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# Ethically Acceptable Compensation for Living Donations of Organs, Tissues, and Cells: An Unexploited Potential?

Running title: Ethically Acceptable Compensation for Living Donations

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## Abstract

*The number of living donations of human organs, tissues, and cells falls far short of the need. Market-like arrangements to increase donation rates have been proposed, but they are broadly considered unacceptable due to ethical concerns and are therefore not policy relevant in most countries. The purpose of this paper is to explore a different approach to increasing living donations, namely through the use of ethically acceptable compensation of donors. We review the compensation practices in Europe and find a lack of reimbursement of incurred costs and lack of compensation for non-monetary losses, which create dis-incentives for donation. We draw on a well-known philosophical theory to explain why donors are rarely fully compensated and why many existing proposals to raise donation rates are seen as controversial or even unethical. We present and discuss three categories of compensation with the potential to increase donation rates in an ethically acceptable way.*

**Keywords:** living donations, reimbursement, compensation, incentives, spheres of justice.

**JEL classification codes:** D63, D64, H51, I11, I12, I38

## Key Points for Decision Makers

- Living donors should be compensated for non-monetary losses as well as monetary costs associated with donation.

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- Compensation beyond the reimbursement of incurred monetary costs should itself be non-monetary.
- Non-monetary compensation may belong to one of three categories: receiving priority for otherwise-scarce health care, receiving free access to health care that is otherwise sold, and receiving non-health care-related benefits.

## 1 Introduction

Medical treatments using donated human organs, tissues, and cells have improved significantly over the recent decades, with increased success rates, lowered risk of complications, and better quality of life [1]. However, donation rates have not been able to match the need, and shortages are substantial. For example, in the European Union, the number of people on waiting lists for a kidney totaled approximately 46,000 as of 2016, and 1,749 patients died while on the waiting list. Likewise, 1,093 people died while waiting for a liver transplant [2].<sup>2</sup> Skin, fat, and other tissues are extensively used in the treatment of burn victims and other patients with poorly healing wounds [1]; hence, a shortage of tissues limits possibilities for treatment. The shortage of reproductive cells (particularly oocytes) may reduce the possibility of successful fertility treatment (e.g., [4], [5]), and the shortage of hematopoietic stem cells from bone marrow and peripheral blood potentially constitutes an obstacle to the treatment of leukemia and several other diseases (e.g., [6]). In 2014, 11 European countries reported experiencing regular shortages of stem cells/bone marrow, whereas 5 and 6 countries reported the same for oocytes and sperm, respectively [7]. Fourteen countries that experienced shortages of tissues and cells reported a lack of donors as the main cause of the shortage. Due to these shortages, there have been numerous initiatives to increase both living and deceased donations throughout Europe as well as in many other parts of the world. However, the shortage persists.<sup>3</sup>

One reason for this shortage is the (often very substantial) burden involved for living donors of organs, tissues, or cells. This burden includes monetary costs related to travel, foregone earnings, and medical care, as well as the non-monetary losses due to inconvenience, anxiety, pain, emotional concerns, the risk of medical complications and adverse health effects, including the (small) risk of death. These costs and losses will often provide a significant disincentive for potential donors.

In this paper, we explore the scope and potential for giving ethically acceptable compensation to living donors of organs, tissues, and cells, and we argue that there exists an unexploited potential for compensating donors in ways that are ethically acceptable and unlikely to impede donors' intrinsic motivation.

The general principle for compensating donors of organs, tissues, and cells is that donations must be voluntary and unpaid (see, e.g., [8]).<sup>4</sup> Although direct payment for donation is illegal in almost all countries, reimbursement of incurred monetary expenses is in line with international rules and guidelines (e.g., [9], [10]) and is even explicitly encouraged by some international organizations, including the European Union (EU) [11], [12]. However, the EU provides little guidance on how to reimburse living donors, and the means of reimbursement are left mostly to the members' national parliaments ([13], article 13, 2.). Monetary compensation for non-monetary losses such as inconvenience, anxiety, and pain, in contrast, is generally not accepted ([8]–[10], [13], [14]).

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<sup>2</sup> For kidneys: Not including Luxembourg and Spain. For livers: Not including Latvia and Luxembourg. Note also that the number of patients who died while on the waiting list is likely to underestimate the true shortage of kidneys, since the scarcity of organs may preclude physicians from including more patients on the waiting lists (e.g., [1], [3]).

<sup>3</sup> See Appendix A for a non-exhaustive list of European initiatives.

<sup>4</sup> Appendix B contains a non-exhaustive overview of international (with a European focus) rules and guidelines on donations of organs, tissues, and cells.

Taking this into account, we propose to reimburse donors for monetary costs *and* compensate for non-monetary losses without violating the general principle of voluntary and unpaid donations. To this end, we present and discuss the use of different types of *non-monetary* compensation to compensate donors for non-monetary losses.

In the discussion of the acceptability of non-monetary compensation, we rely on insights from political philosophy to offer a possible explanation for why the type of compensation proposed in this paper is likely to be considered ethically acceptable by society in general. More specifically, we base our reasoning on a *Spheres of Justice* framework [15]. This philosophical framework conveys the idea that different social goods should be distributed according to different principles, thereby constituting different spheres of justice. Considering living donations in this context also provides an explanation for why monetary compensation for non-monetary losses is, to a large extent, viewed as unethical.

Proposals exist that are related to ours in idea or content. In particular, in the context of living organ (kidney) donation, Delmonico et al. [16] propose giving donors medical leave and disability and life insurance to offset the risk of complications, “access to organs” for previous donors, and a donor medal of honor to show society’s appreciation. The authors explicitly stress the importance of not putting an arbitrary monetary value on organs that will, in practice, amount to a form of payment. In [17], Gaston et al. propose a compensation scheme that also offers compensation for non-monetary losses. In addition to insurance and reimbursement of out-of-pocket expenses, they suggest that donors should be given monetary compensation for lost wages and non-monetary losses such as inconvenience, anxiety and pain. In the context of blood donations, Buyx [18] suggests further researching the use of a wide range of (vouchers for) low-cost goods as compensation.

Our proposal differs from these in several ways. First, while Gaston et al. [17] propose giving monetary compensation beyond reimbursement of incurred expenses, our aim is to provide and discuss non-monetary alternatives. Second, we suggest considering a wider range of non-monetary compensations than those (albeit very natural elements) presented in [16], [17]. Last, instead of proposing a specific compensation scheme for kidney or blood donation, we focus more broadly on proposing and discussing a general approach to compensating living donors of organs, tissues and cells. Following this approach, the given compensation scheme could (and should) then be tailored to fit the specific type of donation in question and possibly to take specific cultural and/or institutional differences into account.

