Integrated Care in the ACT Region:

Consumer perspectives

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About HCCA

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

HCCA involves consumers through:

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

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

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-Profits Commission.

This research is part of HCCA's Integrated Care Project, which was supported by the ACT Health Directorate.

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Executive Summary

This is the second report from the HCCA project *Integrated Care: Consumer Perspectives in the ACT Region.* The aims of this project were to:

1. Gain an insight into what "integrated care" means to consumers with complex and chronic conditions in the Canberra region;
2. Understand the experiences of consumers with complex health circumstances and chronic conditions in accessing and managing their health care, including during the COVID-19 pandemic; and
3. Identify what consumers in the ACT region need the health system to integrate to allow them to make managing their health and wellbeing easier.

The findings of the first report looked at the providers' perspectives about what was needed for consumers to manage their complex and chronic conditions.

This report shares research findings about what integrated care means to consumers with chronic and/or complex health care needs who are living in the ACT region.

HCCA acknowledges and includes the important role of unpaid carers, family members and supporters, and paid carers in supporting consumers to access the care they need[2].

HCCA uses the consumer-led definition of integrated care established by the National Voices UK[3] and recognised by the World Health Organisation[4]:

> "My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes."

It is important to note that health system planners, service providers and policy makers often use the term "integrated care". Most of the participants in this study, however, had never heard of that term before.

Participants were given the definition highlighted above and asked to identify what integrated care meant to them.

For participants, integrated care was care that was **easily accessible**. This meant that care:

- is conveniently located. Whether it was co-located with other services or in close proximity to other services they needed, or even that it was easily accessed by public transport; and
- supported links and communication between the various kinds of care a person needed and took into account the physical, social, emotional and other wellbeing needs that would affect their health and wellness.

Most of the participants in this study felt that their care was **not integrated**. For the few who felt their care was integrated it was purely through their own effort. As one participant stated:

> “You need a degree in management to look after your health” – Participant 18

Participants highlighted **a range of issues** they faced when trying to manage their health across multiple services and providers across the ACT. These challenges included:

- facing difficulties navigating health systems and identifying where and how to seek support and care;
- having to choose when and how they accessed care to balance costs and lengthy wait times for appointments; and
- lack of integration and communication between health care professionals forcing consumers to hold and convey their health information across multiple care providers.

Integrating care for our participants is essential in providing them with the opportunity to focus on improving their health and wellbeing. Care integration for people with chronic and complex health conditions is about reducing the mental and the emotional load of navigating the health system and managing complex administrative tasks across different care providers.

For consumers **an integrated care system** is one where:

- consumers are able to easily identify where and how to seek support and care;
- accessing care is made easier by co-locating services and/or increasing the use of virtual care systems; and
- health infrastructure and communication systems allow consumers’ health information to be easily and securely shared and utilised by their care team.

The findings of this second report are therefore relevant to anyone that delivers health or community services to people with chronic or complex conditions and individuals and organisations wanting to design and implement integrated services.

Semi-structured interviews were conducted with 20 adults living with chronic and complex health conditions from November 2022 to April 2023. The conversations focused on:

- how participants manage their care across multiple services and providers across the ACT;
- what participants know and consider integrated care to be;
- what integration of care would look like for participants and the impact this may have on them; and

- participant's experiences with accessing care and/or services during the COVID-19 pandemic.

With participant consent the interviews were audio recorded and transcribed and coded into themes. The most common themes were understanding of integrated care, management of care and impacts of integrating care for participants.

The findings of this project are limited by the sample size as the experiences of 20 adults with chronic conditions cannot be generalised to the broader population. However, the experiences reported here remain valid and provide in-depth insight into the perceptions of integrated care and management of their health conditions by the participants. Additionally, only one participant resided outside the ACT, warranting future work for regional insights. The ACT Digital Health Record (DHR) was launched during the running of this project potentially impacting findings. Future studies considering the DHR's influence post-2024 are recommended for a comprehensive understanding of its potential impact on the experiences of integrated care.

The learning from both projects will be used in guiding and advocating for consumer-focused integrated care by HCCA.

The overall project was funded by the ACT Health Directorate.

Introduction

The goal of integrated health care has been sought for several decades in the ACT through many initiatives, policies and frameworks. Across Australia and internationally better integration of health services aims to improve consumer experience of care, provide high quality care for the increasing number of people with long-term health conditions and overcome fragmentation between services and parts of the health and social services system. The increasing proportion of people in our community with long-term health conditions has increased the need to develop ways of achieving integrated care for people with chronic and complex health needs. Appendix A provides a brief context of integrated care initiatives that have been attempted both nationally and in the ACT. These initiatives, however, have had limitations to their long-term success due to issues around systematic challenges to implementing integrated care and inadequate and sustained funding for health services and health service staff to work collaboratively.

What is integrated care?

There is currently no agreed definition of what integrated care is and no consistent approach to its implementation, despite continued interest in it. This is partly due to the different perspectives and purposes of the stakeholders involved in designing, funding, regulating and providing services within health care systems[4,5].

HCCA uses the consumer-led definition of integrated care established by the National Voices UK[3] and recognised by the World Health Organisation[4]:

> "My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes."

This definition is use in this report because the overarching aim of the project was to elicit consumer experiences of integrated care.

Care can be integrated within the health care system and between health and community or social service systems[6]. The latter aspect is essential to enabling better health and wellbeing for people with complex and chronic health conditions. This has been shown through the impacts that socioeconomic factors and social factors like income and education can have on health over time. For example, studies have shown that children raised in socioeconomically disadvantaged neighbourhoods often face emotional and psychological stressors like family conflict, instability brought on by persistently insufficient resources and face greater direct physical challenges in maintaining good health [7].

What are chronic and complex conditions?

We define chronic conditions as long-term and persistent, often leading to a gradual deterioration of health and loss of independence[8] To achieve an integrated system of care that meets the needs of people with chronic and complex conditions, it is important to understand what chronic and complex conditions are.

Chronic conditions:

- have complex and multiple causes;
- usually have a gradual onset, although they can have sudden onset and acute stages;
- occur across the lifecycle, although they become more prevalent in older age;
- can compromise quality of life and create limitations and disability;
- are long-term, persistent and often lead to gradual deterioration of health and loss of independence;
- individuals may have one or more chronic conditions; and
- are the most common and leading cause of premature mortality in Australia[4].

In the 2022, 52.3% of all adults living in the ACT reported having at least one chronic condition such as arthritis, asthma, cancer, dementia, lung conditions, heart disease, diabetes, kidney disease, mental health conditions and/or stroke[9]. Over 21% of adults living in the ACT reported living with 2 or more chronic health conditions[9]. Living with a chronic condition can have physical, social, financial, emotional and lifestyle impacts. Living with multiple chronic conditions can have greater impacts as the impacts of different conditions can add complexity as they may be more difficult to manage and require more care.

