

The NLMS: Data Stewardship Policies at Work

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Abstract

The U.S. Census Bureau’s Data Stewardship Program provides the legal and ethical framework for maintaining confidentiality and respecting privacy. The Data Stewardship Program is centered on four Privacy Principles: Necessity, Respect, Openness, and Confidentiality. Data stewardship policies have been developed to support these principles and ensure that current practice is compatible with them.

The session describes the Census Bureau’s National Longitudinal Mortality Study (NLMS) and uses this database as a case study to demonstrate implementation of five data stewardship policies. This paper focuses on two of the data stewardship policies that relate to the NLMS – Reimbursable Project Acceptance and Controlling Non-employee Access to Title 13 Data. Both of these policies are critical components in the Census Bureau’s efforts to ensure respondent privacy and confidentiality.

Key Words: Data Stewardship, Confidentiality, Privacy, National Longitudinal Mortality Study, Title 13, Policies

1. Background on Data Stewardship

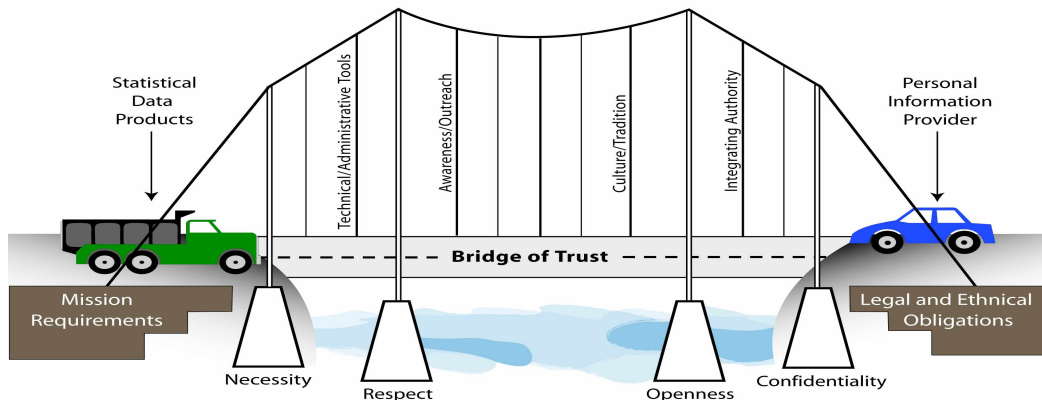
In 2001, the U.S. Census Bureau established a corporate Data Stewardship Program with high level executive support, to help balance the public need for statistical information and the legal and ethical obligation to respect individual privacy and protect data confidentiality. The Census Bureau felt that this

management approach to decision making would facilitate meeting core mission requirements to collect and publish high quality data about the Nation’s people and economy, while satisfying its mandates to protect the privacy and confidentiality rights of all Census Bureau respondents, customers, contractors, and employees.

The data stewardship framework is founded on the Census Bureau’s mission and draws on its strategic plan to form a basis for developing policies, controls, and practices. At its core is the Data Stewardship Executive Policy Committee (DSEP) – an executive focal point for decision making and communication on privacy, security, confidentiality, and administrative records policy issues. The DSEP is comprised of selected Associate Directors and chaired by the Deputy Director of the Census Bureau. It is staffed by the Office of Analysis and Executive Support; three staff committees – on privacy, confidentiality, and administrative records; and a series of task-specific teams that carry out research and develop policies with DSEP guidance.

How does the concept of data stewardship work? As illustrated in Figure 1, just as a bridge permits cars to pass safely from one side of the river to another, data stewardship closes what is often perceived as a gap between the Census Bureau’s mission requirements to collect and provide high quality data for public use and its legal and ethical responsibilities to respect privacy and ensure confidentiality. To provide support for data stewardship, the DSEP adopted a set of four Privacy Principles – Necessity, Respect, Openness, and Confidentiality.

Figure 1. Data Stewardship Bridge of Trust



and Confidentiality.¹ These principles align our mission with the components of data stewardship and assist us in achieving our goals by determining what information we will collect and how we will protect it – as well as its relationship with those who provide and use the information. Each principle has multiple subprinciples that further describe our legal and ethical commitments.

