



August 16, 2021 | A periodic e-bulletin to share results of organ donation and transplantation projects funded by the Division of Transplantation.

Patience for Patients: Making it easy to register as an organ donor

Technology and tailored messaging boost donation registration in Pennsylvania primary care offices



Patient completing form in PCP waiting room
Photo credit: Patients Save Lives Program

Researchers at the University of Pittsburgh found ways to increase organ, eye, and tissue donor registration when patients check-in for primary care appointments. A 2011 study funded by the Health Resources and Services Administration's (HRSA) Division of Transplantation established the "Patients Save Lives" program. In another HRSA-funded study in 2020, researchers looked for ways to modify how staff in primary care offices hand out donation registration forms to patients when they check-in.

The "Patients Save Lives" team used the University of Pittsburgh Medical Center (UPMC) Health System's electronic medical record system (EMR), Epic, to add a patient's name and address onto their registration form and print it when the patient checks in for a primary care visit. The study found that some patients who had declined to register at the Department of Motor Vehicles were willing to register in their doctors' offices. The use of messages tailored to older adults more than doubled the registration rate – from 2.8% to 5.8%.

"The program conveys the message that the decision that you make to donate is self-determined but also has an impact on other people's lives," said Teresa Beigay of the University's Health Policy and Management staff. "We want to do what we can to make patients comfortable and empowered in that decision."

Strategies that work:

- **Involve primary care offices** – Patients are more likely to register as organ donors if the request comes from a primary care physician they trust.
- **Go digital** – Reduce the load on patients by pre-populating their information in the electronic medical record system. It eliminates staff having to scan the papers.
- **Protect the patients' information** – Donation designation should be seen **ONLY** by the organ procurement organization. Keep the patient's donor status out of their medical file.
- **Tailor the messaging** – Addressing age-related concerns about organ donation makes it more likely that older adults will register as donors.



Protecting Privacy

The team, led by associate professor of Health Policy and Management Howard Degenholtz, Ph.D., used UPMC's Epic to create the registration form without storing a patients' donor designation. Staff sent completed forms directly to the Center for Organ Recovery and Education (CORE) to be added to the state organ and tissue donor registry. Once patients completed the form, their EMR record showed that they had been given the opportunity to register, so a registration form for that patient would not print out again until the following year.

“Only the OPO can go into the registry to look up somebody's status, and they're only allowed to do that if there's an imminent death,” Degenholtz clarified. “We don't want that status stored in the EMR because we don't want the perception that physicians or hospitals either consciously or unconsciously let that information affect their treatment decisions. We want that information to be really walled off from the delivery of medical care.”

Reaching an Older Audience

“The likelihood of adults registering as organ and tissue donors declines with age because some people feel that they are too old and no one would want their organs,” Degenholtz explained. “The idea was that messages that encourage organ and tissue donation should be tailored to the audience, and specifically counter those age-related beliefs.”

The “Patients Save Lives” team put together materials for their older audience to counter age-related misconceptions like those below, which made patients over 50 more comfortable registering as organ donors.

What are some of the Myths about Organ Donation concerning Older Americans?



Moving Forward

According to Degenholtz, it was hard to use the registration forms toward the end of the project with the rise in telehealth visits due to COVID-19. Also, limited staff were available to tally the data due to temporary office shutdowns. However, Degenholtz and his team were encouraged to incorporate more technology into the donor registration process as a result.

"I think the logical next step here is to eliminate paper entirely," Degenholtz said. "One of the pieces that we were not successful with was scanning the forms so the data could be sent directly to CORE. The next step in the evolution of this project would be to use a patient kiosk that directly sends donor registrations to the national registry. This is an important avenue for future research."

Want to know more?

Patients Save Lives

<https://patientssavelives.pitt.edu/>

Degenholtz HB, Creppage K, DaCosta D, et al. The Patients Save Lives Program to Facilitate Organ Donor Designation in Primary Care Offices. *Progress in Transplantation*. 2019;29(3):204-212. doi:10.1177/1526924819853836

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