“There’s what your doctors say, and then there’s the real world”

People’s experiences of long-term conditions self-management and support in the ACT, including during COVID-19.

Final Report

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Epilepsy ACT
Hepatitis ACT
Mental Health Consumer Network
Meridian (formerly AIDS Action Council)
Parkinson’s ACT
People with Disability ACT
RSI and Overuse Association ACT
SHOUT ACT (Self Help Organisations United Together)
Toora Women
Women With Disabilities ACT

The Health Care Consumers' Association

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
- research into consumer experience of human services.

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

Executive Summary

Background

Many people in the ACT have long-term health conditions. Half of all adults have one, and over 45 per cent of people over 45 have two or more.[2] This number is expected to keep rising.[3] Care for chronic conditions[a] is one of the fastest growing areas of need for health services in the ACT community. Yet our health system is only starting to re-orient toward person-centred care for people with long-term conditions.[4]

Self-management is a term to describe behaviours and activities that enhance the health of people with long-term conditions.[5] It doesn't mean 'going it alone' – it happens in the context of care and treatment from health professionals. It does mean 'taking charge' and 'looking after' many aspects of our health, day-to-day. While everyone self-manages their health, it is especially important for people with chronic conditions. This is because people with long-term conditions who self-manage tend to have better health outcomes and better quality of life than those who don't.[6] That's why health professionals, health service planners, governments and consumer groups are increasingly interested in what can be done to better support self-management.

The COVID-19 pandemic has presented uniquely challenging circumstances for self-management. People with long-term conditions are among those most at risk of serious health consequences if they contract COVID-19, and they are also at greater risk of poor health outcomes if their routine or urgent care is interrupted as the result of changes to health service delivery.

Aims

This project identifies what self-management means to consumers and carers who use health services in Canberra, what they do to look after their health, and what changes they think would help them to be as well as possible.

We also ask how self-management has been affected during COVID-19, and highlight changes that consumers think will support self-management during the ongoing pandemic. The report also identifies issues to consider when planning for potential future outbreaks of novel zoonotic illness and pandemic.

The recent ACT Auditor General's report, *Management of Care for People with Serious and Continuing Illness*,[7] draws attention to the urgent challenge of improving care for people with chronic conditions in the ACT. This Final Report from HCCA's

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[a] This report uses the terms "chronic condition" and "long-term condition" interchangeably.

project, *Looking after your health with a long-term condition,* provides information about consumer priorities for chronic conditions care, to inform improvement in this area.

Method

This is a qualitative consumer experience research project drawing on a survey of 104 consumers and carers, and semi-structured conversations with 28 people with diverse long-term conditions. Seven participants in conversations speak Mandarin as their first language.

Participants' experiences

Many participants in this project feel that they manage their health well, most of the time, and get the support they need to do this. Self-management is more demanding for participants with serious illness, multiple conditions and complex life circumstances. People who speak limited English face additional difficulty getting, understanding and acting on health information.

For all participants, self-management involves:

- Managing, monitoring and reducing symptoms
- Coping with the life impacts of ill-health
- Learning to get the most out of interactions with health professionals, and
- Navigating health and human services.

From a consumer perspective, self-management involves a mix of self-directed and clinician-led activities. Of the areas described above, only the first (symptom management) is consistently guided by health professionals. For many participants, the more difficult aspects of self-management relate to coping with the life impacts of ill-health and interacting with health professionals and services.

While self-management is term coined by researchers and used by health professionals, it resonates with many consumers. For some participants, it is an unremarkable, accepted part of daily life. For others it is central to a positive sense of self. Some see it as empowering - giving independence and self-reliance. Yet participants also say self-management can be a burden, laden with expectations that can, for some people, seem almost impossible to meet.

Managing, monitoring and reducing symptoms

Many participants would welcome more opportunities to self-manage their symptoms with minimal interruption to daily life. For example, some would like to self-monitor physical indicators such as HbA1c (glycosylated haemoglobin) at home, or at drop-in clinics. Others would welcome information about whether new apps and wearable devices for self-monitoring are suitable for them. Those who use these new technologies would like to see expanded, affordable, access to them. Other participants see potential in community-based models of care for specific long-term conditions. For example, participants are supportive of an expanded role for community health centres, drop-in models and telephone-based advice to support self-management. Many live with pain, and want pain management put front and centre in chronic conditions care.

The benefits of behaviour changes such as healthy eating and regular exercise are clear to most participants. Yet many struggle to make these changes. They would like health professionals to consistently acknowledge the barriers that can prevent people making and sustaining these changes, and to take an appreciative approach to helping people resolve them. Participants value personalised advice and support to help them make dietary changes and find ways of exercising that work for them, and community and sporting facilities that meet their needs.

Coping with life impacts

The time leading up to and following diagnosis is crucial for establishing self-management. Participants value it when health professionals help them get information and support to manage the emotional impact of diagnosis, and refer them to peer networks that can help to answer their questions about how to live well with a chronic condition. Unfortunately, few participants describe receiving care of this kind.

Interacting with health professionals

Participants have learnt to get the best out of their interactions with health professionals, over time. This requires self-advocacy, communication and information management skills. Many participants value the continuity of care that a relationship with a trusted General Practitioner (GP) offers, and some seek to build a team of supportive health professionals around them. Those with multiple conditions in particular often see themselves as the ‘hub’ that joins the ‘spokes’ of their care. Some wonder what will happen to them if they lose this capacity to self-manage.

Navigating health and human services

Many participants have found navigating the health and human services systems difficult. They manage information about their own health, and also find themselves taking responsibility for the transfer of information between multiple services and professionals. They tell their story over and over. Inconsistent support for self-management when in hospital can lead to participants feeling out of control, and unsafe. Inflexible models of care can mean they rearrange their days to attend health appointments at times convenient for services. Impersonal communication can leave participants unsure how to ask questions or discuss their care.

Self-management during COVID-19

COVID-19 has added an additional layer of demand to self-management. Most participants are aware of their vulnerability to significant health impacts if they contract COVID-19. For some this is a source of anxiety. Almost all have adopted new self-protective practices (such as self-isolation, social distancing, and extra attention to hand and respiratory hygiene). Some people have had self-management support and resources stripped back – for example, less contact with family and peers, temporary cessation of in-home support services and reduced income. Several participants struggled with the impact of isolation on their mental and emotional wellbeing. Deferral of non-essential health procedures has negatively impacted some.

Yet many participants say they were well-prepared for COVD-19. Some were accustomed to time at home and limited social interaction, others routinely protect themselves against viral illness such as colds and flu. Those who sought acute care at the peak of concern about COVID-19 spoke of their confidence in the ACT's response to COVID-19 in health services, and the dedication of health professionals.

COVID-19 has prompted unexpected innovations that support self-management, with telehealth and electronic prescribing offering particular benefit. Most participants regard telehealth and e-prescribing as more convenient, accessible, and safer due to the reduced risk of contracting viral illnesses. Participants see telehealth as best suited to routine consultations with health professionals they already know, and less appropriate for first consultations with a new clinician, physical rehabilitation, and some mental health matters. People who speak English as a second language are among those who should be offered the option of face-to-face service if possible.

Participants remain cautious about the continued relaxation of social distancing measures. They want the ACT Government and community to continue to demonstrate compassion and care for people with long-term conditions, by planning for a possible COVID-19 resurgence and following social distancing measures.

Key findings

Participants' experiences highlight approaches and practices that support self-management. They also indicate that there are opportunities to enhance support in the areas of:

- Consumer information to support self-management
- Good communication between consumers and health professionals
- Models of care that support self-management, and
- Self-management support in the ongoing COVID-19 response and in pandemic preparedness planning.

A) Consumer information that supports self-management

1. Organisations that produce health information can support self-management by responding to consumers' priority information needs. This includes information about what self-management is, treatment options, whether new self-monitoring apps and devices are appropriate for the person, and personalised, appreciative, advice about diet and exercise changes.

2. Initial research with a small number of Mandarin-speaking participants indicates interest in information about how to access an accredited interpreter (telephone and in-person), what to do when no interpreter is available, contacting emergency services when you speak little English, where to go for health services, and eligibility and application processes for Commonwealth Government assistance (including My Aged Care, National Disability Insurance Scheme and Centrelink services). [b]

B) Good communication between consumers and health professionals

1. To support self-management, health professionals can:
    - Acknowledge the emotional impact of diagnosis.
    - Practice an appreciative approach to promoting diet, exercise and other 'lifestyle' change, which avoids blame or judgement, commends small changes, and assists people to identify barriers to change, and strategies that work for them.
    - Refer patients early to trustworthy information sources and peer organisations.
    - Clarify your expectations, and patients' understanding, of self-management.
    - Encourage advance care planning conversations.

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[b] HCCA will gather further information about the information and support needs of culturally and linguistically diverse communities, as these relate to self-management, in 2021.

2. Health services can improve communication with patients by providing details about how to contact the service, and the treating team, every time they contact a patient – by phone, SMS or letter.

C) Models of care that support self-management

Health services can develop and invest in models of care that:

1. Acknowledge and respond to the emotional impact of diagnosis, and provide information and support for self-management in the months after diagnosis.
2. Refer people to consumer groups that are an important source of information and support for many people after diagnosis.
3. Expand options for community-based chronic conditions care. This should include exploration of the potential role of community health centres in multi-disciplinary and drop-in models of self-management support.
4. Support people to self-administer medication and self-monitor physical indictors of long-term conditions when admitted to hospital, where the patient has capacity to do this and it is their preference.
5. Provide options for non-acute care outside of weekday business hours.
6. Assist people with long-term conditions to overcome barriers to service access and to navigate complex health and social support systems. Patient and Family Navigator models are one promising example.

D) Self-management support during COVID-19

Agencies involved in the ongoing COVID-19 response, and/or future pandemic response planning can:

1. Continue to promote, support and invest in telehealth, in recognition that this offers superior accessibility, convenience and safety for many people with long-term conditions, particularly for routine health care matters.
2. Work toward becoming a pandemic-ready health system that has capacity to maintain or quickly resume face-to-face consultations for some consumers and some circumstances. This includes consultations with a new clinician, serious mental health matters and physical rehabilitation. Consumers who are likely to gain most benefit from the option of face-to-face consultation include people who speak English as a second language, people with limited health literacy and people in complex circumstances.
3. Recognise that people with long-term conditions are vulnerable to serious health impacts from COVID-19, and to anxiety caused by this vulnerability. This can cause people to defer acute and routine care.
4. Ensure that there is clear public advice, including for people with long-term conditions, that it is important to access urgent and acute health services

when necessary, and to resume routine and preventative health care when safe to do so.

Everyone in the community can:

5. Demonstrate care for people with long-term conditions by continuing to follow any legislated social distancing measures and to practice good hand and respiratory hygiene.

Recommendations

To assist in translating these findings into policy and practice, HCCA recommends:

1. All ACT hospitals explore opportunities to improve support for self-management for in-patients.
2. ACT Health Directorate continue to promote and emphasise the importance of the community maintaining an ongoing commitment to hand and respiratory hygiene post-pandemic in public health messaging.
3. ACT Government and health services continue to explore the potential of social prescribing as an approach that may assist consumers to access individualised support and services to maintain and enhance their health.
4. ACT Health Directorate and publicly funded health services ensure that consumer priorities for self-management are reflected in a collaboratively developed ACT strategy for improving chronic conditions care, that reflects the priorities of the National Strategic Framework for Chronic Conditions.

