

**Response to Consultation on the  
Census and Statistics Amendment (Statistical  
Information) Regulations 2019**



**FUTURE**  
WISE

## Introduction

Thank you for the opportunity to submit to this consultation relating to amendments to the *Census and Statistical Regulations 2016* (“the Census regulations”). Future Wise is alarmed at the marked lack of explanatory material accompanying these proposed changes, and again notes the inadequate consultation period for such important changes to the Census.

## About Future Wise

This submission is authored by Future Wise. We are a group of Australian professionals of varied backgrounds who seek to promote ideas that improve the long-term direction of Australia, particularly in the areas of technology, health and education. More information about Future Wise is available on our [website](https://futurewise.org.au/).<sup>1</sup>

## Summary of Response

The Australian Bureau of Statistics (“the ABS”) and The Treasury **must** develop a protocol for appropriate consultation around changes to the statistical information collected in the Census. This protocol must include: appropriate timeframes with a specific prohibition of short consultation windows over the Christmas period; a requirement for adequate supporting information to allow informed submissions; the requirement that any changes with impact on citizens’ privacy be accompanied by a preliminary privacy impact assessment.

Future Wise does not have a strong position on the collection of information about defence force service. However, we are concerned that this information is not already easily available to the Departments of Defence and Veterans’ Affairs.

We reserve our position on the collection of data about internet access at home, as the explanatory notes are of insufficient quality to make an informed decision about

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<sup>1</sup> <https://futurewise.org.au/>

the consequences of this change. Future Wise supports the universal availability of access to the internet, and believes that questions about the use of the internet at home, or via mobile devices may provide useful information about trends in broadband internet use, availability and access. The utility of collecting this data via the Census lies in the data's ability to be linked with social / economic data, to allow assessment of the degree of "digital divide" in Australia.<sup>2</sup>

However, Future Wise absolutely rejects any move to collect personal health information via the Census. Citizens' healthcare data is too sensitive and confidentiality is valued too highly to risk any misuse of this data.

Despite the absence of any detail about the proposal to collect healthcare information, there are four foundational reasons to reject it:

1. absence of privacy safeguards
2. the inevitability of the capability to re-identify such information<sup>3</sup>
3. the access to such personal data by multitudes of people for purposes distant from the care of the person disclosing enhancing the likelihood of the misuse of data
4. the likely low quality of the data in any event given self-disclosure, lack of trust, possible lack of comprehension of or clarity about one's medical diagnoses amongst the general public, ambiguous breadth of the question (as framed in the discussion paper) and in respect of Aboriginal and Torres Strait Islander Australians in particular, a fear of government

The information made available as part of this consultation is woefully inadequate to make an informed assessment of the risks and benefits of any move to collect healthcare data as part of the Census to be able to make a more specific analysis of the proposal.

Lastly, we also highlight the significant distrust of the Bureau and the online Census program as a result of the challenges with collecting online census information

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<sup>2</sup> Hilbert M. *J Assoc Info Sci Tech* (2013). doi: 10.1002/asi.23020

<sup>3</sup> Chris Culnane, Benjamin IP Rubinstein and Vanessa Teague, 'Health Data in an Open World' (15 December 2017) arXiv:1712.05627.

(referred to in the media as “#Censusfail”).<sup>4</sup> The Bureau and the Department have not only failed to repair this ill-will,<sup>5</sup> public discourse seems to indicate that the Department is aggravating the ill-will by again having a consultation period of less than one month, occurring over the Christmas holidays.

Future Wise looks forward to further engagement with the Treasury and the Bureau on changes to the 2021 Census and beyond, and to ensuring that any further consultations on the collection of sensitive information are thorough, timely and meaningful.

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<sup>4</sup> <https://www.theguardian.com/business/grogonomics/2016/aug/11/lesson-of-censusfail-continued-funding-cuts-mean-agencies-cant-do-their-job>

<sup>5</sup> <https://delimiter.com.au/2016/04/14/australian-privacy-foundation-slams-orwellian-census-data-retention/>

## Response in Detail

### Inadequate and bad-faith Consultation

Future Wise expresses its extreme disappointment in all aspects of this consultation.

#### Timing

The plan for the 2016 Census to retain names and address was announced in a blandly-titled media release - "ABS to conduct a Privacy Impact Assessment"<sup>6</sup> - released at 1130 on 11th November (ie: immediately following the minute silence for Remembrance Day) and called for feedback by 2nd December - a consultation period of only 21 days. The report of the PIA<sup>7</sup> notes that "Public feedback consisted of three responses from private citizens who all raised concerns with the proposal". It was extremely unlikely there would be significant response to a consultation with such obscurity of its announcement. Despite this, the proposal was strongly objected to by privacy peak bodies<sup>8</sup> and commercial privacy consultants.<sup>9</sup>

This 2021 Census consultation was publicised on a Friday (13th December) - the last day of school in many jurisdictions, with a consultation period of 28 days - including the Christmas and New Year period. The email notification of consultation to Future Wise as an involved stakeholder was received at 1735 Friday afternoon.

