

April 2017

Consumer health information needs and preferences:

Perspectives of culturally and
linguistically diverse and
Aboriginal and Torres Strait
Islander people

The Cultural and Indigenous Research Centre Australia (CIRCA) have prepared this report on behalf of the Australian Commission on Safety and Quality in Health Care.

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Preface

The Australian Commission on Safety and Quality in Health Care (the Commission) is committed to supporting meaningful partnerships with consumers as a way of improving the safety and quality of health care in Australia.

Providing understandable and accessible health information can improve people's knowledge, understanding and recall about their health and care. It can also increase their feelings of empowerment, improve their ability to cope, increase satisfaction, support shared decision making and contribute to improved health literacy, so that people can be partners in their health care.

Today, people expect information to be easily available in a format that they understand. People seek out, or are provided with, health information from a variety of sources including:

- their social community, including their parents, families, friends, neighbours and work colleagues
- the education system, including preschools, primary and secondary schools, adult education centres and universities
- the health, social and community care systems, including care providers, health organisations, and government and nongovernment care organisations
- private industry, including manufacturers and providers of food, pharmaceuticals, alcohol, exercise products and services
- mass media, including health promotion campaigns, the internet and private companies promoting their health-related products.

The Commission wants to support consumers to understand safety and quality issues for health care, and aims to develop information materials for consumers in key areas of interest.

The Commission understands that for some populations there may be different requirements, expectations, experiences, needs and preferences when it comes to information about health and health care, and different understanding and perspectives on safety and quality.

The Commission engaged the Cultural and Indigenous Research Centre Australia (CIRCA) to explore the experiences and perspectives of two populations: culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander people. Specifically, CIRCA sought to understand specific issues for these populations in relation to their needs and preferences for health information and information about safety and quality.

In parallel to this work, the Commission engaged the Sax Institute to broker a rapid evidence review on consumer health information needs and preferences. This report is entitled *Consumer health information needs and preferences: A rapid evidence review* and can be found on the Commission's website.

Key points

CIRCA conducted seven focus groups across four CALD communities (Chinese, Vietnamese, Lebanese and Iraqi) and six focus groups with Aboriginal and Torres Strait Islander people from urban and regional communities. In-depth interviews were also conducted with Aboriginal health workers from remote communities.

The focus groups and interview process identified a number of key issues within and across the CALD and Aboriginal and Torres Strait Islander groups. Both groups considered that their confidence in seeking out, accessing and understanding health information was significantly influenced by a combination of their culture and their experience.

Both CALD and Aboriginal and Torres Strait Islander participants preferred simple, plain-language information to be available in both English and their first language. Both groups were seeking information that was short and visually appealing. Aboriginal and Torres Strait Islander participants reported a preference for information with a culturally appropriate visual design.

The majority of CALD participants were seeking to be more involved in their health care, but reported a lack of information and confidence to question doctors. They expressed a strong preference for bilingual general practitioners to meet their language needs. However, there were differing views about capacity for openness, privacy and confidentiality when working within small communities.

Aboriginal and Torres Strait Islander participants reported not feeling culturally safe in hospitals, especially when there was no Aboriginal healthcare worker to provide support and alleviate their concerns. Key themes for Aboriginal and Torres Strait Islander participants included feelings of 'shame' in not understanding healthcare information or asking questions of doctors, and difficulties when having to travel far from home for health care. There was also a preference for culturally sensitive in-person support and information to be provided through face-to-face discussions.

The researchers highlighted a range of opportunities for better aligning health information with the needs and preferences of CALD and Aboriginal and Torres Strait Islander people, such as:

- engaging multicultural agencies, consumer organisations and local groups to assist in identifying information priorities for CALD consumers, facilitating access to and acting as a conduit for healthcare information delivery
- including tailored strategies and information materials in broader health information communication programs
- enhancing access to culturally appropriate resources, in consumers' first language, on health issues
- working with Aboriginal and Torres Strait Islander health and consumer organisations to identify information priorities, to develop tailored information materials and to support strategies for accessing culturally appropriate information through a variety of mechanisms.

Next steps

The Commission's work on health literacy, partnerships with consumers and actions within the National Safety and Quality Health Service (NSQHS) Standards (second edition) all highlight the importance of understanding the diversity of consumers, tailoring strategies for vulnerable groups, and the importance of developing high-quality easy to understand health information to support effective partnerships.

The Commission will consider the findings of this targeted consultation with Aboriginal and Torres Strait Islander people and CALD communities, and the associated rapid evidence review, to develop guidance and key principles that should be considered when developing health information for consumers, including information on safety and quality. This guidance will be used by the Commission when developing resources for consumers, and will also be provided to stakeholders to support the development of consumer health information and to help support health services to meet the requirements of the NSQHS Standards (second edition).



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**Final Report for the Australian Commission on Safety and Quality
in Health Care**

April 2017



Developed by the Cultural & Indigenous Research Centre Australia 2017

All research conducted by CIRCA for this project was in compliance with ISO20252

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Executive summary

The Australian Commission on Safety and Quality in Health Care (the Commission) engaged the Cultural and Indigenous Research Centre Australia (CIRCA) to conduct qualitative research with Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse (CALD) communities to explore healthcare information needs and preferences, and health information-seeking behaviours.

The research explored how information needs and preferences vary across the patient journey (symptoms, diagnosis, treatment decision, treatment and discharge) to better understand, recognise and respond to the information needs and preferences of Aboriginal and Torres Strait Islander and CALD communities.

Seven focus groups were conducted across four CALD communities (Chinese, Vietnamese, Lebanese and Iraqi) and six focus groups were conducted with Aboriginal and Torres Strait Islander people in six urban and regional communities in New South Wales, Victoria and Queensland. In-depth interviews were also conducted with four Aboriginal Health Workers.

The healthcare contexts and experiences of CALD and Aboriginal and Torres Strait Islander communities are very different, and the research findings and implications for each of these consumer groups are reported separately.

CALD findings

Australian Bureau of Statistics (ABS) data shows considerably lower levels of health literacy among people from CALD backgrounds.¹ Effective communication of health information is essential for improved health literacy. There are a range of reasons that influence the effective communication of health information and prevent health information being understood. These include English language proficiency, literacy in first language, lack of access to requisite skills and resources to access certain health information, and differences in cultural perceptions of health.

Culture plays a huge part in a person's understanding of health. Culturally specific stigma may be related to particular illnesses, and home-country experiences vary in terms of exposure to and acceptance of ideas such as shared decision making and enhancing the role of the individual in their own health management. This can affect the engagement of CALD background consumers in Australia towards these concepts.

CALD patients generally felt the standard of health care in Australia was better than in the countries they had come from and they felt relatively safe when receiving health care in Australia.

Health issues are often interpreted and treated differently in different communities. The extent to which service providers understand and respond to these cultural differences can affect the level of community engagement with the healthcare system. For example, doctors were generally held in very high esteem among participants, and some expressed hesitation about questioning health

¹ Australian Bureau of Statistics, (2009), Australian Social Trends, cat.no. 4102.0, Canberra

professionals or seeking clarification on issues they were not clear on. Some participants talked about having little home-country experience of the idea of shared decision making in health care.

While CALD patients expressed a strong preference for bilingual general practitioners (GPs) to meet their language needs, some felt that overseas-born GPs operated in their home-country cultural paradigm and posited that they might have received more patient-centred care from an Australian-born GP. Many recognised that high community demand for bilingual GP services resulted in bilingual GPs being excessively busy, which meant participants did not always feel there was adequate time to ask questions and seek information, which affected their view of the health care they received. There was a general consensus across the CALD people interviewed in this study that good-quality bilingual GPs were scarce.

The majority of participants were seeking to be more involved in their health care but lacked the information and the confidence to question doctors. The research suggests there is a paucity of information available for CALD patients who need resources in both their first language and in English (for medical terminology).

When CALD patients receive from their GP a service they are not happy with, they are often unsure about their rights and the avenues that exist to lodge a formal complaint. Patients expressed a need for GPs to be more accountable for providing a good service and for patients to have a clear route to complain.

Waiting times were a big frustration for CALD patients, with many reporting having to wait a few days before being able to see their GP and experiencing long waiting times for specialist appointments and at the emergency department. This frustration was often exacerbated by GPs and specialists not giving them the time they needed in the appointment to fully understand what was being said or ask questions. Some of the Arabic-speaking participants also reported challenges with access to interpreters, particularly interpreters who spoke the same dialect as they did.

This research provided a CALD consumer perspective on preferred information sources and when during the patient journey they are most likely to need information (symptoms, diagnosis, treatment decision, treatment and discharge). The CALD community members that participated in this research had a greater focus on information that dealt with symptoms, treatment and cure, rather than on prevention, self-management of health care or patient-centred care.

The research also sought some preliminary insight into preferences on look and feel of healthcare safety and quality information. CALD community members preferred simple, visually appealing, plain-language information available in both English and their first language. Information coming from government was highly trusted.

Implications

- Ethno-specific and multicultural agencies can potentially play a key role in identifying information priorities for CALD consumers. They are regarded as trusted sources of information and support and are an important conduit for information delivery.

