

# Financial donor incentives: Problems with pilots

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## Abstract

The dispute regarding incentives in organ donation has been going on for years but has not yet reached a conclusion. To resolve the debate, scholars have advocated pilot studies. However, these proposals leave many questions unanswered. I will address the most pressing questions, which concern the concept of neutrality, the variety of incentives, limitations of pilot studies, fairness in outcomes, the naturalistic fallacy, donor profiles, public communication, and reversibility. My analysis shows that the proposed pilot studies will not mitigate today's moral paralysis regarding incentives in organ donation. These pilot experiments will not provide us with normative answers, unless satisfactory solutions can be found for the problems raised. Basically, to settle the debate, the normative debate itself must be strengthened.

## Introduction

Is it time to implement financial incentives to promote living kidney donation? Several researchers have advocated pilot studies to study the effects of financial incentives, including Schold and Reed [1], Fisher et al. [2], Matas et al. [3, 4, 5], the Working Group on Incentives [6], Gill et al. [7], Hays et al. [8], and Satel and Cronin [9]. The general claim of such studies is that real-life experiments can address speculations regarding the impact of incentives. Speculation about actual future behavior (e.g. the willingness to donate) and about potential unintended effects (e.g. distrust in the system) color the debate [10]. Are policies to introduce financial incentives the best solution for diminishing organ scarcity or are they in the end a system undermining policy? On both sides of the debate, expectations rather than facts seem to be conclusive. Pilot studies can, proponents claim, shift the debate way from speculation to more solid ground.

I will argue why I am less optimistic regarding these pilots by pointing to a number of problems related to some recent proposals made by respectable scholars. Although I believe that financial incentives for living kidney donation can be ethically justified—for instance as a life-long health insurance or a symbolic and significant reward, for which I have argued elsewhere [11], recently proposed pilot studies do not convince. Referring to these proposals, I will address conceptual and normative issues regarding the neutrality thesis, the concept of incentives, pilot limitations, the naturalistic fallacy, fairness, crowding out, a changing donor population, public communication, and reversibility. I will begin the discussion with a preliminary remark on payment structures in general.

## Payment structure

Financial conditions are crucial in organ transplantation. Citing economic evaluations, Schold and Reed [1] discuss how higher risk donors are costlier for hospital finances. Factors such as age or body mass can cause more complications, a longer stay, and give rise to different protocol paths [12]. When reimbursement policies do not account for these higher costs for higher risk donors, these costs become a disincentive for accepting them. Policies should be, the authors assert, in accordance with real costs and establish fair

incentives, thus acknowledging changes in the transplant population. Another example of crucial financial conditions, taken from a review study of my own [11], refers to the need to provide transplant teams with suitable payment for organ acquisition procedures that involve a large amount of irregular work (the context is deceased donation): “institutions are often unable to make ‘optimum’ use of a donor, e.g. due to a lack of time and other factors; the number of organs to be obtained exceeded the number that were removed.”

Both examples show the need (a) for fair, realistic reimbursements of costs—thus removing disincentives, and (b) for additional funding to facilitate initiatives and stimulate programs, e.g. for training medical staff in counselling, thus introducing incentives. Meanwhile, we should be reluctant to introduce incentives, while being aware of the risks of payment. Perverse stimuli can erode good practice when, for instance, unusable organs are unnecessarily taken out for profit.

Overall, incentives per se are not the issue; rather, ethical realism suggests that in all situations we should always critically consider the payment structure and context.

## Rewarding donors

The debate on rewarding donors has hardly made any progress. Rather, the arguments for and against the practice have been repeated over and over. In 1994, Erin and Harris, UK philosophers, published a seminal paper [13, 14]. They argued for (a) a regulated system of government-based payments, thus ruling out direct sales and free markets, and endorsed (b) a regulated system of fair allocation according to existing principles. Succeeding debates did embrace this framework, but many questions remained unanswered [15]:

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- “How should we pay?”: in money (direct) or in kind (indirect): health insurance, tax benefits, education or pension schemes;
- “Whom should we pay?”: anonymous strangers and/or non-anonymous relatives and friends;
- “How much?”: a full compensation for all costs, or beyond this, significant payments (up to \$50,000), either direct or indirect [6, 9];
- “In order to what?”: enough to discourage illegal tourism, to compete with market prices, to persuade individuals to donate, or just to express society’s appreciation with a significant and symbolic reward [6, 11]?
- “Under what conditions?”: focus on the protection of a donor’s health, discourage the exploitation of vulnerable groups, safeguard a donor’s voluntariness, guarantee the quality of transplants, and/or protect public trust?