Context for this Project

Long-term conditions

Chronic conditions affect many people in the ACT. More than half of all adults have one chronic condition, and over 45 per cent of people aged over 45 have two or more.[8] This number is expected to keep rising over time due to medical advances, longer life expectancy and the social factors that increase people's risk of developing chronic conditions. These include poverty and disadvantage, poor nutrition, alcohol and other drug use, and physical inactivity.[9]

By definition, a chronic condition lasts more than 12 months, requires ongoing medical care and affects a person's ability to live their life.[10] The most common chronic conditions in the ACT, as nationally, are:

- arthritis,
- asthma,
- back problems,
- chronic obstructive pulmonary disease,
- cardiovascular disease,
- diabetes and
- mental health conditions, including anxiety and depression.[11]

Some forms of cancer are also recognised as chronic conditions. Like other chronic conditions, chronic cancer can't be cured, but can be controlled by ongoing treatment.[12] The National Strategic Framework for Chronic Conditions also includes include trauma, disability and genetic disorders in its definition of a chronic condition.[13]

While these conditions are very diverse, they share some characteristics. They:

- have complex and multiple causes
- can occur as single condition or along with other conditions
- usually progress gradually
- are more common as people get older
- can affect quality of life
- can create limitations and disability, and
- are not usually immediately life-threatening, but can shorten life expectancy.[14]

The impact of chronic conditions on a person's life can vary from minimal to very significant. Most people with these conditions consider themselves to be well much of the time. They may require more intensive medical or psychosocial care when their symptoms become worse or their condition is poorly controlled.[15]

Chronic conditions are a major public health challenge. This is the case in the ACT as it is nationally and in other developed countries. There is a high rate of hospitalisation among people with chronic conditions,[16] and over 80 per cent of deaths in the ACT are attributable to chronic conditions.[17] Long-term conditions contributed an estimated 80 per cent of the ACT's burden of ill-health in 2020.[18]

This situation has led to a growing interest – from health policymakers, funders, consumers and health professionals – in better models of care to support the health of people with long-term conditions. Our health system, designed to respond primarily to acute illness and injury, has yet to make the shift required to respond to the 'new normal' of chronic conditions. This will require investment in models of care that are long-term, team-based, led in primary and community care, are able to respond to acute episodes at unpredictable intervals, and support an active role from people in their own care.[19] Efforts to support self-management are part of this shift.

Self-management

Self-management describes the health-enhancing behaviours and activities that a person with a chronic condition can adopt.[20] Self-management happens in the context of ongoing care, advice and treatment from a medical professional or care team. It does not mean 'going it alone' without treatment or care. However, the long-term nature of chronic conditions means that people must be self-directed about following medical instructions, and also make decisions and take self-directed action to care for their health. The term acknowledges the role that people can play in "managing their symptoms, recognising deterioration and communicating… with health care professionals".[21] Everyday terms to describe self-management include "taking charge", "being in control" and "looking after your health".

While every chronic condition is different, all chronic conditions pose similar challenges that people must cope with, and manage:

> *"Dealing with symptoms and disability, monitoring physical indicators, managing complex medication regimens, maintaining proper levels of nutrition, diet and exercise; adjusting to the psychological and social demands including difficult lifestyle adjustments and engaging in effective interactions with health care providers"[22].*

Abilities such as problem-solving, decision-making, accessing and using resources, working with health care providers and action planning are central to managing these challenges and looking after one's own health.[23]

Self-management is important because it directly affects people's health and wellbeing. People with long-term conditions who self-manage their health are more likely to have better health than those who don't.[24] The ACT Government recognises that supporting self-management is part of providing safe and high-quality care to people with chronic conditions in the ACT.[25]

Health literacy

People's ability to self-manage relies on their health literacy. HCCA defines health literacy as "the combined knowledge, skills, confidence and motivation used to make sound decisions about health in the context of everyday life".[26.] Being able to access understand and act on health information is central to health literacy. People with low levels of health literacy are more likely than others to have some chronic conditions including diabetes, cardiac disease and stroke.[27] Having lower health literacy may also prevent people from accessing, interpreting, communicating and using health information, an essential skill for self-management.[28] People whose first language is not English are more likely than others to have low health literacy,[29] and this has implications for the support they may require to self-manage.

Self-management support

Most people are better able to self-manage when they have support.[30] Self-management support includes:

- Structured approaches to patient information, education and support, usually provided by health professionals.
- Support from family, friends and community.

Factors that shape self-management support needs and preferences include:

- The individuals' experience of their chronic condition
- The circumstances of the person, including financial, and emotional, family and social circumstances.
- Their relationship with treating health and medical professionals
- Their individual health literacy – the extent to which they can get, understand and act on health information to make decisions in daily life.[31]

COVID-19

The COVID-19 pandemic has presented significant challenges for people with long-term conditions, and changed how they look after their health.

Data collection for this project took place between April and November 2020. During this time the COVID-19 situation evolved rapidly. Australia's initial cases of COVID-19 were identified in late January, among people returning from countries already affected by the pandemic.[32] The first cases outside of returned travellers were identified in early March in NSW.[33] By the end of March the Commonwealth Government had declared a human biosecurity emergency, closed Australian borders to non-residents and non-citizens and introduced social distancing measures to limit the spread of the virus.[34]

The survey for this project opened in early April, when public concern about COVID-19 was very high. The ACT Government had declared a public health emergency on 16 March 2020[35], and social distancing measures had caused significant disruption to daily life. Restrictions in the ACT at the time included a limit of four persons per square metre in enclosed spaces, the closure of hotels, entertainment venues, religious services, and eat-in cafes and restaurants, and strict limits on the numbers of people permitted at funerals and weddings. Public gatherings were limited to no more than two people, visitors to hospital were restricted to one visitor per patient per day, and most ACT school students transitioned to online learning for the whole of Term 2.[36]

The ACT Government advised people over 70, people over 60 with pre-existing conditions and Aboriginal and Torres Strait Islander people over 50 to “stay home whenever possible for their own protection,[37] consistent with advice from the Australian Health Protection Principle Committee.[38]

Many ACT residents – including people with long-term conditions - lost income or employment and relied on Commonwealth and ACT income supplement schemes.[39]

As ACT health services prepared to meet a potential surge of need for COVID-19 care, non-essential health and medical services were deferred. The way some health care services were delivered also changed, in particular with a move toward telehealth consultations (eligible for a Medicare rebate until September 2020).[40]

By the end of August, when the survey closed and after interviews commenced, social distancing measures had relaxed considerably. Routine and non-urgent health care services had recommenced. By the end of November, when interviews ended, social distancing measures were further relaxed, to allow large outdoor venues to operate at 65 per cent capacity.[41] The ACT’s Public Health Emergency remains in place, but at November 27 the ACT had one active COVID-19 case (a returned international traveller in quarantine), with 112 people recovered from a total of 116 cases. More than 100,000 negative COVID tests have been returned.[42]

This project is an opportunity to understand, from the perspectives of consumers and carers, how COVID-19 has changed, challenged or strengthened existing self-management strategies and support needs, and to identify ways that support to self-manage in this context could be improved.

Project outline

Study rationale

This project identifies changes that will help people in the ACT to self-manage their long-term conditions. Its key questions are:

- How do people self-manage their health with a long-term condition in the ACT?
- What helps them to do this, and what makes it difficult?
- What changes, if any, would assist people to self-manage their long-term conditions?

In February 2020, as this project was preparing to hear from ACT consumers and carers, it became clear that the novel coronavirus, COVID-19, could have a potentially devastating impact on the ACT community. Older Canberrans, immune-compromised people and those with long-term conditions were (and remain) among those most at risk of the life-threating impacts of contracting this highly contagious viral illness.[43] In the significantly changed circumstances of the COVID-19 pandemic, the project was amended to ask directly about the impacts of COVID-19 on self-management. It also asks:

- How is COVID-19 affecting how people self-manage long-term conditions?
- Has it changed the support they need to do to this?
- What would make it easier for people to self-manage a long-term condition in the context of COVID-19?

The answers to these questions provide practical information for health services, health professionals, health planners and community services involved in the design, delivery and evaluation of care and support for people with long-term conditions. This includes health promotion, prevention, chronic care and health literacy initiatives that support self-management.

It also provides information to assist agencies and consumers to understand and respond to consumer and carer requirements and preferences during the ongoing COVID-19 situation.

The ACT Government commissioned HCCA to undertake this work as part of the HCCA Community Health Literacy project. This project aims to:

- make it easier for ACT residents to navigate the health system, and
- get the health information they need to make decisions about their health and care.

It focuses on identifying changes that will assist vulnerable groups in the ACT, including people with long-term conditions, and people of culturally and linguistically diverse backgrounds in the ACT.

Philosophical approach

HCCA commits to **consumer-centred care** as a foundation principle in all its work and to promoting consumer-centred care across the health system, within government and across the ACT community. Consumer-centred care meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.[44]

Method

This is a qualitative consumer experience research project which drew on survey and interview data.

- The online survey was open to anyone aged over 18 with one or more long-term condition currently receiving care in the ACT. The survey was promoted widely to HCCA members and via consumer and self-help organisations including more than 18 condition specific organisations (see Acknowledgements for their details).
- People with one or more chronic condition were eligible to participate in semi-structured conversations about self-management. These conversations were one-to-one with the HCCA researcher and took place by telephone or videoconference ('Zoom'). Most conversations lasted about one hour. The opportunity to participate was promoted through HCCA's membership, via health services and through the networks of consumer and self-help organisations. People who expressed interest in participating were sent two documents to consider. These were an invitation to participate that provided information about the project, and an interview guide with a list of topics that could be discussed in the interview.
- HCCA employed a Bilingual Research Assistant to support the participation of Mandarin-speaking participants. The Bilingual Research Assistant promoted the opportunity to participate and supported informed consent. Interviews were a three-way conversation between the two researchers (English speaking and Mandarin/English speaking) and participants. The Research Assistant provided informal translation during these conversations. Participants were all members of a social group for older migrants from China, supported by the ACT Chinese Australian Association. These were conducted face-to-face in November 2020.

The survey took place between April and August 2020. The interviews took place between June and November 2020. As such participant reflections on COVID-19 relate to a rapidly evolving situation.

Interviews were recorded and transcribed with participant permission. Two participants did not consent to record and transcribe interviews. Detailed notes were taken instead. Participants who consented to transcription were provided with a copy of their transcript to ensure it reflected their experience and insights. Three participants made minor changes to their transcripts. Two participants requested a second interview to discuss additional issues.

Thematic analysis was used to identify major themes in the transcribed data, using NVivo software.

HCCA provided all participants with a summary of the research findings and recommendations. Participants will receive a copy of this final report once release is authorised by the ACT Health Directorate.

Ethics

HCCA sought advice on the need for ethics committee approval for the research. The ACT Health Directorate advised that this project is a quality improvement project and does not require approval by the ACT Health Directorate Human Research Ethics Committee.

Participants

Survey

Participants in the survey had more than 60 different long-term conditions. Arthritis, asthma, depression, anxiety and pain are the five conditions affecting the greatest numbers of survey participants. Three quarters of the survey participants had multiple conditions.

This list below details the conditions that most often affected survey participants.

Condition	**Proportion of participants with this condition**
Arthritis	46%
Asthma	32%
Anxiety	25%
Back pain	24%
Chronic Obstructive Pulmonary Disease	11%
Coronary heart disease	4%
Cardiovascular disease	14%
Cancer	12%
Depression	27.5%
Kidney disease	2.5%
Mental health condition (other than anxiety or depression)	10%
Pain (other than back pain)	24%
Other condition[c]	45%

While the demographic profile of participants is diverse, a majority of participants are women aged over 55 who speak English at home. Survey findings are consistent with the findings from analysis of the interview data. The companion document to this report, *Survey Findings: Looking After Your Health With a Long-Term Condition,* provides details of the survey questions, participants, and findings.

