kidney' seems surprising.

The regional bonus variable does not create as many points compared to country balance, but currently partly creates the same effect. The reason extra points are given in case a donor and recipient are from the same region is based on clinical considerations. Keeping cold ischaemic time as short as possible will positively affect the quality of a kidney. This is also the reason why people on the waiting list from neighbouring regions are also given some extra points in case a kidney is available. The current system restricts this option to only neighbouring regions that are in the same country, which shows national considerations in allocation. But in this example of regional bonus these national notions are undesired and are defined as a threat to create fairness of allocation. Therefore the idea is to leave out the country border in case of neighbouring regions.

Research on a valuation system does not only need to closely study the effects of single variables but, due to their interaction, also to understand the effects they generate on fairness of allocation as a whole. This is in line with the findings in the theoretical framework, chapter 2. There is no smoothness in variables operating next to each other, different considerations of fairness influence each other resulting in a conglomeration of different notions of fairness.

The implication for research is that it has to consider and go beyond identification and understanding of values expressed in legislation, protocol and guidelines. It has to be positioned at a point which enables close observation on central debates on valuation and on valuation in action, on the presentation of the system to parties outside government, on comparison to other systems and by interviewing key members in the kidney allocation community. This seems to provide insight in a valuation system and in the composition and conglomeration of fairness of allocation. The consequences for governance will be discussed in the second point of discussion.

4.2 Consequences for governance of a valuation system

Governance of a valuation system, that is based on (pre)defining values and principles separated from its practical setting, would implicate such a system to be the result of external (political) processes. This would entail that governing a system is built on the idea that a valuation system can be defined to function in a certain matter and that third parties implement and monitor the system to ensure valuation in the (pre)supposed way.

The first point of discussion shows that valuation is embedded in practice, in which a complex dynamic is created. There is no smooth composition of notions of fairness, because in practice these notions might conflict. Whether the allocation system for donor kidneys generates the effects that are desired seems questionable. The outcome in practice does not have to represent what is aimed in legislation, protocols and guidelines.

Considering the different aims expressed, governance exists of ensuring different notions of fairness in allocation. The expressed notions of fairness do not show how much they influence the decision in who will receive a kidney and what the consequences are of the trade-off between different notions of fairness. To declare that both optimal use of a kidney and solidarity within a country are ensured seems based on the idea that having these two notions represented by variables in a system should be sufficient, does not take into account that the one may cause undesired effects for the other. There is no smooth balanced trade-off between clinical, national, utilitarian and egalitarian notions of fairness. Tension and conflict between different notions of fairness therefore ultimately lead to the fallacy of the optimum. Conditions can be discussed that seem to enable reconstruction of a composition of fairness, but the dynamic and conflictual 'nature' of the composition is inherently unpredictable. 'Reconstruction' itself therefore is ambiguous, it may cause new or other tension and conflict. The case study provides examples to further discuss this.

In practice allocation of a kidney might not be in accordance with the outcome of the system. Doctors and transplantation centres have different policies in their acceptance of kidneys, mainly in case they are from older donors. All members of the Dutch kidney allocation community are aware of this difference. Although equality in treatment and objectivity in allocation are aimed to be ensured for in governance and these aims are under pressure due to this difference in acceptance policy no awareness

is raised on this matter. Members of the kidney allocation community are pointing at each other in who should put this matter to the table. The reason not to do this is respect for principles of autonomy of doctors. Tension between different values, equality, objectivity and autonomy, in this example inherently exist. The case study also provides examples that shows dynamic and experimental governance towards tension between values.