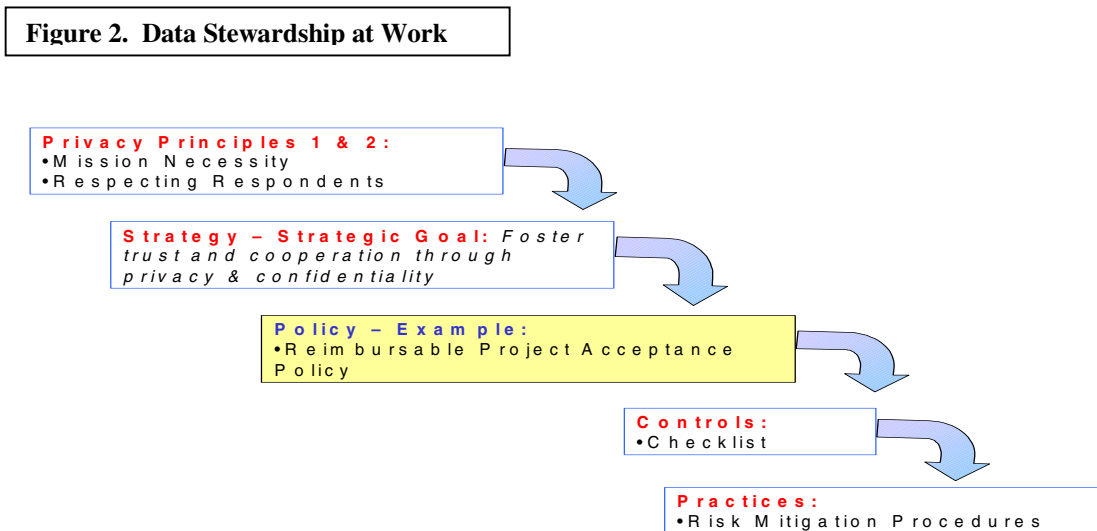
Furthermore, DSEP-approved policies and procedures, based on our mission and strategic goals, define the new controls and practices that must be followed to ensure that the Privacy Principles are met. These form the road of the “Bridge of Trust.” Supports developed to reinforce these components include technical and administrative tools; awareness and outreach efforts; our culture and tradition of confidentiality; and an integrating authority in the form of a Chief Privacy Office, which deals with privacy issues on a day-to-day basis.

Figure 2 demonstrates how this progression works for a specific policy. These policies work with the Privacy

1.1 What Does This Have to Do With the NLMS?

The NLMS is a Census Bureau database developed for the purpose of studying the effects of demographic and socio-economic characteristics on differentials in U.S. mortality rates.² The database consists of Census Bureau survey and census data from the Current Population Surveys (CPS), CPS’ Annual Social and Economic Supplements, and the 1980 Census combined with death certificate information from the National Center for Health Statistics, identifying mortality status, including cause of death. The database combines records for the same individuals over time, using record linkage techniques, to provide information on them from 1973 to the present.

For this session, we use the NLMS as a case study to illustrate how various data stewardship policies work. The NLMS is a particularly unique effort, because it draws on a number of the data stewardship policies to address Privacy Principle gaps. This paper will focus on two of the policies that apply – the Reimbursable Project Acceptance policy and the policy on



Principles to strengthen our cultural commitment to data stewardship.

Thus, we achieve our data stewardship goals by building the trust of our respondents and all those who depend on our data, including government agencies, businesses, and individual citizens.

Controlling Non-employee Access to Title 13 Data. Pat Melvin discusses three other policies that impact the NLMS – the Policy on Negotiating Collaborative Agreements, the Administrative Records Handbook, and the Record Linkage Policy.³

2. What Is the Reimbursable Project Acceptance Policy?

The Census Bureau has conducted work for other parties—chiefly federal agencies—for many years. This work is authorized either under Title 13, United States Code (U.S.C.), Section 8, or Title 15, U.S.C., Section 1525. Sometimes this work requires third-party approval, such as when using federal tax information or when applying government printing regulations. The largest component of reimbursable work is demographic surveys. Other work includes technical assistance to other nations and special data analyses.

The Census Bureau is uniquely qualified to meet many of the data collection, tabulation, and analysis needs of other federal agencies and some other organizations. In addition to its professional experience and skill, the statutorily-confidential decennial and economic census address lists are the basis for scientifically selecting representative samples for a survey. Further, the Census Bureau provides an impartial service to its customers. It has no business interests, stockholders, or political philosophies at stake. This objectivity is essential in measuring and assessing critical and sensitive information that will affect markets and public policy.

Reimbursable projects also benefit the taxpayer by supporting and improving the Census Bureau’s data collection and dissemination infrastructure, required for core census and survey work. The infrastructure includes highly experienced field representatives; headquarters staff members with experience in survey design, analysis, publications, and the like; and a knowledge base about changes in communities.