In this paper, we focus on donor compensation as a means to increase living donations, but many other proposals and initiatives exist that focus on other ways to increase living donation rates. Especially, a vast amount of literature exists on how to increase the supply of living organ donors, and we mention a few contributions below.

Some researchers are strong advocates of solving the organ shortage by establishing a market for organs, and a market has, for example, been proposed as an effective solution by [19]–[22] and others. Becker and Elias [22] propose introducing a market for organs and estimate that a kidney from a living donor should be priced at slightly more than \$15,000, whereas part of a liver should be priced at approximately \$38,000 for the number of donations to be sufficiently high to meet demand in the US. Matas and Schnitzler [20] provide an extensive cost-effectiveness analysis and conclude that society could break even while paying slightly more than \$90,000 or more for a kidney. Hippen [23] argues in favor of a regulated market and proposes and discusses features necessary for a morally defensible market for kidneys.

A related proposal that does not involve cash payments is given by Satel [24] and includes setting up a regulated market-like system in which donors donate (non-directed) to the transplant list and, in return, receive in-kind rewards in the form of, for example, tax breaks/credit, a contribution to a pension fund or vouchers for tuition payment, potentially worth between \$25,000 and \$40,000 in total.

The idea of a market for organs is considered controversial by many policy makers as well as the general public in many parts of the world.<sup>5</sup> The main arguments put forward against a market are ethical concerns about commoditizing the human body, the risk of taking unfair advantage of the poorest and most vulnerable citizens, concerns about undermining altruistic donations (for example, by crowding out potential donors' intrinsic motivation to donate; see [28]) and the risk of human trafficking [9]. Studies exist, however, indicating some support for providing donors with cash rewards, e.g., Niederle and Roth [29], and using a survey among American citizens, Elias et al. [30] suggests that the public opinion on market-like solutions can be affected toward a more accepting direction by providing information about the costs and benefits of such a system.

Another example of an initiative to increase the number of living organ donors is kidney exchanges [31]. A kidney exchange is an option for patients who have a willing donor that cannot be used due to blood or tissue incompatibilities. If several such patient-donor pairs exist, then it may be possible for some patients to "exchange" donors, thereby increasing the number of transplants. Another variant is the kidney "chain" (alternatively "domino") donation, in which an altruistic donor donates a kidney to an unknown recipient, whose willing (but incompatible) donor then donates to someone else in return, and so on, until no further matches can be found. Several examples of kidney exchange programs for matching kidney patients and living donors exist in the US (see, e.g., [32], [33]), and in Europe, a living donor kidney exchange program was established in the Netherlands in 2004 [34].

There may very well be a potential for expanding, for example, the use of kidney exchange programs in Europe, but recognizing the obstacles facing such proposals, we here focus on ethically acceptable donor compensation as an easily implementable means to potentially increase the supply of living donors without the need for legislative changes.

The rest of the paper is structured as follows. Section 2 introduces basic definitions and concepts. Section 3 provides an overview of compensation practices in European member states and reviews some empirical results on the effect of reimbursing donors. In section 4, we discuss the use of non-monetary compensation in a *Spheres of Justice* context. Section 5 presents and discusses three categories of compensation that reduce dis-incentives for donations without relying on direct monetary payment. Section 6 further discusses potential obstacles related to the use of compensation, and section 7 concludes.

## 2 Basic concepts

Most living donation programs rely on altruistic motivation<sup>6</sup> as the main driver for donations. For a potential donor to be willing to donate, the utility gain from altruism must outweigh the potentially significant costs and losses associated with the donation, including the monetary costs related to travel, foregone earnings, and medical care as well as the non-monetary losses due to, for example, inconvenience, anxiety, pain, and the risk of medical complications and adverse health effects.

Before considering current compensation practices, we clarify the terminology used throughout the paper. A *reimbursement* compensates a donor for the monetary costs associated with the donation (for example,

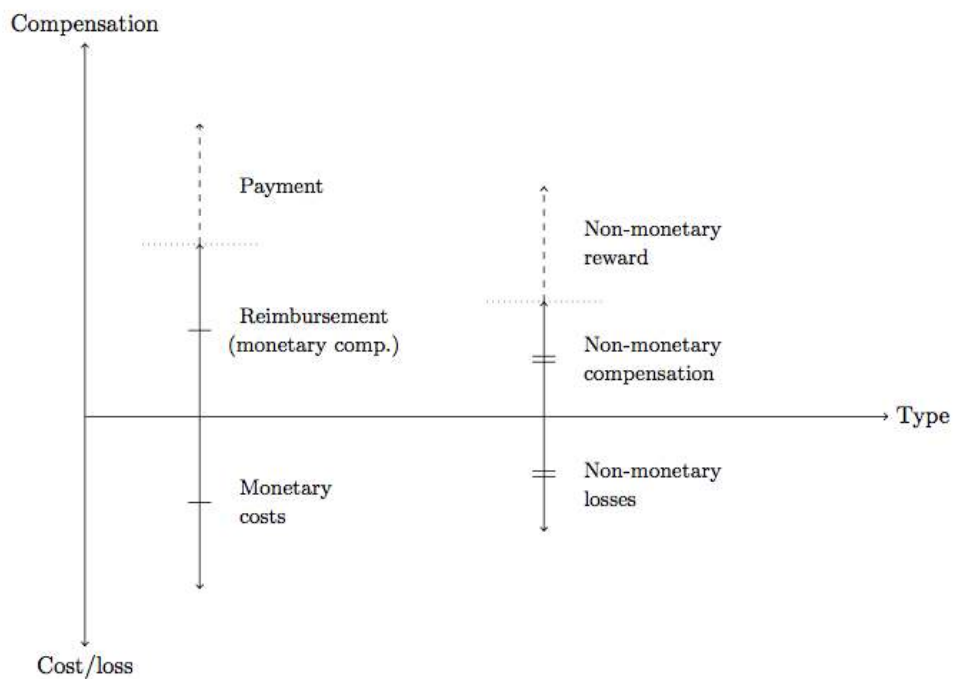
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<sup>5</sup> A notable exception is Iran, where a government-funded and government-regulated living unrelated donor kidney transplantation program was implemented in 1988 ([25], [26]). Donors receive a payment from the program, and "a rewarding gift" from the recipient (or a charitable organization if the patient is poor) is negotiated. This program led to a significant increase in the number of living unrelated donations, and by 1999, the waiting list was eliminated. Whereas the system in Iran has taken precautions to mitigate some of the ethical problems associated with the program, the quality of life for former donors has nevertheless been questioned [27].

