

## **The 2016 Census, Statistical Linkage and Consent**

### **Individual Submission to the Senate Standing Committee on Economics**

#### **Summary**

In 2016, the Australian Bureau of Statistics decided to proceed with an extended period of retention for identifying information and a program of statistical linkage following inadequate public consultation. The subsequent atmosphere of heightened privacy concerns, coupled with failure of the online Census form has depressed response rates consistent with evidence from international experience. In order to remedy the privacy issues with the 2016 Census, the Senate and Australian Parliament should amend the *Census and Statistics Act 1905* to require consent for statistical linkage of Census data, make the provision of names voluntary, prohibit retention of names for more than 18 months without consent, make all questions on sensitive information voluntary (not just religion) and remove the possibility for multiple fines to be issues for non-completion. Additionally, the *Privacy Act 1988* should be amended to provide for mandatory data breach notifications and the ABS should release more detailed information on their statistical linkage processes for review by experts and privacy advocates.

## Introduction

The 2016 Census has been thoroughly bungled in its conception, management and implementation. Its chief failure has been the disregard that the Australian Bureau of Statistics (ABS) management has shown towards privacy. Privacy is an important human right and freedom. While it may not be as glamorous as other freedoms like freedom of speech, it plays an important role in society because it protects people from state and corporate power. Without privacy people would be exposed to risks that they would otherwise avoid and their individual decisions would be ignored by governments.

The failures in the 2016 Census management began long before Census night. The Privacy Impact Assessment (PIA) performed by the ABS to enable the extended retention of names and addresses as well as statistical linkage with other datasets without individual consent was grossly inadequate. The PIA did not follow the Office of the Australian Information Commissioner's (OAIC) Guide to Undertaking Privacy Impact Assessments because it did not involve adequate consultation, mapping of information flows, privacy impact analysis and compliance check and assessment of risks and mitigation options.

No Parliamentary mandate exists for the extended retention of names and statistical linkage of the Census. There was no public debate or legislation enabling this change, rather the ABS has used its inadequate PIA process and the existing coercive powers in the *Census and Statistics Act 1905* (Cth) to enable it to intrude further into people's lives. This should be remedied and the voluntary nature of the religion question should be extended to all sensitive information as defined by the *Privacy Act 1988* (Cth).

The failures of the online Census form, combined with heightened privacy concerns in the leadup to the Census have suppressed response rates. Current estimates of response rates reported in the media are around 80%, while historical response rates have been above 95%. Research on privacy, Censuses and surveys around the world have shown that response rates will be decreased in circumstances where privacy is not respected or individuals have heightened privacy concerns.

Obtaining consent and reducing the coercive aspects of the Census will protect the rights and freedoms of Australians without compromising Census data. Requiring consent for statistical linkage is easily done by adding to the Census form and is unlikely to have much adverse impact on the research that can be done on linked data. Consent cures the paternalism of both data custodians who refuse to release data for valuable research and from researchers who believe their mission is more important than the decisions made by individuals. Some of the coercive powers in the *Census and Statistics Act 1905* should also be curbed to make them more proportionate and in line with failure to complete other civic duties such as voting.

## Why Privacy is Important

Privacy is freedom from arbitrary interference with a person, their home or private space, communications, personal information and unwarranted surveillance. It is protected as a human right by Article 17 of the [International Covenant on Civil and Political Rights](#) and legislation such as the *Privacy Act 1988*. In most contexts, privacy is a negative freedom, i.e. a freedom *from* interference, but this does not make it any less important than positive

freedoms such as free speech or freedom of association. Like all freedoms privacy must be protected and the erosion of our privacy is rightfully recognised as an erosion of freedom.

Information privacy, the rights we have concerning information about ourselves, is fundamentally about respect and individual autonomy. In accordance with the Australian Privacy Principles (APPs) outlined in the *Privacy Act 1988*, individuals have the right to the open and transparent management of their personal information, to access, correct or control their personal information (for example, by being able to consent or not consent to its collection or disclosure) and for their information to be secured. Individuals therefore should be able to make decisions about their personal information – what is disclosed and to whom. Organisations and governments are supposed to respect the decisions that people make about their personal information.

