Note on development of this guide: *At the 24 November 2016 meeting of the SA Health Integrated South Australian Activity Collection (ISAAC) Working Group, Health Performance Council (HPC) was asked to provide a guide to collecting the three additional culturally and linguistically diverse (CALD) data-items that are being piloted in SA Health collections from July 2017. In July 2017, the HPC Chair sent this guide to the ISAAC Working Group as requested.*

Guide to cultural and linguistic data collection

A guide to assist SA Health agencies and staff to collect data relating to the cultural and linguistic diversity of health consumers.

July 2017

Acknowledgement

SA Health recognises Aboriginal and Torres Strait Islander people as two separate groups. However, within this document we refer to Aboriginal people in recognition that Aboriginal people are the original inhabitants of South Australia. We also acknowledge the complexity and diversity of the Aboriginal communities of South Australia, recognising each has its own beliefs and practice.

Introduction

The Department for Communities and Social Inclusion has released Universal Access and Inclusion Guidelines for South Australian Government[1]. To achieve social inclusion the government aims to reduce disadvantage, increase economic and social participation, give people a greater voice in planning and decision making combined with greater responsibility.

Social inclusion is about human rights and the Australian Government's Racial Discrimination Act 1975 prohibits discrimination on the basis of race, the Equal Opportunity Act 1984 seeks to prevent discrimination based on sex, chosen gender, sexuality, race, disability or age. There are several United Nations instruments to protect the rights of all people including Declaration on the rights of Indigenous Peoples, Charter of the United Nations and Declaration of Human Rights. The introduction of new data items to SA Health Integrated South Australian Activity Collection (ISAAC) is to ensure data is collected that acknowledges the cultural and religious diversity of the South Australian community and ultimately improves social inclusion.

Purpose of the Guide

The Universal Access and Inclusion Guidelines provide a structure for SA Government's policy thinking, service planning and delivery that ensures no one is disadvantaged in their access to State Government services. In line with this aim, the purpose of this data collection guide[2] is to assist SA Health to collect data relating to the cultural and linguistic diversity of health consumers. It provides explanations, suggestions and strategies for the collection of this data, including the use of standard variables as reported to ISAAC. The aim of the guide is to improve the quality and quantity of information collected, achieve consistency in data collection, enable meaningful comparisons between population groups and look for patterns and trends in particular health outcomes for population groups.

Why collect cultural and linguistic data?

To facilitate effective planning and delivery of culturally appropriate health services to South Australian culturally and linguistically diverse communities, it is important that SA Health agencies and staff have a clear understanding of and relevant data on, the demographic, socioeconomic and cultural characteristics of the health consumer[3].

---

[1] Department for Communities and Social Inclusion Universal Access and Inclusion Guidelines for South Australian Government http://www.dcsi.sa.gov.au/__data/assets/word_doc/0011/15986/Access-and-Inclusion-Guidelines.doc

[2] We acknowledge our use of the Government of Western Australia's 'Guide to cultural and linguistic data collection for the public sector' Nov 2014 as a source document http://www.omi.wa.gov.au/resources/publications/info_sheets/data_collection_guide.pdf

[3] While we have used the term health consumer throughout this document the terms patient and client are terms that could be used interchangeably throughout this document.

Benefits to Hospitals and Health Services

The collection of accurate data is critical to understand the needs of health consumers using the system and to deliver SA Health's statutory obligations. Data on cultural and linguistic diversity assists hospitals and health services to achieve the following (this list is not exhaustive):

Health consumers:

- Assess health consumers' cultural and linguistic requirements such as the need for interpreters, bilingual staff or practices sensitive to religious beliefs
- Measure and appreciate the diversity of health consumers

Health staff:

- Ensure staffing and skills are representative of SA Health's health consumers
- Ensure that staff work in a culturally safe way

Hospitals and health services:

- Assess and measure the impact of policies and programs on different groups in order to improve outcomes
- Review, plan and deliver services that meet the needs of communities, including new migrants and refugees
- Respond effectively and in a culturally appropriate way to community needs
- Recognise where discrimination and marginalisation may arise
- Meet access and equity requirements
- Compare outputs across hospitals
- Inform the development of legislation, budgets, action plans, reports and proposals.
- Identify recent significant growth rates in specific groups or settlement of new groups
- Substantiate funding applications for culturally and linguistically diverse specific programs and services
- Indicate which groups are using essential health services and their health outcomes.

