



**COMMENTS OF THE
ELECTRONIC FRONTIER FOUNDATION
REGARDING SYSTEM OF RECORDS NOTICES 09-90-2001, 09-90-2002**

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85 Fed. Reg. 43243 (July 16, 2020)

85 Fed. Reg. 43859 (July 20, 2020)

Submitted on August 17, 2020 to the Department of Health and Human Services

The Electronic Frontier Foundation (EFF) submits the following comments to the U.S. Department of Health and Human Services (HHS) in response to two System of Records Notices (SORNs) concerning government processing of personal information to address disease surveillance and COVID-19. *See* Notice No. 09-90-2002 (July 16, 2020); Notice No. 09-90-2001 (July 20, 2020).

EFF is a member-supported, nonprofit, public interest organization dedicated to protecting privacy, civil liberties and innovation in the digital age. Founded in 1990, EFF represents the interests of tens of thousands of dues-paying members and the public in both court cases and broader policy debates surrounding the application of law in the digital age. EFF is particularly concerned with protecting privacy at a time when technological advances have resulted in increased surveillance by the government and actively encourages and challenges government and the courts to support privacy and safeguard individual autonomy as emerging technologies become prevalent in society.

I. INTRODUCTION

The two proposed new HHS Systems of Records pose a grave threat to the data privacy of all Americans. They greatly expand how the federal government collects, uses, and shares all manner of personal information and clearly violate the Privacy Act's strict mandates of accountability, transparency, and privacy. *See generally* 5 U.S.C. § 552a. The SORNs are overly vague in describing the categories of data collected, the data sources, and the proposed routine uses of the data.¹ As such, the SORNs fail to explain to Americans just what data will be collected on them, how that data will be used, and with whom it will be shared.

No doubt, the ongoing COVID-19 crisis requires a coordinated governmental response, which in turn requires robust data concerning the spread of the disease. But HHS has

¹The SORN for 09-90-2002, "COVID-19 Insights Collaboration Records," states that it is a System of Records but that it need not honor subject individuals' rights to access, amendment, or notification because "HHS does not plan to retrieve records by personal identifier when using the resulting database for research ... or other public health activities." Given that HHS expects to retrieve records by identifier while it is creating and maintaining the database, these Privacy Act rights must apply for so long as HHS may retrieve records by personal identifier.

made no showing that the federal government's existing epidemiological data systems, long operated by the U.S. Centers for Disease Control and Prevention (CDC), are not up to the task.

The following forms of HHS data processing, proposed in the SORNs, would substantially burden privacy, yet be neither necessary nor proportionate to actually protecting public health:

- ***New data collection.*** The SORNs would allow collection of personal information about physical and psychological health history, drug and alcohol use, diet, employment, and more. Data collected would also include “geospatial records,” which countless research has shown is impossible to de-identify. Data would be collected not just about people who test positive, but also about their family members, as well as people who test negative, and perhaps people who have not tested at all. Data would be collected from countless different sources, including federal, state, and local governments, their contractors, the healthcare industry, and patients' family members.
- ***New data sharing.*** The SORNs would allow sharing of these vast sets of data with additional federal agencies, unspecified outside contractors, and even “student volunteers.” These additional federal agencies would be allowed, in turn, to share the data with their contractors. Patient consent would not be required for this sharing.
- ***New data use.*** The SORNs would allow use of this data in litigation and “other proceedings” whenever the United States Government has “an interest” in them (such use now is allowed only when HHS is a defendant in litigation).
- ***New data storing.*** The SORNs would allow permanent retention of data with “significant historical and/or research value” (retention now is limited to four years).

Accordingly, EFF respectfully requests that HHS withdraw these two SORNs. They violate the strict mandates of the Privacy Act and create new threats to privacy without any showing of public health benefit. To address COVID-19, HHS should not collect, use, share, or store personal information that the CDC did not process to address earlier public health crises, unless HHS can show, on a case-by-case basis, that particular types of new data processing will advance public health and comply with the Privacy Act, and not unduly burden civil liberties. HHS has not done so.

