field review

Does changing defaults save lives? Effects of presumed consent organ donation policies

Mary Steffel, Elanor F. Williams, & David Tannenbaum

abstract

In this review, we examine whether presumed consent organ donation policies save lives. We compare presumed consent defaults (where people are considered organ donors by default but can opt out of donation) with explicit consent defaults (where people are considered nondonors by default but can opt in to be considered donors). Experimental, cross-sectional, and longitudinal evidence indicates that rates of consent, donation, and transplantation are higher under presumed consent policies than under explicit consent policies. The evidence also suggests, however, that presumed consent is one factor among many that determine the number of organs donated and lives saved; policymakers must balance a number of other considerations to ensure that shifting to a presumed consent system will boost donation and transplantation rates. We underscore the importance of investing in health care infrastructure to support organ procurement and transplantation and offer empirically informed recommendations to enable consent policies to save the most lives.

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Core Findings

What is the issue?
A systematic review of available evidence suggests that setting defaults to presume consent for organ donation offers a promising way to increase consent, donation, and transplantation rates. But the evidence also suggests that presumed consent defaults must be complemented by other features that facilitate donation, including support for families of potential donors and optimized health care infrastructure.

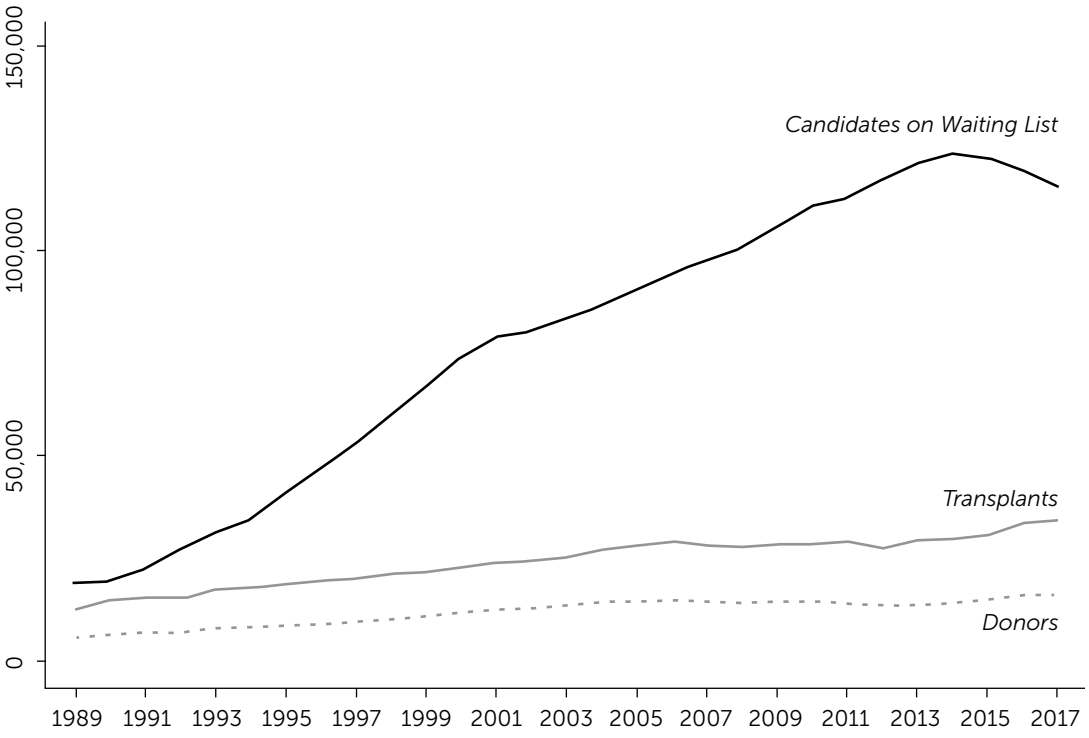
How can you act?
To make presumed consent policies more effective:
1) Simplify the consent process for potential donors
2) Support and facilitate consent from surviving family members
3) Improve infrastructure for donation and transplantation

Who should take the lead?
Policymakers, researchers, and stakeholders in health care

Each day in the United States, approximately 20 people die while waiting for an organ transplant.[1] In 2003, behavioral scientists Eric J. Johnson and Daniel Goldstein made an audaciously simple proposal for how to save the lives of many of those on organ donation waiting lists: Switch from an explicit consent organ donation policy (where citizens are presumed to be nondonors unless they actively elect to become donors) to a presumed consent organ donation policy (where citizens are presumed to be donors unless they actively elect not to become donors).[2] Johnson and Goldstein provided lab and field evidence that this switch could dramatically increase the number of citizens consenting to donation. They were not the first to propose leveraging presumed consent as a solution to the transplantable organ shortage, but their article galvanized research into how default options can influence behavior and improve societal welfare.

In the United States, more than 148,000 people have died since 1995 while waiting for a suitable donor, and the gap between those who remain on the waiting list and those who receive transplants continues to widen (see Figure 1).[3] Meanwhile, legislation regulating consent policies varies widely both across and within countries, and enthusiasm for using defaults to combat the organ donation shortage is inconsistent. In the United States, a handful of states have considered or proposed laws that would switch from explicit to presumed consent, but so far none have enacted them.[4,5] Organizations that help facilitate organ procurement in this country frequently oppose presumed consent legislation, fearing that it could spur a backlash by the public. One president of an organ procurement organization described such policies as well-intentioned but fretted that "if we got this wrong, it would cost lives."[6]

Figure 1. Candidates on waiting list for organ transplant, transplants, & donors in the United States between 1989 and 2017



Note. Data are from "Organ Donation and Transplantation Statistics: Graph Data," by U.S. Government Information on Organ Donation and Transplantation, 2019 (https://www.organdonor.gov/statistics-stories/statistics/data.html). In the public domain.

"an overwhelming majority of citizens in the United States and abroad hold favorable views of organ donation"

In this review, we examine experimental and field evidence for how policy defaults affect the rates of consent, donation, and transplantation. We then consider consent policies within a broader set of factors that influence organ donation and look at how such factors may boost or undermine the effectiveness of different consent policies. We end by offering actionable recommendations for policymakers.

