

Best practice in ascertainment:
cultural, ethnic, refugee, and
migrant backgrounds in clinical
and population health research

Why *Know our story*?

Welcome to the *Know our story* initiative.

Our ambition is to inspire, encourage and support clinical and population health researchers to work towards greater social inclusion and equity in research practices. *Know our story* is about working in partnership with communities of refugee and migrant backgrounds. It is also about consultation, collaboration and co-design of research; the sharing of knowledge; and different ways of working that promote social equity and inclusion.

Learn more about *Know our story*, access resources, and watch the animation: strongerfutures.org.au/know-our-story



We acknowledge the traditional owners and custodians of the lands on which we live and work. We pay our deepest respects and express our gratitude to their Elders past, present and emerging. We recognise and value the resilience and diversity of Aboriginal and Torres Strait Islander people and their spiritual connections to land, community and culture.

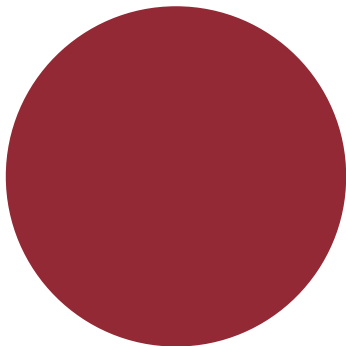
Purpose



The goal of this resource is to provide guidance encouraging clarity, social inclusion and equity in reporting of cultural, ethnic, refugee and migrant backgrounds in clinical and population health research.

Australia's population includes many people who were born overseas or have a parent or parents born overseas, including people with diverse cultural, spiritual and religious beliefs and connections to all regions of the globe. More than one in five people in Australia speak a language other than English at home.¹

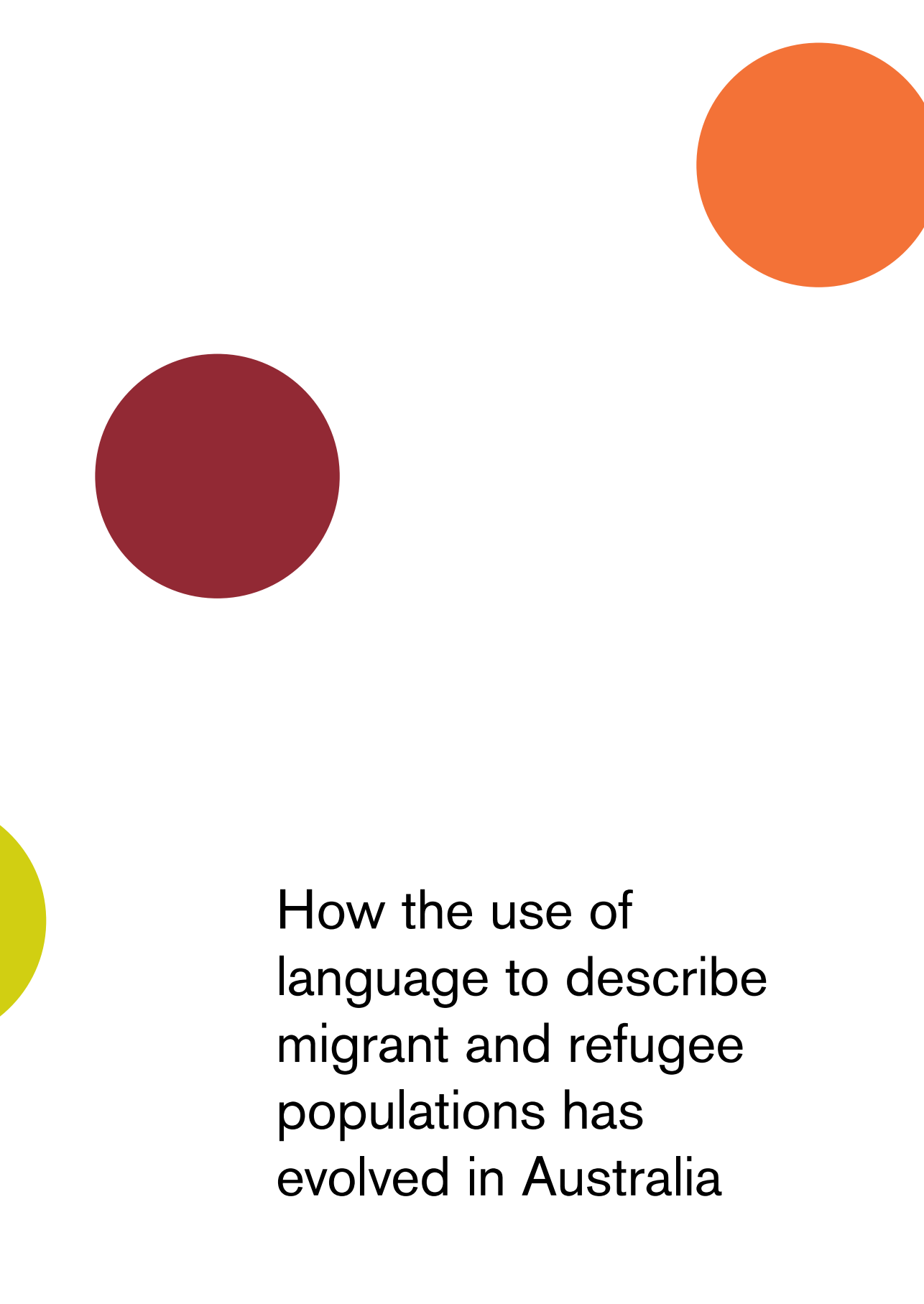
The goals of social inclusion and equity require researchers to be mindful of the ways that research procedures may systematically exclude specific groups of people from participation, and of the potential for commonly used terminology and classification systems to inadvertently reinforce erroneous assumptions.²