These questions demonstrate that essential ethical principles are at stake in these proposals, such as freedom, exploitation, fairness, and trust in the system. Some opponents refer to the principle of human dignity and the issue of commodification of the body and advocate a ban on all payment. Most arguments, however, speculate about the potential effects of incentive strategies. Will donation numbers grow or decline? Will voluntariness be safe or in danger? Will the system be fair, or will deprived groups be exploited? Will trust in the system increase or decrease? A main concern, often mentioned, is the risk of erosion. Rewarding anonymous donors may undermine donations between relatives or friends. This “crowding-out” effect may result in a decline in non-anonymous donations and even in overall numbers [2, 6].

### Pilots: the answer?

Given these uncertainties, policymakers are reluctant to implement incentive schemes. To overcome speculation, scholars have advocated real-life pilot experiments [10]. Fisher et al. [2] and the Working Group on Incentives [6] have made the most detailed proposals. The results of pilots may inform the debate and settle disagreements by mapping outcomes, sorting out misunderstandings, removing unnecessary fear, or making us conscious of unintended effects. The question is if the proposed pilot experiments can settle the debate and unite proponents and opponents. In what follows I will point to some basic flaws and deficiencies with such proposals.

The legal issue will be left aside. Payment beyond compensation for costs requires changes in national and/or federal law. Pilot advocates have argued that Declarations intended to reject direct sales and free markets to prevent coercion and exploitation. A regulatory system precisely precludes this [9, 13, 14, 15].

### Neutrality

Drawing a fine line, as opponents of incentives suggest, between compensation and reward, or reimbursement and payment, is not without difficulty. The same holds for the distinction between disincentives and incentives. Both sides in the debate accept payment as compensation. The concept of neutrality is based on the principle that donors should financially not be worse off than being no donor [7, 8]. Incentives, on the other hand, are clearly beneficial. Neutrality requires the removal of barriers for donation, which can include travel, lodging, and lost wages [8]. This principle, however, is less discriminatory than maintained.

At one end of the spectrum, NOTA (US National Organ Transplantation Act) permits recipients to make out-of-pocket

payments directly to donors to cover donor costs of travel [2], which implies that not all costs are covered and/or conceptualized as costs. Often gifts are allowed as an expression of gratitude, e.g. for a holiday. These gifts are not taken as an incentive. Remarkably, since new insights in human behavior have shown that even subtle, nudge-like incentives can have huge effects [16]. At the other end of the spectrum, significant costs, even lifelong health care needs, can be interpreted within the framework of financial neutrality [7]. By allowing coverage for donation-related health complications only, the question of where to draw the line remains. The strategy of letting experts decide, through “an annotated list of complications potentially eligible for coverage” [8], is not convincing. Rather than taking out the moral sting, it is preferable to address the normative issue straightforward by being explicit about our intentions to offer coverage (or not). Relevant is the social meaning that goes with this offer. Unfortunately, the neutrality principle tends to conceal the ethical nature of the controversy.

### Incentive strategies

Pilot proposals show little consensus on what to implement. Researchers argue that policies that only compensate for costs, such as childcare, transportation, lost wages, paid job leave, have had little effect on donation numbers [17]. It is “time to test incentives” in a benefit program [4, 9]. But what will be the incentive strategy? As described, one can benefit donors in many ways [15]: directly—“cash”, indirectly—“in kind”, through the level of payment, and/or conditions, e.g. a “cooling off period” in months between the decision to donate and the operation [2, 9].

