



SUBMISSION

Looking after your health with a long-term condition: *Perspectives from international students living in the ACT*

August 2022

Health Care Consumers' Association

100 Maitland Street, HACKETT ACT 2602 Phone: 02 6230 7800

ABN: 59 698 548 902 Email: adminofficer@hcca.org.au

hcca.org.au |  [ICCA.ACT](https://www.facebook.com/ICCA.ACT) |  [HealthCanberra](https://www.whatsapp.com/channel/0029va333333333333333333)

Health Care Consumers' Association
100 Maitland Street
Hackett ACT 2602
Phone: 02 6230 7800
Email adminofficer@hcca.org.au

Suggested citation:

Nadia Owuor and Sarah Spiller. August 2022. Looking after your health with a long-term condition: Perspectives of International Students living in the ACT. Health Care Consumers Association, Canberra.

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

Contents

About HCCA.....	2
Acknowledgements	4
1. Executive Summary	5
1.1. About this report.....	5
1.2. Recommendations	7
1.3. Looking after Your Health with a Long-Term Condition.....	7
2. Introduction	9
3. International students in the ACT.....	11
4. Method	13
4.1. Participant recruitment	13
4.2. Participants	13
4.3. Interviews	12
4.4. Data analysis.....	13
4.5. Limitations	13
5. Findings.....	14
5.1. How do participants look after their health?	14
5.2. Barriers and challenges	20
6. Conclusion	28
6. Appendices	30
Appendix 1: Context for this report	30
Appendix 2: International Student Conversation Guide	33
Appendix 3: Organisation Conversation Guide	37

Acknowledgements

The Health Care Consumers' Association (HCCA) thanks each of the international students who shared their experiences and ideas with us in conversations for this project.

HCCA also thanks the representatives of the ANU Students' Association, Canberra Institute of Technology, M Hub and Meridian, who generously shared their experiences of providing services to international students.

We are also grateful for the time and assistance of staff at the Australian Catholic University, Australian National University, Canberra Institute of Technology, and University of Canberra, who shared the invitation to participate with international students.

HCCA also thanks the members of the Health Policy and Research Advisory Committee who provided guidance and advice on this work. They are: Linda Trompf, Marion Reilly, Wendy Armstrong, Fiona Tito-Wheatland and Indra Gajanayake.

This research is part of HCCA's Community Health Literacy Project, which is supported by the ACT Health Directorate.

1. Executive Summary

1.1. About this report

This report shares the findings from community-centred research that investigates how international students undertaking tertiary education in the ACT look after their health when they have a long-term health condition. The report explores the everyday strategies that international students use to look after their health, and some of the difficulties they can experience when using health services and seeking health information in the ACT. The report also identifies opportunities for health and community services, and tertiary education providers, to support international students' health, wellbeing, and health literacy.

The report is based on in-depth conversations with twelve participants: eight international students, and five representatives of organisations (two community health services and two student assistance services at ACT tertiary institutions). Participants in this project were mindful that a perception may exist in the broader ACT community that overseas students as a group are privileged - highly educated, international in outlook, wealthy¹ - and by extension able to manage any health issues that may affect them. Participants were keen to make clear that such stereotypes rarely match a more complex reality for international students. They do not consider that these students necessarily have the resources, the support, or the information they need to look after their health and be well if they have a long-term health condition, or develop one, while studying in the ACT.

International students who took part in this project describe experiencing difficulty navigating an unfamiliar health system. Specific issues they identify include:

1. Difficulty finding trustworthy and appropriately detailed information about health services in the ACT, and about sensitive or personal health issues (in particular mental health)
2. Uncertainty about which community or public health services they are eligible to access (in addition to the student-specific health services provided by tertiary institutions, or when these services cannot meet their specific needs).
3. Lack of clarity about what is included or excluded in overseas student health insurance policies, the process of claiming, and how to choose or change insurers.
4. For some, difficulty communicating with health professionals due to language and cultural differences and variable levels of cultural competency among health professionals.
5. A sense of disconnection from mental health services and support, and lack of knowledge of where to go for mental health care – particularly for complex or acute mental health concerns - compounded by often-minimal family support with these issues

6. Out-of-pocket health costs that are difficult for some international students to manage.

As these findings demonstrate, navigating mental health information, services and support is a major challenge for participants in this project. Participants in this project identified that the stresses on international students – including the demands of tertiary study (often in a second language), financial pressures, a desire to meet family expectations of academic success, cultural adjustment to life in Australia and Canberra, and distance from their usual social and family supports – can create mental health difficulties that include both moderate and more pervasive or acute anxiety and depression. These stresses are compounded by lack of familiarity with the services and support available to students including from their tertiary institutions, through their overseas student health cover, and from public and community health services. The COVID-19 period has added to the challenges, with closed international borders meaning less opportunity to connect with support networks at home, less opportunity for employment, difficulty social distancing in shared private rental housing or student residences, and - for some - reliance on charity assistance in the absence of opportunity to work during “lock-down” periods in 2020-21.²

Whether they are managing mental or physical health conditions (or both), many participants in this project also expressed considerable worry about the out-of-pocket costs of health care, particularly for long-term or more complex health conditions. For some, concern about health costs meant they delayed seeking help (waiting until symptoms were more serious), delayed recommended tests (such as pathology and imaging), and took short breaks from prescribed medication in order to “stretch out” a prescription for cost reasons. Some participants reported the process of claiming a reimbursement from their insurance provider was so complex and opaque they chose not to be reimbursed even though the cost of care had a significant impact on their budget.

Most participants expressed appreciation for the health and wellbeing support provided by their tertiary institutions. This included from student-specific medical and health services; from academic staff who were understanding and kind, and who made reasonable accommodations to course requirements when students were unwell or needed assistance to participate; and from student clubs and associations and other activities designed to foster inclusion and belonging for international students. However, many participants felt that health information and services designed for international students tend to reflect an assumption that international students are generally healthy and well. In their experience, there is minimal recognition that international students can face significant, complex or long-term health issues while studying in Australia. This suggests an opportunity to improve the information and assistance available to international students who have, or who may develop, complex, long-term or acute health issues including mental health and “invisible” health conditions while studying in the ACT.

1.2. Recommendations

Reflecting the experiences and suggestions made by participants, the report makes the following recommendations:

1. Tertiary education institutions take action to improve the provision of health information resources designed for and with international students, including:
 - continued proactive provision of information about health, wellbeing and inclusion services and support provided by tertiary institutions
 - clear provision of information about which public and community health services international students are eligible to access, how to access them, and the cost of services
 - more information about how international student health insurance policies work (e.g. inclusions, exclusions, the claims process, how to choose or change policy)
2. Tertiary education institutions introduce additional ways of sharing information with international students about how to use health services in the ACT, find health information, and look after their health – for example, via regular face-to-face information session or webinars.
3. Tertiary education institutions introduce and evaluate initiatives to engage international students in mental health literacy, stigma-reduction, prevention, and early intervention programs, particularly in relation to anxiety and depression.
4. Tertiary education institutions proactively raise international students' awareness of existing initiatives to assist with out-of-pocket medical costs and explore options to extend these initiatives to assist students of modest financial means struggling with out-of-pocket health costs.
5. ACT Government, tertiary education institutions and all health service providers ensure health service staff receive adequate training and support to provide culturally competent care for all patients, including the group covered by this study.

1.3. Looking after Your Health with a Long-Term Condition

This work is part of HCCA's 2020-22 project, *Looking after your health with a long-term condition* (2020) and *Looking after your health with a long-term condition: Culturally and Linguistically Diverse Community Perspectives in the ACT* (2021-22). This project is supported by the ACT Health Directorate.

The aims of these projects are to

1. Meet a gap in knowledge about long-term conditions care and management, including among culturally and linguistically diverse communities in the ACT; and
2. Document ideas and suggestions from community members about how to improve care and support for long-term conditions, with a focus on the experiences of people of culturally and linguistically diverse backgrounds.

This is the final report from these related projects. Other reports from the projects are:

1. *I try not to see a doctor unless I really have to*: Perspectives of older Chinese migrants to the ACT about long-term conditions self-management
2. *Looking after your health with a long-term condition*: Perspectives of Vietnamese seniors' in the ACT
3. *There's what your doctors say, and then there's the real world*: Long-term conditions self-management and support during COVID-19 in the ACT
4. Findings from a survey of 100+ ACT residents who have one or more long-term condition.

Each of these reports is available at www.hcca.org.au.

