SUBMISSION

Looking after your health with a long-term condition:

Perspectives from Vietnamese seniors in the ACT.

31 July 2022

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About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is committed to **consumer-centred care** as a foundation principle in all its work and to promoting consumer-centred care across the health system, within government and across the ACT community. Consumer-centred care meets the physical, emotional, and psychological needs of consumers, and is responsive to each person's unique circumstances and goals.[1]

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Executive Summary

This report shares the findings from a research project that asks how Vietnamese-speaking seniors (aged 60 or over) in the ACT look after their health when they have one or more long-term health condition. The report also explores some of the difficulties that people in this demographic may experience when using health services and seeking health information, and it identifies opportunities for health, aged care and community services to support self-management, health literacy and health care access for this community.

This work is part of HCCA's 2021-22 project*, Looking after your health with a long-term condition: Culturally and Linguistically Diverse Community Perspectives in the ACT.* This project is supported by the ACT Health Directorate. The aims of this project are to:

1. Meet a gap in knowledge about the factors that influence long-term conditions self-management, and access to health care services, among culturally and linguistically diverse communities in the ACT; and
2. Identify effective strategies consumers use to manage their health when they one or more long-term condition.

This is important information to consider in the design of future health promotion initiatives for people with long-term conditions.

Based on conversations with 15 Vietnamese-speaking people aged 60 or over, this report explores the issues participants told us are important to living well with one or more long-term condition. The report explores:

1. Participants' wealth of everyday strategies for maintaining good health, independence, and community connection.
2. The challenges associated with getting trustworthy health information and communicating with health professionals, for people who are not confident speaking and reading English.
3. The specific difficulty of communicating clearly with doctors and other health professionals about health issues, symptoms and treatments, and understanding medical terminology, including for people who are otherwise confident English speakers.
4. Issues related to interpreter services, including long and variable wait times and concerns about the quality of health interpreter services.
5. High out of pocket health costs, specifically for dental care and specialist medical care.

Based on the experiences and suggestions made by participants, the report makes four recommendations for action by ACT Government, and by health, community and aged care services in the ACT. These are:

1. Improve access to translated health information in Vietnamese.
2. Acknowledge and address community concerns about the quality and timely availability of accredited interpreter services in health care, and work with multicultural communities and organisations to develop a plan of action.
3. Recognise and support the essential role of bilingual health professionals, in particular bilingual General Practitioners, in supporting and enabling health literacy and long-term conditions self-management.
4. Create opportunities for multicultural community members to more easily share their experiences of health, aged care and community services to improve the quality and safety of these services.

HCCA anticipates that the information in this report will be relevant to anyone who delivers health or community services in the ACT, and for people responsible for designing future health promotion, health literacy and self-management support initiatives.

The findings presented in this report are significant because they identify opportunities to support people to be healthy and well, including as they age, in a multicultural ACT where nearly one in three people was born overseas.[2] A large proportion of people hospitalised in the ACT are aged 65 and older. This is a growing population, and this report builds understanding of the experiences and needs of people in this age group who are managing one or more long-term condition that requires ongoing care from health services.

HCCA will use the findings from this project to inform the health literacy learning opportunities that we provide to consumers, carers, and health and community sector professionals. For more information about this work visit www.cbrhl.org.au and www.hcca.org.au.

1. Introduction

The needs, experiences, and priorities of culturally and linguistically diverse communities are not always recognised or adequately considered when it comes to the planning, funding, and implementation of health programs, either at the State and Territory level or nationally.

This report shares learning from a research project exploring the factors that affect long-term conditions self-management among people in the ACT's Vietnamese-born community.

This is the second of three HCCA reports about the experiences of culturally and linguistically diverse communities in the ACT, as these relate to long-term conditions self-management and support. The first of these reports explored the experiences of Cantonese and Mandarin speaking people in the ACT aged 60 or older. This report explores the experiences of Vietnamese seniors (aged 60 or older) in the ACT, and a forthcoming report (August 2022) will explore the experiences of international students with long-term conditions who live in the ACT.

This report addresses a knowledge gap about the factors that affect self-management among members of the ACT's senior Vietnamese community. In this project we asked 15 members of the ACT Vietnamese community, who were all born in Vietnam and have lived in Canberra for several decades, about their experiences of using health care services and looking after their health, what they find helps them to be healthy and well, and any barriers or difficulties they have encountered when managing one or more long-term health condition.

The learning presented in this report is based on in-depth, semi-structured interviews about:

1. How participants look after, or "self-manage", their health
2. How and where they get information about health and health care
3. Any to self-management or health service access that they have encountered
4. Any changes they think would help them, and others in their community, to look after their health when they have a long-term condition.

This report shares what HCCA heard from participants about these issues. It identifies key issues for participants and offers recommendations to enhance access to health services and support self-management among senior members of the ACT Vietnamese community.