People with complex health needs like other consumers may also experience other social needs including needs related to inadequate or insecure housing, social isolation, problematic drug or alcohol use, family or domestic violence and cultural, circumstantial or intergenerational disadvantage[10,11].

Existing health and social service systems are frequently unable to meet the complex needs of people in these circumstances due to the complex ways that social determinants of health impact health outcomes and the long periods of time over which they impact people[7]. Existing models of health care can further isolate and discourage people with complex health needs who are already socially isolated and may experience significant barriers to accessing health and social services[10].

In this project, complex needs (or complexity) are defined as a combination of health needs that can include diagnosis, treatment and rehabilitation and long-term management. A person's circumstances may also include social support needs. For example, access to affordable, secure and safe housing and/or assistance to live independently[12].

What do we currently know about integrated care?

While consumers often have not heard of the term integrated care, their descriptions of what it might mean are consistently focussed on holistic and continuous care and health services that are easy to access[13,14].

In 2013 National Voices UK highlighted that for consumers for whom integration is most needed, including those with chronic conditions, the health system needed to integrate two key things[15]:

- **Knowledge of the patient/service user/carer as a person.** This includes their personal circumstances, lifestyle, preferences, their confidence to self-manage their health and their overall health; and
- **Knowledge of the relevant condition(s) and all options** to treat, manage and minimise, including knowledge of all available support services.

Study aims

The aims of the study were to collect consumers':

- understandings of integrated care and how they thought it would impact on their health and wellbeing;
- experiences of managing and living with their complex health conditions; and
- experiences of the impact of COVID-19 on the management of their health and conditions.

This report adds critical insight and understanding of what consumers want and need to manage their health within the context of the ACT region. This report:

1. defines integrated care as it is understood by consumers;
2. highlights the experiences of consumers living with chronic and complex health conditions in managing their health and wellbeing;
3. identifies, from a practical perspective, what integrated care looks like for consumers with chronic and complex health conditions; and
4. outlines the impacts that these integrations will have on their health and wellbeing.

Understanding of integrated care

We asked participants if they had heard of the term ‘integrated care’ before participating in this project. Thirteen of the participants had not heard of the term before the project and only seven indicated they had heard of it and had some understanding of the term.

For participants who had not heard of integrated care we provided them with the definition we have used for this project: *“My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes.”* [3,4]

We also provided some additional explanation around what integrated care may look like. For example it might look like having multiple services at one site or that care information is passed on from one specialist to another to help manage their care better.

The seven participants who had heard of integrated care before described it as being care that was holistic. For these participants this meant that care providers were able to consider a person’s social, emotional and mental wellbeing needs as well as their medical needs. It meant that there were connections and communication between the different types of care a person accesses. Integrated care also meant that services a person needed were easy to access. Ease of access for participants included ease of finding information about, and connecting with, services and having services that support them clustered together in locations that were easy to access with public transport:

> “…What I’d say is that it would mean a cluster of medical services in a place of easy access. Easy to access on a main bus route or something” – Participant 20
>
> “… it means that there’s a connection between if you’ve got a range of issues or even if you’ve got. … It’s about … having some level of communication and connection between the types of care that you need, how you access those, how those people communicate and how that benefits you as a patient.” – Participant 14

What does integrated care look like for adults with chronic and complex health conditions?

Once all participants understood what integrated care was they were asked to describe what their health care would look like if it were integrated.

1. **Consumers are supported to build their health literacy and understanding of their health and how to manage their health.**

The participants spoke often about how they managed their health from their own knowledge of health care or through adapting their existing professional knowledge to support them to manage their health.

As part of this participants also raised the need for health care professionals and the wider system to support consumers to build their health literacy and skills to effectively manage their health. As one participant discussed:

> “To help a patient journey is to help them understand and give them knowledge and empower them. And there’s so much information that’s out there that is helpful, that is also not helpful and incorrect, and if you’re not astute enough or learned enough, for want of a better word, then you could go down a whole range of rabbit holes that are really unhelpful and really have poor outcomes.” – Participant 15

For participants this meant that there was support given to them following a diagnosis or an episode of care. This could be information of their relevant health conditions, advice on other places to seek information as well as other supports available and how to access them.

For participants this also meant that support was provided for ongoing care and they were educated on things such as side effects of medications and the interactions of different medications on each other when taking multiple medications. It also meant that they received clear communication and advice from their health practitioners about their health appointments. For example the health provider should confirm what will be needed for their next appointment, such as particular test results, or be clear about the purpose of the next appointment so they are well informed and prepared.

Participants also spoke about the importance of improving communication between different health practitioners and the importance of improving communication between health practitioners and themselves as patients. Participants discussed the frustration of not knowing what is being planned in their care or what might have been discussed at multidisciplinary care meetings. For participants it was important to be told and made aware of what is happening in their care, being provided with enough information to be able to understand the implications and to be involved in making the decision about their care. These participants also did not expect this communication and involvement to be onerous or time consuming with one participant discussing:

> "I don't want to touch base every month or anything like that. I want feedback every time something has happened or something has changed. So that we're all on the same page, so I know what they're doing, I know what they're going to do, I know if they have or haven't done it and then if there's something I need to do then that's written down as well." – Participant 9

2. **Health care providers are supported and, where appropriate, funded to facilitate communication with each other.**

Participants spoke about the importance of health care providers sharing health information and communicating with each other to support the care of their patients. Participants felt that multidisciplinary team meetings would be useful so their treating team could discuss their health and care plan across all the different facets of their care needs. Participants felt that enabling this communication and multidisciplinary treatment would mean that they receive better care as all facets of their health are addressed as one. For others this meant that they wouldn't have to repeat their health story over and over again:

> "It would be not being asked afresh about my health condition if I go to a separate hospital. If there was a way they can actually take my data and share it to the hospital that I'm in and I really want attention in so I wouldn't go through a series of test over again" – Participant 3

Participants acknowledged that their care providers are busy and communication should not become more onerous for them. Rather participants suggested that improved communication could be in the form of copying other care providers into changing care plans or when ordering and receiving pathology tests. For others depending on how stable their health was multidisciplinary meetings could be an annual or 6-monthly event to review care and consumers and carers should have the option of attending these meetings.

Participants spoke also about the importance of supporting health practitioners to use digital health to facilitate communication across health care providers and with their patients.

Participants spoke of the different apps and tools they use to manage their own health because health practitioners were not incentivised to use the digital health tools available for supporting and managing their patients' health:

> "When I had a fall and was in hospital, they didn't have all my meds, my conditions and some things they got wrong because they didn't listen to me… And it frustrates the shit out of me when people don't listen, or there's no access to records that helps coordinate my care.