Why Defaults Matter

The rationale for presumed consent comes from the empirical finding that defaults are often "sticky"—individuals tend to stay with the default option, whatever that option happens to be. A recent meta-analysis by Jon Jachimowicz and colleagues, examining 58 studies in a variety of choice contexts and involving a pooled total of 73,675 participants, found that people are more likely to choose an option when that selection is designated as the default (Cohen's d = 0.68, 95% confidence interval [0.53, 0.83]; see note A).[7] Defaults can be powerful tools for nudging people toward desired behaviors, such as using greener electricity,[8,9] saving for retirement,[10,11] making healthier food choices,[12,13] preserving privacy online,[14] and receiving beneficial medical tests and treatments.[15–17]

There are a number of reasons why having organ donation be the default could, in theory, increase donor registration rates. The most basic is that an overwhelming majority of citizens in the United States and abroad hold favorable views of organ donation,[18] and presumed consent makes it easier for their donor status to match their preferences. Defaults can also counteract people's tendency to skip making a decision when they do not have a strong preference; under a presumed consent system, such individuals would be registered as donors.[2] In addition to reducing effort and other costs of making an active decision, a default serves as a reference point against which other options are evaluated; all things being equal, individuals tend to be biased toward staying with their initial reference point. They have this bias because the potential losses associated with switching loom larger than the benefits of switching[19] and because people focus first and foremost on reasons to choose the focal option and not the alternative.[20] A presumed consent policy may also be viewed as an implicit endorsement of donation by the policymaker.[21,22] Further, making donation the default may cause people to construe not donating as a more significant lapse in behavior than they would if nondonation were the default.[23]

Although substantial experimental evidence delineates the benefits of defaults, not all findings are positive. Some studies in the meta-analysis mentioned above failed to find a reliable default effect, and two studies documented backfire effects.[7] An example of a possible backlash against presumed consent for organ donation comes from recent legislation in the Netherlands. When the country switched to presumed consent, many citizens who had previously registered as donors switched their status to nondonor.[24]

One reason why defaults can backfire is that they may sometimes be viewed as an intrusion or imposition by the government, which people may reflexively push back against.[25,26] Another possibility is that citizens become more upset about having their organ donation preferences misrepresented by a presumed consent policy (where people who fail to state a preference are registered as donors) than by having their preferences misrepresented by an explicit consent policy (where people who fail to state a preference are registered as nondonors).[27] Finally, surviving family members may be more hesitant to consent to donation on behalf of a deceased relative under a presumed consent system because they are uncertain whether the deceased's consent status reflects behavioral

inertia or a true donation preference. This uncertainty is eliminated under explicit consent.[28]

Empirical Evidence of the Impact of Presumed Consent

Researchers conducting both controlled experiments and field studies have examined how different defaults affect consent rates for organ donation. Actual donation and transplantation rates do not lend themselves to experimental study; hence, for these outcomes, we examine their association with presumed consent legislation across countries and over time. Table 1 provides a summary of all studies that have compared consent, donation, or transplantation rates under presumed consent policies with rates under explicit consent policies. Table 2 provides a summary of the evidence from controlled survey-based experiments that vary the default for consent and compare hypothetical consent decisions. Table 3 provides a summary of the field evidence from panel studies that compared actual donation and transplantation rates across countries with different consent policies over time. Table 4 provides a summary of the field evidence from pre–post studies that compare actual donation and transplantation rates before and after the introduction or repeal of presumed consent in a country.

Consent Rates

Most researchers conducting studies examining the impact of policy defaults on consent rates have taken an experimental approach. In

Glossary

Consent Systems for Donors

Explicit consent: An individual is considered a nondonor unless the person explicitly registers a preference to donate organs after death. Consent is tracked via a donor registry or by carrying a donor card. Also called an *informed consent* or *opt-in policy*.

Presumed consent: An individual is considered to have agreed to donate organs after death unless the person actively objects to doing so. Lack of consent is tracked via a nondonor registry or by carrying a nondonor card. Also called *deemed consent* or an *opt-out policy*.

Active choice consent: An individual chooses whether or not to donate his or her organs after death, essentially answering *yes* or *no* to some version of the question "Do you want to be an organ donor?" Although technically there is no default status in this system, a failure to choose will typically result in the person's organs not being donated. Also called *prompted choice*. (Although people are asked to explicitly state a preference, this approach is distinct from *explicit consent* as defined above because it does not necessarily assume that people who fail to express a preference are nondonors by default.)

Mandated choice consent: An individual chooses whether or not to donate organs after death. Choice is compulsory and typically requires an individual to register a preference in official government documents (such as in a driver's license application or on annual tax returns) before those documents can be processed.

Consent Systems for Families

Soft consent: A deceased individual's next of kin are actively consulted on organ donation, even if the deceased individual's donation preferences are known. The family's decision typically overrides the individual's. Also called *weak consent*.

Strict consent: A deceased individual's donation preferences (if known) are carried out without actively consulting next of kin. Also called *hard consent* or *strong consent*.

Outcomes

Consent rates: The proportion of citizens granting permission for their organs to be removed for transplantation if brain death occurs. Also called *registration rates*.

Donation rates: The proportion of eligible donors from whom organs are removed for transplantation. Also called *procurement rates*.

Transplantation rates: The proportion of people on an organ transplant list who receive organs.

