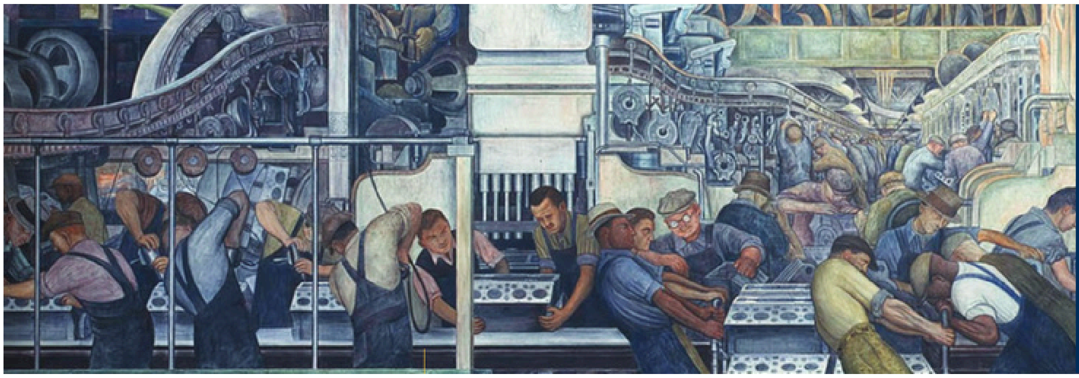

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Smartwatches for Autism Research: Privacy and Surveillance Risks

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KEY FINDINGS

- Insufficient privacy protections for smartwatch health data and federal data sharing with law enforcement place the autistic community at risk of surveillance and targeting by the government and companies without their consent.
- There is a lack of longitudinal and inclusive studies examining the benefits and harms of using smartwatches in applications and interventions for autistic people.
- Researchers must engage in collaborative research with autistic individuals to ensure a high quality of life rather than focusing on "curing" autism.
- Federal agencies and smartwatch companies must implement explicit consent requirements and prohibit broad data sharing policies.

EXECUTIVE SUMMARY

Smartwatches and wearable devices have become increasingly popular tools for health monitoring, and recent research has explored potential applications for autistic individuals. However, wearable health data is not covered by federal health privacy protections which can lead to significant privacy risks such as data breaches and third parties' buying data without user consent.

The Department of Health and Human Services (HHS) plans to create a centralized data platform linking individualized wearable data with broad, nationwide health information in order to investigate autism causes and trends. This could enable researchers to break down data silos and uncover new insights to assist autistic people. However, a lack of ethical and longitudinal smartwatch research, unprecedented federal protected data sharing policies, and the current administration's spread of misinformation around "curing" autism will harm people who are autistic instead of helping them.

Policymakers must establish comprehensive privacy legislation with strict consent and data sharing rules, and researchers should collaborate with the autistic community to ensure any data platform serves their interests.

BACKGROUND

NIH and CMS Partnership

On May 7th, 2025, the US Department of Health and Human Services (HHS) announced plans for a long-term partnership between the National Institutes of Health (NIH) and the Centers for Medicare & Medicaid Services (CMS) to build a "real-world data platform" to investigate the "root causes" of autism. According to HHS Secretary Robert F. Kennedy Jr. and NIH Director Jay Bhattacharya, the partnership will analyze autism diagnosis trends, intervention effects on health outcomes, disparities in access to care, and economic impacts on families and healthcare systems. The platform would link data between insurance claims, electronic medical records, and consumer wearable devices like smartwatches.[1]

The autism community (autistic individuals and their families, along with advocates and researchers) has raised the alarm about the platform. They cite Secretary Kennedy's promotion of debunked claims that vaccines and Tylenol cause autism, the controversial goal of curing autism, and privacy concerns regarding plans for an autism registry. While HHS has stated that they will not explicitly create a registry, expansions of CMS health data sharing with private companies and data use agreements with law enforcement agencies have intensified concerns within the research and autism communities regarding surveillance, privacy gaps, and autism erasure.[2]

Autism in the US

Autism is a lifelong neurodivergence and disability which can impact an individual's social and communication skills, relationships, and self-regulation.[3] Autism is best understood as a spectrum, where each autistic person has a unique set of characteristics. In 2022, about 1 in 31 eight-year-old children were diagnosed with autism, according to a sampling study done by the Centers for Disease Control and Prevention (CDC).[4] Recent studies have shown that the number of adults and children diagnosed with autism has increased by about 10–20% each year due to a variety of factors, including greater awareness of autism signs in women and girls; expanded access to diagnostic services for historically underrepresented minority communities; and screenings recommended in medical manuals such as DSM-5, which have broadened diagnostic criteria.[5] Increased diagnosis rates are also due to successful public health programs that have increased screenings at wellness visits for young children and raised awareness of signs of autism among parents and caregivers.[6]