Future Wise believes that the Bureau and the Treasury should be required to consult in good faith, and that "taking out the trash"<sup>10</sup> late on Friday afternoon falls far short of this standard.

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<https://www.abs.gov.au/AUSSTATS/abs@.nsf/mediareleasesbyReleaseDate/080BA8A92516B088CA257EF9007CD28A?OpenDocument>

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[https://www.abs.gov.au/websitedbs/D3310114.nsf/4a256353001af3ed4b2562bb00121564/9099c77cb979d558ca258198001b27a0/\\$FILE/ATTF8YH1.pdf](https://www.abs.gov.au/websitedbs/D3310114.nsf/4a256353001af3ed4b2562bb00121564/9099c77cb979d558ca258198001b27a0/$FILE/ATTF8YH1.pdf) ABS Privacy Impact Assessment 2016 Census.pdf

<sup>8</sup> <https://privacy.org.au/campaigns/census2016/>

<sup>9</sup> <https://www.salingerprivacy.com.au/2016/08/06/why-im-taking-leave-of-my-census/>

<sup>10</sup> Walsh J & Austin GP. Available online: <https://kenbenoit.net/pdfs/NDATAD2013/Taking Out The Trash.pdf>

## Accompanying Information

Two documents were made available on the Treasury's website<sup>11</sup> for this consultation - the Exposure Draft - which is six pages long and consists of two pages of front matter, two blank pages and two pages of the draft Bill. The first content page relates to administrative matters, and the second content pages consists of three amendments consisting in total of approximately one-third of a page.

The Explanatory Statement is two pages long. The first page is entirely administrative, and the first half of the second page relates to the mechanics of the Bill. This leaves slightly under one-half page of "explanation" to cover the three amendments.

Future Wise believes that this falls far short of what is required to allow an informed submission to the consultation by most of the general public. It is likely that many well-informed citizens would not have sufficient content knowledge of the topics to develop informed positions on the complex topic of demographic and health data.

We feel that this failure to adequately explain the implications of the changes, along with the inadequate time for consultation in combination create the impression that the Bureau has already decided on the course of action and that the consultation is a pretense only.

## **Government Position on Data**

Future Wise supports the use of data for the provision of Government services, population health and demographic research.

However, we believe that the onus is on the individual or organisation seeking to collect additional data that this data request is in response to a defined question (ie has *purpose*), is truly *necessary* for this purpose, and that the risks of collecting this data are *proportionate* to the expected benefits arising from its collection.

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<sup>11</sup> <https://treasury.gov.au/consultation/c2019-41183>

We note that the Government has taken on a position which could be described as “data evangelism” - such as the Minister’s Foreword<sup>12</sup> to the Government’s response to the Productivity Commission’s Data Availability and Use report which begins “Australia’s data is a major national resource”.

Future Wise rejects this framing of the data of Australian Citizens. We believe that the role of government is to act in the best interests of citizens, and that this means ensuring access to data only occurs when the risks are justified by the potential benefits. This means there should be a clear vision of what these benefits are, and that there is an open discussion including these risks and benefits to allow truly informed consent prior to citizens consenting to the use of their data (where appropriate) or release by the data custodian otherwise.

A position of “access to data by default” - as seems to be the theme in the Government’s discussion papers on data creates a default setting where there is risk to citizens’ data privacy, and we believe that this is inconsistent with the Government’s responsibility to act in the best interests of its citizens.

We will address the purpose, necessity and proportionality of this data request later in the submission. We note, however that it is difficult to assess these factors from the very limited consultation material provided.

## **Content of the Bill’s Amendments**

### Defence Service

It is of concern that data relating to Australians’ service in the Defence Forces may not be already available to the Departments of Defence and Veterans’ Affairs. If these data are available, then presumably the desire to include this question in the Census is to allow a more detailed investigation of the Census’ other demographic data in the serving / veteran population. This is supported by the explanatory material highlighting “services and support related to....health, economic and social

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<sup>12</sup> <https://dataavailability.pmc.gov.au/ministers-foreword.html>

wellbeing". This would seem on the surface to be a reasonable *purpose* for collecting additional data.

Further consultation should be undertaken with service groups and veteran bodies to explain whether the additional data is truly necessary or if existing datasets from Defence, Veterans' Affairs, Health and Ageing and Human Services, and other statutory agencies such as the Australian Institute of Health and Welfare or the Commissions for Healthcare / Aged Care can already be used to answer questions relating to defence personnels' health.

### Health Information

Future Wise has a strong interest in the privacy of health data, so our comments will focus on this area in detail.

We note the Bureau of Statistics' Consultation on Topics for the 2021 Census<sup>13</sup> addressed the issue of health information in the Census when it was published in 2018.

It is not clear from either the current or the 2018 consultation how collecting these data using the Census is more "fit for purpose" than the dedicated health data collection surveys, such as those listed in the 2018 consultation. If there is already an existing method for directly gathering these data from Australians, what additional benefit does collecting them through the Census provide? Is it for the purpose of cost-saving, given that the Census occurs anyway? If this is the case, can we be assured that the data being collected via the Census will be of as good a quality as that corrected by a directed health survey?

