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REVIEW

Public attitudes to financial incentive models for organs: a literature review suggests that it is time to shift the focus from 'financial incentives' to 'reciprocity'

Klaus Hoeyer,[1]* Silke Schicktanz,[2]* and Ida Deleuran[1]

1 Department of Public Health, University of Copenhagen
2 Department of Medical Ethics and History of Medicine, University Medical Center Goettingen

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Correspondence
Klaus Hoeyer, University of Copenhagen, Department of Public Health, Section for Health Services Research, Øster Farimagsgade 5A, Building 10, ground floor, 1014 Copenhagen K, Denmark.
Tel.: +45 3532 7996;
fax: +45 35327629;
e-mail: klho@sund.ku.dk

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Summary

Waiting lists for organs have stimulated interest in the use of financial incentives for organ donation (FIs), but the literature does not contain an adequate overview of studies of public attitudes toward this mode of procurement. We conducted a literature review of international peer-reviewed research published between 2002 and 2012 on how members of the public position themselves toward FIs. We identified and analyzed 23 studies using MEDLINE, PsycINFO, Sociological Abstracts and cross-reference search. The search included whole organs, donation, quantitative and empirical qualitative social scientific studies on, public attitudes (excluding professionals and medical students). The review reveals a broad divergence of public opinions on financial incentives. However, quantitative studies showed a low overall level of acceptance of payment for organs in living donation (LD); only a slightly higher one for deceased donation (DD); and a general preference for alternative forms, such as removal of disincentives or expressions of social reciprocity. Across different national and methodological settings we observed a considerable preference of noncommercial forms. This does not preclude the opportunity to consider various types of acknowledgement of economic value given in return for the organ. This provides reason to shift the focus from incentives to reciprocity.

Introduction

This article presents a literature review of international peer-reviewed research published between 2002 and 2012 on how members of the public position themselves toward incentives for organ donation [1–23]. A recent consensus statement from a working group of international scholars suggests increasing the number of living and deceased organs by reducing existing disincentives and also implementing financial incentives under strict legal governance [24]. The authors base their consideration partly on the assumption that 'surveys have shown that the public: (i) support incentives and (ii) would be more likely to donate if incentives were offered' (page 307). However, before health politicians consider soliciting organs with financial incentives (FIs) in the form of direct payment to donors (or their relatives), it would be important first to assess more carefully what we know about attitudes in the general public. This is important also because the use of FIs constitutes a controversial ethical issue in the literature and might be a source of public controversy if used without proper attention to the concerns involved [25–28]. The purpose of this review is to synthesize recent socio-empirical literature to deliver enhanced understanding of attitudes in diverse publics on different 'incentive' options. Only one previous review has attempted to gather some of the existing studies about public attitudes toward financial incentives, but with a very limited sample and limited depth of analysis [29]. To ensure an adequate review of attitude studies, the analyst should reflect on context-related issues such as the methodology of the study; the country in which it was conducted, as well as the framing of the study results and their potential limitations when assessing the contributions of individual papers. With multiple parameters of difference, aggregating numbers of global public attitudes is not a desirable strategy, but limitations on accumulation of data should not hinder the search for the best possible empirical understanding of the reasoning among the people who are supposed to be incentivized and who should find future policies legitimate and trustworthy. This review aims at this type of understanding and wants to stimulate reflections on the category of 'incentive' *per se* as it has been used in the identified studies.

Methods

We conducted a literature review of studies on public attitudes toward the use of FIs for living (LD) and deceased (DD) organ and tissue donation. Social empirical studies encompass quantitative surveys as well as qualitative interview or ethnographic studies [30,31]. We followed the PRISMA checklist for systematic reviews and meta-analysis of clinical trials (www.prisma-statement.org). As these criteria focus on reviews of clinical randomized studies, criteria have to be adjusted and complemented for reviews of other types of studies [32]. So we employed criteria used for reviews of public health policy issues including qualitative research [31,33,34]. Studies were eligible if they measured public acceptance of FIs in general approval of particular procurement models, or as empirical qualitative studies on motives and experience with FIs taking a more explorative approach. For quality reasons we only included studies published in peer-reviewed journals and to give an impression of the current situation only included studies published between 2002–2012. All included studies focus on 'public' attitudes. To encompass the widest possible range of so-called lay persons, i.e. people with no medical training, we included studies on attitudes of potential future donors, living donors, actual vendors, and relatives of deceased donors. Studies solely focusing on potential recipients were not included, as we focus on the willingness to donate and not on the willingness to pay for receiving organs; the latter would also not necessarily enlarge the donor pool, which is the primary purpose of investigating attitudes to the use of incentives. Studies on medical students were not included, as they do not cover the criterion of 'lay people/public'. Studies were identified using a search model of keywords with the electronic database PubMed. We used its database indexation, Medical Subject Headings (MeSH), (see supplementary material (1) for detailed search scheme):