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Autistic people can lead incredibly fulfilling, safe, and rich lives. Especially with the introduction of the internet and accessible text-based communication, people who are autistic have developed strong communities that have bolstered self-advocacy movements to remove stigmas around autism and champion neurodiversity.[7] Self-advocates argue that autistic people do not need to be cured or fixed, they need to be supported. Government acts such as the Individuals with Disabilities Education Act and the Americans with Disabilities Act have enshrined the right to education and necessary workplace accommodations.[8]

However, autistic people still face discrimination and encounter a "disability cliff" where access to necessary benefits and services are removed as they enter early adulthood.[9] These systemic barriers are responsible for increased poverty rates and lower rates of employment for young autistic adults compared to their peers.[10] Despite recent advances in services and societal understanding, people with autism can experience abuse and persecution.

Smartwatches and Applications for Autism

The widespread adoption of smartwatches has spurred research into using wearables to improve health outcomes for autistic people. Smartwatches are the most popular consumer wearable—approximately 33% of Americans use these devices to monitor health and fitness.[11] Recent studies incorporate smartwatch data to evaluate behavioral interventions and therapies for individuals who are autistic. However, research interventions for autism have a problematic history. They often focus on increasing the autistic individual's compliance rather than increasing their quality of life, with their caregivers determining whether or not they are successful. Advocacy groups argue that traditional applied behavioral analysis (ABA) methods for "treating" autism, such as shock therapies, forced conditioning, and excessive pharmaceutical prescriptions, have dehumanized and abused autistic individuals and restricted their bodily autonomy.[12] Advocates have also criticized modern ABA interventions as largely ineffective when compared to personalized occupational and physical therapy.[13]

In one caregiver-oriented study on wearables, researchers trained machine learning models on cardiovascular and motion data from autistic children to predict "aggressive" behavior within one minute of onset, offering caregivers early alerts with 84% accuracy.[14] Additional caregiver-focused applications include GPS tracking to notify guardians of potential safety risks and text notifications to prompt timely interventions.[15] Meanwhile, people who are autistic can use helpful smartwatch features such as text-to-speech conversion, notifications for daily routines, and vital sign monitoring for self-regulation and autonomy.[16]

Smartwatch-assisted autism screening is a key element of HHS Secretary Kennedy's plan, but in comparison with therapies and interventions, research is far more limited. Sensors in wearables, such as accelerometers and gyroscopes, can detect stereotypical motor movements like hand flapping which can be used to inform screening decisions.[17] However, research in using smartwatches for behavioral and diagnostic interventions is limited by small sample sizes, uncontrolled test environments, and a lack of longitudinal studies.[18] Smartwatch haptic feedback can also be overstimulating for autistic people, especially when they are used without the individual's consent.[19]

Health data collected through smartwatches are not explicitly subject to federal medical privacy legislation, such as the Health Insurance Portability and Accountability Act Privacy Rule (HIPAA), which governs individual health privacy in the United States. HIPAA covers Protected Health Information (PHI) and applies only to health plans, clearinghouses, healthcare providers, or their associates that transmit PHI.[20] Without explicit federal requirements, **smartwatch companies can legally sell health data to third parties without users' consent.**[21] Smartwatch companies' complex, ambiguous, and jargon-filled data collection and sharing policies are intentionally opaque and do not adequately inform users of data breaches.[22]

Government Health Data Platforms

In its pilot program announcement, HHS states that the CMS and NIH will establish a data use agreement (DUA) under the CMS Research Data Disclosure Program, focused on Medicare and Medicaid enrollees.[23] Currently, CMS establishes DUAs with researchers, contractors, and government agencies with proper authorization to facilitate research partnerships and external access for health data. DUAs for the pilot program could allow outside contractors and vendors to access and store claims information to analyze long-term trends and connect the claims to other data sources such as wearable data. These agreements have different tiers of data disclosures and privacy protections. Files with the highest level of disclosure—Identifiable Data Files—contain personally identifiable information (PII).

Without explicit federal requirements, smartwatch companies can legally sell health data to third parties without users' consent.