II. BACKGROUND

A. The CDC's Historical Management of Epidemiology Data

The CDC, an operating component of the HHS, has been actively involved in monitoring the spread of infectious diseases in the United States for nearly 80 years and is home to thousands of infectious disease experts who have extensive experience tracking epidemics like Zika, Ebola, and SARS.² For decades, hospitals across the United States have reported data to the CDC via its National Healthcare Safety Network (NHSN),³ a “complex patient safety and quality improvement system, backed by a team of public health physicians, epidemiologists, infection prevention and control professionals, and other data experts.”⁴ And because this reporting system was well-established and already in use by more than 25,000 medical facilities,⁵ beginning in March 2020, hospitals used this same system to report specific data on COVID-19 related hospitalizations.⁶

B. The Proposed HHS Management of Epidemiology Data

However, in July 2020, in the midst of a global pandemic and huge spikes in the numbers of COVID-19 cases across the United States, HHS effectively stripped CDC of authority from tracking all but the barest minimum of COVID cases.⁷ On July 10, HHS sent a notice to hospitals directing them to stop reporting COVID-19 hospitalization data to CDC's NHSN site, effective almost immediately, and to instead report data directly to HHS via a new system called HHS Protect.⁸ Later in July, HHS declared it was creating two vast new databases to track data related to COVID, including sensitive and personal data on both those who test positive for the virus and those who don't. At least one of these databases is explicitly intended to replace CDC's long-standing database tied to disease surveillance.

² *History of CDC Surveillance Activities, Morbidity and Mortality Weekly Report*, CDC.gov, March 01, 1990 / 39(SS-1) iii-iv, <https://www.cdc.gov/mmwr/preview/mmwrhtml/00001595.htm>; <https://www.washingtonpost.com/outlook/2020/07/14/cdc-directors-trump-politics/>.

³ <https://www.cdc.gov/nhsn/about-nhsn/index.html>.

⁴ <https://int.nyt.com/data/documenttools/letter-from-the-hicpac/8d2c6f35818c9599/full.pdf>; <https://www.nytimes.com/2020/08/12/world/coronavirus-covid-19.html>.

⁵ <https://www.cdc.gov/nhsn/about-nhsn/index.html>.

⁶ <https://www.cms.gov/files/document/32920-hospital-letter-vice-president-pence.pdf> (noting hospitals were required to report data on hospitalizations each day to NHSN's COVID Patient Impact and Hospital Capacity Module, starting on March 27, 2020); *see also* <https://www.npr.org/sections/health-shots/2020/07/31/897429054/covid-19-hospital-data-system-that-bypasses-cdc-plagued-by-delays-inaccuracies>.

⁷ <https://www.nytimes.com/2020/07/14/us/politics/trump-cdc-coronavirus.html>.

⁸ *COVID-19 Guidance for Hospital Reporting and FAQs for Hospitals, Hospital Laboratory, and Acute Care Facility Data Reporting*, HHS.gov (July 10, 2020), www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf.

On July 16th and July 20th, HHS issued two new System of Records Notices related to COVID data tracking. The July 20th Notice, 09-90-2001, describes a “new department-wide system of records” called “Records Used for Surveillance and Study of Epidemics, Preventable Diseases and Problems” (hereinafter “2001 Surveillance SORN”). This new system is intended to replace CDC’s “Epidemic Investigation Case Records” system and, according to HHS, will be much broader than that system. Among other changes, it expands the data collected under CDC’s system, includes data collected by other HHS components, allows for sharing with third party contractors, and allows data to be disclosed to the Department of Justice and used in litigation when the U.S. government “has an interest in the proceedings.”⁹

The July 16th Notice, 09-90-2002, creates a new database called “COVID-19 Insights Collaboration Records,” (hereinafter “2002 Insights SORN”), which HHS says it will use “to understand, track, and respond to the novel coronavirus.”¹⁰ It, too, will contain significant additional and highly personal data on COVID-19 patients, including psychological records, occupational data, and information on drug and alcohol use. It will collect data on patients’ family members as well as on people who do not test positive for the virus (and perhaps even people who have not tested for the virus at all). This system will also allow for the collection of locational data as well as additional personal data from private companies.¹¹ And, like the 2001 Surveillance SORN, the 2002 Insights SORN proposes a vast expansion of data sharing, including with contractors, other federal agencies, “student volunteers,” the courts, and the Department of Justice.