The search model generated 2685 titles. The authors independently reviewed the titles. All titles found potentially relevant by at least one author were selected for collection of abstracts. For these 211 studies, the abstracts were assessed in light of the criteria for inclusion/exclusion (see Fig. 1). The first level of review revealed that the literature corpus is grouped into two independent strains, one focusing on blood and one on organs. For the principal of coherence, we decided to focus our review on whole organs and exclude studies of blood and other tissues. At this point additional material from department-related databases, from the related citation function of included abstracts, from references of the included studies; and from a focused search in the electronic database Sociological Abstracts and PsycINFO® (American Psychological Association, Washington DC, USA), which both were expected to include more social science studies. A limited updated literature search was done on 10th August 2012.

Data items

Information was extracted from each included study on (i) characteristics of study participants (gender, age, country, so-called PICOS, (see [32]) (ii) type of study (quantitative oral/written survey or qualitative interview/focus groups/ ethnography), (iii) academic and organizational background of the study conductor and (iv) type of result presentation (quantitative: relevant survey questions and answers in%; qualitative: brief summary of findings and observations) (see table of supplementary material (2)). Review study selections were conducted independently by KH and SiSchi. Disagreement was resolved by discussion between the reviewers.

Based on full text review we identified 23 relevant studies [1–23]. We excluded duplicated publications on the same data, but included studies presenting different elements of the same study.

Method of analysis

We constructed a table with key findings from each paper (see table of supplementary material (2)) and compiled the quantitative data using Microsoft® Office Excel. For conducting such a review, it was necessary to develop umbrella categories to allow comparison between the different styles of surveys used in the different studies (see also [32]). The advantage of this methodology is that despite the given diversity used worldwide for those empirical studies, we can identify some overall tendencies. No two studies used the same questionnaire. Some used questions to be answered with yes/no/not sure; some used closed