> Great, you can look up something, My Digital Health, it would be great if there was a patient version of that, and doctors in the ACT, it was mandatory they put stuff in there, not just the hospital system.”
> – Participant 8

3. **Transparency and flexibility in how health data is managed.**

We asked participants about their perspectives on sharing their health information to support the integration of care. Overwhelmingly participants were supportive of sharing their health information with their health care providers if it meant their care was improved. However participants also discussed wanting to have the flexibility to choose what data was shared and with whom.

Participants acknowledged that managing health is very personal and while sharing some health information is beneficial they wouldn’t want all their health information to be shared. For some participants this meant that there needs to be flexibility when managing health information that can be controlled by consumers and their carers:

> “I would like for my information to be shared where I want my information to be shared, and if I’m available at that region or that state at that point in time and I want to visit the hospital, it would actually be a lot easier for me. And I think it would put me on the front desk, based on the fact that my condition is kind of critical.” – Participant 12

Participants also added that while they were supportive of sharing their health information they also wanted to ensure that their information was kept secure and access was limited to their relevant care team:

> “I don’t particularly want it to be a free-for-all because we’ve all heard the hacking stories… I’m kind of on the fence, but the reality is that I have to share information. I have a GP that I visit (interstate) when I go for holidays and I’ve been to them three or four times. I gave them permission to ring my GP and my specialists so they can have an informed opinion about how they’re going to treat me so they’re all talking the same language.” – Participant 18

For many participants expressed concern about understanding and having transparency over how their health information is managed and shared particularly given recent data hacking and breaches:

> “I want some very clear communication and honesty about how far the information goes, who does have access to it. And I’m perfectly okay with de-identified data being released to other people but information that identifies me, I want to know where it goes, especially health. As I said Canberra’s too small of a place.” – Participant 6

4. Consumers are able to access care and support and manage their health in the ways that suit them best.

Participants spoke of the value of being able to manage their health and wellbeing in ways that suited them best. This ranged from having a balance between face-to-face and virtual care, different ways to hold their health and care information and accessing care in locations that suit them better.

For some participants this meant creating a mobile health workforce than can visit consumers in their homes. As one participant said:

> “There are times that maybe you feel you’re not really in the perfect health… it comes to a point when that happens, you really have to go and see the doctor and here you are feeling very sick. Moving becomes much of a problem. Maybe, if when it comes to such kind of extreme situations where I can’t really move, then I would prefer if maybe the doctor will come home and see me or send somebody to come and see me.” – Participant 16

Participants also talked about providing greater access to virtual care and care available in multiple locations across the ACT. One participant felt that an increased use of telehealth in the public outpatients system might help address many of the access issues faced by consumers.

For all participants having access to multiple services in more locations would reduce the burden of accessing the care they need the most. As one participant explained the care they accessed was across Canberra which involved hours of travel on multiple days as appointments were rarely scheduled on the same day.

Participants also spoke of the importance of having access to care that was inclusive and ensured people from diverse cultural backgrounds and people who are gender diverse felt safe and welcome to access care. As one participant explained they would prefer to access all their care needs with their primary care providers as they felt safe at that service. However they recognise this was not always possible as all their care needs could not be met by one clinician or service. This could be improved through having professionals that are trained to meet these needs or to provide rotational services at the primary care clinic that allow patients to access care in environments that best suit their needs. Such a model already exists in the ACT through the Aboriginal Controlled Health Service Winnunga Nimmityjah and once existed more broadly through locally-based ACT community health centres.

5. Care for chronic health conditions that is holistic and spans treatment, preventative care and promotes social and emotional wellbeing.

The lack of holistic care was an issue that was raised by some participants.

Participants described the 15 minute GP appointment model as care that did not provide holistic care. They described feeling rushed through the appointment and that they didn't always feel like their care was the priority. Rather participants talked of a 30-minute appointment model that allowed the GP to provide more holistic care for their needs:

> "I don't think consumers are given … enough [time] to talk about [what they need] – because when you go to see a specialist or GP, and sometimes you have more than one issue. But it's like maybe they rush you, they say – not directly, maybe indirectly they're giving clues that there's another patient waiting, you have to hurry, hurry. You have to hurry. But you are there, it's better they finish everything, right? And instead of going and then next week you book again because you have to come back because there's some unfinished issue you didn't get to finish with them." – Participant 4

Participants also spoke of the challenge of having to repeat their health information and story to each different health care provider or when their care provider changed. For many participants this not only created health related trauma but they also felt like their care was not a priority to their provider as they had not taken the time to read their existing medical file notes and care file. One participant explained how this created unintended harm when seeking mental health supports as when their care provider changed their treatment plan also changed even if it wasn't the most appropriate care plan for them:

> "But if [the new clinician] just sat down and had a read about how [the previous clinicians] were doing it; I know that they can do it a different way, but they should really fit the way that the client deals with and not train the client to do another way because that's just silly." – Participant 15

Many of the participants spoke about finding their health care team through their own research or through recommendations from friends and family members. For others their care team came from referrals made by one practitioner to another where a trusted relationship already existed. While this worked well for many others found this care to be limiting. They reported that it would be helpful if GPs and specialists knew about other health care services and support options available within the ACT and surrounding region. For participants having a range of care options available to them from their health provider meant that they would be able to receive care that was more appropriate and accessible for them. One participant in particular spoke about receiving a referral to visit a podiatrist that had an out-of-pocket cost of $60 when they already knew they weren't able to financially manage that cost. Another participant spoke about the limited acknowledgement of other supports and services to help them:

> "There's no talk about what assistance might support you in feeling a little bit better, like what alternatives can you use. And there's a limited view on how alternate medicine might help as well. You've got to snag the right person, otherwise it's like, 'well we're not going to talk about that stuff, they're really bad'…"- Participant 14

Other participants discussed how care for chronic conditions should include mental health support. For these participants their emotional wellbeing had significant impacts on being able to manage their physical health:

> "The first things that need to be fixed is your emotions because only by fixing your emotions you will be able to get going." – Participant 1

For participants addressing and supporting emotional wellbeing ranged from being informed of formal and informal community groups that may be able to provide that emotional support and understanding of managing their health conditions. For others this was also about providing information about mental health supports and services early and providing reminders of the services that are available. Other options may be other activities, like hobbies or social activities which are not directly health related but which are enjoyable for the person.

For some participants holistic care meant that preventative care needed to be prioritised. Within current health funding systems preventative care is not prioritised, and consumers often have out-of-pocket costs. For example one participant discussed how their primary condition impacted their teeth which required early intervention. However, due to the long waitlists in Canberra, they had to travel to a private specialist in Sydney for care or they risked losing their teeth. Another participant spoke about the lengthy waitlist to seek preventative care for their feet through the My Aged Care.