HHS has said it created HHS Protect to centralize COVID-19 data collection across the many government and private sector actors involved in controlling the pandemic.¹² The two new SORNs appear to be part of a similar effort to consolidate collection and increase the sharing of COVID-related data. However, as nearly three dozen past and current members of a federal advisory committee that provides guidance to HHS and CDC on strategies for infection prevention and control noted, this “abrupt change” in

⁹ <https://www.federalregister.gov/documents/2020/07/20/2020-15564/privacy-act-of-1974-system-of-records>.

¹⁰ <https://www.federalregister.gov/documents/2020/07/16/2020-15380/privacy-act-of-1974-system-of-records>.

¹¹ Blake Dodge, *The US teamed up with Palantir on a secretive project to analyze coronavirus data. Now, they want to gather personal health information, too*, Business Insider (May 7, 2020), <https://www.businessinsider.com/hhsprotect-palantir-healthcare-data-coronavirus-trump-2020-5> (noting that the federal government plans to collect personal information through HHS Protect, and “efforts are underway to collect it from private companies as well,” including 15 data-use agreements with private firms).

¹² *HHS Protect: Frequently Asked Questions*, HHS.gov (July 20, 2020), <https://www.hhs.gov/about/news/2020/07/20/hhs-protect-frequently-asked-questions.html> (The HHS Protect FAQ site describes the system as a “secure platform for authentication, amalgamation, and sharing of healthcare information, so that the U.S. government can harness the full power of data for the COVID-19 response.”).

COVID-19 reporting “will have serious consequences on data integrity.”¹³ It will make it “even more challenging to perform meaningful inter-state comparisons, and to understand which COVID-19 mitigation strategies were successful (or failed).”¹⁴

So far, these predictions appear to have borne out. Many states have “reported that the change in hospitalization reporting requirements have caused disruptions or challenges in their public hospitalization data reporting.”¹⁵ And the data reported by HHS has differed significantly from states’ own COVID case reporting; in some cases, HHS “has reported far more hospitalized patients than the state does, and in others, the two sets of data rise and fall at different rates.”¹⁶

These problems provide little comfort that HHS’s proposed new Systems of Records will fare any differently, and in fact they argue strongly against taking disease tracking away from CDC and creating two entirely new, unproven databases in the midst of a global pandemic. Given the SORNs’ descriptions of these new databases, it appears the American public has even more to lose if these new Systems fail to live up to HHS’s promises. Not only do they appear to contain significantly more, and significantly more sensitive and private information on Americans, they allow for third-party sharing on a scale that was not allowed with CDC’s systems.

C. COVID-19 Data Collection

In response to the COVID-19 pandemic, the federal government has been collecting significant amounts of data. Under the CARES Act and subsequent HHS guidance,¹⁷ clinics testing for COVID-19 must collect and report to the CDC and HHS a patient’s age, race, ethnicity, sex, zip code, county, and test results.¹⁸ HHS also encourages the collection of information about past health conditions, employment, and pregnancy status. HHS says that personal identifying information, including name, address, and date of birth, should be collected and reported to state and local health authorities, depending on the relevant state and local privacy standards.¹⁹

¹³ <https://www.nytimes.com/2020/08/12/world/coronavirus-covid-19.html>; *see also* <https://int.nyt.com/data/documenttools/letter-from-the-hiepac/8d2c6f35818c9599/full.pdf>

¹⁴ *Id.*

¹⁵ <https://covidtracking.com/blog/hospitalization-data-reported-by-the-hhs-vs-the-states-jumps-drops-and-other>.

¹⁶ *Id.*

¹⁷ *COVID-19 Guidance for Hospital Reporting and FAQs For Hospitals, Hospital Laboratory, and Acute Care Facility Data Reporting*, HHS.gov (Jul. 10, 2020), at 3-10, <https://www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf>.

