

IF WE DON'T COUNT IT... IT DOESN'T COUNT!

Towards Consistent National Data Collection and Reporting on Cultural, Ethnic and Linguistic Diversity





FECCA IS THE PEAK, NATIONAL MULTICULTURAL BODY REPRESENTING AUSTRALIANS FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS. FECCA'S ROLE IS TO ADVOCATE AND PROMOTE ISSUES ON BEHALF OF ITS CONSTITUENCY TO GOVERNMENT, BUSINESS, AND THE BROADER COMMUNITY.

FECCA STRIVES TO ENSURE THAT THE NEEDS AND ASPIRATIONS OF AUSTRALIANS FROM DIVERSE CULTURAL AND LINGUISTIC BACKGROUNDS ARE GIVEN PROPER RECOGNITION IN PUBLIC POLICY.

WE WORK TO PROMOTE FAIRNESS AND RESPONSIVENESS TO OUR CONSTITUENCY IN THE DELIVERY AND DESIGN OF GOVERNMENT POLICIES AND PROGRAMS. WE PROMOTE MULTICULTURALISM AS A CORE VALUE THAT DEFINES WHAT IT MEANS TO BE AUSTRALIAN IN THE 21ST CENTURY.

ACKNOWLEDGEMENTS

FECCA wishes to acknowledge the input of organisations and individuals who have contributed significantly either to advice on CALD data or to the development of this paper.

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Note

The term '**cultural and linguistic diversity**' with the associated acronym '**CALD**' is currently used within Australian government, the private sector, and in research and academic institutions to describe populations other than the Anglo-Celtic majority.

Some commentators view the term as increasingly problematic (see 8.1.5 below) and note that it does not include consideration of race/ethnicity which are regarded as impacting significantly on health and other inequalities. It is also suggested that the term is not readily understood or actively used by the communities which are defined by it.

In this paper, if the term '**CALD**' was used in an original source document, it is retained. Otherwise, the paper refers to '**cultural, ethnic and linguistic diversity**'.

1. RECOMMENDATIONS

- 1 The national collection of data on cultural, ethnic and linguistic diversity should be nationally consistent, comparable and compatible, and apply the FAIR Data Principles (see 8.1.3 below).
- 2 The 1999 Australian Bureau of Statistics *Standards for Statistics on Cultural and Language Diversity* are now twenty years old and there is evidence that they are not being used consistently. It would be timely and appropriate to conduct a comprehensive review of their usefulness and applicability.
- 3 Administrative data sets (including primary health care and general practice) should include appropriate measures of cultural, ethnic and linguistic diversity in order to inform evidence-based policy development, resource allocation and service planning. Only then can we ensure that services are accessible, inclusive, and responsive to the needs of all people in Australia.
- 4 In order to be representative of the Australian population as a whole, general population surveys should ensure that sampling methodologies and collected data are inclusive of people from culturally, ethnically and linguistically diverse backgrounds.
- 5
 - (a) Funding bodies for social and health research (including clinical trials) should require applicants to demonstrate how the proposed research will be inclusive of people from culturally, ethnically and linguistically diverse backgrounds so as to not compound health inequities.
 - (b) Health, including disease onset and outcomes, and health risk factors and determinants are clearly patterned by ethnicity internationally, yet Australian data are severely lacking in this area. Australian data should include, where relevant, an indicator of ethnicity.
 - (c) In addition to the currently required Aboriginal and Torres Strait Islander indicator, measures of cultural, ethnic and linguistic diversity should be included in the National Notifiable Diseases Surveillance System (NNDSS).
- 6 The Australian Government should:
 - (a) refresh its Multicultural Access and Equity Policy and include mandated cultural, ethnic and linguistic data collection requirements from Government departments and agencies.
 - (b) establish a robust mechanism for oversight of implementation and reporting.
- 7 Various mechanisms are required to mandate the collection and reporting of data on cultural, ethnic and linguistic diversity, dependent on the context, to ensure national consistency, completeness and comparability, and the application of the FAIR Data Principles.
- 8 Consideration should be given to the feasibility and usefulness of introducing a self-identifier of culture and/or ethnicity similar to the Aboriginal and Torres Strait Islander self-identifier.
- 9 Consideration should be given to the feasibility and usefulness of introducing a variable relating to race/ethnicity, particularly in health and medical research.
- 10 The Australian Government should establish a high-level national working group, involving relevant stakeholders and expertise to develop recommendations as to how national and jurisdictional data collection and reporting on cultural, ethnic and linguistic diversity can be more consistent, complete and useful.