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[c] Other conditions are detailed in the companion document to this report, *Survey Findings: Looking After Your Health With A Long-Term Condition.*

Interviews

The 28 participants in interview also have a range of health conditions. This includes rare and common conditions, and each of the eight conditions that affect more than half of all adults in the ACT (highlighted in bold below).[45] The list below includes most of the conditions that people who participated in interview are diagnosed with.

- **Arthritis** (including rheumatoid arthritis, osteoarthritis)
- **Asthma**
- **Back pain**
- **Cancer**
- Cerebral palsy
- Cerebral vasculitis
- Chronic gallbladder disease
- **Chronic Obstructive Pulmonary Disorder**
- Crohn's disease
- **Diabetes - Type 1**
- **Diabetes - Type 2**
- Diabetic retinopathy
- Diverticulitis
- Endometriosis
- Fibromyalgia
- **Heart conditions (atrial fibrillation, heart disease)**
- Hypertension
- Lupus
- **Mental health conditions** (anxiety, depression and bipolar depression)
- Osteoporosis
- Parkinson's Disease
- Primary Sclerosing Cirrhosis
- Recurrent Deep Vein Thrombosis
- Reye's Disease
- Stargardt's Disease
- Ulcerative colitis
- Uterine prolapse

More than three quarters of the participants (22 people) have two long-term conditions. Over a third (11) have three or more long-term conditions. One participant has nine diagnosed conditions, each with interacting symptoms and medications. This information is relevant because people with three or more long-term conditions are more likely than other ACT residents to report low health literacy and difficulty navigating health services.[46] This can impact on self-management.

Three participants in this project identify as people with disabilities. Each of these people also have one or more long-term health condition that is distinct from their disability. One participant with disability has several health conditions that are associated with her disability.

Time since diagnosis varied. All the participants had been diagnosed with a first, or subsequent long-term condition more than 5 years ago. Almost three quarters (20 people) were diagnosed over 10 years ago. Some participants had childhood onset conditions (asthma, juvenile diabetic retinopathy, Stargardt's Disease, Cerebral Palsy, and possible post-polio syndrome). A minority (2 people) had been diagnosed in the past two years; however these were diagnoses with a subsequent condition. Most people in this project can therefore be considered experienced self-managers.

Participants have a range of personal circumstances. A majority were aged over 55 (21 people). More women (22) took part than men (6). This may reflect that, in general, more women than men participate in health promotion activities, and are aware of health-related issues.[47] Women may also predominate as members of some of the consumer and community groups that promoted the opportunity to participate.

This project did not ask people directly about socioeconomic status. However, in conversations it became clear that many participants have experiences of disadvantage or have complex circumstances. Five people had stopped working due to ill-health, and some (4) had significantly reduced income or financial insecurity as a result of their health problems. Four participants receive Commonwealth Government allowances as their main or only source of income (Aged Pension, Disability Support Pension, JobSeeker). Three people live in social housing. Four participants are either NDIS participants (3) or are NDIS eligible (1). Four care for other family members with long-term conditions, while a two of the Mandarin-speaking participants were primary carers for their spouses who had died of life-limiting illnesses in the past five years.

Seven participants are migrants from mainland China. Several of these participants speak limited English. Two spoke English with confidence in interviews. These participants migrated to Australia between 5 and 25 years ago. All had joined their adult children in Australia, under immigration provisions for family reunification. They were aged 50 or above, with three in their 70s and one in her 80s. Conversations with these participants were conducted in English and Mandarin (see Method, page 9).

Gaps in recruitment

This project is limited to adults aged over 18. It does not address the circumstances or requirements of children and young people with long-term conditions, or their families. Issues for families with children who require interstate care are comprehensively addressed in HCCA's 2019 report *Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project*.[48]

The project reflects themes in conversations with a small number of Mandarin-speaking ACT residents. This should not be read as reflecting the range of experiences of Chinese-Australian communities or the perspectives of other culturally and linguistically diverse communities in the ACT. This will be a focus of a companion research project that HCCA will undertake in 2021.

One participant in the survey is Aboriginal or Torres Strait Islander. No participants in interview are Aboriginal or Torres Strait Islander. This is a particular gap in the study given that Aboriginal and Torres Strait Islander people are more likely than non-

Indigenous people in Australia to have chronic conditions. The experiences and needs of Aboriginal and Torres Strait Islander Canberrans with long-term conditions should be studied separately in partnership with Aboriginal and Torres Strait Islander organisations.

Self-management from consumer perspectives

Attitudes toward self-management

Self-management is a term coined by researchers to describe health-enhancing behaviour and activities.[49] Not all participants in this project use the term to describe the ways they look after their health. But the term resonates with many of them, in different ways. For some, it is a neutral description of things they need to do to look after themselves, an ordinary and unremarkable part of daily life. Others see self-management as central to a positive sense of themselves as a person with a disability, or with a serious long-term condition. Some people see self-management as empowering – giving them control of their health. To self-manage is to be independent and self-reliant, a concept that is particularly important for many of the Mandarin-speaking participants. But even the most enthusiastic acknowledge that self-management can also be burdensome: a drag on their resources, a demand on their time, and laden with high expectations about what they can and should do to look after themselves.

It's part of life

Some people told us that self-management is a routine part of their daily life.

> *I do self-manage. I mean, that's life. It's a neutral thing. You self-manage going to the supermarket. You self-manage filling the car and getting it serviced. You self-manage your clothes.*

For some, the tasks involved have become habitual.

> *It's so intrinsic to me. It's hard to stop and think, what do I do?*

It's shaped who I am

Some saw self-management as central to their sense of identity.

> *It's shaped who I am. I would have done anything not to have this condition, but now I realise my life has been shaped by it. I would not have had the insights that I've had...*

People diagnosed many years ago, especially those with childhood onset and life-long conditions, have seen medical approaches to the management of their condition change over the years – sometimes dramatically. As a consequence, they appreciate the benefits of medical advances but also see the limits to medical knowledge and intervention.

> *We didn't know what was going to happen with people as they got older with cerebral palsy. Things have got better, it's a hell of a lot better….*
>
> *Because of my experiences of medical care as a child, I have trouble accepting authority which I think is not a bad thing, really… I will always ask for a second opinion.*

In the experience of some, advances in clinical management of their condition has been accompanied by a shift away from a top-down medical model toward one more accepting of the patient's knowledge and expertise.

> *In the good old days, it was very authoritarian model of 'you're doing the right or the wrong thing'. That's difficult because type 1 diabetes is an incurable autoimmune disorder, and it does have a life of its own. Things have got better. When I first heard the term self-management, I welcomed that. I was a great advance from being told, do this, do that.*

For some, asserting their knowledge and ability to self-manage, including in their dealings with health professionals , is an important and positive part of their identity as a person with a serious illness, or disability.

It's a sense of control

Several people drew attention to the empowering quality of being able to manage their symptoms, communicate with health professionals, navigate the system, and know what to do when symptoms worsen.

> *I do feel like I have a lot to coordinate. I do feel I self-manage. It's a sense of control. I'm actually quite happy that I'm at a point where I can do this, and I feel confident enough to do it.*

While the Mandarin-speaking participants did not use the term 'self-management', they prioritise the similar concept of self-reliance to describe taking responsibility for looking after their health and maintaining their independence.

> *I don't want to burden my children, so I take care of myself.*

Burden, burnout and overload

Even those people who felt overall positive about self-management highlight the sheer work involved in looking after your health with a health condition. They describe “burden”, “burnout” and “overload”. This is especially taxing when you’re in poor health, fatigued or “scraping the barrel already.” "Once you’re on the wheel of self-care”, said one participant, “you might as well give up”; another that “I do self-manage, because no-one else helps me!”

Some suggested the term ‘self-management’ can put too much responsibility for good health on patients and consumers.

> *It sounds like you’re the one to do it and be responsible for it. It concerns me when… it starts being a shift of total responsibility from the professionals. That just increases the workload, the responsibility, the expectation.*

Their message is that self-management can be unrelenting hard work.

Even people who pride themselves on their self-reliance need support to self-manage. Most people saw advice and guidance from trusted health professionals as essential.

> *You certainly take on some responsibility. You’ve got to look after yourself and you’ve got a duty of care to yourself. It’s not all the doctor’s responsibility and it’s not all the patient’s responsibility, it’s somewhere in between. You have to have that teamwork. You need a team.*

From this perspective, self-management often works best when supported by a team of health care professionals.

Managing symptoms, life impacts, health professionals and systems.

> *There’s a lot to it. It’s not just, have your insulin and don’t eat chocolate.*

So, what do consumers do to self-manage, or look after their health with a long-term condition? Participants in this project describe taking action in four areas of their lives to look after their health. They:

- Manage, monitor and reduce symptoms
- Cope with the life impacts of ill-health (emotional, financial and relational), and thrive despite these
- Get the most out of their interactions with health professionals , and
- Navigate complex health and human services

Table 1 lists some of the self-management activities people described.

Table 1: Self-management activities

Manage and reduce symptoms	**Cope and thrive with life impacts**	**Interact with health professionals**	**Navigate health and human services**
Self-administer medication Monitor their symptoms, physical indicators (e.g. blood pressure, blood glucose) and mental wellbeing Make “lifestyle” changes for example to diet, movement and exercise, drinking less alcohol and giving up smoking, and managing stress Manage fatigue Physical rehabilitation programs	Seek information about diagnosis, prognosis, treatment options and how to look after their health, Cope with emotional impact of diagnosis Reduced capacity to work and financial insecurity or uncertainty Deal with changes in personal relationships (with partners, family, peers and colleagues, and friends) Maintain a non-medicalised sense of sense Find a new sense of purpose, and opportunity to participate and contribute Build a new support network	Become more confident in communicating with health professionals, and asking questions Resist negative judgements applied to them by some health professionals Find health care professionals I trust Build a health care team Work together with health professionals Seek second opinions Organise medical appointments	Health-related administration (such as making appointments, keeping health records) Information sharing, for example sharing information with different treating professionals and taking health records to hospital in emergencies Coping with transitions in care, particularly from hospital to home, and policies and procedures that limit self-management in hospital

← More often clinician-guided

More often self-directed →

As the table indicates, self-management includes both clinician-led and consumer-directed activities.

Symptom management and monitoring is usually done under medical advice from a GP or medical specialist but not always. Some participants have made 'lifestyle' changes, such as starting or changing patterns of exercise, after medical advice and sometimes they are self-directed. For example, two participants described giving up gluten and sugar, and going vegan or vegetarian, in the absence of medical advice about lifestyle changes that would assist them to look after their health. Medical advice in this area was usually general non-prescriptive. A doctor might advise someone to exercise more, or a physiotherapist might suggest exercises that would be safe and challenging for the person.

This is the only area of self-management where health professionals usually guided their patients. For consumers, monitoring and managing the symptoms of illness is part of a wider canvass of self-management. Many participants described coming to terms with the **life impacts of having a long-term condition** as one of the most challenging aspects of self-management. Coping with the emotions associated with diagnosis, and seeking information about diagnosis, prognosis, treatment options and self-management was a key self-management activity. Some people sought information from their treating health professionals at this time, along from a range of other sources.

> *I am a bit of a bowerbird. I get information from my doctor, specialists, other people, the internet…*

In addition, self-management involves getting the most out of **interactions with health professionals** and **navigating complex health and human service systems**. People had to learn medical terms, and become confident to assert their priorities and ask questions in consultations with doctors. Some needed to resist negative judgements made by health professionals about them. And they had to share information between health services. All of these activities demand health literacy skills, problem-solving, self-advocacy and communication skills, and persistence and motivation.

Practice and *experience* were important in developing confidence and skills to self-manage. One participant diagnosed nearly 20 years ago describes this as follows.

