
SHOULD SEXUALLY TRANSMISSIBLE DISEASE SURVEILLANCE INCLUDE ETHNICITY DATA?

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Abstract

Australia is recognised as having one of the world's most ethnically diverse populations, yet indicators of ethnicity are not consistently collected with data relating to HIV and sexually transmissible diseases. Such information is essential if we are to determine if people of non-English speaking backgrounds and other Australians are at equal risk of STDs. This has implications for effective planning in prevention and treatment. Current ethnicity data for STDs in Australia are examined. Suggestions are made for a staged framework for collecting such information and for uses of these data.

Introduction

Australia's diverse ethnic population is well recognised¹. The importance of tailoring treatment and preventive services to meet the specific needs of our ethnic communities has been well documented^{2,3}. This requires the collection of ethno-specific data, yet few epidemiological studies or national databases in Australia collect indicators of ethnicity⁴. While there are many difficulties in gathering accurate information on ethnicity and health status, collecting these data for sexually transmissible diseases (STDs) including HIV and AIDS is even more difficult, given their often stigmatised nature. However, systematic collection of ethnicity data for STDs is essential if we are to determine whether STD risk for people of non-English speaking backgrounds is higher than, lower than, or is equal to that of the English-speaking Australian-born population. Many migrants arrive as refugees from countries with a level of STDs higher than Australia, and this makes it all the more important to collect uniform and accurate information about ethnicity if we are to assess the need for treatment and prevention among these groups.

There has been much debate around the operational definition of ethnicity and the best way to measure it on a population basis³. In the United States of America, much of the STD and HIV/AIDS data is reported according to race, such as 'Black or African American' and 'Hispanic'. Race is an indicator of biological factors, and is important when, for example, genetic characteristics are responsible for a population's vulnerability to infection. It is important to distinguish biological factors from socio-cultural factors which may expose groups to infection in a different manner^{5,6}. Socio-cultural factors are more important than biological ones in the case of STDs, as sexual beliefs and practices play a key part in the risk of exposure. It is essential that any indicator of ethnicity capture information on social and cultural factors.

Reporting of ethnicity for STDs in Australia

Although the establishment of the National Notifiable Diseases Surveillance System (NNDSS) in 1990 represents a significant advance in public health in Australia, surveillance for STDs is poorer than for many other infectious diseases. Although uniform diagnostic criteria for individual STDs have been defined, the way in which these are used may vary at the State and Territory level⁷. This, along with the variation between requirements in States and Territories about which STDs are notifiable, affects the overall accuracy of national surveillance data⁸. Although there are guidelines recommending a core set of variables for the collection of ethnicity data (Aborigines and Torres Strait Islanders, birthplace, language spoken, English proficiency)⁹, there is wide variation between the States and Territories in the way ethnicity is reported on STD notifications (Table). The most common information on ethnicity collected for STD notifications is country of birth, but some States and Territories do not collect any data on ethnicity.

Although indicators of Aboriginality are often included in ethnicity data, we have purposely not included issues of Aboriginality in this paper for two reasons. First, the difficulties in gathering and interpreting data on Aboriginality are complex and warrant discussion in their own right. Secondly, we acknowledge the principles of health research set out by Aboriginal groups and adopted by the National Health and Medical Research Council, which stress the need for a consultative and cooperative relationship between researchers and Aboriginal communities that are the subjects of the research. Particularly because of the sensitive nature of STDs, we believe that the question of STD surveillance among Aboriginal communities should be addressed with the full involvement of Aboriginal people themselves.

Reporting of ethnicity for HIV in Australia

In contrast to other STDs, the notification system for HIV is good. Surveillance for HIV is maintained by the National Centre in HIV Epidemiology and Clinical Research (NCHECR) in collaboration with State and Territory health authorities and the Commonwealth of Australia. The National HIV Database is notified on the first occasion of an HIV diagnosis within Australia by either the diagnosing laboratory (ACT, NSW, Tasmania and Victoria) or by a combination of laboratory and doctor sources (Northern Territory, Queensland, South Australia and Western Australia). States and Territories differ in the type of data collected on ethnicity and no information on ethnicity is provided to NCHECR (Table).

Table. Measures of ethnicity collected in HIV/AIDS and STD surveillance data in Australia¹

State/Territory	HIV	AIDS	STDs	Comments
Australian Capital Territory	Not collected	COB	COB	all notifiable STDs (mid-1993)
New South Wales	LSH	COB, LSH	COB	Syphilis only
Northern Territory	A/nA	*	A/nA	all notifiable STDs
Queensland	COB, A/nA	COB	COB, EO	optional on all notifiable STDs
South Australia	R	COB	R	all notifiable STDs
Tasmania	Not collected	*	Not collected	all notifiable STDs
Victoria	Not collected	COB	COB	Hepatitis
Western Australia	A/nA	COB	COB, A/nA	all notifiable STDs

1. Source: personal communication with State or Territory health authorities.

KEY: COB Country of birth
 LSH Language spoken at home
 EO Ethnic origin
 R Race: Aborigine, Asian, Caucasian, other
 A/nA Aborigine/non-Aborigine
 * Not collected on State form, but this information is sought for notification to NCHECR

Reporting of ethnicity for AIDS in Australia

AIDS has been a notifiable condition in all States and Territories since 1984, although the mechanism of reporting differs. In 1989 NCHECR developed a new AIDS notification form. Some States and Territories now use this, while others have retained their old notification forms, resulting in some variation between data collected at a State and at national level. All States and Territories notify their AIDS cases to the National AIDS Registry and make efforts to provide the data required by the registry, which includes two questions relating to ethnicity - 'Country of birth - Australia or Other (specify)', and 'If Other- state year of arrival in Australia'.