2. The ACT Vietnamese community

The 2016 Census indicates that the Vietnamese-born population living in Australia is 219,355 people with 3,338 living in the ACT.[3] This makes the Vietnamese community one of the larger, and longer-established, culturally and linguistically diverse communities in the ACT. Vietnamese-born people in the ACT make up the fourth largest culturally and linguistically diverse community from non-English speaking countries in the ACT.[4] The ACT's larger linguistically diverse communities are the ACT Chinese, Indian and Philippine communities.[5]

In the ACT as Australia-wide, the Vietnamese diaspora includes many people who settled in Australia in the 1970s and 1980s. Vietnam experienced extended war and conflict between 1955 and 1975. All Vietnamese people who came to Australia during this time have a refugee background and may have a history of trauma and displacement.[6] People who have come to Australia from Vietnam in more recent decades are less likely to have a refugee background. However, experiences of conflict and seeking refuge overseas are very significant life events for many senior Vietnamese people in the ACT community.

There are some general patterns of health service use, and chronic illness risk, that are identifiable for the Vietnamese Australian community. In Australia, Vietnamese-born people have a greater incidence of dental health issues than Australian-born people. These dental issues including decay, and requiring more restorations and extractions. The prevalence of Tuberculosis in Vietnamese-born Australians is also significantly greater than in Australian-born persons. Southeast Asian migrant women, particularly Vietnamese women, are less likely than Australian-born women to get regular cervical screening (Pap tests).[7] As a result, women born in Vietnam have a higher incidence of cervical cancer, and a greater risk of late detection of cervical cancer, than Australian-born women. Vietnamese Australian men have a greater incidence of mortality from stomach cancer than Australian born men.[8] This may reflect a pattern of lower engagement with preventative health services and later engagement with primary health care which has been identified among migrants from many Asian countries including Vietnam.[9]

Identified barriers to health service access among Vietnamese-born people in Australia include lack of a regular visits to a GP, financial hardship and limited English language proficiency. Access to mental health care is lower among Vietnamese-born Australians than among the overall Australian population.[10] Factors contributing to this situation include a lack of awareness of mental health services, stigma about mental illness, the assumption that mental health problems cannot be treated and difficultly accessing interpreters. These can lead to people avoiding mental health treatment, or delayed help-seeking.[11]

While the trends described above are identifiable at the population level, individuals differ greatly in their attitudes and how they manage a long-term condition or their health generally. Income, education, occupation, gender and other factors also shape how people look after their health with a long-term condition and the ease with which they can access health services and information. For example, low engagement with primary care and preventative health services may be more likely to affect lower-income earners among Vietnamese diasporic communities in Australia. There are also likely to be differences in attitudes toward health and health service use between people who migrated to Australia many years ago, and those who settled here more recently. For example, Vietnamese Australians who are married and have lived in Australia for a longer period tend to have better access to health care than people who have migrated more recently.[12]

Traditional Chinese and Vietnamese medicine are essential aspects of Vietnamese culture, and some people may draw on traditional practices and medicines to help self-manage a long-term condition.[13] Interesting, no participants in this project spoke about their use of traditional medicines or other traditional treatments. This underscores the diversity within this community and the wide variety of ways in which individuals approach their health and health services.

Health professionals, and people involved in the design of health promotion programs for people with long-term conditions, should be aware of this diversity, and seek the preferences of patients and their families.

Appendix 1 provides some additional background about the context for this report, including an explanation of the terms self-management and health literacy, some information about long-term conditions in the ACT, and a discussion of some of the issues that can impact culturally and linguistically diverse communities in relation to health literacy and self-management.

3. Method

3.1. Bilingual Community Researcher

HCCA employed a Bilingual Community Researcher to work on this project, to bring essential knowledge of issues affecting Vietnamese seniors in the ACT and established connections and trust with community members. The role of the Bilingual Community Researcher was to:

1. Provide advice to help ensure the project was culturally appropriate.
2. Promote the opportunity to participate.
3. Liaise with participants and potential participants, including supporting their informed consent to participate.
4. Provide Vietnamese to English interpreting and translating[14]
5. Contribute to analysis of interview data by discussing findings and issues with the research team.
6. Share research findings with participants.
7. Participate in the team's reflection on learning from the research process.

The Bilingual Community Researcher shared a language and common experience with participants, and developed the relationships with them throughout the project. This was essential to maintain a connection to language, common experience and a sense of trust so that participants felt comfortable and supported to talk about their personal experiences of health and health care.

In this project, the Bilingual Community Researcher conducted interviews in Vietnamese and transcribed the transcripts into English. It was invaluable to have the Bilingual Community Researcher conduct interviews rather than taking on the role of interpreter for an English-speaking HCCA team member. HCCA's Multicultural Liaison Officer, who participated in most of the interviews, reflected that "sitting next to the Bilingual Community Researcher listening to the conversations, I could not understand the language but I heard and felt the emotions in those voices. I think these stories would not have been the same if the Community Researcher did not speak the language and had not developed those relationships of trust with the participants".

The participation of the Bilingual Community Researcher in project had significant benefits:

1. Consistency of involvement from a community researcher with an insider's ("emic") perspective and understanding of community issues.
2. Allowing the project to build on the existing connections of trust and shared experience between participants and the Bilingual Community Researcher.
3. Providing an opportunity for members of the HCCA research team, including the Bilingual Community Researcher, to swap perspectives and confirm a shared understanding of key themes.

