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## Medical homes and chronic care: consumer lessons for regional Australia

Mary O'Loughlin<sup>A,D</sup>, Caryn West<sup>B</sup> and Jane Mills<sup>C</sup>

<sup>A</sup>College of Public Health, Medical and Veterinary Sciences, James Cook University, Cairns, Qld 4870, Australia.

<sup>B</sup>College of Healthcare Sciences, James Cook University, Cairns, Qld 4870, Australia.

<sup>C</sup>La Trobe Rural Health School, La Trobe University, Bendigo, Vic. 3552, Australia.

<sup>D</sup>Corresponding author. Email: mary.oloughlin@jcu.edu.au

Medical home models of care, including Australia's Health Care Homes, have the potential to improve health service delivery. This qualitative study explored the primary healthcare experience of people living with chronic conditions in a regional community. The study aim was to use consumer perspectives to inform the further development of a medical home-type model for regional Australia. Participants were recruited from the emergency department of a north Queensland hospital. Twenty-one adults (aged  $\geq 18$  years) participated in interviews, using a semi-structured schedule. Inductive, deductive and abductive analyses were guided by grounded theory methods. Participants were committed to an individual GP, rather than a practice organisation. This finding has implications for medical homes, as individuals may choose not to access team-based practice care. Most participants perceived they currently received high-quality GP care, although challenges were identified. These challenges included disconnected after-hours care and uncertainty around the cost of care. Those living with complex, uncommon, chronic conditions felt the most disenfranchised from existing care models, and could benefit from increased engagement with a medical home-type model. Strengthening the continuity of care between GPs both within and outside the practice may enhance service delivery. Involving consumers in the design of care models supports health services that are fit-for-purpose.

**Keywords:** general practice, Health Care Homes, patient experience, primary care, rural, voluntary patient registration.

### Introduction

Worldwide, there is an ongoing need to strengthen health systems to support an ever-increasing number of people who live with chronic conditions (Australian Institute of Health and Welfare 2018). A range of models have been proposed that outline strategies to improve chronic care by implementing systems that improve accessibility and coordination of care; utilise technology to enhance data collection and sharing; and promote a person-centred care philosophy with an emphasis on consumer-practitioner care partnerships (Grover and Joshi 2015). Medical home models of care, in which people commit to a primary care organisation for their care management, are increasingly being implemented in several countries including the USA, New Zealand and Canada (Green *et al.* 2012; Commonwealth of Australia (Department of Health) 2016; Australian Government Department of Health 2019). In 2015, the Australian Government's Primary Health Care Advisory Group identified a medical home model as one solution to improving care for people living with chronic conditions (Commonwealth of Australia (Department of Health) 2016). Based on the American Patient-Centered Medical Home (O'Loughlin *et al.* 2017) and derived from Wagner's Chronic Care Model (Green *et al.* 2012), Australia's Health Care Homes (HCHs) aim to establish a medical home base for chronic condition care management (Australian Government Department of Health 2019). Aligning with the quadruple aims of high-performing primary healthcare systems: to

improve population health, improve patient experience, reduce the cost of care and improve the wellbeing of practitioners (Bodenheimer and Sinsky 2014); key features of the HCHs model are outlined in Fig. 1.

In Australia, HCHs were trialled across volunteer General Practices and Aboriginal Community Controlled Health Services from 2017 to 2021 (Australian Government Department of Health 2019, 2020). Although over 10 000 people living with a chronic condition were enrolled in the trial (Australian Government Department of Health 2020), this number was significantly lower than the 65 000 projected at commencement (Health Policy Analysis 2019). Evaluation indicated that people appreciated some aspects of the HCHs model, including increased access to practice nurses and improved care coordination for routine requirements, such as repeat prescriptions (Health Policy Analysis 2019). However, the model has been complicated to implement, with consumers having difficulty understanding the model's purpose (Health Policy Analysis 2019). Evaluations of the American Patient-Centered Medical Home identified similar consumer concerns (O'Loughlin *et al.* 2017). Further, most HCHs trial participants were previously known to the practice, and many believed their GP already actively managed their health before the introduction of the new care model, potentially limiting the perceived trial effectiveness (Health Policy Analysis 2019). Despite these challenges, the Australian Government is committed to progressing the implementation of the medical home model through the expansion of voluntary patient registration systems and blended payment funding models in primary healthcare (Commonwealth of Australia (Department of Health) 2021).

