



How the “Opt-In” Option Optimizes Organ Donation Rates

Ghideon Ezaz¹ · Michelle Lai¹

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Although liver transplantation can help extend and improve the quality of life in patients with advanced liver disease, the supply of available organs is always far less than the number of patients awaiting organ transplantation. The resulting waitlist morbidity and mortality constantly raises interest from healthcare providers and policymakers regarding effective ways to increase the donor organ supply.

One possible intervention that might increase the supply of organs is through the design of the process by which individuals indicate their willingness to be donors. Adopting an “opt-out” strategy (an acknowledged public policy mechanism for achieving socially desired goals such as increased retirement savings) in which an option is automatically in place unless an individual chooses to opt out has long been implemented in many countries in order to increase organ donation rates [1, 2]. Indeed, prior studies have shown that countries that have an “opt-out” (a.k.a. presumed donor or presumed consent) process for organ donor preference indication do indeed have higher organ donation rates [2]. Nevertheless, since the effect of changing from an “opt-in” to an “opt-out” policy on the rates of organ donation was not known, the work from Saab and colleagues in this issue of *Digestive Diseases and Sciences* helps to fill this knowledge gap [3].

Employing a pre–post research design, Saab and colleagues studied the impact of changing from explicit consent (“opt-in”) indicating organ donor status to a presumed consent system on the number of organ donors per million in six countries (Argentina, Chile, Finland, Poland, Slovakia, and Uruguay) from 1994 to 2017 [3]. They found significant increases in liver donation rates in all 6 countries and increases in kidney donation rates in 4 of 6 countries in the years following the transition compared to before. During the similar time period, they reported significantly

increased rates of organ donors in only 1 in 4 of other countries matched for physician density and health expenditure per capita that kept a system of explicit consent. Given these findings, they suggest that changing to an “opt-out” approach may be helpful for improving organ donation rates in nations with persistently low rates [3]. Nonetheless, as the authors acknowledge, there are limitations that should be kept in mind when performing transnational comparisons of organ donation and accurately estimating the impact of presumed donor legislation. Delving deeper into their study helps illustrate such limitations.

First, the presumed consent category comprises a variety of laws and practices. The most extreme version is routine removal, wherein organs are procured from the deceased without the consent from the deceased or the family. Yet, most presumed consent laws that have been enacted create a registry for individuals to indicate their desire to opt out of being donors [4]. The legal rights of the family of the deceased also vary across systems and affect the binding nature of failing to opt out of organ donation. Finally, even if legislation indicates that failing to opt out creates a binding presumption of donor status, many practitioners still do routinely make attempts to reach family for consent [4]. Thus, regardless of legislation, prevailing societal preferences on organ donation can still significantly affect organ donation rates.

Two of the study countries, Argentina and Chile, provide illustrative examples to understand how the nuances and incremental changes in legislation make it difficult to estimate the impact of presumed consent legislation on organ donation rates. Argentina passed a presumed donor law in 2005, prompted by low rates of official organ donor registration. Under that new law, healthcare providers could proceed with procurement if they were able to obtain collateral information from family members on the individual’s expressed desire to be an organ donor for those who died and did not register as donors [5]. In Saab et al.’s study, this law was associated with an increase in organ donation rates. Yet, in July of 2018, Argentina passed another presumed consent law that discarded its list of those opting in to be donors

✉ Michelle Lai
mlai@bidmc.harvard.edu

¹ Division of Gastroenterology and Hepatology, Department of Medicine, Beth Israel Deaconess Medical Center, Boston, MA, USA

and created a system for individuals to explicitly opt out of being donors [6]. At the time of its passage, it was still unclear how family members could influence the decision. It is also unclear if this change to an “opt-out” system mirroring those seen in Europe will help increase donations or have an opposite or neutral effect. Still, Chile’s experience may show what is to come from Argentina’s new law.

Chile created a presumed consent system in 2010 wherein individuals could indicate non-donor status when renewing their identification (ID) cards while preserving the rights of the family members of the deceased. In Saab et al.’s study, Chile had a statistically significant 54% increase in liver transplants in the 7 years after this legislation. Nonetheless, in the first year after the transition, there was a 29% decrease in organ donation rates, with 37% of those renewing IDs declining to be donors and 54% of families refusing donation [7]. Contemporaneous surveys done disclosed that 70% of responders did not know the details of the law, 12% believed that only the wealthy had access to transplants, and 13% believed that they would receive suboptimal health care from physicians if they were organ donors [8]. In response to large-scale opt-outs, the law was subsequently amended in 2013. Those wishing to be non-donors had to present a notarized statement to a registry instead of simply indicating preference when renewing their IDs. Furthermore, Chile added a reciprocity principle, where those who did not opt out of being donors are given priority in the event they needed a transplant [8]. Though there have been no previously published studies on the rates of organ donation after these new updates, Saab et al.’s findings help to fill this knowledge gap, showing an improvement at least in liver donations. Nevertheless, the heterogeneity and incremental changes in the law complicate the estimation of the effects of the change in default consents on transplantation rates.

Secondly, the organ donation rates in a given country are largely driven by factors outside of the consent system. The matched controls in Saab et al.’s study help illustrate this point. Romania had a marked increase in organ donation rates during the study period, likely due to an improvement in economic conditions and closer integration with the rest of Europe that likely affect not only per capita health expenditures and capability, but also societal attitudes toward transplantation. Conversely, no significant change in organ transplantation rates was observed in the remaining control countries of Ireland, Israel, and Germany. Still, despite the similar physician density per capita and health expenditures as a percentage of GDP, rates of organ donation in the three control countries are still higher than rates achieved by their respective matched countries that changed to a presumed consent system.

As Saab et al. indicate, there are differences among countries not captured by physician density and health

spending per capita that likely drive these differences. Cultural norms, religious beliefs, population composition, and predominant causes of death are also important determinants of organ donation rates [4]. In addition to facilities and staff with transplant capability, an effective public infrastructure for registering potential donors (or non-donors) as well as a national or regional program to coordinate organ procurement, educate healthcare providers, and promote best practices is also helpful in achieving high donor rates [4]. The success of this infrastructure rests on public trust. A common theme from multiple surveys is the concern that physicians would not work as hard to save the lives of potential donors. The distributional equity in access to health care helps shape views toward organ donation as well. Nonetheless, increased public outreach and incentives such as reciprocity can help mitigate these factors as evidenced by the Chilean example.

Saab et al.’s approach to informing their recommendations based on their data is appropriate. The change to a presumed consent process is in many ways a gamble as the potential downside to adopting presumed consent without having in place the necessary components of a functioning transplant system can be grave. The Brazilian experience from 1998 is a cautionary tale. To address persistently low organ donation rates, the Brazilian government passed legislation creating a binding presumed consent system in 1998 despite opposition from the nation’s two major medical organizations who wanted preservation of family input in organ donation [9]. Moreover, at the time Brazil lacked the infrastructure for transplant coordination, including a national waiting list, and did not have an efficient system for individuals to opt out of being donors [4, 9]. The passage of the new law created public panic, particularly in a large segment of the population with limited access to high-quality health care [4]. Brazil eventually repealed the presumed consent legislation within a year and returned to an “opt-in” system.

Optimal defaults in organ donation consents are an important public policy tool to increase rates. With known limitations, Saab et al.’s study adds to prior evidence that although countries with presumed consent can achieve higher transplantation rates, presumed consent is not a “silver bullet” that solves all of the myriad issues surrounding donor procurement.

Compliance with ethical standards

Conflict of interest All authors in this study declare no conflict of interest.

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