- With appropriate resourcing, ethno-specific and multicultural agencies and organisations are well placed to support local, community-specific, health-based education, partnership projects and capacity-building to build greater familiarity with the Australian healthcare system and to promote culturally relevant healthcare safety and quality information and communication.
- The research suggests that taking a community-focused approach to communication development, and working in partnership with ethno-specific and multicultural agencies and organisations is likely to result in more effective and culturally appropriate communications than mass media campaigns. Certain groups, particularly those from refugee backgrounds, may encounter barriers to accessing digital and online health information, and ethno-specific and multicultural community organisations can help bridge the gap that can exist between healthcare providers, government agencies and CALD communities.
- There are opportunities to work through the peak consumer organisations as the basis for information that is tailored at a local/community level.
- A community focused approach is also relevant for the continued education of healthcare providers about CALD communities and how to meet their needs. There are opportunities to enhance cultural competency among healthcare providers, via partnership projects and knowledge-sharing. It is important that healthcare providers recognise their own cultural perceptions of health, so that they are better able to recognise cultural difference where it occurs. This can be achieved through further development of cultural competency among healthcare providers and greater community engagement. Consideration should be given for a strategy for overseas-born GPs to reflect on and recognise how their home-country cultural paradigm may affect the way they communicate and the quality of health care they provide to their patients.
- There are opportunities, again by working through the peak consumer organisations, to facilitate better access to good-quality, trained interpreters to help bridge the gap between need and provision of interpreter services. There are opportunities to communicate to CALD community members that there is no shame in accepting or requesting an interpreter. Equally, healthcare providers require training in how to work with an interpreter for mutual benefit.
- CALD community members may not engage with information if Western constructs of health and health care are being assumed, even if it is easy-to-read or translated. Communication strategies need to accommodate home-country experiences of health care and respond to the lack of confidence some CALD community members may have about being more involved in their healthcare decisions.
- Information that helps equip CALD patients with culturally relevant strategies for effectively engaging with healthcare professionals should be a priority.
- Prioritise creating resources which will educate patients on the complaint process, giving them clarity and transparency.

- Prioritise safety and quality information about specific health services, hospitals or healthcare providers.
- Prioritise information about illnesses, symptoms and treatment options, as well as safety and quality information in relation to specific health services, hospitals or healthcare providers. Information relating to self-management of health and prevention is less of a priority to CALD audiences.
- Support CALD patients by providing greater access to culturally appropriate resources in their first language.
- Simplicity is key and consider use of illustrations.
- Develop resources in both hard copy and for online. Online information branded as government information will give greater credibility.

Aboriginal and Torres Strait Islander findings

Aboriginal and Torres Strait Islander people experience greater levels of poor health and a much greater prevalence of chronic disease than other Australians. These communities are heavy users of the healthcare system and access health services from a range of providers including Aboriginal Medical Services (AMS).

Many participants were satisfied overall with the quality of health services and the health care they received. The most consistent exception which resonated across the participants interviewed in this study was hospital care. Many Aboriginal and Torres Strait Islander participants reported not feeling culturally safe in hospitals and feeling uncertain, confused, fearful and isolated. There is a lack of Aboriginal workers in hospitals to help alleviate their concerns and they often feel uncomfortable or “shame” in asking questions of doctors in this environment. For patients from remote communities this is often exacerbated by being away from home, in unfamiliar surroundings, and experiencing language and literacy challenges.

To improve the experiences Aboriginal and Torres Strait Islander people have in hospitals, there was a consistent call for more Aboriginal Liaison Officers in hospitals and for a continued commitment to cultural awareness programs. Participants who visited their local Aboriginal Community Controlled Health Service (ACCHS) were often heavily reliant on the support, advice and guidance they received from their Aboriginal Health Worker and identified a need for the same level of support, advice and cultural assurances when engaging with the hospital system. Some participants felt that cultural awareness programs should be compulsory for all staff and as an on-going education program rather than a one-off.

Aboriginal and Torres Strait Islander people living in remote communities experience more challenges with the health system. For these communities, access to services is often problematic, and there are issues associated with sometimes having to travel long distances to receive care.

There is a significant need to help Aboriginal and Torres Strait Islander patients understand more about their health challenges. Many participants reported not feeling confident to ask questions about their own or their family's health (particularly of providers who were not Aboriginal Health Workers) and being left unsure about their condition and why they are taking particular medicines. There is a clear appetite for greater understanding and involvement in healthcare decisions with Aboriginal and Torres Strait Islander participants seeking a wide range of information.

The preferred source of information for Aboriginal and Torres Strait Islander participants is face to face. Some participants already access health information from brochures and posters and a few, particularly the younger people, were accessing information through the internet. Those who live in more remote communities had more intermittent access to the internet and some needed information to be provided in their traditional language.

This research provided an Aboriginal and Torres Strait Islander consumer perspective on preferred information sources and when during the patient journey they are most likely to need information (symptoms, diagnosis, treatment decision, treatment and discharge). Many of the people interviewed were managing pre-existing and on-going conditions and were therefore most interested in information relating to self-management of health conditions.

The research also sought some preliminary insight into preferences on look and feel of healthcare safety and quality information. Many of the Aboriginal and Torres Strait Islander participants reported finding current communications difficult to understand. A consistent theme through the interviews was a preference for resources that are visually appealing and written in plain language, and that are clearly targeted towards Aboriginal and Torres Strait Islander people.

Implications

- Aboriginal Community Controlled Health Services (ACCHS) can play a key role in identifying information priorities for Aboriginal and Torres Strait Islander consumers. They are regarded as trusted sources of information and support and are an important conduit for information delivery.
- With appropriate resourcing, ACCHS are well placed to support local, community-specific, health-based education, partnership projects and capacity-building to promote culturally relevant healthcare safety and quality information and communication. The research suggests that taking a community-focused approach to communication development and working in partnership with ACCHS is likely to result in more effective and culturally appropriate communications than mass media campaigns. ACCHS can help bridge the gap that can exist between healthcare providers, government agencies and Aboriginal and Torres Strait Islander communities.
- There are opportunities to work through the peak bodies, for example the National Aboriginal Community Controlled Health Organisation (NACCHO), and the state equivalent bodies, as the basis for information that is tailored at a local or community level.

- A community-focused approach is also relevant for the continued education of healthcare providers about the needs of Aboriginal and Torres Strait Islander consumers. There are opportunities to work through peak bodies such as NACCHO to enhance cultural competency among healthcare providers, and continuing to educate healthcare providers about Aboriginal and Torres Strait Islander people and how to meet their healthcare needs. In general, cultural awareness programs were endorsed by Aboriginal and Torres Strait Islander people, particularly as an ongoing education program.
- There are opportunities to actively target Aboriginal and Torres Strait Islander organisations, such as Aboriginal Community Controlled Health organisations.
- There are also opportunities to work in partnership with Aboriginal and Torres Strait Islander peaks groups and other organisations and networks to develop community engagement approaches across the healthcare system to increase awareness of rights in relation to healthcare safety and quality, particularly regarding the quality and safety of hospital care.
- There is the need for a suite of materials and strategies to meet the needs of Aboriginal and Torres Strait Islander people. These could include brochures and online resources. In some cases these will need to be in traditional languages.
- Prioritise resources for pre-existing and ongoing conditions, and focus on treatment and self-management of health conditions.
- Focus on simple language with the use of visuals that clearly articulate the key messages.

1. Introduction

1.1 Background

The Australian Commission on Safety and Quality in Health Care (the Commission) was established to lead and coordinate national improvements in the safety and quality of health care. The Commission works in four priority areas:

- Patient safety
- Partnering with patients, consumers and the community
- Quality, cost and value
- Supporting health professionals to provide safe and high-quality care.

The Commission sought research with Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities (CALD) about their needs and preferences in relation to the content and presentation of healthcare safety and quality information.

The Commission was also interested in exploring how information needs and preferences vary across the patient journey, that is, from the initial emergence of symptoms through to diagnosis, treatment and management of acute or chronic healthcare conditions.

While a substantial body of literature exists about the health-information-seeking behaviours of consumers, it is important to be able to understand, recognise and respond to the expressed needs and preferences of groups that are less visible, harder to access and that may be more vulnerable to adverse health outcomes. This research will supplement existing literature.

The aim of this research was to explore, consider and document the healthcare information needs and health information seeking behaviours of two key Australian consumer populations:

- Aboriginal and Torres Strait Islander people
- Culturally and linguistically diverse communities.

Since these communities are themselves diverse, the research acknowledged and explored this diversity to assist the Commission to respond appropriately to the needs, priorities and preferences of these consumers when developing information and resources.

CIRCA used a range of qualitative approaches to capture information across variables such as gender, geographical spread, life stage, socioeconomic status, and levels of contact with the health system.

2. Methodology

CIRCA conducted group discussions and key informant interviews with CALD and Aboriginal and Torres Strait Islander community members.