Table 1. Evidence documenting an increase, decrease, or no difference in consent, donation, or transplantation rates as a function of presumed consent

Increase under presumed consent	Decrease under presumed consent	No difference or inconclusive
Abadie & Gay, 2006 (Panel)	Domínguez & Rojas, 2013 (Pre–post)	Coppen et al., 2005[a] (Panel)
Albertsen, 2018 (Pre–post)		Coppen et al., 2008[a] (Panel & pre–post)
Bilgel, 2012 (Panel)		Healy, 2005 (Panel)
Bilgel, 2013 (Panel)		Moseley & Stoker, 2015 (Postsurvey behavior)
Gimbel et al., 2003 (Panel)		
Gnant et al., 1991 (Pre–post)		
Horvat et al., 2010[a] (Panel)		
Johnson & Goldstein, 2003 (Panel & survey)		
Li, Hawley, & Schnier, 2013 (Survey)		
Low et al., 2006[a] (Pre–post)		
McCunn et al., 2003[a] (Panel)		
Michielsen, 1996[a] (Pre–post)		
Moseley & Stoker, 2015 (Survey)		
Neto et al., 2007 (Panel)		
Roels et al., 1991 (Pre–post)		
Roels & de Meester, 1996[a] (Panel)		
Shepherd et al., 2014 (Panel)		
Soh & Lim, 1992 (Pre–post)		
Ugur, 2015 (Panel)		
van Dalen & Henkens, 2014 (Survey)		
Vanrenterghem et al., 1988 (Pre–post)		

Note. Panel = panel data study; Pre–post = pre–post study; Survey = survey-based experiment; Postsurvey behavior = survey-based experiment in which participants were redirected to a registrar site to complete registration. The references may be found in the reference list in the Appendix.

[a]The study did not report a statistical test of the differences in donation or transplantation rates between presumed and explicit consent conditions.

Table 2. Evidence from survey-based experiments

Citation	Sample	Method	Findings	Limitations
Johnson & Goldstein (2003)	161 online bulletin board members	Participants imagined moving to a state with policy: • Explicit consent: confirm or change status as nondonor • Presumed consent: confirm or change status as donor • Mandated choice: choose whether or not to be donor	95% higher consent rates under presumed than explicit consent	Hypothetical; nonrepresentative sample
Li, Hawley, & Schnier (2013)	270 Georgia State University students	Participants were assigned to one or two treatments across 30 rounds of consent decisions with monetary incentives: • Explicit consent: tick box to change status to donor • Presumed consent: tick box to change to nondonor • Explicit consent + priority on transplant waiting list • Presumed consent + priority on transplant waiting list • Abstract explicit consent: "tokens" in lieu of organs	93% higher consent rates under presumed than explicit consent across all rounds	Hypothetical; nonrepresentative sample; multiround economic game with questionable ecological validity (for example, experiment introduced financial penalties for switching from the default)
Moseley & Stoker (2015)	4,005 British adults	Nondonors invited to visit registrar site in different ways: • Explicit consent: tick a box to visit registrar site to opt in • Presumed consent: untick a box to not visit site • Mandated choice: tick a box to visit or not visit site	53% higher consent rates and registrar site visits under presumed than explicit consent, but less than 1% of all participants completed official registration	Unclear why so few people actually officially registered
van Dalen & Henkens (2014)	2,069 Dutch adults	Participants imagined moving to a state with policy: • Explicit consent: leave status as is and not become a donor, register as a donor, or don't know • Presumed consent: leave status as is and become a donor, object and not become a donor, or don't know • Mandated choice: choose whether or not to be a donor • Active choice: choose whether to be a donor, not be a donor, or delegate the decision to one's relatives	64% higher consent rates under presumed than explicit consent if "I don't know" coded as default; 24% higher consent rates when omitting "I don't know" responses	Hypothetical; atypical wording of consent decisions and questionable ecological validity (for example, participants in explicit and presumed consent provided with "I don't know" option)

Note. The references may be found in the reference list in the Appendix.

Table 3. Field evidence from panel data

Citation	Sample	Factors controlled for	Findings	Limitations
Abadie & Gay (2006)	22 countries, 1993–2002	Health spending, mortality rates, gross domestic product, common versus civil law, religion, blood donation rate	16%–32% higher deceased donation rates under presumed consent compared with explicit consent	
Bilgel (2012)	24 countries, 1993–2006	Health spending, donor pool, common versus civil law, civil liberties, family consent, registry type	13%–18% higher deceased donation rates under presumed consent compared with explicit consent	
Bilgel (2013)	30 countries, 2008–2009	Health spending, income, legislative considerations, procedural considerations, managerial considerations, common versus civil law, civil liberties, religion, education	32%–43% higher deceased donation rates under presumed consent compared with explicit consent	
Coppen et al. (2005)	10 European countries, 2000–2002	None	No observable difference in conversion of potential donors to effectuated donors under presumed consent compared with explicit consent	No statistical controls for potential confounds; no statistical tests reported; United Kingdom misclassified as presumed consent (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Coppen et al. (2008)	10 European countries, 1995–2005	None	No observable difference in conversion of potential donors to effectuated donors under presumed consent compared with explicit consent	No statistical controls for potential confounds, no statistical tests reported; United Kingdom misclassified as presumed consent (Palmer, 2012)
Gimbel et al. (2003)	28 European countries, 1995–1999	Transplant capacity, religion, education	57% higher deceased donation rates under presumed consent compared with explicit consent	Consent policy classified on the basis of practice rather than law; no controls for mortality rates, gross domestic product, health spending, or legislative system (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Healy (2005)	17 countries, 1990–2002	Health spending, mortality rates, GDP	2.7 more donations pmp under presumed consent compared with explicit consent, but difference was not statistically reliable	No controls for transplant capacity, religion, education, or legislative system (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Horvat et al. (2010)	44 countries, 1997–2007	None	63% higher median kidney transplantation rate from deceased donors under presumed consent (22.5 pmp) compared with explicit consent (13.9 pmp)	No statistical controls; no statistical tests reported (Palmer, 2012)
Johnson & Goldstein (2003)	17 European countries, 1991–2001	Health care infrastructure, education, attitudes toward transplantation, presence of national registries	16% higher donation rates under presumed consent compared with explicit consent	
McCunn et al. (2003)	Two transplant hospitals, one in the United States & one in Austria, 2000	None	100% conversion of potential donors to effectuated donors under presumed consent at Austrian transplant center, compared with 46% under explicit consent at U.S. transplant center	No statistical controls; only used one hospital in each country; extremely small sample sizes, no statistical tests reported (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Neto et al. (2007)	34 countries, 1998–2002	Health spending, mortality rates, gross domestic product, common versus civil law, religion, access to information	21%–26% higher deceased donation rates under presumed consent compared with explicit consent	
Roels & de Meester (1996)	4 countries, 1992–1994	None	Higher deceased donation rates and organ transplants under presumed consent compared with explicit consent	No statistical controls; extremely small sample sizes; no statistical tests reported (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Shepherd et al. (2014)	48 countries, 2000–2012	Mortality rates, hospital beds, gross domestic product, common versus civil law, religion, helping behavior	43% higher deceased donation rates under presumed consent compared with explicit consent; 26% higher total number of kidney transplants and 50% higher total number of liver transplants under presumed consent compared with explicit consent	No controls for health spending, transplant capacity, or education
Ugur (2015)	27 European countries, 2000–2010	Health spending, health care infrastructure, mortality rates, religious beliefs, education	28%–32% higher donation rates and 27%–31% higher total number of kidney transplants under presumed consent compared with explicit consent	

Note. pmp = per million population. The references may be found in the reference list in the Appendix.