This resource provides

- an overview and critique of terminology used by the Australian Bureau of Statistics (ABS), Australian Institute of Health and Welfare (AIHW), and in Australian Government reports to describe and report on cultural diversity in the Australian population
- an overview of recent health and medical literature questioning the assumptions underpinning commonly used terms such as race and ethnicity
- a summary of issues to consider in relation to **ascertainment** and **reporting** of cultural, ethnic, refugee and migrant background in Australian clinical and population health research
- a section providing guidance on best practice in **ascertainment** and **reporting of refugee background**.





How the use of
language to describe
migrant and refugee
populations has
evolved in Australia



As Australia opened its borders to an increasing number of European and Asian migrants in the 1970s, the ABS adopted the term 'non-English speaking background' to describe the cultural background of migrants to Australia who came from countries outside of the UK, Ireland, US, Canada and New Zealand.³


From 1999, the ABS and government departments adopted the term 'culturally and linguistically diverse' (CALD) as the preferred way to describe people born overseas, and/or whose parent/s were born overseas, and who speak a language other than English at home. This term encompasses a vast array of communities with different ethnicities, religions, languages, cultural traditions and migration histories.³

The term culturally and linguistically diverse (CALD) was seen as superior for several reasons. First, it does not classify people based on what they are not. Second, it draws attention to both cultural and linguistic differences, each of which may impact people's experiences.⁴

However, recent commentaries note that the term culturally and linguistically diverse (CALD) continues to embed the assumption that 'Anglo' is the default Australian cultural background, with all other cultures positioned as diverse or different.⁵

Commentators note that the term culturally and linguistically diverse is both too broad and too narrow. It collapses people with disparate cultural identities into a blunt category, and potentially masks diverse experiences of culturally based exclusion. It is unclear whether migrants from the UK, Ireland and New Zealand or those with parents who migrated to Australia should be included or excluded.³ In addition, describing people according to their cultural and linguistic background potentially masks the way in which membership of a particular ethnic, cultural or linguistic community intersects with gender, age and other social and contextual factors.⁶

This has resulted in calls for a more inclusive terminology that focuses on specific needs of different cultural communities in particular contexts.³⁻⁶



