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Treasury  
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**Re: Submission into the Census and Statistics Amendment (Statistical Information) Regulations 2019**

Dear Macroeconomic Modelling and Policy Division

Positive Life NSW (Positive Life) welcomes the opportunity to provide a submission into the Census and Statistics Amendment (Statistical Information) Regulations 2019.

Positive Life is the state-wide peer based non-profit organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV) in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all PLHIV, and to change systems and practices that discriminate against PLHIV, our friends, family and carers in NSW.

### Background

The Australian Government Treasury Department is consulting with the public for a period of 29 days regarding the Census and Statistics Amendment (Statistical Information) Regulations 2019 (the Amendment Regulations), which aim to amend the Census and Statistics Regulation 2016 (the Census Regulations) to update the list of topics in relation to which the Statistician shall collect statistical information in the 2021 Census.

The Treasury is proposing to amend one of the Census sections as follows:

- Section 9 (s9) by adding a topic relating to: “health conditions diagnosed by a doctor or a nurse”.
  - The rationale behind this amendment is that: “this topic will be answered by all respondents and assist health service planning and service delivery at the local level”.<sup>1</sup>

Positive Life has concerns about this amendment to Section 9, and potential privacy issues and/or security breaches inherent in it, as detailed below.

### Privacy and Confidentiality

The Privacy Act 1988 (Cth) (Privacy Act) was introduced to promote and protect the privacy of individuals and to regulate how Australian Government agencies and organisations with an annual turnover of more than \$3million, and some other organisations, handle personal information.<sup>2</sup> The Australian Bureau of Statistics (ABS) is subject to the Privacy Act and to the Australian Privacy Principles (APPs) contained in the Privacy Act. In addition to the Privacy Act, the ABS is also bound by the secrecy requirements of the Census and Statistics Act 1905 (Census & Statistics Act) which prohibits the release of information

<sup>1</sup> Minister for Housing and Assistant Treasurer, ‘Exposure Draft Explanatory Statement: Census and Statistics Amendment (Statistical Information) Regulations 2019’, accessible at: [https://treasury.gov.au/sites/default/files/2019-12/41183\\_census\\_explanatory\\_statement.pdf](https://treasury.gov.au/sites/default/files/2019-12/41183_census_explanatory_statement.pdf)

<sup>2</sup> Australian Government Office of the Australian Information Commissioner, ‘Privacy’, accessible at: <https://www.oaic.gov.au/privacy/the-privacy-act/>

collected for a statistical purpose in a manner that is likely to enable the identification of any person or business.<sup>3</sup>

Under the Privacy Act and APP-3 -Collection of solicited personal information, the ABS as an entity must not collect personal information (other than sensitive information) unless the information is reasonably necessary for, or directly related to, one or more of the entity's functions or activities (APP-3.1). Furthermore, under APP-3.3 an APP entity must not collect sensitive information about an individual unless: (a) the individual consents to the collection of the information and: (i) if the entity is an agency - the information is reasonably necessary for, or directly related to, one or more of the entity's functions or activities.<sup>4</sup>

Arguably, given that under S14 of the Census & Statistics Act it is an offence to fail to answer Census questions with up to one penalty unit (\$180) per day, which in practice has been applied per time the person was asked to respond, and S15 makes it an offence to give a false and misleading answer to a Census with up to ten penalty units<sup>5</sup>, this could not reasonably be considered as consent by the individual. Although illegal to knowingly provide false or misleading information on a Census form, perceived risks to privacy and confidentiality may be a sufficient cause for some people to avoid answering the question proposed under s9: "health conditions diagnosed by a doctor or a nurse" in order to protect their privacy. This could potentially jeopardise the viability of the Census and the accuracy and integrity of other data collected in each sample due to the extreme sensitivities around certain types of health conditions including blood borne virus diagnoses (HIV, HAV, HBV, HCV, STIs), mental health diagnoses, alcohol issues, and illicit drug use/addiction/rehabilitation issues. The fact that these issues are often experienced in tandem further exacerbates the risk of non-disclosure by certain members of the community. It should be noted that the Census completion is often done in family units creating additional levels of anxiety over privacy and disclosure. The response rate is vital to the effectiveness of the Census, and this is or may be affected by perceptions of overreach.