> *I'm managing my medications and when I need to do stuff with those, when I need to go to a doctor, keeping an eye on my symptoms and my mental and those kinds of things. And I administer my injections by myself at home.*
>
> *I've got the experience behind me that I can do that. I've gotten to a point where I feel much more confident that I can do this, that I have the right*

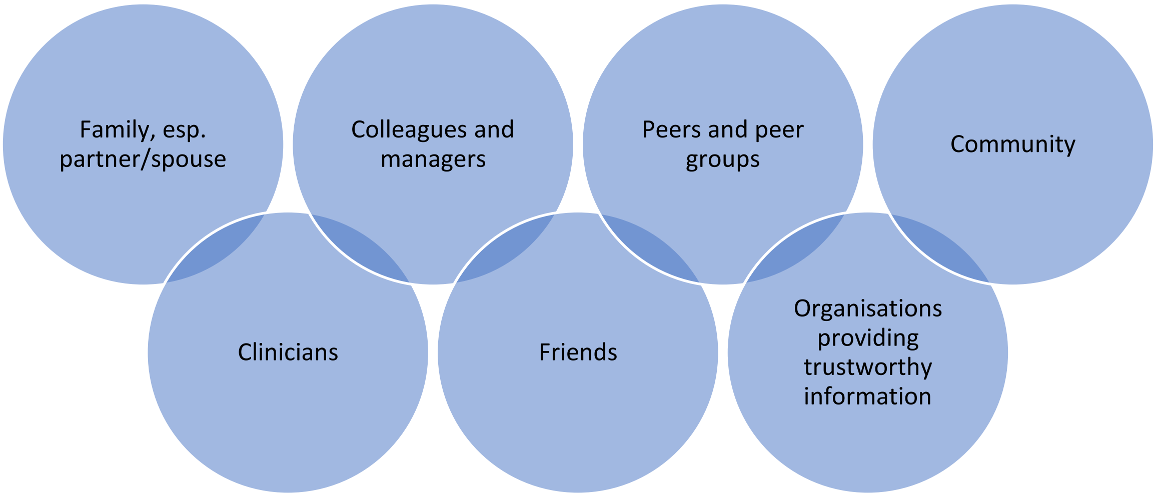
> *to be able to contact professionals if I need because I know what's wrong with me.*

Not every participant engaged in all these activities. People with multiple conditions, people whose conditions are impacting significantly on their health, and people in complex circumstances are more likely to describe taking part in more of these activities. Most participants in the survey and interviews reported managing their health well, much of the time. Participants with serious chronic conditions, advanced illnesses, multiple conditions or complex circumstances were more likely to find looking after their health time-consuming and difficult. And they are also more likely to find dealing with health professionals , and with health and human services, challenging and complicated. However, some people in these circumstances were also more likely to see themselves as adept at managing their health – they have had experiences that have taught them the skills and confidence they need to do this.

Support to self-manage

People in this project identified different sources of support that helps them look after their health.

Diagram 2: Sources of support to manage long-term conditions



In their own words, people describe the support they get from these different sources.

Family and partners

> *If I didn't have my partner, I don't think I would be sitting here.*
>
> *Once I opened up to my family it became a regular conversation, it was easier. I don't think they quite understood the seriousness of it.*

Peer groups

> *That's why Parkinson's ACT is so important, they gave me the information to know what the next step is*

One Mandarin-speaking participant explained she is healthy because she sings every week with the Chinese opera choir. The members share helpful information too. That's how she found out where to go to see a Mandarin-speaking GP.

Other organisations providing trustworthy advice

> *I found the national professional body really helpful. There was good information about how to talk to your employer [about your chronic condition].*

Health professionals

I've got my '-ists'. That's what I call them. The endocrinologist, a diabetes psychologist, podiatrist, neurologist, periodontist. And all sorts of others.

Friends

I lost a lot of friends [when I was sick]. It was a blessing in disguise. I think perhaps I was wasting a lot of time and effort on people that weren't worth it. Then there were these other people who were like, are you OK? I thought, I need to redirect over here.

Community support

This takes different forms. *Public awareness of specific conditions* is important, particularly for people with conditions that are not well known or stigmatised.

> *When I first told someone about endo, they were like 'what, that doesn't sound very real? Now there's starting to be an awareness.*

Community services provide essential practical assistance for some participants. This includes help with activities such as housecleaning, accessible transport, and personal care.

> *I have a great person who helps me with housecleaning.*

People think of self-management, and self-management support, holistically. They seek support to manage their condition in the context of their life. Self-management support is not just about helping people manage with the symptoms of illness, it assists them to cope and thrive despite the whole-of-life impacts of a long-term condition.

Resources for self-management

Participants said it was easier to look after their health when they are:

- Financially secure
- Have control over how they use their time,
- Have the health literacy to get and interpret the information they need, and
- Have access to health information they can understand.

Related to the last point, Mandarin-speaking participants drew specific attention to the dearth of translated information and the importance of community networks and organisations that provide ‘word of mouth’ information about health and health services.

Financial security

These resources for self-management can be depleted by ill-health. Participants with low incomes can find their out of pocket health costs can quickly become untenable. One participant pointed to the recurring costs of doctor’s appointments, prescriptions, non-prescription medications and other costs such as needle disposal bins for people who self-inject medications. Even people with considerable financial resources can struggle to manage financial insecurity and reduced income.

> *I used to wake up with panic attacks in the middle of the night. What the hell are we going to do if I die and you cant’ afford the mortgage?*

Time

Participants see free time as an important resource for self-management. They need control over their time so they can attend appointments, prioritise their health and participate in health-enhancing activities.

> *What’s helped is having time to look after my health.*

Health literacy

Participants described needing to be able to find, or ask for, the information and support they need.

> *My thirst for knowledge has been the most important thing that has helped me to look after my health. And let me tell you, it is not easy to ask doctors questions.*

Health literacy skills are an essential self-management resource, as they allow people to get, understand and act on health information.

Self-management barriers and enablers

> *I want someone to see how my disease fits into my life, not the other way around.*

This section considers people's experiences of self-management in more detail. It identifies opportunities to support self-management, in each of the four areas consumers tell us are important:

1. Coping with the life impacts of ill-heath, including the emotional impact of diagnosis.
2. Managing and monitoring symptoms
3. Getting the most out of interactions with health professionals
4. Navigating health and human services

Whole of life impacts

Some of the most important aspects of self-management for consumers and carers in the ACT relate to coping with – and thriving despite - the impacts of ill-health on their finances, their personal relationships and their identity. Coming to terms with the emotional impact of diagnosis, and seeking information about living well with their condition, are specific areas where support to self-management can be improved. For many, finding a new sense of purpose and maintaining a non-medicalised sense of self, are important to their health and wellbeing. Peer networks, consumer groups and professional organisations are important sources of information and support.

Coming to terms with diagnosis

For most people in this project, diagnosis was deeply affecting. They describe feeling a variety of strong emotions. These include:

- uncertainty – about prognosis, and what the diagnosis means for their lives
- fear – of becoming very ill, losing quality of life or capacity and of dying, and
- shock - which for some was compounded by abrupt delivery of diagnosis.

Two of the participants describe their experiences below.

> *I had a really bad time trying to come to grips with everything…. I went into a bit of a state of depression after getting diagnosed. It just made it very difficult to not know what the next step was or what the future holds.*

> *It was just like, "yes you've got this." The difficulty was on the empathy side. "Just stop. Just leave work". I can't leave work. I've got a mortgage.*

> *I've got little kids. They didn't demonstrate any empathy for my age and stage of life.*

Others felt relief, because a diagnosis made sense of their symptoms, opened access to support, or allowed them to focus on practical next steps.

> *I didn't want to get the diagnosis, but once you get that diagnosis, you fit into a proper category, lots more things open up to you. Blind pension, taxi subsidies, now NDIS. Before that, I mean, I was just a weird person.*

One participant commented that:

> *Thinking back, I would have loved somewhere to go to decipher what my symptoms were. Now I've been diagnosed, and I know what I'm dealing with, I can begin to try and sort my life out and live with it a little bit.*

The common theme is the intensity of their emotions in response to a life-changing diagnosis.

Participants felt they were largely left to their own devices to cope with the emotional and practical impact of their diagnosis on their lives.

> *What you'll hear all the time is, 'we're focusing on this medical issue and the rest of your life, that's up to you'. There' s never any talk about how are you coping at home? That's left to you to fill in the gaps.*

They valued it when health professionals acknowledged the significance of diagnosis. This helps them to manage it.

> *The endo was really empathetic. He was the first person that made everything feel valid for me. Every doctor I'd encountered up until then had just completely dismissed me. And hearing if from professionals, you really start to believe it.*

Seeking information about a new condition

Many people cited unmet information needs during and following diagnosis. The months preceding and following diagnosis involved a lot of interaction with health care services and professionals. Tests were ordered and completed, appointments attended, medication prescribed, treatments or procedures scheduled, and medication regimes altered to get them right.

> *I've been spending a lot of time talking to different people, physicians, pharmacists, other people with the condition, to try to learn about their experiences and figure things out.*

Despite this intense interaction with health services, many participants said that their priorities for information - What does this diagnosis mean for my life? What are my treatment options? What might my prognosis be? - were rarely addressed, or were insufficiently addressed.

> *When I got told I had Parkinson's, they said 'you've got Parkinson's. There was big gap in the next level of information. It was up to me to go out and do the research. I remember saying to him, what do I do about work? What are the future symptoms? I got some information. But.. the next step was to spend a whole heap of time on the web, hunting around. That's where I learnt about my condition.*

Participants were very self-directed in seeking information. They:

- Searched the internet
- Found websites of consumer groups, in Australia or overseas
- Found websites of professional and peak organisations
- Found contacts for ACT consumer and peer support groups
- Asked friends and family

> *My information comes from Dr Google, friends, and by trial and error.*

They identified some specific information they would have liked to have been given. This includes information about:

- Possible prognosis
- Treatment options (including in public and private health care services)
- Reproductive health including the potential impacts of their condition on fertility and pregnancy
- Sexuality and intimacy with a long-term condition
- Local peer support organisations

> *Maybe a handout that could direct you to organisations, so you're not sitting on the web going "where do I go for this?"*

> *I wish I had known sooner about support groups and professional organisations.*

Some people described experiencing information overload, yet felt it was important to find out everything they could.

> *It's good to know what things are before your specialist starts talking about them… you already have a bit of an idea.*

The months following a diagnosis are a crucial period in which consumers need information and support to establish a foundation for self-management. Giving information and referring people to sources of trustworthy information and support can help them to manage the uncertainty and fear that can accompany diagnosis.

Adjusting to major life changes

Most participants had experienced significant changes in life circumstances following a diagnosis. Some participants had to stop working, or reduce their work hours. Relationships with partners and spouses changed.

> *My wife is really important, yes. She's not my carer but she's very protective.*

Some, particularly younger participants, talked about losing friendships.

> *People got frustrated with me, id' gone from this massive bubbly social party girl to in bed, sick in pain all the time. People don't want to be around that.*

> *People say "I'd like to hang out" and I'm like "I actually can't". They don't quite understand. Like, sometimes I actually can't walk. People don't understand because most of the time they see me and they don't see that … I hide it and then people don't know.*

Others grieved no longer being able to participate in activities that had brought them joy.

> *I really mourned the loss of all that stuff – I was doing really well at my job, and racing mountain bikes…*

Some had to accept new limitations. For example, one participant could no longer lift anything heavier than five kilos:

> *As a younger male I don't mind saying it's completely emasculating. I've become less embarrassed about asking for help.*

Participants described finding ways to maintain a sense of themselves as well, capable and contributing people. Some people who had stopped working due to ill-health volunteered with community groups and consumer organisations to use their skills.