6. The health workforce better supports consumers to manage their own health or care as determined appropriate by the consumer over time.

Participants spoke about the challenges they face to manage their health and wellbeing from not knowing how to navigate the health system to managing the logistics of their health conditions.

The suggestions participants provided included:

- **Providing case managers and care navigators** for participants who are newly diagnosed or seeking a diagnosis. The case manager could support consumers to navigate the system from knowing who to see, what questions to ask at appointments and support them to develop the literacy, confidence and skills to manage their conditions on their own. The case manager or navigator can also be an essential person for making and managing appointments for consumers when this support is required and for facilitating the sharing of health information across health care providers. One participant spoke of the assumption that is held by consumers and health practitioners alike that their GP will help them to manage their health and communication. They discussed the challenge of this being that GPs are often managing many patients with multiple care needs and are often constrained by time. They can be further hindered by the lack of communication and information from other specialists as information can take months to receive:

> "It'd be good if one could engage a Case Manager to look after everything and make sure I've got my meds, my appointments without me having to repeat myself across 12 medical providers and ancillary services" – Participant 8

For some participants the case manager is particularly important for when consumers are at their 'least able'. At these times they need support to be able to gather the relevant information for their appointments and manage their condition.

- **Increasing the use of nurse practitioners** across outpatients, community clinics and general practices. In some services, like Walk-in Centres, nurses are specifically excluded from chronic care and this provides another avenue which could be expanded for consumers. One participant explained that a nurse practitioner could provide some advice while waiting for specialist appointments or be able to discuss test results before an appointment where it was appropriate. This would help to improve access to care for consumers and potentially reduce anxiety while waiting or even reduce wait times:

> "I would like to see nurse practitioners used more in the outpatient unit at the hospital, as someone available to maybe speak to and have telehealth and stuff like that. Obviously, not at all as a substitute for your specialist, but maybe in addition to, for example, with the waiting times and things. I think that would be an awesome way to still have people to speak to about things." – Participant 17

7. Wait times for accessing care are reduced and made transparent.

Every participant we spoke to who accessed their health care through the public health system spoke of the frustrations and the challenges of waiting times and wait list management.

Firstly, participants spoke about the lack of transparency of the wait times and when appointments would be scheduled with their relevant specialist. To combat this participants spoke of having to constantly phone the Central Health Intake to try and confirm their appointment only to be told that they would be contacted when their appointment is made. The waiting time when consumers access the Central Health Intake line can also be excessive with wait-times of up to 20-30 minutes being reported before their call was answered by someone. This is inadequate service.

This lack of communication and transparency around wait times at services also creates frustration and anxiety for patients as they can’t plan to take time off work for their appointments. It also impacts their ability to plan work, social engagements or family commitments because they don’t know when they will get an appointment. For some participants this frustration is exacerbated when the appointments are cancelled or rescheduled at late notice. It can feel like services have not thought about the impact of delays in a long-awaited scheduled appointment on the consumers and carers’ lives and the stresses these impose on them.

Some participants also spoke of the frustrations of the lengthy waitlists and the lack of transparency and efficiency of triaging waitlists and the direct impacts it has on their health. Participants discussed the mismatch in the expectations of follow up with their specialist and the reality of when they next saw their specialist. As one participant explained:

> “If for example the doctor says ‘I'll see you in three months’, then let it be 3 months or I can agree if it's four months. But three months turns out to be a year or more than a year, that's not acceptable. At least I can plan 3 months, but 12 months?” – Participant 7

Another participant described how their health continued to decline while waiting to see their specialist despite updates and new referrals from their GP. Neither they nor their GP received any communication or information about wait times or when their appointment would be.

Managing long-term health conditions: experiences, considerations and strategies

Health care not integrated for consumers unless done by themselves

Most participants did not feel their care was integrated**.** For the few who felt their care was integrated it was purely through their own effort that care was integrated.

The findings below describe the experiences of the participants in managing their health. For the purposes of this research consumer management of their health may start with their first diagnosis or their efforts to be as well as possible over an even longer period.

Knowledge of services and supports impacted on management

For all participants deciding how they managed their long-term health was impacted by their own and their clinicians' knowledge of what services and supports were available to them followed by accessibility. This included the costs of care, location of the service and access to transport and how long the wait is to get an appointment.

Following a diagnosis participants described managing their health in several ways. Often this started with a conversation with their GP or other medical specialist about their health condition, its implications and treatment and management options. For most participants this included getting referrals for specialists and/or allied health care to receive education or further treatment for their condition(s). Participants also spoke about conducting their own research into their health needs and finding out about other services and supports available to them.

Participants found services and supports by themselves

For the majority of participants many of the services and supports they used were found as a result of their own research, discussions with friends and family and incidental conversations with care providers:

> "Every health service I have used or accessed has been self-initiated. I didn't find out about any support services from other care providers. There is no integration and continuity of care doesn't exist. There is also no real explanation of the breadth of services someone can provide. There is an assumption that you know what to do or where to go." – Participant 11

Costs influenced access to care and support

Cost was a key consideration for many participants in choosing how they managed their health and where they got care and support. For many participants the out-of-pocket cost of accessing specialist care meant they often had to see clinicians within the public health system which incurred longer waiting times but did not involve high out of pocket costs. For some participants out-of-pocket costs meant that they would forgo non-urgent care, such as allied health care or preventative care, while for others it was about balancing their care across the public and private systems:

> "My GP has given me (referrals) through some public systems. But I balance. If it's urgent I pay up." – Participant 19

Relationships with health providers influence how and where to access care

Some participants placed a higher priority on their personal preferences and the relationships they had with health professionals when deciding how and where they get care and support. For example, one participant talked about how their GP was in a different part of Canberra to where they live and work but they were willing to travel as they felt they were getting the best care from that doctor. Another discussed how they were happy to pay out-of-pocket fees for their GP as they had a good relationship with them and felt they received high quality care. In contrast one participant reported selecting their GP due to them offering bulk billed services and proximity to their home making care more accessible by reducing costs and the need to travel.

Challenges in making appointments and coordinating care increase with condition complexity

Participants faced the challenge of making appointments and coordinating their care after getting referrals for testing or to see other clinicians from their health care provider. As the complexity of their health needs increased the number of specialists and services participants engaged with often also increased. It also meant an increase in the amount of routine testing they would need to undergo to monitor their health. One participant described accessing at least 9 services and specialities and requiring pathology and radiology services every 3 and 6 months to monitor their health condition.