Table 4. Field evidence from pre–post data

Citation	Sample	Year when new consent implemented	Prechange period	Postchange period	Findings	Limitations
Albertsen (2018)	Wales	2015 EC → PC	2014–2015	2016–2017	11% increase in number of registered donors after the introduction of presumed consent; 3% increase in conversion of potential donors to effectuated donors after the introduction of presumed consent	Small time window before and after legislation; no statistical tests reported
Coppen et al. (2008)	Germany Italy Netherlands Sweden	1997 PC → EC 1999 EC → PC 1998 PC → EC 1996 EC → PC	1995	2005	Germany and Italy demonstrated no apparent differences in conversion of potential donors to actual donors before and after the introduction of the new consent system; Sweden and the Netherlands saw temporary changes in conversion of potential donors to actual donors after the introduction of the new consent system	No statistical tests or analyses reported (only graphical data); no statistical controls
Domínguez & Rojas (2013)	Chile	2010 EC → PC	2000–2009	2010–2011	29% decrease in deceased donation rates after the introduction of presumed consent; family refusal rates also increased over this time period	No statistical controls; small time window after legislation; did not account for concurrent trends in donation rates
Gnant et al. (1991)	A single Austrian transplantation center	1982 EC → PC	1965–1981	1982–1985	119% increase in deceased donation rates after the introduction of presumed consent	No statistical controls; only examined a single transplantation center; 16-year base period may not be appropriate comparison (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Low et al. (2006)	Singapore	2004 EC → PC for liver, heart, and corneas	2002–2004	2004–2005	160% increase in liver donations and 43% increase in liver transplants after the introduction of presumed consent	Extremely small sample size; no statistical controls; no statistical tests reported (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Michielsen (1996)	Belgium	1986 EC → PC	1986	1987–1988	86% increase in kidney donations after the introduction of presumed consent	No statistical controls; small sample size; no statistical tests reported (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Roels et al. (1991)	Belgium	1986 EC → PC	1982–1985	1987–1989	106% increase in kidney donations after the introduction of presumed consent	No statistical controls; limitations in the analysis (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Soh & Lim (1992)	Singapore	1987 EC → PC for kidneys	1970–1987	1988–1990	565% increase in kidney donations after the introduction of presumed consent	Small sample size; no statistical controls (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)
Vanrenterghem et al. (1988)	A transplantation network in Belgium (19 nephrology units)	1986 EC → PC	1978–1986	1987–1988	100% increase in kidney donations after the introduction of presumed consent	Small sample size; no statistical controls (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009; Rithalia, McDaid, Suekarran, Norman, et al., 2009)

Note. EC → PC = switched from explicit consent to presumed consent; PC → EC = switched from presumed consent to explicit consent. The references may be found in the reference list in the Appendix.

these experiments, participants are randomly assigned to confront hypothetical consent decisions that use language approximating the wording used in real life for policies based on explicit consent, presumed consent, or another kind of consent (see Glossary). This approach enables researchers to test whether different ways of framing consent have a direct causal effect on consent decisions.

As shown in Table 2, three experiments involved presenting participants with hypothetical consent decisions.[2,29,30] Participants in these studies were 24% to 95% more likely to consent to donation under presumed consent than explicit consent. These results demonstrate that changing the default for donation causally affects consent choices, but they do not address whether consent rates in the lab reflect behavior out in the world. A fourth experiment attempted to test whether these preferences would translate into real behavior. It, too, found that presumed consent increased the proportion of individuals who said they were willing to be donors. But when subjects were directed at the end of the study to an official registry, fewer than 1% actually signed up as donors.[31]

Field studies suggest that presumed consent tends to increase the percentage of individuals registered to donate. Zeynep Burcu Ugur found that people in EU countries with presumed consent policies were less likely than those in EU countries with explicit consent policies to actively register a preference to donate, yet overall, the presumed consent countries had higher donation rates.[27] Apparently, citizens who weakly favored donation allowed themselves to be defaulted into consent without seeking out a donor card, and citizens who weakly preferred not to donate did not go to the trouble of removing themselves from the donor rolls, which led to overall higher rates of consent but lower rates of active choice. A similar pattern emerged when Wales introduced presumed consent legislation in 2015.[32]

Passive enrollment into organ donation may prove problematic if the family of a potential donor is consulted about donation when the person dies: Fewer explicitly committed donors in a country may result in a greater proportion of refusals by surviving family members, who may be uncertain about whether the deceased's consent reflects a true donation preference or a failure to register a preference to the contrary. In Wales, presumed consent laws did not affect family refusal rates, but Chile did see an increase in family refusals after a presumed consent policy was introduced.[32,33]

Donation & Transplantation Rates

To answer the question of whether defaults save lives, as Johnson and Goldstein have suggested, it is not enough to examine consent rates. The ultimate outcomes of interest are whether defaults lead to an increase in donation rates (that is, whether organs are harvested from a donor) and transplantation rates (that is, whether organs are implanted from a donor into a recipient). One approach to determining whether defaults save lives relies on cross-country comparisons in panel studies (see note B). Although panel studies on organ donation defaults cannot isolate whether consent policies directly cause observed differences in donation rates, many of these studies come close by statistically adjusting for a variety of factors that may also affect donation rates, including a country's gross domestic product, health spending, and ability to carry out transplants (we discuss additional factors later in this review). Across the 14 panel studies we identified, countries with presumed consent policies consistently had higher donation rates than countries with explicit consent policies (see Table 3). On average, countries with presumed consent policies demonstrated a roughly 30% higher rate of donations when compared with countries with explicit consent, although the size of the effect varied substantially across studies.