HCCA anticipates that the information in this report will be relevant to anyone who delivers health or community services in the ACT, people responsible for designing health promotion, health literacy and long-term conditions care initiatives, and higher education and student services providers.

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.

2. Introduction

The ACT and region are home to increasing cultural diversity. Almost one in three ACT residents were born overseas and 27.1% of households speak a language other than English.³ Yet the perspectives and needs of people from culturally and linguistically diverse backgrounds are not always fully considered or addressed in the design, delivery or evaluation of health services or policies.⁴

This report shares learning from a community-centred project exploring how international students living in the ACT and studying at four tertiary education institutions (ANU, UC, ACU and CIT) look after their health when they have one or more long-term health condition, and the challenges they face in doing so.

This is the third (and final) report produced as part of a two-year HCCA project exploring the experiences of culturally and linguistically diverse communities in the ACT, as these relate to long-term conditions care and support. The first of these reports explored the experiences of Cantonese and Mandarin speaking people in the ACT aged 65 or older. The second report explored the experiences of Vietnamese seniors (aged 65 or older) in the ACT. This report investigates the experiences of a different culturally diverse community, the community of international students living in the ACT.

The ACT is home to four universities and one large VET provider, making our jurisdiction a significant host community for international students. With over 12,000 international students living in the ACT at May 2022,⁵ this is a large and unique culturally and linguistically diverse community in the ACT.

There is some limited evidence to suggest a perception in the community that international students are, as a group, privileged: wealthy, international in outlook and with high levels of education.⁶ They may be assumed to be a group with overall good health and access to care. As young people, they are less likely than the general ACT population to have long-term conditions that impact their quality of life (as while these can affect people of all ages, their incidence increases with age).⁷ As people pursuing tertiary degrees they may be presumed to have good health literacy (which tends to be associated with more years of formal education).⁸ International students are also able to access health care services provided to students by the institutions where they study and/or through private health insurance coverage for students which they are required to hold for the duration of their studies in Australia.⁹

However, international students are also recognised as a group with specific vulnerabilities including workplace exploitation, discrimination and racism, and facing challenges in obtaining affordable and secure housing (a significant determinant of health).¹⁰ The international student experience can be characterised by loneliness, social isolation, a sense of exclusion from the wider student community and by family pressure to succeed.¹¹ This report shines a light on international students' experiences of health care and long-term conditions condition management, which have been relatively little-documented in Australia.

The report finds that there are significant opportunities to enhance support for international students who have long-term conditions. The report finds that international students who have ongoing or long-term health issues (defined as any condition expected to last six months or more) can experience challenges related to: out-of-pocket costs of some health services, difficulty finding the information they need about conditions and services, lack of clarity about whether they are eligible for community health services, confusion about the detail of overseas student health insurance policies, and challenges seeking assistance for sensitive or stigmatised health conditions in particular mental health conditions.

In this project we asked eight international students, who have lived in Canberra for varying periods of time (from six months to three years) and who identified as having one or more long-term condition about:

1. their experiences of using health care services and looking after their health
2. what they find helps them to be healthy and well
3. any barriers or difficulties they have encountered when managing one or more long-term health condition
4. any changes they think would make it easier for them, or other international students, to look after their health when they have a long-term health condition.

We also spoke with representatives of five organisations – two student support services and three non-government community health services that regularly engage with international students. In these conversations we asked about the support they provide for international students, and any issues or challenges they observe international students facing.

This report aims to fill a gap in understanding about the factors that affect chronic conditions care, and how international students manage their own health, when they have a long-term condition. The findings presented in this report are based on comments and perspectives from in-depth semi-structured conversations with a small number of individuals about their experiences and ideas. Therefore, the findings shared here should not be understood to represent the views of all international students, or as reflecting all of the health-related issues affecting this community.

It is important to note that the number of participants in this project is consistent with best practice in qualitative research of this kind. The findings presented in this report reflect clear and consistent themes in the conversations with all the participants – as would be expected within a participant group of this size.¹²

3. International students in the ACT

Australia hosts a large number of international students. According to the Australian Department of Education, Skills, and Employment there were 355,627 onshore student visa holders in January 2022, with 45% of all international students arriving from China (29%) and India (16%).¹³ In terms of total numbers, this is a significant drop from around 600,000 international students in Australia prior to the COVID-19 pandemic which significantly limited international travel.¹⁴

With five tertiary education institutions (four universities and one large VET provider), the ACT is a significant host community for international students. More than 12,000 international students were enrolled in ACT higher education institutions in May 2022.¹⁵ Again, this is a significant drop on pre-pandemic numbers, when there were more than 18,000 international students studying at just one of the higher education providers in the ACT.¹⁶ Major home countries for international students in the ACT include China, India, Nepal, Bhutan, Vietnam and Pakistan. Students from more than 50 countries currently live and study in the ACT.¹⁷

International students are often discussed in terms of their economic value, both to higher education providers and to Australian governments. Certainly, international higher education is economically important for the ACT. It was the ACT's first billion-dollar export industry and increasing the numbers of international students studying in the ACT is an identified priority for the ACT Government as part of the recovery from the economic impacts of COVID-19 in 2020-21.¹⁸

Survey data indicates that most international students have an overall positive experience of learning and living in Australia.¹⁹ However recent controversies around substandard working conditions and underpayment of international students (who are entitled to work up to 40 hours a fortnight while studying),²⁰ the hardship faced by international students who could not work during COVID-19 lockdowns but were ineligible for government assistance,²¹ and experiences of racism and discrimination against international students²² indicate that the international student experience can also be characterised by precarity and exclusion. The Australian Human Rights Commission finds that the rights of international students are a significant concern across areas including non-discrimination, justice, labour rights, housing, security of the person and equality of treatment.²³

Like domestic students who transition into university life and independent living, when international students first move to a new country for higher education, they must find housing, manage their budget, cope with new financial pressures, look for work and find work, adjust to a new university environment and course requirements, and manage any physical or mental health issues independently.

International students face the additional challenge of navigating these challenges independent of their family and home support networks, and in an unfamiliar country. They may experience a new environment and cultural context that is very different from what they are accustomed to. Those who speak English as a second language

may also face challenges in communicating in a language other than their native tongue. Some students will experience unfair or discriminatory treatment while settling in.²⁴

In relation to health care, international students may not be able to self-advocate effectively for their health needs owing to a lack of knowledge about Australia's health system, and limited familiarity with the services that could assist with their ongoing healthcare needs.²⁵ Most students will not receive assistance to navigate or access health care services, and many are unlikely to be aware that there are processes by which they can provide feedback about their experience of care.²⁶ All or any of these issues can have a negative impact on international students' health and well-being, their experience of learning and studying, and their academic performance.

Since July 2010, international students have been required to pay for private health insurance, known as Overseas Student Health Coverage (OSHC) for the duration of their student visa.²⁷ If overseas students require medical or hospital treatment while in Australia, OSHC can help them pay for it. OSHC also provides some coverage for medications and ambulance services. Despite the existence of OSHC, research looking at health outcomes amongst international students in South Australia and Tasmania suggests that there is still a need to improve both the quality of information and access to health care for international students.²⁸

These issues emphasise the importance of identifying barriers and opportunities to improve international students' experience of health care in the ACT.

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

4. Method

4.1. Participant recruitment

This is a qualitative consumer experience research project based on semi-structured interviews with individuals. To be eligible to take part, participants had to self-identify as having a health condition expected to last 6 months or longer; be a current or recently graduated international student in the ACT and aged 18 years or older.

HCCA developed an invitation to participate, outlining the purpose, eligibility criteria and what was involved for participants as well as the provision of a \$50 gift card to thank participants for their time. The invitation was distributed widely to HCCA members, community organisations that engage with international students, student services at ANU, UC, ACU and CIT, various departments at UC and ACU, and through the social media channels of international student groups. Posters were also shared in communal spaces in the ANU, CIT, ACU and UC campuses. Student services at UC and ACU shared the invitation to participate with students via email.

Participants expressed their interest in participating via an email to HCCA Research Officer (Nadia Owuor), who checked their eligibility and provided them with a document outlining what to expect from the conversation, including potential questions and topics, a written consent form to consider and sign electronically if they wished to proceed, and a survey to provide information about preferred times for a conversation. Conversations were offered in person or online via videoconferencing (using “Zoom”). All participants elected to speak via Zoom.

4.2. Participants

Eight international students took part in interviews for this project. All were aged 35 or younger. The nationalities of participants included:

- | | |
|-------------|--------------|
| - Filipino | - Indonesian |
| - Indian | - Chinese |
| - Kenyan | - Taiwanese |
| - Columbian | - Ghanaian |

Most participants had lived in other countries as well as their home countries before coming to Australia to study. Their previous experiences also influence their health experiences and expectations as international students in Australia.