4. Providing a rigorous and cost-effective approach to bilingual community research about health matters.[15]

3.2. Participant recruitment

Participants for this qualitative consumer experience research project were recruited using convenience sampling. The Bilingual Community Researcher identified and contacted interested participants by phone to organise a suitable time for a conversation. Participation was limited to people aged over 60. People were able to take part if they were born in Vietnam, mostly speak Vietnamese at home, live in the ACT and identify as having one or more long-term health condition. A long-term condition was defined in this project as any health condition that is expected to last 6 months or more and requires care from a health professional.

3.3. Participants

Fifteen people took part in interviews for this project. All participants were aged 60 or older, a majority were over 65 and several participants were in their 70s and 80s. A majority of the participants (three-quarters) came to Australia as refugees from Vietnam in the 1970s and 1980s.

Participants in this project described having the following long-term conditions:

1. Type 2 Diabetes
2. High blood pressure
3. High cholesterol
4. Visual impairment
5. Respiratory illness
6. Digestive illnesses
7. Cardiovascular illnesses

This includes several of the conditions that are among the most prevalent long-term conditions in adults in Australia and in the ACT, among them Type 2 diabetes, and heart disease.[16]

3.5. Interviews

Data collection for this research project was conducted via semi-structured interviews with participants. These were held over telephone, to provide a COVID-safe approach for participants. Interviews were held over a period of 6 weeks in April and May. HCCA staff including the Bilingual Community Researcher, participated at the HCCA office, and interviews lasted between a half hour and one hour each. Interviews were recorded with participant permission. The Bilingual Community Researcher conducted all the interviews in Vietnamese, with the exception of two interviews which were conducted in Vietnamese and English. Another HCCA research team member was present during all interviews. This staff member provided an explanation of the purpose of the interview, some information about the project and confirmed participants' informed consent to participate. This staff member was also available to answer any questions about the project and HCCA's role, and was present throughout the interview to support the Bilingual Community Researcher if required.

Participants were asked a total of five questions from a pre-prepared conversation guide (provided at Appendix 2) which sought to elicit information about self-management of a long-term condition. Topics included:

1. How people look after their health with a long-term condition
2. Barriers to looking after their health with a long-term condition and
3. Their suggestions about what would make this easier for them or for other people in the ACT Vietnamese community.

3.6. Data analysis

3.6.1. Transcribing interviews

The Bilingual Community Researcher interpreted and transcribed the interviews (from Vietnamese to English). This was not word-for-word transcription. The Bilingual Community Researcher translated and interpreted the meaning and key points that interviewees shared in the conversations.

3.6.2. *Identifying key themes*

NVivo software was used to analyse the transcripts, and statements were categorised into themes. Themes were carefully chosen to be mutually exclusive, and statements made by participants were assigned to appropriate themes. One member of the research team undertook initial analysis. To confirm the validity of the analysis, two other HCCA researcher team members validated the categorisation procedure. The major themes discovered were then subdivided to allow for further analysis.

3.7. Limitations

This is a qualitative consumer experience with findings drawn from semi-structured conversations with 15 participants. The findings should not be read as representative of the experience of the whole Vietnamese ACT community, or of all older Vietnamese people in to the ACT. Nonetheless there was strong consistency in the issues and concerns for participants. Data saturation was achieved within the 15 interviews. This is to be expected in a sample of this size, as saturation is generally reached after seven to eight interviews.[17]

The findings indicate a range of issues to consider when designing self-management support interventions that meet the needs of Vietnam-born people in the ACT.

It is also important to note that while conversations were wide-ranging, there may be factors affecting self-management that we did not enquire about and that are therefore not reflected in the findings.

4. Findings

This section shares information about the factors that affect self-management of long-term conditions by older migrants to the ACT from Vietnam. This section begins by discussing *how* participants look after their health, before considering *barriers* to self-management and then *opportunities* to improve self-management support.

4.1. How do participants self-manage their health?

4.1.1. Maintaining physical and mental health

Participants in this project are proactive about managing their own physical health and place a high importance on doing so. They emphasised their perspective that it is possible to maintain a healthy lifestyle and state of mind if you are mindful of the consequences of your daily actions. Participants' statements below illustrate this view:

> *"I like to exercise regularly, and I believe that to look after my health I must do exercise on a regular basis. I must keep active bodily and mentally and not allow myself to be lazy. There is a saying in Vietnamese, "Long-life is not for lazy people!" I do not mean just the number of years that one lives, I mean a healthy long life, a life with excellent quality that is prolonged for those who take diligent care of their body and mind." – Participant 15*
>
> *"I believe that we must first help ourselves, and go and find the answer [to our question, or problem]. We should not just sit and wait for help. I believe that sickness is the result of our diet. What we eat affects our health. When we don't exercise, we will get sick. I've suffered many issues in my family and I've learnt that not all professional people can help us if we don't do the right things ourselves first. I could become mentally unwell if I am not strong and determined to help myself!" – Participant 4*

Participants talked about many things they do to look after their health. This includes scheduling regular GP appointments, and participating in preventative health activities. Many participants are very knowledgeable about, and take maximum advantage of, free and low-cost health services:

> *I attend all the free health services that the government provides in the community, such as the regular health check-up and Flu and Covid vaccinations. – Participant 9*