A concept utilised by the Parliamentary Joint Committee on Human Rights was whether the Census applied the least intrusive way of achieving the objective (AUPJCHR Scrutiny Report 8/2016 - 2.130). "However, it is unclear whether the measures are a proportionate means of achieving their apparent objective. To be proportionate limitations of the right to privacy, the measures must be accompanied by appropriate safeguards and be sufficiently circumscribed with respect to the collection, use, retention and disclosure of personal information. A measure that lacks these elements may not be the least rights restrictive way of achieving the objective of the measure, in which case it would be incompatible with the right to privacy."<sup>6</sup>

### Security and Data Retention

<sup>3</sup> Australian Bureau of Statistics, 'ABS Privacy Policy Summary', accessible at: <https://www.abs.gov.au/websitedbs/D3310114.nsf/Home/Privacy?opendocument>

<sup>4</sup> Australian Government Office of the Australian Information Commissioner, 'Privacy/Australian Privacy/Principles guidelines, Chapter 3: APP 3 - Collection of solicited personal information', accessible at: <https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-3-app-3-collection-of-solicited-personal-information/>

<sup>5</sup> Federal Register of Legislation, 'Census and Statistics Act, No. 1 (1905), Compilation No. 8' (21 October 2016), accessible at: <https://www.legislation.gov.au/Details/C2016C01005>

<sup>6</sup> Parliament of Australia, 'Parliamentary Business/Committees/Joint Committees/Parliamentary Joint Committee on Human Rights/Scrutiny Reports/Committee Reports 2016/Report 8 of 2016/Chapter 2', accessible at: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/Human\\_Rights/Scrutiny\\_reports/2016/Report\\_8\\_of\\_2016/c02](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/Scrutiny_reports/2016/Report_8_of_2016/c02)

*The ABS states that they are bound by the Privacy Act 1988 (Privacy Act), the Census and Statistics Act 1905, the Australian Privacy Principles, the Census Privacy Policy, and the ABS Privacy Policy.<sup>7</sup>*

*In Chapter 5 of the Senate Economics References Committee's report on the inquiry into the 2016 Census, there were a number of security privacy concerns relating to data retention that were raised. Specifically in 5.11 and 5.12, "concerns were raised that by storing the name and address information - as well as future datasets that are created from the linkage of Census information - the ABS is creating a 'honey pot' or target. It was suggested that the nuanced datasets resulting from linking Census data would be very tempting to criminal organisations and foreign governments, as well as susceptible to misuse by Australian government and security agencies. It was pointed out that due to the nature of digital information a single unauthorised disclosure can release huge amounts of information, and once that information is public there is no way to recover it. Furthermore, the longer the information is held the greater the risk of eventual exposure. It was highlighted that if the data is not collected, then it cannot be exposed."<sup>8</sup>*

*Privacy concerns in the public have been increasing in recent years, and there have been a number of high profile health data security breaches worldwide including those recently in the National Health Service (NHS Digital) in the United Kingdom. In Chapter 5.15 of the Senate Economics References Committee's report it is stated that it "was provided details of recent unauthorised data releases from a variety of government agencies such as the Department of Immigration and Border Protection, the Bureau of Meteorology, the Department of Human Services, the United States' National Security Agency and the United States Office of Personnel Management, and the United Kingdom's Ministry of Defence, among other private enterprises."<sup>9</sup>*

*As technology is progressing, we are seeing increasing examples of data breaches of large data sets and the ongoing risk of human error, 'enhanced data sharing' and scamming violations. Additionally, as the ABS will retain all data linked from all ABS surveys and the Census, which is nominally de-identified, there is such a large data reservoir that re-identification is entirely possible. In Chapters 5.30 and 5.34, of the Senate Economics References Committee's report it was noted that "Improvements in technology and digital archiving have been one of the key driving forces behind statistical linkages and data retention. While improvements in this field have opened up new avenues of research and knowledge, improved computing power can also increase the ability of an adversary re-identifying a dataset...It was pointed out to the committee that there have been examples since the 2016 Census of Australian Government agencies releasing datasets that were supposedly de-identified being re-identified. The Department of Health and the Australian Public Service Commission both released datasets that were later able to be re-identified."<sup>10</sup> A 2019 study from Macquarie University concluded that data collected in the 2016 Census was vulnerable to hackers through the exploitation of the ABS' data visualisation tool. While the ABS claimed that the flaw had been subsequently addressed, it was not clear to the Macquarie University*

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<sup>7</sup> Australia Bureau of Statistics, 'Privacy, Confidentiality & Security', (2019), accessible at:

<https://www.abs.gov.au/websitedbs/censushome.nsf/home/privacy?opendocument&navpos=130>

<sup>8</sup> Parliament of Australia, 'Parliamentary Business/Committees/Senate Committees/Senate Standing Committees on Economics/2016 Census/Report/Chapter 5', accessible at:

[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Economics/2016Census/Report/c05](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Economics/2016Census/Report/c05)

<sup>9</sup> *ibid*

<sup>10</sup> *ibid*

researchers that the measures taken would be enough to guarantee security.<sup>11</sup> Requiring details of health conditions within a dataset that also requires full names and current and previous addresses (retained for the first time in the 2016 Census for a period of either 5 years or indefinitely), and other personal demographic information such as date of birth, education level, income, and employment status could therefore compound efforts to protect people's privacy or confidential information.

