

# Consent and Confidentiality for Linked Data

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# Confidentiality Pledges

## Confidential Information Protection and Statistical Efficiency Act (CIPSEA )

- Only employees/legal agents can see answers
- Used only for “statistical purposes”
- Employees/agents subject to fines and jail



FROM THE DIRECTOR  
U.S. CENSUS BUREAU

Thank you for your past cooperation in the U.S. Census Bureau's Current Population Survey (CPS). Your participation in this study continues to play a major role in the development of the employment and unemployment data, which are so important to understanding our Nation's economic situation.

One of our field representatives or telephone center interviewers will call on your household soon to update the regular labor force information. He or she also will ask questions about other subjects that will provide government and private organizations the information needed to understand the economic situation of our population. These questions will concern work experience and income from various sources during the year 2013. The estimated time for each interview is 25 minutes, in addition to the time needed for the regular labor force information. To explain the need for this information and how these data are used, we have enclosed a fact sheet about this survey that may answer some of the questions you might have.

We are conducting this survey under the authority of Title 13, United States Code, Section 182. Section 9 of this law requires us to keep all information about you and your household strictly confidential. We may use this information only for statistical purposes. Any Census Bureau employee who violates these provisions is subject to a fine up to \$250,000 or a prison sentence up to five years or both. Although there are no penalties for not answering any questions, each unanswered item lessens the accuracy and usefulness of the final statistics. The Office of Management and Budget control number for the CPS is 0607-0354, and the expiration date is January 31, 2017. Without this number, we would not be able to conduct this survey.

Some income sources, and medical out-of-pocket expenditures, that the field representative will be asking about appear on the back of this letter. Space is provided for you to enter the income amounts received, and medical expenditures paid, by members of your household who are 15 years old or over. Although the income sources mentioned are not all-inclusive and some may not have been received by anyone in your household, we request that you look up the 2013 income records for yourself and the rest of your household before the representative calls on you. This will ensure the accuracy of the statistics collected and will also serve to minimize the time required for the interview.

Send comments regarding the time estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: Paperwork Project 0607-0354, U.S. Census Bureau, 4600 Silver Hill Road, AMSD-3K138, Washington, D.C. 20233. You may e-mail comments to [Paperwork@census.gov](mailto:Paperwork@census.gov); use "Paperwork Project 0607-0354" as the subject.

Thank you for your continued cooperation.

Sincerely,

John H. Thompson



## How Will My Participation Help Me and My Community?

Billions of government and business dollars are distributed among states, communities, and population groups based on the social, economic, and housing information available for that area.

The information you provide will help you and other individuals, local governments, nongovernmental organizations, and businesses to:

- Help distribute resources to communities.
- Improve your community by deciding where in your town new highways, schools, and hospitals can do the most good.
- Measure changes in the well-being of children, families, and senior citizens to help plan future programs.
- Help communities plan for emergency situations that might affect you or your neighbors, such as floods, fires, and other natural disasters.



## Is the Information I Provide Confidential?

Yes. Your answers are confidential by law (Title 13, United States Code, Section 9). This law requires that every Census Bureau employee—including the Director and every Census Bureau representative—take an oath and be subject to a jail term, a fine, or both if he or she discloses ANY information that could identify you or your household.

Your answers may be used only for statistical purposes. We may combine your survey data with data that you may have provided to other federal agencies. Any combined information is given the same protections as your survey information. Some households that respond to the American Community Survey may be asked to participate in other Census Bureau surveys.

# Cybersecurity Enhancement Act

- Allows DHS employees to monitor for purposes of cyber security
- Required revamp to confidentiality pledge:  
*“Furthermore, your data are protected from cybersecurity risks through screening of the systems that transmit your data”*
- Interagency group assessed impact of new language:
  - R's didn't notice it; no impact on response (Eggleston, Redline, Wilson, Edgar and Ridolfo, 2017)

# Data linkage: Consent

- Consent requirements run continuum depending upon country
- Legislation facilitating linkage (Canada, Finland, Netherlands)

2011 Canadian Census	2016 Canadian Census
<i>To save time, each person can give Statistics Canada permission to use the income information already available in his or her income tax files instead of answering Question 55</i>	<i>In order to reduce the number of questions in this questionnaire, Statistics Canada will obtain your income information from personal income tax and benefits records.</i>

- In US, some agencies allow for Opt-in/Opt out

# National Longitudinal Mortality Study (NLMS)

- Links CPS/ASEC survey data to death certs
- Began in 1973; 39 cohorts in all; 3.8 million records with over 550,000 identified mortalities
- Variables include socio-economic indicators such as place of birth, health insurance, employment, occupation, and income. Also includes race/ethnicity and tobacco use (supplement)
- Strict confidentiality controls in place

# NLMS consent

- Prior to 2015, CPS respondents could “opt-out” of NLMS

Occasionally, we may combine data from the CPS with data we obtain from other government agencies to provide a comprehensive set of summary information about employment, income, and participation in various government programs. ~~The same confidentiality laws that protect your survey answers also protect any additional information we collect (Title 13, United States Code, Section 9). To ensure your protection, the laptops used for the data collection are password protected and all survey responses are encrypted. If you wish to request that your information not be combined with information we obtain from other agencies, we ask that you notify the Field Representative at the time of the interview.~~

FORM CPS-500 (4552-0111) (4-1-2013)

♦ Read if necessary: Anyone else?