2. SUMMARY

The Federation of Ethnic Communities' Councils of Australia (FECCA) suggests that current Australian data collection and reporting on cultural, ethnic and linguistic diversity, particularly in relation to human services planning and delivery (including health, mental health, aged care, disability and social services), is inadequate. This is true of **administrative** (reporting on service delivery) and **survey** data, as well as social and medical **research**.

The most commonly collected variables or criteria for identifying people from culturally and linguistically diverse (CALD) backgrounds are:

- country of birth—excluding the so-called Main English-Speaking Countries (MESCs)
- language spoken at home/preferred language.

Consequently, significant numbers of people who may have been born in Australia, who may have English language proficiency, or who continue to identify strongly with a particular cultural or religious group are often excluded from CALD data sets. In addition, the exclusion of people from diverse cultural or ethnic backgrounds who were born in the MESCs, including UK, Ireland, Canada, United States, New Zealand and South Africa, the populations of which are increasingly diverse, means that Australian data may underrepresent CALD populations. The current measures exclude approximately 1.4 million persons who have English as their spoken language but were born in Australia and have one or both parents born in a non-MESC.

Current inadequacies in relation to these data impacts on research. In addition, many study designs for qualitative and quantitative research into issues affecting all Australians (such as dementia prevention and care) actively exclude diverse cultural or ethnic voices by insisting on English language proficiency as an inclusion criterion. Lack of representation in research studies by diverse populations therefore impacts on the generalisability of research findings and, at a societal level, we need to acknowledge that the potential benefits of health research, for example, may not be reaching the most vulnerable groups. The validity of many studies is therefore compromised by not accurately reflecting the diversity of the Australian population.

Data should be collected in line with agreed data standards and used by all Commonwealth and State/Territory Government departments such as the Departments of Health, Social Services and Home Affairs and agencies such as the National Disability Insurance Agency to ensure access and equity is achieved. These disaggregated data collected by agencies must be available externally for the purposes of analysis and research. Research funding bodies should also develop mechanisms similar to those required by the National Institutes of Health in the United States (see 8.1.4 below) to ensure the inclusion of culturally, ethnically and linguistically diverse populations.

FECCA calls for the establishment and resourcing of a National Working Group to develop consistent and accurate measures of cultural, ethnic and linguistic diversity to ensure adequate, appropriate, accessible and useful data collection.

RECOMMENDATION 1

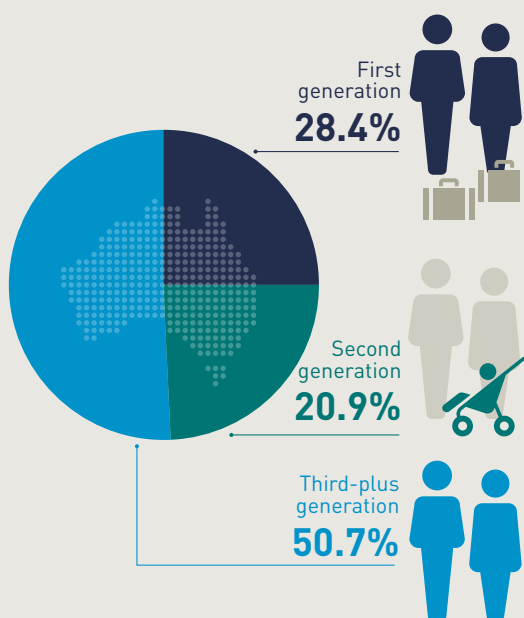
The national collection of data on cultural, ethnic and linguistic diversity should be nationally consistent, comparable and compatible, and apply the FAIR Data Principles, see 8.1.3 below.

3. KEY DEMOGRAPHICS – CENSUS 2016

In **2016**, nearly half (**49%**) of Australians had either been born overseas (first generation Australian) or one or both parents had been born overseas (second generation Australian).

As of **2015**, Australia had the **9th** largest number of overseas-born people, higher than both Spain (10th) and Italy (11th). While the United States of America had the highest total number of people born overseas (47 million or 14% of their population), Australia had a higher proportion of overseas-born people, at **26%**. Australia also had a higher proportion of people born overseas than our neighbour New Zealand (23%) and Canada (22%), other countries founded on migration.

Fifty years ago, in **1966**, Australia's overseas-born population was only **18%** of the total Australian population



In Australia, there were over **300** separately identified languages spoken at home in 2016:

- more than one-fifth (**21%**) of Australians spoke a language other than English at home.
- Of those:
 - **82.3%** reported speaking English well or very well
 - **16.6%** reported speaking English not well or not at all.