Many participants also look after their health by eating a diet abundant in fruits and vegetables, drinking enough water, and regularly engaging in light to moderate physical activity. Participants were clear that maintaining good physical health is an important aspect of looking after their health when they have a long-term condition:

> *"I have my health checked regularly, 3 or 4 times a year. I exercise regularly. I eat carefully and I make sure I drink 2 litres of water a day. When I first wake up in the morning, I drink a glass of warm water, about 200 millilitres." – Participant 14*
>
> *"I go for a walk every morning. I am very careful with what I eat. I eat lots of vegetables - not much meat and less of everything else" – Participant 2*
>
> *"To look after my physical health, I eat what's good for my age, because I am getting older. I eat nutritious food and try never to overeat, for example I eat small amounts of meat, fish, seafood and lots of vegetables. I eat cereal for breakfast, salad and fruit for lunch, and we have our dinner around 4pm. I also exercise regularly!" – Participant 7*
>
> *Firstly, we have a healthy diet and a good sleeping pattern, and we exercise by walking daily. We keep ourselves happy, to look after our mental health. We walk between 10,000 to 15,000 steps a day. Before Covid, we used to swim regularly, but since Covid we've only been able to walk. Hopefully we can resume our swimming. Besides taking vitamin supplements, we also take medication prescribed by our GP. We keep up with our regular check-ups, for example receiving a hearing aid, and women's health checks for my wife. We also attend a social support group organised by MCCI."- Participant 9*

Taking care of their mental health is important to participants. One important way they do this is by spending time with close family and friends. This was mentioned by the majority of participants, with just one person mentioning participation in religious activities. Attending social groups, including exercise groups, organised by Vietnamese community groups or other organisations was mentioned by a majority of participants. They value this because they feel it helps to develop a sense of community connection, and because of the practical information these groups provide:

> *"To look after my health I do gentle exercise daily. I go for a walk. Since I've attended the Social Support Group organised by MCCI, I've learnt more ways to move my body which I have found very useful and helpful. I also attend the Senior's Club organised by Goodwin [aged care service]. This club brings joy to me because I can go out and meet people. Before Covid I used to go twice a week. I find these organisations are very helpful, they help me to be happy and that's good for my mental health." – Participant 5*

Several participants emphasised their individual responsibility to maintain good mental health, feeling that all one needs to do is maintain a positive outlook on life. Perhaps related to this viewpoint, a number of participants were clear that they would rather not seek assistance to manage their mental health:

> *"Psychologically we need to be strong, like in my situation I'm often sick, so I need to be careful not to let myself down by feeling pitiful or depressed*

> *because that would lead to mental health problems. I don't allow myself to feel hopeless about difficult situations relating to my health. I am always hopeful and believe that there will be doctors and medical treatments that will help to cure my illness." – Participant 6*

4.1.2. Support networks

For the majority of participants, family members - particularly spouses and children – provide very important support in managing a long-term health condition. This support includes family members transporting participants to doctor's visits and other health appointments, and having adult children who are fluent in English accompany them to appointments so that they can translate:

> *"I can still drive but only short distances. Long distances, my husband will take me. I used to drive, but since I've have leg pain, I don't feel safe to drive. This is also my children's advice. – Participant 10*

> *"My children will take me to the doctor's and interpret for me, so I do not need to use the [professional] interpreter service." – Participant 11*

> *"I want my children to understand my health problems directly from the doctors rather than me explaining my problem to them in Vietnamese, which they might not fully understand because they grew up here." – Participant 12*

Although many participants in this project described relying on family support to get to health care appointments and communicate with health professionals, they also expressed a strong desire to avoid "being a burden" to their family. Hence, some participants prefer to rely completely on themselves or their spouse to manage their health, rather than call on adult children who some participants feel will be busy with their own responsibilities. These participants typically rely on one designated family member to assist them with their health needs. This excerpt from interview illustrates the dynamic:

> *Bilingual Community Researcher: Do you tell your children about your health problems and get them to help you?*
>
> *Participant 6: "Yes! But not in detail because they are very busy looking after their own family. I don't want them to worry about me and burden them with my health problems."*

A small number of participants reported that they were able to self-manage their long-term condition and address the majority of their health needs on their own. These participants value this level of independence in their lives:

> *"I'm glad I can still do it all well by myself."* - Participant 1

4.1.3. Getting and using health information

All respondents indicated that their primary source of information about health issues is their GP. Two participants mentioned searching the Internet for health information. However, in general participants have a level of scepticism about online information, and a preference for information delivered directly by friends and family. A few people also alluded to a desire for privacy about their health information, preferring to discuss their health with only their spouse and adult children, rather than sharing information with friends or social networks.