In determining the type of people to be involved in discussions, it was important that a range of factors were considered to explore varying information needs and preferences. These included the need to include perspectives from:

- A range of life stages. The approach segmented the audience into parents with young children, parents with older children, and older community members (55+ years). This segmentation allowed the research to focus on those who are heavier users of the health system.
- Males and females in the research. The approach included males and females in each focus group for all fieldwork except the Arabic-speaking mini-groups where separate male and female groups were included.
- People living across Australia in metropolitan, regional and rural areas.
- Specific language groups who are unlikely to be accessed in mainstream research processes. Recruitment and facilitation approaches that enhanced access were used, including separate groups moderated by bilingual researchers from the participants' cultural background. The language groups included in the research were Chinese, Arabic (Lebanese), Arabic (Iraqi) and Vietnamese. These represented major language groups with varying levels of English-language proficiency, settlement experience, cultural practices and recency of arrival.
- Participants across a range of socioeconomic status.

Details of the research participants are summarised in Table 1.

Consultations with CALD and Aboriginal and Torres Strait Islander community members were facilitated by bilingual or Aboriginal research consultants in the participants' language of choice.

Table 1: Research participants

	Parents with children under 10 yrs	Parents with children aged 10+	Older people (55+)
Research with CALD audiences			
7 CALD groups			
Chinese	1 mixed gender group <i>Sydney</i>	1 mixed gender group <i>Sydney</i>	
Arabic (Lebanese, established community)		1 male group <i>Melbourne</i>	1 female group <i>Melbourne</i>
Vietnamese		1 female <i>Melbourne</i>	1 male <i>Melbourne</i>
Arabic (Iraqi, refugee community)		1 mixed gender group <i>Sydney</i>	
Aboriginal and Torres Strait Islander research			
6 mini-groups & 4 interviews with Aboriginal Health Workers			
Urban	1 mixed gender group <i>Brisbane</i>	1 mixed gender group <i>Sydney</i>	1 mixed gender group <i>Cairns QLD</i>
Regional	1 mixed gender group <i>Cherbourg QLD</i>	1 mixed gender group <i>Shepparton VIC</i>	1 mixed gender group <i>Ballina NSW</i>
Remote	4 Aboriginal Health Workers (2 Darwin NT; 1 Broome WA; and 1 Napranum Cape York QLD)		

3 . Consultation findings: CALD

3.1 Perceptions and experiences of the Australian healthcare system

Context

Life expectancy in Australia has improved over time in absolute terms and relative to other nations. The routine reported life expectancy in Australia generally refers to the total Australian population and obscures the effect of widespread migration. According to the World Health Organization in 2007, the net effect of different life expectancies in the country of origin of migrant groups on total life expectancy is unclear. The 'healthy migrant' effect where the healthiest, wealthiest and most highly educated are the most likely to emigrate is a factor here. Variation in how and when people from CALD backgrounds present for particular conditions, and issues with access to health and other services, may also influence life expectancy among some CALD groups in Australia.²

However, Australian Bureau of Statistics (ABS) data shows considerably lower levels of health literacy among people from CALD backgrounds. Only 33 per cent of people born overseas have adequate or better health literacy, compared to 43 per cent of the Australian-born population. This figure drops to 27 per cent for those who arrived in Australia during the past five years and to 26 per cent for people whose first language is not English.³

The impact of low health literacy on people from CALD backgrounds means they are: less likely to access the services that they need; less likely to understand issues related to their health; more likely to experience social isolation, which can lead to damaging behaviours and negatively affect physical and mental health; at risk of mismanaging their medication; and less likely to have an adequate understanding of health issues.

Effective communication of health information is essential for improved health literacy. There are a range of reasons that influence the effective communication of health information and prevent health information being understood, including English language proficiency, literacy in first language, lack of access to requisite skills and resources to access certain health information, and differences in cultural perceptions of health.⁴

Culture plays a huge part in a person's understanding of health. Culturally specific stigma may be related to particular illnesses, and home-country experiences vary in terms of exposure to and acceptance of ideas such as shared decision making and enhancing the role of the individual in their own health management. This can have an impact on the engagement of CALD-background consumers in Australia towards these concepts.

² Page, A, Begg, S, Taylor, R and Lopez, A, Global comparative assessments of life expectancy: the impact of migration with reference to Australia, Bulletin of the World Health Organisation Vol 85, No. 6, June 2007, pp421-500

³ Australian Bureau of Statistics, (2009), Australian Social Trends, cat.no. 4102.0, Canberra

⁴ An Investment Not an Expense Enhancing health literacy in culturally and linguistically diverse communities citation, Ethnic Communities Council of Victoria, 2012.

Relatively good standard of health care in Australia

While there was much discussion within the CALD groups about how the Australian healthcare system did not always work for them, there was consensus that service provision was better than in the countries they had come from. Generally, participants felt that Australia has advanced medical knowledge and that they could trust the health service in this country. There was also a general recognition that government-funded access to free or subsidised public health services was a good thing.

In the main, participants felt that the quality of health care provided in Australia was better than they had experienced in the countries they had come from. Participants also mostly felt safe when receiving health care in Australia. Frustrations with the Australian healthcare system centred on waiting times and the varying quality of health practitioners. The Chinese groups specifically were very unclear on how the Australian healthcare system worked, as it is very different in China. The Arabic groups reported sometimes having problems getting interpreters.

Waiting times are a big frustration

“I think it’s not enough GPs. You can ring up and not get in for a couple of days. They are so busy that they don’t have time to listen to you ... they are rushing you in and out.” (Lebanese female)

“Yes they seem very busy and don’t give you time to digest your diagnoses and ask questions.” (Arab male)

In all the groups, the frustration of long waiting times for GPs, specialists and in hospital emergency departments was one of the central themes. The waiting time for a GP appointment was a particular focus, with participants reporting that GPs tended to be fully booked and they were therefore often unable to see a GP for a few days. A number of participants felt that when they did get to see their GP or specialist, they were not given the time in the appointment to fully understand what was being said or to ask questions.

“It takes four to six hours to see a doctor ...I could have bought Panadeine from the local pharmacy after I was seen by the nurse at Emergency and told to continue Panadeine by the doctor after waiting six hours.” (Chinese)

Good-quality bi-lingual GPs in short supply

There was a general consensus that there is wide variation in knowledge, experience and level of customer care patients receive from health care practitioners. The majority of participants saw bilingual GPs, but many reported that they were not happy with the level of service they received from their GP. Many participants felt their GP was rushed and therefore was not able to take the time to listen or explain things to them. Some participants reported that it was sometimes difficult to get access to these GPs because they were in short supply and there was a high demand for their

services (particularly Arabic-speaking doctors). A number of groups felt like that they would like to see another GP but had limited choices because of the language barrier.

Some participants also felt that their overseas-born GPs operated in cultural paradigm of their home country, where patient-centred care was less of a focus than it is in Australia. The Chinese and Vietnamese groups reported that doctors had a high standing in their community and that the doctor's decision was viewed as final. These groups indicated that they would be unlikely to speak up if they were not satisfied with the quality of care they received; some had not even considered it and others were daunted about the prospect of asking their GP questions or challenging them. Many participants were also unsure about what avenues might exist to raise concerns or make complaints about the quality of care they were receiving from their GP.

"Most of the times people who are non-English-speaking like us have not many choices but seeing the Vietnamese GPs which can be daunting and unclear as the Vietnamese would hardly challenge the GP who are highly respected by the community." (Vietnamese parent)

"The Vietnamese community has no ideas and no directions of what to do or where to go to get help". (Vietnamese 55+)

"My child was one year old and had a fever. I took him to the hospital and the doctor reckoned he might have a form of severe infection and must undergo a spinal fluid test. The doctor gave an intern doctor to perform this test and the intern failed two times to obtain the fluid. I complained and asked the doctor to stop or the senior doctor to accurately do the test. The intern doctor again failed the third time and finally the senior doctor carried out... is it my rights to protest or stop this procedure and request another doctor to carry out the test?" (Chinese)

Some challenges with access to interpreters

There were mixed views about access to interpreters: some groups felt they had good access to interpreters, while others were not always able to access interpreters. A number of the Arabic-speaking participants reported that they were not always able to access an interpreter that was "right for them". The Lebanese female group said they had been provided interpreters from African and other backgrounds who could speak Arabic but they couldn't understand them. Similarly, the Iraqi female group said they would prefer to have an interpreter from their own background who spoke their dialect.

Confidentiality

Confidentiality is of particular concern to CALD groups. It was very usual for friends and family to see the same doctor, and one of the groups reported that it was not unusual to see someone you knew in the waiting room. This creates concerns that the doctor might discuss their health issues with others.

Confidentiality was specifically raised as a concern for members of the Iraqi female group, who discussed that many of the newly arrived refugees from Iraq were suffering post-traumatic stress and

other trauma and they needed specialist care but they did not want anyone to know what they were going through.

Lack of understanding of the Australian system (Chinese groups)

A lack of understanding of the Australian system was a strong discussion point in both of the Chinese groups. Because their frame of reference is the healthcare system in China, they are often unsure about where to seek help and they feel they miss out on appropriate treatment. Participants observed that some Chinese migrants thought they had to go to hospital directly to receive treatment as they did not understand the GP referral system. They feel that they tend to be passive about the process because in their country of origin, where the doctor's decision is final and the patient is less involved in the decisions around their care.