> *When I finally, finally accepted I wasn't going to get better, ever, that's when I started to find something meaningful, which is all my charity work. I'd say it's helped my symptoms. Doing things that feel doing, where the anger, resentment and bitterness and frustration are gone, your health gets better.*

Others found new activities that they enjoy.

> *I've gotten into woodwork. I'm a gardener. Making tables. I like to go away fishing. That makes me feel better. You think of a thing to do and get on with that.*

In these ways, they maintained a non-medicalised sense of themselves as people who are not defined by ill-health. From consumer perspectives, this is part of self-management.

> *You need to ask, what do I want out of life, what do I want to achieve, what's limiting me? If you let it consume you it can become your entire identity, I'm a person who suffers from this condition.*

Building a network of support

Many participants found connecting with peer networks helped them look after their health. Younger participants (in their 20s and 30s) were more likely than others to find peers and networks via social media (Instagram and Facebook in particular). They recognised that depictions of life with long-term conditions on these platforms are not always realistic, and that information people offer may not always be trustworthy. One participant said it is important to find peers who have an optimistic outlook.

> *[Social media] can be dangerous because some [people there] perpetuate the cycle of depression and giving up and feeding into constantly being on painkillers. Then I found one girl who was a little bit hopeful and I was like, she's like me. She wants to get her life back too, she wants to open up a discussion about what works.*

Participants who got involved with consumer groups also felt it was important to strike the right balance between positivity and realism about life with a long-term condition. One participant, seeking information about how to manage her condition when highly symptomatic and in pain, found it tiresome to read “feel-good stories” about “doing this trek on Kokoda or whatever when I felt like I couldn’t even get out of bed in the morning…” She wanted relatable information and a connection to people “as sick as me”.

Another participant described feeling “shamed” for “oversharing” after discussing her mild anxiety at a peer support group. She was also advised that it was inappropriate to ask for people’s advice about which doctors they would recommend - yet this was the information she most wanted from others with her condition.

These reflections should not be read as detracting from the reassurance and practical assistance many people found in peer groups. They demonstrate that self-management support and information is most useful when:

- Providers are clear about the aims and limits of information and support they provide, and
- They understand and can respond to the information needs of their members and people with the condition.

Managing, monitoring and reducing symptoms

Managing, monitoring and reducing symptoms of long-term conditions is central to self-management. Key points in this section are that.

1. Participants who live with pain sometimes feel judged by health professionals when they request prescription medication to assist with pain management. They would like pain management to be recognised and supported as a key aspect of living with many long-term conditions.
2. Health care consumers in the ACT are interested in the potential of new technology to make self-monitoring easier and more precise. This includes interest in self-monitoring apps and wearable devices for continuous monitoring of physical indicators such as blood sugar.
3. Consumers would welcome new models of care that allow routine monitoring, and self-management information and advice, to happen with the least disruption to their daily lives and in community settings. Some suggested nurse-led clinics for specific conditions, an enhanced role for community health centres and walk-in models for regular monitoring and ‘check-ins’, with referral for more intensive support if required.

Many participants had been advised to make ‘lifestyle’ changes to reduce and manage their symptoms. Reflecting the importance of this area of self-management to participants, it is dealt with separately in the next section.

Self-administering medication

All participants in this project take medication. Many had developed routines to help them take medication safely. They divided their medications into a weekly pill box, used Webster packs, or always take medication before lunch. Some participants identified community pharmacists as very important support people – they asked participants questions about their medicines, and had good suggestions about over-the-counter medications. Some pharmacies offered apps that people found useful. They issued text messages when scripts were about to expire, and when medication was ready to collect. People who used these apps appreciated the convenience they offered.

Some participants had experienced adverse medication interactions and events. As a result they are very aware, even vigilant, of the risks of medications. They do what they can do reduce this risk. Some wear medical-alert bracelets. One participant keeps a paper record of all prescription medications and asks a family member to make sure hospital staff get this if she has to be admitted in an emergency.

Many people with long-term conditions live with pain. People in this project recognise that opioids and other prescription pain relief medications are not sufficient as an approach to pain management. However in their experience these medications are sometimes necessary. Some participants perceive that their treating health professionals regard them with suspicion or negative judgement when they request pharmacological pain management. They would like to see better recognition of pain as part of living with a long-term condition, and greater access to non-pharmacological pain management for example physiotherapy and exercise physiology.

Some people used complementary and alternative medicines. In particular, Mandarin-speaking participants used traditional Chinese medicines (herbal medicines and topical creams) to help manage symptoms. They sometimes had friends or family in China post these to them, or brought them home from visits to China. Most said they would not visit Traditional Chinese Medicine practitioners in Australia or buy these preparations here – this would be too expensive, and the product quality might be less pure. Some of these participants found it very useful to "mix and match" Chinese and Western medicine. One participant had used Chinese herbs she credits with resolving gallstones, another carries a bottle of traditional medicine pills that she would use if she had had an elevated heart rate. Both described talking with their GP about their use of these products, and felt it was very important to have a doctor who understands what these medications are and how they work.

Self-monitoring

Every participant monitored their symptoms or physical indicators of their health. Participants described being generally aware of their health and wellbeing (for example stress levels and mental and emotional wellbeing) as well as noticing worsening symptoms such as pain. Most people felt that they would know when to seek medical help for worsening symptoms. However, others reflected that it was easy to underplay the seriousness of their symptoms, and to miss the onset of an acute episode.

> *I've had my asthma for a long time. I don't really think about it. I am complacent in away. I know if I get a virus it'll probably go to my chest [and I'll get pneumonia]. At one stage… I was really, really sick. My family thought I might die. I guess you get used to what other people might find alarming, the amount of [shortness of] breath I can have.*

This suggests a particular need for patient education and information about symptoms designed specifically for experienced self-managers.

People took regular observations of physical indicators – for example regular blood tests, blood sugar monitoring, taking their blood pressure or heart rate. This meant people could monitor when their symptoms were worsening and know why they might need to see a GP, or alter doses of insulin, for example. Some people who used wearable devices and apps for this purpose were enthusiastic about the potential of new self-monitoring technologies. Two examples of devices used by participants are:

- A heartrate monitor (finger pads) connected to a personal mobile device so a person could take their heart rate once a day
- A continuous blood sugar monitor inserted into the upper arm, connected to a mobile app that shares real-time results

The two people who used continuous blood sugar monitors for Type 2 Diabetes control felt this was a great improvement on regular point-in-time HbA1c tests. They had more information about how different food and activity affects them over the course of day, and a clearer picture of blood sugar fluctuations over time. They also appreciated that results could be shared automatically by email with their GP or other health professionals, though one participant was disappointed that her general practice advised that she could not share data from the device with the clinic.

Participants value approaches and technology that make self-monitoring easier and more convenient. This is the main reason they support wearable devices and apps.

> *Having a gadget for self-monitoring could be handy. But I think they're expensive. So I can see why they might not be on the PBS. It would be handy.*

Apps and wearable devices might also offer better quality information for self-monitoring and self-management:

> *It should be possible to get the sensor and monitor, even for an 8-week period. I think people would learn so much that would set them up for the longer-term.*

This level of interest from participants suggests there is an opportunity for health professionals to initiate conversations with patients about these devices, and whether they would be appropriate for the individual circumstances of the patient.

Many participants would like to be supported to take greater control of their own self-monitoring. Some saw the potential for a greater role for community-based care and nurse-led care.

- Routine testing for indicators of how well systems are controlled could happen at a community health centre, with a follow-up medical appointment only if required
- Nurse-led clinics at community health centres where you could 'walk in' to ask a question about your long-term condition
- A telephone support line you could call with questions about your condition and self-management, before the problem becomes acute

> *My view is we need to have a place where people can, once every six months, go and have their HBA1C checked. If they then need to have a medical appointment they can, if they don't, they don't. It becomes more*

of a management of your own health thing, rather than having to go and see the doctor.

What I would really like to see is more centres, like the walk-in centres, with quality nurses to deal with specific conditions. You know how you have walk-in centres for new mothers and things like that? It would be really good to have something where they had some nurses who had a bit of expertise in your condition. That's probably a dream…

Changes to diet, exercise and other 'lifestyle' factors

Health professionals had advised the many participants to make changes to what are sometimes called 'lifestyle' factors, in order to reduce and better manage symptoms. Participants most frequently discussed making changes to diet and exercise. Therefore these changes are the focus of this section.

Participants identified four opportunities to improve support in this area:

1. An appreciative approach from health professionals , in which barriers to lifestyle changes are considered and small changes acknowledged.
2. Personalised advice about the kind of exercise appropriate for people's individual circumstances
3. Affordable access to appropriate exercise equipment and facilities in the community, including outside of business hours
4. A focus on the benefits of incidental movement, physical activity that is enjoyable, and exercise as an adjunct to social activity, will help some people self-manage.

Some people made lifestyle changes quite easily, as two of the participants describe below.

> *I try to make sure that I do about 10,000 steps and I do jobs that are within my capability.*

> *I write all the physio exercises down and I take my book with my notes back in with me each week when I see her. You need to have a system.*

Others had long-established habits of health-enhancing patterns of eating and moving. For example an older married Chinese couple described walking around a suburban park together every day. Another Mandarin-speaking participant never cooked fried food to protect her heart health. One person gave up smoking 'cold turkey' after receiving their diagnosis, two mentioned drinking less alcohol. People who had been more active before their diagnoses had moderated the intensity of their exercise.

> *It is not at the level I used to do but doing some exercise because it keeps you moving and it's generally good for you and always makes your head feel better.*

However, many of those who attempted such changes found it very difficult. It was even harder to sustain these new habits over time. Quite a few people in this project did not consider themselves to be 'exercise people'. One described a life-long dislike of exercise, another said that exercise was a "loaded emotional thing" due to memories of "failing at sports" as a child and young person. Another simply did not enjoy exercise. It is a chore, something you "ought" to do.

> *You know that the best thing to do would be to go and have a push [in my wheelchair] around the block once and have a healthy lunch but… I often think it's all too hard.*

These participants had been told exercise was good for their health, and believed this to be true. But they found it very difficult to motivate themselves to do something they found unpleasant, in the name of this rather abstract and hard to quantify benefit.

> *The idea that you're exercising for the good of your health is so ephemeral. It's ridiculous.*

They identified other barriers to exercise, too. These are:

1. Minimal acknowledgement from health professionals that making these changes can be hard, and little if any discussion of what would make this easier.
2. Prejudicial judgements from some health professionals, which led some to defer seeking treatment unless essential.
3. Lack of accessible and appropriate facilities for exercise
4. Limited advice or support about what kind of movement or exercise would be appropriate for them and no support to find forms of movement that they might find enjoyable.

These barriers, and opportunities to improve support, are explored below.

These changes are hard to make

While health professionals advised people to exercise or move more, there was rarely much discussion about why people might be reluctant or unable to follow this advice. People knew what changes they should make, but found it hard to do for a wide variety of reasons. Unfortunately, even self-management educators did not always acknowledge the difficulty of making these changes.

> *My HbA1c was too high and my weight was too high. My GP sent me off to a diabetes educator who didn't tell me anything I didn't already know. You go to medical professionals like GPs and they say lose weight. But they don't give you any direction. They'll say go to a dietician. But the dietician didn't tell me anything I didn't already know.*

> *There's a big difference between what the doctors would like to you to do… and the real world. A lot of the time I agree with what they want me to do, and I wish I could apply it. For example they say, 'just make sure you get lots of sleep and eat well and avoid stress'. And then there's the real world. I'm a carer. There are completing priorities. There's a context*

> *to non-compliance. Why is that person not doing what they're supposed to be doing?*

The advice to exercise was particularly difficult for people who felt they were genuinely too unwell to follow the recommendation.