Participants in this project described having a wide range of long-term conditions including:

- | | |
|------------------------|-----------------------------|
| 1. Thyroid disease | 5. Respiratory illness |
| 2. High blood pressure | 6. Digestive illnesses |
| 3. High cholesterol | 7. Cardiovascular illnesses |
| 4. Visual impairment | |

8. Mental health conditions including anxiety and depression

9. “Long COVID”

Representatives of five organisations that provide services to international students also participated in interviews. They provided their perspectives on health and wellbeing issues for international students, existing services and support, and how information and services could be strengthened. Three community services participated: MHub (Multicultural Hub ACT and region), Meridian and MeiACT. Student assistance services from two tertiary education institutions participated: Canberra Institute of Technology Student Association (CITSA) and the Australian National University Students’ Association (ANUSA Assistance).

4.3. Interviews

Data collection for this research project was conducted via semi-structured one-on-one interviews with participants. Conversations were recorded, with participant permission, using “Zoom”. The audio files were then transcribed, with participant permission. All participants gave their informed agreement to recording and transcription, with the privacy and confidentiality protections outlined in the participant information and consent form (Attachment 2).

In addition to conversations with international students, two conversations were held with representatives of tertiary institutions’ student support services and two conversations were held with organisations that engage with or provide health services to international students. These conversations were also held over zoom. They were not recorded and transcribed, but details notes were taken. These conversations inform HCCA’s understanding of issues for international students and shape the analysis and findings presented in this report.

All interviews were held over a period of eight weeks in April and May and were conducted by the same HCCA staff member.

Two separate conversation guides were created: one for international students (Appendix 2) and the other for student support services and health organizations (Appendix 3). Conversation guides were designed to elicit the information required for the project while also being relevant for international students.

The conversations guides were based on those used previously by HCCA with Mandarin, Cantonese and Vietnamese-speaking participants in the Looking after Your Health With a Long-Term Condition project. Questions were asked about how students look after their health, their experiences of using health services in the ACT, any barriers or difficulties they had encountered when managing a long-term condition, their perception of any issues faced generally by international students, their experiences of accessing health information and dealing with health professionals, their experience of support from the institutions where they study, and

their ideas about changes they think would make it easier to use health services and look after their health in the ACT.

4.4. Data analysis

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. The major themes discovered were then subdivided to allow for further analysis.

4.5. Limitations

This is a qualitative consumer experience with findings drawn from semi-structured conversations with eight international students and five representatives of organisations. The findings should not be read as representative of the experience of all international students living in the ACT.

However, there was strong consistency in the issues and concerns for participants.²⁹ The findings indicate a range of issues to consider when designing services and support for long-term conditions management, and for international students' health and wellbeing.

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

5. Findings

This section shares information about the factors that affect how participating international students look after their health when they have a long-term condition. It begins by discussing *how* participants look after their health, before considering *barriers* to health services and information, and finally *opportunities* to improve support for international students' health and wellbeing.

5.1. How do participants look after their health?

5.1.1. Maintaining physical and mental health

Participants in this project see themselves as people who actively look after their health. They are mindful of needing to take steps to look after and maintain their health (physical and mental) so they can live a balanced life. For example, this may mean conserving energy and managing the fatigue associated with a long-term condition; or making time to “take care of yourself” instead of always prioritising study:

“...I’m going to use the ‘spoons’ theory here. Especially since I got long COVID, I wake up every day with very limited ‘spoons’, which means the energy I can spend on my daily activities. I have to really prioritise the most important ones of that particular day. I need to do everyday planning to make sure I do not overspend to the point that I stop functioning” – Participant 2

“...It’s really hard to have that balance between study and also taking care of yourself. A lot of the time we’re taught to prioritise study and sacrifice for that. But it’s actually really important to take care of yourself” – Participant 3

Participants spoke about diverse strategies that they use to take care of their health. For example, all participants talked about scheduling regular appointments and check-ups with their General Practitioner (GP). Some participants also see medical specialists, and others draw on support offered by counsellors, nurses and allied health professionals (often but not always employed at student health services) to bring together a team of professionals around them to help look after their health:

I’m very lucky to be able to have a really good team of professional healthcare workers. I think ANU, despite all the complaints, I think ANU does have a lot of great healthcare providers like my GP, and my counsellor, and ANU recently recruited a team [to support student] safety and wellbeing, so that includes nurse and social workers and all sorts of support. And... I go to my GP pretty much on a monthly basis. [...] – Participant 2

Some participants take medication to help manage their long-term condition, and were specific about the importance of taking medication as prescribed:

I’m still following the medication that was consulted to me by my earlier doctors, but now I have actually taken up an appointment in the coming

weeks to consult a doctor over here so I can get my bloodwork done and again check the levels and see if my medicines need to be changed – Participant 4

I take my meds. More importantly, I take my meds the way the doctor told me to take my meds, because I found that when I tried to circumvent that, that was not very productive. – Participant 5

One participant talked about using traditional remedies from their home country to assist in managing their long-term condition:

I do find a lot of comfort in small remedies. We do have those different health remedies that are not really scientific, like not verified by western science. I know a lot of them to be really useless, but I do find comfort in sometimes just cooking them up. And I think that's just bringing a little bit of connection with my home and my childhood. – Participant 2

Most participants in this project feel it is important to actively look after their psychological well-being alongside their physical health. This was particularly important for participants who experience mental health conditions. Among participants, there was a general view that the stresses of being a student can take a toll on mental and physical health and that preventative measures should be taken to mitigate these effects. Participants do this by trying to reduce stress in their lives, taking breaks from studying, getting enough sleep, eating a nutritious diet, drinking enough water, getting outside, doing relaxing and enjoyable activities like watching a movie, and exercising.

“We can’t keep going if we’re not healthy. We have to take a break and I had to take several breaks to care for myself.” – Participant 1

“Since I started to live with long term fatigue, everything just went completely topsy turvy. I just had to really focus on just building a little bit of stamina every day. I think probably just 15 minutes of very mild exercise [is OK]. I can’t even finish one set of yoga. Some low impact cardio exercise, or a little bit of muscle resistance Pilates. And that’s important to me. So diet, exercise and sleep, I have to guarantee. Now it’s 12 hours of sleep a day, otherwise I cannot function.” – Participant 2

“A good meal always helps with my mood. I try not to eat too much dessert because then you’ll get a sugar high and then you’ll feel sleepy afterwards. Walking around near the lake. There’s plenty of lakes in Canberra. They usually have a really good walking path around them so I find that really helpful. Go out and get some sunlight because vitamin D is very important... I think that really helps. – Participant 3

I'm very careful to make sure that I always have free time, just so I can maybe have a think about how my life is going, am I eating right, am I drinking water? – Participant 5

I'm at a point currently where I'm at a lower ebb of my [long-term condition]. ...I'm trying to keep myself up and doing things and just keep myself distracted. I watch a lot of movies and stuff like that – Participant 7

Among the participants who discussed their experience of mental health matters, those who are able to also schedule appointments with mental health professionals such as counsellors, therapists and psychiatrists to help them manage their health.

I also speak with psychologists, psychiatrists, make sure that I try to do something that cares for myself every day. – Participant 1

When there were times that I had more pressing, more acute issues, regular check-ups with my psych for example were helpful. – Participant 5

One participant talked about the importance of these professionals in sharing techniques and strategies to manage their own health over the longer-term:

I have been in therapy in the past... and I was told certain techniques and coping mechanisms. So just like for example, in terms of self-harm for example, like earlier on I wouldn't really have an idea of what to do about it, but at the moment, giving the coping techniques... that I've been educated about I have a grip of how I can stop things from going to the unhealthy route. – Participant 7

5.1.2. Student health and wellbeing services

For a majority of participants, student services provided by their educational institutions have been instrumental in helping them manage a long-term health condition. Participants mentioned specific health and wellbeing services offered by their universities and CIT and events such as “stress-less week” in positive terms:

CIT has been really supportive. They organised a meeting with me so I could manage my health and my studies at the same time. We worked together to find that balance. I could easily get an extension for assessments, and stuff like that, when I needed it. I've been really lucky that the department that I'm in is really supportive and really understanding about everything that's going on. – Participant 1

With my student contact officer, for my scholarship, I talked to her about my condition and why I feel down and not [getting] optimally getting my classes. She said that I can go to ANU counselling, so I went to ANU counselling but I hadn't got medical help before that. I think counselling helped a lot and also by going to ANU counselling, I knew that it is okay to get help. – Participant 6