In recent years, the Census Bureau has been approached about projects beyond what would be considered within the agency’s mission or “routine” work. For example, it has been asked to conduct employee satisfaction surveys for other government agencies. It has been asked to take biological specimens (e.g., blood samples) for a health survey. It also has been asked to provide nonstatistical data processing services to another federal agency. While none of these projects was undertaken, much of the decision making about which work to accept was decentralized, generally taking place at the division level.

As part of strategic planning activities, the Census Bureau’s Executive Staff identified the need for a formal policy defining the scope of acceptable work

for the agency. The purpose of the Reimbursable Project Acceptance policy is to set standard criteria for determining whether or not to accept different types of reimbursable projects. A review of past reimbursable work revealed that the Census Bureau has carried out reimbursable efforts that fall into seven general categories:

1. Data collection from households or individuals,
2. Data collection from businesses,
3. Administrative records/data linking,
4. Technical assistance/consulting services,
5. Analytic research or reporting,
6. Special censuses, and
7. National Processing Center projects not involving data collection.

The policy established seven criteria that proposed projects must meet: mission, reputation, resources, privacy and confidentiality, quality, other agency requirements, and sensitive populations and topics.⁴ These criteria are intended to be fully consistent with, and in some cases elaborate on, the Census Bureau’s mission statement and Privacy Principles. The purpose of these criteria is to ensure conscious and deliberate consideration of, and adequate planning for, legal, ethical, and other obligations inherent in some projects.

A checklist approach is used to assess a proposed project and determine if it meets each of the criteria.⁵ The first three criteria are applicable to all reimbursable projects. The rest are applicable to subsets, such as household surveys.⁶ More specifically, a project must:

1. Be consistent with the Census Bureau’s mission.
2. Have a positive or neutral effect on the Census Bureau’s reputation.
3. Be feasible without jeopardizing resources and infrastructure needed to support other Census Bureau commitments.
4. Be consistent with the Census Bureau’s commitment to privacy and confidentiality.
5. Be consistent with the production of high-quality data.
6. Accommodate source agency requirements for using administrative records.
7. Address sensitive populations and topics thoughtfully.

The criteria also consider risk to the Census Bureau’s mission and reputation, particularly if the data involve sensitive populations and/or sensitive topics. The policy establishes procedures to guide decision making

when risk is moderate or high. Primary aspects of determining risk include:

- Extent to which anonymity or confidentiality can be maintained.
- Targeting of one or more sensitive population groups.
- More than nominal incentives.
- One or more sensitive topics.
- Potential for social, economic, legal, or psychological harm.
- Medical or psychological intervention.

If risk is a factor, then the program area cannot accept the reimbursable project unless it adopts one or more risk mitigation steps to reduce the risk to the agency’s reputation and mission. Primary aspects of mitigating risk include ensuring the following:

- Informed consent.
- Confidentiality of data.
- Presence of appropriate medical or other professional personnel, as warranted.
- Appropriate training or procedures to address problematic situations.

In addition, projects involving high risk require decision concurrence at the executive level, to ensure that corporate considerations are taken into account.

2.1 How Did This Policy Apply to the NLMS?

The NLMS is sponsored by a consortium of agencies, including the National Institute on Aging, the National Cancer Institute, and the National Heart, Lung and Blood Institute. These agencies provide the funding to expand the number of years of data in the NLMS for analysis of socio-economic, demographic, and occupational differentials in mortality.

Prior to entering into agreement with these agencies, the NLMS staff completed the Reimbursable Checklist to verify that the work the Census Bureau was to take on was consistent with the criteria set forth in the policy and that performing the work involved would not adversely impact the Census Bureau. In so doing, the program area confirmed that the NLMS work could be conducted within the confines of the Census Bureau’s Privacy Principles and that the resulting data could be produced in a manner consistent with the ethical and legal strictures related to privacy and confidentiality.

3. What Is the Policy on Controlling Non-employee Access to Title 13 Data?

Title 13, U.S.C., Section 9 requires the Census Bureau to protect the confidentiality of respondent information. Therefore, no one can access respondent information unless authorized to do so under this title and subject to its confidentiality requirements.

Those with data access fall into two categories: (1) employees and (2) non-employees who receive Special Sworn Status (SSS). Title 13, U.S.C., Section 23(c), permits the Census Bureau to provide SSS to non-employees who help the Census Bureau carry out its work by making them liable for penalties for unauthorized disclosure and use of protected information, just as employees are. Most non-employee access to Census confidential data takes place at Census Bureau facilities, which are operated and managed by Census Bureau employees. Occasionally, access takes place “off-site” – at a non-Census Bureau site, such as at a Census Bureau-approved secure location at another agency, university, or contractor’s facility.