The regional bonus variable in the valuation system created a conflict between values that was defined undesirable. Solutions were searched for in the kidney advisory committee of Eurotransplant to act upon them. This variable was being redefined by changing the factors that created these undesired notions of fairness. It was debated within the committee that national considerations are not considered to create the fairness that is aimed for. The decision has been made that this variable has to translate clinical considerations solely, not regarding from which country a person is. The solutions that are forwarded in the committee are challenged with complexities, for example in how to deal with countries that are more distanced. These complexities are recognized within the committee and currently ideas are brought forward to deal with these complexities. This example of regional bonus shows awareness to effects and their consequences, which is created by performing research on the waiting list, this is brought on the table for debate and to redefine this variable and hence to redefine fairness of allocation. Also it shows the importance of dynamic and experimental governance, because this reconstruction is ambiguous itself due to the possible other or new tensions that are created by it.

The way the effects caused by the blood group variable was acted upon roughly shows a similar path. The difference is that it took more time to undertake action, which caused negative effects to become larger. This example can be used to show how institutions, institutional arrangements, actors and the complexity of the system can both constrain and enable adequate governance.

Looking at the influence of actors the example of dealing with effects caused by the variable of blood group shows that awareness to the effects was raised by single actors, in this case some nephrologists. Because these actors are part of the Dutch kidney meeting, the LONT, there was a possibility to forward their concern in the Eurotransplant kidney advisory committee. Having these different committees or arrangements for action on the one hand seems to restrict a rapid response, on the other hand creates a possibility to put matters on the table for debate and for joint action.

The reason provided in the case study is that no awareness in undesired effects by Eurotransplant was raised because attention was paid on other variables like HLA matching. The example of HLA matching is returned to later in this point of discussion. For now, it can be said that HLA matching has a dominant, institutionalized, role in Eurotransplant, which may cause less attention for other values and variables. Also understanding effects caused by a single variable is a complex undertaking due to the multiple variables interacting in one system. At first the effects did not seem to cause concern, but they became larger over time. Due to alertness from certain actors on effects of equality of treatment on the waiting list they discovered these effects.

Apparently the system itself can cause a complexity to create awareness. By repeatedly bringing forward effects, showing that people with blood group 0 on the waiting list had to wait longer, this matter was debated upon. The result of this debate was to readjust the use of this variable in the system to correct for the undesired effects.

It may be assumed that because actors or third parties are made responsible to implement and monitor an allocation system this means they will act on undesired effects and will constitute a debate. In practice having third parties might entail that other parties or actors do not have a direct incentive to act and be aware. Third parties may assume that certain actors, doctors/nephrologists, will bring forward negative effects that are created by the system. But in practice doctors can be unaware of effects, because they only monitor their own patients and hence only deal with allocation on a centre- and patient level.

Committees in which these parties and actors are part of enable a joint awareness and debate on the valuation system and a condition to compose fairness in allocation. Altogether more conditions to enable matters to be put forward and to debate on fairness of allocation seem necessary, next to the composition of arrangements in which this enablement has to take place. The next examples are used to show how conditions for adequate and sufficient governance are challenged.

The use of HLA matching by Eurotransplant is declared and presented to external parties like patient groups to be based on clinical considerations. The risk of defining HLA matching to only be a clinical factor is that the role of HLA matching and its effects are considered somewhat inevitable and not up for discussion.

Comparison with other systems reveals that HLA matching does not necessarily have to be part of a valuation system for donor kidneys. The option of leaving it in or out of the system seems to relate to a choice in either accepting the undesired effects caused by not matching on HLA or accepting certain groups to have lower chances in having a kidney. About the undesired effects of not matching on HLA seems to be no consensus. One of the arguments is that it causes less optimal chances for survival time of the kidney, which shows HLA matching is based on utilitarian considerations as well.

The aim of allocation is optimal use of a kidney, this is stated to be without regard for personal or social background. Both notions of fairness operating in one system does not have to go 'hand in hand', but causes the one to create negative effects on the other. This again shows the conflict between values which leads to a fallacy of the optimum. The idea that is discussed upon in the kidney committee of Eurotransplant is to redefine HLA matching itself, to reduce some of the undesired effects of the current use of this variable. The idea to leave HLA matching out of the system and the tension it creates with different notions of fairness is not brought forward for debate. Medication is improved there is no debate taking place to discuss these matters.