"In China, you go to the hospital and directly put your name down and request a doctor with a speciality. In Australia, you have to go through the GP to be referred to specialised services. This will prolong your symptoms as you have to wait for GP then wait again for specialist appointment." (Chinese)

Generally feel safe

Participants were asked how safe they think people feel when they are receiving health care and to share any times they or people they knew had felt unsafe. The feedback from the groups was that generally they feel very safe in the Australian healthcare system and notably so compared to the country of origin. Generally, participants put lots of faith in doctors and hospitals and believe that although sometimes health professionals can be rude or don't listen, that generally services are safe.

"I think in general we feel quite safe receiving health care but I believe we have to trust our own instincts and if we feel unsafe we should do something about it."
(Lebanese female)

Given that participants mainly felt safe in the Australian healthcare system, there was limited discussion in the groups around when participants or people they knew had felt unsafe. In most instances the groups discussed their experiences with GPs when they talked about safety.

In the main, people felt safe with their GPs. The Chinese groups discussed feeling unsafe when there was prolonged investigation which led to delays in treatment and to smaller problems becoming a large problem. The Chinese groups found the system slow and wanted more efficient and speedy resolutions to their health problems. The groups were not explicit, but these observations could be driven by the differences in the Chinese system and the Australian system referred to earlier.

"I had a fever and coughing for a few weeks and a few time my GP told me just to rest and it is typical cold system and not to worry. At the end, I had a severe lung infection and had to be treated in hospital. I reckon my doctor did not recognise the severity of my symptoms and made a wrong judgement." (Chinese)

3.2 Information-seeking behaviour

Patients seeking to be more involved but lack information

Generally the CALD groups wanted to be more involved in their healthcare decisions but either did not know what questions to ask or did not feel confident enough to ask questions. The majority of participants did not always understand the information they received about their health care and did not know who to ask or where to go to access information, tending to relying on family and friends or trust in the doctor. Many, but not all, were comfortable with the notion of accessing health information online but found the number of websites they are faced with overwhelming. Some participants were not computer literate.

“I had a hernia and I was on a waiting list for over a year and then they called me to hospital ... the doctor explained what they were going to do with me during the operation and I got really scared, and she said the operation would ruin my body and my stomach would look awful and she said to me, don't think we are plastic surgeons, we don't care about you looking good after your operation, you will have big scar. I got so worried about what she was saying and very rude to me so I didn't go ahead with the operation and I still haven't done it”. (Iraqi female)

“When the doctor said I had to do a breath test, I had no idea what this was, I thought I would just blow into something. However, before the test they give you a tablet which is radioactive or something like that and actually the doctor didn't explain anything about this and when he sent me for a blood test I was scared about what the doctor was looking for because the doctor didn't tell me and when I asked the nurse all she said was they are obviously looking for something, but no one told me what that something was. So I got very worried, again I thought it must be cancer and they don't want to tell me. So I blame the doctor for my stress because he didn't explain anything to me, just send me for tests which worried me. Thank God it wasn't cancer but I was very stressed for quite a few weeks because of lack of information from my doctor”. (Lebanese female)

Feedback on specific statements

When discussing specific statements about health and healthcare, the following themes emerged:

“I want to be more involved in decisions about my health care”

The majority of groups agreed that they would like to be more involved in the decisions about their health care. The exception was the Chinese groups, who felt that some level of involvement was beneficial but that they were heavily reliant on the doctor's advice.

“Sometimes I don’t know what questions to ask”

The majority of groups agreed that they were often unsure about what questions to ask. The Vietnamese groups sometimes felt intimidated by doctors and were scared to ask questions. The Chinese groups reported they were both lacking in medical knowledge and unsure about issues such as self-management of their condition, and possible side effects and symptoms from their medication.

“I always understand the medicines I am taking”

There was a mixed response to this question. The Vietnamese groups tended to be confident about the medications they were taking; one group talked about being lucky enough to have doctors and pharmacists in their area who spoke Vietnamese and who they could ask about their medication. For the other groups, lack of understanding about the medicines they were taking represented a significant issue for them. Participants reported not being clear on why they were taking certain medicines or what the possible side effects could be. Some of these groups felt that pharmacists were doing a much better job of explaining their medication to them than the doctors.

“I feel confident to ask questions”

Some participants felt confident about asking questions, but many did not. The reasons for not feeling comfortable about asking questions centred on the receptiveness of the doctor to questions. Many participants reported that doctors were very busy and that they felt they were rushed out of the door before they could ask questions. Other participants felt that some doctors empowered and encouraged people to ask questions while others did not. The Arabic male group felt they wouldn’t want to question a professional such as a doctor because the doctor had more knowledge about health than them and they wouldn’t want to insult a doctor by querying the treatment.

“One doctor said to me you only have to ask one question at a time when you come. I don’t have time to answer too many questions, make another appointment.” (Iraqi female)

“One doctor told me, I’m the doctor, not you, I have been working 15 years getting this degree how dare you ask questions, that was a specialist.” (Lebanese female)

“I know where/who to go to access information”

Across the board, participants were unsure where to go to access information beyond asking their GP, friends and family and internet searches.

“I always understand the information I receive about health care”

The majority of participants did not always understand the information they received about health care. Many were unable to understand information unless it was in their first language, and even then they were sometimes confused by the medical jargon.

“I always read brochures that are given to me”

Participants didn't always read the information that was given to them. Some participants found brochures hard to read and either trusted the doctor to provide the right treatment or asked friends and family if they didn't understand.

"I like to access health information online"

Many participants did like to access health information online. The majority of the Iraqi female group had not accessed health information online and some of the Chinese group rarely used the internet at all. The Arabic male group claimed to play a very passive role in managing their own health, rarely discussing their health problems with anyone. If they did discuss these issues it would be mainly be with their wives and doctors. None of the Arabic male group had accessed health information online. Among participants who did access health information online, there were mixed views, with some feeling the information was useful and some finding it very confusing.

"My cultural needs are not always met by the health system"

Participants generally agreed that the health system did not always meet their cultural needs. Many felt that they compensated for this by choosing doctors who spoke their language and better understood their cultural needs, and that they were generally able to access these doctors in their local area. A few had experienced problems with getting interpreters when they accessed other health services such as hospitals. A number of the Asian groups raised the problem of getting access to Chinese medicines, with some going to Chinese herbalists in the area to receive the services they needed.

When participants were asked what information they would like to have access to, they were largely unable to articulate their needs, apart from information about how to raise concerns or make formal complaints. This is likely to be influenced by many participants being unclear about what sort of questions they should be asking and therefore what sort of information they should be looking for.

"I know there is probably a lot of information out there that we can access, both in Arabic and English, but Lebanese men are very lazy about their health, I must admit, and we always have this cultural attitude about what will be will be, sort of our fate, so that stops us from looking for too much information". (Lebanese male)

Paucity of available Ability to find information on safety and quality in health care

Most people were unaware of any information regarding safety and quality in health care. Generally participants relied on family and friends to find information or trusted that their GP was providing them with the correct information. Some participants also searched the internet to help with diagnosis and treatment, but found this could be an overwhelming and frightening approach with the amount of information available online.

"Sometimes too much information is not good because you start obsessing about your illness if you look into it too much." (Lebanese female)

"We actually don't know what information we should be asking for." (Iraqi female)

People who had had previous concerns about quality and safety almost unanimously felt they had not received information to allay these concerns. Most people tended to discuss concerns with their friends and family and many felt uncomfortable with the notion of raising quality and safety problems with their GP. Many participants were unsure how to raise concerns or make formal complaints and were keen to understand what the process might be. The few who had complained felt that they had never received a satisfactory response.

3.3 Information priorities and sources

Patients prioritise information about illnesses, symptoms, treatment and safety and quality

Participants were asked to prioritise their need for information across a range of topics. This exercise resulted in a clear polarisation between the most and least important topics.

The highest priority for information was very consistent across the groups and that was to have information about illnesses, symptoms and treatment options and to have safety and quality information about specific health services, hospitals or healthcare providers. Participants prioritised clear information about a specific condition they or their family member may be experiencing, rather than more general information about managing health care and patient involvement in health decisions. Similarly, participants prioritised health and safety information about specific services, rather than more generic information about health and safety. A couple of groups said that safety and quality information was important because it would empower them to make more informed choices about where they went for their health care. Another group felt that if they had better medical knowledge then they would be more likely to be compliant in treatment.

The lowest priority was for information about cancer care and for healthcare options for terminal conditions or end-of-life care. Some groups believed they had a general knowledge and that this sort of information might be more useful if they were caring for elderly or terminally ill family members. The Lebanese female group reported that it was contrary to their cultural norms to discuss cancer and cancer care, and that people tended not to use the name “cancer” but tended to call it “that illness”.

The other topics ranked similarly overall in the importance participants placed on receiving information.

In line with some of the earlier discussions among the groups, some also mentioned it would be good to have information on where to go to complain. There was a view expressed that doctors would be more accountable if they felt that everyone had this information and knew their rights.



GPs, health specialists and friends and family are the primary source of information

Participants were asked which information sources they were most likely to use for information about health.