Panel investigations are complemented by pre–post studies examining rates of organ procurement before and after the introduction of presumed consent in a country. The number of countries that have switched to presumed consent in recent decades is relatively small, so not many empirical studies have been able to address this question. These studies also come with their own limitations, as they typically do not adjust for other concurrent trends

or legislative changes affecting donation rates, and they apply inconsistent time horizons when comparing donation rates over time. Still, findings from pre–post studies are generally consistent with the panel evidence and suggest that donation rates increase after countries implement presumed consent legislation (see Table 4). Some anecdotal evidence suggests that donor efficiency rates (the conversion of potential donors into actual donors) may also increase with presumed consent.[34] One exception to this trend was Chile, where organ donation rates decreased over a two-year period after presumed consent legislation was introduced.[33]

To our knowledge, only five studies have looked specifically at transplantation rates rather than at donation rates. These studies compared rates in countries with presumed consent and explicit consent policies and again found a positive effect of presumed consent legislation, although these increases were not always statistically significant.

Other Consent Policies: Active & Mandated Choice

As we noted when discussing experimental research, explicit and presumed consent policies are not the only kinds of consent policies available to states and countries. Whereas explicit and presumed consent policies focus on what happens when individuals fail to make a decision, two other systems—active and mandated choice policies—focus on clarifying donor preferences. They prompt individuals to specifically state whether they prefer to be registered as donors or as nondonors, rather than asking merely whether they wish to maintain or change their default status. People are given both *yes* and *no* options to the question of whether they want to be a donor and are told to pick one. On the one hand, mandated choice systems make the choice compulsory, typically by requiring people to register their preferences in official government documents before those documents can be processed (such as in driver's license applications or annual tax returns).[35–38] Active choice systems, on the other hand, allow people to defer making a decision on the matter, in which case individuals are typically registered as nondonors. (Although both active and mandated choice systems ask people to make explicit choices, this does not automatically make them explicit consent systems, because they do not necessarily assume that people who fail to express a preference are nondonors by default.)

Richard H. Thaler and Cass R. Sunstein championed active and mandated choice systems in their 2008 book *Nudge: Improving Decisions About Health, Wealth, and Happiness*,[39] as have organizations such as the American Medical Association and the United Network for Organ Sharing.[38] Mandated choice has some meaningful drawbacks compared with presumed choice (see Table 5), but it is a particularly appealing alternative when having a presumed consent system is not feasible. It is attractive for several reasons. First, many people believe that consent for organ donation is best achieved by having adults decide for themselves whether to donate.[36] Second, mandated choice systems help to alleviate the uncertainty that many surviving family members face when deciding whether to consent to donation; experimental evidence suggests that individuals have more confidence that they know someone else's donation preferences under mandated choice systems than with presumed consent systems.[28,40] As we discuss in more detail later, being sure of a potential donor's wishes can increase the rate at which surviving family members consent to donating the deceased's organs. However, both of these virtues diminish in active choice systems if choice-deferral rates are high.

Evidence on the efficacy of active and mandated choice legislation is sparse. Researchers who have examined hypothetical consent decisions have usually found that active and mandated choice systems yield consent rates higher than those of explicit consent systems but similar to those of presumed consent.[2,30,31] Yet some studies cast doubt on the effectiveness of active choice systems. A laboratory experiment in which participants' organ donation preferences were entered into an official registry did not find reliably different consent rates under active choice versus explicit consent approaches.[41]

Table 5. Summary of benefits & drawbacks for presumed consent, explicit consent, & active or mandated choice

Policy	Potential benefits	Potential drawbacks
Explicit consent	• *Makes preference to donate explicit to surviving family* Because a person must opt in to become a donor under explicit consent, it is clear to surviving family members that a deceased person's status as a donor reflects a desire to donate.	• *Least effective at increasing donation rates* Explicit consent tends to lead to lower consent, donation, and transplantation rates than presumed consent or active or mandated choice. • *Requires people to take action to become donors* When most citizens hold positive attitudes toward organ donation (as in the United States), explicit consent makes it difficult for a nation's majority to behave in accordance with its preferences.
Presumed consent	• *Most effective at increasing donation rates* Presumed consent tends to increase consent, donation, and transplantation rates—often substantially so—compared with explicit consent. • *Makes it easy to consent* When most citizens hold positive attitudes toward organ donation (as in the United States), presumed consent makes it easy for a nation's majority to behave in accordance with its preferences.	• *Makes preference to donate ambiguous to surviving family* Because a person is assumed to be a donor unless they opt out under presumed consent, it is unclear to surviving family members whether the deceased person's status as a donor reflects a desire to donate or a failure to opt out. • *More likely to result in political blowback* Presumed consent is viewed as a more intrusive policy than explicit consent. Citizens may also be more upset if their preferences are misrepresented under presumed consent than under explicit consent.
Active choice & mandated choice	• *May increase donation rates relative to explicit consent* Although field data are sparse, they suggest that mandated choice may increase donation rates compared with explicit consent. • *Make preferences clear to surviving family* Active and mandated choice alleviate the uncertainty that surviving family members often face in deciding whether to consent to donation, as the deceased individual's preferences are known and can be honored. • *Less likely to result in political blowback* Survey data suggest that active and mandated choice are likely to receive support from the general public, as many people believe that consent for organ donation is best achieved by having each adult explicitly register a preference.	• *Require people to take action to become donors* Active and mandated choice require people to actively register their preference to be a donor or not. • *May be logistically difficult to register individuals' preferences* Mandated choice may be logistically difficult, as it should be carried out in a setting that gives all citizens equal ability to register their preferences (for example, registering organ donation preferences at a driver's license renewal will reach only those citizens who drive). • *Can be ineffective if individuals do not register their preferences* Active choice can be ineffective when individuals can easily decide not to respond and are then defaulted to nondonation.