> *Different doctors told me exercise was good but when you're really sick, I would get angry. It was like it was a bit insulting.*

Negative judgements from health professionals

Negative judgements from some health professionals were another barrier to lifestyle change. One participant's GP said she was "naughty" for having high blood sugar, another was told she had "been bad" for not making recommended changes. Two participants described being told to lose weight when they presented for non-related health issues. They found this distressing and felt that their priority health issues were overlooked due to negative stereotypes applied by some health professionals to obese people.

Such judgements could lead people to feel a sense of guilt, failure, or self-blame when lifestyle changes did not happen as advised.

> *There are bits [of your life] you can take responsibility for but there's a whole pile of it that you've got no control over that you can still feel guilty about because they're telling you that, and that guilt is so pervasive.*

For some, this became a further barrier to change. An expectation of negative judgement led some people to defer or not seek treatment unless absolutely necessary.

> *[Their attitude] becomes a blocker because you have to kind of prepare – you're not only preparing yourself to deal with telling the story again but you're preparing yourself to deal with the fact that they're going to be awful [to you] and you're preparing yourself for that, you're going to have to deal with all that.*

Another participant said that:

> *It does limit my ability to access health services. How many times do you want to have to go and see a doctor to find out that the doctor is really bad when it comes to this sort of stuff?*

Another person, who smoked for many decades before quitting, felt she was judged as "to blame" for having developed COPD. She feels she must explain to doctors that:

> *We used to smoke in maternity hospitals. We used to smoke in aeroplanes. And did you know that smoking cures asthma? Smoking cured everything. I had a GP tell me to smoke when I was 17.*

Participants valued it when health professionals acknowledged the context of the person's life, did not blame them for their health circumstances, discussed the barriers that might prevent them making lifestyle changes and offered relatable examples of a person like them who had made changes. Participants notice and appreciate when health professionals "talk with them as equals", as one participant put it.

> *My doctor would say, you could probably go off all your medication if you were willing to live a really spartan lifestyle but I don't know that's the way to fix it because then you get stressed about living a spartan lifestyle. She actually understands. It's the whole thing about the reality of life.*

Personalised advice and appropriate facilities

Lack of advice about what specific kinds of exercise and movement is safe and appropriate was an issue for some people.

> *What about stretches and exercises that are right for my husband who is 67? He looked everywhere. There's no easy source to go to. In the end he found a blog on the internet on a site for women's weightlifting! If you could ring a physio and say what you needed… or if you could get three or four sessions with a physio or exercise physiologist a year imagine what they would do.*

Absence of advice about appropriate diet and exercise led some people to make self-directed changes. One participant went vegan and gave up sugar after watching a documentary about the purported health benefits. Prior to this a specialist had said there were no lifestyle changes that would reduce his symptoms. He judged these changes could do no harm, and might help. Another person with a gastrointestinal condition had experimented with eliminating different foods from her diet in an effort to manage symptoms. When she was diagnosed she was very underweight and was grateful for her GP's referral to a dietician. Health professionals might consider proactively inviting their patients to talk about diet and exercise changes they have made, or think could work for them, to start a conversation about possible health benefits and harms in the context of self-management.

Some people found it difficult to access appropriate facilities for exercise. Two people who underwent physio-led rehabilitation programs felt these worked well, but stopped exercising when these time-limited gym-based programs ended. There was a cost to join private gyms, and they weren't sure which ones would offer equipment or classes suitable for their level of fitness and specific rehabilitation and disability requirements. Many people with long-term conditions are conscious of the risk to their health if they over-exert or injure themselves. One participant expressed the view that gyms are for the very fit.

Specialist facilities (e.g. hydrotherapy pools, gyms that offer disability accessible equipment) are not always open on weekends or after 5pm on weekdays. This is a barrier for people who work during the week.

> *There are lots of us who are very motivated independently, but we need access to different facilities, so having an arm bike if you're in a wheelchair, a lot of gyms just can't make the modifications.*

So, what works for people?

Participants who had made lifestyle changes despite barriers identified approaches that work for them. They found it helpful to:

- Focus on incidental exercise and an active life, rather than 'exercise' as such – for example they play with grandchildren, garden, visit an outdoor area.
- Accept that some movement is better than none – particularly for people who had been very active before their diagnosis.
- Make exercise and movement social activities – walk with a friend, throw a ball with a spouse, go to a café and walk from the car or bus
- Find an activity they enjoy and can do, rather than persisting with formal exercise classes if they don't like them – walking, instead of attending the strength class.
- Do something that brings them satisfaction or joy.
- Create an incentive - for example only watching a favourite TV show when using a stationary bicycle.
- Set achievable goals for the sense of accomplishment of achieving them.
- Keep a sense of balance – don't berate yourself if you don't do it.

Below, some participants describe their strategies.

> *My partner says let's go catch the ball for a bit. I'm not stupid enough to not realise it's exercise, but if he says let's do some upper body exercise, I'll say no way.*

> *We set up the TV in the exercise room and you can't go in there unless you exercise. It's an hour and half each day for me I do that. But hey, I*

get through my TV programs. The inclination is not to do it. Still, eight years later. If you could give me a pill to take and I'd never have to do it, I'd take it.

You can test out your own self by doing small things. As long as I'm not thinking of it as exercise, I think gee, I really would like to go and have a walk.

It's just a real joy to be able to walk in water and just feel free. I have this real desire that the way to get better, kind of innate, swimming is kind of healing thing for me.

Interacting with health professionals

> *Maybe discussions between the medical professional and the patient about what is working and if not, “where are you struggling?’ If your 3-month HBA1C is too high, ask ‘why’? Perhaps you need a referral to help you deal with it*

Getting the best out of interactions with health professionals is an essential part of self-management. Participants in this project described a range of techniques to get the most of their appointments, and build a team of health professionals who are involved in their care. Many see a long-term relationship with a trusted GP as essential to self-management. Some participants worry about what will happen when their GP retires, and what could happen if they lose capacity to self-manage in the future.

Getting the most out of consultations

Participants describe a range of tasks related to managing health appointments. This doesn’t just involve attending the consultation. You may need to book the appointment, have pathology or other tests beforehand, and make sure that you and the doctor have the results. Many participants try to keep a record of everything that happens too, and develop systems to manage this information.

> *An appointment in this chronic world is not just an appointment. It’s up to you to make sure that you regularly book those appointments, and the follow-ups. Often there’s a test required beforehand. What tests do I need to do beforehand? Oh, I can’t get in for another six months to see the specialist. You’ve got to make sure you’ve listed everyone involved, then you’ll be sent for tests or referred to other people, so there’s follow ups. There are many parts to ‘an appointment’. Most of that falls into your own self-management, so organisation. I often say, I need an EA to manage the paperwork. I just keep an A4 book and write everything down in that. I document as I go because I can’t possibly remember everything. I know an online version could be easier, with search function sand so on, but you don’t usually take your laptop into your medical appointment with you.*

> *I take a piece of paper when I go to the doctor and on the top I just write “why am I here”? there’s no point coming home and going, oh I forgot to do this and that.*

Asking questions during appointments is important, but not easy. It takes confidence, practice and gumption.

> *I think you need to have the confidence to talk to your GP about things, find out the answers, don't feel rushed if you still have questions. Just ask the questions. Don't get rushed out the door.*

People who speak English as a second language face an extra level of challenge in this area. Participants who speak little English explained that finding a bilingual doctor is essential. One participant prepared for her first visit to a bilingual GP by practicing some of her few words in English. She and a friend had agreed that if she could just repeat the name of the doctor she wanted to see, the receptionist would eventually understand and her help.

Some Mandarin-speaking participants had used the Translating and Interpreting Service in consultations with health professionals and found it helpful. Others had tried, and given up because the wait time to speak with an interpreter was too long. One participant said that while she prefers for her adult son not to translate for her, sometimes it is almost unavoidable. Once she was in hospital and her son was there when the doctors did their bedside rounds – if her son hadn't spoken with the doctor she would not have understood what was happening at all. Another participant appreciated that at Canberra hospitals a call will sometimes be put out via loudspeaker for Mandarin-speaking staff member to help interpret in urgent situations.

Building relationships with a health care team

Participants described building a team of health professionals that they trust. Most (but not all) participants valued having a long-term relationship with a key treating health professional. Usually this was their GP. It is important to have a rapport with this person, to be able to talk to them, and to trust them.

> *The attitudes of GPs can be profound in your feelings of health and feeling of control of your own health.*

> *Find someone that works for you. Because yes, it's your body, it's your responsibility, the onus is on you. But they will help you.*

> *But having a good GP who you trust and can talk to really matters. It's really about trust. There's no shame, that's inherently important. You can just go and say 'oh god, I'm not coping'*

An attitude of mutual respect was essential:

> *What I love about my GP is he was very open at the beginning many, many years ago. He said, I don't know much about CP so I want you to teach me about it.*

Being able to talk the GP about personal or sensitive health topics was important.

> *Who wants to hear about it? It's embarrassing. My gastroenterologist kind of just, he looked at me and went, you have to talk to me about this. It was good for him to just say that to me. This isn't polite conversation.*

Participants saw asserting their own needs and expertise in looking after their health as part of self-management. This was particularly true for people who see many health professionals.

> *Everyone is interested in their area of expertise. And not uninterested in the other, but it's difficult for them [to see the connections]. I see a rheumatologist, a neurologist, a gastroenterologist, an ophthalmologist, and a gerontologist as a general physician. I have to help them fill in the gaps and help direct how we're going go forward with some of it.*

Some participants wonder, or worry, about what will happen if they lose the capacity to self-manage and self-advocate in these ways. Others were concerned about the interruption to their care if their GP retires. Should they plan for this change, and if so how? One participant wondered about asking her GP for a recommendation, another had "interviewed" several potential new GPs. These experiences underline the importance of continuity in general practice for many people who self-manage a serious long-term condition.

Navigating health and human services

Participants describe this as an aspect of self-management that demands time, persistence and work. The challenges in this area include:

1. Poorly coordinated care that means patients must take responsibility for sharing information across services
2. Inconsistent support for self-management when admitted to hospital
3. Intensive health literacy demands related to accessing health and human services, including through schemes such as the NDIS, My Aged Care and Commonwealth Government income support.
4. Impersonal communication from health and human services staff, and inflexible service models.

Participants identified the following opportunities to improve self-management support:

- Hospitals could introduce a system to identify when people who self-manage are admitted and to assess their capacity to continue to do this – in particular for people who usually self-administer medication and monitor physical indicators.
- Invest in systems that help patients and services share information in a timely and accurate way, with patient consent.
- Invest in health care staff whose role includes helping patients to coordinate and understand information and overcome barriers to care.
- Offering more health services outside of business hours.
- Include details about how to contact the relevant team or person, in every communication with patients (email, phone call, SMS or letter)
- Community education about eligibility for and how to access schemes such as My Aged Care and the NDIS, including in languages other than English.
- Expanded access to accredited interpreters.

Poorly coordinated care

Disjointed or poorly coordinated care was evident in:

- Important patient information (e.g. test results and discharge papers) not being shared between different services, or treating health professionals within the same service.
- People being unsure who was in charge of their care, and decisions about their care.
- Participants receiving conflicting information from different health professionals , and not knowing how to reconcile this.
- A lack of connection between different health and human services (e.g. the NDIS, My Aged Care)

One participant described their experience in this area as follows.