In addition, participants appreciated the flexibility and understanding of academic staff who offered alternative assessment arrangements and extra time for assignments:

I am very lucky to have a lot of support from my college, which is extremely flexible and understanding. All my conveners have been so supportive. They're very good in giving me the flexibility in terms of time that I need to complete an assessment. – Participant 2

Something I truly appreciate about my professors is... they're always saying that if this is getting too much for you, let us know, we'll find out ways for you, we'll give you extensions if you need, if you need any help, the doors are always open, walk in, talk to us. So it's good to know that there are people on your side and who are supporting you. – Participant 4

The lecturers are very welcoming and understanding... I remember that I was spacing out a lot in class, because of my condition... it was hard to concentrate. I talked to one of my lecturers about my condition and they were very understanding about that. They knew I was struggling and they were willing to make adjustments to my class and talk slower and things like that. – Participant 6

5.1.3. Peer support

Several participants said their friends and peers are an important source of emotional support that helps them manage a long-term condition:

If I have sometimes fallen off the wagon of getting in touch with a very close friend, I would put it in the calendar to get in touch with them at a certain point, so that I keep the contact, and I guess find consolation in the social support that I could gather. – Participant 2

I would say, stay connected with friends, that's the first thing. If you stay connected with friends, you're less likely to feel stressed. They can hear you out and you can rant to them. You can go grab a meal. That really helps – Participant 3

Some participants found being part of international student associations and clubs was an important way to connect with their peers, which in turn benefitted their sense of wellbeing:

UC has a number of international students' societies, so being an active member of those, being around people who are in a similar boat as well, new to the country or people who have 'been there', it's good. – Participant 4

5.1.4. Family support

Half of the participants mentioned that family members – particularly parents and partners - provide support to help them manage their long-term condition. This includes financial and emotional support as practical advice about how to look after

their health. Some of those with family members living with them said they also help with day-to-day tasks around the house:

I live with my sister and my brother-in-law, and they've been a great help. They've supported me emotionally and financially as well. Sometimes you don't get to work consistently so they've been supporting me with that. - Participant 1

If there are any worries, if there's an exam that's coming up, I talk it out with my mum and she helps me calm down in terms of the stress and stuff [...] My mum has been specifically helpful in helping me deal with that, even though she's far away, she keeps a constant check on me about how I'm going. I'm stressing about something unnecessarily, she helps me calm down. I think that's the beauty of technology today... She can guide me on keeping a proper routine, sleeping on time, waking up on time.. Over here [in Australia], I haven't really spoken to anyone much about [stress and anxiety]... in a way where they can help me, like a direct impact. But definitely sharing the day-to-day worries and stuff... [with family at home], it helps me in managing my routine. – Participant 4

My partner came to Australia with me, so it was just my partner's, kind of, job to take care of me. He always reminds me to take medication... He's cooking for me and doing things when I'm not capable to, he's doing the household chores. I think my partner is the biggest support – Participant 6

Some students mentioned that family members who live overseas can only provide limited help since they are so far away. Other participants said they had not asked for help from their family members at home, so as not to worry them:

In terms of actual help... they can't do anything for you. Apart from listen to you, I guess. – Participant 3

Of course, my dad and my mum sort of check in once in a while, but I don't want to bother them, Like I really don't want to bother them. I'm in a different country and if I tell them that I'm not exactly doing that great, they're immigrant parents, they worry. I don't want to put that idea into their head. I have two younger siblings as well and I don't want to, yeah, push them into that thought space of worrying about what's happening, and whether I'm able to handle myself alone here. – Participant 7

5.1.5. Getting and using health information

All respondents indicated that their primary sources of information about health matters are online resources that they search for themselves. They use a wide range of online resources including Google search to find health services and information, Australian government initiatives such as Health Direct, health service websites such as the 'Mayo Clinic', medical journals, online forums where people with similar experiences share information, and the websites of health insurance providers.

I usually go on to, I think it's Health Direct, and Mayo Clinic. Otherwise, I would just go on NCBI to find some papers and read their abstracts, and see if they are relevant. If you live with a condition for long enough, you become half an expert yourself. Like, well, I better equip myself with a certain level of knowledge, so that I know how to take care of myself. – Participant 2

Allianz [my insurer] had sent me a bunch of information about how if I ever need to consult a doctor, what the process of it would be and how it would go. – Participant 4

A lot of internet resources were helpful from people who have gone through similar experiences. – Participant 5

Participants were careful to stress that it's important to use their judgement when identifying which sources are reliable, particularly when connecting with online peer networks:

I try to find groups online that can give support and advice and everything. Of course, you've got to take those with a pinch of salt, you can't – because it's the internet, right, it's not professional opinion, but I just try to find sources that are reliable in the sense that they've got experience. – Participant 7

Well, most of the time I just have been researching on the internet. I know that a lot of the things on there are very extreme, like, "if you have this pain, you're going to die!" But when you have researched so much, you know that some of that is not true. Like it might be true for someone but it's not the case usually, you know? – Participant 8

Participants also sought information from medical professionals:

My GP is very good at explaining all the medical knowledge. He would provide me with the information I need, like where I can go to find the useful knowledge that I would need – Participant 2

For many participants, student services at the institutions where they are studying have helped point them towards information, help and support to manage a long-term condition:

CIT often has these orientation days where a lot of people come in and find out what services you can get a hold of, how to contact everyone and stuff like that. – Participant 1

At UC we advertise the health and wellbeing centre on our website. And also, on the student portal. I think knowing about that is really important because you know who to talk to and where you can seek help, if you need an extension or someone to talk to, you know where to go. – Participant 3

The first time I went to the hospital, was because I saw a poster in the ANU Library, the Chifley Library, about beyondblue and then I decided to call them

and they told me to go to the hospital because I was crying and I didn't want to go home. – Participant 6

Participants also rely on their social networks made in Australia as important sources of health information. They interact with their closest friends to gather information about how to manage a long-term condition or where to go for medical help:

After I started to actually build connections here, then that was more helpful for things like, "I went to this person for this?", networking to find out. – Participant 5

I got my information from friends, another friend from [my home country]. I think they are very helpful as well because they were the ones who encouraged me to go to ANU counselling as well and they told me that it's okay to get help and they also always support me and send me resources about what to do. So yeah, I think my friend helped me a lot. - Participant 6

Some participants shared that when they first arrived in Australia, they had no idea where to get health information. With limited information about health matters provided to them proactively as part of their orientation to studying in Australia, they searched the internet for information about health services in the ACT:

At the beginning, I had absolutely no idea of where to get the information from. – Participant 2

While most participants described becoming more confident about where to find the information they need over time, this suggests an opportunity to improve provision of health information for international students early after their arrival in the ACT.

5.2. Barriers and challenges

Participants identified difficulty accessing information about health services available to them as the most significant barrier to looking after their health with a long-term condition. Other barriers they encounter include uncertainty about where to seek help with mental health matters, social isolation and stigma associated with mental illness, the out-of-pocket costs of some health services and medicines, and variable levels of understanding and support for "invisible" long-term conditions from some teaching staff in the institutions where they study.

5.2.1. Mental health: isolation and stigma

When participants were asked what they perceive the most significant health challenge for overseas students to be, every participant responded: mental health. Participants explained that being an international student can come with experiences of cultural dislocation, isolation and loneliness that have a big impact on people:

Some people do feel isolated and that pushes them into a long period of low moods and everything. Apart from that – and the reason that I mention that is because as international students you're completely new in this city, so if you don't have any existing connections in the city, it's a given that you will start feeling quite isolated and alienated, especially if you're a person that's not very extroverted or doesn't really go out as much. I'm that kind of a person, so it's something that I have to had to struggle with, but speaking to people, that's something that I definitely notice. A friend of mine told me she feels, especially in Canberra, she feels like the people here are quite guarded and she comes from a culture that's quite collective, but when you shift into like an almost completely different culture, a culture that focuses on individuals, you notice. Like most of the Asian cultures, we're very collective and family oriented or community oriented, but [here]... what you encounter is just like people in their own worlds and in their own bubbles. – Participant 7

I think just from personal experience, also because I... stay in touch with a lot of students, in particular, international postgrad students... I think mental health is definitely one of the biggest challenges for international students for various reasons, really. Like they are here without familial and social supports, as they would have in their own home town, or surrounded by people who are close to them. And living alone, maybe this is the first time they are away from home, they have to face all the challenges on their own. Really the lack of a cultural and social support network is a contributing factor. I guess not to mention the language barrier can be an issue as well. Probably, I guess for me, like from my experience dealing with students from various backgrounds, I think it's mostly the lack of support [with those challenges]. – Participant 2