¹⁸ *COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115*, HHS.gov (Jun. 4, 2020), <https://www.hhs.gov/sites/default/files/covid-19-laboratory-data-reporting-guidance.pdf>.

¹⁹ *Id.* Hospitals can report this data in one of several ways, according to the FAQs: They can publish data to their website in a standardized format; they can ask their health IT vendor or other third party to share

Additionally, HHS Protect allows for access to more than 200 disparate data sources, including data from federal, state, and local governments and the healthcare industry.²⁰ These datasets include information on COVID-19 case counts, hospital capacity, supply chain data, census statistics, testing data, emergency department data, and de-identified data from electronic health records.²¹ In a letter to HHS Secretary Alex Azar, a group of Senators and Congressmembers expressed concern over the vast data collection.²² The authors noted that in addition to HHS Protect, the CDC has been using location data from smartphone apps to track the movements of Americans in order to understand the spread of COVID-19.²³ The data is purportedly stripped of identifying information; however, it is nearly impossible to truly anonymize this type of location information.²⁴ An HHS spokesperson told Business Insider that “efforts are underway to collect [personal information] from private companies as well,” and that HHS has 15 data-use agreements with private firms.²⁵

The SORNs do not clarify what, if any, of the data described above will be incorporated into the new Surveillance and Insights databases.

D. Contractors

HHS has been sharply criticized for outsourcing data collection and tracking to a host of private contractors, and both the 2001 Surveillance SORN and the 2002 Insights SORN expressly allow data sharing with “HHS contractors, consultants, agents, or others.”

information directly with HHS; or they can submit data through the HHS Protect TeleTracking portal. <https://www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf>.

²⁰ <https://www.hhs.gov/about/news/2020/07/20/hhs-protect-frequently-asked-questions.html>.

²¹ Dave Nyczepir, *Inside the HHS system informing White House coronavirus decisions*, fedcoop (Apr. 21, 2020), <https://www.fedcoop.com/hhs-system-white-house-coronavirus-response-jose-arrieta/>; <https://www.hhs.gov/sites/default/files/covid-19-laboratory-data-reporting-guidance.pdf>.

²² *Letter to HHS from Democratic senators and members of Congress on HHS Protect Now incentive*, Washington Post (Jul. 1, 2020), https://www.washingtonpost.com/context/context-card/e33ec35b-9455-4da1-a035-815d195fb65c/?itid=lk_inline_manual_5; <https://www.warren.senate.gov/imo/media/doc/2020.06.30%20Letter%20to%20HHS%20on%20COVID-19%20data%20privacy.pdf>.

²³ *Id.*; Byron Tau, *Government Tracking How People Move Around in Coronavirus Pandemic*, Wall Street Journal (March 28, 2020), <https://www.wsj.com/articles/government-tracking-how-people-move-around-in-coronavirus-pandemic-11585393202>.

²⁴ Stuart A. Thompson and Charlie Warzel, *Twelve Million Phones, One Dataset, Zero Privacy*, New York Times (December 19, 2019), <https://www.nytimes.com/interactive/2019/12/19/opinion/location-tracking-cell-phone.html>.

²⁵ Blake Dodge, *The US teamed up with Palantir on a secretive project to analyze coronavirus data. Now, they want to gather personal health information, too*, Business Insider (May 7, 2020), <https://www.businessinsider.com/hhs-protect-palantir-healthcare-data-coronavirus-trump-2020-5>.

According to a letter from members of the Congressional Hispanic Caucus, HHS is working with at least six technology companies in the development and operation of HHS Protect, including Oracle, Amazon, and Palantir Technologies, Inc. (Palantir).²⁶ In April, HHS awarded two contracts, worth a total of nearly \$25 million, to Palantir for HHS Protect. According to reporting, Palantir’s technology will “pull[] data from across the federal government, state and local governments, healthcare facilities, and colleges, to help administration officials determine how to ‘mitigate and prevent spread’ of the coronavirus.”²⁷