Dynamic and experimental governance might enable reconstruction of the system. Reconstruction of the system, for example by leaving HLA matching out of the system, seems to be ambiguous. It may create less inequality but will cause a new dynamic and tension between values. Institutionalized beliefs in HLA matching, created by powerful actors influencing allocation policy and by the historical role of HLA matching, do not enable but restrict a dynamic and experimental governance of the system

Practice shows that tension between values is inherent, but the composition of current arrangements to debate and decide might negatively affect the possibility of an open and experimental attitude towards reconstructing fairness of allocation. Current arrangements consist of actors that seem institutionalized by the institutions they operate in. In these arrangements no external or public influences are present, which also entails that whether the current composition of fairness of allocation represents societal notions of what is considered fair is questionable.

Increasing the possibilities for HLA matching was the reason for collaboration between countries in allocating donor kidneys. Optimal use, in terms of survival time of the kidney, is primarily aimed for in allocation. Medical criteria have to be taken into account, but also waiting time and principles of solidarity within each country have to be considered. This solidarity within each country is implemented through a mutually agreed balance system. In the system this mutually agreed balance system is translated in a country balance variable that has quite some impact on valuation as a whole due to the points it gets. This will stop too many kidneys from countries that have relatively more kidneys available to go to countries with relatively less kidneys available. Only a few countries have a permission based system and generally have less kidneys available, it is argued that as a consequence of having this type of system and because it is a relatively big country compared to the others, Germany has more people on the waiting list.

Political pressure from other countries and the increasing influence of countries in allocation policy are the reason for notions of solidarity within each country are becoming more important. Also in this example, prioritizing for these notions causes other notions of fairness that are expressed to be aimed for to become (partly) overruled. Fairness of allocation seems to be more and more redefined in the translation of a national kidney. Eurotransplant has recently introduced a council in which countries have more influence in allocation policy. Whether this will positively influence a more dynamic and experimental type of governance towards valuation in practice remains unclear.

Chapter 5 Conclusion and Recommendations

‘Who should get a kidney’?

The aim of a valuation system is to allocate. The desire to value before allocation takes place shows that the decision ‘who should get (a kidney)’ is not intended to be a matter of coincidence. The manner in which this is done reveals what system and what interpretation of governance are considered to be best capable to achieve a desired way of valuation.

In case of kidneys the person who *should* get a kidney depends on which kidney is available. Valuation takes into account, and is apparently *desired* to take into account, characteristics of the donor of the kidney available and of the potential recipient on the waiting list. But does it mean that looking at what valuation takes into account shows what is desired? Which brings forward the questions: how to look and what is desired?

What is desired in valuation might or might not be expressed. In case legislation, guidelines and protocols are available they may formulate the grounds and aims of valuation. Having this information available gives the impression that transparency in what valuation is and what is supposed to be desired in valuation is transparent. Which reveals that governance that aims for this transparency is based on the idea that creating transparency is supposed to ‘do to the good thing’ in the governance of a valuation system.

The manner in which valuation takes place may differ. The decision who should get a kidney can be made by (certain) actors, individually or organised, and by the use of a (technical) system. Governance can consist of the assumption that a (technical) system creates (more) objectivity in deciding who should get a kidney. Hence, for governance to aim and to create a computer driven system to value donor kidneys would accordingly be based on the idea that objectivity in valuation is ‘a good thing to create’.

For the thesis at hand the question whether transparency and objectivity of a valuation system are or should be considered as being examples of ‘doing the right thing and of good governance’ is not so much the question. The question is whether identification of principles, values and grounds of valuation provided by having a transparent and objective system goes hand in hand with the actual outcome of valuation.

Assuming it does would entail that once principles and grounds are identified by the use of guidelines, providing a transparent understanding in the aims of a valuation system and the means to achieve these aims, an understanding is created in how fairness is defined. For governance it would mean that designing a system by defining principles and grounds that represent which is considered to be ‘good or fair’ and translating them in input variables will create an outcome that once implemented in practice is based on ‘doing right and creating fairness’ in the question who should receive a kidney.