Participants think that international students may face particular barriers to timely help-seeking for mental health matters. Several participants talked about stigma they've grown up with around mental health as the most significant barrier that prevented them, or other international students they know, from seeking treatment. One participant said they'd prefer to manage their mental health themselves, and another said they were too busy with work and study to seek assistance, which might also contribute to delayed help-seeking:

Well, everyone's different but I think from the people I've talked to a lot of people are suffering from mental health issues. Where we're from, mental health - there's a big stigma around it. When we come here usually we're alone and we don't have a lot of support. We miss people back home and we're struggling with our studies, we're struggling with work and making things sustainable for us. – Participant 1

When you're far from home, it is quite difficult to reach out. Actually, it's quite difficult for me because, it's because of my resistance to getting help, like from my cultural background, it's common to think that you can do this alone. But when I got my orientation at the ANU, we were told that there's a lot of help from ANU counselling and the student centre and beyondblue and

things like that. I think it's not lack of information per se, but the resistance that I had from myself to getting help.- Participant 6

I've handled this on my own for quite a bit, quite a long time, ever since the beginning I'd say. But now the reason that I want to reach out is because I've realised that I'm not exactly able to handle it alone anymore and I understand that it's quite unhealthy to do that for a long period of time. So yeah, I just thought I'd reach out, but I'm not really in a situation where I will get that help at the moment. And that's fine, it's not something that I'm not used to, so I can handle myself, I'm sure I can hang on for quite a bit more. But yeah, I definitely could use that help [with mental health issues] – Participant 7

5.2.2. Limited information on how to navigate the ACT health system

While participants have a range of sources from which they seek health information (see section 3), most also felt that information relevant to international students is hard to find. Specific areas in which participants wanted more information include:

1. Knowing what services they are eligible to access in the community
2. Knowing more about free and low-cost health services
3. Knowing which health services accept their international student private health cover, and what out-of-pocket cost they can expect

Students also said that it can be difficult to find resources that provide the right amount of information about health issues. For example, mental health and wellbeing resources for students tend to be pitched toward people with minimal to moderate mental health challenges and do not need the needs of people with more acute or complex mental health issues.

Speaking from my own experiences, [I have] a lot of fatigue about looking for health information. From a mental health perspective, you're searching and searching for someone who can help you and also affordability is an issue, you don't want to look for something and then you find out you can't afford it as well. So there's a lot of fatigue in terms of searching for information.

People who are also citizens here also struggle with finding information. But there's an extra step for us. Specifically, not being from this country and being someone who outright looks different from the general population, you just feel somewhere that okay, is it me who is dumb, who does not know about this? You have this feeling of self-consciousness about whether or not I should actually ask about this. People just kind of swallow their mental health issues and they're like, oh yeah, it's just normal. A lot of the stuff that they [health services and education providers] put out there for mental health is very much surface level, it's like oh you need more sleep. But can we more like deal with like serious stuff? – Participant 4

These participants describe some of the issues related to information about overseas student health insurance cover:

For me and maybe for a lot of people, we get the basic overseas student health cover and I think that it's not very clear what's covered where. You have to come upon a problem to then know that it's not covered, which is not great. Some more really quick facts of, "For the most part, this is what's covered, but also there are hidden things," [would help]. When I moved here, I paid out of pocket for my glasses in spite of that [being covered], and then somebody then told me, "Every two years or one year or whatever, you're entitled for them to actually cover that". – Participant 5

The hardest thing for me was just understanding what do I have to do? If I go to a doctor and I'm like, "Hey, these are the things that are going on," and then say to me for example, "Okay, you need to get a test for this," my next question is always, "Where? I don't know where." That was just really frustrating, just being, "Where do I get this test? Do I pay them, or (will they bill) me?" And even something like processing claims. I just send it anyway and hope... because I was just, "I don't know what's covered. I've read the statement five times and I'm still unsure." We're in a new healthcare system that we don't understand as international students. There has to be a lot more handholding obviously at the beginning just for that understanding of if you went to the doctor, this is what to expect. I think there's no help [with that] – Participant 5

5.2.3. Financial barriers

Most participants reported that the cost of managing their long-term health condition is a significant issue for them. While they are aware that the OSHC covers essential necessities outlined in the Medicare Benefits Schedule (MBS) (such as ambulance expenses and medical testing) and prescription costs outlined in the Pharmaceutical Benefits Scheme (PBS) participants also need a range of medical tests and medicines that are not covered. In other issues related to cost, participants were unclear about whether or not the health services they need to see bulk bill, and about the practical process of making an OSHC claim. Students can find their out-of-pocket expenses mount, which can be really distressing. They describe undertaking a lot of “leg work” to keep health costs manageable:

You have to call a lot of people to be able to minimise the costs. There's a lot of labour around that and that doesn't feel great when you're already struggling with your condition [...] There are a lot of costs with my condition, and a lot of my healthcare, I can't access it in anywhere Canberra with a lot of providers. I have to travel to Gungahlin and I don't drive so I have to commute every single time. I buy a lot of medicine. They [health insurance] don't cover the medicine so I don't get anything back for that. I have to get pathology tests. I have to pay out of pocket, but I can get it reimbursed. If I have to do it four times in a year I run out of money because then it's not covered. It's expensive, I think once I had to pay \$250 out of pocket for a pathology test – Participant 1

I think I signed up with Allianz, which I think was just recommended by the university. What I did not know was they cannot do bulk bill with pathology tests. So I think over the years, I did a few, not a lot, of pathology tests. But I ended up with quite a big bill. I actually went to on a school trip, on a field trip, it's part of our course, over the holiday and then the bill came in, but I was overseas on the field trip, so I had no knowledge of it. And when I came back after the long field trip, these debt collecting letters caused so much unnecessary stress for me. I didn't know at the time that maybe I could claim them, but it's not bulk billed, so there's a lot of paperwork to do. And I did not know that at the time, so I just paid the bills, and then just let it be. It was like hundreds of dollars, and it was not cheap. Later on I met a friend who was with Bupa for OSHC coverage. And she told me that Bupa could do bulk bill for pathology. I think if I had known the information beforehand, I would have chosen differently. – Participant 2

I always have to get medication for my condition. So the first thing I do when I get to a place is find a doctor that can prescribe that. The doctor at UC, she prescribed the medicine, which isn't like the most expensive, but it isn't exactly cheap either. But she also got me to get a test, like an MRI or something like that, I don't remember what was it and I went to see how much was it, just to get that test, it was like \$400 and I was like, yeah. Thank you for your time. Since we have insurance but it's only very basic, it doesn't cover most things, like the most we can do is just go to UC and get a doctor there and whatever there, but other than that everything else is very expensive. So affordability is definitely an issue. – Participant 8

One student mentioned stretching out their medication by skipping certain days to last until they are able to buy more. Another described not looking for information or seeking treatment for a condition, discouraged by their perception that they will not be able to afford it:

I would only be able to get five or six counselling sessions free in a year. Also, I don't know who I can go to for help, because then I might have to pay for a counselling session and they're not really cheap. – Participant 3

I'm on medication that's quite a high dosage, so I need a lot, which means I have to shell out a lot more. And [my private health insurance] not covering medication costs can be huge. So if that's not affordable, it can definitely be a deterrent in people choosing to go ahead with medication. Yeah, I mean if you can't afford it, it's difficult. – Participant 7

I haven't looked into [treatment] because I know that's going to cost money and how I will afford it? What's the point of me looking for it if I'm not going to be able to afford it? I feel like it would be a waste of time to find out how much it is if I cannot afford it. I barely can afford the pills and that's it. – Participant 8

One participant observed that many students feel they cannot ask their parents or other family members for help to cover unexpected health costs, because of the financial strain that tuition already places on their family.

For a lot of us, we rely on our parents for the tuition and everything, so it's not a source we can depend on perpetually, like we can't keep asking. So given that, I feel like international students, at least some of them, have a basic constraint in financial issues. - Participant 7

Specifically in relation to mental health matters, one participant observed that student health services may not be equipped to assist students with complex mental health issues. As a result, students may be directed to private mental health services that are more expensive and which may not be covered by their private health insurance:

I wasn't sure if postgraduate students could access university counselling and I wasn't sure if it was like clinical psychologists or not. I mean, I've got a history. Given my diagnosis, I just wasn't sure if they would be able to handle a case like mine. A lot of the time I've noticed that if I go into a counselling centre, they usually want to know a bit about me and once they get to know that my case is a little like more of a long term condition and everything, they would suggest I go to another place. - Participant 7

The cost of health care is, of course, an issue that affects many people and is not specific to international students. However, international students – like many culturally and linguistically diverse communities – face particular issues related to understanding and navigating an unfamiliar health system in a new country.