HHS also awarded a multi-million dollar contract to collect COVID-19 hospital data to another company, TeleTracking Technologies, and in July, with little more than a few days’ notice, required all hospitals to stop reporting this data to CDC and instead report it to TeleTracking.²⁸ According to a letter from Rep. James Clyburn and the Select Subcommittee on the Coronavirus Crisis to TeleTracking’s CEO, “[f]ollowing this decision, CDC abruptly removed previously collected hospitalization data—which has been relied upon by public health experts, reporters, and the public to determine which states are running out of hospital capacity—from the agency’s website, restoring it after a public outcry.”²⁹ TeleTracking creates software for hospitals to track patient status, but, other than a few small contracts with the Department of Veteran’s Affairs, the company does not have much of a track record with the federal government. As Rep. Clyburn noted in his letter, this new contract with HHS “is nearly twenty times larger than all of your previous federal contracts combined.”³⁰

HHS has released little information about any of these contracts.³¹

III. NEITHER SORN COMPLIES WITH THE PRIVACY ACT

A. The 2001 Surveillance SORN and HHS’s Plans to replace CDC’s “Epidemic Investigation Case Records” System

HHS’s 2001 Surveillance SORN proposes to rescind CDC’s Epidemic Investigation Case Records system and replace it with a much broader, department-wide database. CDC

²⁶<https://chc.house.gov/sites/congressionalhispaniccaucus.house.gov/files/6.25.20%20Letter%20CHC%20to%20HHS%20re%20HHS%20Protect%20FINAL.pdf>.

²⁷ Erin Banco and Spencer Ackerman, *Team Trump Turns to Peter Thiel’s Palantir to Track Virus*, The Daily Beast (April 21, 2020), <https://www.thedailybeast.com/trump-administration-turns-to-peter-thiels-palantir-to-track-coronavirus>.

²⁸ <https://www.npr.org/2020/07/29/896645314/irregularities-in-covid-reporting-contract-award-process-raises-new-questions>.

²⁹ https://coronavirus.house.gov/sites/democrats.coronavirus.house.gov/files/2020-07-28.Clyburn%20to%20Zamagias%20re%20TeleTracking_.pdf.

³⁰ *Id.*

³¹<https://chc.house.gov/sites/congressionalhispaniccaucus.house.gov/files/6.25.20%20Letter%20CHC%20to%20HHS%20re%20HHS%20Protect%20FINAL.pdf>.

established its Epidemic Investigation Case Records system in 1986 as a means by which professional staff at CDC could collect and review data to help them better understand diseases that have “public health significance.”³² The system collected data such as medical histories and case reports on “adults and children with disease and other health conditions . . . , their contacts, [and] others with possible exposure and appropriate controls.”³³

HHS’s proposed new system not only expands the categories of data collected far beyond those listed in the original CDC SORN, it expands the categories of individuals from whom that data is collected and entities with whom the data may be shared. For example, while CDC Epidemic Investigation Case Records were kept internal to Department staff, HHS states the records in its new disease surveillance database will be available to unspecified outside contractors, consultants, and “student volunteers.” They will also be available to other federal agencies outside of HHS. And, while under the previous SORN, CDC was allowed to disclose records to the courts and the Department of Justice only when it or its employees were *defendants* to litigation, “provided that such disclosure is compatible with the purpose for which the records were collected,”³⁴ HHS now claims it may disclose records when HHS or its components or one of its employees or even the U.S. Government, merely “*has an interest in the proceedings.*” Further, these records may be used outside of the courts in “other proceedings” before other “adjudicative bod[ies].”³⁵

The 2001 Surveillance SORN fails to meet the mandates of the Privacy Act because it impermissibly expands the Routine Uses to include disclosure to contractors, other federal agencies, and other third parties without an individual’s prior written consent.

B. The 2002 Insights System Will Collect Sensitive and Private Data on Patients, Will Share that Data with Contractors and Other Third Parties, and Will Retain that Data Forever.

