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Patients worried about autism 'registry'? Encourage them to 'be heard.'

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Compliance

The recent HHS announcement of an autism "registry" caused an outcry and a pullback. It also raised the question: How safe is your vulnerable patients' data when the government demands it, and what can your patients do, and what should they know, if they have concerns?

In an April 19 press conference on autism, HHS Secretary Robert F. Kennedy Jr. made several statements considered provocative by advocates for autistic people, including his assertion that autistic children "will never pay taxes, they'll never hold a job, they'll never play baseball, they'll never write a poem, they'll never go out on a date." Kennedy had previously promised to deliver a study that would reveal the causes of "the autism epidemic," which he'd previously hinted was caused by vaccines, in September 2025.

The outcry increased some days later, when CBS News and others reported that National Institutes of Health (NIH) director Jay Bhattacharya, M.D., had told an advisory meeting that the NIH would be "amassing private medical records from a number of federal and commercial databases to give to [Kennedy's] new effort to study autism."

No sources went on record about the comments, which allegedly took place at an April 22 Council of Councils Meeting, though a slide deck from Bhattacharya's presentation says that "NIH is launching an Initiative... integrating diverse data enabling researchers to examine complex factors influencing ASD [Autism Spectrum Disorder] rates," and cites "partnerships across HHS and with external stakeholders," with "Pharmacy chains," "Health organizations," "Clinical data," "Claims & billing," "Environmental," and "Sensors & wearables" as data sources.

Autism organizations complained, as did rights groups such as the American Civil Liberties Union, which wrote in a Facebook post that "an autism 'registry' culled from private medical records could potentially violate federal privacy laws and runs the risk of abuse. It also harkens back to a time when disabled people were labeled, segregated, and excluded."

CBS later reported an HHS official told them that "we are not creating an autism registry. The real-world data platform will link existing datasets to support research into causes of autism and insights into improved treatment strategies."

Can they do it?

Nonetheless, the furor raised concerns among patients with autism who considered their diagnosis and treatment information confidential — which it is, generally, but not always.

Kathleen Stengel, a senior advisor with Provident Healthcare Partners in Boston, thinks it's worth noting that "the CDC has operated a registry program since 2009 through the Autism and Developmental Disabilities Monitoring (ADDM) Network, tracking the number and characteristics of eight-year-old children with autism spectrum disorder (ASD)."

Also, Stengel says, seven U.S. state government "maintain some form of state-level autism registries" — though these are "typically confidential, often allow opt-out options, and are used exclusively for service planning, not for public disclosure or punitive purposes."

HIPAA restrictions on use of protected health information (PHI), while fairly comprehensive, have some exceptions — for example, in cases of criminal investigation and imminent danger (*PBN 3/4/24*).

Kyle R. René, a partner with Whiteford, Taylor & Preston LLP in Richmond, Va., says there's a "relative lack of restriction" when it comes to the government's use of such data in population health and other research: Under 45 CFR § 164.512(b), he says, "a covered entity, which includes individual providers but could also include a commercial or governmental health plan, is not required to obtain patient authorization to disclose PHI to 'a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury or disability.'"

In fact, the force of law tends to run in favor of such permitted disclosures rather than against them, René, says: "In recent years, enforcement actions have actually arisen when providers have done the opposite, engaging in 'information blocking' practices."

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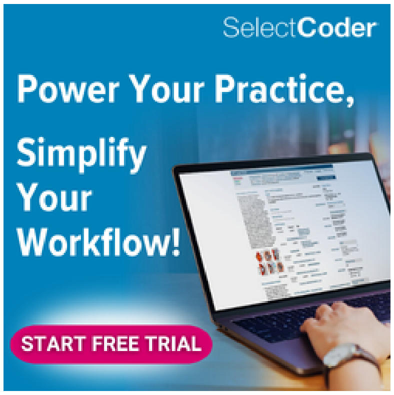

PHI used for research is generally anonymized, and even when it is not it’s legally protected. Per Shannon Britton Hartsfield, a partner with Holland & Knight LLP in Tallahassee: “Federal agencies that maintain information about individuals in a system of records are bound by the Privacy Act of 1974, which requires them to protect information containing names or other identifiers of individuals.”

Nonetheless it’s important to keep in mind that, in the real world, it’s not guaranteed that anonymized or de-identified PHI won’t be re-identified — something that has been accomplished in some ransomware attacks on protected data. “It depends on the characteristics of the data set and whether the information can be used alone or in combination with other information to identify individuals,” Hartsfield says.

On the other hand, this is true wherever the PHI is found, whether in a practice EHR or in a registry.

What to tell patients

Patients on the spectrum and their caregivers may come to providers and patient advocates with concerns. One thing they may be disappointed to learn is that there are no takebacks, so to speak, on legally permissible use of their data by the government.

It’s true that patients have the right to bar release of their data to most outside parties, and that right can be extended in some circumstances. For example, HIPAA allows patients to keep insurers from getting their information if they agree to pay for treatment themselves. But public health authorities are another matter. “If such a registry were established, I don’t see how [these patients] could get around having their information put in it,” says Avery A. Dial, partner with Kaufman Dolowich LLP in Fort Lauderdale, Fla.

The basic truth, which may be comforting to some patients, is “that efforts to promote public health are not new, and there are laws and rules in place to govern how federal agencies must protect this information,” Hartsfield says.

Dial would have them “look at [existing] cancer registries, which many states have. You can’t generally opt out of having your information reported to those, but the information is protected and used in a limited way under the law. If we were to have a national autism directory, I would think it would be used in the same manner.”

Outside of that, Dial says, if the registry idea is revived, “advocates should make sure their voices are heard and that it really is used for research and improving the lives of people who are affected by autism.”

Resources

- Kennedy autism press conference, April 19, 2025 (video): www.youtube.com/watch?v=1QCrkk34TfE
- CBS News, “RFK Jr.’s autism study to amass medical records of many Americans,” April 22, 2035: www.cbsnews.com/news/rfk-jr-autism-study-medical-records/
- Slide deck, NIH Director’s Update, Council of Councils, April 21, 2025: https://dpcpsi.nih.gov/sites/default/files/2025-04/Council-of-Councils-04.21.25-Director-Update.pdf
- ACLU post on Kennedy remarks, April 24, 2025: www.facebook.com/100064593888082/posts/1122777296552056/

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