> *"I usually ask my family doctor; I do not ask anyone else about my health." – Participant 10*

> *"[I] only [talk to] my family doctor and my children. I do not talk about my concerns with anyone else. I can search on the Internet regarding health topics, but of course I do not completely trust the source that I read from. I trust my family doctor and my children when I have any questions concerning health, although I do search on Google just for fun."- Participant 15*

> *"I will talk with my GP or search on the Internet for general information related to health." - Participant 8*

For most participants, family and social networks are crucial sources of health information. Some participants rely on their children who are proficient in English to translate health information communicated by their GPs, and written information that is only available in English. Additionally, participants obtain information about the management of their long-term condition from close friends and others in the ACT Vietnamese community. In particular, participants rely on their peers for recommendations about which doctors and specialists to see, as well as for lifestyle and self-management adjustments. One participant noted that sharing their personal health issues and experiences with friends and social groups encouraged others share as well, and felt this was positive:

> *"I usually ask my children and my doctors. I also talk with my friends, whom I have known for as long as I have lived in Australia. I do not have many friends, but those who are my friends are good friends!" – Participant 12*

> *"The first person I will find the answer from is my GP, after that I will talk with my children and ask them to look for more information so they can help to look after me better. I also talk with my friends at the [Vietnamese] Senior's Club about my dental problems and I found the answer form talking with people. Many people started to share their problems too, which helped everyone to be more open with each other." – Participant 5*

4.2. Barriers to self-management

Difficulty accessing health services is the main barrier to long-term conditions self-management described by participants. The specific barriers they face include: language barriers, the perceived poor quality of accredited interpreter services, financial barriers, and lack of awareness about the services that are available.

4.2.1. Language Barriers

Language barriers were identified as a significant barrier to looking after your health with a long-term condition. Specifically, many participants indicated that even if they speak English, it is often difficult to communicate their symptoms to doctors when they don't understand medical jargon or don't know the English name for what they are attempting to describe. Several participants said that this can cause feelings of frustration, as well as difficulty getting necessary medical care. One participant said that relying on interpreters hindered them and their friends from receiving preventive treatment. As a result, they said, preventable chronic conditions can worsen, and diagnoses can be late or even missed:

> *"This has been a problem for a long time. There aren't many interpreters who are medically knowledgeable. This has resulted in so many health issues among people who don't speak English as their first language because their conditions unfortunately aren't diagnosed soon enough to be provided with effective preventative treatment.*
>
> *This is especially sad in my case, because many of my health problems could have been prevented if the interpreters said exactly what I said to the doctors. I might not speak English well when it comes to the medical field, but I can tell whether the interpreter did a good job or not. So, interpreter services really need to change to provide better health service for all the communities where people speak English as the second language!" – Participant 6*

Another participant, who receives care in her own home from a My Aged Care service provider, described experiencing great frustration when trying to communicate with caregivers, particularly when attempting to explain when something is wrong. This is emotionally distressing, and left this participant feeling angry and neglected.

> *"I am trying not to be upset when people who are supposed to care for me do not do a good, caring, job, because I know that I do not speak English so it is difficult for me to talk directly with the carer. In the same way, the carer who does not speak my language cannot talk with me. However, I can feel how people relate to me by their tone of voice and their actions towards me.*
>
> *I am so upset that they keep changing carers. I feel that they do not care about my requests and my complaints, and this upsets me greatly! Angry is how I am feeling right now because I have suffered emotionally enough because of these uncaring people who are working for me! I am blind but not deaf! I can hear when people do a proper job, because I used to have very responsible and caring carers in the past." – Participant 13*

As this participant indicates, the language barrier not only makes it difficult to communicate with caregivers directly, it also makes it much harder to provide feedback or make a complaint about the quality of their care.

Participants pointed out that important information about self-management and access to health services is often only available in English. One participant described having difficulty following directions in a hospital setting, because there were no directions available in Vietnamese:

> *"I have difficulty following directions, for example I drove around for hours one time because I couldn't find the entrance when I wanted to visit a friend in the hospital." – Participant 3*

In addition, accents and Australian slang can be very problematic for participants, as they are hard to grasp and understand.

> *"In my experience, so many people have difficulty answering simple questions in English because they cannot understand because of the accent of the speakers. So it seems English itself is not the only problem, people's accents can also make it hard for people who speak English as a second language." – Participant 6*

4.2.2. Quality and availability of interpreter services

Challenges regarding interpretation services are intertwined with language barriers. Nonetheless is it important to address the quality of interpreter services separately in this report, because this is a major issue for participants.

Several participants had used accredited professional interpreters while seeing a GP or medical specialist. Many of those who had accessed this assistance felt that interpreter services requires significant improvement to be useful. The main difficulty that participants raised is that many interpreters lack specific expertise in healthcare issues, and are often unfamiliar with the illness or condition of the person for whom they are interpreting. In participants' experience, this results in superficial interpretation which can miss important nuances. One participant, who is reasonably confident speaking English, voiced apprehension, saying that poor quality interpreter services could result in serious errors such as misdiagnosis. This participant was especially concerned that people who do not speak confident English might not be able to identify translation errors:

> *"Yes! I personally have had a bad experience when I went to the health centre in the City. The interpreter did not seem very good at all, she didn't seem to have good knowledge about health, so the interpretation was very shallow." – Participant 1*
>
> *"I know that I don't have much knowledge about medical issues, so when I need to see a specialist, I often ask for an interpreter. But often, there's no-one available. My specialist was very helpful, but I personally encountered a sad situation, which is that the interpreter who was provided to help me, didn't really understand the technical term for my problem and she didn't understand my illness correctly. She just spoke from her own head. I was terrified and asked my doctor to repeat and explain things to me so I could understand directly instead. He did. Can you imagine that situation*

> *happening to someone who doesn't understand any English at all, and who took the advice of the interpreter? What a disaster!" – Participant 5*
>
> *"Language seems to be the most difficult factor in looking after my health. Even though I can speak English, I still find it difficult because I cannot explain all my health troubles in English, even with the assistance of an interpreter. Interpreters often don't know the technical terms to explain in Vietnamese. Maybe they don't speak Vietnamese well or they simply don't understand medical terminology in Vietnamese so they cannot interpret well! I have many health issues, so I need to see so many specialists, but the interpreter service is not very good in this specialist field." – Participant 6*

In addition to problems with the quality of interpreter services, participants described issues with availability and wait times for interpreters. Wait times are often very long, and it wasn't always practical or comfortable to wait. Participants explained that sometimes, there's no interpreter available, which leaves them reliant on a family member or friend to translate for them.