The feedback was very consistent across the CALD groups. Participants prefer to receive information from health specialists and friends and family. Online sourcing of information was most likely to be through websites. One group discussed how it would be beneficial to have a centralised and regulated government website which also had the option of online forums to read about the experiences of others. There was some limited discussion that social media could be a good way of sharing information with family and friends, but the majority of participants in this research did not use social media or did not use a computer at all. A couple of groups also discussed going to the pharmacist for information about diagnosis and medication.

Participants were least likely to source information through television, radio, online videos and DVDs. They were fairly ambivalent about the other sources for information put forward.

Most Likely Source



Medical specialists
Friends and family
Website information
GPs

Bilingual GPs/health workers
Tips and tools
Pharmacists
Social media
Brochures
Posters at GPs
Face to face
Migrant resource centres
Q&A's
Workshops
Fact sheets
Telephone help lines

TV
Radio
Online videos
DVDs

Least Likely Source

All groups wanted to receive information in both their first language and in English. This was noted as particularly important for older people who were less likely to be fluent in English and likely to be heavier users of the healthcare system. Information in both languages was also seen as beneficial where one partner was more fluent in English than the other. The Chinese groups wanted information in both languages so they could look up the English medical terms on the internet.

Information needs most prevalent in the first three stages of the patient journey

For most participants, their GP is their key source of information throughout the patient journey. Information needs seemed to be more prevalent in the initial stages of the patient journey – upon first symptoms, receiving a diagnosis and thinking about treatment.

In the main the GP was the key source of information at the earlier stages of the patient journey, particularly if they were really sick. Many also consulted with family and friends when they first had symptoms or were diagnosed. On first symptoms, some would go online. Participants discussed how this could be helpful as they would have a basic idea of what the problem may be, but that it could also often be more worrying as it gave information about a lot of possible illnesses. Other participants reported not having the skills to search the internet themselves and not wanting to worry their kids by asking them to search for them.

“In our culture you do ask around and see if somebody had this problem before and how they got treatment and solved it. You do talk to people.” (Lebanese female)

“Well first you check with your wife, because they seem to know everything about sickness and treatment.” (Lebanese male)

The key tension point around lack of information across many of the groups was on receiving a diagnosis. Some participants felt that their GPs really didn't have the time to spend with them so they felt they were left with not enough information. Some participants chose to ask lots of people for their opinions and information while only a few looked online.

“Really you only trust the doctor to give you the right information so you have to be assertive and keep asking him or her questions and insist that they answer your questions and not rush you out the door.” (Lebanese female)

The pharmacist played a more significant role for some participants when they were thinking about treatment.

CALD patients need information in both their first language and in English

Participants were shown two existing resources from the Commission and prompted about likeability, relevance, target audience, tone, format, appropriateness of the imagery and suggestions for improvement.

Generally, participants really engaged with the “10 Tips for safer health care” and did not engage with “How should care be delivered at the end of life?”

Most groups liked the simplicity of the 10 Tips, with some participants noting the readability of case studies and others liking the question approach taken in the booklet. The illustrations were received well by many but there were a few who were uncomfortable with them because they felt they were making light of a serious situation. Consistently across the groups they would prefer a larger font. A couple of participants raised that this initiative would be better in a booklet format that you could carry around. A few participants were so excited about the 10 Tips that they wanted to keep it, while others had not seen anything like this before and were keen to see more of this sort of information, particularly in their own language. There was a view from some of the participants that they might be missing out on



existing information because they did not know where to find it.

The end-of-life care booklet resonated less well with participants and many participants found the topic less relevant to them. The Lebanese groups did not tend to read about the subject because it was not discussed much in their community. The Chinese groups found the wording “end of life” quite frightening as it did not translate well into Chinese. Besides the appropriateness of this sort of document, participants found the end-of-life care booklet very text heavy and complicated to read.

There were different views about accessing materials online: some participants were comfortable with online access, some would still want to print out materials sourced online and others were not open to sourcing materials online at all. The level of comfort with accessing material online depended largely on the age of the participant, with many of the older participants not having access to a computer at all. For those who would access information online, there was predominantly a need to have the material available in their first language as well as English. Some participants wanted to download or scan it onto their phone using QR code. There were also a few participants who wanted to be able to share information with family and friends through social media.

The majority of participants would prefer to source information from official websites from health organisations or the government, feeling that this would make the material more reliable. Participants mostly did not specify which websites they currently used with some noting that they just searched using Google. The exception was the members of the Vietnamese 55+’s group, who accessed lyhoung.net (Vietnamese Community in Australia) and WWW/Facebook/SBS Vietnamese (Vietnamese SBS in Facebook)

3.4 More on cultural needs

Priorities are different across Vietnamese, Chinese and Arabic groups

Towards the end of the session, participants were asked to sum up how the health system could better meet their cultural/language needs. The conversation varied across the language groups and largely reflected earlier discussions. The discussion in the Vietnamese groups centred on lack of respect and consultation time with doctors that spoke their own language, and providing more interpreters to encourage the use of mainstream doctors. The Chinese groups were more focused on their requirements for efficient and quick problem-solving and that if they understood the system better that might relieve the frustration and misunderstanding that can hinder treatment. There was also general agreement in the Chinese groups that integration of Western and Chinese medicines is difficult. The Arabic-speaking groups’ discussions centred more on ensuring they had access to the right interpreters.

“In reality, most Vietnamese peoples go to the Vietnamese family doctors for their health services. Many peoples have been treated with no respect and unsafe (emotionally). They are continue to be the same if there aren’t changes in the health system.” (Vietnamese 55+)

“Mostly we get respect and access to interpreters when we need them.” (Lebanese Female)

More GP accountability and clarity on the complaints process

At the end of the session, participants were asked “if you were going to give a single piece of advice to government to improve information about the safety and quality of health for people from Aboriginal and Torres Strait Islander/Chinese/Vietnamese/Arabic-speaking backgrounds, what advice would you give?”.

Across many of the groups was the consistent desire for a transparent feedback system on GPs and better understanding of the complaints process. A number of participants wanted their GP to be more accountable for the service they provided. Ideas raised about how to increase GP accountability and transparency included a star rating system for GPs where their knowledge and skills were tested, and a rating system that patients could access to complain or praise their GP and view other patients’ experiences with specific doctors. Another group suggested that if there were more doctors, then doctors would not be so rushed, they would be able to ask questions and would receive better-quality care. Another group suggested more training for doctors on how to be respectful with patients.

As well as looking for greater transparency of other patients’ feedback on doctors, many participants also sought greater transparency about official complaint channels. Some participants wanted clarity on what their rights were regarding patient care and complaints, another group suggested a first point of contact to raise concerns, and another suggested an official website to access complaints and inform the public on how complaints are handled

“Need a first point of contact for the Vietnamese to raise their concerns. And this has to be confidential and safe as they might be scared to talk openly.” (Vietnamese parent)

“A transparent rating system would improve the healthcare services. This will support doctors to satisfy the standard set by the government board.” (Chinese)

4 . Consultation findings: Aboriginal and Torres Strait Islander people

4.1 Perceptions and experiences of the Australian healthcare system

Context

Despite a small narrowing in the life expectancy gap in recent years, the life expectancy for Aboriginal and Torres Strait Islander people is still around 10 years shorter than for other Australians.⁵ A major contributor to this mortality gap is chronic disease, which is estimated to account for around two-thirds of all premature deaths among Aboriginal and Torres Strait Islander Australians.⁶

Results from the 2012–13 Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS) have highlighted the extent of poor health among Aboriginal and Torres Strait Islander people compared with other Australians. The National Aboriginal and Torres Strait Islander Health Measures Survey (NATSIHMS) also showed that large disparities in chronic disease prevalence (particularly circulatory disease, cancer, diabetes, respiratory disease and kidney disease) account for two-thirds of the health gap between Aboriginal and Torres Strait Islander people and non-Indigenous people.⁷ For example, the rate of circulatory disease among Aboriginal and Torres Strait Islander Australians is 1.7 times the rate for non-Indigenous Australians; incidence of patients end-stage renal disease commencing with renal replacement therapy is seven times that of non-Indigenous Australians. The gap is widening in deaths from cancer between Aboriginal and Torres Strait Islander people and non-Indigenous Australians.

Indigenous Australians were less likely than non-Indigenous Australians to access preventive health services aimed at promoting health or preventing illness.⁸

Overall satisfaction

Participants in the research were accessing health services from a range of healthcare providers and were providing feedback across a range of services from Aboriginal Medical Services (AMSs), local GPs, medical centres and public hospitals. While many participants were satisfied overall with the quality of health care provided, in hospitals many participants reported bad experiences. There were mixed views on how safe people felt when receiving health care, primarily driven by the bad experiences participants had in hospitals.