Of the 2,139,277 persons who arrived from the beginning of 2007 to August 2016:

- **34%** identified with a Christian religion
- **31%** identified with another religion
- **30%** reported no religious affiliation



Source: ABS Census of Population and Housing, 2016

Census data provide rich insights into Australia's cultural, ethnic and linguistic diversity. The data are, however, only collected every five years.

The significant diversity established by the Census underscores the importance of the collection and reporting of complete, consistent and comparable administrative, survey and research data which is inclusive of all Australians.

4. THE NATIONAL STANDARDS

The Australian Bureau of Statistics (ABS) [Standards for Statistics on Cultural and Language Diversity](#)¹ (the Standards) were published in 1999 in response to a widely recognised need for a nationally consistent framework for the collection and dissemination of data on cultural and language diversity.

Endorsed by the then Council of Ministers of Immigration and Multicultural Affairs in April 1999, it was intended that the Standards be used by government, academic and private sector organisations in all relevant data collection activities to improve the compatibility and comparability of data derived from different sources.

The Standards recognise that there are many elements to cultural and language diversity which must be considered to provide an accurate measure of such diversity. It is proposed that to use a single standard variable, such as country of birth, or a non-standard composite such as [the former] Non-English-Speaking Background (NESB), is inadequate. The Standards establish a number of variables.

The **Minimum** Core Set of Cultural and Language Indicators includes four variables:

- Country of Birth of Person
- Main language other than English spoken at home
- Proficiency in spoken English
- Indigenous status

The **Standard** Set of Cultural and Language Indicators includes additional variables:

- Ancestry
- Country of birth of father
- Country of birth of mother
- First language spoken
- Languages spoken at home
- Main language spoken at home
- Religious affiliation
- Year of arrival in Australia

The Standards include:

- recommended questions
- classifications and coding structures
- output for categories.

The Standards are reviewed prior to each ABS Census of Population and Housing. At a minimum, the order of response options in the questions for *Ancestry*, *Country of Birth*, *Languages Spoken*, and *Religious Affiliation* are updated using results from the previous Census. The *Year of Arrival in Australia* standard includes the *Country of Birth* question and it is updated to reflect any changes to the *Country of Birth* question. All ABS household surveys are required to use these Standards where these indicators are collected.

The 2016 Census was the first time that the country of birth of a person's mother and father was collected.

Implementation of the Standards by Commonwealth Government departments and agencies was supported by the release of [The Guide—Implementing the Standards for Statistics on Cultural and Language Diversity](#)² (the Guide) in June 2001. The Guide was developed by the then Commonwealth Interdepartmental Committee on Multicultural Affairs and contains practical advice on how to improve statistical practices in relation to CALD, whilst not mandating any indicators. The then Minister for Immigration and Multicultural Affairs encouraged all departments and agencies to implement the Standards.

The Standards are directly relevant to all data collection and reporting on cultural, ethnic and linguistic diversity.

The emergence of a number of data integration projects, such as the Multi-Agency Data Integration Project (MADIP), raises the potential of rich insights into cultural and language diversity derived from a range of data sources, provided that there is consistency in the data collection. MADIP can be further mapped to other data sources such as the ABS National Health Survey to provide a greater depth of knowledge on the health of diverse populations. By integrating aspects such as risk factors and chronic conditions, this information could be used more broadly to inform health service planning and data-driven policy.

In 1999 the Standards proposed that the adoption of a Standard Set of Cultural and Language Indicators, with standard questions and data collection procedures, would provide a number of significant benefits, including:

- providing a consistent method for measuring cultural and language diversity in all statistical and administrative collections
- allowing data from different sources, and different time periods, to be compared and integrated in a meaningful way
- improving the quality, relevance and accuracy of data produced
- reducing development and operational costs for agencies collecting data on cultural and language diversity by providing a ready-made and reliable method for use in all service provision settings.

RECOMMENDATION 2

The 1999 Australian Bureau of Statistics *Standards for Statistics on Cultural and Language Diversity* are now twenty years old and there is evidence that they are not being used consistently. It would be timely and appropriate to conduct a comprehensive review of their usefulness and applicability.