Under any of these scenarios, access to Census confidential data pursuant to Title 13, U.S.C., Section 23(c) is not a right. Access is discretionary on the part of the Census Bureau, which solely makes the determination under Section 23(c) of when it is appropriate to confer SSS to assist the Census Bureau in performing work authorized by Title 13.

The purpose of this policy is to establish criteria and procedures for determining when it is appropriate to confer SSS on an individual for purposes of working with Census confidential data and when it is appropriate for access to those data to take place at a non-Census Bureau site or facility. In so doing, this policy enhances guidance provided by the Privacy Principle for Confidentiality, by establishing clear criteria for Census Bureau staff. The policy identifies four project criteria and three individual/organizational criteria for determining if a non-employee should be given SSS. It also sets four additional criteria to be used by the DSEP in determining if a project can take place at a non-Census Bureau facility, if needed.

In order for an individual to qualify for SSS, the *project* must:

- Require access to Census confidential data.
- Benefit the Census Bureau's Title 13 programs.⁷
- Be a viable project.
- Be feasible within the time constraints and with the proposed data.

In addition, the *individual* and the *organization* with which he/she is affiliated must:

- Have a good track record for handling sensitive or confidential data.
- Have no identified conflict of interest in dealing with the Census Bureau – i.e.,
 - No *real* conflict of interest from having taken an oath or pledge that conflicts with the Title 13 pledge of confidentiality – e.g., the Internal Revenue Service oath; or
 - No *real* or *perceived* conflict of interest – i.e.,
 - Financial – a representative from a company who might use his access to the data to produce results that are biased; someone who might use the data to benefit his employer;
 - Personal – a family member who is related to the Census Bureau project decision maker; a previous close collaborator who recommends approval of an External research project; or
 - Partisan – an individual or organization that displays partisan political or issues advocacy motives.
- Pass the background investigation for SSS candidates.

Projects involving individuals or organizations with a *real* conflict of interest will be denied; those with a *perceived* conflict of interest must be approved by the DSEP – e.g., individuals who work for an enforcement or regulatory agency or credit bureau personnel who could raise perception concerns if they are provided access to Census confidential data.

If a project and associated people meet the above criteria, SSS may be conferred. In most cases, the SSS individual is going to access the Title 13 data at a Census Bureau facility.

Off-site access depends, in part, on which of the five project types is involved:

- **Internal** – projects authorized by Title 13, U.S.C., operated and managed by Census Bureau employees (including SSS people who are covered by the Intergovernmental Personnel Act Mobility

Program). These projects are generally funded by Census Bureau appropriated funds.

- **Joint** – projects with a Title 13 purpose, to which both the Census Bureau and another participating federal statistical agency or unit contribute confidential data and resources. Work is jointly managed and access can – though it is not required – take place at both agencies.
- **Reimbursable** – projects for which the Census Bureau receives reimbursement, in whole or in part. For purposes of this policy, reimbursable projects are limited to those projects carried out under the authority of Title 13, U.S.C.
- **External** – projects with a predominant Title 13 purpose that are proposed by academic, governmental, nonprofit, and for profit organizations' researchers, approved by the Census Bureau using the existing Center for Economic Studies' (CES) Project Review procedures,⁸ and carried out by the non-employees at a Census Bureau site – usually at a Census Bureau Research Data Center (RDC) – under Census Bureau supervision.
- **Oversight** – projects to oversee or audit some aspect of Census Bureau operations, carried out by an organization with specific legal authority to conduct oversight activities, such as the Government Accountability Office or an agency from which the Census Bureau obtains confidential administrative records data.

External and Oversight projects must be carried out at a Census Bureau facility.⁹ Internal and Reimbursable projects also should occur at a Census Bureau facility, but the DSEP may grant exceptions.¹⁰ Requests for exceptions must meet the criteria set forth, as follows:

- Provide a technical/logistical advantage (acceptable interpretations of these criteria provided in Attachment B of the policy¹¹) *and*
- Meet the Required Security Models for Off-site Access (see Attachment C of the policy) *and*
- In the case of a governmental agency or organizational unit, have legal or regulatory functional separation of the data collected for statistical purposes¹² *and*
- Obtain DSEP approval prior to any major commitment of resources.

Under some circumstances, a Joint project may require SSS individuals to access the data at the partner's location. Such access will be granted by the DSEP if the criteria noted above are met.

If the DSEP approves off-site access for any project, such access must meet the Census Bureau's physical security and information technology security requirements, which ensure adequate protection during the period of access.