Privacy has been increasingly under threat since the late 20<sup>th</sup> century. The recent advent of compulsory retention of telecommunications metadata for everyone (not just people under investigation) which is accessible without a warrant is just the latest example of the erosion of privacy. In the United States, revelations of government surveillance and the increasing availability of personal information enabled by the internet has been credited with increasing the proportion of people very concerned about threats to their privacy from 31% in 1978, to 52% in 1998 (Robbin, 2001). Big data analytics now enables inferences about circumstances regarding our jobs, family, interpersonal relationships, political beliefs, religion or health from phone metadata alone (Mayer, Mutchler, & Mitchell, 2016).

The massive availability of personal information makes the protection of privacy more important, not less. As Bock (2016) has argued, “We do not protect data because the data would take harm; rather, we seek to protect the rights and well-being of individuals who might be harmed by certain uses of their data.” Harmful uses of data may include fraud, discriminatory practices in health or customer services and social shaming or ostracism for embarrassing moments or unpopular beliefs. The wide availability of personal information means that the risks to individuals have been heightened, not decreased. Consequently, we should be more concerned that the rights and wellbeing of individuals may be harmed in the current low-privacy environment. In the current environment we should strongly resist anything that does not respect a person, their privacy or individual autonomy.

Privacy therefore protects people from state and corporate power. By forcing governments and corporations to consider the individual and their privacy preferences, privacy prevents arbitrary interference or discrimination. It prevents unlimited access to people’s lives by law enforcement, curious policymakers or eager salespeople. If powerful institutions show respect for individuals and their privacy, then it creates a society where there is greater trust and cohesion. This is something to be protected.

### **Inadequate Privacy Impact Assessment**

The preparation, administration and management of the ABS and the Government in the leadup to the 2016 Census involved a grossly inadequate privacy impact assessment. As outlined by Clarke (2009), a PIA should have broad scope with respect to the privacy issues and stakeholder perspectives and expectations considered. The OAIC also provides detailed

guidance on conducting PIAs. However, the [ABS PIA](#) failed to follow the OAIC's [Guide to Undertaking Privacy Impact Assessments](#) by:

1. Failing to consult stakeholders including advocacy organisations like the Australian Privacy Foundation and Electronic Frontiers Australia;
2. Inadequate mapping of information flows;
3. No privacy impact analysis and compliance check; and
4. Inadequate consideration of risks and risk mitigation options.

### *Failure to Consult*

OAIC Guidelines explicitly call for external stakeholders such as “regulatory authorities, clients, advocacy organisations, service providers, industry experts, academics and others” to be consulted. Although the ABS Privacy Impact Assessment records consulting with regulatory authorities and running preliminary focus groups, no consultation with any other stakeholder was actively sought out. In fact, a media release was issued on 11 November 2015 for the public consultation with submission due just three weeks later on 2 December 2015. Advocacy organisations with interests in privacy, such as the Australian Privacy Foundation and Electronic Frontiers Australia were not contacted. Indeed, a short and poorly publicised consultation at the end of the year would have been difficult for small, volunteer advocacy organisations. Indeed, the OAIC Guidelines explicitly state:

*For consultation to be effective, stakeholders will need to be sufficiently informed about the project, be provided with the opportunity to provide their perspectives and raise any concerns, and have confidence that their perspectives will be taken into account in the design of the project. Many consultation models are available, including telephone or online surveys, focus groups and workshops, seeking public submissions, and stakeholder interviews.*

This evidently did not happen, at least for civil liberties and privacy advocates. As a result, the ABS PIA received just “three responses from private citizens who all raised concerns with the proposal”. They have since received criticism from the Australian Privacy Foundation and others that there has been inadequate consultation, just as predicted by the OAIC Guidelines. Further, it appears that the perspectives of stakeholders were not taken into account because they all raised concerns with the proposal yet the ABS still assessed the risk of a reduction in participation levels in ABS collections due to loss of public trust as “Very low”.

