https://doi.org/10.1038/s41591-025-04056-0

Lessons in public trust

Heidi J. Larson & Alexander H. Toledo

What the organ donation system can learn from global experiences with vaccine programs.

In organ transplantation, ensuring that the donor is dead before proceeding with the donation, and distributing those organs fairly, are non-negotiable. These are the cardinal rules that establish a foundation of trust in the system. In the USA, the organ donation system has recently struggled with breaches in these processes and faced public scrutiny. We believe that there are valuable and hard-earned lessons to be gleaned from the global vaccine experience.

On 21 July 2025, the Department of Health and Human Services (HHS) issued a press release calling for reform of US organ donations after their review revealed a "systemic disregard for the sanctity of life in the organ transplant system". The key issue related to concerns around donor hospitals and organ procurement organizations putting patients forward for organ removal prematurely, with "signs of life" still present. The HHS statement specifically calls out "poor neurologic assessments, lack of coordination with medical teams, questionable consent practices, and misclassification of causes of death"[1].

The truth or mere perception of these assertions risks jeopardizing a system that saves hundreds of lives a day, and could save many more. The 2023 Global Observatory on Donation and Transplantation reported that less than 10% of the global demand for organ donations are met[2]. At this critical time, the transplant community must navigate these concerns carefully and promptly. Vaccine scares have sometimes paralyzed immunization programs, with small risks amplified by social media to seem far more common than they are. But, when well-managed, identified risks can be a springboard to needed reform and can bolster public confidence.

Managing risks

When procedural, safety and ethical issues are identified, reforms are important to ensure a safe and trustworthy system — whether national immunization programs or organ donation systems. Although the first step is transparency around any newly identified risks, it must be coupled with a path forward. Announcing a risk and doing nothing, or being perceived as doing nothing because of a lack of communication, is as much of a trust breaker as the risk itself[3].

One of the challenges in sustaining public trust is finding the balance between being transparent and not creating undue panic that can lead people to refuse vaccinations or to withdraw their intention to donate organs. According to one report, an unprecedented 20,000 people withdrew their organ donor registration during the month after the HHS announcement and related media coverage[4].

These consequences go well beyond the individual who opts out and have considerable public health ramifications. In the case of immunization, panic around a vaccine risk can undermine herd immunity or overwhelm medical resources in times of an epidemic. In transplantation, each organ donor that withdraws represents up to eight lives that might have been saved[5].

Different political or cultural settings handle risk communication and public trust challenges in different ways. Trust and distrust resonate with individuals and communities on a visceral level and can create a dramatic response in their willingness to cooperate towards a collective goal. This is especially evident when fear or fairness are involved.

One of the biggest lessons from vaccines is that uncertainty is fertile ground for misinformation and fears to spread and for trust to wane. Preparing and engaging publics around new policies and health interventions as early as possible can help to mitigate misinformation and distrust[6]. During the COVID-19 vaccine rollout, particularly for the new mRNA vaccines, the scientific and policy community failed to communicate widely that, although the mRNA platforms were a new approach to making vaccines, there had already been decades of mRNA research[7]. Earlier communication might have helped to mitigate anxieties around the vaccine being made too quickly.

Political contexts

The introduction of a new dengue vaccine in Brazil and the Philippines in 2017 is another valuable example. After vaccination had started, both countries were notified by the vaccine producer, Sanofi, that there was a small risk for those vaccinees who had no previous exposure to dengue viruses. Specifically, virus-naive individuals risked developing more serious dengue after vaccination, whereas others living in endemic areas or who had previously been infected with dengue viruses, gained valuable protection against future infections.

In the Philippines, public outrage and politicization of the situation led the government to suspend the dengue vaccination program[8]. Accusations were made that blamed the previous government for a lack of vigilance, followed by a notable drop in public confidence not just in the dengue fever vaccine but in vaccines more broadly[9]. This led to preventable dengue fever deaths, and to a 30% drop in the uptake of the measles vaccine between 2014 and 2018.

In Brazil, the news from Sanofi instead prompted a change in the dengue vaccination policy to focus only on those who had been previously exposed to dengue viruses. Without the political element in play, Brazil successfully continued their Dengvaxia vaccination program, although they did have to manage public concerns about the reported risk at a local level[10].