⁵ Australian Bureau of Statistics 2013, Life Tables for Aboriginal and Torres Strait Islander Australians, 2010-2012, ABS cat. no. 3302.0.55.003 <<http://www.abs.gov.au/ausstats/abs@.nsf/mf/3302.0.55.003>

⁶ AHMAC (Australian Health Ministers' Advisory Council) 2012. Aboriginal and Torres Strait Islander Health Performance Framework 2012 report <[http://www.health.gov.au/internet/main/Publishing.nsf/Content/F766FC3D8A697685CA257BF001C96E8/\\$File/hpf-2012.pdf](http://www.health.gov.au/internet/main/Publishing.nsf/Content/F766FC3D8A697685CA257BF001C96E8/$File/hpf-2012.pdf)>

⁷ Australian Bureau of Statistics 2013, Australian Aboriginal and Torres Strait Islander Health Survey: Biomedical Results, 2012-13

⁸ Australian Institute of Health and Welfare, 2012, Access to health services for Aboriginal and Torres Strait Islander people, Canberra, <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737418951&libID=10737418950>

There were also mixed views on local AMSs, with some satisfied with these services, and others feeling that the quality of care was not up to standard. One group attributed the perceived poor quality of care from their AMS to a lack of funding and lack of clarity around what services the AMS was able to provide (for example, a local AMS was considered to be good for dentistry but not for other health care).

Quality of health care varies by remoteness

There was a view amongst the urban and regional groups that those in more remote communities “seem to be getting a rougher deal” when it came to health care. This was echoed in the in-depth discussions with remote area health practitioners. Remote communities experience more challenges with the health system. For these communities, access to services is often problematic as are issues associated with sometimes having to travel long distances to receive care.

The participants who were least satisfied with both quality and safety of health care that they received were the Cairns, Cape York and Torres Strait group.

A couple of the groups discussed the need to take a more preventative approach to health care, with people focusing more on better lifestyle and food choices so they didn’t get sick in the first place.

“We gotta educate people about health so they don’t get sick... food choices, lifestyle choices, that sort of thing. That’s what we have to do ...instead of coming in there (medical services, hospitals etc) when you’re sick and then having to spend the rest of your life on medicines.” (Brisbane)

Many Aboriginal and Torres Strait Islander people do not feel safe in hospitals

There were mixed views on how safe participants felt when receiving health care. The participants who felt safe generally attributed it to a good relationship with their health professionals, GPs or the local AMS. Some participants reported that they trusted health professionals, feeling confident that they act in the best interest of the individual. One group compared this to safety in the mental health system. All the participants in this group agreed that they did not feel safe in the mental health system, referring to a lack of referring information, little follow-up and bad personal experiences.

“The most recent appointment was a paediatrician and he explained things in a lot more simplicity so my son could understand. The posture of the doctor made my son feel more comfortable.” (Shepparton)

“Telling numerous doctors and nursing staff in emergency you are allergic to an antibiotic they were going to administer and they do not listen and give it to you anyway, the result an elderly Torres Strait Islander lady having a severe reaction and ending up in the cardiac unit. She went in with a cyst on her leg.” (Cairns)

For those who did not feel safe, this tended to be more associated with a lack of cultural safety in hospitals. Participants reported feeling uncertain, fearful and isolated in hospitals. For many participants this was compounded by a lack of Aboriginal workers in hospitals to help alleviate their concerns and explain what was happening. Many felt uncomfortable asking questions of doctors in this environment. For people travelling from remote communities, feeling unsafe was exacerbated because they were far away from home, friends and family and sometimes in very unfamiliar surroundings. Language and literacy challenges are also often greater for people in remote communities if English is not their first language.

The group in Cairns unanimously agreed that people did not feel safe when receiving health care. This reflected bad experiences that they or people they knew had had across a range of different service providers.

“A client of mine went down to Cairns for a specialist appointment at the Cairns Hospital and got lost down there. Apunipima have a bus service to collect clients and take them to accommodation and they did not pick him up, so he walked into town, later that evening he was picked up by the police, he missed his appointment and went back with nothing achieved medically for him.” (Remote Aboriginal Health Worker)

In some instances, the patients who had not received satisfactory care had raised complaints through formal channels but had not received a satisfactory outcome. The group agreed feeling safe depended on the quality of the doctor and nursing staff, how well they listened to their concerns and how comfortable they felt speaking up.

Helping Aboriginal patients understand their health challenges

One of the themes throughout the Aboriginal and Torres Strait Islander interviews was a feeling of uncertainty and fear when accessing the health system, particularly visiting hospitals. Many participants found the language that health practitioners use too technical and difficult to understand.

Many participants experienced a high level of “shame” when being given medical advice (treatment options, treatment plans, palliative care information, medicines and dosage) as they did not understand the directions and advice and felt too “shamed” to ask for more information or clarification. As a result, many Aboriginal and Torres Strait Islander people in the focus groups felt confused about their medical conditions and the medicine they were taking.

“When I am at the Aboriginal Medical Service, staff explain things to me. They are good and tell me what’s going on. At the hospital, if they tell me something I don’t understand it (they use medical terms and jargon) and I felt “shamed” to ask as they say it once but I don’t want to ask again because they think I’m dumb. So I say “yes” when they ask me if I know what they said.” (Brisbane)

“It’s like a lucky door prize if you get a good doctor and nursing staff who understand, respect your cultural background, explain things thoroughly and just respect you as a human being.” (Cairns)

A number of groups noted a lack of cultural awareness and understanding from medical staff, GPs, hospital and specialist medical service providers, with a few groups suggesting that cultural awareness training should be more of a regular dialogue than a one-off education session.

Some participants reported that they had difficulty with print, particularly print which used more formal language and lacked diagrams. A few of the younger participants reported that they went online when they had health concerns, but most did not.

The importance of Aboriginal Health Workers

Many participants seek out Aboriginal Health Workers to support, explain and guide them through the medical system. This is particularly the case in the hospital and emergency settings, and with specialist medical service providers. A number of participants reported limited availability of Aboriginal Liaison Officers to speak with in hospitals.

“Administration staff at emergency at Cairns Hospital are rude and disrespectful towards Aboriginal and Torres Strait people.” (Cairns)

“They don’t have enough blackfella nurses (and liaison officers) in hospital. Everyone is white and you don’t want to be there.” (Brisbane)

Limited access to doctors and medical services in remote communities

Aboriginal Health Workers raised the challenges faced by people living in remote communities to access services; this limited access is often exacerbated by high levels of staff turnover. Aboriginal people who live in these areas often have to travel long distances to access health care for more chronic illnesses and this brings a set of challenges associated with being a long way from home. The paucity of affordable and accessible accommodation for community members who need to travel was raised consistently by Aboriginal Health Workers, as was the struggle that many people have with a lack of finance, and feelings of “shame” to share these financial challenges. Community members who need to travel to receive health care often experience feelings of isolation in a system that they are not familiar with. This often coexists with difficulties in understanding the language and poor literacy levels.

The feedback from some of the group participants echoed these sentiments.

“My Aunty travelled from Kowanyama to Townsville to get cancer treatment, she was in an advanced stage of her illness, and she was not allowed to take a support person with her to help, she did her treatment and came back to Kowanyama and passed away. She was in her last few weeks on this earth you would make considerations to make her life a little easier.” (Mareeba)

“On Moa Island we have a weekly doctor clinic and a highly skilled and trained nurse who pretty much knows as much as the doctor, she is with us full-time and has been on Moa for 15 years.” (Cairns)

One Aboriginal Health Worker in a remote community spoke of challenges with services getting to the community, unreliable fly-in and fly-out services, inexperienced doctors in remote communities and high levels of staff turnover. High levels of staff turnover meant that patients were constantly feeling the need to explain their health and personal history to new doctors.

“The Apunipima Cape York Model of care – fly-in fly-out (FIFO) – does not provide an adequate standard or level of care for her community. Services like GPs and Allied Health teams cancel at short notice, usually with no reason given. This leaves workers on the ground to do a lot more home visits to reschedule appointments.” (Remote Aboriginal Health Worker)

A number of remote Aboriginal Health Workers spoke of challenges because of services working in silos. This seemed to be associated with a lack of communication between the different organisations and administrative challenges like having to enter information on separate medical databases.

“We have permanent doctors at the Queensland Department of Health Clinics. The two services need to work better together to provide a seamless service. At the moment we are two silos, there is a lot of duplication as well.” (Remote Aboriginal Health Worker)

4.2 Information-seeking behaviour

Patients seeking to be more involved but lack understanding

The vast majority of Aboriginal and Torres Strait Islander participants wanted to be more involved in their healthcare decisions. The main sources of trusted information tended to be from Aboriginal Health Workers, Aboriginal Liaison Officers and GPs. Almost everyone was clear about where to go to access information but many did not understand the information that they received. The reasons for this centred on not being confident to ask questions (although there was a sense of growing confidence reported across a couple of the groups), not understanding the brochures and not being given timely access to Aboriginal Liaison Officers. Most reported not understanding the medicines they were taking.

Feedback on specific statements

When discussing specific statements about health and healthcare, the following themes emerged:

“I want to be more involved in decisions about my health care”

The vast majority of participants agreed that they would like to be more involved in the decisions about their health care.

“I always understand the medicines I am taking”

Most participants reported they did not understand the medicines they were taking. A few stated that over time they had learnt more about the tablets they were taking and what they were for.

“I feel confident to ask questions” / “Sometimes I don’t know what questions to ask”

Many participants did not feel confident to ask questions, particularly of GPs and specialists. Some felt “shame” to admit they didn’t understand, some felt shy and others felt overwhelmed. There was a sense of growing confidence to ask questions reported by a couple of the groups.

