
**OFFICE OF
THE INSPECTOR GENERAL**

SOCIAL SECURITY ADMINISTRATION

**COLLECTION, USE, AND DISCLOSURE
OF SOCIAL SECURITY NUMBERS
IN STATES' NEWBORN SCREENING PROGRAMS**

November 2011

A-08-11-11181

AUDIT REPORT



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- Review and make recommendations regarding existing and proposed legislation and regulations relating to agency programs and operations.**
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- Access to all information necessary for the reviews.**
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SOCIAL SECURITY

MEMORANDUM

Date: November 28, 2011

Refer To:

To: The Commissioner

From: Inspector General

Subject: Collection, Use, and Disclosure of Social Security Numbers in States' Newborn Screening Programs (A-08-11-11181)

OBJECTIVE

Our objective was to evaluate the collection, use, and disclosure of Social Security numbers (SSN) in States' newborn screening programs.

BACKGROUND

Each year, State Departments of Health (DoH) screen millions of newborns for disorders that require early detection and treatment to prevent serious illness or death. To assist in this process, many hospitals and birthing facilities collect mother and infant demographic information, including the mother's SSN, on the State's newborn screening form.¹ Although no single Federal law regulates overall use and disclosure of SSNs, the *Social Security Act*,² and the *Privacy Act of 1974*³ contain provisions that govern disclosure and use of SSNs. Additionally, the Administrative Simplification provisions in the *Health Insurance Portability and Accountability Act of 1996* (HIPAA) address the privacy and security of all ". . . individually identifiable health information, including SSNs."⁴ See Appendix B for more information on the specific provisions of these laws.

¹ Hospitals and birthing facilities may collect other data, such as the name of the hospital, physician, and insurance, on the newborn screening form. The hospital or birthing facility generally sends this form, along with the infant's blood sample, to a State laboratory for processing.

² *Social Security Act* § 205(c)(2)(C)(viii), 42 U.S.C. § 405(c)(2)(C)(viii).

³ Pub. L. No. 93-579, § 7, 88 Stat. 1896, 1909 (1974), 5 U.S.C. § 552a, note (Disclosure of Social Security Number).

⁴ Pub. L. No. 104-191, §§ 261–264, 110 Stat. 1936, 2021-2033 (1996), *Social Security Act* § 1171-1180. 42 U.S.C. §§ 1320d-1320d-9, 45 C.F.R. Parts 160 and 164.

To accomplish our objective, we reviewed relevant laws from all 50 States to determine whether SSN collection is legally mandated for their respective newborn screening programs. We contacted the States' DoHs to determine their use of SSNs or alternate identifiers in their newborn screening programs. We visited six DoHs and one hospital in each of these six States. For each DoH and hospital visited, we interviewed personnel and reviewed policies and procedures for the collection, use, and disclosure of SSNs in the newborn screening program. See Appendix C for additional details regarding the scope and methodology of our review.

RESULTS OF REVIEW

Our review of State DoHs' newborn screening programs disclosed that many routinely collected and used mothers' SSNs as identifiers, despite the continuing rise in identity theft. We believe such practices increase the risk of SSN misuse and unnecessarily subject mothers to the possibility of identity theft. Based on our previous audit and investigative work, we believe unnecessary collection and use of SSNs increase the potential for dishonest individuals to obtain these numbers and misuse them.

Our review also disclosed that privacy issues or identity theft concerns have led several DoHs to eliminate SSN collection and use in their newborn screening programs. One DoH eliminated SSN collection because of State law.⁵ Low compliance rates in providing SSNs, driven by concerns over privacy, led another DoH to eliminate the collection of mothers' SSNs in its newborn screening program. We applaud those State DoHs that have taken steps to eliminate SSN collection and use in their newborn screening programs.

While pending Federal legislation, if enacted, would change how such entities as DoHs collect and use SSNs,⁶ we believe it is necessary to highlight the continued over-reliance on the SSN and the inherent risks associated with such use. We recognize that the Social Security Administration (SSA) has conducted outreach efforts to educate such entities as State and local governments. We also believe SSA is well-positioned to encourage DoHs that use SSNs in their newborn screening programs to eliminate this practice and adopt alternate identifiers in their record systems.

⁵ NY Pub. Off. Law § 96-a (McKinney 2010).