Used in combination with information on gender and age, collected data can identify levels of access to services by particular groups such as culturally and linguistically diverse women and culturally and linguistically diverse seniors or young people.

Benefits to Health Consumers and Communities

Collection of cultural, linguistic and religious data may potentially benefit health consumers by facilitating:

- Increased access to health information in preferred language
- Provision of more culturally aligned care and subsequently improved service delivery
- Improve access to appropriate services
- Increased access to interpreters and translated information

What data to collect?

In November 1999, the Australian Bureau of Statistics (ABS) released its Standards for Statistics on Cultural and Language Diversity[4]. This document sets national standards for measuring diversity through a core and standard set of cultural indicators (4 and 11 respectively) and includes standard questions.

Deciding the variables

To date the SA Health ISAAC database has included two ABS core indicators – Country of Birth and Indigenous Status. At the 24 November 2016 meeting of the ISAAC Working Group it was agreed that three additional culturally and linguistically diverse (CALD) data-items reporting will be piloted from July 2017 – Religious Affiliation, Preferred Language and Interpreter Required. It is noted that most sites have been collecting some of this data, but not reporting to SA Health. This data may have been used by the hospital or health service for local review and planning of health services.

Religious affiliation and preferred language are part of the ABS Standards for Statistics on Cultural and Language Diversity. Interpreter required is not required in the ABS standards but was deemed by ISAAC Working Group to be of sufficient clinical value for service delivery to be added to ISAAC are included within the ISAAC standard set.

It is not compulsory for the health consumer to answer these questions. However, as a service provider, your ability to provide consumer-centred care will be improved if you ask these questions.

What questions to ask and why?

Country of Birth

Country of birth is mainly used to determine if someone is a migrant to Australia and the country from which they originate. It may provide an indication of the community group to which they may associate. It's important to note that a person's country of birth may not align them with particular cultural practices and needs.

Ask: 'In which country were you [was the person] born?'

Response: [ISAAC Country of Birth list][5]

Note: a revised reference file has been loaded into the Patient Administration System.

Indigenous Status

This provides data on the number of people who identify as being of Aboriginal and/or Torres Strait Islander origin. This question is included to support better health service planning for Aboriginal and Torres Strait Islander people and monitor health outcomes for Aboriginal and Torres Strait Islander people. It is not possible to determine someone's identity based on their appearance. This is a mandatory field.

Ask: 'Are you [Is the person] of Aboriginal or Torres Strait Islander origin?'

[4] ABS 1289.0 – Standards for Statistics on Cultural and Language Diversity
http://www.abs.gov.au/ausstats/abs@.nsf/mf/1289.0
[5] SA Health ISAAC reference Manual effective 1 July 2008

Response:	1	Aboriginal but not Torres Strait Islander origin
	2	Torres Strait Islander but not Aboriginal origin
	3	Both Aboriginal and Torres Strait Islander origin
	4	Neither Aboriginal nor Torres Strait Islander origin
	9	Not stated/inadequately described

Religious Affiliation

Religious affiliation is defined as the religious beliefs and practices to which a person adheres or the religious group to which a person belongs[6]. This item can be considered a measure of 'culture' and could be part of a conversation about the practices the person engages as part of their religion. This may provide insight into how to best tailor health care services to the person, providing consumer-centred care eg fasting is a common practice in Hinduism, and consumers may wish to discuss the implications here in light of the medical/dietary care plan.

Religious Affiliation is considered sensitive information and clearly identified as optional.

Ask: 'What is your [the persons] religion?' Answering is OPTIONAL

Response: [ABS 1266.0 Australian Standard Classification of Religious Groups][7]

Note: A revised reference file has been loaded into the Patient Administration System.

Preferred Language

Preferred language (including sign language) denotes the language most preferred by the person for the purposes of communication. Preferred language will assist health service providers in determining the best form of communication and/or language to communicate with a health consumer, to be able to provide culturally sensitive, consumer-centred care.

Note: a revised reference file has been loaded into the Patient Administration System.

Ask: 'What is your [the persons] preferred language?'