Public policy research does not generally assume that designing and implementing valuation creates an outcome in line with its design. Institutions, institutional arrangements, actors and the technical apparatus of the system itself are all examples used by theories on analysing public policy to explain for this.

Looking at the case study valuation of a kidney aims to represent a composition of different notions of fairness. The impression made is that creating fairness is a matter of translating these notions of fairness in input variables and inserting these variables in one algorithm to provide a desired outcome. For governance this implies that a decision has to be made which values and principles define and constitute fairness and maybe how much they should define and constitute fairness. It would implicate that mother nature can design a chameleon of fairness, colour and shape it with different notions of fairness and put it alive in the world.

For research observation on guidelines to understand the algorithmic definition of fairness, composed of different notions of fairness, requires a detailed look and (certain) mathematical skills. Observing the design of a fairness chameleon does not automatically mean you understand its design and how fairness is constituted in it. To understand it, certain skills and interest in performing observation on a detailed level are required.

Comparison of the system to other allocation systems, without performing a comprehensive comparative research, shows differences and similarities between systems. Differences imply that (to some extent) choices can be made which and how much certain values and principles define and constitute fairness. The design of a fairness chameleon may be similar to the design of other chameleons and lizards, but it has its own characteristics. There are more examples of computer based allocation systems, but variables operating in it may differ between these systems creating different outcomes.

A constructivist view on values and valuation, used by Latour in his essays on policy processes, is that they are embedded within practice. For research this implies that observation in practice, on the level in which the system is constructed in, debated on and operating in, will show the actual valuing that is taking place. Hence, will show the real composition and definition of what fairness of allocation is.

Qualitative research methods, observation of central debates on the valuation system, of meetings with external parties, of the settings in which valuation and allocation happens and by interviewing key members in the kidney allocation community, can provide understanding in the enactment of different notions of fairness operating in one system in practice. The outcomes of these qualitative research methods shows that in practice a valuation system may create different and unexpected, surprising outcomes.

A kidney allocated manifests itself as a local kidney, a national kidney, an optimal kidney, a young or old kidney and an ethnic kidney. A fairness chameleon may be red, blue, grey and green.

It is likely not to show all of these colours at the same time, one colour of fairness will prevail over the other. Optimal use of a kidney cannot smoothly go hand in hand with equal chances of having a kidney, in practice these notions conflict. HLA matching causes certain ethnic groups to have lower chances in getting a kidney. Maybe optimal use of a kidney is expected, for it to cause discrimination of certain groups is probably unexpected. The points for the variable of waiting time that represent a green, egalitarian, colour of the fairness chameleon do not resemble the actual amount of green colours the fairness chameleon manifests. The presence of for example HLA matching not only causes the chameleon to colour red, next to its green colours, but also fades away some of the green by causing inequality itself. Interaction between different notions of fairness create the fairness chameleon to be dynamic and to inherently experience internal stress.

Although its internal stress is inherent, its level of stress depends on the surroundings in which the fairness chameleon lives in. A fairness chameleon that is kept in a cage might never show more of its green colour. Not leaving HLA matching out of the system due to the actors, institutions and institutional arrangements that surround the system will continue to cause discrimination of certain ethnic groups. It may be supposed that the chameleon in a cage has less predators and has better chances to survive, its red colour still fades away its green colour.

Leaving it out of the box is an experimental and ambiguous thing to do. Dynamic and experimental governance on the one hand creates the possibility and enables it to colour green but on the other hand causes it to be possibly exposed to new levels of stress, which again may challenge and influence its colours. Changing the blood group variable has made the chameleon to look more green and less red. Changing the regional bonus variable in the system created the chameleon to overall look more green, but did show new levels of stress expressed in unexpected colours.