Chronic conditions are more common in Australia's regional areas than in major cities (Australian Institute of Health and Welfare 2020a), with high rates of diabetes, coronary heart disease, hypertension and chronic obstructive pulmonary disease documented (Northern Queensland Primary Health Network 2019). Opportunities to create positive change by empowering regional consumers to inform the delivery of health services are needed (Bourke *et al.* 2010). For people living with chronic conditions, considering their region-specific context in planning health services provides an opportunity to collaborate and rework current models of care to one that is fit for purpose.

The aim of this study was to explore the primary healthcare experience of consumers living with chronic conditions in a regional community; and identify how this experience might influence the future expanded implementation of a medical home model in Australia. This study was undertaken in a community that is not a HCHs trial site. By examining this proposed model of chronic care with healthcare consumers before the Australia-wide rollout, this study is an example of how healthcare systems can be informed by the people who will use them.

## **Methods**

This qualitative study is part of an ongoing mixed-methods project. This phase of the project explored consumer views on the delivery of health services, with a focus on adults living with chronic conditions and their perspectives on the HCHs model. Ethics approval was obtained from the Far North Queensland Human Research Ethics Committee (FNQHREC; HREC/16/QCH/81–1068).

### *Recruitment and study sample*

Study participants were recruited from a previous consumer perspective survey conducted inside the Emergency Department (ED) of the Cairns Hospital in far north Queensland. This 2014 project examined people's rationale for their ED visit (ethics approval HREC/14/QCH/9–887 LR; results reported elsewhere; O'Loughlin *et al.* 2019). As

part of this previous survey, respondents indicated their potential interest in future research participation and provided their contact details. It was from this group that interview participants were recruited. Inclusion criteria involved adults (aged  $\geq 18$  years) that had self-reported they were local-dwelling and had a long-standing or chronic condition ( $n = 124$ ).

Initial recruitment used purposive sampling (Braun and Clarke 2013), based on age, sex and type of chronic condition, with the intention to obtain maximum variation in the sample. Recruitment commenced in mid-2017 through to late 2018, 3–4 years post the previous project. Given the time lapse, 32 people were unable to be contacted, as their details were no longer current or they were deceased. All participants who responded and agreed to an interview were accepted into the study, with the exception of three people who reported not having a current chronic condition. The final sample for interview comprised of 21 people (response rate 24%) recruited by email ( $n = 6$ ), landline telephone ( $n = 4$ ) and mobile phone ( $n = 11$ ). Prior to study participation, all participants received and reviewed a Participant Information Sheet and Consent Form, and provided their written, informed consent.

### *Data collection and analysis*

For consistency, the first author (M. O.) conducted all interviews using a semi-structured interview schedule. Participants were asked to respond to specific HCHs model features to explore their preference and need for health service delivery. Face-to-face interviews were conducted in non-public spaces identified by participants; these were homes, workplaces and university rooms. Interview duration ranged from 25 to 75 min. Participants received a \$50 gift card in recognition of any inconvenience. Funding for these gift cards was sourced from the Far North Queensland Hospital Foundation through their research grants program.

Interviews were audio recorded and transcribed verbatim. Guided by a pragmatic mixed-methods approach, grounded theory methods were employed for data analysis, not for the purpose of generating a theory, but to use methods that could best address the study aim (Creswell and Plano Clark 2011). Initial coding of early interviews was undertaken line-by-line utilising the grounded theory method of constantly comparing data with data, data with incident and incident with incident (Birks and Mills 2015). Researcher-derived coding was based on the HCHs model features, and data-derived coding was generated by participant responses (Braun and Clarke 2013). The first author (M. O.) conducted the initial analyses with team members checking for coding consistency. Using the method of concurrent data collection and analysis, the interview schedule was modified and a process of theoretical sampling implemented (Birks and Mills 2015). The ongoing data generation and analysis allowed for theoretically sampling of the participant group, to fully saturate the developing categories. A storyline approach was used formatively to conceptualise and organise the data analyses, and summatively to integrate the final thematic constructs (Birks and Mills 2019). Both NVivo 12 and Microsoft Word 2016 software were used for data management.