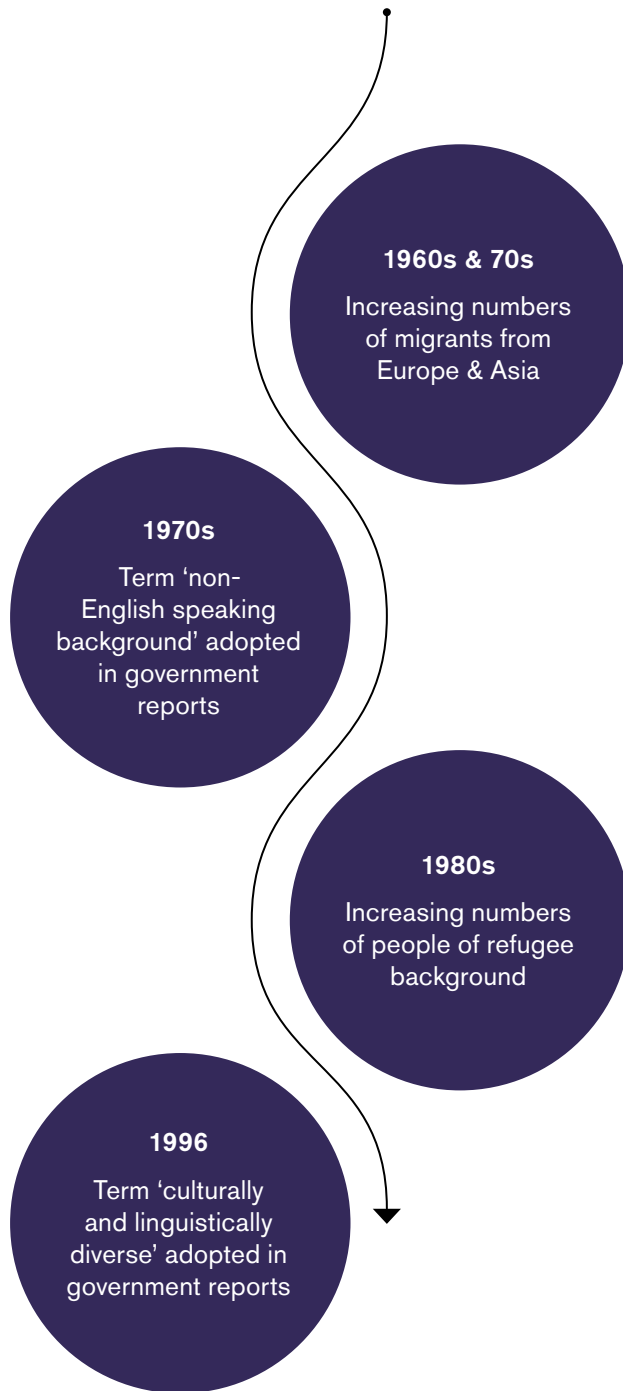
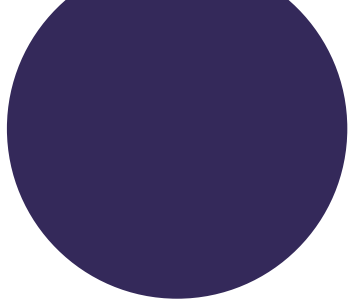


Figure 1. Timeline showing Australian context for changes in terminology.

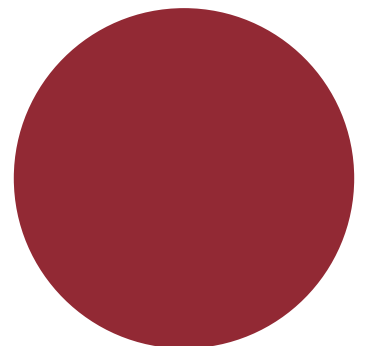



In 2001, the Department of Immigration and Multicultural Affairs in conjunction with the ABS launched a guide to implementing standards for reporting on cultural diversity.^{7,8} They identified four core variables considered critical for inclusion in health and administrative data sets:

- country of birth
- Indigenous status
- language spoken other than English at home
- proficiency in spoken English.⁷


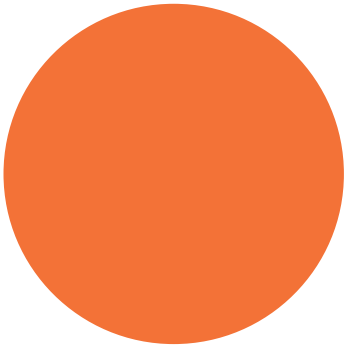
In addition, they identified several other variables of interest: including parents' country of birth, religious affiliation, year of arrival, and self-identified religious or cultural background.^{7,8} However, many health and administrative data sets do not include these variables. As a result, country of birth has been prioritised as the main descriptor used in comparative analyses and reporting on Australia's health.¹

Furthermore, the ABS has modelled an approach that compares the Australian born population with people born outside of Australia, commonly grouped together by region, using categories such as Sub-Saharan Africa, Asia (sometimes further categorised by region), North Africa and the Middle East, the United Kingdom and Ireland, the 'rest of Europe', Americas, and New Zealand and the Pacific.