5.2.4. Lack of cultural sensitivity and inclusive care

Some participants reported a lack of cultural awareness when accessing health services:

I did need to switch counsellors, because the first counsellor I was with, let's say was not so culturally sensitive. To begin with he was white Australian. And at one point he started to explain to me, kind of like mansplaining a little bit, he has some knowledge of Chinese culture, but on a very superficial level. And he's like "Oh, have you tried this, there's some Tai Chi movements that can help you with meditation and all that". And I started to think, "I know a lot more than you about this", you don't need to treat me as if I know nothing about this. It was a bit condescending of him... I was like, okay, I think I'm switching to a different one.

Probably he was very well intentioned, it's just I think there's a lack of awareness, that I do not want my own – like this really intrinsic knowledge, cultural knowledge, that I've been living with since I grew up – [someone to] swoop in and use this [in a condescending way]... I think after I felt uncomfortable with that counsellor, I stopped going to the [university

counselling centre] for a very long time. During which I think my mental health also deteriorated quite a bit. I got to a point when I realised, okay, this is a time I really need to find professional help. So I went in and asked them if they could give me a different counsellor. But it definitely had a negative impact on me. I think it was six months, when I did not go in at all. – Participant 2

Others described difficulty accessing reasonable accommodations to assist them to participate in their courses. This was particularly an issue for students who have “invisible” conditions or disabilities.

So, the story goes that if I have a valid Education Access Plan, I do not need to explain to anything to course conveners of the specifics of my condition, and they should just provide me with the reasonable adjustments, as stated on my plan. I have encountered some teachers who asked me, “You appear perfectly normal in class, you appear fine. So why are you asking me this?”. But they came from, I guess, very caring and good intentions, so I didn’t really take offence. I just had to explain them what’s been going on, and they were very understanding. But I think more training is needed to let the staff members as well as the academic staff team know that it’s not appropriate for you to ask a student this type of question. It’s their privacy, you should not. – Participant 2

A migraine sounds like just a headache, something that everybody gets, like get over it. But for me, it’s something that I have to deal with, because if I don’t, then I will get worse. I guess most of the time [university staff] expect that most people that are going to university, they’re very healthy in every way. But that’s a generalisation. I feel like if someone is not in a wheelchair or something that is more... visual, then they’re like, oh you’re fine. They don’t take it seriously, they don’t give any extensions or anything. – Participant 7

In general, international students are required to take four units every semester as a condition of their student visa. This course load can be difficult for people who are managing long-term health conditions that impact their lives but are not regarded as severe enough to warrant an extension of student visas or alternate study arrangements.

We have to do four units per semester, unless you have medical reasons. Then you have to apply for a study variation, and a visa extension which is expensive. It’s also a long process and you’re not sure if you’ll be granted it or not. The local students can choose to do one or two units. And they don’t have to worry about – they can just enrol. They don’t have to apply for a study loan variation. And that can be stressful because we have to do four units and work at the same time. – Participant 3

Sometimes it’s really difficult because I’m in a masters course, there’s a lot of reading and writing and everything, so it can be difficult. And it’s definitely brought me to a point where I’ve thought about dropping out because it was

just incredibly difficult to deal with. [...] As an international student, you've got to maintain a certain course load, you can't even switch to part time. So I mean that would have been an ideal solution for my situation at the moment, but I can't do that. It's one of my visa conditions, so I have to be studying full time. I feel like course load and having to keep with it, that's a huge problem and that's specific to international students because we need to be studying full time. – Participant 7

As these participants indicate, they would value more flexibility in visa requirements, to allow international students with health conditions to more easily reduce their full-time course load.

5.2.5. Language barriers

Two participants cited language barriers as a factor affect their ability to find information and support for a long-term condition. In particular, while overseas students may have strong English proficiency, medical terms and jargon can nonetheless be challenging:

There's this assumption that we speak English because that's a requirement for when we come here, but how strong is everyone's English really? And in a clinical setting, the language is so technical. If you don't know the word for it in English, you cannot express yourself. – Participant 5

I think at the beginning, when I first came here, I think language played a big role. I know this from personal experience, it actually adds a lot of stress to an international student trying to explain a situation, like you're not familiar with the medical jargon, or proverbs or phrases that are specific to an Australian context, to explain that to a doctor or nurse... that's actually a lot of stress. I know friends who actually have to ask their other friends to come and help translate it to them when they are seeing a doctor, because they're just not confident enough to make the healthcare provider understand what they're going through.

And it's like the quality of [professional] translation sometimes cannot be trusted. I've heard complaints from friends very close to me. They would prefer to get their friends, who they can trust, to accompany them and translate, rather than finding a professional translation service. – Participant 2

These issues, while not a focus for participants, indicate that some international students may appreciate being provided with information about where to find translated health resources specific to the ACT, and about the role of accredited interpreters in health care and how to access interpreter services. In addition, the small number of participants who discussed interpreter services, echoed concerns raised about the quality of interpreter services, which were also shared in previous HCCA research with Vietnamese, Cantone and Mandarin-speaking communities in the ACT.

6. Conclusion

This project asked how international students living 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 experience, and what they see as the opportunities to improve health services and self-management support.

Participants in this project identify a range of challenges for international students who are managing a long-term health condition. These include:

1. Difficulty finding trustworthy and appropriately detailed information about health services in the ACT, and about sensitive or personal health issues (in particular mental health matters).
2. Uncertainty about which community or public health services they are eligible to access (in addition to the student-specific health services provided by tertiary institutions, or when these services cannot meet their specific needs).
3. Lack of clarity about what is included or excluded in overseas student health insurance policies, the process of claiming, and how to choose or change providers.
4. For some, difficulty communicating with health professionals, including due to language and cultural differences and variable levels of cultural competency among health professionals.
5. A sense of disconnection from mental health services and support, and lack of knowledge of where to go for mental health care – particularly for complex or acute mental health concerns - compounded by often-minimal family support with these issues
6. Out-of-pocket health costs that are difficult for some international students to manage

As these findings demonstrate, navigating mental health information, services and support is a major challenge for participants in this project.

While participants identified a number of barriers and challenges that they experience, they also highlighted positive experiences they have in regard to managing their long-term conditions. This was particularly emphasised by participants who accessed mental health support and services that would not have been easy to access in their home countries. Participants also spoke about the quality of the health services they receive in the ACT. Most participants expressed appreciation for the health and wellbeing support provided by their tertiary institutions. This included from student-specific medical and health services; from academic staff who were understanding and kind, and who made reasonable accommodations to course requirements when students were unwell or needed assistance to participate; and from student clubs and associations and other activities designed to foster inclusion and belonging for international students.

For the international students who participated in this project, the key opportunities for improving long-term conditions care relate to the provision of information about health and health care services, and the cost of services. Reflecting the priorities they shared in conversations, HCCA makes the following recommendations to better support international students who experience long-term health concerns while studying in the ACT:

1. Tertiary education institutions take action to improve the provision of health information resources designed for and with international students, including:
 - continued proactive provision of information about health, wellbeing and inclusion services and support provided by tertiary institutions
 - clear provision of information about which public and community health services international students are eligible to access, how to access them, and the cost of services
 - more information about how international student health insurance policies work (e.g. inclusions, exclusions, the claims process, how to choose or change policy)
2. Tertiary education institutions introduce additional ways of sharing information with international students about how to use health services in the ACT, find health information, and look after their health – for example, via regular face-to-face information session or webinars.
3. Tertiary education institutions introduce and evaluate initiatives to engage international students in mental health literacy, stigma-reduction, prevention, and early intervention programs, particularly in relation to anxiety and depression.
4. Tertiary education institutions proactively raise international students' awareness of existing initiatives to assist with out-of-pocket medical costs, and explore options to extend these initiatives to assist students of modest financial means struggling with out-of-pocket health costs.
5. ACT Government, tertiary institutions and all health service providers ensure health service staff receive adequate training and support to provide culturally competent care for all patients, including the group covered by this study

6. Appendices

Appendix 1: Context for this report

5.2.6. *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.³⁰ 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.³¹ 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.³² 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.³³ 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.³⁴

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”.³⁵ Given that chronic conditions care is one of the fastest growing areas of health need in the ACT,³⁶ 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.³⁷

5.2.7. 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.³⁸ Demand for long-term conditions care is one of the fastest growing areas of health service demand in the ACT.³⁹ 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.⁴⁰ 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.⁴¹ Providing appropriate, consumer-centered, support for self-management is part of the challenge of improving long-term conditions care.