The politicization of the Dengvaxia risk in the Philippines is not unlike the HHS statement about organ donations, which used the episode as an opportunity to undermine the previous administration, saying that the reported incidents reflect the "entrenched bureaucracies, outdated systems, and reckless disregard for human life" of the previous government, while championing the new government and HHS leadership as "restoring integrity and transparency"[1]. Although the identified risks in both scenarios are real and merit swift corrective action, the unnecessary political framing of the issues can create more barriers when working towards the public good. This is especially true in times when trust in government and its agencies is low.

Sensitivity to political and cultural settings are key to building public trust. The 2017 memo from Sanofi did not engage local

and regional organizations to anticipate how cultural variance might shape responses to the announcement. As one commentator put it, "The statement, which Sanofi had sweated over and planned around for days, lacked context, local or otherwise. It didn't offer probabilities or degrees of risk; it didn't explain what 'severe dengue' meant,"[11]. That worked for some countries, but not all. In the Philippines, it created a ripple of distrust across the government and health system.

The loss of confidence after the 2017 Dengvaxia announcement informed later efforts to rebuild trust. A major measles outbreak in 2018–2019 prompted the Philippines Department of Health to shift attention to the measles vaccination campaign, which became an important avenue to rebuild trust in the larger immunization program. The Philippine Foundation for Vaccination, a 25-year-old trusted non-governmental organization, created regular forums for the public and organized scientific meetings with local government units to restore trust. Experts from medical and pediatric societies joined local physicians for media conferences on the dengue vaccine. Podcasts and videos were circulated on social media platforms. Local engagement was prioritized.

Collective actions

During the early management of the US organ donation situation, the relevant medical societies, organ procurement organizations, and government agencies all promptly denounced the problems observed with neurological assessments of potential donors and reaffirmed that donor safety must be paramount. All parties pledged to work together to protect patients but, crucially, no specific action plans were offered at this time. Months later, HHS called for better feedback mechanisms for cases of concern, but details remained unclear. All entities deflected culpability from their specific purview. These defensive statements lacked the accountability and leadership needed to restore public trust in the organ donation process.

As a transplant community, we cannot compartmentalize these challenges as merely an organ procurement organization or donor hospital issue and take shelter behind the scrutiny they have faced in recent months over allocation practices and confirming donor death. There is considerable pressure on these organizations as more than 100,000 people are on the waiting list for organ transplants in the USA, and an average of 13 patients die each day waiting for an organ. The demands on the Organ Transplantation and Procurement Network are immense and coming from all angles. Donor hospitals, donor families, transplant centers and organ recovery services are all being managed simultaneously under the stresses of time and cost constraints, regulatory standards and variations in local practice.

Public trust rises and falls collectively along the entire donor journey, and all stakeholders need to support change. As urged by the American Society of Transplantation, "This is a time for collective action. Ensuring patient safety requires everyone involved in the transplant system to work together to drive meaningful, lasting change"[12].

What does meaningful, lasting change look like? It starts with prioritizing the silent and most essential stakeholder — the donors themselves. Moving to a shared decision-making model has become popular in other pivotal moments in healthcare, such as surgical consent or chemotherapy discussions, and could be a valuable approach with donor families[13]. Similarly, in the context of vaccination, giving families an opportunity for discussion and asking questions is a trust builder, particularly in the current environment fraught with misinformation.

Beyond improving transparency, shared decision-making allows the patients' intentions and values to guide care. Most donors and families are not interested in the particulars of strict death criteria that handcuff providers and lawmakers, and are more compelled by the devastating neurological prognosis as they decide to withdraw care for a loved one. Frequent neurological checks should be standardized and reported to the family to ensure there has not been a real change in neurological status as the team works towards donation. Any provider or family member should be empowered to call a safety pause and re-assess any new findings. Once these safeguards are firmly in place, we can recenter on the reality that facilitating donation can provide meaningful autonomy to the donor and immense comfort to the grieving donor family in these final moments.