With the 2002 Insights SORN, HHS announced it is creating a new database to “understand, track, and respond” to COVID-19. According to the SORN, the purpose of the system of records is to create and maintain a single database for HHS to use for analysis, research, and other public health activities related to the study of COVID-19. An HHS press release announcing the COVID-19 Insights Partnership declared that the “[r]esearch and analysis conducted by the COVID-19 Insights Partnership will focus on vaccine and therapeutic development and outcomes, virology, and other critical scientific

³² <https://www.cdc.gov/SORNnotice/09-20-0113.htm>.

³³ *Id.*

³⁴ *Id.*

³⁵ <https://www.federalregister.gov/documents/2020/07/20/2020-15564/privacy-act-of-1974-system-of-records>.

topics to understand COVID-19 better.”³⁶ The Department of Energy (DOE) will create and maintain the database for HHS at DOE's Oak Ridge National Laboratory (ORNL).

Yet despite the Privacy Act's mandate that agencies only maintain information about individuals that is “relevant and necessary,” 5 U.S.C. § 552a(e), it appears that HHS will be collecting extremely sensitive records on patients without explaining why those records are necessary to track and respond to this pandemic. Further, the Privacy Act requires agencies to explain to individuals what records the agency is collecting. Yet, this SORN is so vague that, for most individuals, it is not clear whether or not their records would be included. For example, by describing individuals in the database as including “patients who have not tested positive” for COVID-19, the database could include patients who have not been tested at all.

The 2002 Insights SORN also leaves it to HHS's discretion to determine which records to include and from which sources, stating “[c]ustodians of the records that HHS, as a public health authority, determines are useful for COVID-19-related public health activities will donate data” to be included in the database. The SORN notes that this will include people seeking care from Veterans Administration and Department of Defense facilities, but “[o]ther sources of records may be added later,” and those sources may include “other federal, state, local or tribal agencies or private sector entities which those custodians donate to HHS.” This description, again, is impermissibly vague.

Not only are the potential sources for data broad, the data HHS plans to collect on patients is even broader. It includes:

- Patient identifying information (*e.g.*, name, address, date of birth, social security number, medical record number) and family information (*e.g.*, next of kin; family medical history information).
- Service information (*e.g.*, dates, branch and character of service, service number).
- Occupational and environmental exposure data.
- Medical and dental resources data.
- Sociological, diagnostic, counseling, rehabilitation, drug and alcohol, dietetic, medical, surgical, dental, psychological, and/or psychiatric information compiled by health care providers.
- Information pertaining to the individual's medical, surgical, psychiatric, dental, and/or psychological examination, evaluation, and/or treatment (*e.g.*, diagnostic, therapeutic special examinations; clinical laboratory, pathology and x-ray findings; operations; medications; allergies; consultations), including COVID-19 illness or antibody status.

³⁶ *DOE, HHS, VA Announce COVID-19 Insights Partnership*, HHS.gov (Jul. 28, 2020), <https://www.hhs.gov/about/news/2020/07/28/doe-hhs-va-announce-covid-19-insights-partnership.html>.

The new database will also include geospatial records, population density records, and “other types of existing records.” HHS claims these records are “not individually identifiable,” but it is well known that location data is almost impossible to de-identify, especially when it is combined with other descriptive information about individuals.³⁷

Once collected, this data may be shared, without the patient’s prior written consent, with third-party contractors, consultants, student volunteers, and other federal agencies. And those other federal agencies are free to “re-disclose” records to “contractors and others engaged by that agency” that are assisting the agency with creating or maintaining the database. The data may also be shared with the Department of Justice, the courts, and other adjudicative bodies if HHS or its employees or even the United States government “is a party to the proceeding or has an interest in the proceeding.” And finally, the records will be retained permanently.

The 2001 Surveillance SORN fails to meet the mandates of the Privacy Act because its descriptions of categories of individuals and data included in the System as well as sources for that data are impermissibly vague. It appears to include people who have never even been tested for COVID-19 at all and places no meaningful limits on the possible “private entity” sources for its data. This could result in even more sensitive information about individuals being included in the System without those individuals’ knowledge or understanding of where their data is going and with whom it is being shared.³⁸

HHS also has not shown that this vast expansion of data collection and data sharing are necessary to fight or even understand the COVID-19 pandemic. This is also inconsistent with the Privacy Act.