## **Results**

The characteristics of 21 adult, interview participants who live with chronic conditions are described in Table 1. Eight major themes were identified and are described below.

### *Committing to a regular GP*

Participants identified the importance of having a regular GP to manage care, with most asserting that their regular GP was excellent:

He knows how to manage me [P11].

Participants described a process of initially consulting a range of local-area GPs to find a GP that understood their needs. Once found, people highly valued their care partnership and expressed concern around losing access to their regular GP, citing examples of GPs moving out of the local community, retiring, taking extended leave or becoming too popular:

You can't move [I told them] ... you know, good doctors are rare to find [P14].

A few participants ( $n = 3$ ) were not satisfied with their regular GP, mainly because of their prioritisation of prescribing medicine over other care options:

He's what I call a prescription doctor ... I've been seeing him all these years [15] and he still has to think what my name is ... the longest interview I've had with him is six minutes, usually three, maximum, ... [he] just print[s] out a script, that's it, see you later [P15].

Despite having limited satisfaction with their existing regular GP, these participants reported being unlikely to change their regular GP, citing issues of uncertainty around finding another GP who would listen to their complex health history. The potential cost of accessing alternative GP care was a notable factor that prevented those dissatisfied with their current GP from attempting to change providers.

#### *The practice organisation and alternative GP care*

Having a single practice organisation act as home base for a person requiring chronic care is central to the HCHs model, with team-based care a key model feature. Study participants reported limited connectivity to the broader team at their regular GP's practice organisation. This team included other GPs within the practice, nursing and allied health practitioners, and administrative staff:

There are some there (other GPs in regular practice) that I would never go to [P11].

Personal factors were identified, with positive and negative participant reports of individual staff attitudes, activities and effectiveness.

There's a couple of reception staff ... and they're awesome ... but the other couple ... I hope they don't answer the phone [P12].

Nevertheless, participants expressed loyalty to their regular GP irrespective of their experiences with other individual members of the practice organisation.

Access to alternative care when their regular GP was unavailable was a concern for participants. Some reported using alternative GPs at their usual practice; however, many reported seeking care from unconnected GPs or the local hospital emergency department:

If she's not there [the regular GP], I'll go to the hospital over seeing anybody else [P9].

Participants identified various roles for different GPs. Care planning and management was provided by the regular GP; whereas an alternative GP service was helpful for routine-type needs, such as prescription or pathology requests, with some participants observing that they would not attend the alternative GP for any other type of care. The complexity of the chronic condition, alongside the cost and availability of alternative care, influenced this decision:

You go in and you have to start again, even though they have got your notes, they want to know ... the whole big long story ... so I generally don't like to take appointments with other GPs in that

practice ... if I'm going to see a random doctor I'd rather them come to me and for it to be free, because ... that one that I see [regular GP] ... is quite expensive [P1].

One participant described the frequent use of an alternative GP at a different practice to their regular GP. Importantly, the participant acknowledged that there was no direct connection between these two GPs, and that their alternative GP was not included in any communications with their medical specialist or when investigations and/or test results were obtained. For this participant, the perceived poorer quality and higher cost of other GPs at their regular GP practice deterred them from sourcing all their care in one place.

#### *Sharing knowledge and making decisions about care*

Most participants reported that they were responsible for managing their own care. Although many reported that family were aware of their care, the majority asserted that care decisions were their choice, not their family's choice.

Give me the information and I'll do it, I'll sort it out myself [P19].

Some participants reported withholding information from the GP that could influence their care management. One participant was not willing to disclose details of their challenging financial circumstances and struggled to pay the scheduled fee. They described how their GP assumed they were retired and expressed concern about how this impacted the GP's approach to managing their care:

We got caught in the GFC [global financial crisis], so my husband and I are both working, he is 70, we've got to keep working or we lose our house ... he [the GP] doesn't even know if I work. So for all intents and purposes I could be lying down all day ... but I'm not. I'm actively working. It's very, very, very, very frustrating [P8].