We are aware of only one field examination of active choice's effect on consent rates and none looking at mandated choice. In the study, California's switch to active choice from an explicit consent approach in 2011 was examined.[41] Introduction of active choice led to a decrease in consent rates of roughly 2 to 3 percentage points relative to the rates in other comparison states over the same time period. Consent rates were examined over a short time horizon (less than a year), however, so the long-term effects of the change are unclear. Anecdotal evidence from other states is consistent with the data from California, though. Virginia instituted an active choice law in 2000 and reconsidered the policy because of low enrollment rates; large numbers of citizens failed to register a decision and were defaulted to nondonation.[42–45]

Thus, active choice systems appear to offer no advantage if nonenrollment is the implicit default and individuals can easily decide not to respond. If that impression were borne out, it—combined with the other data described in this article—would suggest that states would end up with the most donors by using presumed consent, rather than the active choice or explicit consent that is currently in place in all 50 states.

Putting Consent Policies Into Perspective

Consent policies are just one factor among many that determine donation and transplantation rates—including specific features of the consent process, how surviving family members are consulted, and broader social

"families of potential donors almost always make the final call, officially or unofficially"

and cultural values around organ donation. Moreover, consent is helpful only insofar as viable organs are available for transplantation and only if health care infrastructure is in place to facilitate efficient organ procurement and transplantation.

Features of the Consent Process

A number of obstacles, including seemingly minor ones, can interfere with getting people to register as donors. Too much paperwork can reduce registration rates, so minimizing that paperwork or finding other ways to make registering more efficient helps.[7] Until 2014, New York had a notoriously complicated procedure, requiring a person to have multiple witnesses present to officially certify his or her donation consent, and approval was granted only after one received a driver license but was not given at the Department of Motor Vehicles (DMV) itself. Likely not coincidentally, New York had one of the lowest consent rates in the United States. The state changed to an active choice system in 2012 and afforded people multiple ways to register their preferences; it has since seen a meaningful expansion of the donor roll.[46]

Incentives may also help motivate citizens to explicitly register their donation preferences. Policy proposals have included monetary compensation for families of donors[47,48] or giving registered donors priority in the event that they themselves need a transplant.[49]

The setting where people are approached also matters: not all settings will attract the same population of potential donors, nor will all settings give all citizens equal ability to register their preferences. For instance, combining donor registration with the process of obtaining a driver's license is certainly efficient, as relevant information is already being gathered. But asking about organ donation during license renewal will mean that only drivers will have a convenient opportunity to register their preferences. In addition, settings like DMVs can make it difficult for people to give the appropriate amount of time, attention, or gravity to a decision about an end-of-life matter, leading them to possibly abstain from choosing.[50] (Individuals can instead make the decision at home, using an organ procurement organization website, but many people do not know that.)

As for donation rates, one frequently overlooked donation determinant is that the families of potential donors almost always make the final call, officially or unofficially. For this reason, some have suggested that increasing donation consent rates from families may be the most promising way to increase organ availability.[51]

Countries differ in how much weight they give to the preferences of the family members.[52,53] In countries with a "soft consent" policy, survivors are typically consulted and make the final decision, whereas under a "strict consent" policy, registered preferences are followed without active consultation with next of kin. Austria has perhaps the strictest policy: doctors recover organs without conferring with family as long as the deceased did not actively elect out of donation.[54] In practice, in most countries, family members are consulted and are less likely than the donors themselves to approve donation. Donation rates are lower in countries where family consent is routinely sought,[52] and transplantation rates in countries where family consent is legally required are half those of countries lacking this requirement.[55]

However, in contrast to families whose permission is sought, those who are informed about the wishes of the deceased and told that the organ procurement organization's goal is to honor those wishes are less likely to oppose donation.[56,57] Personal contact between donation coordinators and families can also help: In one study, surviving families who were contacted about possible cornea donation were considerably more likely to approve the request when approached in person (81.6%) than by telephone (55.2%).[58] Further, education and counseling for families has been

found to increase consent. Families of patients who are brain dead (as is the case for many potential donors) are more likely to agree to donation when they understand brain death and are counseled by on-site coordinators with specialized training.[59] This finding has led some observers to argue that new presumed consent policies must be combined with on-site coordinators to work with families.[50]

The Social Context of the Consent Process

The political climate in a state or country can have a substantial influence on which organ donation policies are set and thus how potential donors are solicited. For example, part of the concern with a switch to presumed consent in the United States is that public opinion on the topic is not well understood.[45] The most recent national survey of attitudes toward presumed consent, conducted in 2012 by the U.S. Department of Health and Human Services, found that roughly half of adults supported a presumed consent default (51%)—a substantial increase over the 42% support rate found in 2005.[6,18] It is unclear how or whether people's preferences have changed in the intervening seven years, and getting a handle on public preference is noteasy.

Public support for presumed consent is also often dwarfed in public opinion polls by a preference for mandated or explicit choice. In one such study, which examined families who had made decisions about donating a loved one's organs, families tended to be more supportive of a strict mandated choice system in which families would not have an override (43%) than a presumed consent system (23%).[45] Other research has found a similar pattern but with greater approval for presumed consent.[2,30,36,60] Aaron Spital found in a 1992 analysis that most respondents supported presumed consent (62% approval), but it was still less popular than mandated choice (90% approval).[60] Other polls show that presumed consent is sometimes preferred to explicit consent: When the United Kingdom was starting initial deliberations about a presumed consent law to increase organ donation, 65% of those surveyed in a national panel supported a change from explicit to presumed consent, and the proportion jumped to 72% when the panel learned more about the proposed changes.[61]

Given the uncertainty about how presumed consent policies will be received, some organ procurement organizations in the United States have been hesitant or even strongly opposed to presumed consent as a policy.[62,63] Presumed consent is unlikely to gain much traction until those organizations feel comfortable lobbying on behalf of such a policy.

