

Review of 2021 Census Topics: Submission Form

On completion, check and submit your form via

Email: census.content@abs.gov.au

Or

Mail: Census Topic Review, GPO Box 9817, Brisbane QLD 4001

Consent to Publish

While all responses received will be included in the analysis of this consultation, the ABS intends to make submissions publicly available after the closing date of 30 June 2018 to share views about the data needs of the Australian community.

If your submission identifies or names an organisation you have collaborated with, please consider obtaining their consent prior to agreeing for the ABS to publish your submission.

Can we publish your submission after the consultation period closes? (see below for details of what each option represents)

Yes	
Yes, but do not publish any parts that are identifia	ıble
No	

After the closing date of 30 June 2018, submissions received will be available on this consultation where your approval has been given.

- By selecting Yes:
 - You give permission to publish your responses to the assessment criteria as well as who you are representing and organisation name (if applicable). Contact details, including name, phone number and email address will not be published.
- By selecting Yes, but do not publish any parts that are identifiable: You give permission to publish your responses to the assessment criteria only. Who you are representing, organisation (if applicable) and contact details will not be published.
- By selecting No: No part of your submission will be published.

Contact Details

Department of Health

Should we need to communicate regarding this submission, please provide details of the appropriate contact. We will contact you only if we have questions regarding your submission.

The ABS Privacy Policy outlines how the ABS will handle any personal information that you provide to us.

Contact name: \$22
Email address: \$22
Phone number: s22
Who you are representing:
(please select applicable)
oxtimesCommonwealth government department
\square State/territory government department
☐Local government
□Business
☐Industry body/association
☐Community group
☐ Educational institution
\square An individual
□Other
If other please specify:
Name of your organisation (if applicable):

Please list any other organisations you have collaborated with on this submission.

Please consider obtaining their consent prior to agreeing for the ABS to publish your submission.

What is your submission about?	
Below is a list of topics related to data curre	ently collected on Census.
Choose one that is the most closely related	d to your submission.
\square Population	
\square Sex and gender	
\square Households and families	
\square Aboriginal and Torres Strait Islander	peoples
\square Income and work	
\square Unpaid work and care	
\square Education and training	
\square Disability and carers	
\square Housing	
□Location	
\Box Transport	
\square Cultural diversity	
□Religion	
⊠ Other topic	
If Other topic please specify: Chi	ronic Conditions
Please note: If you would like to submit submissions.	ideas on more than one area of interest, please complete separate
Please provide a brief summary of you	r submission

. . .

This submission seeks the inclusion of a topic in the 2021 Census on self-reported prevalence of chronic conditions, to support planning and delivery of health care services for regions, communities and population groups.

The topic is of current national importance.

You may wish to consider the following points in your response.

- data is required for an electoral or legislative purpose
- data is needed to support policy development, planning or program monitoring
- data is used for research purposes

Data on chronic conditions are required to support policy development, planning and service delivery and program monitoring.

Chronic conditions are the leading cause of illness and death in Australia. The burden of chronic conditions in Australia is growing – a factor in the increased demand for services and rising health expenditure.¹

Chronic conditions are becoming increasingly common due to our ageing population as well as our changing lifestyles. The increasing prevalence of chronic conditions, combined with their long term and persistent nature, and their impact on quality of life and overall health, is placing unprecedented pressure on individuals, families, our communities, and the health system. ²

According to self-reporting in the 2014-15 National Health Survey, 1 in every 2 Australians (50%) have at least one prominent (i.e. arthritis, asthma, back pain, cancer, cardiovascular disease, chronic obstructive pulmonary disease, diabetes or mental health) chronic condition. The 2014-15 National Health Survey data also shows that nearly a quarter of all Australians (23%), and 3 in every 5 Australians (60%) aged over 65 years, had two or more chronic conditions.³

The National Strategic Framework for Chronic Conditions was publically released in May 2017 following endorsement by all health ministers⁴. During consultation to develop the Framework, feedback highlighted the need for progress against the Framework to be monitored in a consistent manner and informed by a nationally agreed set of performance measures which, where possible, align with Australia's international reporting commitments. Monitoring progress against the Framework would assist to create accountability and to enable formal and consistent reporting on chronic conditions in Australia.

Chronic conditions are being addressed at a national level through a wide range of programs and initiatives to support prevention, treatment and management. Significant funding is also provided to ensure that quality clinical research is conducted into chronic conditions, and to maintain national monitoring and surveillance measures.

- 1. Australian Institute of Health and Welfare 2016, Australia's health series no. 15, Cat. no. AUS 199, Canberra
- 2. Australian Health Ministers Advisory Council, 2017 National Strategic Framework for Chronic Conditions, Australian Government, Canberra
- 3. Australian Bureau of Statistics, National health Survey: First Results 2014-15 ABS Cat. no. 4364.0.55.0014
- 4. Australian Health Ministers Advisory Council, 2017 National Strategic Framework for Chronic Conditions, Australian Government, Canberra

There is a need for data from a Census of the whole population.

You may wish to consider the following points in your response.

- data is needed for small population groups
- data is needed for small geographic areas
- the value of the topic is enhanced through combining with other characteristics collected in the Census

Despite the scale of the problem, there is limited information on the prevalence of chronic conditions at the local level, and for particular population groups. This hampers the ability to develop effective policies and programs to target health services to areas of need, and to evaluate their outcomes. It also limits the research and reporting on the social determinants that increase the likelihood of developing a chronic condition.