<sup>6</sup> I.e., an individual's willingness to act in the consideration of the interests of other persons without an ulterior motive [35].

transportation costs). In Figure 1, such monetary costs are illustrated by the solid line marked “-” below the horizontal axis. If the donor is fully reimbursed, she will receive a reimbursement of the same size as illustrated by the solid line marked “-” above the horizontal axis. Any monetary compensation that more than offsets the monetary costs associated with the donation is a *payment*, as illustrated by the dotted line above full reimbursement. Non-monetary losses are illustrated by the solid line marked “=” below the horizontal axis. The donor can be fully compensated for non-monetary losses by receiving a *non-monetary compensation* of the same size as illustrated by the solid line marked “=” above the horizontal axis. Note that monetary compensations can only compensate for monetary losses, whereas monetary compensation used to compensate non-monetary losses (i.e., a monetary compensation beyond monetary costs) will be denoted as a payment. Any non-monetary compensation that more than offsets the non-monetary losses associated with the donation is considered a *non-monetary reward*, as illustrated by the dotted line above full non-monetary compensation.

Figure 1: Types of compensation



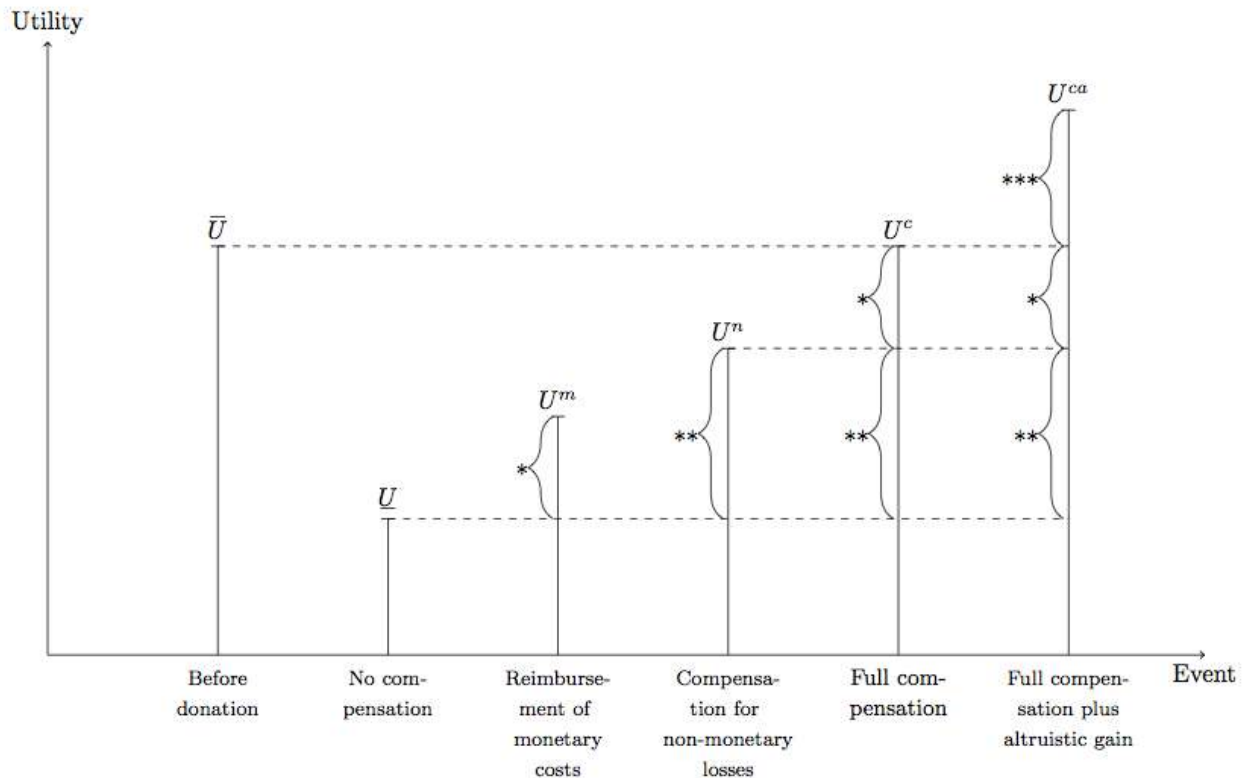
A donor who is only partially reimbursed and/or compensated may still wish to donate. This is so if the intrinsic motivation to donate (i.e., the utility gained from altruism) is large enough to make up for the remaining losses. To illustrate, consider Figure 2 and suppose a donor’s utility is  $\bar{U}$  before donation and  $\underline{U}$  after donation, where  $\underline{U}$  does not include any utility gain from the altruistic act. It is natural to assume  $\underline{U} < \bar{U}$ .<sup>7</sup> Let  $U^m$  denote the donor’s utility level if she is fully reimbursed for all monetary costs but *not* compensated for non-monetary losses. Analogously, let  $U^n$  denote the donor’s utility level if she is fully compensated for non-monetary losses but *not* reimbursed for monetary costs.<sup>8</sup> Let  $U^c$  be the donor’s utility level if she is both fully reimbursed for monetary costs and

<sup>7</sup> We can think of  $\underline{U}$  as the utility of the donor if the donated material does not benefit a patient but is used for some other “morally neutral” purpose.

<sup>8</sup> In Figure 2, we assume  $U^n > U^m$ . Of course,  $U^n < U^m$  is possible as well.

compensated for non-monetary losses. Finally, let  $U^{ca}$  be the donor's utility level if she is fully reimbursed for monetary costs and compensated for non-monetary losses *and* we take into account a utility gain from altruism.

Figure 2: Utility under different levels of compensation



Notes: Brackets (and hence utility gains) marked with the same number of stars are of the same size. In the Figure,  $U^n > U^m$ , while  $U^n < U^m$  is also possible. The illustration is under the assumption that utility gains are additive.

An individual is only likely to donate if the expected utility after the donation (including costs, losses, compensations, and gains from being altruistic) is as least as high as the initial level of utility. If a donor is not compensated for the utility loss associated with donation, the utility gain from the altruistic act will have to at least outweigh this loss (i.e., the difference  $\bar{U} - U$ ) for the individual to be willing to donate. This explains why people are rarely willing to sacrifice a kidney for a stranger but are more frequently willing to do so for a loved one [36]. The greater the reimbursement and compensation, the less utility from altruism is required for a potential donor to actually choose to donate. However, even with full compensation, the decision to donate is still based on an altruistic motivation, as long as no payment or reward is given, since the compensations merely remove the dis-incentives that may otherwise cause the individual to refrain from donation despite her altruistic motivation. A utility level above  $\bar{U}$  can also be obtained if the donor receives compensation beyond the level necessary to restore her to the initial level of utility, such as by means of a payment or reward. In this case, the donor would have an incentive to donate regardless of any altruistic gain.