5. CURRENT PRACTICE

5.1 ADMINISTRATIVE DATA

There is a body of evidence that administrative data on cultural, ethnic and linguistic diversity are not collected consistent with the Standards:

- Annual Reports on Government Services (ROGS), in [2019](#)³ and [2020](#)⁴, define CALD recipients of aged care services simply as *'those born overseas from countries other than the United Kingdom, Ireland, New Zealand, Canada, South Africa and the United States of America'*. This definition also appears in the current version of the Australian Institute of Health and Welfare's (AIHW) [National Aged Care Data Clearinghouse Data Dictionary](#).⁵
- The National Disability Insurance Agency (NDIA) uses a similar definition, with the addition of a language indicator: *'CALD is defined as country of birth is not Australia, New Zealand, the United Kingdom, the United States of America, Canada or South Africa; or primary language spoken at home is not English'*.⁶
- Unlike Aboriginal and Torres Strait Islander indicators, variables capturing cultural, ethnic and linguistic diversity are not consistently collected in general practice software programs and are therefore not integrated with Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) data. The Practice Incentive Program (PIP) Eligible Data Set does not contain any measures of cultural, ethnic and linguistic diversity. This is a missed opportunity given that 90% of Australians will visit a GP at least once every 12 months.
- The AIHW manages a number of national health and welfare data sets the majority of which use only 'country of birth' and/or a language indicator.



Table S5.3.4: CALD measure in AIHW health data collections

	Country of birth	Main language other than English spoken at home	Preferred language	Interpreter service required	Period of residence in Australia
Adolescent and young adult cancer (clinical) NBPDS		x			
Alcohol and other drug treatment services NMDS	x		x		
Australian National Infant Feeding Survey	x				
Community mental health care database	x				
Disability Services NMDS	x			x	
National Bowel Cancer Screening Program NBEDS		x			
National Hospital Morbidity Database	x				
National Mortality database	x				x
National Perinatal Data Collection	x				
National Prisoner Health Data Collection	x	x			
Non-admitted patient National Best Endeavours Data Set	x				
Public dental waiting times	x		x		
Residential mental health care	x				

Source: AIHW data collections
Supplementary tables for Australia's Health 2018

- There are some specific data on cultural, ethnic and linguistic diversity within the AIHW publication Australia's Health 2018 (Chapter 5.3).⁷ Australia's Health 2020 does not, however maintain this focus. In the new Australia's Health 2020: Health Data Insights, of some 60 data tables,⁸ none refer to diversity indicators, other than to Aboriginal and Torres Strait Islanders. This deficit is acknowledged on page 6: '*some notable gaps in Australian health data and analysis—relating to health status; patient pathways and health system use; and health system activity and performance—are: [...] information on some population groups, including people with disability; culturally and linguistically diverse populations; refugees; and lesbian, gay, bisexual, transgender, queer and intersex populations*'.
- There are no such readily accessible data in the AIHW's Australia's Welfare 2019.⁹ This despite the observation that '*demographic and cultural changes have affected how governments and organisations delivering welfare services respond. Through shifts in cultural norms and attitudes, age structure and migration, Australia's population is one that is ageing, growing and becoming more socially and culturally diverse, and has higher levels of education*' (page 7).
- In relation to health-related data, in 2018 the Western Australian Department of Health released its Review of Cultural and Linguistic Diversity (CaLD) Data Collection Practices in the WA Health System.¹⁰ The paper provides analysis of the issues and makes several recommendations for the jurisdiction in relation to both the variables collected, and the quality of data collection.
- Rich analysis of various sources of data relating to migrants (who are more readily identifiable as a specific culturally, ethnic and linguistically diverse cohort) is, however, available through the ABS Migrant Statistics Program which aims to understand and support high priority emerging needs for migrant statistics by providing relevant statistical solutions, including analysis, to inform policy and research in relation to migrants and their settlement outcomes.
- Administrative data linked to the Census through MADIP can provide additional information on the population identified in the most recent Census and therefore allow for follow-up of the health of the known population in the intervening years.

RECOMMENDATION 3

Administrative data sets (including primary health care and general practice) should include appropriate measures of cultural, ethnic and linguistic diversity in order to inform evidence-based policy development, resource allocation and service planning. Only then can we ensure that services are accessible, inclusive and responsive to the needs of all people in Australia.

5.2 SURVEY DATA

The Census provides rich data on cultural, ethnic and linguistic diversity, mainly because it applies the National Standards, and offers support to people of diverse backgrounds in completing the census form. The Census is, however, a snapshot of the population at a single point of time, collected every five years.

The ABS National Health Survey does collect indicators such as 'language spoken at home', 'language proficiency', and 'country of birth of parents'.