⁶ H.R. 220, *Identity Theft Protection Act of 2011*, introduced January 7, 2011. This bill includes an amendment to the *Privacy Act of 1974* that prohibits any Federal, State, or local government agency or instrumentality from requesting an individual to disclose his/her SSN on either a mandatory or voluntary basis.

SSN COLLECTION AND USE IN STATE NEWBORN SCREENING PROGRAMS

Of the 50 DoHs contacted, 17 (34 percent) collected and used mothers' SSNs in their newborn screening programs.⁷ These DoHs stated that they collected and used mothers' SSNs in their program for a variety of purposes. For example, they generally used SSNs to associate infants with mothers and track infants' initial and subsequent screenings in the State's record repository. DoHs also collected mothers' SSNs for billing purposes, because insurance companies and healthcare facilities use SSNs as primary or secondary identifiers. Yet, one hospital we visited collected mothers' SSNs only because the State DoH newborn screening form had a space asking for the SSN.

According to these DoHs, they did not use the SSN as the *primary* identifier in their programs. Instead, these DoHs generally used the SSN in conjunction with other data elements, such as the names and dates of birth for mother and baby. Other identifiers used by DoHs included hospital name, patient number, or mother's address and telephone number. While these DoHs stated the SSN was not the primary identifier in their programs, several used SSNs as an identifier when healthcare providers accessed infants' screening results by telephone.

Some DoH officials told us they continued collecting SSNs because the number was important for identification. One DoH official stated that notification is crucial when screening results indicate an infant has a life-threatening disease. These DoHs also told us that, if the mother did not provide her SSN, they processed the infant's screening without the number. One official stated that the SSN is the best identifier because it is unique to an individual and will not change like other identifiers. Yet, we believe other unique identifiers can be used that will not put mothers at risk of identity theft.

POTENTIAL RISKS ASSOCIATED WITH SSN COLLECTION AND USE

Although none of the State DoHs or hospitals we contacted was aware of any SSN misuse in the newborn screening programs, one hospital had inadvertently disclosed mothers' SSNs. The official with whom we spoke told us that the hospital had mailed completed newborn screening forms containing SSNs to the wrong address. The DoH advised us that, because of HIPAA and State data breach notification laws, its newborn screening program notified the affected mothers.⁸

⁷ These State DoHs were in Alabama, California, Florida, Illinois, Kentucky, Louisiana, Maryland, Michigan, New Jersey, North Carolina, Oklahoma, Pennsylvania, South Carolina, Tennessee, Texas, Virginia, and West Virginia. Of these 17 State DoHs, Michigan and Pennsylvania officials told us that they only collect a partial SSN. In addition, California DoH stated they were in the process of revising their practice and plan to begin collecting only a partial SSN. Only South Carolina DoH stated that it collects mothers' SSNs in its newborn screening program because it is lawfully mandated. S.C. Code Regs. 61-80.

⁸ Pub. L. No. 104-191, Title II, § 262(a), 110 Stat. 1936, 2024, (1996), Social Security Act § 1173, 42 U.S.C. § 1320d-2; Cal. Civil Code § 1798.29 (2011).

Our prior audit work has highlighted risks associated with the collection and use of SSNs. In 2007, we reported that State and local governments' collection and use of SSNs contributed to instances in which some public documents containing SSNs were posted on the Internet.⁹ In 2006, we also reported on hospitals' collection and use of SSNs that contributed to individuals unlawfully using patients' SSNs and other identifying information to open credit card accounts and file fraudulent tax returns.¹⁰ These examples show that each time individuals disclose their SSNs, dishonest individuals are given an opportunity to obtain this personal information and use it to commit unlawful acts.

STEPS TAKEN TO LIMIT SSN COLLECTION AND USE

A recognition of current identity theft concerns and the critical role of the SSN as a personal identifier have led several DoHs to eliminate the use of SSNs in their newborn screening programs. In 2010, the State of New York enacted a law restricting the use of SSNs by its agencies.¹¹ As a result, the State's DoH issued a policy prohibiting the collection, use, or transmittal of SSNs in its newborn screening program. Because of the change in its process, the DoH excluded the SSN field on its form and began relying primarily on an accession number to match infants' screening results.