Coordinating care takes time

Coordinating care meant that a significant amount of participants' time was spent trying to make appointments to see their relevant clinicians. It also involved juggling multiple referrals for pathology or other tests. Participants also talked about collecting the results and ensuring they were shared with their clinical team which often also required multiple phone calls. For one participant sharing test results with a specialist they saw privately meant that they had to personally collect hard-copy reports from the hospital as there was no integration of communication systems to support sharing of information across public and private specialists.

Location of care is chosen by proximity and transport costs need to be budgeted

Participants had to consider the logistics of travelling to and from the various health service locations to attend appointments or for routine tests. Many of our participants discussed that they chose care providers who were within easy reach of their home to minimise the need to travel. However for some accessing the care they needed required traveling to different parts of Canberra or even interstate. For these participants travel meant additional costs incurred including accommodation, fuel and parking that they had to budget for. Some participants experienced additional stress due to their reliance on public transportation as missed transport connections could impact their appointments. While a couple of participants discussed being eligible for and using community transport services to attend appointments they also discussed the challenges of using this service. They had to book well in advance, had limitations around the hours of use and the service was sometimes unreliable which had impacts on attending appointments:

> “It's hard because I don't have a car and sometimes when your appointments are not on pay weeks, you have to try and negotiate transport, and sometimes the transport either rings up really late or they don't come at all... So it's hard to try and get things done” – Participant 15

Carers play an important role in support & access to care

While some participants had family members to support them many did not and those without family or friends to assist them discussed the additional challenges of accessing the health care they needed. Participants spoke about having to rely on friends and family to support them to attend appointments or to pick them up and take care of them following discharge from hospital and creating burdens on family and friends.

Health literacy affects ability to optimise health

Pre-existing knowledge of the ACT health system and levels of health literacy had an impact on participants’ ability to optimise their health. When participants saw their respective care providers they spoke about needing the ability to effectively describe and explain their diagnosis, symptoms and treatment and have the literacy to understand what their health professional was discussing with them.

Consumers carried their health information with them to each provider

Almost all participants spoke about how they carried their own health information across each care provider they saw to ensure that each professional had complete and accurate information about their health and care plans. Participants talked about how with each doctor they often found themselves repeating their health story despite the doctor already having this information. For participants this repetition added frustration and created health-related trauma and for others it delayed care. One participant reported that even though they had previously given a full history and developed a treatment plan with another physiotherapist at the same clinic they were still required to pay for additional appointments with a new physiotherapist to provide a full history and develop a plan. This caused frustration, added to cost of accessing care and ultimately caused a delay in getting the care they needed.

Self-advocacy requires health literacy and confidence

Self-advocacy was a key theme that emerged when participants discussed accessing the care they needed and managing their health. However ths ability to self-advocate was often reliant on their health literacy, their confidence and being well enough to advocate for themselves. One participant described having to stop clinicians prior to receiving treatment to ask why it was necessary and for alternatives as this wasn't provided. Similarly another participant talked about having to push for alternatives with clinicians because a procedure that had previously had negative impacts was still being performed despite being noted in their care notes.

Integrated care driven by consumers not health providers or health systems

The participants who reported their care was integrated and they were managing well felt it was a result of the work that they have put in to integrate it. Participants talked about the time and energy they had to invest into building relationships with their care providers and their persistent efforts to support and facilitate coordination and collaboration among their care team. For many participants managing their own care took a heavy toll on their personal lives. For some it had negative impacts on employment or being able to do other activities such as volunteering or caring for others as they were unable to be able to be consistent with their time or had to take a lot of time off to attend appointments. For others spending hours on the phone making and following up appointments, left them with even less time to relax or spend with their families and friends.

Participants managed administration of their health condition(s)

For the participants who were less satisfied with their care integration they had to integrate their own care. Participants managed their health in different ways. Some used apps to record all their appointments, medication, health information and anything else they needed. Others kept comprehensive binders with medication plans and some used a combination of technology and hard copy systems. One participant discussed how they channelled their professional background and training into developing a system that helped track and manage their appointments, medications and track and monitor their symptoms. Participants took this information to each appointment to ensure the same information was shared across each care provider. One participant spoke about taking their referrals for pathology testing to each provider so they could add to the existing request and minimise duplicate testing.

Aged and disability support systems added to the burden of managing their conditions

For some of our participants the complexity of managing their own care was complicated through their use of Commonwealth government funded support packages such as My Aged Care or the NDIS. These supports which have been developed to support older adults or those with disabilities to better manage their care often added to the work they needed to manage their care.

The participants using the NDIS described the number of forms they needed to complete to even be eligible for support. However to ensure that they would be accepted by the NDIS and receive support one participant put in a significant amount of work in developing templates of letters and documents for their doctors to complete. They described the differences in the language used by their medical specialists and the language required by the NDIS. This mismatch often meant that accessing funding for their care would often be delayed because administrative processes would need to be redone.

Similarly the participants who used My Aged Care discussed the challenges of accessing the supports they needed through aged care packages. For some of our participants accessing certain home care supports meant that they had to call and obtain quotes from providers for the care they needed and organise it all themselves creating additional burden.

Working out integrated care & doing it for themselves

What was common amongst all participants was that they had to work it out for themselves regardless of how they managed their health service needs,. The participants highlighted that they did not receive any support to coordinate and manage their health needs and had to work it out for themselves and advocate for their own care at times when they were least able:

> "To be able to manage your own health when you have so many conditions you need to be a note-taker. You need to note down the time, date, who you saw, what they said and make notes of everything so you can remember what happens and take charge of your health. But we are expecting people to do this when they are unwell and already struggling to cope. I can do this because I am able to. I can also look after myself. But imagine how hard this is for someone who doesn't have that health literacy or needs the support or who is really unwell." – Participant 11

Participants also discussed the impact of managing their health on their lives. They often spoke of needing to take time off work to get to appointments or having to stop working completely to be able to manage their own health.

While some participants described as having family members to support them many did not and discussed the additional challenges of accessing the health care they needed.

The individual needs and circumstances of consumers mean that managing their chronic health conditions is complex and varied. Where they are only given the option of managing it all themselves it takes a lot of time, effort, knowledge and understanding to do it well. As one participant neatly explained:

> "You need a degree in management to look after your health" – Participant 18

Similarly the silos of care and support continue to exist in a vacuum. Providers often appear to not to know of each other's existence. There are frequently no formal links between the individual services to make sure that they are best able to meet the needs of the consumers they are supposed to serve. This often results in gaps and duplications neither of which are creating an effective nor efficient system for consumers.

COVID impacts

We asked participants how the COVID-19 pandemic had impacted their care or the way they accessed their care.