Another felt that they were being judged by their regular GP and withheld information about their decision to take a medication. Additionally, they did not want their care team to share information:

I just made the decision ... I just did it online; I got the pills. you shouldn't have to do that ... you should be supported ... by your doctor. But I don't feel that ... I don't want her [the GP] knowing ... but I'm a bit worried that he [the psychologist] is going to tell her. There's lots of problems with interaction with your medical people [P18].

#### *Using a shared care plan*

Only a few participants ( $n = 4$ ) indicated they had developed care plans with their GP. Those that had a plan reported positive usage:

Whenever ... I've got to see a strange doctor ... or if I get taken into hospital for admission, I take it with me and the doctor has a look at it ... it saves me trying to stutter my way through stuff and I've got no idea what I'm saying [P11].

Other participants reported having no care plan ( $n = 5$ ). Some remembered they had developed a care plan ( $n = 4$ ), although they did not review it collaboratively with their GP. Overall, current care plan usage was perceived to be limited:

He's got some sort of thing worked out for me ... I think it's a care plan ... It doesn't seem to mean anything ... It's basically about the codeine [P19].

### *Accessing bulk-billed services*

The discretionary nature of bulk billing, in which GPs choose which consumers and which consultations are to be bulk billed, influenced people's experiences of care and reduced their feelings of control over managing their health:

Because I'm lucky enough to be bulk billed, I sit there and keep my mouth shut because I don't feel I've got the right to say something [P12].

More than half of participants ( $n = 14$ ) described how their regular GP bulk billed their consultations irrespective of whether or not the practice advertised as a bulk-billing practice. Bulk-billed consultations positively influenced access to care. Some participants commented that bulk billing was inconsistent and they were never certain if they were being bulk billed or fee paying.

I pay a fee. But sometimes he'll take pity on me and bulk bill me [P8].

I don't think it's fair ... every now and then she'll bulk bill it, but I'd say the majority of times I'm paying out [P18].

### *Accessing routine/urgent/after-hours care*

Being known to reception staff facilitated access to routine care:

The one that's been there for a while ... the receptionist, she's really good ... if I'm having a, you know, upset day, to get me in with the doctor straight away [P12].

I've been with him for 15 years. Normally I just have to take my turn. But this year [with an exacerbation of illness] ... they will move things to accommodate me [P3].

Several participants reported how a high turnover of front of office staff impacted their access to care:

They have got a really high turnover so ... you are pretty faceless in there ... it's really hard ... 'I've got a problem and I am not being hypochondriac' is hard to explain to ... new reception staff [P1].

Working participants and those with caring responsibilities found accessing in-hours care the most problematic:

Even if it was just after work in the afternoon, because they close at 4[PM] [P1].

Several participants ( $n = 14$ ) who required urgent care reported they were able to obtain a same day, in-hours appointment with their regular GP, whereas others ( $n = 5$ ) were only able to access care with an alternative GP. Those living with cardiac and diabetes conditions described how their GP directed them to attend the ED in the event of an exacerbation of ill health.

Only one practice provided an after-hours service within the existing practice structure. Participants reported accessing either one or more alternative services for after-hours urgent care. These included the 24-h medical centre ( $n = 8$ ), after-hours doctor home visiting service ( $n = 10$ ) and the ED ( $n = 13$ ).

### *Sharing medical records*

The concept of having medical records all in one place was well supported. Sharing of information within the practice was perceived to be advantageous:

All your information's there on the computer ... if you did have to see someone your information's there [P17].

The willingness of participants to share their medical records varied between types of health professionals. GPs, hospital medical staff and medical specialists were identified as key personnel who could be trusted with health data. Pharmacists were noted to need access to some health records; however, participants preferred that other allied health professionals did not have access to their health information:

They're not prescribing me any medications so, no, they had no need to know [P10].