5.2.8. 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.⁴² Defined as “the knowledge, skills, confidence and motivation to make sound decisions about one’s health in everyday life”,⁴³ having self-rated low health literacy is also an independent predictor of lower use of health care services, and worse health outcomes.⁴⁴

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.⁴⁵

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.⁴⁶

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.⁴⁷

Appendix 2: International Student Conversation Guide

Conversation Guide – for the HCCA team

Introduction

Welcome. Thank you for coming and I really appreciate you taking time to talk to me about your experiences. I am **Nadia Owuor (introduce self)** from the Health Care Consumers' Association. HCCA is not part of the government. We are an organisation of ordinary people who use health services and advocate for the various needs of health consumers. In this project, HCCA is talking with people from Culturally and Linguistically Diverse backgrounds and have long-term conditions, to find out how health services can improve the care they offer. To document and share the stories/experiences to help improve their health care experience.

Today we will talk about what you do to look after your health and manage your long-term condition. And I'd like to learn from you, about anything that makes it hard for you to look after your health, and what you think could make it easier – for you, or for other International Students living in Canberra.

I can't promise that health services will make changes because of this project, but I promise that HCCA will share what we learn with people who can make decisions about how health care is provided in Canberra – this includes the ACT Government Health Directorate and Canberra Health Services.

When we talk, you can stop or take a break anytime, and you can skip any questions you want to. You can ask us, if you're not sure what we mean.

Do you have any questions before we start? Are you happy for me to record the conversation?

1. Name, country of origin, program studying, undergraduate or postgraduate, years lived in Australia

What do you think are the biggest/ most important health issues for international students?

We can explain that: Regardless of how long you've been living in Australia there may be conversations you may have in passing about health with other international students. Is there anything that stands out to you or any health issues you feel international students need more support for?

People might talk about:

- Mental Health

What do you do day to day 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

Does anyone help you look after your health?

We can explain that: Some people need some help to look after their 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
- Support groups

We can also ask:

- **Who are the most important people in helping you looking after your health?**
- **What services have been helpful to you when managing your condition?**
- **What, if any, health and wellbeing support services and programmes are you aware of and which of these, if any, do you use?**

Have you seen a health professional since you've lived in Australia?" If yes, what kind of health professional/s have you seen?

We can explain that: There are various health professionals that people go to, to manage their health including pharmacists, dentists and General Practitioners

People might talk about:

- GP (at uni or elsewhere)
- Medical specialist
- Nurse
- Dentist
- ED
- Pharmacist

We can also ask:

- **Do you have a regular GP too?**
- **How did you find out about health professionals and support services?**

Where do you find information that you need about your condition?

We can explain: Access to information and health services is an important aspect of managing health. People have varying experiences with information on and identifying health support.

People might talk about:

- Access and inclusion
- A General Practitioner (GP)
- Pharmacy
- Student Services/Groups
- Friends/Family
- Internet
- Health Insurance companies

We can also ask/ follow up questions:

- **What worked well and what was difficult?**

What is your experience of going to university and managing your condition?

We can explain that: Managing a long-term condition may require adjusting or can be difficult while studying. The university usually has services put in place to support students whose participation in academic studies is impacted by various factors, including long-term conditions. What has been your experience?

People might talk about:

- Extra time on exams
- Remote studying
- Feelings of isolation or frustrating, OR
- Having a pleasant experience and limited inconveniences

We can also ask:

- **How does the university support you with managing your condition?**
- **What's it like studying full time with your condition? Are there allowances made for you?**

How does managing your condition in Australia compare to when you're in your home country?

We can explain that: Managing your condition in different countries can differ slightly or significantly depending on the level of resources, support, and information one has access to.

People might talk about:

- Access to a GP they've known for a long time
- Cost of medicine and appointments
- Knowing where to go for services and information

We can also ask:

- **Are there any differences between managing your health in Australia and in your home country?**

What makes it difficult to look after your health?

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

People might talk about:

Financial Barriers

Difficulties balancing Uni and managing health

Requesting extensions for assignments

We can also ask:

- **What's the hardest thing about using health services?**
- **Do you experience any challenges in terms of balancing university, managing your condition and other parts of your life?**

Positive experiences while managing health

This is my last question. How do you feel you could be better supported by the University, lecturers and/ or health and support services?

We can explain: There's always room for improvement and I'd like to give you give you the chance to share any suggestions or other thoughts you may have on this topic.

We can also ask:

- **What services, resources or support do you think would be helpful to you and other international students when looking after their health?**

Appendix 3: Organisation Conversation Guide

Conversation Guide for Organisations

Thank you for taking time to talk to me today. I'm **Nadia Owuor** from the Health Care Consumers' Association. As mentioned in our emails HCCA is a member-based health promotion organisation and the peak non-government organisation representing people who use health services in the ACT. In this project, HCCA is talking with people from Culturally and Linguistically Diverse backgrounds who have long-term conditions. To document and share the stories/experiences to help improve their health care experience. This meeting is basically to find out if there are ways to reach out to the international student base at [organisation] and for me to find out about the kind of support and experiences around access to health services you've observed that international students experience?

Questions to Ask

(Introductions) Do you mind telling me a bit about what organisation offers in general, and what your role is?

How does your organisation support students' health and wellbeing and engage with international students?

What is the need international students come to your organisation for?

Would you say the biggest unmet need is the same as the need international students seek out from your organisation?

Would your organisation be willing to advertise for participants for this project through any of your channels of communication?

6. References

¹ Mingjun Xie, Desiree Qin, Shizhu Liu, Yemo Duan, Mikiko Sato and Chi-Fang Tseng. Crazy Rich Chinese? A mixed-methods examination of perceived stereotypes and associated psychosocial adaptation challenges among Chinese international students in the United States. In *Applied Psychology*, Vol 12, issue 3, August 2021

²

³ Australian Bureau of Statistics. 2021 Census Data 2021 All persons QuickStats, Accessed at [2021 Australian Capital Territory, Census All persons QuickStats | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/2021-Australian-Capital-Territory-Census-All-persons-QuickStats)>

⁴ Australian Commission for safety and quality in health care. April 2017. Consumer health information needs and preferences, perspectives of culturally and linguistically diverse and Aboriginal and Torres Strait Islander people. ACSQHC, Sydney.

Ethnic Communities Council of Victoria. An investment not an expense, enhancing health literacy in culturally and linguistically diverse communities. ECCV Policy Paper.

⁵ Department of Education Skills and Employment, Australian Government 2022, International Student numbers by country, state and territory, Accessed at: <[International student numbers by country, by state and territory - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](https://www.des.gov.au/international-student-numbers-by-country-by-state-and-territory)>

⁶ Mingjun Xie, Desiree Qin, Shizhu Liu, Yemo Duan, Mikiko Sato and Chi-Fang Tseng. Crazy Rich Chinese? A mixed-methods examination of perceived stereotypes and associated psychosocial adaptation challenges among Chinese international students in the United States. In *Applied Psychology*, Vol 12, issue 3, August 2021

⁷ Australian Health Ministers' Advisory Council. 2017. National Strategic Framework for Chronic Conditions, page 6. Accessed at: <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf>

⁸ Osborn CY, Paasche-Orlow MK, Bailey SC, Wolf MS. The mechanisms linking health literacy to behavior and health status. *Am J Health Behav*. 2011 Feb;35(1):118–28.

⁹ Overseas Student Cover. [Insurance | Overseas Student Health Cover \(OSHC\) \(studyaustralia.gov.au\)](https://www.studyaustralia.gov.au/insurance/overseas-student-health-cover)

¹⁰ Australian Human Rights Commission, International Students. Accessed at: [International Students | Australian Human Rights Commission](https://www.humanrights.gov.au/international-students)

¹¹ Belford N, International students from Melbourne Describing their cross-cultural transitions experiences: culture shock, social interaction and friendship development. *Journal of International Students*, 7, 3 (2017).

I love Australia, 3 things international students want Australians to know. A Lehman, June 2020, *The Conversation*. Accessed at: ['I love Australia': 3 things international students want Australians to know \(theconversation.com\)](https://theconversation.com/i-love-australia-3-things-international-students-want-australians-to-know/1478).