Identity theft awareness and privacy issues have also caused changes. For example, informed mothers do not always provide their SSNs for newborn screening. Because of the resulting low compliance, one DoH stopped requiring hospitals to collect mothers' SSNs for its newborn screening program. In addition, one hospital we visited did not collect or use SSNs for the newborn screening program, although the State DoH requested this information on its form.

As identity theft and privacy concerns have moved to the forefront, Federal agencies, such as SSA and the Internal Revenue Service, have reached out to organizations, such as educational institutions and government agencies, to encourage reduction of SSNs in their business processes.¹² SSA's Philadelphia Regional Office also has initiated a public information program on its Website¹³ to encourage businesses, government agencies, medical facilities, and educational institutions to protect SSNs by

⁹ SSA OIG, *State and Local Governments' Collection and Use of Social Security Numbers* (A-08-07-17086), September 10, 2007.

¹⁰ SSA OIG, *Hospitals' Use and Protection of Social Security Numbers* (A-08-06-16056), January 27, 2006.

¹¹ NY Pub. Off. Law § 96-a (McKinney 2010).

¹² SSA's Kansas City region has an initiative directed toward educational institutions; http://www.socialsecurity.gov/kc/id_ssn_ed.htm (last modified February 9, 2011). The Internal Revenue Service initiatives are at <http://www.irs.gov/privacy/article/0,,id=228444,00.html> (last updated December 20, 2010).

¹³ See SSA's Philadelphia region's initiative at <http://www.socialsecurity.gov/phila/ProtectingSSNs.htm> (last modified November 14, 2011).

using alternate identifiers in their record systems. While we believe these initiatives have increased awareness, we also realize it may take Federal legislation to compel some entities to reduce or limit SSN collection and use. Nonetheless, as the Agency that assigns SSNs, we believe SSA provides a valuable service to the numberholder, and inspires public trust, when it encourages others to take steps to reduce SSN collection and use. Accordingly, we encourage SSA to continue its outreach efforts.

CONCLUSION AND RECOMMENDATION

Despite the potential risks associated with using SSNs as identifiers, many State DoHs continue collecting mothers' SSNs in their newborn screening programs. We believe this practice increases the risk of SSN misuse and unnecessarily subjects mothers to the possibility of identity theft. While SSA cannot prohibit SSN collection and use, we believe it can take steps to enhance SSN integrity. Accordingly, we recommend that SSA encourage State DoHs to eliminate the collection and use of mothers' SSNs in their newborn screening programs.

AGENCY COMMENTS AND OIG RESPONSE

SSA agreed with our recommendation. See Appendix D for the Agency's comments.



Patrick P. O'Carroll, Jr.

Appendices

[APPENDIX A](#) – Acronyms

[APPENDIX B](#) – Federal Laws that Govern Disclosure and Use of the Social Security Number

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[APPENDIX D](#) – Agency Comments

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Appendix A

Acronyms

C.F.R.	Code of Federal Regulation
DoH	State Department of Health
HIPAA	<i>Health Insurance Portability and Accountability Act of 1996</i>
H.R.	House of Representatives
OIG	Office of the Inspector General
Pub. L. No.	Public Law Number
Regs.	Regulations
SSA	Social Security Administration
SSN	Social Security Number
Stat.	Statutes
U.S.C.	United States Code

Appendix B

Federal Laws that Govern Disclosure and Use of the Social Security Number

The following Federal laws establish a general framework for disclosing and using the Social Security number (SSN).

The Privacy Act of 1974

The *Privacy Act of 1974* indicates, in part, that it is unlawful for any Federal, State, or local government agency to deny any individual any right, benefit, or privilege provided by law because of such individual's refusal to disclose his/her SSN, unless the disclosure is required by Federal statute or is to any Federal, State, or local agency maintaining a system of records in existence and operating before January 1, 1975, such disclosure was required under statute or regulation adopted before such date to verify the identity of an individual.¹ Further, any Federal, State, or local government agency requesting that an individual disclose his/her SSN must inform the individual whether the disclosure is voluntary or mandatory, by what statutory or other authority the SSN is solicited and what uses will be made of the SSN.²

The Social Security Act

The *Social Security Act* provides, in part, that "Social security account numbers and related records that are obtained or maintained by authorized persons pursuant to any provision of law enacted on or after October 1, 1990, shall be confidential, and no authorized person shall disclose any such social security account number or related record."³ The *Social Security Act* also provides, in part, that ". . . [w]hoever discloses, uses, or compels the disclosure of the social security number of any person in violation of the laws of the United States; shall be guilty of a felony . . ."⁴ The *Social Security Act* authorized certain State and local agencies to use the SSN for certain purposes and allows, or in certain instances requires, such agencies to require individuals to furnish their SSNs for such purposes.⁵

¹ Pub. L. No. 93-579, § 7, 88 Stat. 1896, 1909 (1974), 5 U.S.C. § 552a, note (Disclosure of Social Security Number).