One participant described the challenge presented by living in a regional community where their medical record may be viewed by people known to them:

I hadn't told anybody in my network ... but she [nurse/friend] picked up my referral [for cancer treatment]. And it's a small town ... So having my very good friend find it; and then she had to sit on it for a couple of days until I texted her ... She was crying. She said ... 'I couldn't tell anybody ... I'm a mess.' And I said, 'Well who cares about you? What about me?' [P3].

Even though most participants felt there was value in a shared data management system, they reported that their GP did not plan to use the My Health Record system.

She said [GP] 'it's not going to work. I'm not doing that' [P10]; and,

I wanted to go on it but ... the medical clinic told me they were not, in no uncertain terms, interested in getting on a system like that [P11].

Participants reported poor usage of the My Health Record: some had not heard about My Health Record ( $n = 2$ ); others knew of the system, but had not accessed their own record ( $n = 7$ ) or did not know if they were on it ( $n = 3$ ), and a few reported that they did not want to participate in the system ( $n = 3$ ). A small number ( $n = 3$ ) supported using the My Health Record system and provided examples of successful usage:

It was perfect in that situation, because I'd totally forgotten about this new drug I was on [P12].

#### *The condition matters: one size does not fit all*

The type of chronic condition notably impacted care management. Participants living with cardiac and endocrine conditions, including diabetes, were more likely to identify that their care was best managed by a medical specialist or diabetes care team. They identified that their GP was useful for routine prescriptions and conditions not related to their chronic condition; however, it was the specialist, not the GP, who was in charge of their chronic condition care management:

The GP is ... a general practitioner, but doesn't have any in-depth experience in the heart, whereas my condition is directly related to the heart ... prescriptions, medications, GPs fine, but your heart specialist is really the one that knows what's going on [P2].

Correspondingly, the nature of the chronic condition influenced the perceived need for routine GP care. Participants with cardiac conditions reported a less frequent need for GP consultation (3–6 monthly), whereas those with highly complex, multiple conditions or conditions that had unknown aetiology reported a need for more frequent visits (weekly to at least monthly).



The participant group who reported the most negative experiences of primary healthcare were those with complex, difficult to manage, chronic conditions, such as chronic pain, fibromyalgia and conditions of unusual aetiology. Anxiety and depression were additional diagnoses consistently self-reported by this group.

Participants with complex, uncommon, chronic conditions detailed the challenge of finding a GP who was willing to work with them to address their health concerns:

About six months before I was diagnosed, I was in tears ... it was just so frustrating ... I felt that I wouldn't be like this if I had doctors years ago that listened to me ... because they've added fuel to the fire of this condition in me ... taking me to a deeper depression level that I've built anxiety because of people just not listening to me. ... I hate going around to different doctors ... But I've had to go to different ones ... it's kind of like you're just a number [P14].

Not being understood by GPs was a recurring concern:

She listens, but she doesn't understand ... she tries to help; of course she's a doctor ... she hands out all these prescriptions that I don't get filled because I don't want to be on drugs. And you feel like you're not being heard. I've cried. But I didn't do it intentionally, I did it because ... 'You [their GP] don't understand me.' And you feel like getting mad but you can't. You just can't. And you feel like you have to be respectful. And I was really sick of that. I thought 'I don't want to be respectful. I want you to get it' [P18].

Those that found a GP willing to listen carefully to their concerns highly valued their GP's commitment and expertise. Even if the GP was not an expert in the condition, their willingness to admit they were not an expert, to listen to the person's experience as an expert in their own care and their effort to learn about the condition, made a significant difference to the person's experience of care:

He's always been good ... whenever I come up with something new... he'll go 'yes, I don't know either – we'd better see what we can find out about that' and he'll go and read up on it [P20].

## **Discussion**

Although consumers living with chronic conditions in this study reported positive experiences with their regular GP, consumer loyalty was not extended to the practice organisation or practice staff, including other GPs situated within the practice. Additionally, those living with less common or poorly understood chronic conditions reported an unmet need to be supported in their care. A consideration of these findings in the implementation of medical home care models has the potential to enhance primary healthcare service delivery for people living with chronic conditions.