Data on self-reported prevalence of chronic conditions can support:

- Primary Health Networks (PHNs) which are focusing on the health of the populations within their regions, including whether some groups are more at risk of poor health outcomes than others. PHNs have a key role in ensuring that health services are more accessible and tailored to community needs, supporting general practitioners and other health professionals to deliver high quality care, and improving care coordination for those at risk of poor health outcomes;
- Possible local, regional and national targets that are determined by the Closing the Gap refresh, and supporting Aboriginal and Torres Strait Islander people to have access to effective health care services in urban, regional, rural and remote locations; and
- Stronger remote, rural and regional health outcomes by informing planning for health workforce distribution and health care infrastructure.

A chronic conditions topic would be significantly enhanced through combining with other characteristics collected in the Census to understand social determinants of health, and inform actions to address health inequalities.

Assessment criteria 3

The topic can be accurately collected in a form which the household completes themselves.

You may wish to consider the following points in your response.

- the topic is likely to be easily understood by respondents
- the topic can be collected in a simple question or questions
- respondents will easily know the answer to the question(s)
- The question(s) is easy and quick to answer

Short question modules on chronic or long term health conditions are currently included in a number of ABS and non-ABS collections.

The increased awareness of chronic conditions in the community will help to support the collection of meaningful data. It would be possible to focus on particular chronic conditions by selecting from a number of conditions which are easily recognisable by the public. If this approach is taken, the Department would like to have a further opportunity to provide input. Conditions of particular interest include dementia, arthritis, asthma, chronic pain, cancer, cardiovascular disease, chronic respiratory disease, chronic kidney disease, diabetes and mental health conditions (depression and anxiety). Other specific conditions may be nominated for particular sub-populations.

The topic would be acceptable to Census respondents.

You may wish to consider the following points in your response.

- the topic is not likely to be considered intrusive, offensive or controversial
- respondents are likely to be willing and able to answer accurately
- are there other considerations for specific groups?

ABS may be able to advise on the acceptability of the topic to Census respondents, as we understand that this topic was included in initial testing for the 2016 Census, but did not proceed given there were no changes to topics in the 2016 Census.

While the topic is not likely to be considered intrusive, offensive or controversial, questions on chronic conditions may be sensitive for some respondents, as is the case for some other Census questions. It will be important to provide information on the privacy and security safeguards for Census information, and public value of collecting this information in the Census, in order to assist respondents to be willing to answer accurately.

The collection of self-reported data on chronic conditions is known to have some limitations e.g. some individuals may be unwilling or unable to identify as having the condition, or family members may identify household members as having a condition without a formal diagnosis. However the lack of clinical data with respect to the prevalence of many chronic conditions means that the Census provides the best alternative to obtaining population level data.

Assessment criteria 5

The topic can be collected efficiently.

You may wish to consider the following points in your response.

- the topic or question will not present major difficulties for coding the information
- the topic or question will not require extensive processing
- the topic will not significantly add to the overall cost of the Census
- the topic will not require a lengthy instruction or explanation
- the collection of data on the topic will not require a large number of response categories or multiple questions

A topic on chronic conditions can be collected efficiently via a question which includes a number of specified conditions to be selected.

We do not envisage the need for lengthy instruction or explanation, but it will be important that the question wording and instructions provide guidance to ensure that information is collected with respect to conditions which are current (or very likely to re-occur), long-term and persistent, and likely to have been diagnosed and/or treated by a health care professional.

There is likely to be a continuing need for data on this topic in the following Census.

You may wish to consider the following points in your response.

- there is a need for time series data on the topic
- the topic is likely to remain relevant in the future

The increasing prevalence and impact of chronic conditions - particularly with the ageing of the population - means that there is a need for ongoing data collection on this topic.

The longitudinal data arising from this time series will provide another powerful tool in assessing health outcomes arising from policies and programs, directing further policy development, and providing warning signs of emerging issues.

Assessment criteria 7

There are no other alternative data sources or solutions that could meet the topic need.

You may wish to consider the following possible data sources and identify any barriers to access in your response.

- data which is collected for administrative purposes
- the topic is collected in an ABS survey or by another organisation
- data is produced through integration of existing data sources

Data on long term health conditions is collected via a number of ABS surveys, particularly the ABS National Health Surveys and the ABS National Aboriginal and Torres Strait Islander Health Survey. These will continue to be important in providing high quality information at the broad level, and to allow the data to be correlated with other detailed health information including risk factors, and use of health services. However it is not possible for sample surveys to provide disaggregated data at the level that is required – for small geographic areas and for small population groups.

There is registry information for some chronic conditions, but they only contain limited socio-demographic information, which limits the potential analysis that can be undertaken.

The Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme do not contain information on health conditions. While hospital morbidity data does hold this information, it is restricted to hospital presentations, and so does not provide adequate information for the population.

The Shared Health Summary within the My Health Record contains information on medical conditions, medicines, allergies and adverse reactions, and immunisations. This will not be a source of information for the entire population.

Any further comments?

If you would like to tell us anything else about your submission, please comment below.

You can also provide additional documentation to support your submission.