Self-protection

During the pandemic the general population was asked to take many precautionary measures to avoid transmitting or becoming infected with the virus. This included isolating and avoiding public places where possible, wearing masks in public areas and practising proper hygiene. Participants felt the risks of getting COVID-19 and potential negative health impacts were higher than the limitations placed on them through measures required by the Public Health Emergency and this was felt particularly by those who were immunocompromised and/or had lung conditions. Some participants described the extra limitations they placed on themselves to reduce the risks of getting COVID-19 such as limiting their movements by reducing contact with their family and friends as well as reducing the number of in-person doctor's appointments.

Covid impacts on mental health and isolation

Multiple participants described the negative impact of COVID-19 on their mental health which stemmed from the anxiety around the disease and exacerbated by feeling isolated when trying to protect themselves.

Virtual care reduced travelling time & costs and avoided crowded waiting rooms

Participants spoke of the changes to accessing their regular health care from in-person appointments to virtual appointments as part of the COVID-19 precautionary measures.

For some participants the change to virtual care proved to be a boon. It reduced the amount of travelling they needed to do to access care or it meant that they could wait for their care provider at home in a more comfortable environment than in crowded and noisy waiting rooms. As one participant said:

> "My psychiatrist said it's the best thing for me because I didn't have to deal with people, and I didn't have to go out. COVID suited me down to the ground given my medical conditions. When I have to engage and go out more, it creates problems." – Participant 8

Participants also discussed that while virtual appointments for some circumstances were welcome they felt virtual care was not always appropriate. For some participants managing care remotely was very difficult as they often needed their care provider to be able to assess their health physically and visually. Participants also spoke about the challenge of discussing test results and asking questions over video conferencing or telephone rather than in-person. Virtual care worked better when participants had a good relationship with their care provider and knew that they understood them as a patient and their circumstances. This made it easier to communicate and trust their care. As one participant explained:

> "I wouldn't want to do it every time. And I wouldn't want to do it if I didn't have a really good relationship with the practitioner, but we did and so that was fine. If it was with this new one now..., we don't have that kind of relationship with her, so we would want to do it face to face until we got to know and trust her as well." – Participant 9

The rapid changes to care during the acute phase of the pandemic meant that the consistency of administrative processes was not maintained properly. One participant described how their annual follow up with their specialist was not automatically scheduled as was done when attending appointments in-person. This oversight led to delayed care as the participant was not able to attend the appointment within their scheduled time and were then delayed due to waitlists.

Impact of integrating care

We asked participants to describe the impacts integrating care would have on their health and wellbeing.

For all the participants integrated care would lead to positive outcomes for their overall health, general wellbeing and quality of life.

Participants explained that improving communication between their health care providers would mean that they would see a faster overall improvement in their health and wellbeing as they would be able to effectively plan and manage care across all their health needs and speed up and improve health outcomes:

> "For me, the optimal would be if I could make an appointment and see Dr A, Dr B, Dr C and whoever in one day - in one consultation, at the same time, nut it all out in one go. No-one's to-ing and fro-ing letters, chasing things up over a number of months to try and get one outcome. Because you get an outcome on one of my conditions, it always impacts on the others, so it needs to be an integrated treatment." – Participant 18

As discussed above many participants described the amount of time and effort needed to manage their health and wellbeing which placed significant strains on their mental and emotional wellbeing. Integrated care would reduce much of the burden on the individual to be the integrator of their health care:

> "it's going to be like lifting of weights off my shoulders because I wouldn't have to make sure I keep updating the GP, the doctor, or the community health centre, anyone I find myself and try to get treatment. It saves a lot of time and the stress of having to talk about it all over again." – Participant 13

Additionally integrated care would mean participants could focus on getting better rather than on administration of the health system. They wouldn't need to spend their time and mental energy on securing appointments, remembering appointments and documentation. Integrated care could reduce the need to travel repeatedly for tests, appointments or documents. Integrated care would also reduce the burden of cost that is placed on consumers.

Participants also recognised the impact that integrated care would have on their care providers:

> "Eventually when everything is brought together to a point, accessing them becomes easy. It's less strenuous (on me), it's less strenuous on them and recovery speed becomes so quick and it saves on time, and probably, costs also." – Participant 16

Overall, integrated care for participants meant that the burden of managing their health was reduced and they would be able to manage their health better and see better outcomes:

> “If my care was integrated when I went to hospital with a broken thigh, everything would have happened without me asking. I would have been seen by a dietician and the social worker without me seeking them out. I would have been seen by the physiotherapist without needing to make a complaint first. There would have been better timing with being given my medication and pain relief and seeing the physiotherapist.” – Participant 11

Summary of Findings

These conversations with consumers have very clearly highlighted that care for consumers is not perceived as integrated. They highlight that the health system is regularly failing to address the burden faced by consumers involved in managing and maintaining their health outside of what happens in the doctors or clinician's offices.

The burden of overseeing, organising and integrating their health care falls on consumers (and their families and carers) who are living with the day-to-day consequences of chronic and complex conditions. Consumers are regularly spending their time trying to make appointments, collecting health records and rearranging their personal lives to accommodate health services to maintain their health because there is no consistent person-centred approach to support and care provision within the ACT that can help to reduce this burden.

These findings are consistent with the feedback reported in the consultation commissioned by Canberra Health Services (CHS) around designing ACT Health Services[16]. The outcomes of the consultation identified that for consumers integrated care was about "multiple healthcare providers communicating and working together to deliver the best possible healthcare to a patient" (p.15). The consultation identified that consumers found it difficult to navigate the health system and coordinate their care. The challenges included administrative burden, access to transport to get to services, cost of services and a lack of communication across health service providers all of which were confirmed by the present research. Consumers also discussed the excessive wait times for services as impacting the quality of the care they receive.

The relationship between physical and mental health that was discussed by participants raises an essential component of providing integrated and holistic care. This finding aligns with those of a 2017 study[14] where consumers discussed the influence of mental health and physical health on each other and the value of communication among mental health and primary care providers in understanding their complete health needs.

Many of these findings correlate with the findings of the Integrated Care: Conversations with Service Providers in the ACT and Region report. Consumers and service providers alike discussed the need for better communication and information sharing amongst service providers to support integrated care. They also discussed the need for improving communication and information sharing with consumers and carers to help support integrating care.

The findings of this report show that the key challenges consumers face when accessing and managing their health is consistent with what the service providers perceived their challenges to be. This consistency is important as it shows that service providers are aware of the issues that their clients face when trying to manage their health and wellbeing. However, this also highlights the key challenges that should be addressed by the health and social systems to support individuals living with chronic and complex health conditions.

What does this mean for integrating care in the ACT?

To achieve meaningful consumer-centred care and care integration, health care and social support services across the public, private, community and NGO sectors need to work together to meet the needs of consumers as discussed above.