### Alternative Data Collection

S95A of the Privacy Act allows the Privacy Commissioner to issue guidelines for collection of health information and imposes a public interest test for collection disclosure of such information collected under s16B. The Privacy Commissioner guidelines suggest that: "in deciding whether the collection of health information is 'necessary' to provide a health service, an organisation should consider if there are reasonable alternatives available."<sup>12</sup> Health data is a different category of data than previously collected via the Census. Previously collected data was of an economic (income/debt/education) or social (religion/marital status) type. There are ample other data collection mechanisms that the Australian and State governments can, do and should utilise for the purposes of health service planning and delivery, including expert data reporting processes.

The notification of a health condition diagnosed by a doctor or a nurse is self-reported, and would not provide specific, accurate or sufficient data to inform health service planning or delivery. Furthermore, the mere notification of a health condition does not in itself provide information as to the level or complexity of that condition which can vary considerably on an individual basis, and may or may not be a condition that impacts health service planning and/or affects service delivery. This level of individualised health information would be better suited to a person-centred health service delivery model to ascertain the specific health and social determinants of health requirements and service needs of individual people on a case-by-case basis. Other health-related government departments, health providers, community sector and not for profit organisations, and research institutions are already well placed to collect data, develop public policy, and plan service delivery models where there is delegated remit for this data collection, as well as significantly reduced risk of identifiable confidential health information being breached. Additionally, question 23 of the existing Census list of topics already asks: "What are the reasons for the need for assistance or supervision shown in Questions 20, 21 and 22?" with responses capturing: "No need for help or supervision; Short-term health condition (lasting less than six months); Long-term health condition (lasting six months or more); Disability (lasting six months or more); Old or young age; Difficulty with English language; and Other cause".<sup>13</sup>

A case could be made that different topics around health and other social determinants of health topics could be included in the Census questions, such as the lived experience of domestic violence, incarceration, homelessness, etc. as public policy and service planning and delivery at local, state and federal levels go much further than health-related initiatives.

### Consultation

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<sup>11</sup> Joseph Brookes. Which-50. 'Uni researchers found a way to identify individual census responses and reconstruct the entire database.' (22 February, 2019), accessible at: <https://which-50.com/uni-researchers-found-a-way-to-identify-individual-census-responses-and-reconstruct-the-entire-database/>

<sup>12</sup> Australian Government, National Health and Medical Research Council (NHMRC), 'Guidelines approved Under Section 95A of the Privacy Act 1988' (March 2014), accessible at: <https://www.nhmrc.gov.au/sites/default/files/documents/attachments/guidelines-s95a-privacy-act-pr2.pdf>

<sup>13</sup> Australia Bureau of Statistics, 'Census Household Form', (2016), accessible at: [https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2901.0Main%20Features802016/\\$FILE/2016%20Census%20Sample%20Household%20Form.pdf](https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2901.0Main%20Features802016/$FILE/2016%20Census%20Sample%20Household%20Form.pdf)

*Prior to the 2016 Census, respondents could opt-in to having personally identifiable information retained (including names and addresses, which can now be potentially retained indefinitely). Positive Life believes that the 2021 Census should have the same privacy protections provided to respondents, in line with community expectations and the right to privacy.*

*Positive Life requests that the Macroeconomic Modelling and Policy Division of the Treasury extend the consultation period for this important amendment to the Census regulations in order to conduct a thorough research and consultation process with the aim of protecting and safeguarding Australians' privacy and confidentiality of personal and health information, while balancing the intended outcomes of the Census to make it as strong as possible for all Australians including those living with HIV, and enhancing confidence in the Census more broadly.*

*If this submission requires additional information or clarification, I can be contacted at [janec@positivelife.org.au](mailto:janec@positivelife.org.au) or on 02 9206 2177.*

*Yours respectfully,*

A handwritten signature in black ink that reads "Jane Costello". The signature is written in a cursive style with a long horizontal stroke underlining the name.

*Jane Costello  
Chief Executive Officer*

*10 January 2020*