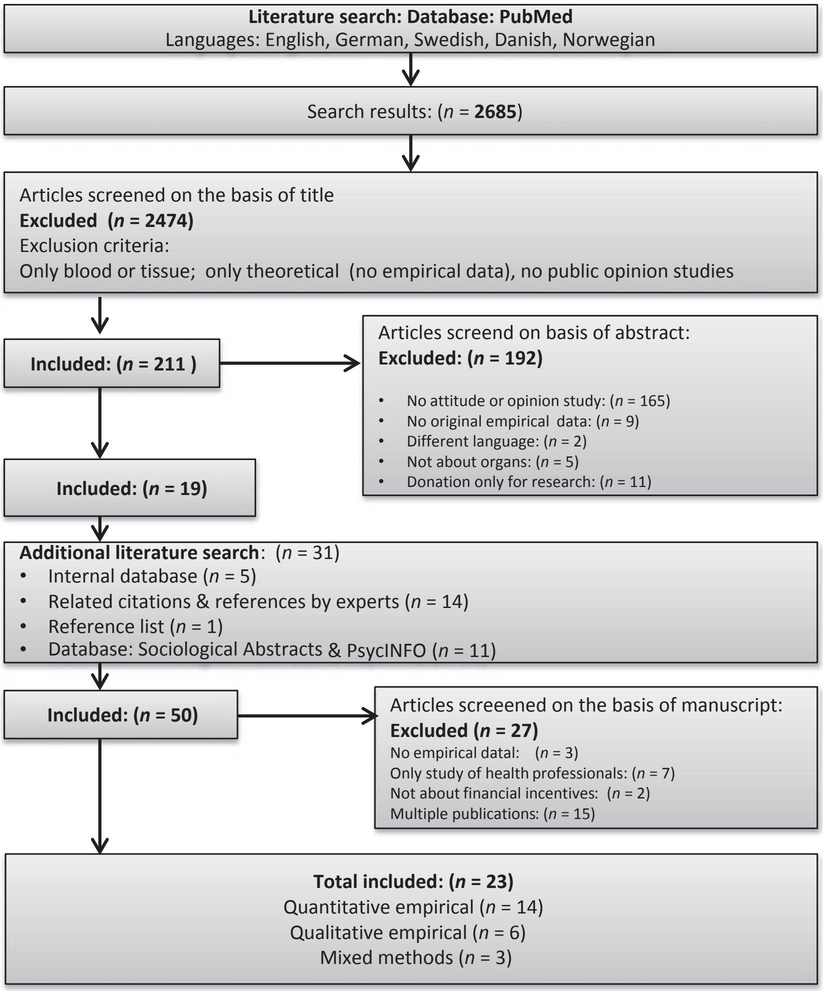

Figure 1 Search model for 2002–2012 literature covering socio-empirical studies on public attitudes towards FI in organ transplantation.

statements where participants had to mark agree/disagree/neither; some used scenarios asking participants whether they would increase their willingness to donate or not or whether it would be likely/very likely/less likely/unlikely that they would donate. Some surveys offered a range of answer options (e.g. who should regulate/control incentives?) (see table (1) of supplementary material). We decided on categories as concrete as possible to capture study differences. We differentiate between categories of financial incentives (direct or indirect payments), removing disincentives (e.g. high medical expenses paid by donors), or reciprocity (charity, funeral expenses) (see supplementary material (3) for a detailed list of the categories).

Finally, quantitative data were plotted in a scatter plot in three different figures (see Figs 2–4). Each scatter plot displays the two variables: model of financial incentives and % of approval/positive answer for a particular model) for a set of data collected in one of selected studies. The figures allow a heuristic analysis of tendencies for support for different solutions for LD/DD. Because of the limited overlap of studies asking the same question(s) and because studies were conducted in different settings, we refrain from statistical or meta-analysis. The qualitative studies were analyzed for empirical themes, categorized and the arguments for each study were identified and compared and then grouped corresponding to similarities and differences in accordance with guidelines for content analysis [35].

Results

Overall characteristics of the studies

The final search generated 23 studies conducted in 17 different countries (Argentina, Austria, Brazil, Cyprus, Egypt, France, Germany, Great Britain, India, Iran, The Netherlands, Pakistan, the Philippines, Qatar, Switzerland, Sweden, and USA). In the following text, the respective studies are referred to with # followed by the number

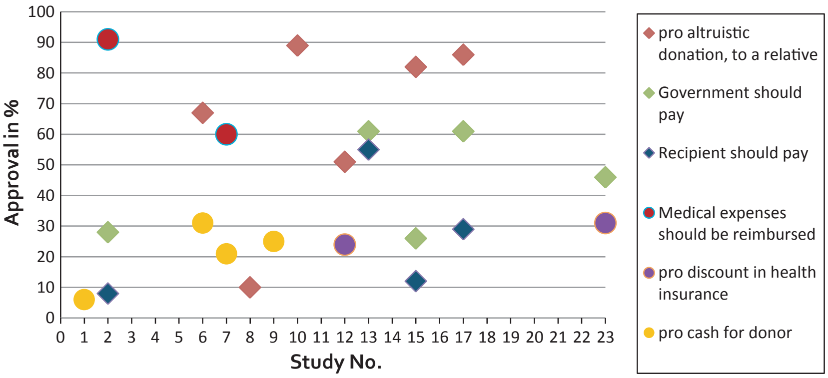

Figure 2 Percentage of approval of different models of FI for LD in comparison to percentage of willingness to donate altruisticly to a relative (data presented for quantitative studies only).

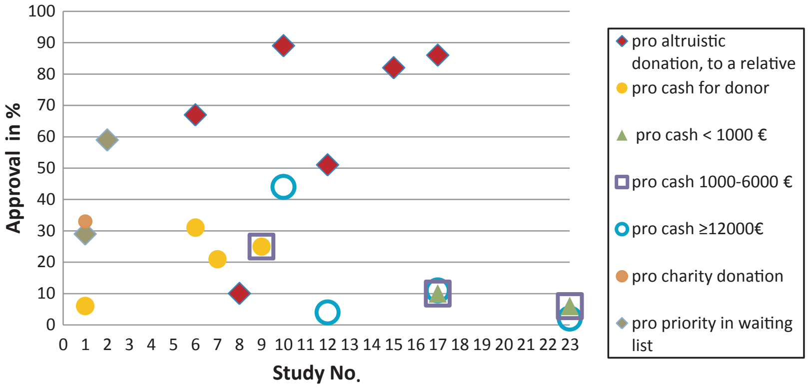

Figure 3 Percentage of approval of different amounts of FI for LD in comparison to percentage of willingness to donate altruisticly to a relative or a donation to a charity or getting priorty in a waiting list in case one needs later an organ transplant (data presented for quantitative studies only).