Consumers living with chronic health conditions and complex health needs require the health system to adapt their models of care to meet their needs. The consumers we spoke to require their health care providers to:

- Provide holistic care that meets their needs across stages of life and as their health care needs change overtime. This means understanding the person, their life circumstances, their overall health status and their knowledge and ability to care for themselves and manage their health; and
- Have an in-depth knowledge of their health condition and options for treating and managing health as well as comprehensive knowledge of other services and supports that can help.

Additionally consumers living with chronic health conditions are regularly engaging with the health system and need the system to adapt and innovate to make managing their health easier. This includes:

- Supporting consumers and their carers to navigate the health system and access the right care at the right time;
- Creating a truly holistic health system in the ACT that not only supports treatment and management of chronic conditions but also supports managing health across the life span. This holistic care supports easy and low-cost access to preventative care and care that supports strengthening social and emotional wellbeing;
- Having an effective system for managing changes in health and social circumstances so consumers can get timely access to assistance and not risk exacerbation of their condition;
- Improving the waitlist system within the public health system. The findings of this report have clearly shown that for consumers using public health services there is a distinct lack of communication with consumers about how the triage system works, the level at which they have been placed and how long they may need to wait. The opacity of waitlists for consumers and uncertainty creates further stress and anxiety, exacerbating their illness;
- Improving appointment systems to allow consumers to coordinate and streamline their care easily;
- Increasing the use of virtual care to provide greater access to health care for those consumers who prefer it; and

- Improving communication systems and incentivising multidisciplinary communication and collaboration for practitioners to provide holistic care. This also includes improving communication between practitioners and their patients to support improved care and information sharing.

These findings demonstrate the need for greater work to be done around supporting health literacy, addressing communication barriers across the health system and improving collaboration among public, private and community services.

Methods

This is a qualitative research project that elicits consumers' understandings and perceptions of integrated care and their experiences of managing their chronic health conditions through semi-structured interviews. This study was approved by the ACT Health Human Research Ethics Committee (reference number: 2022.ETH.00135).

Participant eligibility and recruitment

To be eligible, participants had to:

- be at least 18 years old;
- self-identify as having at least one chronic health condition;
- access three or more health or community services to manage their conditions;
- live in the ACT or the surrounding areas of NSW; and
- and have access to the health care and community services they need.

An invitation to join in the study was widely disseminated through HCCA networks, newsletters and bulletins issued by community organisations that focus on chronic conditions and broader community publications. The invitation outlined the aim of the project, eligibility criteria and what participants could expect when participating. Participants received a $50 gift card on completion of their interviews to encourage participation and to recognise the time and efforts involved in contributing to the project. All participants provided informed consent prior to enrolment in the study.

Data collection and analysis

Data for this project was collected through 20 semi-structured, one-on-one interviews. The interviews were conducted from November 2022 to April 2023 and were conducted by the lead researcher. Based on participant preference the interviews were conducted either in-person, via telephone or online via Zoom.

The conversations focused on:

- participant knowledge and perception of what integrated care is and what integration of care would look like for participants and the impact this may have on them;
- how participants manage their care across multiple services and providers across the ACT; and
- participants' experiences with accessing care and/or services during the COVID-19 pandemic.

Interviews were recorded and transcribed using a portable audio-only recording device or on Zoom. This was done with participant's permission and in accordance with the privacy and confidentiality precautions indicated in the participant information and consent form. One participant did not consent to recording and handwritten notes were taken and transcribed by the lead researcher.

NVivo software was used to analyse the transcripts and were categorised into themes. The interviews were coded by two coders and in two rounds. The first round of coding was based on the predetermined codes that were guided by the research questions and to identify new themes or sub-themes from the transcripts. The predetermined codes were:

- understanding of integrated care;
- current experiences of managing care;
- what is involved in managing health;
- impact of COVID-19 on health and health management;
- how care can be integrated; and
- impacts of integrated care.

Following the first round of coding the two coders reviewed coding on 5 transcripts to ensure consistency.

Participants

20 adults took part in interviews for this project. 11 participants identified as female and 9 identified as male. Participants were all over the age of 20 (Figure 1.)

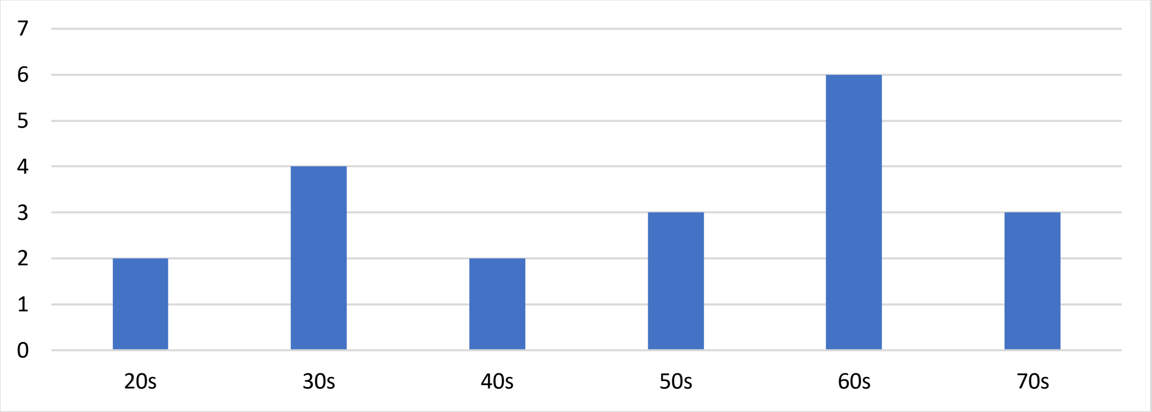

Figure 1. The number of participants by age in decades.

One participant lived in the Yass Valley region of NSW, north east of the ACT. The remaining participants were spread across the districts of Belconnen, Tuggeranong, Woden Valley, Central Canberra and Gungahlin. One participant identified as Aboriginal and Torres Strait Islander and 5 participants described themselves as having a culturally and linguistically diverse background including from African, Latin, East Asian and multiethnic backgrounds.

Participants in this project identified the chronic conditions they lived with:

- Asthma
- Osteoporosis
- Depression
- Anxiety
- Arthritis
- Diabetes
- HIV
- Acquired brain injury
- Cancer
- Hypertension

- High cholesterol
- Parkinson’s disease
- Panhypopituitarism
- Ankylosing spondylitis

Participants also described a range of chronic conditions they also suffered from as a result of their conditions and management of their conditions which included organ failure, eye conditions, chronic pain and loss of immunity as a result of treatment.

Two participants also self-described as being a carer for a person with chronic conditions and complex care needs.