### 3 Compensation principles and practices

To obtain an overview of the current state of compensation schemes, we start by reviewing compensation practices in Europe and proposed solutions to the organ shortage problem.

#### 3.1 Compensation practices in the European member states

**Cells and tissue donations** Below is a brief overview of the European compensation practices as of 2014. The data are from European Commission [7], which summarizes the results of a survey of the compensation practices of 28 member states and Lichtenstein and Norway. In the survey, 19 countries reported having guiding principles for the possibilities of providing donors with compensation. This is an increase from 13 countries in 2009 [7].

Table 1 provides an overview of the number (percentages in parentheses) of countries in the EU that provide specific types of compensation for donations of non-reproductive (NR)<sup>9</sup> and reproductive (R)<sup>10</sup> cells and tissues. Twenty-two countries reported providing some kind of compensation to living donors of non-reproductive tissues and cells, whereas 8 countries reported that such compensation was not allowed. For reproductive cells and tissues, 18 countries reported providing compensation and 1 did not respond. Of the 11 that did not compensate donors, 5 stated that non-partner donation was not allowed at the national level [7].

*Table 1: EU member states providing compensation for different dis-incentives related to donations of cells and tissues*

Compensation	Non-reproductive <sup>1,2</sup>	Reproductive <sup>1,2</sup>
Medical costs	15 (50%)	6 (20%)
Travel costs	16 (53%)	10 (33%)
Loss of earnings	15 (50%)	9 (30%)
Time off work (private)	9 (30%)	3 (10%)
Time off work (public)	10 (33%)	3 (10%)
Physical check-up	1 (3%)	2 (7%)
Compensation for inconvenience (e.g., pain)	2 (7%)	5 (17%)
Fixed sum of money	0 (0%)	12 (40%)
Small tokens	6 (20%)	2 (7%)
Refreshments	10 (33%)	7 (23%)
Food vouchers	4 (13%)	1 (3%)
Other forms	4 (13%)	0 (0%)

Notes: Percentages in parentheses are rounded to the nearest integer.

<sup>1</sup>Commission Staff Working Document on the implementation of the principle of voluntary and unpaid donation for human tissues and cells [7].

<sup>2</sup>30 countries: 28 EU member states, Liechtenstein and Norway.

As seen in Table 1, medical costs, travel costs, and loss of earnings are reimbursed in approximately half of the member states for the (NR) case and in 20%, 33%, and 30% of states, respectively, for the (R) case. In both cases, the remaining types of compensation are less common, with the exception of 40% of countries providing a fixed sum for

<sup>9</sup> For example “(...) skin, bones, tendons, corneas and hematopoietic stem cells”.

<sup>10</sup> Reproductive tissues and cells are defined as “(...) all tissues and cells intended to be used for the purpose of assisted reproduction” [37], mostly eggs and sperm [8].

the donation of reproductive cells. Physical check-ups and compensation for inconvenience (e.g., pain) are noticeably infrequent and reported by only 1 and 2 countries (NR) and 2 and 5 countries (R).

**Living organ donations** Kidney donations account for the major part of living organ donations, with donations of (part of) a liver accounting for most of the remaining donations, e.g., [2]. Since living donation of a kidney or part of a liver is associated with a significant amount of recovery time (e.g., Fehrman-Ekholm et al. [38]), the costs involved (including loss of earnings) are potentially substantial. However, a survey by EULOD [11] of 113 kidney transplant centers and 39 liver transplant centers in 40 European countries (including 25 and 18 EU member states, respectively) concluded that slightly more than half of the transplant centers for kidney donation and slightly more than two thirds of the centers for liver donation did not reimburse donors for their monetary costs [39].<sup>11</sup> This lack of compensation implies a significant dis-incentive for potential organ donors throughout Europe.<sup>12</sup>

### 3.2 Effect of increased reimbursement on living donation rates

As mentioned in the introduction and in Appendix B, several international sources highlight that the prohibition of payment to donors does not preclude reimbursing monetary costs. In addition, some sources explicitly stress the importance of reimbursing donors for the costs involved since reimbursement of monetary costs removes (at least some of) the obstacles to living donations, as argued by several authors (e.g., [39]–[41]). However, as described in Section 3.1, many countries do not (fully) reimburse donors.

A few papers have studied the effect of increased reimbursement on donation rates. Lacetera et al. [42] studied the effect of leave and tax legislation on the number of bone marrow and organ donations. They found a significant increase in the number of bone marrow donations but no significant increase in the number of organ donations. However, as the authors note, “(...) although tax breaks and leave provisions may be sufficient to induce, at the margin, individuals to undergo a moderately invasive procedure such as a bone marrow donation, they may be too low for the more ‘costly’ organ donations.”<sup>13</sup> Similarly, Wellington and Sayre [43] studied (among other things) whether state laws that provide some financial reimbursement to living organ donors increase the availability of transplantable organs. Specifically, they studied whether there was a significant increase in the number of donations in the 24 US states that, as of August 2007, had passed legislation granting state employees who underwent living kidney donation up to 30 days of paid leave or a tax deduction of up to \$10,000. However, no effect was found. This led the authors to conclude that the level of financial reimbursement was not great enough to encourage people to donate who were not already inclined to do so. Boulware et al. [44] and Venkataramani et al. [45] also investigated the impact of tax legislation on living kidney donations in the United States and found no effects.

To explain these findings, we can refer to Figure 1 and note that although the reimbursement scheme may fully reimburse the donor’s monetary costs from donation, the non-monetary dis-incentives associated with donation might not be outweighed by altruism alone, whereby no increase in donation rates occur. Referring to Figure 1, the reimbursement scheme might lead the donor to utility level  $U^m$ , but this still leaves the difference  $\bar{U} - U^m$

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<sup>11</sup> At the remaining centers (46% for kidneys and 30% for livers), income loss during recovery and hospital stay was mostly reimbursed (86% and 84% of the centers respectively). Income loss during wake up and costs for the evaluation process, hospital stay or postoperative follow-up were reimbursed in 54% to 76% of centers.

<sup>12</sup> It should be noted that considerable differences exist between European countries, with North-Western Europe having the highest share of transplant centers that provide reimbursement for living kidney donation (66%) compared to the Mediterranean and Eastern parts of Europe, with a share of approximately 20% [39].

<sup>13</sup> Here, “costly” refers to “(...) pain, suffering, scarring, time away from work and leisure, and undocumented long-term donor health effects implied by an organ donation”, i.e., both monetary and non-monetary losses.