These files may also contain protected health information (PHI) such as treatments and health history.[24] Any PHI and PII data CMS shares through a DUA is subject to HIPAA and the Privacy Act of 1974's regulations. The proposed DUAs fall under the established protocols for how government agencies share data, but recent actions by the current administration have exceeded those standards and triggered lawsuits. In July 2025, CMS reportedly established a DUA with US Immigration and Customs Enforcement (ICE), handing over PII data such as the names, ethnicities, addresses, and Social Security numbers of over 79 million Medicaid enrollees in order to help identify undocumented immigrants.[25] A coalition of 20 states has filed a lawsuit against HHS and DHS to prevent the further transfer of Medicaid data to any federal agency for "immigration enforcement" and "population surveillance" purposes. The coalition claims that CMS's broad transfer of sensitive data to ICE, without providing notice to state agencies or affected individuals, violates HIPAA and the Privacy Act of 1974. A federal judge issued a temporary injunction ordering HHS to stop sharing Medicaid data with ICE.[26]

What does this mean for the proposed autism data sharing and collection program? The NIH—the agency on the receiving end of the proposed DUA—already maintains a centralized, cloud database which links data between wearables, electronic health records, surveys, and other sources for its All of Us research program. The database is publicly available to researchers to study precision-medicine based approaches for a variety of disorders. The program's leadership committees include community-based disability organizations as partners to oversee the program's design, implementation, and governance.[27]

The NIH has a continuous consent and information sharing process with participants, who can fully access their collected data and educational materials. PII data is not shared publicly with researchers in the All of Us Program, and the NIH has instituted governance mechanisms to prevent unauthorized data re-identification and breaches. Similar to the CMS data sharing protocols, the NIH has a tiered access system for sharing PII and PHI data with government agencies.[28] The public access tier only includes aggregate statistics, which do not reveal any individual-level PII. The mid-level tier contains individual-level information where fields such as date of birth, zip code, and race are hidden or transformed.[29] Unlike the proposed NIH program, the All of Us program does not include insurance claims data. Additionally, under the E-Government Act of 2002, federal agencies are required to publicly release Privacy Impact Assessments (PIA)—analyses of how PII is collected, stored, protected, shared, and managed for any information technology system. If they proceed with the pilot, the NIH should emulate the All of Us model and conduct regular PIAs.

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ANALYSIS

A centralized data platform linking individualized wearable data with broad, nationwide health trends could empower researchers to break down data silos and uncover new insights to assist the autistic community. However, the lack of ethical and longitudinal smartwatch research, unprecedented federal protected data sharing policies, and the current administration's prioritization of misinformation around autism erasure will harm autistic individuals instead of helping them.

Smartwatch Privacy Gaps

While smartwatches can help autistic individuals track important vitals and manage their daily life, centralized databases of wearable data have inherent security and privacy risks that could harm them. In 2021, a database containing 61 million PII records of Fitbit and Apple wearable users was found to be unsecured and vulnerable to hackers selling information on the dark web. Although federal databases must adhere to privacy protections such as HIPAA, there are no uniform privacy standards for wearables.[30]

Smartwatch companies also sell data to data brokers who create detailed profiles of users for advertisers, insurance agencies, and pharmaceutical companies. In a 2023 study, Duke researchers discovered multiple data brokers willing to sell highly sensitive mental health diagnosis data without restrictions on its use, verification of buyers, or consumer privacy protections.[31] Without a comprehensive federal privacy law, companies can use smartwatch data bought from brokers to target individuals. On June 30, 2025, HHS announced a partnership to share patient data with sixty companies, including wearable makers and insurance companies. The new proposal would bypass data brokers, but the patchwork set of privacy regulations is confusing for users, who must rely on businesses to inform them of the secondary use of their data.[32] Studies have also shown that even de-identified wearable activity data can be re-identified using simple machine learning methods and demographic datasets.[33] **Establishing an expanded wearable and health records data sharing platform with only vague privacy protections places autistic people at risk of surveillance and targeting by the government and companies without their consent.**

Erasure, Misinformation, and Surveillance Harms

Smartwatch and health records used for targeting and surveillance can be particularly dangerous given the current administration's research goal of "curing" autism (or erasure), which contradicts modern scientific understanding of autism. Secretary Kennedy has spread misinformation linking vaccines and environmental toxins to autism and has advanced dangerous rhetoric that autistic individuals tear families apart since they can "never hold a job...never write a poem."