### *Inadequate Mapping of Information Flows*

The ABS PIA maps the information flow on pages 12-15 but it is not “detailed information mapping” as recommended by the OAIC Guidelines. For example, the PIA does not describe which “other datasets” information will be collected from in addition to the Census data collection. No limits on the information being collected are described in terms of

age, type or features. The method(s) by which datasets will be linked is also not stated despite the proviso from preliminary focus groups that the ABS needs to be transparent about how it handles personal information. Absolutely no consideration is given to identifying or describing the information that will be given to individuals and how it will be given, as outlined in the OAIC Guidelines.

### *No Privacy Impact Analysis and Compliance Check*

The ABS PIA does not follow the OAIC Guidelines' Suggested PIA Report Format because it does not include a section on analysis that systematically goes through a Privacy Impact Analysis and Compliance Check. As stated by the OAIC Guidelines, "You will need to consider whether your project complies with each of the APPs." The ABS PIA does not do this at all.

If the ABS PIA had included a Privacy Impact Analysis and Compliance Check, the ABS may have considered some of the following issues described by the OAIC Guidelines:

- Processes in place for the handling of sensitive information (e.g. health-related information)
- Consent for data collection or secondary use or disclosure
- The role of disclosure of personal information to an overseas recipients and the steps taken to ensure they do not breach the APPs
- Adoption, use or disclosure of government identifiers. Perhaps the statistical linkage keys constitute a government identifier as the Australian Privacy Foundation has argued.
- Matters related to security of personal information, such as period of retention and audit mechanisms for identifying inappropriate access.

### *Inadequate Consideration of Risk and Mitigation Options*

The ABS PIA identified five risks, but inadequately assessed each of these risks and did not consider obvious mitigation options. In each case the ABS evaluated the risk as "Very low". The first two risks relate to data breaches either from either ABS staff or outsiders. However, as reported by [The Guardian](#) on 29 July 2016, the ABS has voluntarily reported 14 data breaches to the OAIC since 2013. Importantly, these are voluntary reports only since Australia has no mandatory data breach notification laws so the true number of data breaches suffered by the ABS might actually be higher. It seems absurd to report that the risk of data breach is very low if they are happening at an average rate of four or five per year.

As noted above, the ABS also identified a loss of public trust as a possible risk but rated it as "Very low" despite all of the submissions from private citizens raising concerns about the proposal. Its consideration of mitigation options appears grossly inadequate because none of their mitigation strategies included giving individuals the option to consent to the extended retention of their name and address and linkage with other datasets. The OAIC Guidelines include the following possible risk, "Use or disclosure: Individuals may be surprised or upset by a secondary use or disclosure, resulting in privacy complaints and/or negative publicity" and the following suggested mitigation strategy, "Undertake further

stakeholder consultation to test community expectations about your proposed uses and disclosures. Consider whether it is possible to seek consent for secondary uses and disclosures.” The ABS PIA includes no evidence that seeking consent for extended retention and statistical linkage was even considered. In fact, the word “consent” is only mentioned once in the entire PIA, in a footnote relating to the Census Time Capsule where a form can be transferred to the archives and released after 99 years. It is unacceptable that the ABS allows that the Census Time Capsule is opt-in yet the ABS did not even consider seeking consent for extending the retention and statistical linkage in accordance with OAIC Guidelines.

### **Collection, Retention and Use of Data in the 2016 Census**

The purpose of a Census is to collect a snapshot of the population and some of its key statistical features. The scope of the Census is generally non-invasive, despite some questions on the census form relating to sensitive information (as defined by the APPs) such as health, race and religion. However, only the religion question is listed as optional. There is no reason why the collection of one type of sensitive personal information should be optional and others should not be. Questions relating to someone’s race, ethnicity, health or any other type of sensitive information as defined by the *Privacy Act 1988* should therefore be optional as well.