There are two potential dangers to be aware of when using this approach. First, grouping people together in this way is likely to mask differences within categories. For example, people coming to Australia from South Asian countries have very diverse cultural, linguistic and socio-political backgrounds. By categorising people from this region as South Asian and conducting analyses comparing health outcomes of this population with the Australian-born population, much information highly relevant to understanding disparities in health outcomes is lost. The second and related danger is that researchers focus on looking for biological or genetic causes of disparities, rather than recognising the global, historical, and socio-political contexts that underpin persisting health inequalities.



Greater precision in the application of the social constructs of 'race' and 'ethnicity' and attention to underlying assumptions in the way that these constructs are applied is important to ensure that the socio-political causes of health disparities are identified. This information is critical to inform effective strategies for intervention.



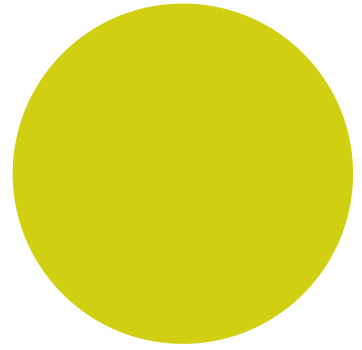
A cautionary tale

In 2021, the UK National Institute for Health and Care Excellence (NICE) issued guidance recommending that 'White women with uncomplicated pregnancies' should be offered induction of labour from 41 weeks' gestation, and that women of 'Black, Asian, and Ethnic Minority backgrounds' be offered induction of labour from 39 weeks' gestation. This recommendation was based on evidence that women of 'Black, Asian, and Ethnic Minority backgrounds' may be at higher risk of perinatal morbidity and mortality outcomes.⁹

Several commentators were critical of the NICE guidance for grouping together disparate groups of women under the category 'Black, Asian, Ethnic Minority', with insufficient evidence or attention to the factors that may underlie apparent differences in perinatal outcomes. Christine Ekechi, Co-chair of the Royal College of Obstetricians and Gynaecologists' Race Equality Taskforce told the BMJ that 'stratifying by race alone is a blunt tool'. She commented that 'Although highlighting higher risk is important, it does not move our understanding further as to why this group of women is at greater risk.' More than 25,000 people signed a petition urging the UK government to reject the guidance.¹⁰

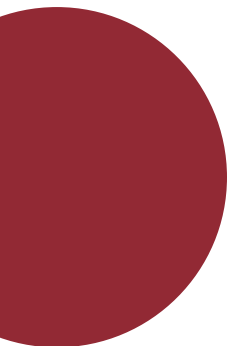
NICE subsequently withdrew this guidance and recommended that further research was needed to understand what sits behind apparent disparities in outcomes and establish at what gestation induction of labour should be offered to women of 'Black, Asian and Ethnic Minority backgrounds'.

Assumptions underpinning the language of race and ethnicity



Although many clinicians and researchers continue to use race as a biological classification, especially in the United States, there is growing recognition that both race and ethnicity are socially constructed concepts with no fixed scientific or biological meaning.^{2,11} Accordingly, it is important for clinical and population health researchers to apply these constructs with caution.

The Journal of the American Medical Association (JAMA) has produced guidance on the reporting of race and ethnicity in medical and science journals.² In their latest guidance, they recommend that reporting of race and ethnicity should be accompanied by reporting of other social and contextual factors to facilitate consideration of intersectionality, social stratification, social justice, and inequities. To assist researchers in the collection and reporting of demographic data on race and ethnicity, they have made a series of suggestions regarding terminology and what to report in study methods and results (see next section).





JAMA guidance on the Reporting of Race and Ethnicity²

JAMA have recently updated their guidance with respect to collection and reporting of demographic data on race and ethnicity. They recommend:

- collection and reporting of specific racial and ethnic categories, rather than collective categories that group together people with diverse cultural, linguistic, and migration histories
- reporting of individuals' self-identified ethnicity and countries of origin wherever possible
- including information about:
 - i. who identified participant race and ethnicity;
 - ii. the source of data (e.g. self-report, electronic health record, survey); and
 - iii. reasons why data on race and ethnicity were collected
- inclusion of specific information about any groups labelled as 'other'
- avoidance of terms such as 'minorities' that imply a hierarchy among groups
- recognition that many people identify with more than one racial group or ethnic background.