Proposals for experiments differ greatly. Whereas one proposal suggests amounts up to \$50,000 [9], another proposal seeks to find the middle ground by “not giving too much and not giving too little” [2]. Often, in-kind rewards are advocated [15], but some proposals favor only health-related benefits, whereas others suggest alternative rewards, such as a retirement fund, income tax credit, a tuition voucher [9, 15] or contribution to a charity [15]. Mostly, rewards are restricted to anonymous donations [6, 9]; sometimes, rewards are also suggested for relatives and friends [6] and for deceased donation, e.g. \$300–3000 paid directly to the funeral home [9, 15]. In the absence of a consensus, it remains unclear what kind of pilot studies should be done. Each proposal has its own distinct incentive strategy and scheme of payments, and each pilot has its own objective, meaning and limitations. It is hard to see how these diverging experiments, which point to quite different directions, will contribute to the debate.

### Endpoints

In most of the proposals, well-defined endpoints for the pilot outcomes are lacking. Clear endpoints are necessary to assess and evaluate the effects. The authors of the proposals argue that incentive strategies should raise donation numbers in an ethically responsible way [9] without increasing the risks for donors or recipients [4]. Authors acknowledge the risk that, for instance, only disadvantaged individuals will be attracted to donate but give no further clue on how to assess this risk and when to consider outcomes a success or a failure.

Fisher et al. [2] have elaborated their objectives and endpoints in more detail. The authors mention the risks of exploiting vulnerable individuals and a negative public reaction toward payment. Pilots are needed to address the ethical concerns raised by opponents: “... we do not endorse any regulated system until the results of carefully constructed pilot studies are available.” In their proposal, the protection of individuals prevails: a pilot should intend “to assess if

there is a balance point where the risk/benefit ratio serves to increase living kidney donation without subjecting individuals to unnecessary psychological risks.” “Undue incentives”, such as offers that are “excessive, unwarranted, inappropriate” or an “improper reward” should be avoided. Payment need not cloud a participant’s judgement but can be accepted within a context of autonomous decision-making. The authors’ objective is to find “a middle zone between not giving too much and not giving too little.” In other words, the authors advocate an incentive that is enough to raise donation numbers and persuade potential individuals to donate within ethical constraints. Their modest goal, as they call it, is to find “the right dose”. Given the significant risks, the authors favor small studies, as in a “phase-I” drug trial a dose can become too toxic. They frankly admit that such a pilot is only a first and non-speculative step in understanding the effects of incentives.

Attractive as this proposal is, it raises several issues: (a) if this is only one step, what steps should follow to settle the debate? (b) How should the potential effects of erosion, e.g. on donations between relatives or friends, be assessed? (c) How should the ethically appropriate level of payment be determined? (d) When the authors acknowledge the risk of negative public response, how will this risk be mitigated? Below, these issues will be further addressed. The authors are aware of most of them but fail to provide guidance. Precisely because their defined endpoint is (too) modest, it is hard to see how this proposal can bridge the gap between both camps in the debate.

### Next steps

When advocates intend “to address the ethical concerns raised by opponents” [2], a first-step proposal is incomplete. Although admitting that next steps are needed, the authors fail to describe the path to the more ambitious goal. Equally problematic is that the proposal does not describe how the first step can contribute to this end. In medical trials first steps (“phase-I” trials) are useless and even unethical if one does not define the subsequent steps to be taken. The authors claim in rather general terms that although “all pilot studies will be underpowered”, they “nevertheless ... provide qualitative insights ...” [2], but acknowledge also that larger studies are necessary to address the issue of fairness, e.g. risks of erosion. In summary, the proposal fails to provide the bigger picture as it does not describe how the steps progress nor what the intermediate endpoints are.

### Fairness

Although issues of fairness are difficult to grasp in pilots, proposals fail to address these issues. Fairness demands equal protection and fair shares of benefits and burdens in a population. The focus shifts from individuals to groups, particularly vulnerable groups, such as those who are unemployed, have low-income, are low-educated, are deprived, are in debt, or are a dependent. All those who may either be attracted by payments or are in a subordinate position, as a mother, a daughter, a friend, etc. In particular, monitoring changes in the donor population is indispensable, given the risks of erosion and new emerging donations, e.g. through Facebook. Pilot experiments not only demand a larger scale [2] but also a solid normative framework, without which changes cannot be evaluated. Pilots that do not face these issues fail to meet the concerns of opponents.