In a range of other surveys, language barriers can lead to an under-representation of CALD people where English is used or is required for self-reported information. Language barriers can also prevent culturally and ethnically diverse people with limited English proficiency in participating in other survey mechanisms, such as focus groups.

Exceptions include surveys or focus groups which target specific populations such as: refugees, humanitarian entrants, new and emerging communities, and recent migrants. These specific populations are considerably easier to identify.

FECCA representatives attending the University of New South Wales 2019 Social Policy Conference asked numerous presenters if their research had been inclusive of diverse populations. The most common response was that it had not, usually because of increased expenses arising from interpreter use.

Many population-based surveys do not include a question or questions that could identify respondents as being from a culturally, ethnically and linguistic background, often relying on indicators such as 'country of birth' or 'preferred language'. These indicators alone, as outlined at 4.1 above, are not necessarily adequate or accurate.

Even if interpreters are used or the survey instrument is available in other languages, insufficient attention is paid to ensuring that participants understand key concepts relevant to the survey.

For example, surveys into complex social issues such as: carers; sexual harassment; family violence; child protection; and dementia, often fail to address cultural understandings of these issues or their relevance in the Australian context.

RECOMMENDATION 4

In order to be representative of the Australian population as a whole, general population surveys should ensure that sampling methodologies and collected data are inclusive of people from culturally, ethnically and linguistically diverse backgrounds.

5.3 RESEARCH

Current inadequacies in relation to data on cultural, ethnic and linguistic diversity impacts on research, as evidenced by frequent underrepresentation or exclusion (conscious or inadvertent) of people from diverse backgrounds in social and clinical research. Many qualitative and quantitative studies into issues affecting all Australians (such as dementia) actively exclude these voices by insisting on English language proficiency as an inclusion criterion.

The validity of many studies is therefore compromised by not accurately reflecting the diversity of the Australian population. The use of administrative datasets for research has huge potential to address this issue by providing population representative research samples. However, in order to be an effective resource for examining cultural and ethnic differences in health and health care access, these administrative datasets need to contain adequate measures of cultural, ethnic and linguistic diversity.

There is also an issue with research where **ethnicity**, as opposed to cultural or linguistic diversity, is an important element. Australian research tends to rely on country of birth as the sole measure of ethnic diversity, mainly because this is usually the only variable available in datasets. Country of birth is an inadequate measure of ethnicity in certain individuals such as ethnic Chinese born Singapore, Indonesia or Malaysia, ethnic Indians born in countries such as Fiji, the United Kingdom or Uganda, displaced refugees born in other countries, and the growing population in Australia who are Australian-born but whose parents are migrants from a variety of ethnic backgrounds. Country of birth also does not capture other socially determined factors that can have a significant impact on inequalities in access to and the quality of provided health services such as English language proficiency and discrimination based on race/ethnicity.

The Australian Clinical Trials Alliance is currently embarking on work to increase the awareness of and access to clinical trials by people from diverse backgrounds.

Some examples of exclusion of these population groups in clinical and research settings include the following:

1. In October 2019, a paper¹¹ by academics from Sydney University and the National Ageing Research Institute (NARI) in the Medical Journal of Australia suggested that Australian dementia research is not sufficiently inclusive of Australians from CALD backgrounds and that, as a consequence, they may be receiving inequitable or inappropriate dementia care.

42 of the 94 registered active dementia clinical trials in Australia excluded patients not fluent in English. CALD Australians were also excluded from epidemiological research on dementia. Of 16 studies identified, all collected data exclusively in English, and six excluded participants who were not fluent in English. A roadmap has since been developed to further research in this area.

2. In 2015 FECCA commissioned a Review of Australian Research on Older People from CALD Backgrounds.¹² The review identified research gaps in the evidence base on older CALD Australians, including research about: particular CALD groups, including new and emerging communities; older people from refugee backgrounds; those who arrive in Australia at an older age; people from smaller population groups; or those who live in regional, rural or remote areas.

Further gaps were identified in particular topic areas including: treatment and care options for older people from CALD backgrounds once a health diagnosis has been made; communications between CALD residents in aged care facilities and care workers; and the increasing proportion of people from CALD backgrounds in the aged care workforce.

The same review identified a number of items in the literature which highlighted the difficulty of including and retaining CALD participants in research, and the need for appropriate strategies to address this, including the provision of relevant language services

3. In 2019, at the Clinical Oncology Society of Australia Annual Scientific Meeting, Cancer Council Victoria hosted a breakfast symposium to explore the underrepresentation of CALD people in cancer clinical trials due to various barriers including challenges with communication, opportunity and awareness, and cultural issues.

