

As COVID-19 Delta variant spreads, some Arizonans with disabilities hesitate to get vaccinated



[Meena Venkataramanan](#)
Arizona Republic

Fifteen months into the ongoing COVID-19 pandemic, Robert Scanlan remains unvaccinated.

The 78-year-old from Phoenix, who has received two liver transplants and a kidney transplant, has no immediate plans to receive the coronavirus vaccine. He has been taking immunosuppressant drugs for the past 25 years and worries that the vaccine could have negative impacts on his immune system.

“What I've been watching for the last six months or so now is to find out whether the vaccine itself has adverse effects on transplant patients,” Scanlan said.

Scanlan, who is on the board of the Transplant Community Alliance, a local charity and solid organ transplant support group, is just one of the millions of Arizona residents who have not yet

received a single dose of the vaccine. Arizona is in the bottom half of states when it comes to the percentage of its population — 49% — that has received at least one dose.

Some unvaccinated Arizonans are simply ineligible because they are under the age of 12. Others suffer severe allergic reactions to the vaccine's components. Many are afraid of getting the vaccine because they are immunocompromised or because they have a disability.

In the clinical trials for the Pfizer and Moderna vaccines, [solid organ transplant patients were not included](#), which gave Scanlan pause. "There were tremendous political and financial issues involved to get that vaccine out ASAP," he said. "So it came out in record time, but with no indication as to what it would mean to someone like myself to receive it."

There is no evidence to suggest that the vaccine is unsafe for transplant recipients. In fact, the [vaccine was deemed safe to administer to transplant recipients](#), but recent data show that organ transplant recipients who have received both doses of an mRNA vaccine may remain at risk of contracting COVID-19, according to a [Johns Hopkins University study](#) from May.

The Centers for Disease Control and Protection's website similarly warns: "If you have a condition or are taking medications that weaken your immune system, you may NOT be fully protected even if you are fully vaccinated. Talk to your healthcare provider. Even after vaccination, you may need to continue taking all precautions."

"Realistically, just from a pragmatic standpoint, science says it ain't doing me much good," Scanlan said of the vaccine.

Even though the vaccine may not be as efficacious in transplant recipients, meaning they may not mount an antibody response to the vaccine, "most transplant patients now accept what the doctors tell them," said Dr. Michael Abecassis, the dean of the University of Arizona College of Medicine who specializes in transplantation and virology.

Abecassis said he tells patients that they should get their vaccine, but that they should still be careful and wear a mask be careful "because we just don't know whether it's going to be as effective" in preventing illness and death. He said [recent data](#) suggest that solid organ transplant recipients who receive a third dose of the vaccine may have a higher likelihood of developing antibodies against the coronavirus.

As the highly contagious Delta variant of the virus rages across the country and makes inroads in Arizona, Scanlan and others remain unfazed about getting infected with the coronavirus. Scanlan wears a neck gaiter when he's out in public, always has a mask on hand if he needs one, and says he goes out often.

"I went to a restaurant last night," he said. "It was jammed. And I saw one couple come in wearing masks out of literally a few hundred people I probably saw over the course of the evening, and I just felt happy that those restaurants are being revitalized. I was happy to see people had their jobs back."

Tariq Abu-Saada, like Scanlan, has not received the COVID-19 vaccine.

The 31-year-old from Tucson suffered a head injury in October 2017, followed by a stroke three weeks later. The events caused a traumatic brain injury, which led him to lose both his vision and short-term memory.

Abu-Saada, who is visually impaired, says he does not want to get the COVID-19 vaccine because he is concerned that it will impede his vision recovery.

“I was a little worried about my vision recovery if I got vaccinated,” he said. “My doctor's office or my vision specialist had said, people that got vaccinated said that their vision regressed. I was worried about the health of my traumatic brain injury recovery and my vision.”

Abu-Saada pointed to the Vaccine Adverse Event Reporting System (VAERS), a database administered by the Department of Health and Human Services to track adverse events and reactions experienced by vaccine recipients. He said that he has read reports of heart inflammation and blood clots after vaccine administration.

The VAERS website cautions that while it is “very important in monitoring vaccine safety, VAERS reports alone cannot be used to determine if a vaccine caused or contributed to an adverse event or illness. The reports may contain information that is incomplete, inaccurate, coincidental, or unverifiable. In large part, reports to VAERS are voluntary, which means they are subject to biases.”

Like Scanlan, Abu-Saada worries about the speed with which the vaccine was made available to the public. Unlike other vaccines, which typically require years of research and testing before the clinical trial phase, the COVID-19 vaccine reached clinical trials just months after the pandemic erupted last March.

“I think that it's still a little too early to get the vaccine; it's still in a trial phase,” he said, referring to the fact that different COVID-19 vaccines are still undergoing clinical trials. “Maybe three years after the vaccine is open, maybe that's the best time to get it because that's when it would have been tested.”

But while Scanlan has said he isn't afraid to go out into public spaces, Abu-Saada said he has remained cautious and “good about social distancing”. He lives with his mother, who also isn't vaccinated.