### Local contexts

Given the many limitations of pilot studies, it will be difficult to draw general conclusions. Pilots are not only too small as we have seen, but contexts also differ significantly. Cultural circumstances and

situational factors are highly relevant. For instance, it is not easy to draw lessons unambiguously from the Iranian model and experiences; positive and negative perspectives appear in an ongoing debate [2, 18]. Matas et al. [3] emphasize the meaning of context and oppose the idea of “a global “one size fits all policy”. In their view, we should find solutions for organ scarcity by conducting local, structured trials in countries that can provide regulation and transparency. This modest goal is, as I see it, both “realistic” [5] and ethically sound. What can work in one context and at one moment in time may fail in another place and at another time. In short: generalizations of pilot outcomes may easily be contested.

### The naturalistic fallacy

Proponents of pilots seem to overlook the issue known as ‘the naturalistic fallacy’. The fallacy, also known as the “is-ought problem”, coined by Scottish philosopher David Hume (18<sup>th</sup> century), refers to the problem of how to jump from “is”-statements to “ought”-statements, from what “is” to what “ought to be”, from facts to norms. The data that will be collected in the proposed pilots does not explicitly convey how normative results will be reached [19]. The move from empirical data to normative judgment requires a theoretical framework. This framework is lacking. More data per se do not automatically lead to better normative insights. Proposals suggest in rather general terms how real-life experiments can “inform the ethical debate” [2] but how this will be done lacks further guidance.

To illustrate this, authors’ claim that “the ethically appropriate amount of financial incentive remains to be empirically determined” [2] falls prey to the naturalistic fallacy, as described above. The claim lacks argument and neglects normative content. Also, when talking about finding “the right dose” [2], this normative concept is not defined. More precisely, the proposed study aims at collecting data about individual donor perceptions, which will yield a wide range of subjective experiences that include personal characteristics and individual circumstances. How to determine “the right dose” in this specific case is not discussed. One could opt, for instance, for some sort of maximum tolerable reward but also for a much lower reward that does not hurt but is hardly effective in raising donation figures, or select any intermediate option. Likewise, when talking about “undue incentives” no distinction is made between the facts (what is subjectively perceived by donors) and the norm (when should perceptions be judged as based on “undue” rewards). The authors neglect the fallacy and overlook the normative issues. The fallacy problem points to the fact that without an interpretative and normative framework, it is impossible to evaluate pilot outcomes (as good, worse, desirable etc.). Normative issues should be treated explicitly and cannot be bypassed by pointing to the data [19].

### Crowding out

The authors do not address concerns of erosion. Incentives may lead to detrimental effects, such as a decrease in donations between relatives or friends. Although they are aware of these effects, authors fail to give guidance. Recently, Soofi has emphasized, by referring to the Iranian model, that crowding out effects indicate real risks. Payments may seriously undermine altruistic motivations and complicate pleas to conduct a trial in the U.S. [18].

Fisher et al. [2] point to the risk of crowding out, which is that recipients will prefer a kidney from a stranger and are even more reluctant to ask family or friends to donate. The small-scaled pilots they advocate cannot address these concerns. To study shifts in the donor

population, larger studies are needed, they admit, but they do not point out how these shifts should be assessed. Criteria to judge pilot outcomes are missing, and questions are many: is a crowding-out effect per se undesirable or even unacceptable? Is it acceptable if overall donation numbers increase? Advocates of pilot studies should at least give some clue on how outcomes can be judged and how underlying issues can be dealt with. The main question is, if incentives steer donations and have effects on the donor population, to what end are we going to steer? How to use incentives?

## Donor profiles

Illustrations of similar weaknesses and a lack of normative support can be found in the proposal of the Working Group on Incentives, who seek to present standards for a system that is internationally acceptable [6]. An incentive is described as “of adequate value (and able to improve the donor’s circumstances)” and “sufficient to significantly improve the donor’s well-being.” Donor protection is seen as a key element that is based on respect, benefit, and transparency.