(corresponding to \*\*) to be offset by altruism for the individual to actually donate. A reimbursement scheme that allows full reimbursement of donors' monetary costs might therefore not be sufficient to increase donation rates significantly, as indicated by the reviewed studies. Thus, to significantly increase living donation rates, a compensation scheme that includes both reimbursement of monetary costs and compensation for non-monetary losses should be developed.

One example exists in Israel, which has one of the most comprehensive reimbursement schemes. Laws have been implemented to increase donation rates, including reimbursement of 40 days of lost earnings, reimbursement of transportation costs, reimbursement of seven days of recovery in a recuperation facility, five years reimbursement of medical costs, work capability loss and life insurance, and reimbursement of five psychological consultations and treatments [46]. The exact effect of this reimbursement/compensation scheme is, however, difficult to assess since a law banning transplantation tourism was implemented at the same time. Nevertheless, the number of living kidney donations significantly increased from 71 in 2010 to 117 in 2011 after the implementation of the laws.

## 4 Non-monetary compensation and a Spheres of Justice argument

We have seen that in many European countries, living donors receive no or only limited reimbursement of monetary costs and compensation for non-monetary losses. We have argued that this can create significant dis-incentives for potential donors of tissues, cells, and, in particular, organs. To increase the number of donations, an obvious approach is therefore to try to remove these dis-incentives.

First, since EU directives and guiding principles from the World Health Organization (WHO) explicitly state that reimbursement of monetary costs should be allowed, and since reimbursement of monetary costs merely compensates an incurred loss that can be measured with great accuracy, it should be ethically acceptable in most societies. Thus, the lack of reimbursement in Europe may be seen as an informational issue rather than due to ethical concerns.

We have reviewed empirical evidence suggesting that simply reimbursing monetary costs is, however, unlikely to be sufficient to induce an increase in donation rates, and although reimbursement of incurred monetary costs seems generally acceptable, compensating donors for discomfort, pain, and risks using monetary payments (as proposed by, e.g., Gaston et al. [17]) is far more controversial and in violation of current European legislation.

If we want to reduce dis-incentives for donation beyond the reimbursement of incurred costs, and we cannot provide monetary compensation for non-monetary losses, then we may instead consider compensating donors for non-monetary losses using non-monetary compensation. Before we discuss this possibility in further detail, we may, however, discuss whether we should expect such non-monetary compensation to be perceived as ethically acceptable by policy makers and the general public.

As discussed by Roth [47], some transactions are considered repugnant even in the absence of negative externalities and concerns for coercion, and some transactions that are acceptable when involving gifts or in-kind exchanges may become repugnant if money is introduced in the exchange. Therefore, when designing market mechanisms or the like, one should be aware of such constraints. Whereas Roth accepts the presence of repugnance and tries to find ways to design solutions that avoid it, Sandel [48] argues that instead of trying to circumvent the repugnance, we should inspect it to determine whether it is unreasonable and should be challenged or if it is based on weighty moral concerns that should be taken into account, which in turn could imply that we (as a society) should refrain from carrying out the transaction in question. Furthermore, Roth [47] notes that what is perceived as repugnant is likely to vary both between societies and over time. Therefore, we cannot necessarily generalize findings on people's attitudes towards donor compensation from one society to another.

In the context of markets for kidneys, Sandel [48] states that in general, people hold one of three different views: selling a kidney violates the sanctity of the body, in which case kidney donation is opposed regardless of compensation type; commoditizing the body is problematic, but in-kind compensation with respect for the altruistic motivation is acceptable; or a market is supported, since people should be free to sell their organs. Taking this view,

we may conclude that even though societies differ and repugnance is likely to be a real constraint that should be taken into account, this categorization implies that whereas only the latter group is likely to support monetary compensation to donors, two out of the three groups could be expected to find (reasonable) non-monetary compensation ethically acceptable.

The argument that non-monetary transfers are potentially more ethically acceptable to policy makers and the general public than monetary transfers is supported by Costa-Font et al. [49], who found that approximately two-thirds of a sample in 15 European countries was in favor of non-monetary transfers for blood donations, whereas only a little less than one-fifth favored monetary transfers. In Barnieh et al. [50], a survey among the Canadian public, health professionals, and individuals affected by kidney disease found some support for direct monetary payments in the general public (45% of respondents) but less so among health professionals and individuals with or affected by kidney disease (15% and 25%, respectively). Reimbursement of expenses was, on the other hand, strongly supported by all groups, whereas indirect payments in the form of a tax break or credit achieved support from approximately 40% of all three groups.

One possible explanation for why non-monetary compensation is likely to be perceived as ethically acceptable by a larger share of the general public than monetary compensation can be found in Walzer's *Spheres of Justice* [15], which made a crucial contribution to the social justice literature.<sup>14</sup> Walzer argues that the distribution of different types of social goods in a society is a matter of justice and that different social goods, together with the appropriate criteria for distribution of the goods, constitute different spheres (that is, aspects of life) [51]. Although societies differ, several categories of social goods are likely to exist in most societies, including *Security and Welfare*, *Money and Commodities*, *Education*, *Office (position of employment)*, *Recognition*, *Political power*, and *Love and Kinship*. The distribution of each of these social goods is governed by one of three distributive principles, *Free exchange*, *Need*, and *Desert*, which coupled with a social good constitute a distinct sphere. *Money and Commodities* should, for example, be governed by *Free exchange*, *Need* should be the distributive principle of *Security and Welfare*, and the distribution of *Office* and *Recognition* must be based on *Desert*.

Walzer theorizes that the meaning of a social good, in turn, determines the principle of distribution. However, for our purposes, it is sufficient to say that for each social good, people in society have a common understanding of the social good and which principle the distribution of that particular good must follow to be just.

In the context of donations, two social goods are of particular interest: *Money and Commodities* and *Security and Welfare*. Health care is part of *Security and Welfare*, and the distributive principle of health in most European countries is based on equal access to health for all members of the society (i.e., the *Need* criterion), whereas the distributive principle for *Money and Commodities* is *Free exchange*.

Walzer also argues that no individual should receive more in one sphere due to his or her standing in another sphere or with regard to another social good. This restriction, which is referred to as *Complex equality*, must not be violated if social justice is to prevail. For justice to be obtained, some exchanges (of goods) should therefore never occur. A number of these so-called *blocked exchanges* can be identified, including exchanges involving human beings, political power, criminal justice and so on.<sup>15</sup>

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<sup>14</sup> We will not present a detailed exposition of the different elements of Walzer's theory or discuss the arguments or counterarguments of the subtler details of the theory. For a collection of comments on and criticisms of Walzer's ideas along with his own response to the issues raised, we refer to [51]. See also [52].

