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# Decision solution, data manipulation and trust: The (un-)willingness to donate organs in Germany in critical times

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### ABSTRACT

In 2011 and 2012 a change of rules and a data-manipulation scandal focused German public attention on organ donation. This increased citizens' background knowledge as well as their willingness to respond to surveys. The present study is an effort to seize this research opportunity and to create evidence on which policy recommendations can be conceivably based. It uses data from two major representative surveys from 2011 to 2012 to address four central questions: Which characteristics, experiences and attitudes correlate with the written or unwritten willingness of individuals to donate (WTD) their own organs post-mortem? How has the WTD changed over time? To what extent does the WTD depend on normative trust? Which factors correlate with trust?

The data is analyzed through summary statistics and regression models. Several hypotheses regarding factors connected with the WTD are confirmed in the survey results. Altruistic motives, relevant knowledge and trust are decisive. The special role of trust is corroborated by the data. As current German politics prevents the introduction of post-mortem donation incentives, potential policy making proposals are restricted to institutional changes to regain trust including the implementation of an organ donor registry and the advancement of counselling talks with general practitioners.

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## 1. Introduction

The gap between supply and demand of human organs for transplantation has dramatic effects worldwide, thousands of deaths, human suffering while waiting for a suitable organ, and huge additional public healthcare expenditures [1,2]. Increasing the number of organ donations is paramount. Currently in most countries policy measures must comply with public opinion's requirement that post-mortem donations have to be purely unselfish [2,3]. More radical reforms would include some form of

'do ut des' based on non-financial or financial incentives [1,4]. A prominent example is the reciprocity rule recently introduced in Israel where those who are willing to donate have priority in case of their own need [5–9]. This rule seems to exert positive effects on organ donation rates already. Yet ethical concerns among laypeople are rendering the implementation of principles of mutual insurance and solidarity [10] into the organ donation and allocation process politically unfeasible in most countries.

In Germany as in many other countries the separation of allocation from donation decisions is so deeply entrenched in law and public opinion that it will prevail in the foreseeable future. However, there is some room for political reform, which especially arises when organ donation moves into the focus of public opinion. This tends

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to affect the willingness to donate (WTD) and the willingness to support political reforms of organ donation rules. Due to positive symbolic events such as the German case of a prominent politician serving as a living donor for his spouse, such a window of political opportunity opened in the years 2010–2012 [11]. However, a major scandal involving German physicians manipulating priority on waiting lists damaged potentially positive effects and destroyed public trust in the entire organ donation system.

These processes are of interest not only for the German case but may have tentative implications for other countries that also cannot (yet) introduce more fundamental reforms. In Section 2 the German events are sketched. Section 3 describes the data and statistical methods. Section 4 presents results while Section 5 discusses the findings and concludes.

## 2. Recent German developments concerning organ donation

### 2.1. The implementation of the decision solution

Due to the European Union directive of July 2010 aimed at assuring quality and safety of organ transplantation, the necessity of amending regulations of the German Transplant Act arose [12]. Also, in August 2010 the leader of the main opposition party in the German parliament, Frank-Walter Steinmeier, donated a kidney to his sick wife. Hence, the shortage of donated organs received enormous media attention and politicians seemed to be prepared to rethink the present legislation [11,13]. The main public discussion revolved around the question of whether the German ‘extended consent regime’ (opting in) should be replaced by presumed consent for deceased organ donation (opting out). According to German law the declared will of the deceased potential donor is binding. If the donor has not documented it in writing, in particular by completing an organ donor card (ODC), his close relations should be asked concerning his will. If his intentions concerning post-mortem donation are unknown, next of kin could (voluntarily) opt-in to donation [4,12,14]. The system did not work well. For instance, under the old scheme 60–80% of survey respondents declared their WTD organs post-mortem, while only between 18% and 25% stated they had an ODC [15,16]. Assuming that the WTD was truthful in most cases this seems to be a procrastination case, which made asking for the donor intention of the deceased and the permission of next of kin to ex-plant unnecessarily awkward. Since the ‘nudge’ of introducing the presumed consent [17] was prevented by German public opinion, other changes of rules had to be considered.

Legal policy converged on what the Germans call the ‘decision solution’ as an acceptable compromise between those who raised concerns against presumed consent as it may reduce levels of altruism, personal freedom and social solidarity, and others who highlighted the poor performance of extended consent in Germany [11,18]. The new solution became law on November 1, 2012, and supplemented the opt-in solution that remains valid in principle.

According to the decision solution adult citizens are regularly informed mainly by their health insurance company about organ donation, and asked to decide for or against becoming a potential organ donor and to document it in an ODC. The option of *not* making a choice still exists. In this vein, in November 2012, the Techniker Krankenkasse was the first large health insurance company to inform its members.

Two aims of implementing the decision solution can be identified. First, the number of documented declarations of donor intent should be raised. Second, the number of organ donors should be increased. First surveys show indeed that the proportion of Germans possessing an ODC has increased e.g. from 22% in 2012 to 28% in 2013 [19].

### 2.2. The data-manipulation scandal

Parallel to the legislative initiative a second major event struck the German organ donation system. In July 2011 an anonymous phone-call to Germany’s organ procurement organization (DSO) drew attention to breaches of rules at the university clinic of Göttingen [20]. In the aftermath, investigations successively revealed that over the last 10 years doctors at five German hospitals had manipulated medical tests and falsified medical records to move their patients up the waiting list for livers [20–23]. Recently, further cases of queue-jumping in heart transplants between 2010 and 2012 have been discovered [24,25]. Starting in July 2012 the problems became widely known. A first peak of media interest was reached in September 2012, when it became apparent that data had been manipulated not only by one surgeon at two transplant centres, but also by other doctors at another hospital. Further reports of other transgressions and investigations by public prosecutors followed [22].

Support for organ donation has decreased since the second half-year 2012 [26]. The post-mortem organ donation rate of 14.7 per million inhabitants dropped to 12.8 in 2012 and 10.9 in 2013, making Germany the country with the lowest rate in ‘Eurotransplant’, the supranational association of transplant centres to which Germany belongs [26,27].

The data manipulations concerned the allocation of already donated organs, but the problems were referred to by the public at large as an ‘organ donation scandal’, thus also included donation which is institutionally separated. As a consequence of this the data-manipulation scandal attained the potential to *destroy* the trust of the German public in the institutions of organ allocation and donation altogether [20,27].

Finally, it is also remarkable that the public debates during that period of time have almost entirely ignored the international dispute about the definition and diagnosis of death [28], although controversially discussed issues regarding brain death had previously been picked-up in the scientific literature and covered by the media [29–31].

### 2.3. The central role of trust

Trust is widely regarded as the most important influence on donor rates [32,33]. To measure trustworthiness

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