Do Not Ask Respondent  
Who is opting-out?

Enter all that apply, separate with commas  
Enter 96 for all persons SSN/opt-out

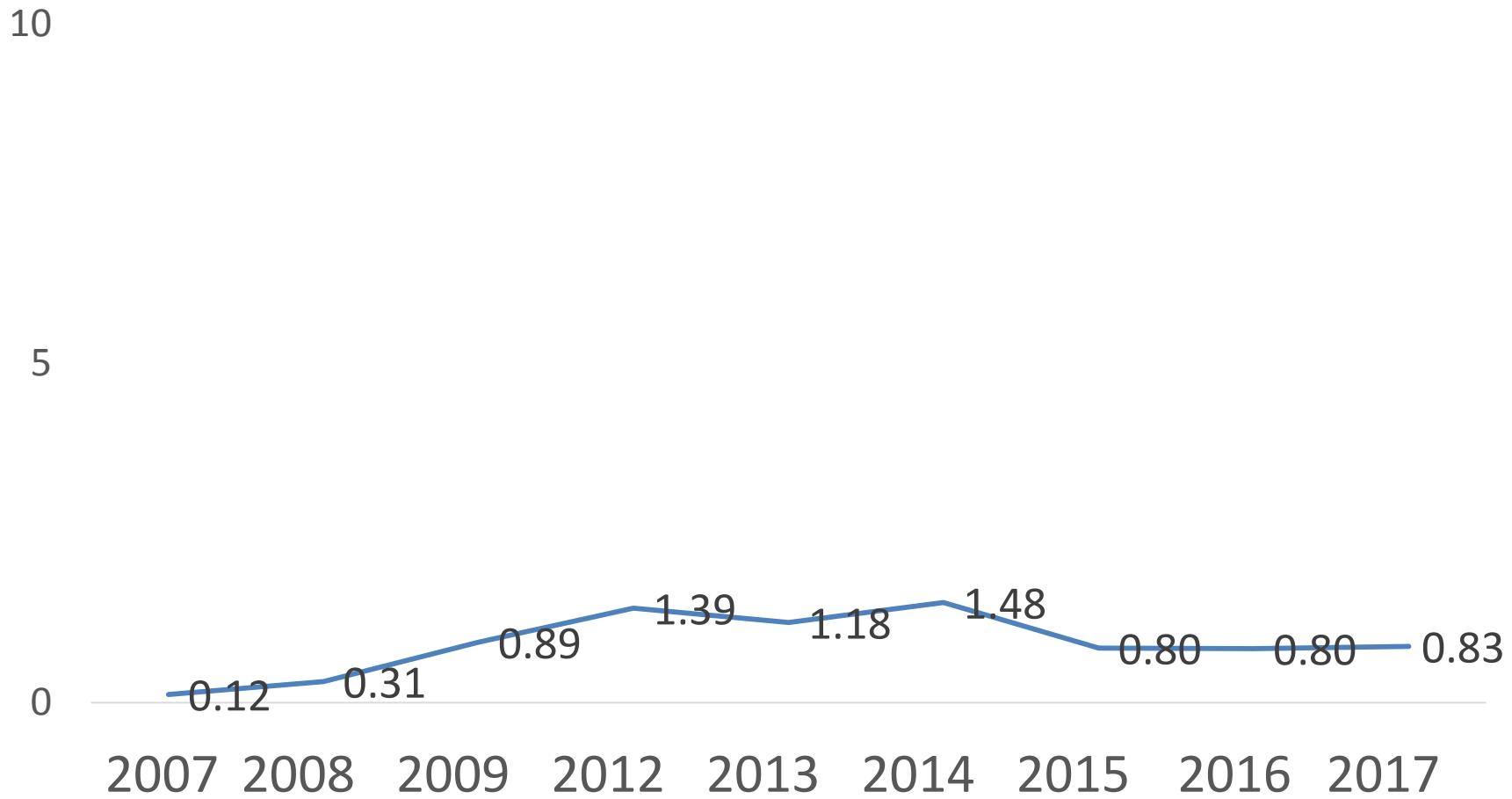
Press ENTER to return to interview

Opt Out	LN	NAME	RELATION
01	Holly	Reynolds	Ref Per
02	Thomas	Reynolds	Spouse
03	Maureen	Griffin	Child
04	Ricky	Griffin	Grandchild
05	Sherry	Griffin	Grandchild

<input type="checkbox"/> 1. Holly Reynolds	<input type="checkbox"/> 96. All Persons Listed
<input type="checkbox"/> 2. Thomas Reynolds	
<input type="checkbox"/> 3. Maureen Griffin	
<input type="checkbox"/> 4. Ricky Griffin	
<input type="checkbox"/> 5. Sherry Griffin	

H\_optout

# Percent opting out of data linkage – NDI/CPS\*



Source: CPS, U.S. Census Bureau (personal communication with G. Weyland)