<sup>15</sup> Judith Andre gives an account of blocked exchanges and different reasons for blocking exchanges [53]. She lists, for example, the reasons that some things cannot (or should not) be sold, some things cannot (or should not) be alienated, and some things should not be changed for gain; human organs belong to the latter category.

Applying the *Spheres of Justice* framework to the case of living donations, compensation in the form of *money-for-health* would be an example of a blocked exchange, i.e., a violation of complex equality, since an individual receives more in one sphere due to her standing in another sphere. Consider instead the possibility of giving non-monetary compensation within the sphere of health care (or, more generally, *Security and Welfare*) for non-monetary losses, or giving *health-for-health*. *Health-for-health* can be viewed as an exchange of one type of health for another, i.e., a trade that is within the same sphere and, therefore, just and ethically sound.

If those who oppose payments for donation hold views that are broadly consistent with the ideas of Walzer, then this would explain their reluctance towards the use of monetary compensation, and furthermore, it would explain why we might expect non-monetary compensation, especially of the *health-for-health* type, to be perceived as ethically acceptable.

In a report discussing donation in the UK, the Nuffield Council on Bioethics [54] recommends keeping a focus on altruistic motivation as a driver for donation. Furthermore, to aid policy makers in assessing the ethical acceptability of different encouragements given to donors, the council suggests the use of an “intervention ladder” as an analytical tool, see Appendix C. The intervention ladder has 6 rungs that describe different categories of encouragement or compensation, ranging from “simple information about the possibilities of donating or volunteering” (rung 1) to “financial incentives that leave the donor/volunteer in a better financial position as a result of their participation” (rung 6) [54]. The Council recommends evaluating interventions on this scale and suggests that the higher the intervention lies on the scale, the more ethically complex it can be considered, and the greater the caution that should be taken in ensuring the ethical acceptability of the intervention. Interventions belonging to rungs 1-4 are considered to have an altruistic focus and be aimed at those already inclined to donate, whereas rungs 5-6 are focused on providing incentives to donate for people that are otherwise not inclined to do so. Our proposal of reimbursing donors for incurred costs and providing non-monetary compensation for non-monetary losses with the aim of fully offsetting the loss but not leaving the donor better off than before donation would correspond to rung 3.

## 5 Ethically acceptable compensation schemes

As argued above, an ethically acceptable solution to the problem of donor compensation could be to provide donors with non-monetary compensation for the non-monetary dis-utilities associated with living donations, particularly compensations of the *health-for-health* type. Using the *health-for-health* approach, the most problematic aspects of monetary payments can be avoided. If a *health-for-health* package is given to the donor instead of a monetary compensation, this reduction in the dis-utility is usually non-transferable to other individuals, implying that the potential problem of individuals donating, for example, a kidney to obtain a financial gain that might be transferred to others (for example, a creditor) is avoided. In particular, the problem of potential coercion (direct or indirect) of donors is significantly reduced.

There are several different ways in which non-monetary compensations can be made. We distinguish between three broad categories:

- *Prioritization*: Receiving priority for health care that is otherwise scarce.
- *Free access*: Receiving free access to health care that is otherwise sold.
- *Non-health care-related benefits*: Receiving non-health care-related benefits.

### Prioritization

The first category, *prioritization*, is strictly *health-for-health*; a person who has donated can be non-monetarily compensated for non-monetary losses associated with the donation by being prioritized in the health care sector. The prioritization can be implemented to different extents. First, and less controversial, is the example of a kidney donor being prioritized over other patients on the waiting list if she should need a kidney transplant in the future.

This type of prioritization is, to some extent, implemented in the algorithm for kidney allocation with the Eurotransplant cooperation [55].<sup>16</sup> However, it is rare that a transplantation to a previous donor is needed, so this is hardly a significant compensation for donors.

The prioritization category can, however, be broadened depending on the desired magnitude of the compensation. As a second step, the prioritization category can be broadened to include priority for transplantations of other organs besides the one donated by the donor in the past. As an example, a kidney donor who later in life is in need of a liver or a heart transplant might be prioritized over other patients who never donated. As a third step, the prioritization category can be broadened to include priority for other procedures in the health care sector as well, such as a hip replacement, that do not rely on donated material but might nonetheless be limited by waiting lists in some countries. In general, the more the category is broadened, the more controversial (and difficult to administer) it becomes.

A potentially problematic aspect of the prioritization category is that it violates the principle of equal access to the health sector, which is viewed as an essential part of most European societies, especially in countries with national health insurance. However, in the context of Spheres of Justice, a patient is *not* receiving more or less in one sphere due to his or her standing in another sphere. Rather the patient is receiving one good to compensate for the loss of another good in that same sphere. Therefore, the exchange does not violate the principle of complex equality.

### Free access

The second category, *free access*, is also *health-for-health*, but it is more broadly interpreted; a donor can receive free access to goods that are otherwise sold in the health sector or in related sectors. This compensation category is in accordance with the proposal by Gaston et al. [17] to compensate the risks of dying and of medical complications by life insurance and health insurance, respectively. Other examples could be receiving free medicine, a free fitness membership, free physiotherapy, chiropractic or psychotherapy, or receiving a free eye laser surgery as compensation for a donation. A real-life example is the egg-sharing program in the United Kingdom, where women can receive fertility treatment free or at a reduced cost in exchange for donating some of their fertile eggs to patients who require donated eggs (see, e.g., Johnson [56] for a discussion of the medical ethics of this program).

A problematic aspect of the free access category is that since the goods used to compensate the donor are sold in a market, their value can be measured in monetary units. There is thus a risk that the compensation will be viewed as similar to monetary compensation even though the donor does not receive money or a good that can be easily exchanged in the market. Nevertheless, since the donor receives free access to a good in the health care sector or a related sector, the compensation does not violate the boundaries of the sphere of *Security and Welfare*, and no individual receives more or less in one sphere due to his or her standing in another sphere. Furthermore, since the donor is basically trading one type of health for another, reasonable compensation of this type should be ethically acceptable.

### Non-health care-related benefits

The third category, *non-health care-related benefits*, is clearly not in the health sector but covers compensations that lie in other (possibly related) sectors. The practice of giving tokens of appreciation, refreshments and food vouchers that is already in place in some countries would be contained in this category. In principle, one could think of many other types of (vouchers for) low-value goods that could be used to compensate donors.<sup>17</sup> Since such goods are

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<sup>16</sup> In the form of extra points awarded to previous donors in a system that ranks patients according to number of points.