An analysis of 20,000 cancer patients in South West Sydney suggested limited access to clinical trials as being most significant for CALD people whose preferred language is not English, with recruitment of these patients as low as 3.9% compared to 8.4% for non-CALD patients and 7.7% of CALD patients who were proficient in English.¹³

4. In relation to the COVID-19 pandemic, with the exception of an Aboriginal and Torres Strait Islander indicator, no other measures of ethnicity are required to be reported at the national level in the National Notifiable Diseases Surveillance System (NNDSS).

This would seem an omission of serious concern, given these data would be essential to inform targeted public health initiatives and messaging to culturally, ethnically and linguistically diverse communities, for research purposes, and to improve national capacity to respond comprehensively to future disease outbreaks or pandemics.

The AIHW publication [Australia's Health 2020: Data Insights](#)¹⁴ addresses COVID-19 impacts (*Chapter 2: Four months in: what we know about the new coronavirus*). A consequence of the diversity data deficit in the NNDSS is that the only demographic variables reported on are age, sex and Aboriginal and Torres Strait Islander status.

RECOMMENDATION 5

- (a) **Funding bodies for social and health research (including clinical trials) should require applicants to demonstrate how the proposed research will be inclusive of CALD people so as to not compound health inequities.**
- (b) **Health, including disease onset and outcomes, and health risk factors and determinants are clearly patterned by ethnicity internationally, yet Australian data are severely lacking in this area. Australian data should include, where relevant, an indicator of ethnicity.**
- (c) **In addition to the currently required Aboriginal and Torres Strait Islander indicator, the reporting of a measure of ethnicity should be included in the National Notifiable Diseases Surveillance System**

6. INADEQUACIES IDENTIFIED BY AIHW

The need for consistent, comparable and compatible data on cultural, ethnic and linguistic diversity has frequently been raised by the AIHW—for example, in [Australia's Health 2018](#) (Chapter 5.3 *Culturally and linguistically diverse populations*).

WHAT IS MISSING FROM THE PICTURE

The ABS has a set of Standards and Statistics on Cultural and Language Diversity that includes a Minimum Core Set of Cultural and Language Indicators: country of birth, main language other than English spoken at home, and proficiency in English. While these standards exist, their use in national health data collections could be improved to better understand diverse CLAD populations and identify their specific needs. As well, it would be useful to have more information related to how long individuals have been in Australia, language use patterns, their need for an interpreter, parent's country of birth, and refugee status.

Language barriers can lead to an under-representation of CALD people where English is used in surveys or is required for self-reported information.

Although the two publications addressed below related specifically to aged care, it can be assumed that the issues identified would be similar to those in other data sets.

- [*Cultural and linguistic diversity measures in aged care*](#)¹⁵

This 2014 working paper presented findings from an evaluation of CALD measures identified in 43 data sets and assessment instruments, and recommendations for implementing the 'top-10' measures in aged care data sets. The paper found that only 1 in 3 data sets used the very basic and minimal ABS indicators of country of birth and language spoken and that other measures of linguistic diversity, including first language spoken, or English language proficiency were collected inconsistently, or not at all.

The paper recommended that:

- data sets **without** CALD measures should employ, as a minimum, the ABS measures 'Country of birth' and 'Main language spoken at home', augmented with 'Interpreter required', 'Preferred sex of interpreter' and 'Preferred language', where the main language is other than English
- data sets **with** selected ABS measures should ensure they comply with ABS data collection methods, and where possible, augment the measures to include 'Interpreter required', 'Preferred sex of interpreter' and 'Preferred language', where the main language is other than English, 'Proficiency in spoken English' and 'Year of arrival', along with 3 linked measures that are associated with spirituality, are also recommended for supplemental inclusion.

- [*Exploring the aged care use of older people from culturally and linguistically diverse backgrounds: a feasibility study*](#)¹⁶

This 2016 paper again found considerable inconsistencies and gaps in accurately reporting on CALD data and made recommendations for improvement

FECCA is unaware of any substantial progress made in relation to implementing these AIHW recommendations.

7. AUSTRALIAN GOVERNMENT MULTICULTURAL ACCESS AND EQUITY POLICY

The Multicultural Access and Equity Policy aims to ensure that Commonwealth departments and agencies take primary responsibility for identifying, understanding and responding to the needs of their clients. The associated 2018 [Policy Guide](#)¹⁷ offers guidance to non-corporate Government agencies in implementing the policy. It should be noted that corporate Government agencies, such as the National Disability Insurance Agency, are out of scope of the Policy.