Response: [ABS 1267.0 Australian Standard Classification of Languages at the languages level] [8]

Interpreter Required

Interpreter preferred ascertains whether an interpreter service is required as perceived by the health consumer It is best practice to use professional interpreter services - the length of stay and readmission can be reduced by the timely and appropriate provision of interpreter services to

[6] ABS, 1999 1289.0 Standards for Statistics on Cultural and Language Diversity http://www.abs.gov.au/ausstats/abs@.nsf/mf/1289.0

[7] ABS, 2016 1266.0 Australian Standard Classification of Religious Groups http://www.abs.gov.au/ausstats/abs@.nsf/mf/1266.0

[8] ABS, 2016 1267.0 Australian Standard Classification of Languages http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/1267.02016

culturally and linguistically diverse consumers at admission and discharge[9]. Using a child to interpret for their parent is never appropriate, even if the child is an adult and speaks English well.

This item can be used in conjunction with preferred language to determine the interpreter needs of the health consumer. A series of questions are required to ascertain the nature of the 'interpreter required' – to specify the language preferred including sign language as well as preferred gender of interpreter.

The preferred gender of the interpreter is important to clarify that appropriate cultural sensitivities are addressed when dealing with personal health issues. For example a Muslim health consumer may express strong, religiously/culturally-based concerns about modesty, especially regarding treatment by someone of the opposite sex. A Muslim woman may need to cover her body *completely* and should always be given time and opportunity to do so before anyone enters her room. Women may also request that a family member be present during an exam and may desire to keep on her clothes during an exam if at all possible. Muslim men may find examination by a woman to be extremely challenging[10].

Ask: 1. 'Do you [the person] require an interpreter?'

2. 'Do you [the person] prefer a female or male interpreter?'

Response:
1 Yes—for spoken language other than English – Female interpreter required

2 Yes-for spoken language other than English – Male interpreter required

4 Yes—for non-spoken communication – Male interpreter

5 Yes – for non-spoken communication – Female interpreter

6 No

9 Not stated

Non-spoken communication supports health consumers with a disability who require additional communication support, this may include sign language such as AUSLAN.

For many Aboriginal people, they may not say they need an English interpreter, but they may well need someone with them to help 'translate' the complexity of the hospital system and advocate for them. If this is the case we suggest as a service provider, you make contact with an Aboriginal health Worker or Aboriginal Hospital liaison services.

[9] Lindholm, M., et al., Professional Language Interpretation and Inpatient Length of Stay and Readmission Rates. J Gen Intern Med, 2012. 27(10): p. 1294-9.

[10] Ehman J. Religious Diversity: Practical Points for Health Care providers Pastoral Care & Education Penn Medicine_http://www.uphs.upenn.edu/pastoral/resed/diversity_points.html

Collecting the data

Privacy and confidentiality

These culturally and linguistically diverse health consumer questions meet the standard applicable principles of privacy and data collection. All personal information collected is treated with the same respect and confidentiality. People generally will not object to supplying information if there is an explanation of its purpose and a guarantee of confidentiality. If objections persist in individual cases or for particular questions the wishes of the health consumer should be respected as it is not compulsory for consumers to answer.

Applicable principles of privacy and data collection are that:

- Individuals should have the option to indicate that they do not wish to provide personal profile information
- All proposals to collect data should be non-intrusive and rely on commonly collected items such as country of birth or interpreter required
- There should be transparency about what health consumer information is collected and how it is used[11].
- Any information sharing should be in accordance with the SA Health Privacy Policy Directive and Framework[12].

Informed Consent

Obtaining informed consent for medical treatment is a legal duty of healthcare providers. A professional interpreter should be used for consumers who are not proficient in English and for non-spoken communication who are being asked to provide consent.

Cultural competence

Cultural competence of staff may affect the quality and quantity of data collected. For this reason cultural competency training is important. For example health consumers may:

- Speak some English but not be competent to respond appropriately to complex health related questions or not be proficient in English
- Speak their preferred language but not be able to read it
- Be reluctant to respond to some (or all) questions for cultural reasons or due to past experiences.

Increased cultural awareness will ensure that staff do not make assumptions about health consumers on the basis of their appearance, accent or language proficiency.

Data can be collected over the telephone, by filling out a paper-based form, face-to-face or using a computer. Cultural competency training will assist staff to identify the most appropriate method for

[11] Your Rights and Responsibilities A charter for Consumers of the SA Public Health System. Government of South Australia, SA Health. ISBN: 9780730898276 (pbk.) For community languages: http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Health+topics/Legal+matters/Your+rights+and+responsibilities

[12] SA Health Privacy Policy Directive
http://inside.sahealth.sa.gov.au/wps/wcm/connect/60b8550041526f138c0d8ee8f09fe17d/directive_privacy_30052017.pdf?mod=ajperes&cacheid=60b8550041526f138c0d8ee8f09fe17d&cache=none

the health consumer. Low levels of spoken English may require questions to be translated or for an interpreter. Using a child to interpret for their parent is never appropriate, even if the child is an adult and speaks English well. Some cultural groups, although verbally literate in their own language may not be in a position to complete a written form or sign a consent form in their own written language.