> *I had a GP who would refer me off to specialists. The reports came back to her, but at any time I was going to the liver clinic, the gastroenterologist, I had pain, I couldn't sleep, I had a counsellor, I had a dietician, I had whoever else I had. I was sick. I couldn't read all those reports. I was stressed. There is no one person in the health system who is your coach through all that. One person to bring it all together. You're in the centre of your wheel, you've got all these spokes coming to you, you're trying to digest it all. I almost begged, "is there one place I can go to, to take my file and manage it?"*
>
> *I don't think that's the role of my GP. She was awesome, but she only worked part-time, and you'd see her for maybe, if you booked a double, 30 minutes. And a lot of the information from all those places is conflicting. Completely conflicting.*

To manage these situations, people with long-term conditions described:

- Keeping (or feeling that they ought to keep) comprehensive notes and paper records of past treatments, appointments, medications and adverse events.
- Proactively sharing information with their treating professionals, for example requesting copies of paperwork and emailing or taking copies of documents from one health professional to give to another doctor or their administrative staff.
- Telling their stories many times.
- Dealing with onerous administrative requirements to ascertain eligibility and then apply for financial assistance through Commonwealth Government agencies (NDIS, Centrelink, MyAged Care).

Participants described their experiences as follows.

> *I'm often telling the doctors what the other specialists have said and whilst they "CC" [carbon copy on emails] at times, maybe the doctor you need to see isn't on the list or they haven't got it yet or you have to chase. A lot of self-management is being on the phone… I wish the admin people would do what they promise they will. It sounds so trivial, but it wastes so much time.*
>
> *I refuse to go on the NDIS, my time is worth more than the process to go on that. I pay for all my own stuff, out of pocket. To get on the NDIS is so hard. The idea of filling out a novel's worth of paperwork is impossible. I cannot do that.*
>
> *Here is something that plagued me for 10 years. When I was critically sick, we were trying to fill in forms. And we were both EL1s and my wife*

> *has worked with computers her whole life, and we couldn't figure out how to fill out some of the forms, or how to apply.*
>
> *Every time I rang the doctor's office I'd get in with a different GP, and you get put in a position where you're constantly telling people your history over and over and over again, which is really frustrating.*
>
> *No-one explains what's happening next, "what's the next stage? Where are we going?"*

When someone in the health system is tasked with the role of coordinator, or navigator, it helps people to pull the threads of their care together. One participant identified that the breast cancer care nurses at the Canberra Hospital are an example of how care of this kind can support self-care.

> *There were some really good nurses. One became an advocate for me. We'd debrief after whatever appointment. You'd speak to some doctor and he'd be like 'oh you can get a wig' but that was the least of my concerns. She could break it down. I had no idea what T cell counts, or white blood cells were. When you're bombarded with information, she could break it down into layman's terms. She was so eloquent in saying, keep a diary. You go and see him then come back and we'll go downstairs and break it down.*

Care and support of this kind was the exception rather than the norm, and was much more likely to happen when care coordination or care navigation was an explicit part of a model of care or a named role for a health professional. The positive experiences participants had of these models suggests their value in supporting self-management.

> *I just wish there were nurses you could talk to. Like, not a 000 sort of thing, just you know, this has happened, and I need to do this, so it doesn't escalate to the point where you end up in hospital. You can have a nurse on call to talk.*

Impersonal and inflexible service models

People in this project would welcome the opportunity to attend more health appointments outside of weekday business hours. This was a particular consideration for people who worked on weekdays.

> *The assumption that someone who has a disability doesn't have other commitments – they say, oh we can see you at 10am on a Monday.*

> *There's this assumption that you aren't working, and that's a real problem too because a lot of the services are only available during business hours.*

Some participants had received correspondence from services – for example hospital booking forms and appointment confirmations – with no number to call or details about who to contact to follow up with questions. Two participants had received phone calls from health services that did not provide a number to call back on, or a message – just a missed call from a private number.

> *One of my issues is that ACT Health, when they call, they've got no number ID, so if you miss a call because you're in the shower or on the toilet, then they'll call up again. You can't call them back – and then they're like, "You missed an appointment." And you feel like a teenager, like you're in trouble, and you didn't do anything wrong. They didn't leave a message, you didn't do anything wrong, but you feel like you should say you're sorry – like you're guilty.*

Self-management during a hospital admission

Some participants felt that they were seen as competent self-managers when at home, under the care of a general practitioner; but were not trusted to do this when in hospital. People who usually self-administer their medication and monitor their symptoms would like to have the option to continue to do this in hospital.

> *You get told you have to self-manage and then that gets pulled out from under your feet, when you are in a really critical and vulnerable position in hospital. Your role as a self-manager that is so prominent and respected can get thrown out the window… You can't be a self-manager on Monday, and not the next day. It has to be consistent.*

They recognise that in some circumstances they may be unable to do this, for example if they are sedated or unconscious. But in many circumstances they would be able to continue these tasks. One participant felt she would be safer in hospital if she did – then she would not have to remind nurses her insulin is due or that she needs her blood sugar taken.

> *You're quite capable of doing that for yourself at home, I don't know why they won't let you do it in hospital. It throws your sugars out so much if you're late. You get sick of asking for your glucose to be read and for your injection.*

This participant would like hospitals to have a process to ascertain on admission whether a person is self-managing aspects of their care, and whether they can continue to do so safely while in hospital.

In relation to diabetes management in hospital, others report great difficultly arranging for food to be delivered on time, essential to keeping blood sugar within a safe range. One participant reported that despite requesting diabetic meals as an in-patient these were not provided. These experiences suggest significant opportunities to improve self-management support for people with Type 1 Diabetes and Type 2 Diabetes when in hospital.

Self-management during COVID-19

Summary of issues

COVID-19 presents significant challenges for how people look after their health.

- Most participants in this project had a heightened awareness of their vulnerability to serious health impacts if they were to contract COVID-19.
- Some experienced significant anxiety about the potential impacts of COVID-19 on their lives, and people in the ACT.
- Participants were early adopters of a range of protective practices (social distancing, self-isolation, hand and respiratory hygiene) intended to reduce their risk of getting COVID-19 and contribute to preventing community transmission.
- Many people with long-term conditions saw themselves as ‘well-prepared’ for the pandemic due to their experience in self-managing their health.

Some impacts of COVID-19 have been unexpectedly positive for long-term conditions self-management.

- Many people have embraced telehealth – it offers accessible and convenient care for routine issues.
- Some report having their healthiest winter in many years due to social distancing and greater community compliance with advice about hand and respiratory hygiene.
- Some valued the quiet and opportunity to reflect that social distancing and self-isolation have offered.
- Some participants are hopeful the general community will have more empathy for the circumstances of immune-compromised people, having now experienced a collective life-threatening health experience.
- Some describe a new appreciation for the professionalism and personal courage of health professionals, and confidence in the ACT response to COVID-19.

However, interruptions to health services during COVID-19 have also led to significant interruptions in care for some people.

- Participants are clear that face-to-face health services remain a priority for some people, and some situations, even in pandemic conditions.
- Some participants’ health has declined due to deferral or cancellation of non-urgent procedures.
- Social isolation has been accompanied by loneliness, anxiety, depression and declining emotional wellbeing for some people.

People with chronic conditions remain cautious about the continued relaxation of social distancing requirements in the ACT and nationally. They hope that the ACT community and Government will continue to socially distance, and actively plan for a possible resurgence of COVID-19.

Heightened sense of vulnerability

People with chronic conditions are among those most vulnerable to serious health impacts if they contract COVID-19. Many participants in this project were acutely aware of this.

> *I would go an awful long way not to end up in hospital intubated, let me tell you. My husband and I had that conversation. About what we would want if it came to that. Our determination was that we're going to be here on the other side of this.*

Some described significant anxiety about the potential impact of COVID-19 on their lives, and on people in the ACT. A number reflected that COVID-19 had followed a summer of extreme bushfires and hazardous air quality in the ACT. Some people, particularly those with respiratory conditions, were still recovering from the health impacts of this time. For example one participant with COPD and asthma had a lingering cough that she worried could become pneumonia. Another participant described a sense of cumulative worry and pressure building throughout the year.

> *My catastrophising doesn't help. It just increases my anxiety. If you're not a very healthy person to start with, COVID's boding fairly poorly.*

Not everyone with a long-term condition was troubled by the potentially serious consequences of contracting COVID-19. One participant said that:

> *Paradoxically, I haven't felt vulnerable. I don't see myself as weak, so I've not been scared… I had near death experiences in my 20s, I grew up in developing countries. I'm just not fearful.*

It's important to remember that people with long-term conditions assess risk differently, and in the context of their individual values.

Protective practices

Most participants made significant changes to daily life in order to 'self-manage' their vulnerability to serious health impacts from COVID-19. They were early adopters and strong advocates of protective practices such as self-isolation, social distancing, hand-washing and mask-wearing.

Most participants chose to self-isolate at home early, before the ACT Government introduced time-limited restrictions on movement and activity. This decision was taken to protect the person with serious condition but also affected all household members and extended family. For example, one family began home-schooling their children weeks before the ACT Government reduced face-to-face teaching, and spouses and partners drew down their holiday and personal leave to stay at home.

> *Whatever we have to do to make sure we're here on the other side of this is what we will do. Our premise was, within our grounds, within the fences of our boundary, we have no COVID-19 so we can relax in here.*

Households and families developed new routines to reduce the risk contracting COVID-19. They nominated one person to deal with tasks such as grocery shopping, some washed and dried groceries outside. Others left mail on the veranda for a couple of days before opening, or changed clothes before coming into the house. Benchtops were sanitised frequently. Some people cancelled in-home services provided through NDIS or My Aged Care.

> *Carers can't come in due to risk. I've cancelled my lovely person that does my house cleaning. I'm wondering if I'm game enough with masks and sanitiser, whether I'm prepared to let them come back. They've got a very busy life and lots of interactions and I'm just a bit worried.*

While this made daily life more challenging, one person found an unexpected silver lining in this situation:

> *I have to confess I like the peace and quiet of not having people in our home.*

Some participants wore masks in public, including before official government advice recommended mask wearing in some circumstances. For example one Mandarin-speaking participant wore a mask in public from February 2020, because family members in China had told them the situation there was very serious and that masks work. Some felt somewhat bemused by the initial hesitance to encourage mask-wearing, though they did appreciate the concern that limited national supply made access for health workers the priority.

> *From day one I wore a mask. For the simple reason I've got more to lose than what anybody else has to lose.*

Welcome to our world!

Some participants felt they were better prepared for the pandemic than others in the wider community. This was because they already knew how to protect themselves from highly contagious respiratory illnesses (such as colds and flus), knew how to pace themselves and manage their time at home, and had adjusted to getting less done in a day. Three participants describe this, below.

> *I was already pacing myself because of my zero immunity. If my kids came home sick, we'd quarantine them. I already washed my hands 20 times a day. We were always wiping our dining table.*

> *As a household of two disability pensioners with long-term conditions who don't normally have a lot of money… The isolation part really isn't that different. Welcome to our world! We're at home a lot and these restrictions aren't too different.*

> *I was already used to pacing [myself], not expecting to do too much every day.*

As people became more used to pandemic conditions, they described some positive impacts of these protective practices. Some people were the healthiest they had been in years, due to social distancing and public awareness of hand and respiratory hygiene.

> *In a way COVID-19 has suited me quite well. I haven't been out and the flu's not around. I feel really good.*

Others appreciated new opportunities to work from home. Participants, including people with disability, felt this positive for accessibility, reduced risk of viral illness, and for managing fatigue.

> *There have been more options for people who don't want to leave home or who are too ill to leave home… Being able to work from home. I've found it beneficial. I've felt quite safe because I've been able to do those things from home.*

Isolation

Social isolation has impacted negatively on the support some people receive to look after their health. Some people have felt anxious and depressed while cut off from face-to-face activities and interactions. Two participants describe this below.