The Policy encourages each department or agency to have a Multicultural Access and Equity Plan or to incorporate obligations under the Policy into other strategic documents. Departments and agencies are required to report on outcomes on an annual basis to the Department of Home Affairs.

The Policy does not, however, mandate specific data requirements. Examples of general guidance in relation to data include:

- *'Use CALD client data collected by your department or agency to measure the effectiveness of multicultural access and equity initiatives.'*
- *'Collect CALD data for the programmes and services you manage (whether you interact directly with them or through a contracted service provider). **Key indicators of diversity could include country of birth, ancestry and/or language preferences.**'*

Administrative data collected by agencies are therefore neither consistent nor comparable.

RECOMMENDATION 6

The Australian Government should:

- (a) refresh its Multicultural Access and Equity Policy and include mandated cultural, ethnic and linguistic data collection requirements from Government departments and agencies**
- (b) establish a robust mechanism for oversight of implementation and reporting.**

8. TOWARDS CONSISTENT NATIONAL DATA COLLECTION AND REPORTING

8.1 CRITICAL DECISION POINTS

Given the acknowledged diversity of the Australian population, if it is agreed that current data on cultural and linguistic diversity are inadequate and are neither complete, nor comparable nor compatible, then it is timely for key stakeholders to develop a way forward.

Critical decision points in establishing national consistency involve securing agreement on:

- 8.1.1 The purpose of and justification for the collection data about Australia's cultural, ethnic and linguistic diversity.
- 8.1.2 Minimum indicators required to be collected and reported on and how to ensure the capacity of government and non-government service providers and research bodies to do so.

8.1.3 The application of the FAIR data principles. The [FAIR Data Principles](#)¹⁸ (Findable, Accessible, Interoperable, Reusable) were drafted at a Lorentz Center workshop in Leiden in the Netherlands in 2015.

The principles have since received worldwide recognition by various organisations including FORCE11, the National Institutes of Health (NIH) and the European Commission as a useful framework for thinking about sharing data in a way that will enable maximum use and reuse. The Australian National Data Service (ANDS) and the Australian Research Data Commons (ARDC) are supporting the uptake of the FAIR Data Principles.





8.1.4 Mechanisms to mandate data collection include requirements for:

- the collection of defined data on cultural, ethnic and linguistic diversity in administrative data sets.
- the inclusion of participants from culturally, ethnic and linguistically diverse backgrounds in relevant surveys.
- the inclusion of such participants in social, health and medical, and other research (including clinical trials), particularly when such research purports to be representative of the Australian population as a whole.

Mechanisms to mandate agreed diversity data collection are clearly required, as evidenced by the inconsistency in the application of the National Standards, the current reliance on 'country of birth' and/or a language identifier, and the lack of definitive requirements in the Guide to assist Australian Government non-corporate entities in implementing the Multicultural Access and Equity Policy (see 7 above).

There are overseas examples of mandatory diversity data collection and reporting, particularly in health services and research, when priority is placed on inclusion and equity. This has involved specific legislation for example:

- *United Kingdom*
The [Equality Act](#) of 2010 and the [Health and Social Care Act](#) of 2012 legislate the need for health services to provide evidence that they are working towards reducing health inequalities by regularly publishing equality information, including differences in access and outcomes by ethnicity.
- *United States*
The [Patient Protection and Affordable Care Act](#) of 2010 requires federally funded health programs to collect data on race, ethnicity and primary language. In addition, the [National Institutes of Health \(NIH\) Revitalisation Act](#) of 1993 and NIH policy amended in 2001 require that NIH funded research must include minority ethnic groups or provide sound scientific arguments for their exclusion.

RECOMMENDATION 7

Various mechanisms are required to mandate the collection and reporting of data on cultural, ethnic and linguistic diversity, dependent on the context, to ensure national consistency, completeness and comparability.

8.1.5 The introduction of a self-identifier. It is evident that the term 'CALD' is not well understood or used by many people from culturally and linguistically diverse backgrounds who may instead refer to themselves as from 'migrant or refugee backgrounds' or by terms such as 'Chinese-Australian', 'Lebanese-Australian' etc...

There is also increasing academic and community debate about the usefulness of the term CALD.^{19 20 21 22}

It may therefore be useful to explore the desirability and feasibility of introducing a self-identifier, similar to the mechanism developed originally by the ABS to facilitate self-identification by Aboriginal and Torres Strait Islander people.