> *"Doctors know I need an interpreter so they normally will book an interpreter for me, but it's not always easy! Because sometimes there's no-one available or there's a waiting time before the interpreter can come. It can be difficult. Most of the time I have to call my daughter to help me because there's no interpreter service available." – Participant 4*

Some participants circumvent the need for an interpreter by finding Vietnamese-speaking health professionals whenever possible. Vietnamese-speaking GPs are particularly important to participants:

> *"Language is always the challenge because we don't speak English as our own language. [So] we go to a Vietnamese GP." – Participant 9*
>
> "*I don't often use the interpreting service, unless it's a serious situation. If possible, I speak directly to the doctor myself. Although there have been times when I forgot the word to describe certain things, and when I tried to explain the doctor still couldn't understand me. Then I felt really frustrated! For example, I often feel full of air in my tummy, but I don't know how to explain this in English! And with my heart problem, the scan showed nothing, but I do experience certain symptoms at home and the doctor did not seem to understand what I was saying. That's why I prefer to see Vietnamese doctors. So I can talk freely." – Participant 4*

Participants' reflections about the importance of bilingual GPs echoes a similar finding from HCCA's 2022 report on the experiences of Mandarin and Cantonese-speaking people who have one or more long-term condition.[18] This project recommended that ACT Government and health services implement initiatives to make it easier for people to find a bilingual health professional, for example by providing an ACT-specific database, making this information more easily searchable on existing resources such as the Health Direct "Find a Health Service" website, and promoting the Health Direct "Find a Health Service" resource among multicultural communities and organisations. These recommendations also relevant for Vietnamese-born participants in this project, and have broad relevance for culturally and linguistically diverse communities in the ACT.

4.2.3. Out-of-pocket health care costs

A minority (under a quarter) of the participants described experiencing cost barriers to health care. This suggests that this was not a substantial barrier to self-management and health care access, across the group of participants. However, among those who did mention financial barriers, the cost of seeing medical specialists and seeking dental care were major issues.

> "*Seeing specialists is very expensive" – Participant 1*

One participant expressed concern about the cost of transport to medical appointments:

> *"Travelling by taxi is very expensive unless you are given a taxi voucher. There are people who don't have help with transport. For example, when I needed to go to see my specialist [by taxi], I paid a lot." – Participant 5*

One participant avoided scheduling dental appointments due to the high cost. This is an important issue because regular dental examinations can prevent major dental issues developing, and because poor dental health is connected with an increased risk of developing long-term illnesses.

> *"The cost of dental care is a real issue in Australia. It's very expensive if you pay up front; otherwise, you must wait for a long time if you go to the dental clinic run by the government. By the time you get to see the dentist the condition has often worsened, so it's not good. The government could help by providing more dental clinics with more dentists. That's the change I'd like to see." – Participant 1*

4.2.4. Lack of awareness of available health services

Participants with limited English proficiency rely on their GP, family member, and social networks for information about how and where to access health services. Some participants said they did not know where to go for health services because of a lack of Vietnamese-language information resources, with one participant noting that it is hard to find information in Vietnamese and they are too busy with the rest of life to make time to search for it:

> *"I have found my English getting rusty as I'm getting older. I know that my non-English speaking friends find it difficult because they don't read English. For example, my guide to my Home-Care Package is only in English! I am so glad that I can read the information in English so I can find out about services I may need." – Participant 5*

> *Bilingual Community Researcher to Participant 6: "Even with your English, which is pretty good, you've never heard of the NDIS before, simply because you're too busy helping your family."*

These experiences indicate that there is no substitute for written information in Vietnamese, and they also suggest a significant opportunity to improve the provision of translated information.

4.3. Suggested improvements

Participants in this project are generally satisfied with the health care they receive. As a group, they spoke with great appreciation of the quality of care provided in Australia.

> *"The Australian health system is exceptionally good, and all the health services are helpful. I have been living in Australia for more than 30 years. It is incredibly good. I did not need much when I first came, but now that I am older and weaker, I feel I might need help more!" – Participant 10*
>
> *"I have been in Australia 41 years, and I must say the health system in Australia is very, very, good compared to other countries in the world; so, I do not have any complaints! I am grateful that I live in such a wonderful country." – Participant 12*

However, when asked directly, some participants identified the potential for improvement in key areas to assist them better self-manage their long-term condition. The most important of these areas are discussed below.