“There has been a case when I’ve seen a different doctor and was not comfortable with what he was going to do, so I waited to see my own doctor.” (Shepparton)

“It’s hard to absorb that you’re just been told you’re a diabetic or have kidney failure but as you get use to the health system and health professionals its one step at a time.” (Cairns)

“I know where/who to go to access information”

Almost everyone felt clear on where they could go to access information; the challenges centred more on comprehension of the information they received and being afraid to ask questions. Participants who visited an AMS or clinic used these as sources of information. Many participants reported seeing brochures in clinics and a few used “Dr Google” as a source of information.

“They have at the health centre a community notice board in the waiting room and outside waiting area where all sorts of health information is placed. Most of the information placed there is all health-related and a couple about community meetings and men’s/women’s business meeting.” (Remote Aboriginal Health Worker)

“I always understand the information I receive about health care”

The majority of participants reported they did not always understand the information they receive about health care. Participants often found the GPs and specialists difficult to understand because of the medical terms and jargon they used. Many participants preferred to receive information from Aboriginal Health Workers and Aboriginal Liaison Officers and some had experienced trouble accessing these people, particularly in hospitals.

“When my wife went through her cancer treatment and we didn’t see the Aboriginal support worker (Aboriginal Liaison Officer) until the very end (of her treatment). This was no good, you know the fear and stigma around cancer and we thought it was bad (patient treatment). We wanted to ask them (Aboriginal Liaison Officer) about what we didn’t know about cancer. The (written) information was too hard (to understand). It was a big let-down, we never saw anyone, spoke to anyone... no-one come and explained what was going on.” (Brisbane)

“I always read brochures that are given to me”

Most participants said they read the brochures that were given to them, choosing to read them when they were back at home.

“I like to access health information online”

The majority of participants did not access health information online. The exceptions were a few of the younger participants who used search engines such as Google. One participant often had trouble accessing online information because they didn’t have credit on their phone.

“My cultural needs are not always met by the health system”

Participants generally agreed that the health system did not always meet their cultural needs, particularly in hospitals

“Having an Aboriginal print on the wall at the Cairns hospital does not meet my cultural needs, it’s a lot more than that, it’s about having the right policy or protocols in place to keep the Indigenous workforce across the whole system in place, it’s also about training and education and ongoing cultural awareness for staff who deal with Indigenous patients.” (Cairns)

“You go there (hospital) for hours or days and you still don’t see a black face (Aboriginal Liaison officer), one of your mob who will help you and tell you what’s going on. (To tell you) what’s happening and what they are doing (to your kids or family member/s).” (Brisbane)

4.3 Information priorities and sources

Aboriginal and Torres Strait Islander participants seeking a wide range of information

Participants were asked to prioritise their need for information across a range of topics. For the Aboriginal and Torres Strait Islander groups, many thought that it was either essential or important for

them to receive information on most of the topics. This is likely to be linked to the high levels of chronic disease experienced by Aboriginal and Torres Strait Islander people. There was less of a clear polarisation between the most and least important topics compared to what was seen in the CALD groups. The following statements were the statements that most consistently appeared as being absolutely essential:

Information about different medicines
Information to help me make health decisions
Information on the services that are available to me and how I can access them
Information to help me look after my own health
Information to help me know what questions to ask
Information about cancer care
I want safety and quality information about specific health services, hospitals or healthcare providers

Similar to the CALD groups, end-of-life information was only something you looked for when you needed it.

Participants offered a range of topics that were missing from the list where it might be useful to have additional information:

- Information for medical staff about meeting our cultural needs
- The implications of mixing different medicines
- A “Who to Contact” booklet for emergencies, particularly when assisting elderly clients to move to a nursing home
- A booklet from the Patient Travel Scheme.⁹

Primary source for information is face to face

Participants were asked which information sources they were most likely to use for information about health.

The feedback was reasonably consistent across the groups with most participants choosing face-to-face information from GPs, specialists, pharmacists and from Aboriginal Health Workers for those who visited AMSs. It was noted that Aboriginal Health Workers did not rank as highly as GPs and some of the other sources of information. This will be influenced by the fact that not all of the participants visited an AMS. Some groups also talked about friends and family playing an important role in health information.

Some of the groups, particularly in remote communities, found posters at GP practices and AMSs a useful source of information. A number of groups reported, however, that an excess of posters at their

⁹ <http://www.qld.gov.au/health/services/travel/subsidies/>

local AMS and that it was difficult to know what to read first. Brochures and fact sheets were a useful source of information for some participants, but others commented that they could be hard to read.

Most participants did not access health information through the internet. The exception was younger participants who were comfortable with sourcing health information on-line. For some participants, particularly in the remote communities, internet access was intermittent or non-existent. Accessing health information through social media was a preference overall for participants compared to the internet.

Participants tended to think that they would be less likely to engage with television, radio, online, telephone help lines and DVDs.

“The network is always down so website, social media, online videos, telephone helplines were least likely to use for this information. Aboriginal people just do not access these from remote areas.” (Remote Aboriginal Health Worker)

“It’s what we do (information coming from family and friends) and everyone else when we meet up, have a good yarn about everything.” (Mareeba)

“It’s not personal speaking to a stranger over the phone.” (Cairns)

“Fact sheets are too hard to read.” (Brisbane)

Most Likely Source



- GPs
- Medical specialists
- Face to face
- Friends and family
- Pharmacists
- Posters at GPs

- Aboriginal Health Services
- Aboriginal Health Workers
- Brochures
- Social media
- Fact sheets

- Website information
- Q&As
- Workshops
- TV
- Tips and tools
- Radio
- Online videos
- Telephone help lines
- DVDs

Least Likely Source

Information needs most prevalent for treating pre-existing and ongoing conditions

Most of the conversations on the patient journey were in the context of pre-existing and ongoing conditions so tended to focus on the 'treatment' and 'discharge' stages in the patient journey, rather than prevention or diagnosis. This is different to what was found in the CALD groups and is reflective of the high prevalence of chronic conditions amongst Aboriginal and Torres Strait Islander people.

One group discussed the high prevalence of chronic kidney disease leading to end-stage kidney failure in their community. Discussion centred around clients from the Torres Strait and Cape York not having information about when they should have further treatment. Issues included understanding at what stage of kidney failure they should come down to Cairns for treatment. These participants felt that better information around this would avoid urgent trips. Participants in the same group spoke about their relatives being bombarded with information in hospital when they were too sick to take in the information.

Another participant who had had diabetes for a long time had a problem getting a referral from his GP, so he went to another GP and eventually got to see a specialist who was able to review the medications and insulin. Another participant expressed dissatisfaction that a family member had been

discharged from the emergency department on more than one occasion with major changes to medications, including starting on insulin, but no information being provided to the AMS. The patient continued to take type 2 diabetes medications also and became very ill.

In line with the discussions earlier in the groups, most participants preferred face-to-face discussions for sourcing information along the patient journey.

“It’s good to have information for those things (A-E), but you still need Aboriginal people in hospitals as I get lost in there and don’t understand. When my kids are sick at hospital I worry and can’t think straight. (That’s when) I need to talk to Aboriginal Liaison Officer to explain to me what’s happening.” (Brisbane)

Many participants were comfortable with information in English if the information was clear and simple. Participants from more regional areas preferred their local language.

Aboriginal and Torres Strait Islander resources in plain language

The majority of participants found the resources hard to read and understand. Some participants didn’t like the look and feel of the materials. For these participants, the materials did not have Aboriginal and Torres Strait Islander look and feel, and they were not considered to be in plain language. The materials were too long for the majority of participants and the text was too small.

Some participants claimed they would access these resources online, but the majority didn’t, preferring to have them available as a hard copy resource available at GPs, medical centres and AMSs.



4.4 Meeting cultural and language needs

Towards the end of the session, participants were asked to sum up how the health system could better meet their cultural/language needs. Participants were also asked “if you were going to give a single piece of advice to government to improve information about the safety and quality of health for people from Aboriginal and Torres Strait Islander backgrounds, what advice would you give?”.

Three themes were consistent across the groups – more Aboriginal and Torres Strait Islander health professionals, more cultural awareness training and simpler communications. One group also discussed the need for more government funding to properly fund Aboriginal and Torres Strait Islander health services.

More Aboriginal and Torres Strait Islander health professionals in hospitals, specialist services and GP clinics

Many Aboriginal and Torres Strait Islander people reported that they feel overwhelmed, confused and afraid when they visit the hospital. There was a consistent theme across the groups that more Aboriginal and Torres Strait Islander health professionals were needed in hospitals to help alleviate these concerns and help them understand what was happening.

Some groups felt that their local AMS provided an adequate cultural space and met the language needs for their community while another group felt that their local AMS needed better funding. Some participants reported good relationships with GPs in their local clinic.

More cultural awareness training

All the groups believed strongly that there was a need for more cultural awareness sessions for non-Indigenous staff to help them better understand Aboriginal and Torres Strait Islander people. Some participants felt that cultural awareness training should be compulsory, others felt that cultural awareness would be better handled by an on-going program than a one-off session.