<sup>17</sup> For the case of blood donation, [18], for example, recommends discussing and researching the use of a wider array of non-cash compensations that may appeal to different groups of donors. Some examples are listed as (among other things) vouchers for songs on iTunes, phone credit and software; museum entrance; tickets to the theater, concerts or lectures; charity donations in

typically also sold in the free market, this type of compensation would, strictly speaking, not be considered acceptable in the *Spheres of Justice* context. The monetary value of a voucher will usually be easy to assess, so there is a risk that such compensation will be perceived as payment. However, if the value of the good is sufficiently small, it may not be problematic in practice. Goods that cannot otherwise be bought in the market, such as medals of honor or access to exclusive donor events, should be less likely to be seen as unethical, as long as they are relatively modest in form.

A somewhat different example of a non-health-related benefit could be no or reduced military service in countries with conscription. In the same way as donating can be viewed as a contribution to society as a whole (at least if the recipient is unknown), military service is a contribution to society as a whole, which often involves the risk of injury or death. Since a similar argument could be made for jury duty (although without the risk of physical harm), being exempted from this task is another example.

One could in principle imagine going even further and, for example, also consider prioritization for potentially scarce non-health care-related goods/services such as education, child care, or even public housing.<sup>18</sup> Depending on the method of implementation and the structure of these institutions in a given country, such benefits may be considered relevant and/or controversial to varying degrees. However, at least two issues should be addressed. First, the perceived value of such compensations is likely to vary greatly between potential donors depending on age and social background, similar to the case of cash payments. Secondly, if the prioritization is sufficient to make a difference (in the extreme case, to fully ensure the donors' desired outcome), then this could provide some people with great incentive to donate despite a lack of altruistic motivation. This would imply moving the intervention from rung 3 on the Nuffield Council incentives Ladder to rung 5, which, in turn, means that extra caution should be taken to ensure ethical acceptability.

When considering the three categories of compensation presented above, the associated degrees of controversy differ both within and between categories. When we move down the list, the type of compensation moves increasingly further away from the act for which it is compensating, namely, a donation of health, which for some would mean that it is increasingly controversial. However, whereas some may find that a reduction of military service is controversial because it is not related to health, others may find that compensation in the form of free access is more controversial since it is easily comparable to a monetary value.

## 6 Discussion

In general, answering the question of how far one should go in adapting compensations within the different categories is beyond the scope of this paper. However, the least controversial elements should naturally be adapted first, whereas a more controversial element should only be adapted if the implementation of the former is (or would be) insufficient to increase donation rates.

There is a potential risk that increasing reimbursement and non-monetary compensation to fully offset the disutilities associated with a donation will crowd out altruistic donations (i.e., donors' intrinsic motivation to donate), as noted by Titmuss [28]. Some recent works seem to support the hypothesis of a crowding out effect when monetary transfers are made to donors (e.g., [57], [58]), but these papers found no crowding out effect when

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the name of the donor; donor-exclusive t-shirts and access to exclusive donor events. Today, vouchers for app purchases and temporary access to a streaming service or news site might also be added to this list.

<sup>18</sup>In this context, priority simply implies getting (increased) priority to a good for which you already fulfill the criteria but may be on a waiting list. For example, when applying for acceptance to an education with limited enrollment, a donation may count towards your total score along with other things such as education, vocational training, stays abroad, and charity work.

transfers were instead made to charitable organizations or given in the form of vouchers.<sup>19</sup> The potential issue of crowding out is also discussed by Le Grand [59]. Here, the author refers to and discusses conflicting empirical evidence that shows crowding out for blood donations, although payments can have a positive effect in other cases, such as long-term care and foster parenting. He suggests as a partial explanation that there might be a threshold level, such that smaller payments relative to costs are considered compensation (and a recognition of one's sacrifice) that may positively affect the supply, whereas payments that are too large and that fully or even excessively compensate for costs and losses could reduce the supply, since the altruistic utility from the action is reduced. If payments become large enough, they may, of course, again increase supply, but this will then be due to financial incentives, rather than intrinsic motivation.

Another aspect of concern that could be raised in the discussion of compensation is the fact that since people differ, their preferences for the different types of compensation outlined above will differ, implying that any implemented compensation scheme is likely to affect different donors to different degrees. This in turn implies that facing the same compensation scheme, some donors could be "overcompensated" in the sense that the compensation more than outweighs the dis-utility related to the donation, while others might be "undercompensated", implying that the compensation is not enough to offset the dis-utility from donation. Whereas the latter would harm the donor and make the scheme less efficient in increasing the supply of donors, the former would tend towards an increased ethical complexity and a greater risk of crowding out.

Regarding the risk of overcompensation and taking the above empirical evidence and discussions into account, one could conjecture that non-monetary compensation for non-monetary losses would be less likely to crowd out intrinsic motivation. Nonetheless, when implementing a comprehensive compensation scheme, the potential crowding out effect should be given special consideration to ensure that the net effect of the scheme is not negatively affected by the potential decrease in altruistic donations.

More research on the attitudes towards donor compensations of populations in specific regions could be useful to more accurately assess the potential effect of different compensation schemes before implementation. However, if the alternative is no compensation for non-monetary losses, then the risk of undercompensating donors should not be a great concern. So, if uncertainty about the right level of compensation is an obstacle to providing compensation, then taking a conservative approach would (although potentially inefficient) be ethically defensible.

## 7 Conclusion

Significant dis-incentives exist for potential living donors of organs, tissues, and cells throughout Europe and in many other parts of the world. The dis-incentives include the lack of full reimbursement of the donor's monetary costs and the lack of compensation for non-monetary losses. Due to these dis-incentives, a considerable amount of altruistic utility derived from donation is required for a potential donor to actually be willing to donate. The lack of reimbursement and compensation therefore contributes to exacerbating the shortage of organs, tissues, and cells.

Although reimbursements are allowed and outright encouraged in several international documents, actual monetary payments for donations are illegal in all European countries. A possible explanation for the reluctance against monetary compensation for non-monetary losses can be found in the philosophical literature, specifically in *Spheres of Justice* [15].

We have presented three categories of non-monetary compensation (prioritization, free access, and non-health care-related benefits) that can be used more or less directly, but since non-monetary losses are difficult to measure, the

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<sup>19</sup> Note that this strain of the literature does not distinguish between reimbursement or compensation for non-monetary losses (hence the term monetary transfers).



magnitude required to fully compensate donors for their inconvenience, emotional concerns, the risk of medical complications and adverse health effects and more remains to be determined. If donors are both fully reimbursed for their costs and non-monetarily compensated for their losses, it may be sufficient to induce potential donors to donate, since any altruistic utility from the donation will be enough to make the donor better off after the donation.

Although this paper addresses just one of many aspects of the complex problem of organ shortage, we have made the case that there exists an unexploited potential for increasing donation rates through the use of alternative means of compensation for living donors.