Other issues that require cultural awareness in data collection processes relate to cultural interpretations of concepts and questions. For example:

- Some health consumers may perceive confidentiality differently and it will therefore be important that any concepts be explained using simple terms and language
- Some health consumers may interpret questions from their own cultural perspective. For example, some health consumers may have limited understanding of Western cultural concepts such as place of birth. They may interpret birthplace as ancestral country rather than being a citizen of Australia or another country. Similarly, shifting global boundaries means that some people may identify countries that no longer exist[13]
- Although not a core culturally and linguistically diverse indicator, date of birth is often collected by service providers. Some health consumers may not be able to answer this question. They may calculate their birth dates according to a different calendar or birth documentation may have been lost due to civil unrest or war.

Resources

Cultural Competence Training

1. Community Door Work with diverse people:

   http://etraining.communitydoor.org.au/course/view.php?id=10

2. Centre for culture, ethnicity and health – training programs to improve health outcomes for migrants and refugees:

   http://www.ceh.org.au/training/

3. eCALD – provision of CALD courses to support the health workforce to develop culturally and linguistically diverse cultural competence for working with health consumers, families and colleagues:

   http://www.ecald.com/

4. South Australian Government Universal Access and Inclusion Guidelines: https://www.dcsi.sa.gov.au/__data/assets/word.../Access-and-Inclusion-Guidelines.doc

[13] as defined in the ABS data dictionary

For Hospital and Health Service Staff

SA Health Policy Guidelines

1. Your Rights and Responsibilities A charter for Consumers of the SA Public Health System. Government of South Australia, SA Health. For community languages: http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Health+topics/Legal+matters/Your+rights+and+responsibilities
2. Consent to Medical Treatment and Health Care Policy Guideline http://www.sahealth.sa.gov.au/wps/wcm/connect/f0ee918046d8588f8b8ffb22d29d99f6/Guideline_Consent+to+Medical+Treatment+and+Health+Care_June2015.pdf?MOD=AJPERES&CACHEID=f0ee918046d8588f8b8ffb22d29d99f6
3. Department of the Premier and Cabinet Circular PC012 – Information Privacy Principles (IPPS) Instruction 20 June 2016 http://www.dpc.sa.gov.au/documents/rendition/B17711
4. Public Sector (Data Sharing) Act 2016 SA https://www.legislation.sa.gov.au/LZ/V/A/2016/PUBLIC%20SECTOR%20(DATA%20SHARING)%20ACT%202016_61/2016.61.UN.PDF
5. SA Health Privacy Policy Directive http://inside.sahealth.sa.gov.au/wps/wcm/connect/60b8550041526f138c0d8ee8f09fe17d/directive_privacy_30052017.pdf?mod=ajperes&cacheid=60b8550041526f138c0d8ee8f09fe17d&cache=none

Development of this guide

At the 24 November 2016 meeting of the ISAAC Working Group, Health Performance Council (HPC) was asked to provide this guide to collecting the three additional culturally and linguistically diverse (CALD) data-items that are being piloted in SA Health collections from July 2017.

Feedback on draft guide

In the preparation of this guide, HPC sought feedback from:

HPC Culturally and Linguistically Diverse Communities (CALD) Leaders' Forum Planning Group:

- Helena Kyriazopoulos – Multicultural Communities Council of SA
- Tina Karanastasis – Ethnic Link Services, UnitingCare Wesley Port Adelaide / Federation of Ethnic Communities' Councils of Australia (FECCA)
- Evelyn O'Loughlin – Volunteering SA/NT
- Kathy Ahwan – SA Department for Health and Ageing
- Mary Patetsos – Deputy Chair, Health Performance Council
- Steve Tully – Chair, Health Performance Council
- Professor Lisa Jackson Pulver – Member, Health Performance Council

SA Health staff:

- Anna Bent
- Catherine Garvey
- Alida Minchella

- Jill Edwards
- Krystyna Parrott