

HHS Walks Back “Autism Registry” Plans

On Monday, April 21st, the Department of Health and Human Services (HHS) announced plans to collect federal and private health data for upcoming autism studies. National Institutes of Health (NIH) Director Dr. Jay Bhattacharya also [announced](#) that NIH would create a “new disease registry” focused on autism. This announcement led to public outcry and alarm across the autism community. Yesterday, Thursday April 24th, HHS [said in written statements](#) to multiple journalists that they will not be creating an autism registry, contrary to Dr. Bhattacharya’s statements. This is positive news, but given this administration’s previous actions and comments, particularly those related to autism over the last several weeks, we are not assuming that there is no longer anything to worry about. We will continue to monitor this research initiative, and any other autism-related administration efforts, with extreme vigilance.

“Registry” and “data collection” can mean many things. The lack of clarity about what NIH actually intended to do, coming from an administration that has acted against autistic people’s interests [across the board](#), led to immense concern among autistic people, family members, privacy advocates, and researchers. This underscores one of the major problems with how this administration has approached autism policy: that it has completely frozen out autistic people and many [leading autism organizations](#). Under previous administrations led by both Democrats and Republicans, we and other organizations had direct lines of communication with autism policy experts inside HHS. Back then, we were able to give feedback, raise concerns, and ask questions. If we had been given the opportunity to provide input into Monday’s announcement, we would have urged the administration to clarify important details, such as whether they planned to collect personally identifiable information, and how this data would be used. Since now we get no information beyond what is reported in the press, we have no choice but to apply public pressure to try to get answers for our community.

HHS’ reversal on creating an autism registry shows that even when it seems that no one is listening, your voice matters. Public outcry seems to have caused HHS to change course and walk away from some of the most concerning aspects of the project. Right now, HHS

does not appear to be creating a centralized list of autistic people that could be used against our community. We will keep the community involved, and provide updates if there is any indication that that might happen. If you're feeling scared, know that we are fighting by your side for your rights, privacy, health, and safety. We encourage you to [join us](#).

We continue to have many unanswered questions about what data is going to be collected under this project, whether people's personal information will be protected, and how it will be used. If the data provided to researchers is actually deidentified — meaning that it is scrubbed of information that could be used to identify individual people — then it is normal for data to be linked together from multiple sources, and to be used for this kind of research purpose without requiring the consent of the people whose data is collected. For example, a [number of Developmental Disabilities Projects of National Significance](#) rely on claims and healthcare data to study service needs and outcomes for our community. This work is extremely valuable and should be continued, and is only possible through the use of health data with meaningful privacy protections.

Given everything this administration is saying and doing about autism, [privacy](#), and public health, we have every reason to distrust this initiative under current leadership at HHS. If individuals are identifiable in the information HHS distributes to researchers, then serious concerns about privacy are very much warranted. Personally identifiable information (PII) should not be shared with researchers without rigorous consent procedures and additional privacy protections. This administration has already demonstrated that it is [reckless with our data](#) and does not value the [privacy of vulnerable communities](#). So far we have not heard that PII will be given to researchers, but we will continue to closely watch this project and demand answers, and we will push back if we see that people's privacy is being violated.

Even if autistic people's PII is not compromised in any way, we want the government to use this data for research that will help autistic people. Secretary Kennedy's research proposals would not help autistic people. Secretary Kennedy's decision to hire [David Geier](#) for this research effort demonstrates that his HHS is willing to disregard their obligations to protect our health and safety. They are less interested in good science than in making sure they produce the answers they want to find. Secretary Kennedy has also [recently cited another anti-vaccine "study" that used accurate data to reach an inaccurate conclusion](#). This study was not published in a reputable scientific journal and did not go through legitimate peer review. It used Medicaid data from Florida to show that children who had doctors' visits to receive vaccinations were statistically more likely to also have doctors' visits to receive care for autism. The authors falsely claimed that this demonstrated that getting vaccinated could cause autism. All this study actually means is

that parents who take their children to the doctor are more likely to both get their children vaccinated and to have their children evaluated for autism, and to get them care if they are autistic. Handing over huge amounts of data to people like these researchers would increase their ability to mislead the public by generating phony evidence for Kennedy's predetermined conclusion: a link between vaccination and autism that real scientific studies have [repeatedly](#) disproved [over](#) and [over](#) and [over](#) again.

This turbulent week has shown that the administration has lost the trust of the entire autism community. Secretary Kennedy's remarks over the past two weeks demonstrate that the administration does not understand us, does not like us, and does not intend to help us. In that context, when the administration announces new policies affecting our community without consulting us, the natural result will be fear, anger, and confusion. If the administration wants to change that, it owes us clear answers, an apology for all the lies it has spread about autistic people so far, and opportunities for autistic people to advocate for our own needs to the administration. HHS' walk-back is a success for our advocacy; it shows that our community has power, and that it is vital to speak up when potential threats emerge. As always, we will continue to do everything in our power in every forum available to protect autistic people.