Improving ethnocultural data to inform public health responses to communicable diseases in Australia

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It is well established that ethnocultural groups of migrants are associated with a differential risk of communicable disease, including measles, tuberculosis and hepatitis B. Global public health agencies[1] are now focusing on improving the collection of ethnocultural data to better define communicable disease risk in migrant populations to support community-level disease prevention and control.

In Australia, there is no national strategy to support the collection of ethnocultural data in communicable disease surveillance. Ethnocultural data refers to any data that identifies an individual's cultural heritage, background or affiliation, e.g. country of birth (COB); language spoken at home (LSH) or religious affiliation etc. In Australia, Aboriginal and Torres Strait Islander status is routinely collected in communicable disease surveillance. COB is commonly collected for most notifiable diseases, however other variables used to describe the ethnocultural identity of cases vary (**Box 1**). These data are collected either via general practitioners recording this information on the disease notification form and/or public health unit staff recording the data during follow-up interviews with individual cases.

Ethnocultural identity is a self-constructed phenomenon related to the many social and cultural factors that influence people's lives including migration status, religious affiliation, language, cultural practices and political ideologies.[2] Collecting valid ethnocultural data can be challenging because ethnocultural identity is not a singular and easily defined concept. Ethnocultural identity may change over time and it often changes unpredictably over subsequent generations.[2] Therefore, Australian standards[3] for the collection of such data reflect the need for a multidimensional concept of ethnocultural identity, including several variables to ensure reasonable specificity and sensitivity.

Box 1. **Ethno-cultural data collected in routine notifiable diseases surveillance in Australia**

State/territory	Ethnocultural data collected*
Australian Capital Territory	Indigenous status, COB
New South Wales	Indigenous status, COB, LSH
Northern Territory	Indigenous status
Queensland	Indigenous status and COB†
South Australia	Indigenous status only‡
Tasmania	Indigenous status and COB
Victoria	Indigenous status, COB, year arrived in Australia§
Western Australia	Indigenous status, COB, EO

COB – country of birth, LSH – language spoken at home, EO – ethnic origin/ethnicity (Indigenous status or other). Indigenous status includes options of Aboriginal only, Aboriginal and Torres Strait Islander, Torres Strait Islander only or neither Aboriginal or Torres Strait Islander for identification purposes.

* As listed on the state or jurisdiction-specific notifiable diseases form online and/or through personal communication with state and territory Health Departments.

† Data on ethnicity and whether English is the preferred language spoken at home (Y/N) are collected in Queensland for some notifiable diseases.

‡ COB and LSH not routinely collected in South Australia but included for some priority notifiable diseases, i.e. sexually transmitted infections and food-related diseases.

§ Only collected for individuals born overseas.

Despite these challenges, the ethnocultural data currently collected during routine communicable disease surveillance have assisted in disease prevention and control in Australia. Collecting COB data, though limited in scope, has helped to identify a differential disease

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burden in recently arrived migrants or refugees, leading to national targeted prevention and treatment programmes for migrants emigrating from countries with high-burden disease, e.g. tuberculosis and chronic hepatitis B in South Asian migrants.[4]

While COB helps to identify disease risk in newly arrived refugees or migrants, communicable disease risk related to ethnocultural group remains underexplored for generations of Australian-born residents. This is an important issue in a context where net overseas immigration increased two to threefold in the past decade, and second and third generation Australians now make up 20% and 53% of the population, respectively.[5]

The ad hoc collection of ancestry data as determined by the Australian Bureau of Statistics (ABS) in a recent outbreak investigation in New South Wales has illustrated its utility over COB and LSH for defining at-risk populations for selected diseases. During the 2012 measles outbreak in New South Wales, ancestry data revealed that 21% of all notifications were associated with Australians of Pacific Islander ethnicity, and 17% occurred in Pacific Islanders with Samoan ethnicity.[6] This understanding enabled a quantification of the measles risk for this ethnocultural group at more than 50 times the non-Samoan population (notification rates of 189 per 100 000).[6] This led to targeted public health action, including vaccination clinics in churches and schools attended by a large number of young-adult Pacific Islanders, particularly for those of Samoan descent. Culturally specific and language-appropriate communication materials were also developed.

Foodborne disease outbreaks caused by the consumption of culture-specific foods are also common in New South Wales.[7] The utility of collecting data on the ethnocultural background of cases has been highlighted in New South Wales as it prompts the inclusion of ethnic food-specific questions into routine investigation tools. These specific food-related risks are inadequately identified by COB or LSH alone. To further explore which additional data variables might be useful to accurately represent ethnocultural identity, we used previously established surveillance criteria[8] to review commonly used variables. As shown in **Table 1**, COB and LSH have conceptual validity, objectivity and are relatively easy to define. However, the inherent strengths of variables such as ethnicity or ancestry include self-determination of cultural identity and the ability to describe the ethnocultural background of non-Aboriginal and Torres Strait Islander Australian-born residents.