3.1 How Does This Policy Relate to the NLMS?

Since the NLMS starts with the linkage of CPS and census data, it is governed by Title 13 and its confidentiality protection is guaranteed by Section 9 of the Census Bureau statute. However, one of the principal components of the longitudinal file is the fact that the Census Bureau identifies which individuals on the file have died and flags those microdata as belonging to decedents. The NLMS uses the National Death Index (NDI), described by Robert Bilgrad, as the basis for identifying decedents.¹³

In order to obtain current mortality data from the NDI to update the NLMS, the Census Bureau must search the NDI for potential decedents in the CPS-census matched files. Since the NDI can only be accessed either at the Centers for Disease Control and Prevention in Atlanta or remotely from the National Center for Health Statistics (NCHS), an abstract of Title 13 personally identifying data must be sent to individuals at the NCHS to conduct the search and return potential matches. The individuals at NCHS who handle the search are not Census Bureau staff, so they must obtain Census Bureau Special Sworn Status. Also, since the work must occur at the NCHS site, this represents an off-site access to Title 13 data and requires DSEP approval under the policy on Controlling Non-employee Access to Title 13 Data. Taking the precautions to swear in the NCHS staff who will handle the Title 13 data and having the DSEP approve the off-site access ensure appropriate privacy, security, and confidentiality safeguards are being observed, including restricted access and secure procedures for information technology data handling. These steps also help the Census Bureau keep better track of sensitive data that are not under its direct control, thus mitigating any risk that might be involved in permitting the data to be used at a non-Census Bureau facility.

4. Conclusion

These are just two data stewardship policies applicable to the NLMS. While their implementation added considerable time to the project, they ensured that decision making related to the NLMS was undertaken

based on stringent standardized criteria. Only after applying the policies – completing the Reimbursable Checklist, granting Special Sworn Status to NCHS staff handling Title 13 data, and getting DSEP approval for off-site access to Title 13 data – was the program area able to move forward, thus ensuring a project consistent with the agency's mission and Privacy Principles.

Notes and References

*This paper is released to inform interested parties of ongoing research and to encourage discussion of work in progress. The views expressed on operational issues are those of the author and not necessarily those of the U.S. Census Bureau.

- ¹ For full detail of the Privacy Principles and their subprinciples, see Attachment 1 of Martinez, S. W. (2003), "Using Privacy Impact Assessments to Implement Data Stewardship Principles and Practices," 2003 Proceedings of the American Statistical Association, Government Statistics Section [CD-ROM], Alexandria, VA: American Statistical Association: 2711-2718. (The Privacy Principles were updated in 2005. Figure 1 represents the current version.)
- ² Johnson, N. (2006), "The National Longitudinal Mortality Study," 2006 Proceedings of the American Statistical Association, Government Statistics Section [CD-ROM], Alexandria, VA: American Statistical Association.
- ³ Melvin, P. (2006), "Census Bureau Administrative Record Data Stewardship Policies for Administrative Records Use," 2006 Proceedings of the American Statistical Association, Government Statistics Section [CD-ROM], Alexandria, VA: American Statistical Association.
- ⁴ As a practical matter, special censuses – undertaken at the request of a local jurisdiction to obtain an official population count between decennial censuses – are assumed to meet these criteria. Additional criteria or review may be required for some other types of projects before a decision can be made. Specifically, this is the case for administrative records projects (see Melvin (2006)). Implementation of the Reimbursable policy can often be accomplished by integrating it into other existing reviews.
- ⁵ See the U.S. Census Bureau (2003), "Reimbursable Project Acceptance Policy," internal data stewardship policy, DS015.
- ⁶ In some cases, two categories could apply (e.g., data collection involving households that will link results to administrative records). If so, questions in both sets of considerations apply. Externally proposed research projects involving census

confidential data, typically conducted at the Center for Economic Studies' Research Data Centers, are considered analytic research or reporting projects.

⁷ See U.S. Census Bureau (2002), "Articulating the Title 13 Benefit of Census Bureau Projects," internal data stewardship policy, DS002.

⁸ See <http://www.ces.census.gov/ces.php/home>

⁹ The exception to this is when Oversight projects housed off-site require auditing.

¹⁰ Projects involving access to files with personal identifiers on them will undergo special scrutiny before off-site access is permitted.

¹¹ See the U.S. Census Bureau (2002), "Controlling Non-employee Access to Title 13 Data," internal data stewardship policy, DS006.

¹² The one exception to this rule is to permit off-site access for selected Joint projects carried out at the Social Security Administration (SSA). Although the SSA's functional separation is in practice, not in law or regulation, this exception is made in view of the SSA's more than 30-year history of protecting Title 13 data and the integral role that SSA data play in ongoing Title 13 programs.

¹³ For information on the National Death Index, see <http://www.cdc.gov/nchs/ndi.htm>