4.3.1. Improve interpreter services

When it comes to making healthcare more accessible to those who don't speak English fluently, one of the most prominent pieces of advice from participants is for health care services to improve the quality of professional interpreter services. Participants in this project felt it is particularly important to ensure that interpreters are well-versed in health care and the health issues affecting the people they are interpreting for face.

> *"So, to me it's very important to provide interpreters who have knowledge in the area they are interpreting in, in both Vietnamese and English. If they only speak English well but lack the specific knowledge in Vietnamese this will not serve the patient well!" – Participant 5*

4.3.2. Access to more written information in Vietnamese

Several participants spoke about the difficulty of getting health information in Vietnamese. While most participants get information and share it in conversations with their family, friends and social networks, they would also like to have more printed material available to them in Vietnamese.

> *"The lack of health information in Vietnamese compared to other languages [is an issue]. There seems to be a great lack of information in Vietnamese." – Participant 5*

4.3.3. More opportunity to provide feedback to health services

Some participants identified that speaking English as a second language creates an extra barrier to providing feedback or making a complaint about health and other services:

> *"You can imagine there are so many people in our community who do not speak English and they do not have anyone to talk to about their disappointments with service providers. Then who knows they need to change? The people must suffer the injustice, and no-one knows!*
>
> *…To me, if the government cares about elderly and disabled people then they need to investigate how effective these organisations who call themselves aged care service providers are in providing care for people who need it. Otherwise, the government pays a lot but the people like me do not really have good care, like we are supposed to receive."* – Participant 13

This suggests that community members would value opportunities to more easily share their experiences and provide feedback in order to improve the provision of health, aged care and community services.

5. Conclusion

This research project asked how Vietnamese-speaking seniors in the ACT look after their health with a long-term condition. It explored what they do in their daily lives to care for their health and be as well as possible, the challenges they confront, and what they see as the opportunities to improve health services and self-management support.

Participants' overall positive view of the ACT and Australian health systems is evidence of the many existing strengths in the provision of services and self-management support. However, the project has also identified opportunities to improve access to health services and support self-management. For the Vietnamese seniors who participated in this project, the key priorities for change relate to improving communication in health care. Specifically, they see an opportunity for the ACT Government, and all health, community and aged care services to:

1. Improve access to translated health information in Vietnamese.
2. Acknowledge and address community concerns about the quality and timely availability of accredited interpreter services in health care, and work with multicultural communities and organisations to develop a plan of action.
3. Recognise and support the essential role of bilingual health professionals, in particular bilingual General Practitioners, in supporting and enabling health literacy and long-term conditions self-management.

4. Work with consumer and multicultural organisations to create opportunities for multicultural community members to more easily share their experiences of health, aged care and community services to improve the quality and safety of these services.

This project has also identified a range of everyday strategies that older Vietnamese community members in the ACT use to look after their health with a long-term condition. These strategies include gentle exercise, healthy eating, maintaining a positive attitude and keeping strong connections with family members and with Vietnamese community groups. These ways of approaching self-management matter to participants in part because they help to maintain independence and self-reliance. However, the practical support of peers and family members (including with informal translating, transport to appointments and sharing health information) is an essential support for self-management. These are important factors to acknowledge and to highlight in future health promotion initiatives and efforts to support long-term conditions self-management.

This report has also identified the specific difficulty that talking with doctors and other health professionals presents, including for people who are otherwise confident English speakers. It can be very difficult to explain health issues and symptoms, and talk about treatment options, because medical terms are often very subject-specific and technical. This highlights the importance of high-quality and timely interpreter services where staff are equipped and trained to interpret conversations about health and medical matters.

Appendix 1: Context for this report

Self-management and self-management support

Self-management is a term sometimes used in health policy debates and health services research to describe behaviours and activities of the person with a long-term condition, that may preserve or enhance their health.[19] These activities and behaviours can include eating well, being physically active, exercising, taking prescription medications, being alert to changes in the acuity of your symptoms, and using devices to self-monitor indicators of your health (such as heart rate or oxygen levels) or to self-administer medications or treatments (for example self-injecting insulin to manage Type 1 or Type 2 Diabetes, or inhaling asthma medications). These aspects of self-management are generally encouraged, recommended or prescribed by health professionals as part of a clinical approach to managing the symptoms of a health condition.

In addition, many people with long-term conditions describe developing a range of strategies to look after their health, and get the most out of their interactions with health services and professionals.[20] These strategies are highly individual but can include finding ways to cope with fatigue and other symptoms in daily life, becoming more confident to ask questions of health professionals, actively seeking information about a health condition and treatment options, finding a network of peers for support, and managing administrative tasks such as booking appointments, keeping health records and sharing information between different services involved.[21] These aspects of self-management are self-initiated and self-directed, and they indicate the significant but often-overlooked labour involved in looking after your health when you have a long-term condition. In fact, an estimated 80 to 90% of all care for people with long-term conditions is undertaken by people with long-term conditions and their families.[22] This is “self-management”. It matters because people with long-term conditions who seek to actively self-manage their health tend to have better health outcomes and better quality of life than those who aren’t.[23]