One can judge, like or dislike the behaviour and colours of this fairness chameleon, but only close observation of the fairness chameleon will show all of its colouring and bring understanding in how and why it colours and behaves the way it does. But one has to keep in mind that its colouring and behaviour will stay inherently unpredictable.

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Reports

Eurotransplant Ethical chapter

Eurotransplant chapter 4 ET kidney allocation system (ETKAS)

Appendix

Figure 1: Amount of (kidney) transplantations per year in the Netherlands, 1997-2011: total, living- and postmortal donortransplantation.

Aantal transplantaties per jaar, 1997 t/m 2011: totaal, levende- en postmortale donortransplantaties.

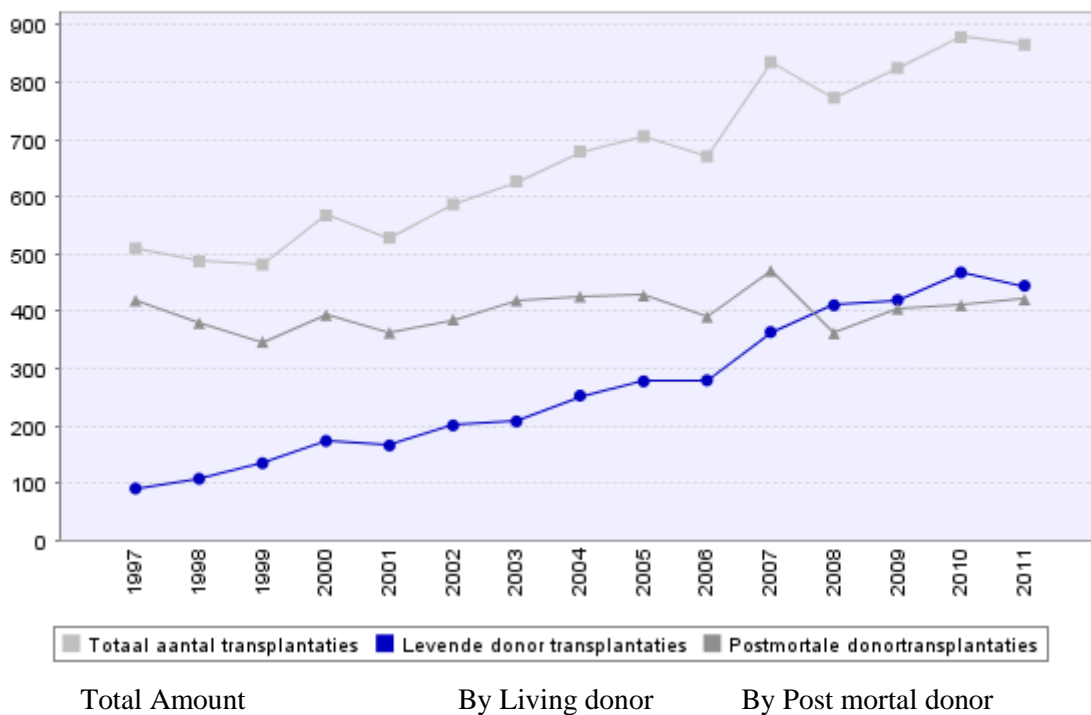
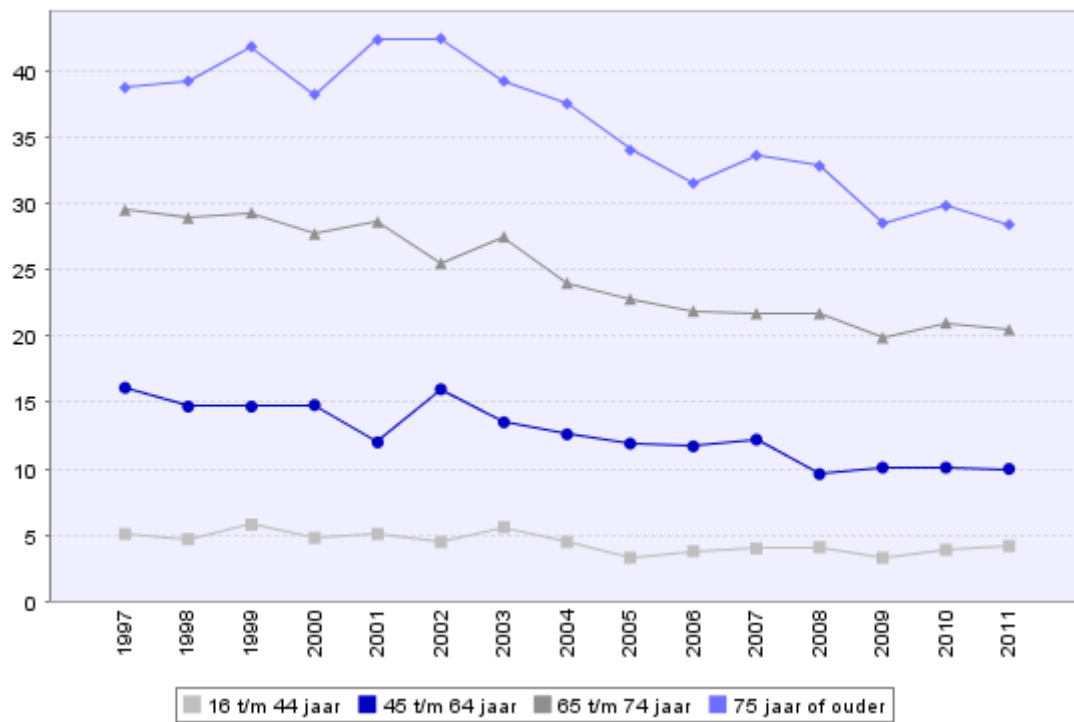