Although normative issues are raised in the discussion paragraph, the answers of the Working Group remain ambivalent. For instance, regarding the risks that vulnerable individuals are attracted to become donor, given “the likelihood that the majority of incentivized donors will come from lower income groups”, one argues that “an income threshold could become a requirement for future participation ... if follow-up studies were to show that low income incentivized donors had worse outcome than nonincentivized donors”. This focus on health status only discloses a normative choice that is not further justified. The is-ought problem of how to bridge the gap between facts and norms remains implicit: “All arrangements should be adjustable in the light of experience” [6].

Another illustration is its treatment of crowding out. At first, an unambiguous standard for payment is advocated: “The donation should be anonymous and nondirected” (guideline 6, table 2). In the discussion paragraph, however, the option of incentives for all donors is raised, as anonymous payment may discourage direct donations by relatives or friends. We therefore should consider that “The optimal system is perhaps a two-tier system, with incentives for all donors”, in which both groups receive—probably unequal—rewards. Remarkably, the concept “optimal” is neither described nor discussed; a definition or normative criterion is lacking. This reasoning is confusing, as this logic undermines the proposed standards of the Working Group and the suggestion of a consensus on internationally accepted standards. It is hard to see how this proposal can be a solid basis for pilot experiments. The Working Group asserts that in trials we can find out “which proposal would best succeed”, but fails, again, to define “best” and “success”, both normative concepts. In short: normative considerations are absent. What could be a fair balance between anonymous and non-anonymous donations? The proposal leaves us without an answer.

## Communication

A primary concern has been the issue of public trust. Incentive proposals may induce negative public response and public fear and undermine the donation system [2, 5, 10]. For instance, politicians dismissed a review study of my own [11], as soon as it got media attention, due to misconception and prejudice, even before the report has been read. Also, the many proposals over the years to change the Dutch deceased donor system from opt-in to opt-out have learned that public communication is crucial. Pilot advocates should indicate how this concern could be met. Because public trust and public support are

essential, public communication and the evaluation of public perception should be part of pilot studies [10, 20, 21]. Communication strategies can evoke the (partial) success of a pilot but can also be the cause of its failure. Surprisingly, all the authors I referred to do not include public trust as a determinant in their proposals. They do not address public perception nor discuss public communication as a determinant factor. Pilots require support and consensus in the transplantation community and a firm legal basis [10, 18], but also communication and public perceptions should be discussed, monitored, and evaluated as an important part of pilot studies.

## Reversibility

The issue of reversibility has been a blind spot. Pilot proposals suggest that if an experiment fails, we can easily return to the old situation. Pilots, by restraining the risks, are presented in the studies above as rather harmless. We should ask ourselves: can an incentive policy really be reversed, once it is introduced? This is not evident and should be demonstrated. There is enough evidence that reversibility cannot always be warranted, as shown in the following example. In a children’s nursery, parents had to pay a fine when they failed to pick up their child before 5 p.m. [22]. This incentive policy was introduced in order to change parents’ bad behavior. The unintended effect was that parents went on to pick up their child too late, paid for it, and felt less ashamed about it [23]. The lesson was that incentive policies could change people’s minds. Perceptions of detrimental behavior can turn into prevailing behavior. Reversing a policy may therefore be difficult or even impossible. Once payment is perceived as a valid option, it cannot simply be dismissed. Those who advocate pilots should consider this concern.

## Conclusion

For many years, financial incentives in organ donation have been the subject of an intense ethical debate, but no conclusion has been reached. Pilot experiments have been advocated to sort out the debate. In this paper, I have pointed to the flaws and deficiencies of these proposals so far. My conclusion is that pilots as proposed will not mitigate today’s moral paralysis regarding financial incentives in organ donation. The proposed pilot experiments will not provide us with normative answers, unless we find satisfactory solutions for the problems raised. Thus, to generate a resolution for the ethical dispute, we must strengthen the normative debate itself.

## Note

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The author has no conflicts of interest to report.

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