Anecdotally, some countries have experienced political backlash after changing from an explicit consent policy to a presumed consent policy. In addition to the controversy in the Netherlands mentioned earlier, Brazil offers an example: It enacted a presumed consent law in 1997 only to repeal it a year later. Not only was the legislation poorly implemented, as it did not provide resources to improve donation infrastructure, it also sparked a great deal of pushback from people who feared that doctors would prioritize harvesting organs over saving lives.[64] There were also concerns that the poor and illiterate in Brazil would be less capable of opting out, as consent decisions were registered when obtaining or renewing a driver's license, which many poor citizens did not have.[65,66]

Cultural beliefs and values may influence consent, too. Organ donation rates from deceased donors are higher in predominantly Catholic countries, where organ donation is viewed as an act of service,[55,66–69] and lower in countries in which religious beliefs about keeping the body intact after death are common.[55] More broadly, positive public attitudes toward helping and giving correlate positively with donation.[67,69]

Trust in government and medical systems also likely play an important role in shaping public attitudes about organ donation. In the United States, a number of ethnic groups and minorities are less likely to consent to donate, citing disbelief that the government has their best interests in mind or suspecting that physicians may not be as motivated to save them in a medical emergency if they are a registered donor.[70] Mistrust in

the government and the health care system has been cited as another possible source of resistance to presumed consent in Brazil[69,71] and a reason for the unpopularity of organ donation itself in Japan.[72] Additionally, emotional considerations, such as disgust at the idea of organ donation and superstitious beliefs that registration will somehow lead to harm or death for the potential donor, may play a role in how people respond to consent policies.[73,74]

Education[55,68] and access to information[66] can help build support for organ donation; even dramatizations in popular television shows have been shown to increase knowledge and willingness to donate.[75] Likewise, awareness of consent policies can help to increase consent: presumed consent has a greater advantage over explicit consent when citizens are aware of their country's approach to consent than when they are not.[71] Informational campaigns may do little, however, to curb negative opinion grounded primarily in religious, emotional, or superstitious considerations.[76]

The Process for Organ Procurement & Transplantation

Donation and transplantation rates depend, in part, on the supply of viable organs. Several organs can be procured from living donors, including kidneys and partial livers, but most other donated organs and tissues must come from patients who have been declared brain dead but whose hearts continue to beat so that their organs and tissues remain viable for transplantation.[77] Thus, donation and transplantation rates may depend critically on whether public policy and medical practices permit organs to be harvested from donors efficiently.[78]

Because procurement rates depend on the number of people who experience brain death but maintain a heartbeat, the frequency of different causes of death in a country has a sizeable impact on organ donation rates.[34] Causes of death that leave people in the appropriate state for donation are relatively rare: The most generous estimates suggest that, at most, 40,000 deaths fit the criteria in the United States,[79] and this estimate does not take into account additional information about potential donors that could preclude donation. In comparison, a 2003 estimate attempting to account for such exclusions put the maximum number of potential donors at 14,000 annually in the United States.[80] Further, the supply of viable organs for transplantation has been falling in many countries due to improvements in traffic safety and advancements in treating what in the past would have been fatal brain injuries.[78] In the United States, however, the recent opioid epidemic has led to a surge of eligible donors that has partly offset those other trends.[81]

A hugely important factor for donation rates—one at least as substantial as presumed consent legislation—is the medical infrastructure supporting organ donation.[52,53,55,66,68] An analysis of organ donation trends in countries of Europe, North America, and South America found that the effect of presumed consent legislation on donation rates was dwarfed by the impact of per capita spending on health care.[66] Another cross-country analysis found that the single strongest predictor of donation rates was the per capita number of transplant centers in a country (the second strongest predictor was presumed consent legislation).[68]

Additionally, in the United States, a concerted effort to improve the efficiency by which organ procurement organizations converted medically eligible donors into "effectuated" donors (whose organs were actually used for transplants) corresponded with an increase in conversion rates from 57% in 2004 to 73% in 2012.[82] Indeed, some have argued that the success of the Spanish model of organ donation, one of the most effective and widely emulated systems in the world, is due not to the addition of presumed consent alone but to its combination with other policies, such as those focused on improving infrastructure for donation and transplantation.[83,84]

Cost Considerations

Policies designed to increase organ donation tend to be cost-effective when compared with other policies for improving health.[42] And implementing a change to a presumed consent policy is likely to be inexpensive relative to other policy

20

Americans who die every day while waiting for an organ transplant

30%

Average increase in successful organ donations in countries with presumed consent policies

14k

Estimated maximum number of viable heart-beating donors per year in the US

or infrastructure changes designed to increase organ donation, because many of the forms, registries, and procedures already in place to administer an explicit consent policy can be adapted to administer a presumed consent policy. In general, nudge-style interventions, such as changing a default option, tend to yield a better return on investment than traditional policy tools, such as financial incentives or educational campaigns.[85] However, a presumed consent policy will be most successful when implemented alongside other policy and infrastructure changes that carry additional costs. For example, when the United Kingdom considered switching to a presumed consent policy for organ donation in 2008, the Organ Donation Taskforce estimated that approximately £45 million (about $59 million) would be needed for setup costs (such as for initiating a public awareness campaign and developing a secure database) and £2 million (about $2.6 million) would be needed for annual operating costs.[86]

Recommendations for Making Consent Policies More Effective

On the basis of the available evidence, we believe that presumed consent policies offer a promising way to increase the number of potential organ donors and save more lives. Policymakers will need to balance a number of other considerations to ensure that these policies are successful, however. In Table 5, we provide a summary of the potential benefits and drawbacks associated with each consent system discussed in this article. In the text that follows, we highlight the importance of investing in health care infrastructure that supports organ donation, and we offer recommendations informed by behavioral science for promoting the conditions that will make presumed consent policies most effective.

Make It Easy for Individuals to Register Their Preference

One of the most powerful lessons from studies of choice architecture (that is, how options are presented) is that even small frictions and difficulties can dramatically influence the decisions people make—a fact often underappreciated by policymakers.[87] Making it easy for people to become organ donors can help to increase donor registration rates. For example, organ donor registration rates in the United States rose 21.1-fold relative to the baseline average when Facebook enabled members to specify *organ donor* on their profile and provided links to educational materials and members' state registries.[88] Presumed consent is appealing in part because it eliminates these frictions by defaulting citizens to an outcome that matches the majority preference to donate.