Retention of names and addresses for anything other than the immediate administrative purpose of collecting the Census is unethical without consent. The Census is a form of research involving humans and a fundamental principle of research involving humans is respect for individual autonomy and informed consent (NHMRC, 2007). While it is acceptable that the government should have some coercive powers for the purpose of an occasional anonymous statistical snapshot of the population in order to inform public policy, it is unacceptable for the government to extend this power without the approval of a robust democratic process. The names of individuals who have not consented for statistical linkage should therefore be destroyed as soon as possible and no later than 18 months after Census night.

The retention of names and addresses for the purpose of statistical linkage and research is a privacy intrusion with no Parliamentary mandate. Governments have never been able to track individuals as easily as data integration and statistical linkage now allow them to do. By applying statistical linkage to the compulsory Census, the government is effectively applying data-based surveillance to the entire population. This is a huge extension of government power which previously only allowed for the collection of specific, anonymous information through the Census. In this respect, the change to the Census is worse than metadata retention because at least that was recognised as an additional power and was legislated by Parliament. In contrast, the *Census and Statistics Act 1905* was last substantially amended to add provisions for the Census Time Capsule before the 2001 Census. It could not, as originally passed, have reasonably accounted for the advent of computers, the internet and statistical linkage. The extended retention of names and statistical linkage is therefore an extension of government power without Parliamentary mandate and a completely arbitrary invasion of privacy by a government agency. Since names are not relevant statistics, the *Census and Statistics Act 1905* should be amended to clarify that their provision is voluntary.

## **Undermining Privacy and Confidentiality Undermines Response Rates**

The lack of respect for privacy, as well as the spectacular website crash on Census night, are the key reasons for the reduced response rate to the Census. While final information on response rates will not be known for some time, on 9 September 2016, [Crikey](#) reported that only 80% of households have submitted Census forms and the ABS claimed a 90% return rate on [13 September 2016](#). According to the [ABS](#), the response rate for the 2011 Census was 96.3% and 95.8% for the 2006 Census. If the low 80-90% response rate persists, it will be entirely consistent with a loss of public trust because of privacy concerns.

Historical expectations about the anonymity of the Census and the competence of the ABS have been violated, reducing the public trust needed to maintain response rates. Apart from the expectation of anonymity, the ABS is normally expected to be a highly competent agency. However, the ABS has violated these expectations by changing a fundamental aspect of the Census following a completely inadequate PIA and demonstrated incompetence via the crash of the online Census form. Philosophers have argued that the Census is part of a social contract where citizens assist with informing good government and in return the government should protect their information from arbitrary use (Heeney, 2012). According to Resnik (2011), public trust is both essential and multifaceted. People need to trust researchers to be competent, professional and to protect their privacy. If trust is difficult, they will be more difficult to recruit for research studies. Low response rates therefore reflect a loss of public trust in an agency that has broken its social contract and demonstrated incompetence.

Low response rates are consistent with an environment of heightened concern for privacy specifically. In the United States, the 1990 Census had response rates low enough that it spurred research into privacy concerns (Robbin, 2001). It was found that the proportion of individuals returning the Census was 15-20 percentage points lower for people with high privacy or confidentiality concerns than people with no privacy or confidentiality concerns (Singer, Mathiowetz, & Couper, 1993). Moreover, when the UK developed the care.data program to centralise patient health data and make it available it also evoked many strong negative reactions from the public centred around concerns around transparency, privacy and trust in government and even affected their willingness to confide in their doctors (Sterckx, Rakic, Cockbain, & Borry, 2016). It is therefore reasonable that disregarding privacy, as has been done for the 2016 Census, would result in lower response rates.

## **Privacy, Statistical Linkage and Consent**

Statistical linkage with the Census should proceed only where the consent of individuals has been obtained. Statistical linkage has been envisioned and practiced in Australia for a long time (Hobbs & McCall, 1970; Holman et al., 2008). Epidemiologists have benefited enormously from the power of statistical linkage to produce large studies necessary to understand health effects, which has resulted in a decrease in requests for name-identified data (Trutwein, Holman, & Rosman, 2006). This typically occurs without the consent of individuals but with the oversight of institutional Human Research Ethics Committees and proceeds only with the approval of data custodians (Holman et al., 2008; Mathews et al., 2013). Despite this, epidemiologists still complain of “privacy protectionism” if their access to data is refused or delayed (Allen, Holman, Meslin, & Stanley, 2013).