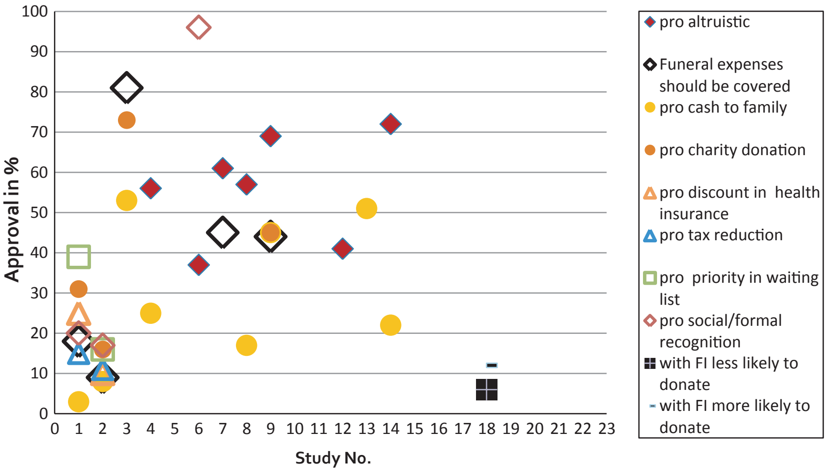

Figure 4 Percentage of approval of different forms of incentives for DD in comparison to percentage of willingness to donate altruisticly (data presented for quantitative studies only).

according with the study in the list of references (see [1–23]) to differentiate them from other references in the article. The majority (n = 14) were surveys (internet based, face-to-face, postal, or telephone interviews) (#1, 2, 3, 5, 6, 7, 8, 10, 12, 13, 14, 17, 18, 23). Six studies were only qualitative (#11, 16, 19, 20, 21, 22) and three (#4, 9, 15) used quantitative as well as qualitative methods. Three of the six qualitative studies drew on the same material.

To synthesize the 23 studies, we first present findings from the quantitative studies (distinguishing between attitudes to living organ donation and deceased organ donation), then we present findings from the qualitative studies. Finally, we summarize how the literature review can adjust some impressions one might receive by singling out individual studies.

Financial incentives in living donation (LD)

Below we represent the results from the selected studies in general categories illustrating respondents' opinions about who should ideally pay for a living donation: the government, the recipient, or health insurance. Ten of 15 quantitative studies covered questions about FIs in LD.

Figure 2 illustrates a diverse and heterogeneous spectrum of data. Agreement with the idea that the government should provide financial incentives differs greatly (between 25% and 60%), and similar discrepancy can be found in support of the idea that the recipient should pay (from below 10% to over 55%). A tendency, however, can be identified insofar that there is relatively low support for the idea that the donor receives cash (#1, 6, 7 & 9) and that the recipient pays (#2,15,17; except 13), while the idea that medical expenses are covered, gains higher support 60% resp. 91% (# 2, 7). FIs seem consistently more positively valued if they take a nonmarket form, i.e. if the government pays or the exchange medium is in-kind and health-related rather than a direct payment from recipients. Except for the study conducted in Qatar (#8), other studies indicate highest agreement for a nonmonetary (altruistic) living donation to a relative (51–89%).

Figure 3 summarizes results of the agreement for a particular amount of money and compares it to the willingness to donate without remuneration, again synthesizing results in categories that encompass diversity among individual studies. Compared with a considerable majority agreement for so-called altruistic donation, all versions of cash payment (general, or different sums) gain much less agreement. Questions with regard to particular sums (# 9,10, 12, 17, 23) are below 30% or even less, except for #10, which shows 44% agreement but still double for altruistic (89%). There are no considerable differences in whether the sum is below 1000 € or above 12000 €. One study conducted in the Philippines found high support (96–98%) for some form of remuneration, called a 'token of gratitude' (#6), but was unspecific with respect to the kind of remuneration this should be, and only 31% supported cash payments.