The 'dead donor rule' mandates cardiac or neurological death before organ recovery and is essentially a global standard. It is intended to provide clear boundaries for pursuing organ donation and public confidence in both end-of-life care and the donation process. However, in the USA, approximately one-third of organs intended for donation after cardiac death are not used because potential donors miss the time window to facilitate organ recovery once life support is removed. Typically, if the patient does not expire within one to two hours after support is removed, organ viability can be jepordized and the recovery teams, equipment and hospital operating room space cannot remain on standby indefinitely. The opportunity is lost and the patient returns to palliative care for their remaining hours or days. Beyond the loss of thousands of organs annually under the dead-donor rule, donor families often feel extraordinary anguish of this 'double death' as their loved one is denied the opportunity to die with purpose[14].

Engaging critical care and palliative care experts to create defined pathways that better synchronize end of life care and patient intentions in these cases is essential. We urge the creation of a taskforce to engage key stakeholders in modernizing practice guidelines and distributing for public comment. We need to empower treating physicians to minimize harm and maximize autonomy as terminal care pivots to organ donation.

Statement of intent

As with vaccines, there will always remain potential rare risks of harm in the organ donation process. These real concerns must be addressed, ideally without stoking undue fears. The short-term loss of registered donors might have been averted with better messaging and clarity, but the most important issue now is to minimize the period of uncertainty and make clear what actions will be taken to build longer term trust. The public statement from HHS[1] will hopefully be a catalyst to drive these improvements; however, the unnecessary political framing has the potential to distract and create public resistance, as has happened when vaccine safety issues have been politicized.

Like vaccination, transplantation has grand ambitions, aspiring to save lives and improve health on a large scale. Future questions around xenotransplantation, equitable organ allocation, biomarkers and other scientific frontiers will require public trust[15]. The trust and goodwill earned in responding to this crucial moment will also be the capital required for these bold endeavors moving forward.

Heidi J. Larson [1,2] ✉ **& Alexander H. Toledo** [3,4] ✉

[1]Department of Infectious Disease Epidemiology and Dynamics, London School of Hygiene & Tropical Medicine, London, UK. [2]Institute for Health Metrics & Evaluation, University of Washington, Seattle, WA, USA. [3]Department of Surgery, Division of Abdominal Transplantation, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA.

[4]Center for Bioethics, Department of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA.
✉e-mail: heidi.larson@lshtm.ac.uk; alexander_toledo@med.unc.edu

Published online: 02 January 2026

References

1. US DHHS. *HHS Finds Systemic Disregard for Sanctity of Life in Organ Transplant System* [press release]; https://go.nature.com/4hI60Kk (21 July 2025).
2. Global Observatory on Donation and Transplantation. *International Report on Organ Donation and Transplantation Activities 2023* (WHO, 2023).
3. Petersen, M. B., Bor, A., Jørgensen, F. & Lindholt, M. F. *Proc. Natl. Acad. Sci. USA* **118**, e2024597118 (2021).
4. Rosenthal, B. M. *New York Times* https://go.nature.com/4oTjVj3 (28 August 2025).
5. Larson, H. J. & Toledo, A. H. *Global Discourse* **13**, 290–315 (2023).
6. Sharfstein, J. M. *JAMA Health Forum* **6**, e254252 (2025).
7. Xu, J. et al. *npj Vaccines* **9**, 218 (2024).
8. Lasco, G. & Larson, H. J. *Glob. Public Health* **15**, 334–344 (2020).
9. Larson, H. J., Hartigan-Go, K. & de Figueiredo, A. *Hum. Vaccin. Immunother.* **15**, 625–627 (2019).
10. Preto, C. et al. *Vaccine* **39**, 711–719 (2021).
11. Fry, E. *FORTUNE* https://go.nature.com/4nC0XfA (26 November 2019).
12. American Society of Transplantation. *Statement on July 22 Hearing on Organ Procurement and Transplant Oversight* (22 July 2025).
13. Gordon, E. J. et al. *Am. J. Transplant.* **13**, 1149–1158 (2013).
14. Dutchen S. *Harvard Medicine Magazine* https://go.nature.com/47p1YmG (2016).
15. Oniscu, G. C. et al. *Lancet* **406**, 313–315 (2025).

Competing interests

The authors declare no competing interests.