² *Id.*

³ *Social Security Act* § 205(c)(2)(C)(viii), 42 U.S.C. § 405(c)(2)(C)(viii).

⁴ *Social Security Act* § 208(a)(8), 42 U.S.C. § 408(a)(8).

⁵ *Social Security Act* § 205(c)(2)(C)(i), (ii), (v), (vi), (D), and (E); 42 U.S.C. § 405(c)(2)(C)(i), (ii), (v), (vi), (D), and (E).

The *Health Insurance Portability and Accountability Act of 1996 (HIPAA)*

HIPAA's Administrative Simplification provisions address the privacy and security of health data, including SSNs. HIPAA's Privacy Rule protects all "individually identifiable health information" held or transmitted by a covered healthcare entity or its business associate, in any form or media, whether electronic, paper, or oral. HIPAA's Security Rule specifies administrative, technical, and physical safeguards the covered healthcare entity must comply with to assure the confidentiality of electronic protected health information.⁶

⁶ Pub. L. No. 104-191, §§ 261–264, 110 Stat. 1936, 2021-2033 (1996), *Social Security Act* § 1171-1180. 42 U.S.C. §§ 1320d-1320d-9, 45 C.F.R. Parts 160 and 164.

Scope and Methodology

To accomplish our objective, we:

- Reviewed relevant Federal laws and regulations.
- Reviewed relevant laws from all 50 States to determine whether Social Security number (SSN) collection is legally mandated for the newborn screening program.
- Contacted all 50 State Departments of Health (DoH) to determine whether each collected or used mothers' SSNs in the newborn screening program.
- Visited six State DoHs and one area hospital near each DoH. For those sites visited, we interviewed DoH and hospital personnel regarding their collection, use, and disclosure of mothers' SSNs in the newborn screening program.
- The States visited were California, Colorado, Florida, North Carolina, New York, and Ohio. The hospitals visited were California Pacific Medical Center, Exemplia Saint Joseph, Tallahassee Memorial, Wake Med, Albany Medical Center, and Riverside Methodist.

Our review of internal controls was limited to gaining an understanding of State DoHs' collection, use, and disclosure of SSNs. The Social Security Administration entity reviewed was the Office of the Deputy Commissioner of Operations. We conducted our audit from February through August 2011 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objective. We believe the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objective.

Appendix D

Agency Comments



MEMORANDUM

Date: November 01, 2011 Refer To: S1J-3

To: Patrick P. O'Carroll, Jr.
Inspector General

From: Dean S. Landis /s/
Deputy Chief of Staff

Subject: Office of the Inspector General Draft Report, "Collection, Use, and Disclosure of Social Security Numbers in States' Newborn Screening Programs" (A-08-11-11181)--INFORMATION

Thank you for the opportunity to review the draft report. Please see our attached comment.

Please let me know if we can be of further assistance. You may direct staff inquiries to Frances Cord at (410) 966-5787.

Attachment

**COMMENTS ON THE OFFICE OF THE INSPECTOR GENERAL DRAFT REPORT,
“COLLECTION, USE, AND DISCLOSURE OF SOCIAL SECURITY NUMBERS IN
STATES’ NEWBORN SCREENING PROGRAMS” (A-08-11-11181)**

Recommendation 1

The Social Security Administration should encourage the States’ Departments of Health to eliminate the collection and use of mothers’ Social Security numbers in their newborn screening programs.

Response

We agree.

Appendix E

OIG Contacts and Staff Acknowledgments

OIG Contacts

Kimberly A. Byrd, Director, Atlanta Audit Division

Theresa Roberts, Audit Manager, Birmingham Office of Audit

Acknowledgments

In addition to those named above:

Kozette Todd, Senior Auditor

Josh Torres, Program Analyst

Chicago Audit Division

Dallas Audit Division

Financial Audit Division

New York Audit Division

San Francisco Audit Division

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