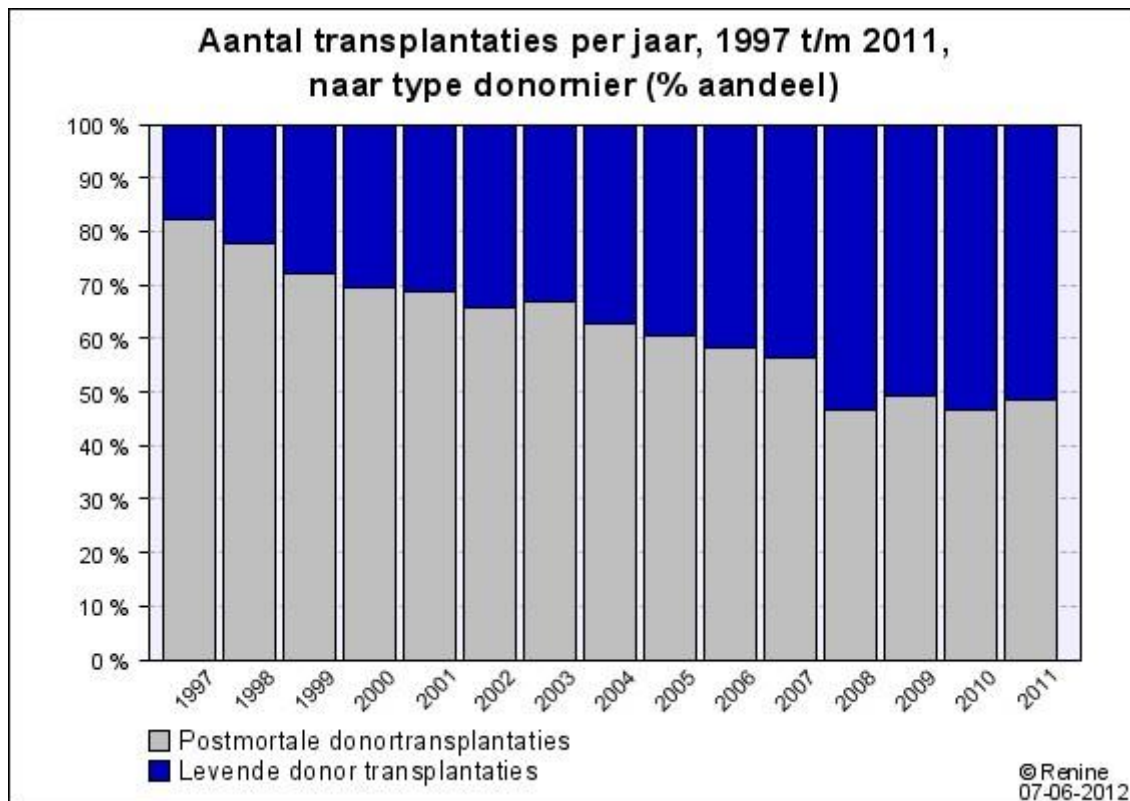
Figure 2: Mortality (%) dialysis per age group, 1997 – 2011 in the Netherlands