However, as much as statistical linkage has value for researchers, consent is still a desirable feature of projects that include statistical linkage because it protects individual autonomy (Magnusson, 2002). The Census should therefore involve statistical linkage only where there is individual consent.

Obtaining consent for statistical linkage for the Census would not be impractical or threaten data integrity. When Young, Dobson, and Byles (2001) obtained a rate of consent of just under 50%, Holman (2001) criticised the impracticality of obtaining consent for these studies because it is simply too resource intensive, could involve unblinding participants or might result in an inadequate response rate. None of these obstacles apply to the Census. Firstly, completion of the Census is compulsory and consent could be requested on the Census form. Secondly, there is no issue with unblinding because the Census is a general purpose survey of mostly non-sensitive information. There is no risk that participants will be ‘tipped off’ to the nature of any specific study. Thirdly, the majority of people are likely to consent, as they do for the Census Time Capsule. Rates of consent for statistical linkage can be as high as 90% of survey respondents (Sakshaug, Couper, Ofstedal, & Weir, 2012). Individuals also seem to be more willing to consent to linkage of their health data than economic data (Mostafa, 2016), but in both cases rates of consent can be above 80%.

The risk posed to data quality by non-consent rates is no worse than that from imperfect linkage. Depending on the matching strategy and dataset, the commonly used SLK-581 usually matches around 87-89% of records but may match as few as 44%. Moreover, SLK-581 is just an anagram of name, date of birth and sex so it provides relatively poor privacy protection, especially when compared against newer techniques (Randall, Ferrante, Boyd, Bauer, & Semmens, 2014; Randall, Ferrante, Boyd, Brown, & Semmens, 2016; Taylor, Irvine, Iannotti, Harchak, & Lim, 2014). Obtaining consent therefore poses no greater risk to data quality than imperfect linkage.

Consent is the most ethical approach for dealing with statistical linkage in the Census. As noted above, consent protects individual autonomy and freedom and respecting the privacy decisions of individuals is important in civil society. While individuals whose data is non-consensually linked in epidemiological studies are protected by the oversight of institutional Human Research Ethics Committees and data custodians, the ABS PIA includes no mention of the approval process for statistical linkage. In the absence of formal ethics committee protections, consent is surely an ethical necessity.

Consent also makes it more ethical for data custodians to release information. This would reduce the paternalism that Allen et al. (2013) associate with “privacy protectionism”. Consent cures paternalism by giving the decision to the individual rather than an authority, whether they are a data custodian or an epidemiology expert. Obtaining consent for statistical linkage in the Census is therefore the most ethical way to proceed.

Consent for statistical linkage should include some differential control for different domains. As Mostafa (2016) found, rates of consent for the main respondent in UK Millenium Cohort Study were 81% for economic data and 87% for health data. Although health data is generally seen as more sensitive than economic data, there might be a clearer association between health data and beneficent medical research. Each individual should also be given the option to consent or not consent to statistical linkage. Individuals differ in their propensity consent with people who are more concerned about privacy and confidentiality

less likely than others to consent than others (Sakshaug et al., 2012). It is therefore logical to give each individual in a household a few general options for linking data to their Census form, such as separate consent for economic, education and health linkage. Supplementary information on exactly what is included in each of those domains should be made available on the ABS Census website so that individuals can make an informed decision about what datasets they want to be permitted for linkage with their Census. Providing information on the kinds of research that has been performed, as is done for the [UK Millenium Cohort Study](#), would also help people to see what kinds of research is being done and whether they want to facilitate this work.