\*data not available for 2010-2011

# Change in consent policy 2015

- Data Stewardship Executive Policy Committee (DSEP)
- DSEP ruled to *remove the passive, or implicit, opt-out* of record linking for voluntary surveys
  - Title 13 requires the agency to use *other data sources in lieu of direct inquiries* when possible
  - Title 13 does *not require permission* to conduct linkages
  - *increased transparency* in linkage activities
- Respondents can opt-out of record linkage by refusing survey request

# New NLMS notification

We would like to remind you that we collect this information for the Bureau of Labor Statistics in order to provide vital up-to-date estimates of the number of persons working, the number who are unemployed, and many other related facts. We are conducting this survey under the authority of Title 13, United States Code, Sections 8(b), 141, and 182; and Title 29, United States Code, Section 2. Section 9 of this law requires us to keep all information about you and your household strictly confidential. We may use this information only for statistical purposes. Any Census Bureau employee who violates these provisions is subject to a fine up to \$250,000 or a prison sentence up to five years or both.

## **Current Population Survey (CPS) – Frequently Asked Questions**

### **Who uses this information? What is this survey all about?**

In a country as big as ours and one that changes so rapidly between decennial censuses, people in government, business, and other groups need up-to-date facts in order to plan efficient and adequate programs. It is important to know how many people are working or out of work (to help direct programs which would contribute to an expanding economy and provide new jobs), how many children will be attending school (to plan for schools and the training of an adequate number of teachers), how many new families are forming (to plan for adequate housing to meet their needs), and so on. Occasionally, we may combine data from the CPS with data from other government agencies to provide a comprehensive set of summary information about employment, income, and participation in various government programs. The CPS is one of the most important and timely sources of information used to make such plans.

# Mortality Disparities in American Communities (MDAC)

- Links American Community Survey (ACS) to death certificates
- 2008 ACS combined with NDI = 4.5 million records with over 265,000 identified mortalities
- Variables include: death certificates, neighborhood environment, social and economic differentials, Medicare/Medicaid information

# MDAC notification

## *Frequently Asked Questions*

### *Do I have to answer the questions on the American Community Survey?*

Yes. Your response to this survey is required by law (Title 13, U.S. Code, Sections 141,193, and 221). Title 13, as changed by Title 18, imposes a penalty for not responding. We estimate this survey will take about 40 minutes to complete.

### *How will the Census Bureau use the information that I provide?*

The Census Bureau can use the information you provide for statistical purposes only and cannot publish or release information that would identify you and your household. Your information will be used in combination with information from other households to produce data for your community. Similar data will be produced for communities across the United States.

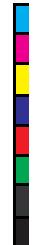
We may combine your answers with information that you give to other agencies to enhance the statistical uses of these data. This information will be given the same protections as your survey information. Based on the information that you provide, you may be asked to participate in other Census Bureau surveys that are voluntary.

### *Will the Census Bureau keep my information confidential?*

Yes. All of the information the Census Bureau collects for this survey about you and your household is confidential by law (Title 13, U.S. Code, Section 9). By law, every Census Bureau employee—including the Director as well as every field representative—has taken an oath and is subject to a jail term, a fine, or both if he or she discloses ANY information that could identify you or your household.

### *Where can I find more information about the American Community Survey or get assistance?*

You may visit our Web site [census.gov/acs](http://census.gov/acs) or call 1-800-354-7271 if you need assistance or more information.



# Who consents?

- Evidence in literature is not consistent:
  - Age positive (Young et al. 2001; Jenkins et al. 2006; Bates and Pascale, 2006)
  - Age negative (Banks et al.; Dahlhamer and Cox, 2007)
  - Poor health positive (Dahlhamer and Cox, 2007)
  - Poor health negative (Haider and Solon, 2000; Young el at. , 2001)
- Consent is lower in self-administered modes

# Tenants of Consent

- First, **thank respondent** for providing survey responses
- Second, communicate **goal of the data linkage**
- Third, communicate the **scope of the request**
- Finally, **communicate confidentiality protections** of the linked data

# Increasing consent

- Consent framing - “Loss” versus “gain”  
(Krueter, et al., 2015; Kreuter et al. 2016 ;  
Tourangeau and Ye. 2009).
- Placement of request? (Sakshaug, 2014;  
Sakshaug and Vicari, 2017; Eisnecker and  
Kroh, 2017).
- Normalizing the request (Welch, et al. , 2017)

# Consent research

- Conduct experiments of:
  - mode,
  - framing,
  - placement, and
  - normalization
- What do the “opt-outers” look like (NLMS)?
- Qualitative studies
  - How to communicate what consent means e.g., where will data come from? What’s it linking to? Who can see it? What will be done with it? How protected?
  - How do older populations comprehend consent requests?

# Future of surveys and consent

- JASON report (2016) recommends 2030 Census be mostly administrative record-based
- Miller (2017) argues that “blending” government survey data and administrative records data are the future but... legal and practical matter arise
  - “Owners” of admin data want confidentiality assurances
  - And...is consent required? If so, how to obtain it?

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