Even though collected, this information was not included in the database at its commencement but more recently has been included for current, and updated for retrospective, notifications. Some ethnicity data remain missing despite having been actively sought. This has resulted in the absence of information on country of birth for 22% of the total of 3,160 AIDS cases diagnosed in Australia between 1981 and 1992. The remaining data show, however, that until 1992 the proportion of people of non-English speaking backgrounds with AIDS was lower than for the proportion of people of non-English speaking backgrounds in the Australian population¹⁰. Surveillance figures for the population of Victoria, with less than one per cent of missing data, show the proportion of people of non-English speaking backgrounds with AIDS to be the same as the proportion of people of non-English speaking backgrounds in the Victorian population¹¹.

What kind of information on ethnicity is worth collecting?

Ethnicity has commonly been measured through a variety of variables including country of birth, first language, languages spoken at home, proficiency in languages including English, and length of residence in Australia^{1,12}. Which of these measures would be most useful to collect for STDs?

First, data on country of birth should be collected because it provides opportunities to compare rates of STDs with rates of other diseases and with rates in home countries⁹. However, within any one country there may be many different ethnic groups and a diversity of religious, cultural and social patterns. Country of birth does not capture these other indicators of ethnicity. For example, country of birth for people who migrated from Vietnam does not distinguish between Chinese Vietnamese or ethnic Vietnamese, nor those who migrated in the 1970s and those who arrived more recently. All these factors may play an important role in patterns of health and disease including STDs, thus country of birth alone as a measure is insufficient.

A second indicator of ethnicity is the language spoken at home. This identifies the diversity of ethnic populations migrating from a country or a series of countries and is important in determining the need for interpreter and translation services. It is also important for targeting prevention campaigns to specific subgroups within non-English speaking background populations.

Thirdly, length of residence in Australia can be an indicator of the migration patterns which may impact on prevention or risk. For example, patterns of STDs may differ with recent migrants who have arrived in Australia as refugees, compared with those from the same country who migrated for socio-economic reasons.

Finally, religion can provide additional information about intra-ethnic diversity and about specific beliefs and practices which may impact on risk and prevention.

How should ethnicity data be collected?

Given the difficulties of gathering a comprehensive set of data on ethnicity, we suggest a three-tier approach. First, we recommend that data on country of birth and language spoken at home be routinely collected as part of all HIV and other STD notifications. Although the current levels of compliance of notification for diseases other than AIDS is a problem, we believe that these two variables should be included while efforts are being made to improve surveillance, especially as this information is already being collected in some States and Territories^{13,14}. This is in line with current recommendations on the collection of ethnicity for health data Australia wide¹².

At the second level, we propose length of residence in Australia be added to the data about country of birth and language spoken at home in any periodic epidemiological or sentinel survey of STDs. These studies generally require greater efforts than routine surveillance, so the addition of this variable should not be too burdensome. At the third level, we suggest that data on religion be collected for public health research studies on STDs.

This three-tier system for collection of ethnicity data from the most basic to the more specific in both surveillance and research projects will greatly improve our ability to describe prevalence and risk for STDs within Australia's multicultural population. It will also enable us to direct education programs to specific risk groups for specific STDs.

A critical process in changing any standard data collection is consultation with the providers of the information about easy and reliable methods of eliciting, recording and reporting these data. Providers of data frequently do not perceive the benefits of their labours, so feedback to them is important¹⁵. One of the difficulties of surveillance generally is the lack of denominator data for calculation of rates. In the area of ethnic health, this is compounded by the fact that the number of members of any single ethnic group may be quite small. For the purposes of STDs and ethnicity, data collected by the Australian Bureau of Statistics on indicators of ethnicity are available for both the non-English speaking background populations as a whole and for specific groups. These data are adequate to provide denominator information on the socio-demographic characteristics of specific ethnic groups.

How should ethnicity data be used?

Data need to be easily accessible to those providing services, conducting research and developing policy to improve STD prevention and treatment for people of non-English speaking backgrounds. Despite the poor history of STD surveillance, collation of data nationally

has provided some useful recommendations, for example about screening for gonorrhoea¹⁶.

Access to ethnicity data would be improved through a national register of ethnicity-specific information on STDs. Some States already collect country of birth on their notification forms, yet this information is not readily available to researchers because it is either not added to the database or not collated. Many researchers are unaware of its existence.

Despite the benefits of collecting these data, consideration must be given to the potential unanticipated harmful consequences of more thorough collection of ethnicity data. While more accurate data can assist in targeting prevention programs to the specific needs of non-English speaking background communities, this can also serve to stigmatise already marginalised groups. Migrants are vulnerable to being singled out for importing diseases, especially infectious diseases, into Australia. It is also possible that sensitive and detailed epidemiological data could be misused, for example by carrying out selective screening of specific communities, or by supporting discriminatory treatment in relation to access to employment or health care^{17,18,19}.

Conclusion

At present, few data are available on STD rates in people of non-English speaking backgrounds compared with the rest of the Australian community. This has led to difficulties in developing effective strategic planning for prevention and treatment. If non-English speaking background communities suffer less from the burden of STDs than the rest of the Australian community, then we have nothing to worry about. However, if they suffer more, then they may be further disadvantaged by the stigma of these diseases, which can also hinder access to prevention and treatment. We suggest a staged framework for improving what is known about the burden of STDs in Australia's multicultural population.

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