Autistic people have advocated to end such discriminatory language and for policies to recognize the “inherent collective strength in neurodiversity” as a valuable facet of society.[34] Many people who are autistic view their neurodivergence not as a defect, but as arising from the interaction between neurodiverse individuals and an unaccommodating environment.[35] Scientific experts agree that autistic individuals should be permitted bodily autonomy, and efforts to cure them should be discouraged.[36]

However, much early intervention research—especially involving smartwatches—does not center autistic perspectives and aims to reduce certain behaviors without providing children with sufficient coping mechanisms.[37] Congress’s slashing of Medicaid funding, HHS’s removal of programs supporting the independence of people with disabilities, and CMS’s violation of HIPAA and Privacy Act statutes in working with ICE to conduct surveillance have fostered deep distrust and anger within the autism community who fear that similar tactics will be used to target them.[38] The research directive of erasure and unprecedented trampling of health privacy standards are akin to eugenic thinking and the dehumanization of autistic individuals.

RECOMMENDATIONS

U.S. Department of Health and Human Services

Clear and informative data policies

- Develop data privacy policies which explicitly state how and what patient data is collected, used, stored, and shared.
- Write policies in plain, concise, and accessible language and supplement with engaging formats like videos or infographics to enhance user understanding.[39]
- Implement a tiered data access system and prohibit sharing of PII in DUAs.

Explicit consent for data collection and sharing

- Explicitly ask users of any digital services if they consent to data collection, and prohibit collection if users do not provide consent.
- Implement processes for users to easily modify their data collection preferences at any moment and remove any of their data which has been collected. Ensure that users who do not provide consent for data collection are not discriminated against.
- Conduct regular privacy impact assessments to evaluate PII consent and collection processes, privacy safeguards, and DUAs and other data sharing procedures. PIAs should also outline any data breaches and actions taken to notify affected individuals and to fix the root cause of the breach.[40]

Combat misinformation and language of erasure

- Use affirming language that recognizes the inherent humanity and lived experiences of autistic people in all public and internal communication.
- Cease promulgating debunked lies about the causes of autism and calls for “ending” autism.

Legislators

Health data privacy legislation

- Pass comprehensive consumer health data privacy laws at the state and federal levels which would
    - require businesses to obtain explicit consent for any data collection and sharing
    - prohibit the sale of health data without user authorization
    - provide users with the right to delete their health data
    - prohibit the use of spatial data to locate a consumer.[41]
- Policymakers should develop regulations to restrict the sharing of activity data by device manufacturers.[42]

Prohibit DUAs with law enforcement agencies

- States should not participate in CMS’s DUA agreements to share broad datasets of sensitive health information with law enforcement groups.

Establishing an expanded wearable and health records data sharing platform with only vague privacy protections places autistic people at risk of surveillance and targeting by the government and companies without their consent.

Researchers

Collaborate throughout design process

- Program administrators should include autistic individuals and advocates on executive and steering boards to define research goals and provide input on research processes.
- Include therapies and services which improve effective communication, daily living skills, self-determination and self-advocacy, and other goals that are important to the autistic person for improving quality of life and addressing lifelong needs.[43]
- Conduct longitudinal studies, situated in real-world scenarios, which must include significant and diverse samples of participants.

Conduct Neuro-diverse informed research

- Adopt a balanced view of neurodiversity, recognizing that diversity is important for offering multiple perspectives and that neurological differences can be advantageous or disadvantageous depending on the environment and the individual.
- Include the expertise of autistic adults to inform early intervention and child-focused research, and researchers must not have goals of “curing” and “normalizing” autistic people.

Avoid disproven theories and surveillance

- Steer clear of revisiting disproven theories, such as that vaccines or environmental toxins cause autism.
- Do not create tracking and surveillance tools, other than for the purpose of enabling authorized caregivers to find their loved ones in emergency situations.

Smartwatch Companies

Participatory co-design

Understand that autistic individuals may not need or want to use wearables. Smartwatch designers must engage in participatory co-design of any smartwatches with autistic individuals but also recognize that there is no one-size-fits-all solution. Design considerations should include:

- flexible materials
- accessible language and instructions
- comfortable haptic feedback

Affordability

Companies must establish programs to make devices affordable and accessible for users from various backgrounds.

Explicit consent for data collection and sharing

- Explicitly ask smartwatch users for their consent to all aspects of data collection and sharing. Users should be able to opt out at any moment and remove any data that has been previously collected. Consent must be provided when collection and sharing policies are modified.
- Do not share activity data, even partially aggregated or de-identified data, with individuals’ employers, advertisers, health care organizations, or other third parties without explicit consent.[44]

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