### **Ministers Have Disregarded Public Concerns**

The comments of Michael McCormack, the Minister for Small Business who was responsible for the ABS on Census night show that he had little regard for privacy or freedom. His suggestion that the privacy concerns were “much ado about nothing”, accompanied by Christopher Pyne’s “[tin foil hat](#)” comments completely ignored importance of the government’s coercive power with respect to the Census. People concerned with civil liberties and privacy are interested in protecting people’s freedom from arbitrary intrusions and freedom to choose what to share about themselves and with whom it is shared. Freedom is not “nothing”. The appointment of Ministers who are competent and actually care about their portfolios is the job of the Government.

### **Census-Related Penalties Are Disproportionate**

The *Census and Statistics Act 1905* provides for fines of one penalty unit for failing to follow a direction to complete the Census or other ABS survey and ten penalty units for a false or misleading statement. However, the ABS claims that they have the power to fine people up to \$180 per day (this claim is repeated on the “Final Notice” given to residents who have not completed the Census and is signed by Duncan Young). This is completely disproportionate to the offense.

Surveys do not need a 100% response rate in order to provide useful information, nor does all of the information have to be absolutely accurate. In fact, some ‘perturbation’ of unit-level data is performed by the ABS to [protect confidentiality](#). This involves randomly changing some data cells so that the data is more difficult to tie back to an individual but that the overall statistical findings are still accurate. Accordingly, the penalty for a false statement specified in s 15 should be reduced to five penalty units. At \$900 this would be a strong disincentive to giving false information without being disproportionate.

The *Census and Statistics Act 1905* should be amended to remove the possibility that the non-response fines under s 14 could accumulate. [Failure to vote](#) incurs an initial fine of just \$20 and refusal to pay the fine then may result in a conviction and a fine of \$180. Similarly, it should be possible to fail to complete the Census only once. The coercive power of a \$180/day fine is disproportionate to the harm caused by not completing the Census, which was negligible for the 2006 and 2011 Censuses which both had response rates of more than 95%.

## Conclusions and Recommendations

The ABS has completely botched every aspect of the 2016 Census. Its PIA for the changes to the 2016 Census did not consult adequately and completely neglected the privacy impact analysis and compliance check recommended by the OAIC Guidelines for Performing PIAs. The extended retention of names and address for statistical linkage is an extension of government power with no Parliamentary mandate. However, it is highly practical for statistical linkage to proceed in a future Census where consent options are provided to individuals. Giving individuals the freedom to consent or not consent to statistical linkage is the most ethical response and the *Census and Statistics Act 1905* should be amended accordingly.

The purpose and scope of the Census is reasonable and not too invasive, but the voluntary nature of the religion question should be extended to all questions related to sensitive information as defined by the *Privacy Act 1988*. These include questions about race, ethnicity and health.

Additionally, ministerial oversight of the ABS and the Census has been inadequate and the penalties associated with the Census are disproportionate, especially when compared against similar civic duties such as voting. This has allowed public narratives of heightened concern for privacy and coercion to dominate, reducing the response rates for the Census and its statistical value. Therefore, I urge the Senate and the Australian Parliament to:

1. Amend the *Census and Statistics Act 1905* to require consent for statistical linkage of Census data. Separate consent should be required for each individual and each domain (e.g. economic, education and health data);
2. Direct the ABS to release more detailed information on the processes of statistical linkage that they are using for review by experts and privacy advocates, including but not limited to the actual statistical linkage key or encryption method used;
3. Amend the *Census and Statistics Act 1905* to make the provision of names voluntary. The ABS should still collect names for administrative purposes, but should have no power to prosecute those who do not provide this information;
4. Amend the *Census and Statistics Act 1905* to prohibit the retention of names beyond 18 months without consent;
5. Amend the *Census and Statistics Act 1905* to make all questions on sensitive information as defined by the *Privacy Act 1988* voluntary;
6. Amend the *Census and Statistics Act 1905* to remove the possibility for multiple fines to be issued under s 14 and to reduce the number of penalty units specified in s 15 from 10 to 5; and
7. Amend the *Privacy Act 1988* to provide for mandatory data breach notification, i.e. notification and restitution to affected persons if an agency discovers that personal information has been subject to unauthorised access or disclosure.

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