We note the comment in this consultation document:

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<sup>13</sup> [https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by Subject/2007.0~2021~Main Features~Other topics~18](https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by+Subject/2007.0~2021~Main+Features~Other+topics~18) - accessed 8 Jan 2020



*"Questions that are controversial or could cause adverse reactions may also not be answered correctly. Such questions could also adversely affect the quality of other responses."*

However, the collection of health information ignores this crucial fact in a number of ways.

First, the individuals may have poor recall or accuracy of the data themselves, given the well-known propensity for patients to retain only a tiny fraction of information presented to them.<sup>14</sup> If the Census is being completed as a household group, then there may be a lack of knowledge about all of an individual's health conditions. This could occur through it being forgotten, not disclosed in the first place, or deliberately concealed from another member of the family. Collecting information in this way runs the risk of either threatening the privacy of an individual who wants to keep their information personal, or compromising the quality of the dataset.

#### Wording of the Question

The utility of asking about "health conditions diagnosed by a doctor or nurse" is potentially extremely limited in a number of ways, best illustrated with a number of examples:

- a) a post-menopausal woman in her 50s lists "pre-eclampsia" - she was diagnosed with this during her first pregnancy more than 20 years ago
- b) a manual labourer in his 30s suffers back pain and receives chiropractic care for it. He does not list this on the Census as he has not received a diagnosis from a doctor or a nurse
- c) a woman in her 70s who is a chronic smoker lists "bronchitis" - does she have a viral upper respiratory tract infection, chronic bronchitis, or bronchiectasis?

#### Duplication of Data Collection

We also highlight that there are other ways of assessing this sort of data; the prevalence of hypertension in the Australian population could be estimated by

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<sup>14</sup> Ley P. *Brit J Clin Psychol* (1979). doi: [10.1111/j.2044-8260.1979.tb00333.x](https://doi.org/10.1111/j.2044-8260.1979.tb00333.x)

interrogating Pharmaceutical Benefits Scheme data for the number of individuals dispensed one or more prescription for an antihypertensive medication. This method would likely result in a much more accurate snapshot of hypertension in the population than collection via the census.

There are a large number of health datasets collected in Australia which provide a number of different angles on the health of the Australian population - including the MBS / PBS datasets and the extensive information collected by the Australian Institute of Health and Welfare.<sup>15</sup> We also note that the one of the potential benefits of secondary use of myHealthRecord data was to allow health service planning, which appears to duplicate the stated objectives of collection this information via the Census.

There seems then to be only one *purpose* to the collection of the data via the Census.

#### Data Linkage

As discussed above, the Census allows the localisation of data to smaller statistical areas than these other datasets, and also allows the linkage of health data with the other demographic information obtained by the Census.

We note the 2018 consultation discussion explicitly includes the following:

*"Stakeholders have expressed an interest in getting data on people with certain long-term health conditions at small geographic areas and for smaller population groups"*

Greater granularity of the data as outlined here inherently increases the privacy risk. The presence of an unusual condition in a remote area, or other division with a small number of individuals greatly increases the risk that the very presence of a health condition will allow the unique identification of the data belonging to this individual. This is referred to as the "small cell size problem" and was discussed in the paper by Culnane, Rubinstein and Teague.<sup>3</sup>

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<sup>15</sup> <https://www.aihw.gov.au/reports-data/australias-health-performance>

We also register our concerns about who exactly the stakeholders wanting access to these data are, and restate our complete opposition to private health insurance companies or private hospital operators from having access to these data.

Future Wise is not aware of any discussion about how the collection of health data will interact with the previous discussion about retaining reidentifiable Census responses. We categorically reject any consideration of retaining Census responses which contain health information and are able to be linked to an individual.

## Conclusions

Future Wise looks forward to greater engagement with the Bureau of Statistics and The Treasury on future consultations about changes to the Census.

We call on ABS and The Treasury to introduce and publicise a formal procedure for consultation on changes to the Census which explicitly

- allows sufficient time for informed and reasoned submissions to be submitted
- ensures that consultation drafts / statements contain relevant information to allow these submissions to be informed by the facts
- all changes to the Census be proposed with an accompanying privacy impact assessment prior to the consultation phase
- there be a formalised process for engaging with civil society organisations such as Future Wise, Electronic Frontiers Australia, the Australian Privacy Foundation, or other relevant organisations, and to also include peak health consumer representative bodies

With regards to the substantive changes to the Census, Future Wise

- objects very strongly to the collection of health data via the census on the basis that there is no clearly articulated *purpose* for the data collection
- believes that collection of the data via the Census has a number of flaws including accuracy and completeness and significantly duplicates existing datasets for no clear benefit
- strongly believes that the linking of health data with demographic data places the privacy of Australian citizens at risk - and for small-area demographic data this includes linked data which is not reidentified

We therefore call for the reading of the Bill to be deferred until after these critical issues are addressed.

Future Wise has also reviewed the Submission by Mr Daniel Axtens, and strongly commends its suggestions in addition to our own.