The identifier could be collected along with other measures of cultural, ethnic and linguistic diversity.

The language used to describe the identifier would require considerable discussion and consultation.

RECOMMENDATION 8

Consideration should be given to the feasibility and usefulness of introducing a self-identifier of cultural, ethnic and linguistic diversity, similar to the self-identifier for Aboriginal and Torres Strait Islanders.

8.1.6 Consideration of an indicator of race/ethnicity

Comparable countries to Australia directly address the issue of race and/or ethnicity in data collection. In the United States, it has been recognised that governments, the private sector and the not-for-profit sectors must address inter-ethnic and inter-racial inequities, and the term 'minority' is widely used. In Canada the term 'visible minority' is used in official data collection and reporting. The United Kingdom has adopted the category 'black, Asian and minority ethnic' (BAME). There has been considerable criticism of these terms as divisive or simplistic, and emphasising 'otherness'.

These countries are, however, attempting to address the issues of race/ethnicity as important markers in a range of contexts. In Australia there has been a reluctance to go down this path. Even the National Standards and the Census use the term 'ancestry' instead.

Given the significant importance of race/ethnicity in health and impacts on inequalities, it is timely to have a national discussion on the usefulness and viability of the introduction of a specific race/ethnicity variable in data collection.

RECOMMENDATION 9

Consideration should be given to the feasibility and usefulness of introducing a variable focussing on race/ethnicity, particularly in health and medical research .

8.2 Establishment of a national working group

FECCA calls for all relevant parties to acknowledge that the collection of data on cultural, ethnic and linguistic diversity is currently inadequate - in the absence of the consistent application of agreed measures, the data are not complete, comparable or compatible.

FECCA therefore proposes the establishment and resourcing of a National Working Group to:

- include representatives of relevant Commonwealth and State/Territory governments and agencies, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare, appropriate peak research organisations; academics and researchers; Human Rights Commissions; and peak multicultural organisations such as FECCA and the National Ethnic Disability Alliance (NEDA)
- recommend measures of cultural, ethnic and linguistic diversity to be applied in administrative, survey and research data collection and reporting
- consider the feasibility of means by which people could self-identify (similar to the Aboriginal and Torres Strait Islander identifier)
- consider the development of an indicator of race and/or ethnicity
- explore mechanisms to mandate the collection of data on cultural, ethnic and linguistic diversity where appropriate. Such measures could include:
 - legislation and/or regulation
 - accreditation criteria in, for example, aged care, disability, health and welfare services
 - eligibility criteria and funding agreements for grants from governments and bodies funding research
 - integration into mandatory reporting in general practice software.
- require the National Health and Medical Research Council, the Australian Research Council and other research funding bodies, including universities, to develop mechanisms to ensure that research is actively inclusive of people from cultural, ethnically and linguistically diverse backgrounds so that that research reflects the diversity of the Australian population
- seek endorsement of the recommended measures by the National Cabinet to ensure national consistency through whichever body replaces the COAG Data and Digital Council, or another appropriate mechanism.

RECOMMENDATION 10

The Australian Government should establish a high-level National Working Group, involving relevant stakeholders and expertise to develop recommendations as to how national and jurisdictional data collection and reporting on cultural, ethnic and linguistic diversity can be more consistent, complete and useful.

ENDNOTES

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FECCA MEMBERSHIP LIST

Australian Capital Territory

Australian Capital Territory Multicultural Council

New South Wales

Ethnic Communities Council of NSW
Multicultural Communities Council of Illawarra
Hunter Multicultural Communities
Multicultural Council of Wagga Wagga
Multicultural Council of Griffith
Young and District Multicultural Association

Northern Territory

Multicultural Council of the Northern Territory

Queensland

Ethnic Communities Council of Queensland
Ethnic Communities Council of Logan
Multicultural Communities Council Gold Coast

South Australia

Multicultural Communities Council of South Australia

Tasmania

Multicultural Council of Tasmania

Victoria

Ethnic Communities Council of Victoria
Sunraysia Mallee Ethnic Communities council
North East Multicultural Association
Gippsland Ethnic Communities Council
Ballarat Regional Multicultural Council
Diversitat (Geelong Ethnic Communities Council)
Ethnic Council of Shepparton and District
Albury-Wodonga Ethnic Communities Council

Associate Members

Canberra Multicultural Community Forum
National Ethnic Disability Alliance



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