In addition, they advocate that researchers:

- avoid study designs and statistical comparisons of White groups versus "non-White" groups
- specify racial and ethnic groups included
- conduct analyses comparing specific groups.

The recent JAMA guidance recommends reporting of self-identified countries of origin in preference to collective groupings, such as Asian or South Asian.² However, both country of origin and country of birth can be poor proxies for cultural background given that within a particular country, there may be people living side by side with very different cultural and spiritual beliefs and languages. Even the addition of knowledge about languages spoken may not be sufficient information to identify cultural background given the extent of global forced displacement. War, famine, extreme poverty and environmental crises have resulted in mass displacement of millions of people globally, leading to many people spending long periods (sometimes spanning multiple generations) in 'transit' countries, where they become fluent in local languages. This is one of the reasons why the collection of additional contextual information is so important.

In Australia and other high-income countries receiving people of refugee backgrounds, it is especially important that contexts of migration are noted.¹²





Looking forward: how do we improve identification and inclusion of people from communities of refugee and migrant backgrounds?

In the absence of clear guidance or national standards, Australian clinical and population health research studies have adopted variable practices with respect to identification and inclusion of people from communities of refugee and migrant backgrounds. This limits the ability to assess representativeness of populations taking part in research and has important flow on effects for the generalisability of findings.

Many clinical trials continue to have eligibility criteria that either overtly restrict participation of people who are not proficient in English or make it difficult for people with limited English language proficiency to participate (e.g. no one able to facilitate communication in participant's preferred language, study materials not available in languages other than English).¹³

Population health studies are often limited in similar ways (i.e. people who are not proficient in English are excluded from participation or study procedures are not sufficiently tailored to encourage participation). Studies utilising routinely collected health and administrative data have the potential to be more inclusive, but commonly lack information on variables such as self-identified country of birth or country of origin, languages spoken and year of arrival in Australia that are needed to enable accurate identification of people of refugee and migrant backgrounds.¹⁴

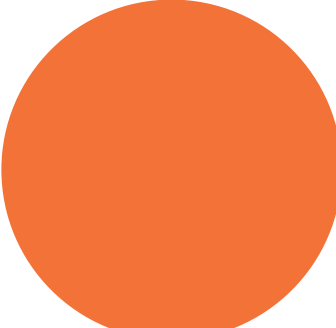
Contexts of migration are not routinely recorded in Australian health and administrative data sets, despite evidence that the context for migration is known to affect patterns of health.^{1,12}



Without information that may assist in identifying the context for migration, it is not possible to distinguish people who have come to Australia seeking asylum, as refugees or people with a refugee-like background from other people migrating to Australia.

Accurate ascertainment of refugee and migrant background is important for identifying disparities in health service use and health outcomes. Without accurate data providing a picture of the health service use and experiences of health care of people of refugee and migrant backgrounds it is not possible to gauge the extent or nature of health inequalities experienced by children, young people and families, or evaluate the effectiveness of health policy or programs intended to reduce disparities.

Accurate ascertainment of migrant and refugee background in clinical and population health research is also important to ensure that research studies are socially inclusive and relevant to sub-populations that may have different experiences of health and health care.





Ascertainment of refugee background

Migration patterns to Australia have varied over time with respect to the number of people coming to Australia, the places they have come from and the contexts or reasons for migration.

A significant number of people have come to Australia since WW2 because they were forcibly displaced. Some of the people who have come to Australia in these circumstances have been formally recognised as refugees and come under Australia's Refugee and Humanitarian Program. Others have arrived without visas seeking asylum, requesting that the Australian Government recognises them as refugees. Other people with a history of forcible displacement have been granted visas to settle in Australia through the ordinary migration program for reasons such as their links with family already in Australia.

After arrival in Australia in the context of forced displacement, some people may be reluctant to identify themselves as refugees. Asking someone 'Are you a refugee?' or 'Did you come to Australia as a refugee?' may evoke concern about why the questions are being asked and how information will be used. As a result, there is a risk that questions will not be answered accurately or consistently.¹⁵

To address this issue, we trialled the use of four data items in routinely collected administrative data to identify women (and children) of refugee backgrounds attending public maternity hospitals and early childhood health services.¹⁵ The four data items were: maternal country of birth, year of arrival in Australia, women's preferred language, and identified need for an interpreter. By combining information from ***all four data items***, it is generally possible to identify people with a likely refugee background, especially when ***combined with knowledge of patterns of humanitarian migration***.