A lack of cultural awareness seems to be more prevalent in hospitals. One group talked about discrimination and being treated poorly in these environments, with everyone in this group feeling that discrimination existed in hospitals. A number of participants reported being not triaged or being triaged later than others. Another participant reported assumptions of alcohol abuse when they didn't drink. This group discussed the need for medical practitioners to treat Aboriginal people with dignity and respect and to treat them as individuals rather than making assumptions or taking a blanket approach.

Communications in plain English and/or traditional language

Many of the participants did not always understand what conditions they or their family members were being treated for, and did not understand the medicines they were taking. Overwhelmingly participants reported a need for communication to be in plain English and easier to understand. Aboriginal and Torres Strait Islander participants reported this was a problem with both verbal and written communication. Many of the groups also suggested that they would be more likely to read brochures if they had a familiar look and feel and were more culturally relevant to them.

Some Aboriginal Health Workers from more remote areas stated that more information in traditional languages was needed.

“Broome has many different traditional languages so clients prefer their own language. English is about third or fourth language.” (Remote Aboriginal Health Worker)

A couple of the groups discussed the need for more local health promotion, with one group suggesting health days with community and the local AMS, and another group suggesting that allowing for some local production helps local people relate. Another group reported that there was a need to shift more health spending into health promotion and prevention of disease.

Appendix 1: Community websites

CALD community websites

Table 1: Commonly accessed in-language social media and news and community sites.

Language group	Website
Chinese	<p>Social media</p> <ul style="list-style-type: none"> • Facebook (Australia only) • WeChat / weixin • Sina Weibo • QZone <p>News/community/media sites:</p> <ul style="list-style-type: none"> • http://ozjob.1688.com.au/ • http://www.yeeyi.com/ • http://www.oursteps.com.au/bbs/portal.php • http://www.6park.com/au.shtml
Arabic	<p>Social media</p> <ul style="list-style-type: none"> • Facebook https://www.facebook.com/arabsinaustralia <p>News/community/media sites:</p> <ul style="list-style-type: none"> • Muslim Village have job forums: http://muslimvillageforums.com/forum/73-employment/ • Lebanese print media includes El Telegraph http://eltelegraph.com/ • Australian Arab community portal - http://www.arabicpages.com.au/
Vietnamese	<p>Social media</p> <ul style="list-style-type: none"> • Facebook https://www.facebook.com/BBCVietnamese?ref=profile https://www.facebook.com/SBSVietnamese?ref=profile https://www.facebook.com/RFAVietnam?ref=profile https://www.facebook.com/VOATiengViet?ref=profile https://www.facebook.com/AnhDoOfficial?ref=profile <p>News/community/media sites:</p> <ul style="list-style-type: none"> • Online newspaper: The Viet Luan - http://www.vietluan.com.au/ (includes job listings) • Vietnamse weekly TV magazine: TV TuanSan: - http://tivotuansan.com.au/Index.asp
Korean	<p>Social media</p> <ul style="list-style-type: none"> • Facebook https://www.facebook.com/koreanculturoo <p>News/community/media sites:</p> <ul style="list-style-type: none"> • Online newspaper: Korea Times http://koreatimes.com.au/ (does not include job listings)
Hindi	<p>Social media</p> <ul style="list-style-type: none"> • Facebook <p>News/community/media sites:</p> <ul style="list-style-type: none"> • Indian Link http://www.indianlink.com.au/ and Indus Age http://www.indusage.com.au/

Aboriginal and Torres Strait Islander community websites

Attached is a list of commonly accessed in-language social media and news and community sites.

Social media

- Facebook

Common sources of information for community members are the Facebook pages of local Community Controlled Health Services, Aboriginal Community Corporations and Land Councils. For example:

[National Aboriginal Community Controlled Health Organisation \(NACCHO\)](#); [Mungullah Community Aboriginal Corporation](#); [NSW Aboriginal Land Council](#)

Some government departments are using Facebook to target Aboriginal and Torres Strait Islander audiences. For example:

https://www.facebook.com/StayStrongAndHealthy/info?tab=page_info

- [IndigenousX](#) is a popular Twitter channel

News/community/media sites:

- Local Aboriginal radio
- NITV – national television station <http://www.sbs.com.au/nitv/> and <https://www.facebook.com/NITVAustralia>
- The National and Indigenous Times – weekly national newspaper <http://www.nit.com.au/>
- The Koori Mail – fortnightly national newspaper <http://www.koorimail.com/>
- Aboriginal News Australia – Facebook page <https://www.facebook.com/AboriginalNewsAustralia>

Appendix 2: Organisations and programs working with CALD communities

CALD communities

This tool provides an outline of some of the key organisations and programs supporting and working with CALD communities in NSW and Victoria. The focus on NSW and Victoria is reflective of the high proportion of the Australian CALD population that resides in these states (72% of all people who speak a language other than English at home in Australia reside in NSW and Victoria (ABS Census 2011)).

Peak organisations and lead agencies

The Federation of Ethnic Communities Councils of Australia (FECCA) is the peak, national body representing Australians from culturally and linguistically diverse backgrounds - <http://fecca.org.au/>

The Ethnic Communities' Council of NSW (ECC) is the peak body for all CALD communities in New South Wales - www.eccnsw.org.au.

The Ethnic Communities' Council of Victoria (ECCV) is the peak body for all CALD communities in Victoria - <http://eccv.org.au/>.

Multicultural NSW is the lead agency for implementing the policy and legislative framework to support multiculturalism in NSW - <http://www.crc.nsw.gov.au/home>.

Office of Multicultural Affairs and Citizenship is the lead agency for implementing the policy and legislative framework to support multiculturalism in Victoria - <http://www.multicultural.vic.gov.au>

The Refugee Council of Australia is the national umbrella body for refugees and the organisations and individuals who support them - <http://www.refugeecouncil.org.au/>

Migrant Resource Centres

Migrant Resource Centres are community based, not-for-profit organisations which provide welfare and support services to community members, particularly to newly arrived migrants, refugees and humanitarian entrants.

NSW MRCs

- Auburn Diversity Services Inc - www.adsi.org.au
- Community MRC - www.cmrc.com.au
- Fairfield MRC - www.cabracc.org.au/fmrc
- Illawarra Multicultural Services - www.ims.org.au
- Liverpool MRC - www.lmrc.org.au
- Macarthur Diversity Services Inc - www.mdsi.org.au
- Metro Assist (formerly Metro MRC) - www.metromrc.org.au

- Northern Settlement Services - www.nsservices.com.au
- Advance Diversity Services (formerly St George MRC) - www.sgmrc.org.au
- Sydney Multicultural Community Services - www.sydneymcs.org.au
- SydWest Multicultural Services - www.sydwestmsi.org.au

Victorian MRCs

- Spectrum MRC <http://spectrumvic.org.au/>
- Migrant Information Centre (Eastern Melbourne) <http://www.miceastmelb.com.au/>
- Phoenix Migrant Resource Centre Westgate Region <http://www.wmrc.org.au/>
- Southern Migrant & Refugee Centre <http://www.smrc.org.au/>
- New Hope Foundation <http://www.newhope.asn.au/>
- Migrant Resource Centre North West Region <http://mrcnorthwest.org/>

Community, ethno-specific and faith-based organisations in NSW

Prominent organisations providing social services to the CALD communities included in this research.

Arabic	Arab Council Australia - http://www.arabcouncil.org.au/ Victorian Arabic Social Services (VASS) - http://vass.org.au/
Chinese	Australian Chinese Community Association (NSW) - http://www.acca.org.au/drupal/ Chinese Australian Services Society (NSW) - http://cass.chinatown.com.au/ Chinese Community Social Services (VIC) - http://www.ccssci.com.au/
Vietnamese	Vietnamese Community in Australia (NSW Chapter) - http://vietnamese.org.au Vietnamese Community in Australia (Victorian Chapter) - http://vietnamese.org.au

Humanitarian Settlement Services

Under the Humanitarian Settlement Services (HSS) program, the Australian Government Department of Social Services funds services to provide early practical support to newly-arrived refugees and humanitarian entrants to help them settle into the community.

Information about the location of HSS providers can be found at the DSS [website](#).

Aboriginal and Torres Strait Islander community resources: examples of good practice

Examples of organisations that develop resources targeting Aboriginal and Torres Strait Islander people that follow best-practice principles:

- National Centre of Indigenous Excellence: <http://ncie.org.au/>. Note their digital excellence section: <http://idx.org.au/#-/home/our-work>
- Secretariat of National Aboriginal and Islander Child Care (SNAICC): <http://www.snaicc.org.au/index.cfm>
- Deadly Vibe: <http://www.deadlyvibe.com.au/>
- Get Up and Grow: <http://www.health.gov.au/internet/main/publishing.nsf/Content/gug-indig-handbook>
- Lowitja Institute: <http://www.lowitja.org.au/>
- National Aboriginal Community Controlled Health Organisation (NACCHO): <http://www.naccho.org.au/>
- Baker IDI: <https://bakeridi.edu.au/>
- Your Room – good example of creating an Aboriginal and Torres Strait Islander specific section of a website: <http://yourroom.com.au/>



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