Appendix 1: Primary health care in the ACT: Consumer experiences

HCCA Submission for Senate Inquiry into Out-of-Pocket Costs in Australian Healthcare

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Primary health care in the ACT: Consumer experiences

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1. Summary of key findings

Between September and November 2013, the Health Care Consumers' Association conducted nine facilitated discussions and 29 consumer interviews as part of a project funded by the ACT Medicare Local. These discussions and interviews aimed to explore participants' interactions with the primary health care system in the ACT and to identify potential gaps and opportunities for action by the ACT Medicare Local.

The consumer experiences collected during facilitated discussions and interviews comprised a number of themes, including

- navigating the system and identifying the right service;
- coordination and fragmentation;
- finding the right provider for your needs;
- understanding the scope of practice of health services;
- cost;
- waiting times;
- transport; and
- access to interpreters.

Information obtained from consumers during the project was then compared against the ACT Medicare Local's Population Health Commissioning Atlas to identify issues for further exploration.
HCCA identified the following areas as worthy of further investigation and action by the ACT Medicare Local:

- Access to GPs in residential aged care facilities

    - The Atlas notes that in Canberra, rates of visits by GPs to Residential Aged Care Facilities are considerably lower than the national average, something that is echoed by the findings of this project. Few people were aware of, or had access to, the GPADS Program offered by the ACT Medicare Local.

    - HCCA suggests that the ACTML explores an expansion of this service in Canberra. HCCA also suggests that the ACTML works through its GP networks to discuss this issue and how it can be addressed from a provider perspective.

- Education, training and awareness of health care professionals

    - Project participants with specific and/or complex needs raised the issue of the lack of available GPs with the requisite knowledge to undertake diagnosis and ongoing condition management. While the Atlas discusses the prevalence of neurological disorders like dementia and Parkinson's Disease, it fails to address rates of other disorders like epilepsy (estimated to affect 3-3.5% of Australians at some point in their lives), chronic pain (estimated to affect 20% of Australians at some point in their lives, or more than 30% of Australians over 65), and hepatitis B (estimated to affect 110 000 Australians) and hepatitis C (estimated to affect 5000 Canberrans). People with gender identity issues, which is admittedly only a small proportion of the ACT population, experience similar issues at the GP level, further reinforcing the need for greater education for general practitioners in a number of emerging health areas.

- HCCA suggests that the ACTML works through its GP networks to discuss the issues of training and professional development, potentially with a view to developing/facilitating the delivery of training packages around issues like chronic pain and epilepsy.

- Navigating the system and coordination of care

  - Many participants reported that the main stumbling block for them in accessing timely care was working their way through the system. Few people had a comprehensive idea of what kinds of services were available to them, instead relying in GPs to recommend services and coordinate their care. However, participants with complex needs often felt that their GPs had not provided them with enough information or the right kind of support, due to their lack of knowledge in dealing with particular issues. While some people sought out information for themselves, this can prove difficult if it is not consolidated, or available in the right format and language.

  - HCCA suggests, in addition to the investigation around training for diagnosis and management of particular conditions, the ACTML investigate opportunities for GP training and education around assisting patients to navigate the system, such as what community services and consumer self-help support groups are available that might be useful. HCCA also suggests that the ACTML work with providers and consumers to develop some resources about navigating the primary health care landscape in the ACT.

2. Background and introduction

The Health Care Consumers' Association ACT (HCCA), incorporated in 1978, provides a voice for consumers on local health issues as well as opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

In late August 2013, the ACT Medicare Local (ACTML) funded HCCA to undertake a series of consultative fora around primary health care services in Canberra. The outcomes of these consultative fora were designed to feed into the second phase of the ACTML's Population Health Needs Assessment process.

HCCA and the ACTML worked together to identify priority target groups, which included older people, people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, parents of young children, young people, and mental health consumers.

Discussion guides for the interviews and focus groups were developed by HCCA in concert with the ACT Medicare Local. Questions were based on HCCA's *Consumer experience of general practice in the ACT 2013* survey and the ACTML's discussion guide from a previous round of focus groups.

Between September and November 2013, HCCA conducted 17 key informant interviews with community sector stakeholders; 29 interviews of consumers within the organisation's networks; and 10 facilitated discussions.

This report documents the project's methodology and limitations, discusses the themes of the consumer feedback generated, and identifies areas for further exploration.

3. Methodology

3.1 Selection of target groups

Target groups were identified by HCCA and the ACTML and align with the engagement priorities of both organisations. In selecting the target groups, the main consideration was to identify sectors of the community whose views have not been well-represented through previous feedback mechanisms. Older people, people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, parents of young children, young people, and mental health consumers have often been alienated by traditional forms of community engagement and so require a more tailored and flexible approach to gauge their valuable opinions.