Financial incentives in deceased donation (DD)

For those 11 studies that in one way or another asked for FIs to promote deceased donation, the picture is even more heterogeneous than in living donation (see Fig. 4). Only a few studies asked for agreement to altruistic donation in general. Hence, the support of nonincentivized donation varies here between 41% and 72%. Support for the coverage of funeral expenses ranges between 9–81%, where the study with lowest support (#2) generally shows very low support of any kind of incentive, while the study with highest support (#3) shows highest support for other alternative models (including donation to a charity and cash to a family). Agreement with the idea that cash is given to the family of the deceased donor ranges between 3–53% (#1, 2, 3, 4, 8, 13, 14). All studies which explicitly asked for altruistic and monetary motivation found higher support for the altruistic option (#1, 2, 3, 4, 7, 8, 9, 14). Tax reduction (11–15%) and priority on the waiting list for an organ donor card holder (16–39%) get rather low support. In comparison to living donation, people are slightly less opposed to remuneration in DD than in LD.

Perceptions of FIs in qualitative studies

Nine studies employ qualitative methods (#4, 9, 11, 15–16, 19–22). Throughout all these studies there is opposition to the idea of regular trade in body parts. In two studies (#9, 11) the use of FIs was described by informants as 'immoral', while in other studies remuneration *per se* was not assessed as a problem in its own right but seen as problematic when used as an incentive for donation. In fact, focus group studies indicate some level of support of some forms of remuneration, mainly for deceased donation (#9, 21). Importantly, however, the coverage of funeral costs was described more as a sign of fairness, respect or gratitude, than as an incentive.

According to one study (#19), some informants employ an idiom of ownership in relation to their own body, but it serves as a metaphor for autonomy to stipulate the right of self-determination, not as a stated interest in sale. In fact, the same people employing this idiom express concern that money would distort the voluntary decision and thereby destroy their autonomy. For some informants, opposition to FIs reflected a more general opposition to organ donation based on the perception of organ transplantation as 'unnatural' (#19).

A theme in most studies is the idea that organ transfer establishes an enduring reciprocal relationship. Focus groups with living donors and recipients highlight how nonremunerated organ transfers create a strong sense of obligation and debt on behalf of the recipient (#20–21). This corresponds to what in the literature is often termed the 'tyranny of the gift' [36]. It appears that recipients may long to repay this debt, for example through payment. Again payment is seen less as an incentive and more as a tool for managing duties in a relationship. Such views among recipients are complemented by studies of the experiences of vendors. They, conversely, do not seem to acknowledge payment as relieving recipients from their debt (#16, 22). Kidney vendors from Egypt, Iran, and Pakistan (based upon both legal and illegal organ trade practice) expressed deep concerns about their health, social stigma, and unintended medical harm. Pakistani informants also complained about being paid less than agreed. In both countries, vendors reported about being worse off than before the organ sale, socially, medically, and economically. They were disappointed and left with a sense of suffering. They are almost always driven by debts and perceive of the trade as a necessity not a choice. In short, the qualitative studies focus on mostly harmful social, moral, and medical consequences of organ transplantation elicited with FIs.

Discussion

Granted that qualitative social science studies are not indexed as systematically as quantitative ones, we might have a disproportionate number of quantitative studies and might not have covered all existing studies in the chosen period. It is also striking that some studies were not sufficiently indexed with key words or MeSH terms and were found with indirect search strategies. Another caveat relates to the aim and purpose of the synthesis. Comparing studies conducted with different methods, in different contexts, with different modes of respondent selection is challenging, and the results can never come to represent one aggregate picture of attitudes in a presumed global public [41] – and indeed the results show great variance in public opinion between the different studies. Differences across studies can reflect variance among investigators, methodologies, and/or the investigated groups. It might be, for example, that healthcare systems influence perceptions of FIs for organ donations. The small sample of studies within the respective regions does not allow for a sufficient meta-analysis. On the level of hypothesis building, however, we can observe a slight indication of US studies being associated with higher acceptance of FIs for organ donation (# 3, 10, 13, and slighter effects in #2, 18). In Mid-European countries (Germany, Austria, Switzerland, the Netherlands) we can observe very low approval of direct payments while a moderate acceptance of indirect benefits (#7, 12, 14, 19, 20, 21, 23). The three studies in Great Britain/Scotland seem to share higher approval of cash payments than Mid-European countries (#9, 15, 17). Studies in developing countries with organ vendors overall report greater ambivalence and even disappointment of, as well as mistrust in a commercialized organ transplantation system (#4, 11, 16, 22). However, we warn to over-interpreting these regional differences based on the existing data as the heterogeneity of the tested population and of the applied methodologies do not yet allow more substantiated conclusions. Therefore, we think of our review as exploring common modes of reasoning as they emerge through academic studies of public responses to questions about FIs, rather than an aggregate picture of stable global public attitudes. Our findings indicate a need for more systematic research to allow better assessment of how different publics evaluate and feel motivated to donate organs under different economic, legal, and social conditions.