Participants accessed a range of services and supports to manage their health. These included: General Practitioner (GP), medical specialists, nurse educators, government-funded community-based programs for managing health and wellbeing, services from specialist non-governmental organisations and informal support from condition specific community groups and forums (e.g. Facebook social groups). Three participants were accessing services and supports from the Commonwealth My Aged Care program and 2 participants were accessing support packages from the National Disability Insurance Scheme (NDIS).

Limitations

This project is a qualitative study of consumer s’ understanding of integrated care and their experiences of managing their complex/chronic health conditions. As such it is focussed on exploring participants thoughts, feelings, perceptions and experiences in-depth. Semi-structured conversations were conducted with twenty adults most of whom were over the age of 50. The findings should not be read as representative of the experience of all adults living with chronic and complex health conditions in the ACT and its surrounding region. However, there was strong consistency in the issues and concerns for participants. Additional work will need to be undertaken to explore the experiences of younger people living with chronic health conditions.

A second limitation to these findings is that only one participant in this project resided in the surrounding regions of the ACT. Further work will be needed to fully understand the health experiences and needs of adults living with chronic health conditions who live outside the ACT.

The findings of this project do include the use of the ACT Digital Health Record (DHR) initiative which was launched at the beginning of our recruitment and interview process. The Digital Health Record was designed to support the integration health information across the ACT public health system and support access to information and improve patient care. It is worth noting that the timing of our project may have influenced the findings and these results may have varied if the project were conducted in 2024. The DHR may have introduced changes and effects that could have a significant impact on our findings. Therefore a future study on the impact of the DHR for people with chronic and complex conditions may be required for a deeper understanding.

Appendix A: Context for Integrated Care in the ACT and region

Integrated, patient-centred health care has been a policy objective in all Australian states and territories since following a Council of Australian Governments (COAG) agreement in 1995. Over the years many different health strategies, reforms and commissions and various programs have attempted to highlight the need for and tried to achieve integrated care.

On the national stage, there have been a myriad of strategies and programs developed to improve care integration, which includes:

- The National Health Strategy 1990-1993;
- National Health and Hospital Reform Commission 2007;
- National Primary Health Strategy 2010;
- National Primary Health Care Strategic Framework 2013;
- Primary Health Care Advisory Group 2015;
- Coordinated Care Trials; and
- Health Care Home Program Trial 2015 – 2021

The goals and outcomes of many have of these have been summarised in a 2021 report by Tito Wheatland[17].

Since this work we have seen further work been undertaken nationally to integrate care for consumers with chronic and complex health conditions including:

- National Strategic Framework for Chronic Conditions 2017-2025[8]
- National Health Reform Agreement 2020 – 2025[18]
- National Guidelines to improve coordination of treatment and supports for people with severe and complex mental illness 2022[19]
- Urgent Care Clinics 2023[20]
- Primary Care Pilot 2023
- Partners in Recovery 2011-2016[21]
- My Health Record 2019[22]
- MyMedicare Program 2023[23]

During this time the ACT has also developed more localised strategies and initiatives to integrate care for the residents of the ACT and the surrounding region. These include:

- ACT Chronic Conditions Strategy – Improving Care and Support 2013-2018[24]
- Chronic Conditions Working Group (CCWG) was established in 2019-2022
- ACT Health Digital Health Strategy 2019-2029[25]
- ACT Health Services Plan 2022-2023[26]
- ACT Health Directorate Strategic Plan 2020-2025[27]
- Canberra Health Services (CHS) Strategic Plan 2020-2023[28]
- Framework for the ACT public Health System 2020-2030[29]
- Canberra Health Services Integrated Care program including

  - Paediatric and adult patient navigation and liaison services
  - Walk-in centres
  - Health hubs
- Canberra Health Literacy Network
- Atlas of mental health care in the ACT ongoing from 2016[30]
- myDHR electronic health records management 2022

The national and the ACT electronic health records management tools were developed to allow consumers easier access to their own health information and to support the transfer of health information between their healthcare providers and to support information transfer for care integration and meet the national safety and quality health service standards[31].

Recently the ACT state budget supported the development of a Patient Navigation Service (PNS) to better coordinate care across the health system for people with chronic and complex conditions or who are vulnerable or disadvantaged. The service will work across the public hospitals, general practice and community-based services to provide support for people with chronic or complex health needs who find it difficult to navigate the system.

These trials, services and programs have all attempted to integrate care for consumers to varying degrees of success. The evaluation of the Health Care Homes (HCH)[32] trial highlighted that the trial allowed for better access for care planning and chronic disease managed through changes to chronic disease management at practices. However the overall success of the trial was hindered through limitations around implementation. The evaluation found that there was a lack of time for practices to set up, lack of adequate tools and resourcing to meeting the operational needs for the trial which included inadequate funding for clinicians.

The HCH trial highlighted that for individuals with chronic health conditions the full impact of chronic disease management programs can only be measured over the medium to long-term. This is also a critical challenge for national and local strategies and programs and trials trying to effect positive change by integrating care for those with chronic and complex health conditions. A chronic health condition by definition is a condition that is long-term or recurring and many of these strategies and programs are often not planned, implemented and evaluated over the medium and long-term to realise the true benefits and lessons of integrating health care for people with chronic and complex health conditions.

A 2020 report from the ACT Auditor General[33] has found that between 2013 and 2020 strategies like the ACT Chronic Conditions Strategy 2013-2018 have not created any change or impact on existing services or in creating new services or projects. The report also identified that the partnerships and collaborative work that ACT Health Directorate had participated in had limited success in undertaking shared care planning, equal commitment, taking joint responsibility and developing high levels of trust. The report however identified that the collaborative work between the ACT Health Directorate and the Capital Health Network to develop and deliver integrated mental health services had been an effective partnership and described as truly collaborative.

The ACT health system is well placed to become a national model for integrating health care. However, there still remains room for improvement. While there are a lot of models and elements of integrated care that have been trialled and evaluated, integrating and coordinating care for people with chronic conditions and complex care needs to adopt a more flexible approach that can go beyond a single-disease focus. A 2018[34] review of the models and elements of integrated care for multimorbidity found that many evaluations of models focussed on the clinical (micro) and organisational (meso-) integrations of the model and did not discuss the systematic (macro) environment. They also identified that elements relating financing and use of technology and medical products were not as frequently discussed as elements like service delivery or workforce, highlighting a potential gap in the understanding of elements that make care integration successful.

The evaluations of programs like the Partners in Recovery Program, the Health Care Homes Trial and the ACT Auditor General’s report on management of care for people living with chronic conditions identify challenges that occur at a systemic level. The evaluations outline clear and consistent recommendations on how to achieve positive change in the integrated care space which need to begin at a systemic level with elements such as financing and supporting infrastructure that is sustainable for supporting long-term integration.

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