“I don't go out, I don't go downtown, I don't go to the big clubs or anything like that,” he said, adding that he goes to a restaurant “every now and then” and brings a mask wherever he goes, even if he doesn't wear it. “I'm not acting wild. I'm not putting myself in danger of getting (the virus).”

Overcoming vaccine hesitancy

Disability advocacy groups and transplant support groups have tried to help their members overcome vaccine hesitancy.

Jamie Neidorf is the quality improvement manager at Direct Advocacy and Resource Center, a nonprofit organization operated by and for people with disabilities where Abu-Saada is a member. Neidorf says that when the pandemic hit, Direct focused on disseminating information about COVID-19 tests.

“Now, of course, we focus more on what we can do to get you vaccinated and to dispel any myths they may be subscribing to and choosing not to get vaccinated,” she said.

Neidorf said “there's definite hesitancy among some of (her) participants” when it comes to getting vaccinated. Part of this comes from the fact that many people with disabilities are also immunocompromised and may not be fully protected from COVID-19 with the vaccine—even if they're more likely to contract the virus because of underlying medical conditions.

The CDC's website warns that “adults with disabilities are three times more likely than adults without disabilities to have heart disease, diabetes, cancer, or a stroke.” Neidorf says that these inequities have led to skepticism about the vaccine among some Arizonans with disabilities. “We know that people vaccinated within our population aren't going to have the same 91% effectiveness from the Pfizer or Moderna vaccine that you or I would,” she said.

This possibility of reduced vaccine efficacy in some individuals with disabilities is similar to the reason that Scanlan, the liver and kidney transplant recipient, is hesitant to receive the vaccine: he isn't sure if it will benefit him enough, even though studies have shown it is safe to administer to people like him.

Neidorf says Direct is considering putting together a panel to inform people with disabilities about the vaccine. The panel would include “peers, so people with disabilities who have gotten the vaccine, and can speak to the experience, as well, of course, a doctor or public health official, you know to dispel the information that's still circulating about why you should run from the vaccine instead of to it,” she said.

“It is a little disturbing to hear that so many of our participants subscribe to our former president's way of thinking,” she said, alluding to the vaccine skepticism with which former President Donald Trump flirted during his time in office. Trump did get vaccinated and ultimately expressed support for the vaccine, but many of his supporters remain skeptical.

Erica McFadden, the executive director of the Arizona Developmental Disabilities Planning Council (ADDPC), which is affiliated with the Governor's Office and advocates for people with disabilities.

“The people who are going to get the vaccine have gotten the vaccine,” she said. “Now the issue has come down to addressing the misinformation out there regarding the vaccine among our community. Some people are fearful because they're not getting information in a way that they can understand.”

McFadden said the ADDPC has received funding from the CDC “to basically try to get out information written for people with disabilities that they’re able to understand, and then working with doctor’s offices, clinics, and community groups to make sure that we’re able to give them that information.”

Overcoming barriers to information access, McFadden explained, is one way to overcome vaccine hesitancy among people with disabilities. “The biggest barrier that we’ve encountered throughout this entire time is being able to have information that they can understand and that they have the accommodations to be able to ask questions,” she said.

As for transplant recipients, most are “eager to get the vaccine,” according to Zoe Severyn, the executive director of the Transplant Community Alliance, where Scanlan is a board member.

Approximately 90% of her group’s members were enthusiastic about getting the vaccine, even after Johns Hopkins research showed it may not be entirely efficacious in transplant recipients," Severyn said.

Even though the efficacy of the vaccine in this population is uncertain, "it's safe for the transplant population to get the vaccine," said Dr. Rohit Nathan, a clinical assistant professor at the University of Arizona College of Medicine – Phoenix.

“The message that we spread through email and social media is, ‘get two shots, wear your mask, and wash your hands, and get the blood tests,’” Severyn said, explaining that after getting the second dose of the vaccine, transplant patients should get a blood test to see if they’ve built an immune response. Then they can go out in public, following social distancing and masking protocols.

Severyn said it helps to partner with experts. “We’ve reached out to the transplant centers, and when the message comes from them, it’s a little bit louder,” she said, adding that her organization hosted a Zoom meeting where transplant patients could ask questions to an expert. “We were able to get rid of some of that mystery around the vaccine by letting them speak directly to the expert.”

Scanlan is still open to getting the vaccine once he confirms with doctors that there is no possibility of negative effects on transplant recipients. “I have a couple of doctors in mind that I want to confirm this with, and then I’ll probably get vaccinated,” he said, explaining that the vaccine would allow him to travel. “It’s a practical thing to do.”

Abu-Saada said he has no immediate plans to get the vaccine.

Severyn said that she hopes that immunocompromised individuals, and others who are skeptical of the vaccine’s efficacy on their bodies, will reach out if they are hesitant to get the vaccine.

“If someone is running into resistance or trouble, they can give us a call and we can help or put them in touch with someone who can,” she said. “They’re not alone. I don’t want them to feel like they’re suffering alone.”

