

Senate inquiry into the 2016 Census

Dear Senators,

I would like to comment on the intrusiveness and insensitivity of the medical and disability questions and on the compulsory nature of those questions, in breach of the patient rights of people with a disability. This falls under the 'scope' sections of the terms of references for this inquiry:

- the scope, collection, retention, security and use of data obtained in the 2016 Census;
- Australia's Census of Population and Housing generally, including purpose, scope, regularity and cost and benefits;

The specific questions this relates to are Questions 20, 21, 22, 23, 32, 47 and 49. The archiving question at Question 60 is also relevant as this may cause the answers of a person with a disability or illness to be retained without their consent, and without the option to revoke consent at a later date.

20 Does the person ever need someone to help with, or be with them for, self care activities?

21 Does the person ever need someone to help with, or be with them for, body movement activities?

22 Does the person ever need someone to help with, or be with them for, communication activities?

23 What are the reasons for the need for assistance or supervision shown in Questions 20, 21 and 22?

32 For each female, how many babies has she ever given birth to?

47 If the person had found a job, could the person have started work *last week*?

49 In the *last two weeks* did the person spend time providing unpaid care, help or assistance to family members or others because of a disability, a long term health condition or problems related to old age?

60 Does each person agree to his/her name and address and other information on this form being kept by the National Archives of Australia and then made publicly available after 99 years?

Questions 20 to 22 relate to the care needed by persons with a disability.

Question 23 relates to the reason why they need that care, and provides the options of short or long term health condition, disability, age or language reasons.

Question 32 asks for the total number of babies born to females, including stillbirths.

Question 47 relates to job readiness and provides an option of being 'temporarily ill or injured'.

Question 49 relates to caring activities and may imply information about third parties if 'carer' has been listed as the relationship at Question 5.

Question 60 is the archiving question, which could easily be answered by someone other than the person it relates to without their knowledge, and which provides no avenue to check or change consent status at a later date.

With the exception of Question 60, none of the above questions are optional. The medical information requested is done so on a compulsory basis, under threat of a fine. This is at odds with the sensitivity and the undignifying nature of the information requested, and also with basic patient rights. It is a fundamental right of all patients to choose whether to share or to withhold information, and with whom to share it. The ABS is claiming a right of access to medical information which even doctors don't (and shouldn't) have.

The rationale given for this forced disclosure of disability information is to help with the planning and delivery of disability services. While important, I don't agree that that is sufficient reason to override the rights of people with a disability. I don't think that it's appropriate for a government body to demand, under threat of a fine, information regarding people's toileting and personal care needs, and to leave them with no option to protect their dignity except to lie and risk that fine. Whatever benefits there may be from collecting this information have to be balanced against the message being sent to people with a disability about how much their rights and freedoms are valued compared to those of able-bodied people. These questions should be optional.

I would also like to draw attention to Question 32, which asks for the total number of babies born to female residents, including any who may have been stillborn. Again, given the high level of sensitivity of the information being requested in this question, it should be optional.

Add to the above that the public are now being asked to trust the ABS to store our identified data for four years. Add to that that statistical linkage keys are now going to be attached to our census data, as well as to other highly sensitive data sources such as medical records, Medicare and PBS records, linking them all together without our consent. Add to that also that we are being asked to trust that our data can't be re-identified from those linkage keys, despite how detailed those data sources are when put together. All of this should be optional.

One final thought. Please think about what the reasons are for the religion question being optional, and then consider if those reasons also apply to disability. There are similar dark histories in the treatment of disability as for religion, even if census data wasn't then available for use with both. Any medical and disability information requested in the census should be optional.

Thankyou,

Rebecca Flynn.