People cannot look after their health with a long-term condition in the absence of support and services that make this easy. Supporting people to self-manage their health is part of a consumer-centred approach to long-term conditions care. Self-management support includes “health care, social services and community-based initiatives aimed at supporting individuals and families to live well with chronic conditions”.[24] Given that chronic conditions care is one of the fastest growing areas of health need in the ACT,[25] there is an urgent need to find out what good self-management support looks like for the diverse communities of people who live with them – so that future self-management support initiatives meet the needs of a diverse and multicultural Canberra community, where almost one in three people were born overseas and nearly 24% of households speak a language other than English at home.[26]

Long-term conditions in the ACT

Long-term conditions are very common in the ACT, as they are Australia-wide. Half of all adults have one, and over 45 per cent of people over 45 in the ACT have two or more.[27] Demand for long-term conditions care is one of the fastest growing areas of health service demand in the ACT.[28] Despite this prevalence, health services are only beginning to pivot toward providing integrated care for long-term conditions.[9] Many decades of reform intended to improve the coordination and integration of care for people with long-term conditions have resulted in little, if any, meaningful improvement in the quality of care most people receive.[29] The 2020 ACT Auditor General's Report on Chronic Conditions Care has demonstrated that the challenge of improving chronic conditions care in the ACT remains an urgent priority.[30] Providing appropriate, consumer-centred, support for self-management is part of the challenge of improving long-term conditions care.

Health literacy and multicultural communities

Health literacy is an essential skill for looking after your health with a long-term condition, and navigating the many health services and professionals who may be involved in providing your care.[31] Defined as "the knowledge, skills, confidence and motivation to make sound decisions about one's health in everyday life",[32] having self-rated low health literacy is also an independent predictor of lower use of heath care services, and worse health outcomes.[33]

Migrants from non-English speaking backgrounds in Australia are among those more likely to experience health literacy challenges. Research consistently finds that people of culturally and linguistically diverse backgrounds are more likely than people born in Australia to self-assess as having low health literacy.[34]

People from non-English speaking backgrounds can face significant challenges to developing their health literacy and accessing culturally appropriate services. These include:

1. Difficulty accessing interpreters and translated health information

2. Differences between the understanding of health and illness prevalent in their country of origin, and in the biomedical model of Australia health care – these can be complex to communicate, even when an interpreter is involved, and can lead to people feeling that their understanding of their situation is disregarded.

3. Lack of familiarity with how the ACT and Australian health system works, and how to access information and services.

In addition, past experiences of health care can shape migrants’ expectations of care in Australia, and patterns of service use (or under-use). For example, migrants and refugees from countries with authoritarian governments may lack trust in public-funded health services. People who have experienced civil conflict or displacement may have significant physical and mental health needs. Australian health services and professionals are not always equipped to provide a trauma-informed response.[35]

Cultural influences also affect participation in self-management. For example previous research has looked at chronic illness self-management in Hispanic seniors has identified social support, coping strategies, spirituality, chronic disease health literacy, anger, and depression as important concepts to address when designing a health promotion intervention for this group.[36]

8. Appendix 2: Conversation Guide

Welcome. Thank you for coming. We are ***[Names]*** from the Health Care Consumers' Association.

Today we will talk about how you look after your health when you have a long-term condition. It's very common to have a long-term health condition. Sarah has one, and so do about half of all adults in Canberra.

We would like to hear your ideas about how you look after your health, what makes this difficult and what changes would make it easier.

Do you have any questions before we start?

Q1. What do you do, to look after your health?

We can explain that:
Some people need to take medicines, or see their doctor, or cope with feeling tired. Some people are told to eat differently, or exercise. You might use traditional remedies. Or you might do other things!

People might talk about:

- Taking medication
- Seeing doctors or specialists
- Going to hospital for emergency care
- Being told to eat different food
- Being told to exercise
- Using traditional remedies

We can also ask: **What helps you feel well?**

Q2. Who helps you look after your health?

We can explain:
Many people need some help to look after our health. It might be people in our family or community, health professionals, or a health or community service. Or something else!

People might talk about:

- Family members
- Friends
- Community groups or community members
- Health services
- Community services

We can also ask:

- **Who is most important in helping you looking after your health?**
- **Are there any health or community services that really help you look after your health?**

Q3. What makes it difficult to look after your health?

We can explain:
Sometimes it is not easy to look after our health, or get the health services we need.

People might talk about:

- Cost of services
- Transport – cost of transport, no car, long time on public transport
- Not knowing which service to use
- Language difficulties
- Not having time
- Their health is not a priority
- They want to manage their health themselves if they can

We can also ask: **What's the hardest thing about using health services?**

Q4. If you have used an interpreter in a health service, how was this?

We can also ask:

- **What worked well and what was difficult?**
- **Who do you trust to interpret for you? Why?**
- **Overall, how do you find talking to health professionals? (Easy or hard, why?)**

Q5. If you have a question about your health, where do you go for the answer?

We can explain:
There are lots of places to get information about our health. This includes our family or friends, other people in the community, the internet and from health services.

People might talk about:

- Family or friends
- Information in community language
- Translated information
- Doctors or other health professionals
- Others

Q6. This is our last question. What changes do you think would help you, or other people in the community, look after their health?

Thank you for your time and for talking with us.

If you have any questions please be in touch. We are having other conversations like this one. When we have finished all the conversations we will share what we learnt with you. We would welcome your ideas then!

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