> *This woman came over [from community care] and said, your place is clean. What do you want me to do? I said, can we go out and get a coffee? It was a COVID thing. I just needed to talk. It was that social experience… you've been so isolated. We just talked, and I cried, and we did some of my rehab exercises and it was fantastic.*

> *People with chronic stuff go, "Well, I can't go to the door, I can't do this, or that". That has a big impact on their life. The more you isolate when*

> *you have anxiety, the harder it is to then socialise again. The longer that you don't, the harder it is.*

Some participants embraced new ways of connecting virtually with friends, family and peer groups. But these are not good substitutes for everyone. Some really miss the human connection of meeting face-to-face.

> *What COVID's done to me is, I forget things! You can't have a normal conversation anymore. You've got that distance between you, you can't say all the things you want because of that distance between you.*

There were some practical difficulties associated with self-isolation too. Some people ran out of staple foods briefly during lock-down, or had trouble accessing special shopping hours that were introduced at major supermarkets for people vulnerable to COVID-19. Others did not like relying on family members to shop for them while others, including older Mandarin-speaking participants, were concerned about being a burden on their families.

Access to services

Some COVID-driven changes to health service delivery have positive impacts for self-management. Many participants have embraced telehealth, particularly for routine health issues and with a health professional they know. This participant appreciated that her GP had moved to telehealth to protect his health:

> *My GP was very adamant, she said 'were going to have a very different relationship for the next little while. You will not be coming in unless we absolutely need to see you.*

Telehealth's benefits include convenience (less waiting, no travel time) and accessibility (no need to arrange disability accessible transport or deal with inaccessible buildings). Participants in this project also welcome electronic prescribing. Like telehealth, it offers convenience, saves time, removes accessibility barriers for people with disabilities or limited mobility, and limits potential exposure to viral illnesses – colds and influenza as well as COVID-19. Some participants described benefiting from other changes including pharmacy home-delivery, having a GP fax a script direct to a pharmacy for collection, and drive-through services such as flu shot in the car. They appreciated the new awareness of social distancing and hygiene and sanitation in waiting rooms and inside health facilities.

Most participants in this project continued to access the health services they needed during the months of COVID-19, "with a bit of common sense". For example one participant tried to pick quiet times at their general practice to limit interaction in the waiting room, another waited outside the clinic before appointments. Some participants would like their GP to be more open to the option of videoconferencing, rather than only offering telephone consultations, which might offer more interaction and opportunity to read body language, for example.

However, telehealth is not always the preferred or most appropriate modality. Not everyone thinks it superior to face-to-face appointments. Participants were concerned it might increase the chance of miscommunication:

> *Personally I like to be able to read what I think people are thinking. You know, the body language and being able to ask more questions, where you can miss that on a phone call. There is potential for mis-steps, I think.*

> *I'd really much prefer to stay face-to-face. If you know the person, it can work. My doctor knew me well enough to tell from my voice, I guess.*

More importantly, telehealth is not appropriate for every person or in every circumstance. People with mental health conditions, people who speak English as a second language and people with complex circumstances said they found it harder to engage with health services without the option of a face-to-face appointment. For some participants, this has meant health needs aren't addressed. A participant who needed to arrange an initial mental health consultation wanted to do this face-to-face, but initial consultations "came to a screeching halt" during COVID-19. Even while health services return to 'COVID-normal' it has been hard to re-engage with health services.

> *With COVID it's been really, really hard to actually do anything when your mental health takes a nosedive… It's compounding the mental health challenge, the lack of being able to get into services face to face. It is really important. I do need to see the doctor, the dentist. I think the thing that was particularly disheartening for me was I spent a year focusing on getting my mental health back up. I started to get there and then with the start of COVID every little thing is a lot of work. Setbacks like that are really hard.*

The temporary deferral of non-urgent appointments and procedures in hospital and clinics did affect some participants. One person had her cataract surgery deferred, causing significant rapid loss of vision while waiting for her surgery to be rebooked. A Chinese-speaking participant was unsure how to reschedule an appointment for minor surgery that had been deferred at a private clinic. Many deferred routine and preventative care procedures such as dentists appointments, and self-management activities such as water exercise and gym classes. Other people had some difficulty filling scripts, for example for asthma preventers and relievers during the lock-down period.

Three participants had to seek medical care in an emergency between March and August 2020. One person who needed to go to hospital in March delayed seeking treatment:

> *I delayed going into hospital because of COVID-19. My family said, we were really worried you would be dead in the morning. They said, get in the car now. But the messaging you were getting back in the beginning was, don't come in. I thought emergency was just for COVID people.*

Two participants admitted with chest infections were initially treated as potential COVID diagnoses. They expressed deep gratitude for the health professionals who cared for them.

> *Anyone came into my negative pressure room I would bow to them and say I am so deeply appreciative, because I was. Back then, there were doctors, nurses, dying in other places in the world. They thought there was a tsunami coming. I felt responsible for them to be honest. It took them forever to gown up. One of them told me she had little kids and how scared she was. I just thought, you're so brave, it's such a selfless thing. You're coming into this room where possibly… Like, I was coughing and coughing and coughing.*

Relaxing social distancing measures

People with long-term conditions were the first to adopt protective practices, and are among the last to stop them. Participants were generally pleased that social distancing restrictions were easing in the ACT, and were relieved that we had avoided a worse experience of COVID-19. However most participants are not contemplating a return to pre-pandemic normality yet. Concern and even anxiety about the potential for a resurgence of COVID-19 remains.

> *"Until there's a vaccine" is a bit of a fantasy land at the moment. It'll be a very slow return to 'normal' for me, and for our household because the stakes are too high.*

> *My anxiety's high because I suspect we'll have a second wave.*

Participants were annoyed, even angry, at others who don't follow social distancing requirements. For some, there is a sense that they may not be able to rely on people in the community to take necessary precautions.

> *You don't know, walking down the street, who's sensible.*

One participant is concerned that people she knows are easy targets for COVID-19 misinformation. Another has heard family members express views such as “COVID is a leveller”. She feels diminished by these views.

> *I wish people would see COVID through my eyes. Everyone who could die is someone’s parent or grandparent*

By contrast, some participants were hopeful that the pandemic might lead to greater community awareness of what it’s like to be immune compromised, and to live with a sense of vulnerability relating to your health.

With few exceptions, people with long-term conditions remain cautious about the continued relaxation of social distancing requirements in the ACT and nationally. They hope that the ACT community and Government will demonstrate care and compassion by continuing to socially distance, and actively planning for the possibility of a COVID-19 resurgence.

Conclusion

Many participants in this project feel confident to look after their health, most of the time. However this can be exceptionally challenging, particularly for people with multiple conditions, complex circumstances or advanced illness. The period leading up to and following diagnosis can be especially difficult, and participants place a high priority on information and support in the weeks and months following diagnosis. This lays a foundation for self-management, and makes it easier to develop the skills and confidence required to self-manage - and to cope with and thrive despite the emotional and whole-of-life impacts of a new diagnosis. While 'self-management' is a term used by health professionals, it resonates with some consumers as a term to describe both the genuinely empowering quality of taking charge and looking after your own health, and the hard work involved in doing this. For many participants the most difficult aspects of self-management relate not to the management of their symptoms, but to navigating health and human services, interacting with clinicians and coping with the impacts of ill-health on their sense of self, personal relationships and financial security.

The COVID-19 pandemic has highlighted the work that people with long-term conditions do to look after their health. Participants describe a range of new routines and practices to reduce their risk of contracting COVID-19 and to manage their vulnerability to serious health impacts of COVID-19. Participants in this project have benefited from and built on their existing repertoire of self-management strategies. COVID-19 has also presented unexpected opportunities for improved self-management and self-management support, post-pandemic – in particular, telehealth and e-prescribing.

Key findings

Participants' experiences highlight approaches and practices that support self-management. They also indicate that there are opportunities to enhance support in the areas of:

- Consumer information to support self-management
- Good communication between consumers and health professionals
- Models of care that support self-management, and
- Self-management support in the ongoing COVID-19 response and in pandemic preparedness planning.

A) Consumer information that supports self-management

1. Organisations that produce health information can support self-management by responding to consumers' priority information needs. This includes information about what self-management is, treatment options, whether new

self-monitoring apps and devices are appropriate for the person, and personalised, appreciative, advice about diet and exercise changes.

2. Initial research with a small number of Mandarin-speaking participants indicates interest in information about how to access an accredited interpreter (telephone and in-person), what to do when no interpreter is available, contacting emergency services when you speak little English, where to go for health services, and eligibility and application processes for Commonwealth Government assistance (including My Aged Care, National Disability Insurance Scheme and Centrelink services). [4]

B) Good communication between consumers and health professionals

1. To support self-management, health professionals can:
    - Acknowledge the emotional impact of diagnosis.
    - Practice an appreciative approach to promoting diet, exercise and other 'lifestyle' change, which avoids blame or judgement, commends small changes, and assists people to identify barriers to change, and strategies that work for them.
    - Refer patients early to trustworthy information sources and peer organisations.
    - Clarify your expectations, and patients' understanding, of self-management.
    - Encourage advance care planning conversations.
2. Health services can improve communication with patients by providing details about how to contact the service, and the treating team, every time they contact a patient – by phone, SMS or letter.

C) Models of care that support self-management

Health services can develop and invest in models of care that:

1. Acknowledge and respond to the emotional impact of diagnosis, and provide information and support for self-management in the months after diagnosis.
2. Refer people to consumer groups that are an important source of information and support for many people after diagnosis.
3. Expand options for community-based chronic conditions care. This should include exploration of the potential role of community health centres in multi-disciplinary and drop-in models of self-management support.

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[4] HCCA will gather further information about the information and support needs of culturally and linguistically diverse communities, as these relate to self-management, in 2021.

4. Support people to self-administer medication and self-monitor physical indictors of long-term conditions when admitted to hospital, where the patient has capacity to do this and it is their preference.
5. Provide options for non-acute care outside of weekday business hours.
6. Assist people with long-term conditions to overcome barriers to service access and to navigate complex health and social support systems. Patient and Family Navigator models are one promising example.

D) Self-management support during COVID-19

Agencies involved in the ongoing COVID-19 response, and/or future pandemic response planning can:

1. Continue to promote, support and invest in telehealth, in recognition that this offers superior accessibility, convenience and safety for many people with long-term conditions, particularly for routine health care matters.
2. Work toward becoming a pandemic-ready health system that has capacity to maintain or quickly resume face-to-face consultations for some consumers and some circumstances. This includes consultations with a new clinician, serious mental health matters and physical rehabilitation. Consumers who are likely to gain most benefit from the option of face-to-face consultation include people who speak English as a second language, people with limited health literacy and people in complex circumstances.
3. Recognise that people with long-term conditions are vulnerable to serious health impacts from COVID-19, and to anxiety caused by this vulnerability. This can cause people to defer acute and routine care.
4. Ensure that there is clear public advice, including for people with long-term conditions, that it is important to access urgent and acute health services when necessary, and to resume routine and preventative health care when safe to do so.

Everyone in the community can:

5. Demonstrate care for people with long-term conditions by continuing to follow any legislated social distancing measures and to practice good hand and respiratory hygiene.

Recommendations

To assist in translating these findings into policy and practice, HCCA recommends:

1. All ACT hospitals explore opportunities to improve support for self-management for in-patients.

2. ACT Health Directorate continue to promote and emphasise the importance of the community maintaining an ongoing commitment to hand and respiratory hygiene post-pandemic in public health messaging.
3. ACT Government and health services continue to explore the potential of social prescribing as an approach that may assist consumers to access individualised support and services to maintain and enhance their health.
4. ACT Health Directorate and publicly funded health services ensure that consumer priorities for self-management are reflected in a collaboratively developed ACT strategy for improving chronic conditions care, that reflects the priorities of the National Strategic Framework for Chronic Conditions.

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