## Notes

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### Author contributions

All authors participated in the design of the study. NS gathered the data and prepared the first draft of the manuscript. All authors reviewed drafts. TTP prepared the final manuscript. All authors read and approved the final manuscript.

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## Appendix A

### European initiatives to increase living and deceased donations

A wide range of projects to increase both living and deceased donation rates have been implemented by the European Union: *European Training Program on Organ Donation (ETPOD)*, which aimed to design and validate a

professional European training program to increase the knowledge of organ donation, to maximize the impact on the growth of organ donation rates and to disseminate reliable information to the health community in order to raise donation consciousness and to encourage a positive attitude towards it<sup>20</sup>; *Euro Living Donor* (EULID), which was developed to reach a consensus on European common standards regarding legal, ethical, protection and registration practices in relation to living organ donors to guarantee their health and safety<sup>21</sup>; *European Framework for the Evaluation of Organ Transplants* (EFRETOS), which aimed to provide a common definition of terms and methodology to evaluate the results of transplantation by promoting a registry of registries on follow-up<sup>22</sup>; *Euro Living Donor Psychosocial Follow-Up* (ELIPSY), which aimed to contribute to guarantee the good quality of living organ donation for transplant through a living donor long-term psychosocial and quality of life follow-up and to correlate those aspects with the recipient's outcome with the creation of a follow-up methodology<sup>23</sup>; *Living Organ Donation in Europe* (EULOD), which aimed to increase collaboration between EU Member States in order to improve the exchange of best practices for living organ donation programs and to enhance the organizational models of organ donation and transplantation across the EU<sup>24</sup> (cf. the ACTOR study by ). Work package 2 (WP2) of the EULOD project reviewed the various practices of living organ donation in Europe and aimed to identify possible legal, ethical, and financial barriers experienced by transplant professionals in living organ donation. EULOD suggests a *best practice* where (among other things) it is stated that all donors' possible expenses resulting from living organ donations should be reimbursed [11]. This was also the conclusion reached by the *Euro Living Donor* (EULID) program from 2003-2008. The objective of the *Living Donor Observatory* (LID OBS) was to obtain consensus among professionals regarding ethical, legislation and protection practices, as well as to improve the quality of the procedures by monitoring living donors through follow-ups and registry to protect living donors and promote health and safety<sup>25</sup>. *European Day for Organ Donation* each year helps a different EU Member State to encourage debate and provide information on organ donation and transplantation, legal and medical measures so that each person can decide on donation and make their wishes known to their family<sup>26</sup>.

## Appendix B

### International rules and guidelines on compensation

There are various international rules and guidelines that stress the importance of donations being “voluntary and unpaid”. The EU directive addressing standards for blood donations states that “*Member States shall take the necessary measures to encourage voluntary and unpaid blood donations with a view to ensuring that blood and blood components are in so far as possible provided from such donations.*” The analogous EU directive related to donations of human tissues and cells states that “*Member States shall endeavour to ensure voluntary and unpaid donations of tissues and cells. Donors may receive compensation, which is strictly limited to making good the expenses and inconveniences related to the donation. In that case, Member States define the conditions under which compensation*

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<sup>20</sup> <http://www.etpod.eu>

<sup>21</sup> <http://www.eulivingdonor.eu/eulid/what-is-eulid.html>

<sup>22</sup> <https://www.eurotransplant.org/cms/index.php?page=efretos>

<sup>23</sup> <http://www.eulivingdonor.eu/elipsy/index.html>

<sup>24</sup> <http://www.eulod.eu>

<sup>25</sup> <http://www.eulivingdonor.eu/lidobs/index.html>

<sup>26</sup> <https://www.edqm.eu/en/European-day-for-organ-donation-1223.html>

may be granted” [8]. The European guidelines on organ donations state, “The principle of non-payment shall not prevent living donors from receiving compensation, provided it is strictly limited to making good the expenses and loss of income related to the donation”([13], article 13, 1.).

Considering the international documents related to the more general concept of donation, the World Health Organization [9] states in their Guiding Principle no. 5 that “The prohibition on sale or purchase of cells, tissues and organs does not preclude reimbursing reasonable and verifiable expenses incurred by the donor, including loss of income, or paying the costs of recovering, processing, preserving and supplying human cells, tissues or organs for transplantation.” [60], chapter VII, article 21, states that “The human body and its parts shall not, as such, give rise to financial gain or comparable advantage. The aforementioned provision shall not prevent payments which do not constitute a financial gain or a comparable advantage (...)”.

Several of these documents explicitly mention that the principle of voluntary and unpaid donations does not preclude reimbursing the donor for monetary costs incurred. They all generally stress, however, that payments should be strictly limited to reimbursing incurred expenses. Two words are worth noticing in the abovementioned guidelines: the *inconvenience* mentioned in [8] is, strictly speaking, a non-monetary loss. This can, however, be interpreted as the more general compensation for the time used on the donation (i.e., compensation for the next best use of the donor’s time, such as to work). For example, donors of sperm and oocytes receive a fixed monetary compensation for their inconvenience in several European countries (see, e.g., [61] for an overview of compensation practices for reproductive cell donations in Europe). Next, the *comparable advantage* mentioned in [60] precludes compensation that leaves the donor better off after the donation compared to before. Returning to Figure 2, any use of incentives from payments or rewards is thus not accepted. In conclusion, it is generally not acceptable to compensate non-monetary losses by means of monetary payments. Note, however, that all of these documents treat the question of monetary compensation.

## Appendix C

### The intervention ladder of the Nuffield Council on Bioethics

The Nuffield Council on Bioethics [54] recommends the use of an “intervention ladder” as a tool in assessing the ethical acceptability of interventions. It is emphasized that “the ladder should not be seen as moving from “ethical” actions to “unethical” actions, but rather from actions that are ethically straightforward to those that are ethically more complex” [54]. The rungs of the ladder are illustrated below.

Altruist focused	<b>Rung 1: information</b> about the need for the donation of bodily material for others’ treatment or for medical research
	<b>Rung 2: recognition</b> of and gratitude for altruistic donation, through whatever methods are appropriate both to the form of donation and the donor concerned
	<b>Rung 3: interventions to remove barriers and disincentives</b> to donation experienced by those disposed to donate
	<b>Rung 4: interventions as an extra prompt</b> or encouragement for those already disposed to donate for altruistic reasons
Non-	<b>Rung 5: interventions offering associated benefits</b> in kind to encourage those who would not

altruist focused	otherwise have contemplated donating to consider doing so
	<b>Rung 6: financial incentives</b> that leave the donor in a better financial position as a result of donating