Best practice for ascertainment of refugee background

To improve ascertainment of refugee background in clinical and population health research studies we recommend inclusion of four data items:

- participant's country of birth
- participant's year of arrival in Australia
- participant's requirement for an interpreter
- participant's preferred language.¹⁶

By combining information from all four data items with knowledge of patterns of humanitarian migration, it is generally possible to identify people of likely refugee background.

For example:

- a research participant who was born in Afghanistan, arrived in Australia in 2022, requires an interpreter and whose preferred language is Dari is highly likely to have a refugee background
- a research participant who was born in Sri Lanka, arrived in Australia in 2017, does not require an interpreter and whose preferred language is Sinhalese is highly likely not to have a refugee background

- a research participant born in Sri Lanka who arrived in Australia in 2017, does not require an interpreter and whose preferred language is Tamil is highly likely to have a refugee background.

Additional considerations apply to the identification of children and young people with refugee backgrounds. In general, ascertaining one or both parents' or caregivers' country of birth, year of arrival, requirement for an interpreter and preferred language will provide useful information for contextualising the salient aspects of children and young people's experience of migration.

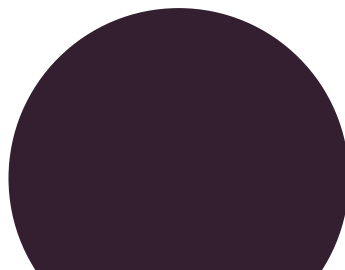
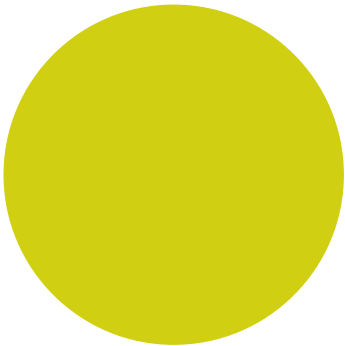


In summary

Australian health and administrative data sets remain highly variable with respect to collection of data on cultural, ethnic, refugee and migrant backgrounds. Many variables of interest – such as country of origin, self-identified cultural or ethnic background, languages spoken at home and year of arrival in Australia – are not available in routinely collected data sets. By default, country of birth is the variable most often used in comparative analyses and reporting on Australia's health.

There is growing recognition that both race and ethnicity are socially constructed concepts with no fixed scientific or biological meaning. It is important for clinical and population health researchers to apply caution when using these constructs in their studies. JAMA has issued guidance on reporting of race and ethnicity in medical journals, recommending that reporting of race and ethnicity should be accompanied by reporting of other social and contextual factors to facilitate consideration of intersectionality. They emphasise the importance of collecting and reporting:

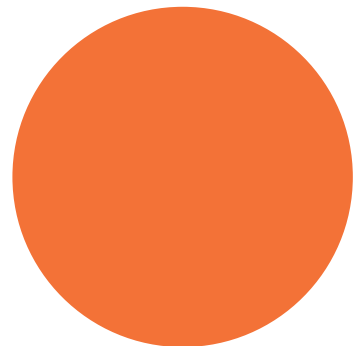
- individuals' **self-identified** ethnicity and countries of origin wherever possible
- **specific racial and ethnic categories**, rather than collective categories that group together people with diverse cultural, linguistic and migration histories.