Under such a system, policymakers should also strive to make it easy for citizens to register a preference not to donate. As discussed earlier, Brazil overturned its presumed consent law in part because people who did not drive or own a car (that is, the country's poorest citizens) did not have a viable way of opting out.[66] This barrier will become even more important as autonomous vehicles and other new alternatives to driving reduce the likelihood that citizens will have to interact with the DMV. Making registration easy to accomplish outside the DMV should not only boost the number of consenting donors but also ensure that those who do not want to donate their organs are properly accounted for on donor rolls.

Educate the Public

Ensuring that the public is aware of consent policies can increase the effect of presumed consent on donation.[71] Also, the more overtly a policy frames organ donation as good citizenship and a life-saving action, the more effective such a policy may be.[89] For example, knowing specifically how others are helped by one's donation can increase consent rates.[41] Policymakers should also address concerns of minority and ethnic groups who might be skeptical of the medical system or government.[70] Switching to presumed consent without addressing cultural values or obtaining buy-in from the community will likely exacerbate people's worries and could lead to political blowback.[24] More generally, a systematic approach to education on organ procurement policies and practices may increase people's understanding of and receptivity to organ donation.

Craft Public Messaging Carefully

The success of any policy is at least partly determined by how that policy is presented to the public. Policymakers considering a change to presumed consent can highlight the fact that most people wish to donate and that their new policy proposal would better align with people's preferences. Such messages may go far toward mitigating skepticism, especially among people who view presumed consent legislation as an attempt by policymakers to coerce individuals into donation.[24] Other kinds of messages should also increase consent rates over the rates that would be achieved with standard messaging—for instance, ones that highlight notions of reciprocity (such as "If you needed an organ transplant, would you have one? If so, please help others"), calculate the lives lost due to a shortage of donors (such as "Three people die every day because there are not enough organ donors"), emphasize social norms in favor of donation (such as "Every day thousands of people who see this page decide to register"), or highlight the number of lives that could be saved by donation (such as "You could save or transform up to nine lives as an organ donor"). These messages are ranked in order from most to least effective according to 2013 findings of the Behavioural Insights Team, an organization devoted to applying behavioral science research to inform public policy.[90]

Roll Out New Policies Gradually

Gradual, transitional steps to a new consent policy may also help boost acceptance of presumed consent or any other consent system. For example, active or mandated choice may serve as a useful interim step, because they tend to garner a lot of popular support and have increased consent rates in hypothetical studies[2,30,31] and in real decisions about blood donation,[91] health program enrollment,[92] and advanced directives.[93,94] However, such policies may need to be executed more carefully than simply requesting a *yes* or *no* answer to some form of the question "Do you want to be an organ donor?" (see the Supplemental Material for consent language by state in the United States).[41] For example, enhanced active choice—active choice with informational or normative nods to the desired response[95]—can help to encourage consent. Utah, for one, highlights the prosocial effects of consent by wording its request, "I would like to register my desire to help others by being an organ, eye, and tissue donor (life-saving anatomical gift)."

> "active and mandated choice may serve as a useful interim step"

Support & Facilitate Consent From Surviving Family Members

Surviving family members often have the final say on donation either by law or in practice, and family decisions to consent largely depend on their knowledge of their loved ones' donation preferences. Unfortunately, many families lack such information—less than half of the families in one study reported having had an explicit discussion about organ donation with their loved ones.[51] When officials do know that a deceased person has volunteered to be a donor, they would be wise to take guidance from the research, mentioned earlier, indicating that informing families of the deceased's wish and expressing the organ procurement organization's goal of honoring the deceased's preference can increase consent relative to simply asking for permission to carry out the organ donation.[56]

Policymakers should further be aware that surviving family members may be less certain of the potential donor's preferences under presumed or explicit consent policies than under a mandated choice policy.[28,41] Also important to consider is that families are being asked to make a grave choice at an often unexpected and traumatic time. Ensuring that families are approached in a quiet and private place, educated about brain death before discussing donation, and counseled by on-site coordinators with specific training is key both to tactfully respecting the family members' relationship with their loved one and to increasing

the chances that they will ultimately consent to donation.[50,59]

Final Thoughts

Overall, the research suggests that presumed consent often yields higher consent, donation, and transplantation rates. However, presumed consent is not a panacea but rather one factor among many that determine the number of organs donated and lives saved. Evidence suggests that presumed consent policies will be most effective if they are backed up by a simple process for registering preferences, accurate information about organ donation, clear public messaging that highlights the value of donation and addresses concerns, a gradual rollout of new policies, on-site support and counseling for families making consent decisions, and efficient infrastructure for organ procurement and transplantation.

Perhaps the most important lesson to be drawn from this review is the importance of further research and of continued learning by researchers and policymakers at all stages of the policymaking process. Although the bulk of research suggests that presumed consent is the most effective consent policy for promoting organ donation, many open questions remain about the extent to which presumed consent can increase donation rates, under what conditions such policies are most effective, and whether active or mandated choice is a viable alternative when presumed consent is seen as politically untenable.

Further, policymakers should strive to take an evidence-based approach to crafting consent policies and managing the context surrounding consent. The Behavioural Insights Team's "test, learn, adapt" approach[96] uses randomized controlled trials to determine how best to execute new policies and serves as an example of how other policymakers can ensure that data, rather than intuition, drive important policy decisions.

Johnson and Goldstein's research opened eyes to the possibility that consent defaults are vital to the success of organ donation.[2] In the 16 years since, more evidence in support of this contention has accumulated, along with important information about how to make defaults most effective. Now researchers and policymakers need to build on what is known and ensure that defaults truly do improve public welfare and save lives.

author affiliation

Steffel: Northeastern University. Williams: Washington University in St. Louis. Tannenbaum: University of Utah. Corresponding author's e-mail: m.steffel@northeastern.edu.

supplemental material

- https://behavioralpolicy.org/publications/
- Supplemental table

endnotes

A. Editor's note to nonscientists: Researchers assess the size of observed effects using measures such as Cohen's *d*, for which values of 0.2, 0.5, and 0.8 typically indicate small, medium, and large effect sizes, respectively.

B. Published reviews of panel studies by Rithalia and colleagues,[97,98] Palmer,[99] and Shepherd et al.[69] discuss the methodological approaches and quality of various studies of presumed consent; see these reviews for more information about how these studies were conducted and how such methods may affect the interpretation of the findings.

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