A need for increased access to after-hours GP care, and the concomitant demand for connected, alternative primary care has been identified previously and was supported in this study (Song *et al.* 2019; Northern Queensland Primary Health Network 2020). Both informational and interpersonal continuity of care are necessary for effective, alternative after-hours service provision (Cosgriff *et al.* 2020). Cost, quality and accessibility were concerns raised by study participants in regard to alternative GPs within their regular practice. Some of these challenges are difficult to solve, particularly the perceived care quality of alternative GPs. However,

continuity of care between GPs both within and outside the practice, as well as the cost of care, are areas for consideration.

Existing HCHs payments include after-hours care, but only when it is provided by the practice *in situ*. HCHs are only required to ensure that there is awareness of how to access after-hours care (Australian Government Department of Health 2019). In the absence of in-practice after-hours care provision, mechanisms to support continuity between care providers are needed. Policymakers can encourage this using existing tools. Active use of shared care plans by all medical providers would be advantageous, including the after-hours service provider nominated by the HCHs practice. Reports in this study of a focus on care plans to satisfying administrative requirements indicate that more work is needed.

Consistent use of the My Health Record system is another approach that could better support informational continuity of care, although barriers to uptake of this tool have been encountered in the HCHs trial (Health Policy Analysis 2020). Despite the lack of consumer awareness and provider uptake described in this study and others (Lupton 2019), continued development and systematic evaluation of tools, such as My Health Record, should be considered. If the goal of a health system is to be truly person-centred, a fundamental approach is to enable consumers to take control of their own health records; to have ready access to information as needed, and to determine boundaries around health professionals accessing their records.

Financial incentives could be used to foster commitment to a medical home practice organisation. As an example, service usage is likely to be encouraged if consumers are not required to pay an additional fee when accessing alternative GPs at their regular GP's practice. The process of making a formal commitment to enrol with a Medical Home can facilitate person-practitioner discussion around payment expectations. Our study has indicated that removing inconsistency in bulk billing as part of the medical home model could better support the needs of individuals living with chronic conditions.

A need for consumers to be 'known' by health practitioners has been identified previously (Cosgriff *et al.* 2020) and is supported in this study. Focusing the medical home model to purposively include those whose current treatment pathways are poorly planned, particularly those living with complex, uncommon, chronic conditions, has the potential to be advantageous for individuals and the wider healthcare system. By formalising the person-practitioner commitment to care management in the medical home, opportunities exist to enhance understanding and work towards longer-term solutions. Additionally, given that people with existing, positive relationships with GPs were the majority of participants enrolled in the HCHs trials (Health Policy Analysis 2019), if most have common chronic conditions with clear treatment pathways, at trial end there may be no discernible improvement in the person perspective of care. This has been the experience of consumers in the Patient-Centered Medical Home model implementation (Aysola *et al.* 2015). An increased focus on people with uncommon chronic conditions may promote understanding of how the model can better support those with complex care needs.

For consumers living with diabetes and cardiac conditions, specialist providers were preferred to primary care providers for care management. This has implications for the medical home model, as those who perceive that their care is being well managed by existing services may be hesitant to participate in a new model of primary care. Although managing chronic conditions in primary care is the approach espoused by policymakers (Commonwealth of Australia (Department of Health) 2016), reflection on this consumer preference for specialist care delivery is indicated to promote successful model implementation.

### *Study strengths and limitations*

Participants in this study were recruited from the local health service, were longer-term residents of the local community (Table 1), attended a range of GP practices and the majority reported little previous involvement in health research. These were strengths of the study. The single community setting is a study limitation and reduces the representativeness of findings across all settings.

### **Conclusion**

Although there were perceived benefits of having care all in one place, consumers are predominantly committed to an individual GP, rather than a practice organisation. This finding has implications for medical homes, as individuals may not access team-based practice care. Further development and evaluation of existing tools, including the My Health Record and care plans, could strengthen the model. Formalising the person–GP care partnership in a medical home may better support the shared understanding of health conditions. This is of particular interest to people living with uncommon chronic conditions, who feel the most disenfranchised from existing care models.