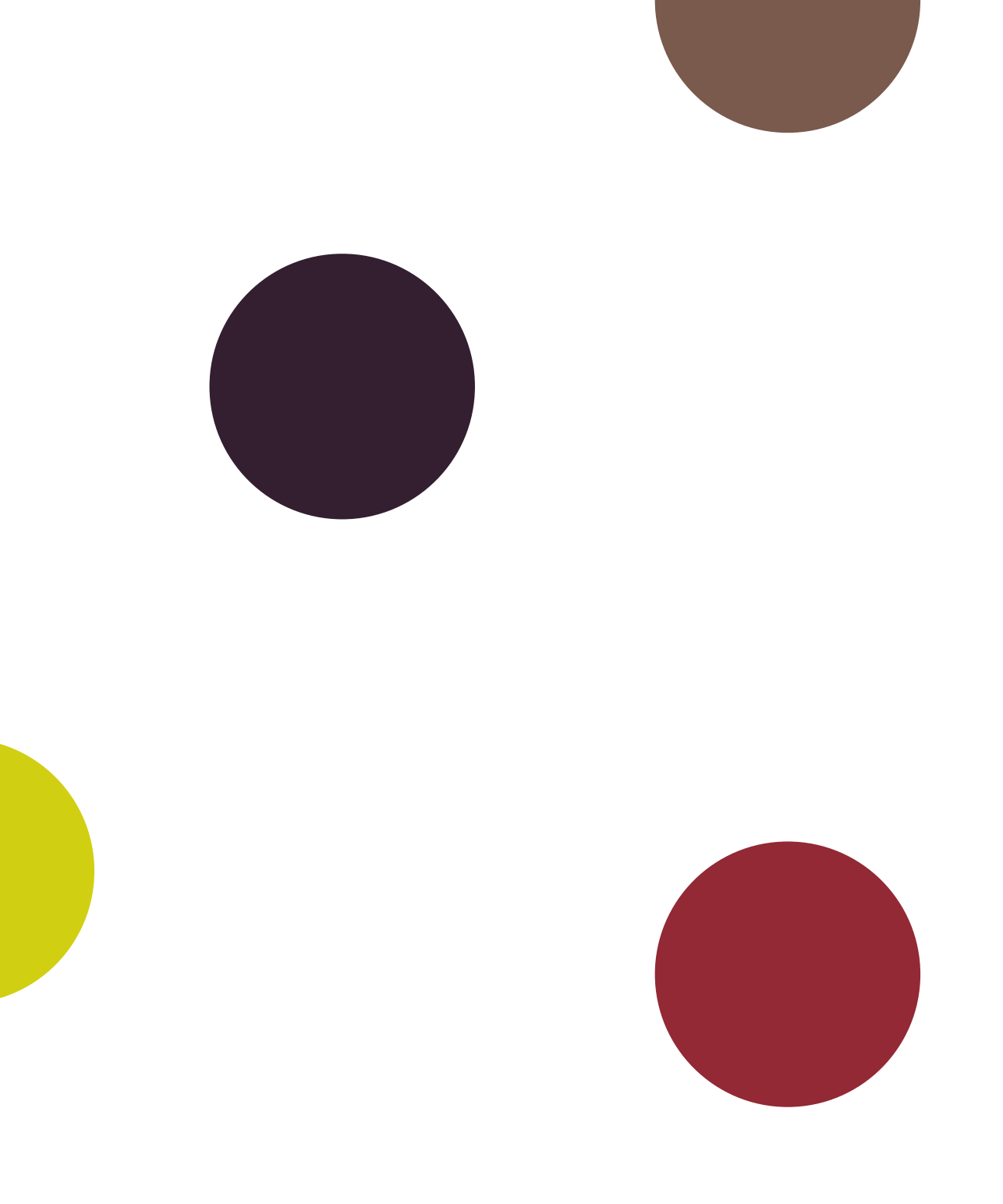
Accurate ascertainment of refugee and migrant background is crucial for identifying disparities in health service use and health outcomes that may differ according to contexts of migration.

Without accurate data providing a picture of the health service use and experiences of health care of people of refugee and migrant backgrounds it is not possible to gauge the extent and nature of health inequalities experienced by children, young people and families, or evaluate the effectiveness of health policy or programs intended to reduce disparities.

To **improve ascertainment of refugee background** in clinical and population health research studies we recommend inclusion of four data items: participant's country of birth, participant's year of arrival in Australia, participant's requirement for an interpreter, and participant's preferred language. By combining information from all four data items with knowledge of patterns of humanitarian migration, it is generally possible to identify people of likely refugee background.



Learn more about *Know our story*, access resources, and watch the animation: strongerfutures.org.au/know-our-story



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Know our story resources



Know our story:
a toolkit for social equity
and inclusion



No one size fits all:
working with communities
of refugee and migrant
backgrounds in clinical and
population health research



Community researchers and
community advisors: why they
are central to working with
communities of refugee and
migrant backgrounds



Best practice in
ascertainment: cultural,
ethnic, refugee, and migrant
backgrounds in clinical and
population health research



Lost in translation: using
standardised self-report
measures in cross-
cultural research

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