A national approach to ethnocultural data collection may enable the strengthening of disease control for at-risk populations. We recommend that surveillance of COB and LSH be maintained in New South Wales and considered in other relevant jurisdictions. However, the collection of data on ancestry or ethnicity for defining communicable disease risk in multicultural groups (above and beyond COB and LSH) is warranted in Australia, particularly as social and cultural practices influence disease risk, in combination with a variety of other factors.[9]

The collection of data according to the ABS Australian Standard Classification of Cultural and Ethnic Groups[10] in our routine communicable diseases surveillance would be valuable for estimating disease risk in generations of Australians that identify with particular cultural and/or ancestral groups. Denominator data would be available online from the ABS website via the population census carried out every five years. Estimation of disease risk related to ancestry would be helpful during outbreaks of notifiable diseases where transmission risk is associated with social or cultural practices, e.g. consumption of culturally-specific foods, cultural gatherings or family-related travel to disease-endemic countries. This type of information would help inform specific community-level prevention and control activity.

Further discussion is needed regarding acceptability, database development needs, resource implications and training required to introduce new variables into the routine surveillance of communicable diseases in Australia. The development of strategies to collect these data could follow existing best practice guidelines on how to implement, collect and use data appropriately on Aboriginal and Torres Strait Islander peoples. Consideration of enhanced surveillance of ethnocultural background could initially be given for a small number of specific diseases such as measles and meningococcal disease, which cause significant morbidity and/or mortality, where notifications are routinely followed up by public health staff and where socio-cultural practices may play a role in transmission.

Table 1. **Advantages and disadvantages of collecting various ethnocultural data according to established surveillance[7] criteria***

Variable/Description	Advantages	Disadvantages
Country of birth		
Based on the country where the individual was born	• Relatively easy to define and valid in measurement • Objective and exhaustive • Reliable – categories related to specific countries unlikely to change over time • Denominator data available online through ABS website	• Potential discrepancy between 'nationality' and 'country of birth' • Provides no information about cultural or social differences • Provides no information about the ethnocultural group of Australian-born residents
Main language spoken at home		
Based on the main language (other than English) spoken by the individual in their home on a regular basis	• Objective and conceptually valid • Potential for consistency in assessment • Can be exhaustive and exclusive • Can help determine need for language or interpreter services • Denominator data available online through ABS website	• People who speak the same language might come from different countries or cultural and social backgrounds etc. • Does not capture any information about proficiency in language of home country (i.e. English) or other languages spoken in the home.
Country of nationality		
Based on the individual's passport/citizenship	• Easy to define and objective to measure • Can be exhaustive and exclusive • Reliable – categories of nationality unlikely to change • Conceptually valid • Denominator data available online or upon request from DIBP	• Issues about classifying people with several nationalities or people without passports (e.g. some refugees) • Provides no information about ancestry or ethnicity for Australian-born residents • Provides no information about cultural or social differences (e.g. religion, lifestyle)
Ethnicity/ancestry		
Based on the individuals self-perceived ethnic group – which could be a country, region, religious or cultural group, etc.	• Allows respondents to self-identify their own ethnicity based on whatever classification they see fit • Conceptually valid from the point of view of the respondent • Flexible for the respondent • Denominator data available online through ABS website	• Multiple response categories may present difficulties for analysis • Self-reported ethnicity may change over time • May not be exclusive • More of a process than a static well-defined concept • Question may lead to offence, particularly among refugees where racial, ethnic or religious tensions exist in the community
Length of stay in current country		
Based on the length of time (years) that the individual has resided in their current country from arrival	• Objective and conceptually valid • Potential for reliability and consistency in assessment • Potential to distinguish between newly arrived and long-term migrants • Denominator data available online through ABS website • Year of arrival may be sufficient here	• May be sensitive for recently arrived migrants/refugees and therefore may not be asked consistently by surveillance staff • May require discussion around why this information was being collected (in terms of meaningfulness to respondents) • Provides no information about cultural or social differences (e.g. religion, lifestyle)
Proficiency in English		
Based on the individual's self-assessed ability to speak English when the main language spoken at home was a language other than English	• Conceptually valid • Can be exhaustive and exclusive	• Potential for great measurement bias – meant to only represent spoken English (not reading, writing or listening) • Reliability/objectivity may be compromised • May require discussion around why this information was being collected (in terms of meaningfulness to respondents)
Religious affiliation		
Based on the individuals self-identified main religious belief or the religious group to which they belong	• Conceptually valid • Potential for valid and reliable measurement over time if religious groups do not change markedly • Self-assessed, i.e. individual declares affiliation	• Can result in sensitivity if individuals do not understand the value in collecting these data • People with the same religious affiliation may come from different countries or have different ancestry or ethnocultural backgrounds.

ABS – Australian Bureau of Statistics; DIBP – Department for Immigration and Border Protection.

* The criteria include[8] conceptual validity, measurement validity, exclusivity/exhaustiveness, meaningfulness, reliability, consistency and flexibility.

Conflicts of interest

None declared.

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