³⁷ Stuart A. Thompson and Charlie Warzel, *Twelve Million Phones, One Dataset, Zero Privacy*, New York Times (December 19, 2019), <https://www.nytimes.com/interactive/2019/12/19/opinion/location-tracking-cell-phone.html>.

³⁸ For example, could it include transcripts of text conversations from a consumer-facing, text-based therapy company like Talkspace? *See, e.g.*, Kashmir Hill & Aaron Krolik, *At Talkspace, Start-Up Culture Collides With Mental Health Concerns*, N.Y. Times (Aug 7, 2020) <https://www.nytimes.com/2020/08/07/technology/talkspace.html>.

IV. CONCLUSION

While some additional data collection and sharing may be necessary to track and stop a pandemic such as COVID-19, there must be limits. These two proposed new Systems move far beyond appropriate limits. Given the importance of containing the virus, we must ensure Americans understand and trust in the government's collection and use of their data; if not, they will not be willing to seek appropriate testing and treatment and will not provide accurate and complete information to their healthcare providers when they do. HHS should withdraw these two SORNs.

Respectfully submitted,

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Table Comparing Former CDC System with Proposed New HHS Systems

	CDC Epidemic Investigation Case Records 09-20-0113³⁹ (to be replaced by 09-90-2001)	HHS 2001 Surveillance SORN 09-90-2001	HHS 2002 Insights SORN 09-90-2002
Summary & Purpose	To provide professional staff at the CDC with more complete knowledge of the disease or condition.	To understand and respond to disease and health problems in the U.S.	To create a single database for analysis, research, and other public health activities related to the study of COVID-19.
Categories of individuals covered by the system	People who may have diseases and conditions of public health significance, their contacts, and others. Also, people in a “control group.”	People who may have diseases and conditions of public health significance, their contacts, and others. Also, people in a “control group.”	People who have and people who have not tested positive for COVID-19.
Data Sources	State and local health departments and possibly other sources.	Records come from individuals, family members, public health departments, private medical providers, labs, and contractors like HHS “call centers.”	Patient data will be “donated” by government agencies, public and private medical providers, and “private sector entities.”
Categories of Data Collected	Medical histories, case reports, and related documents.	Medical records and related documents, including: Case reports, lab requisition forms, patient consent forms, assurance statements, analytical testing data, questionnaires, and contact tracing reports.	Patient data, including the following: <ul style="list-style-type: none"> • Identifying information like name, address, DOB, SSN, etc. • Family information • Military service information. • Occupational and environmental exposure data. • Medical and dental data. • Sociological, diagnostic, counseling,

³⁹ <https://www.cdc.gov/SORNnotice/09-20-0113.htm>.

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			<p>rehabilitation, drug and alcohol, dietetic, medical, surgical, dental, psychological, and/or psychiatric information and treatment, x-rays, lab reports, etc.</p> <ul style="list-style-type: none"> • COVID-19 illness or antibody status. • Geospatial records
Data Retention	Generally four years.	Generally retained indefinitely.	Maintained permanently
Routine Uses (Data May be Disclosed to):		Records may be disclosed without the subject individual's prior written consent	Records may be disclosed without the subject individual's prior written consent, including to parties outside HHS.
Courts and the Department of Justice	Data may be disclosed in litigation to the courts and the Department of Justice but only where HHS or an HHS employee is the defendant to the litigation and disclosure is necessary for DOJ to provide an effective defense.	Data may be disclosed in litigation or “other proceedings” whenever HHS or an HHS employee or “the United States Government, is a party to the proceeding or has an interest in the proceeding.	Data may be disclosed in litigation or “other proceedings” whenever HHS or an HHS employee or “the United States Government, is a party to the proceeding or has an interest in the proceeding.
Contractors and other third parties	No	Data may be disclosed to HHS contractors, other federal agencies, student volunteers, etc.	Data may be disclosed to HHS contractors, other federal agencies, student volunteers, etc. and may be redisclosed by other federal agencies to contractors and others.
Government agencies and research entities for research purposes	No	Yes	No