Mortaliteit (%) dialyse naar leeftijdsgroep, 1997 t/m 2011



Source: Renine 2012

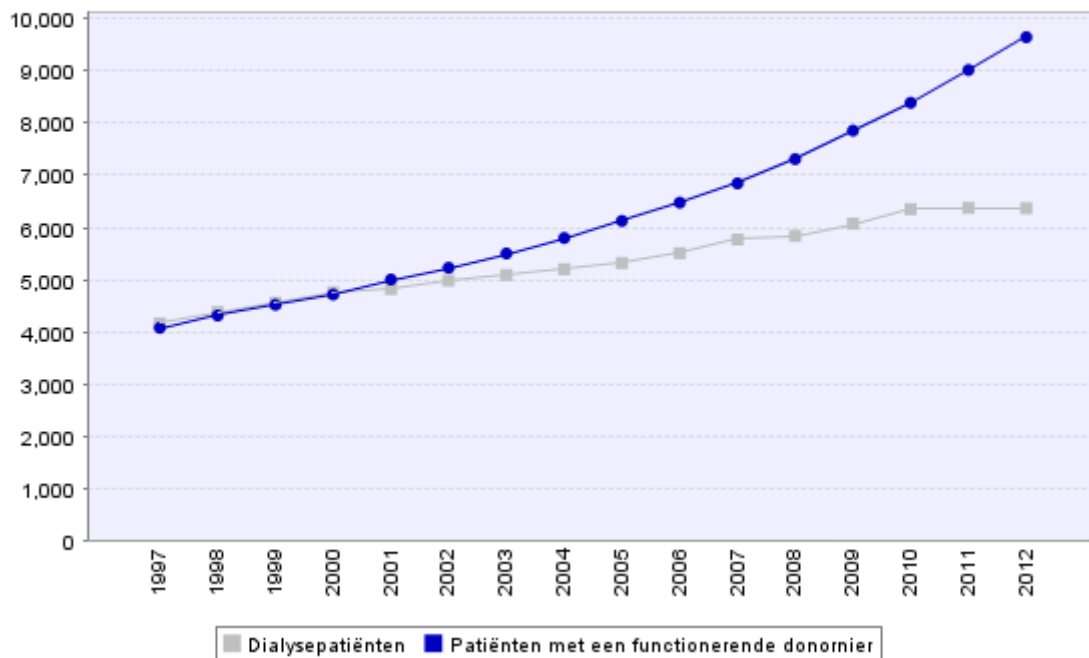
Figure 3: Amount (%) of kidneytransplantations per year in the Netherlands, 1997-2011, blue part represents post mortal donortransplantations, grey part represents living donor transplantations



Source: Renine 2012

Figure 4: Amount of patients on January the first in the Netherlands, 1997-2012. The blue part represents patients on dialysis and the grey part represents patients on dialysis who have a donor kidney.

Aantal patiënten op 1 januari, 1997 t/m 2012. Dialysepatiënten en patiënten met een functionerende donornier.



Source: Renine 2012