### **Data availability**

The data that support this study cannot be publicly shared due to privacy reasons.

### **Conflicts of interest**

The authors declare that they have no conflicts of interest.

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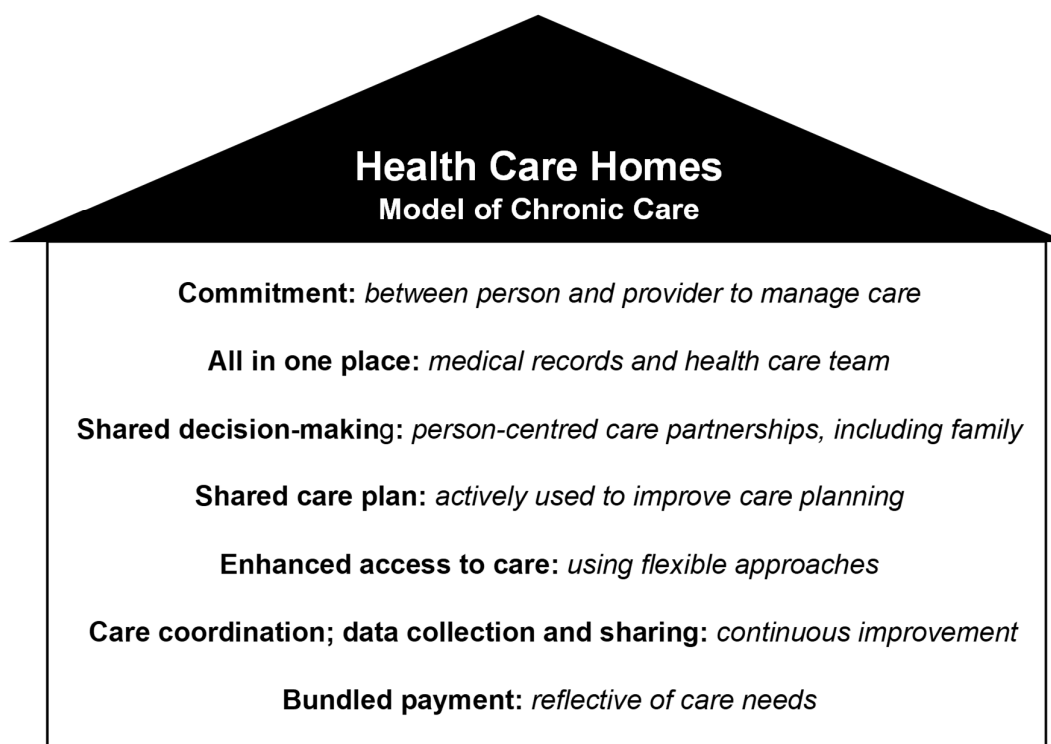
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**Fig. 1. Key features of the Health Care Homes model**



**Table 1. Characteristics of interview participants**

Characteristics (N=21)	N (%)
Female	11 (52%)
Male	10 (48%)
<b>Age range:</b>	
25-44 years	4 (19%)
45-64 years	11 (52%)
65-84 years	6 (29%)
Indigenous	1 (5%)
Has a regular GP	21 (100%)
<b>Employment status:</b>	
Employed	6 (29%)
Unemployed	1 (5%)
Sickness/Disability	7 (33%)
Retired	7 (33%)

**Years living in Cairns**

<b>1-4</b>	1 (5%)
<b>5-9</b>	5 (24%)
<b>10-20</b>	6 (29%)
<b>20 or more</b>	9 (43%)

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**Number of chronic conditions**

<b>1</b>	3 (14%)
<b>2</b>	4 (19%)
<b>3 or more</b>	13 (62%)

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**Has at least one uncommon chronic condition<sup>A</sup>** 14 (67%)

<sup>A</sup>Uncommon chronic condition: not one of the 10 major chronic condition groups reported by AIHW (Australian Institute of Health and Welfare 2020b). Examples of uncommon chronic conditions include chronic inflammatory conditions such as fibromyalgia; and conditions of unknown aetiology.