Overall, among the identified studies, we see a picture where the quantitative studies tend to view organ donation as a technology with a consistent medical purpose and effect, irrespective of the suggested procurement model; the qualitative studies tend to view organ donation as a technology with different (partly unintended) social and medical consequences dependent on, for example, the procurement model and the context. In the former view, transplantation technology is seen as essentially the same irrespective of the procurement model (the procurement model affect only the number of organs harvested); in the latter the procurement model is seen as influencing what organ donation does and for whom. The qualitative studies in this sample, for example, explore how organ donation potentially influences perceptions of bodies and changes social relations and has some negative health consequences for donors when the procurement models change; while the quantitative studies tend to focus on how many will get a transplantation with different models. Perhaps as a consequence of the more explorative methodology, the qualitative studies are more likely to find negative implications of the use of FIs to increase donation rates (see also, e.g. [37–40]), while the quantitative studies tend to focus on the practical feasibility of using FIs to enhance organ procurement. We believe both approaches explore important aspects and should be included in future reviews when assessing the likely implications of changes in procurement models in organ transplantation [31].

The most obvious finding reflecting common modes of reasoning suggests a need to consider a conceptual shift from financial *incentives* to other perceptions of financial *means* as explained below. Although three studies (#2, 10, 15) conclude that financial incentives hold potential (see also [24,42,43]), our literature review does not support this conclusion. Hence, we suggest greater care when referring to selective public opinion studies. Overall, when surveys invite members of the general public to assess procurement models, they rate direct payment and similar FIs lower than so-called altruistic donation models or the removal of disincentives. However, the surveys also indicate an acceptance of some uses of financial means in organ procurement. The reasoning found in the qualitative studies indicates that remuneration can be seen as an expression of fairness rather than as an incentive. If people perceive an offer as fair, they are more likely to accept it. This is the case when donors get medical expenses covered instead of incurring costs as a result of their donation. While in many industrialized countries, direct medical expenses are covered by health insurance or national health care, there are still cases of under-coverage [24]. It appears that when people opt for remuneration, the communicative effects of the exchange are valued higher than the material effects. It might explain the preference for so-called symbolic incentives also consistently found in the quantitative studies (#1, 12, 23), as well as the interest in finding ways of communicating gratitude (e.g. in #15) or providing 'tokens of gratitude' (#6). The qualitative insights into common modes of reasoning thereby allow us to also reassess the findings of quantitative studies: FIs might not be expected to motivate a great number of additional donations and it will not be appreciated if exchanges were to take on a market form. FIs other than cash might primarily be seen as measures of ensuring good reciprocal relations by aiming for fairness; by expressing gratitude; and by expressing respect in the relation between donor and recipient. Why people would value body parts differently than other material goods cannot be answered based on the included studies. The findings, nevertheless, indicate that financial means are preferably seen as means of communication in reciprocal relationships after organ donation has been decided on, rather than as incentives motivating donation in the first place. This conclusion would be in harmony with findings from a systematic review of public perceptions of allocation models [44], which found that the ability to pay for an organ should not influence allocations. It is compatible with recent legal scholarship suggesting gift law as the optimal juridical framework for organ donation [45], as well as recent assessments of the relative success of already implemented initiatives to improve donation rates [46]. It can also be seen as compatible with proposals aiming at removal of disincentives [24].

Granted that most studies have found a common dislike of financial incentives, but not of the use of reciprocal exchange dependent on various financial means altogether, the debate might benefit from a shift from ideas about a future market model for procurement (whether governmentally regulated or not), and instead focus on conceptions of fairness, expressions of respect, alternative forms of reciprocity, and other means of upholding balanced relationships. We would then need to rethink the very concept of FIs and consider alternatives, such as, means of reciprocity. This shift could set a new agenda for the study of public attitudes toward procurement models for organs and potentially provide new avenues for development of robust policy solutions in this area.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Data S1. Methods.

Data S2. Table of Content: Questions and results of opinions as presented in the publication.

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