Ryan J and Viète R, Respectful interactions: learning with international students in the English-speaking academy. *Teaching in Higher Education*, 14 (2009), Issue 3,

¹² See Guest G, A Bunce and L Johnson 2006. How many interviews are enough?: An experiment with data saturation and variability. *Field Methods* 18; 59.

¹³ Department of Education Skills and Employment, Australian Government 2022, International Student numbers by country, state and territory, Accessed at: [International student numbers by country, by state and territory - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](https://www.dese.gov.au/international-student-numbers-by-country-by-state-and-territory)>

¹⁴ Ravichandran Ammigan and Debra Langton. 2018. International Education Association of Australia 2018. International Student Experience in Australia. Accessed at: [1478 \(ieaa.org.au\)](https://ieaa.org.au/)

¹⁵ [International student numbers by country, by state and territory - Department of Education, Skills and Employment, Australian Government \(dese.gov.au\)](https://www.dese.gov.au/international-student-numbers-by-country-by-state-and-territory)

¹⁶ CMTEDD [Bringing international students back to Canberra - Chief Minister, Treasury and Economic Development Directorate \(act.gov.au\)](https://www.act.gov.au/treasury/bringing-international-students-back-to-canberra)

¹⁷ See Note 14.

¹⁸ [Bringing international students back to Canberra - Chief Minister, Treasury and Economic Development Directorate \(act.gov.au\)](https://www.act.gov.au/treasury/bringing-international-students-back-to-canberra)

¹⁹ [2020-ses-international-report.pdf \(qilt.edu.au\)](https://qilt.edu.au/2020-ses-international-report.pdf)

²⁰ [International Students and Wage Theft in Australia by Bassina Farbenblum, Laurie Berg :: SSRN](https://ssrn.com/abstract=3444444)

²¹ [Covid spotlights hunger struggles for Australia's overseas students | Times Higher Education \(THE\)](https://www.timeshighereducation.com/news/covid-spotlights-hunger-struggles-for-australia-overseas-students)

²² [International Students | Australian Human Rights Commission](https://www.humanrightscommission.gov.au/international-students)

²³ [International Students | Australian Human Rights Commission](https://www.humanrightscommission.gov.au/international-students)

²⁴ International Student Health and Wellbeing: A Health Lens Project. Supporting South Australian Vocational Education & Training Sector International Students Final Report. Prepared by South Australia Health, Government of South Australia. March 2013.

International Students and their mental health and physical health. Prepared by Orygen, Australian Government, Department of Education, Skills and Employment. June 2020.

²⁵ International Student Health and Wellbeing: A Health Lens Project. Supporting South Australian Vocational Education & Training Sector International Students Final Report. Prepared by South Australia Health, Government of South Australia. March 2013.

²⁶ International Students and their mental health and physical health. Prepared by Orygen, Australian Government, Department of Education, Skills and Employment. June 2020.

²⁷ International Student Health and Wellbeing Fact Sheets. Prepared by South Australia Health, Government of South Australia. September 2019

²⁸ International Student Health and Wellbeing: A Health Lens Project. Supporting South Australian Vocational Education & Training Sector International Students Final Report. Prepared by South Australia Health, Government of South Australia. March 2013.

International Students and their mental health and physical health. Prepared by Orygen, Australian Government, Department of Education, Skills and Employment. June 2020.

²⁹ See Guest G, A Bunce and L Johnson 2006. How many interviews are enough?: An experiment with data saturation and variability. *Field Methods* 18; 59.

³⁰ Chronic Illness Alliance. *Chronic Disease Management*. nd CIA. Accessed 6/3/2020 at: <<https://www.chronicillness.org.au/chronic-disease-self-management/self-management-programs/>>

Australian Health Ministers' Advisory Council. 2017. National Strategic Framework for Chronic Conditions. Accessed at: <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf>

³¹³¹ Health Care Consumers Association. 2020. Looking after your health with a long-term condition during COVID-19. HCCA: Canberra.

³² See Note 17, and also: de Silva, D. 2011. Evidence: Helping people to help themselves, a review of the evidence considering whether it is worthwhile to support self-management, The Health Foundation, London.
file:///C:/Users/bourk/AppData/Local/Temp/HelpingPeopleHelpThemselves.pdf

³³ de Silva, D. 2011. Evidence: Helping people to help themselves, a review of the evidence considering whether it is worthwhile to support self-management, The

Health Foundation, London.

file:///C:/Users/bourk/AppData/Local/Temp/HelpingPeopleHelpThemselves.pdf

³⁴ O'Connell S, V McCarthy and E Savage. 2018. Frameworks for self-management support for chronic disease: a cross-country comparative document analysis. BMC Health Services Research 18, 538.

³⁵ Koen S, Jarvis P and Kobayashi K, 2011. Taking care of chronic disease: realizing approaches for Canada's aging ethnic population: a workshop. Proceedings

³⁶ ACT Auditor-General's Report, Management of Care for People Living with Serious and Continuing Illness, Report No. 7/2020. ACT Audit Office, ACT Government, Canberra. Accessed 31/11/2020 at: Report No. 7 of 2020 - Management of care for people living with serious and continuing illness (act.gov.au)

³⁷ Australian Bureau of Statistics. Census Data 2016, Factsheet, Cultural and Language Diversity Population at [https://www.abs.gov.au/websitedbs/d3310114.nsf/home/Census+Data+Seminars/\\$File/Canberra+Fact+Sheet.pdf](https://www.abs.gov.au/websitedbs/d3310114.nsf/home/Census+Data+Seminars/$File/Canberra+Fact+Sheet.pdf)

³⁸ ACT Health. 2018. *Healthy Canberra*, Australian Capital Territory Chief Medical Officer's Report 2018. ACT Government, Canberra ACT.

³⁹ ACT Auditor-General's Report, Management of Care for People Living with Serious and Continuing Illness, Report No. 7/2020. ACT Audit Office, ACT Government, Canberra. Accessed 31/11/2020 at: Report No. 7 of 2020 - Management of care for people living with serious and continuing illness (act.gov.au)

⁴⁰ Fiona Tito Wheatland. 2021. Breathing Easier: HCCA Project on Improving Care for People with Chronic Obstructive Pulmonary Disease (COPD). HCCA, Canberra. See Appendix A, Coordinated care for people with complex care needs: a brief history and lessons from two decades of trials

⁴¹ See Note 25

⁴² Health Care Consumers' Association. Health Literacy Position Statement. 2017 Available from: <http://www.hcca.org.au/component/rsfiles/download.html?path=Health%2BLiteracy%2BPosition%2BStatement%252FHealth%2Bliteracy%2Bposition%2Bstatement%2BFINAL.pdf>

⁴³ See Note 28

⁴⁴ Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011 Jul 19;155(2):97–107.

Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, et al. Health literacy interventions and outcomes: an updated systematic review. *Evid Rep Technol Assess (Full Rep)*. 2011 Mar;(199):1–941.

⁴⁵ Zhang, Ling. 2019. Health literacy of Chinese immigrants living in Australia: measurements, health consequences and opportunities for interventions. University of Sydney. Accessed at: [Health literacy of Chinese immigrants living in Australia: measurements, health consequences and opportunities for interventions \(usyd.edu.au\)](http://healthliteracyofchineseimmigrantslivinginAustralia.usyd.edu.au)

Australian Bureau of Statistics. Health literacy - Summary of findings [Internet]. 2008 [cited 2017 Mar 29]. Available from:

<http://abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4233.0Main%20Features22006?opendocument&tabname=Summary&prodno=4233.0&issue=2006&num=&view=>

Australian Bureau of Statistics. 2019. Health Literacy, Australia, 2018.

Australian Bureau of Statistics. Health literacy - Summary of findings [Internet]. 2008 [cited 2017 Mar 29]. Available from:

<http://abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4233.0Main%20Features22006?opendocument&tabname=Summary&prodno=4233.0&issue=2006&num=&view=>

⁴⁶ Australian Commission for safety and quality in health care. April 2017. Consumer health information needs and preferences, perspectives of culturally and linguistically diverse and Aboriginal and Torres Strait Islander people. ACSQHC, Sydney.

Ethnic Communities Council of Victoria. An investment not an expense, enhancing health literacy in culturally and linguistically diverse communities. ECCV Policy Paper.

⁴⁷ Jacobs RJ, Ownby RL, Acevedo A, Waldrop-Valverde D. A qualitative study examining health literacy and chronic illness self-management in Hispanic and non-Hispanic older adults. *J Multidiscip Healthc*. 2017 Apr 20;10:167–77.