

Presumed consent not answer to solving organ shortage in US, researchers say

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Removing organs for transplant unless person explicitly opts out of donation before death not best way to address scarcity, raises sticky ethical questions.

Changing the organ donation process in this country from opt-in -- by, say, checking a box on a driver's license application -- to opt-out, which presumes someone's willingness to donate after death unless they explicitly object while alive, would not be likely to increase the donation rate in the United States, new Johns Hopkins research suggests.

Some organ donation advocates have pushed for a switch to an opt-out system, arguing it would be a positive step toward addressing the nation's profound organ shortage. They say most people support donation but never formally record their wishes and that an opt-out system -- known commonly as [presumed consent](#) -- might ease the burden of decision-making on grieving families at the time of death. Many thousands of people die every year waiting for organs that never come, and many viable organs are never made available for donation.

"Opt-out is not the magic bullet; it will not be the magic answer we have been looking for," says Dorry L. Segev, M.D., Ph.D., an associate professor of surgery at the Johns Hopkins University School of Medicine and leader of the study published online in the journal *Transplantation*. "With opt-out the perception becomes, We will take your organs unless you take the time to fill out a form. That's a dangerous perception to have. We only want to use donated organs from people who intended to donate."

Enforcing an opt-out policy raises tricky [ethical questions](#) and could challenge the relationship between the transplant community and the general public, which should be mutually supportive, Segev adds.

Segev and his team conducted in-depth interviews with transplant experts in 13 European nations with presumed consent legislation. They found that, despite the laws, the process of organ donation in those countries does not differ dramatically from the process in countries, such as the United States, that require explicit consent. They also found that the United States ranked third among the nations surveyed in rates of organ donation from the deceased, with 26.3 deceased donors per million population. Only Spain (34.1) and Portugal (26.7) did better.

"It does not appear that by simply having presumed consent legislation on the books that donation rates will rise," says Brian J. Boyarsky, the Hopkins researcher who conducted the interviews.

Segev says that in the United States, whether or not someone is declared as an organ donor prior to death, physicians will approach family members and ask whether they would still like to donate their loved one's organs. The family gets to make the final decision, regardless of the deceased's stated intentions, Segev says.

What he and his colleagues learned was that even in the countries with presumed consent, donation was still discussed with the potential donor's family at the time of death, even though doctors were legally permitted to transplant those organs. In six of the 13 countries, there is actually a legal requirement that doctors speak with relatives. This is done to be transparent with the family about the donation process and to obtain a complete medical and social history of the potential donor. Donation would not proceed if the family objected, just as in the United States, in all but one of the countries surveyed (Portugal), the researchers found. This is because of a fear of negative press, the participants told Segev's team, and a desire to respect the wishes of the grieving family so as to prevent psychological harm.

Implementing presumed consent legislation, Segev argues, would take a huge amount of time and energy with minimal payoff. Many countries with presumed consent have much lower rates of [organ donation](#) than the United States, he notes.

Segev says there are still lessons to learn from countries like Spain, whose donation rate far surpasses the United States. In Spain, there are dedicated physicians at every hospital who are knowledgeable about transplant issues and who screen for potential donors, manage their care and approach families. He believes these dedicated physicians are a key reason why Spain has a higher rate of donation, not the mere existence of presumed consent.

"We need to foster more awareness of transplantation and transplant issues to procure more organs for lifesaving transplants rather than force people to donate their relatives' organs if they fail to opt-out before death," he says.

The most important thing, Segev adds, "is that people need to be very clear with their next of kin while they are still alive about whether or not they want to be organ donors. That's who will ultimately make the decision."

Provided by Johns Hopkins Medical Institutions

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