3.2 Development of discussion guides

Discussion guides for the identified consumer interviews and facilitated discussions were developed initially by HCCA and were based on the *Consumer experience of general practice in the ACT 2013* survey structure as well as previous work done by the ACTML. The facilitated discussion guide was delivered to the ACTML for feedback, and several minor amendments were made. The discussion guides were tested out in two preliminary consumer interviews, and in one trial facilitated discussion, comprised of HCCA Consumer Representative Training attendees. Some ad hoc modifications were made to the guide, depending on the nature of the facilitated discussion group and the direction of the conversation.

The full discussion guide can be found at Appendix 1.

3.3 Key informant interviews

Community sector key informants were identified by HCCA, taking into consideration both the target groups and work previously undertaken by the ACTML during the interim Population Health Needs Assessment process. Key informants were asked to provide an overview of key issues experienced by their organisation's members or clients when accessing primary health care services. Key informant interviews were conducted with the following organisational representatives and community leaders:

- West Belconnen Child and Family Centre
    - Team Leaders: Brian Mupangure, Denise Small
    - South Sudanese Group Facilitators: Khuyen Tran, Rebeca Gonzalez
    - Aboriginal and Torres Strait Islander Strong Women's Group Facilitator: Tammi Eppelstun
- Karralika Programs: Camilla Rowland
- Canberra Multicultural Community Forum: Chin Wong
- Mental Health Consumer Network: Dalane Drexler, Amanda Davies
- Migrant and Refugee Settlement Service: Dewani Bakkum
- Youth Coalition: Emma Robertson, Natalie Oliver
- Mental Health Community Coalition: Ian Rentsch
- Epilepsy ACT: Jacinta Cummins
- ACT Hepatitis Resource Centre: John Didlick
- Toora Women: Kristy McIntyre-Smith

- Tjabal Centre: Anna Martin
- The Junction Youth Health Service: Laura Dawel
- Multicultural Youth Services: Mohamed Bangura
- Mental Illness Education ACT: Pam Boyer, Ben Matthews
- A Gender Agenda: Peter Hyndal
- Ainslie Village: Terri Stiller
- Canberra Men's Centre: Wayne Pash
- Hazara Community Leader: Hasmat Shafaq

HCCA expanded on the agreed target groups during the key informant interviews by including other marginalised groups such as those with drug and/or alcohol dependencies, people at risk of homelessness, and people with chronic conditions.

3.4 Consumer interviews

Soon after commencing the project, it became clear that facilitated discussions with all target groups would be difficult to organise due to participant availability, and individual willingness to engage in an open and broad forum. As such, HCCA decided to supplement the feedback to be received via the facilitated discussions with information gathered from semi-structured interviews with consumers in the organisation's network.

These interviews followed the same structure as the facilitated discussion, including ad hoc changes which took into account the direction of the conversation and the preoccupations of the interviewee. We interviewed 29 people. The majority of interviews were conducted face to face and five were conducted via telephone. Summaries of the interviews were documented and verified by the participants.

These consumer interviews are a valuable source of feedback. The structure of the interview allowed for deeper exploration of some issues, which is not always possible within a facilitated discussion-type context.

3.5 Facilitated discussions

Nine facilitated discussions were held between 25 September 2013 and 25 November 2013. These discussions followed the format set out in the facilitated discussion guide, with some deviations, as explained above. Facilitated discussions were held with ACT Aged Care Consumer Reference Group members, A Gender Agenda older members, A Gender Agenda younger members, Ainslie Village residents, Dickson College students, Lung Life ACT members, Pain Support ACT members, the West Belconnen Child and Family Centre South Sudanese Mothers' Group members, the West Belconnen Child and Family Centre Aboriginal and Torres Strait Islander Women's Group members, and a Playgroups ACT group for parents of children under one year old. Facilitated discussions were held in the HCCA Meeting Room in Hackett, the Burns Club in Kambah, the A Gender Agenda offices in Ainslie, the West Belconnen Child and Family Centre in Holt, and the Playgroups ACT office in Cook.

Brief background statements about each group can be found at Appendix 2. Demographic information for facilitated discussion participants can be found at Appendix 3.

3.6 Online feedback forms

In addition to conducting consumer interviews and facilitated discussions, HCCA also employed online feedback forms to capture feedback from consumers who were unable to attend facilitated discussions. These forms offered a simplified and cut-down version of the questions presented in the discussion guide, and invited respondents to identify barriers and key issues they have experienced in accessing primary health care services in the ACT. Feedback forms were completed by Pain Support ACT and Playgroups ACT members, Mental Health Consumer Network members. The Mental Health Consumer Network and the ACT Hazara community were invited to participate in the project but were unable to be involved due to the timeframes and competing demands.

4. Limitations of the project

Firstly, the timeframe associated with this project has limited the scope of participation and necessitated some deviations from the original work plan. Several organisations which indicated that they would like to be involved in the project were unable to participate within the necessary timeframe, including the Mental Health Consumer Network and the Canberra Multicultural Community Forum. Additionally, several other groups which were involved in the facilitated discussion process could only participate towards the end of the project, resulting in a delay in compiling this report.

Furthermore, the short time frame did not allow for appropriate relationship building with organisations, particularly in the culturally and linguistically diverse (CALD) context. While HCCA has forged some strong relationships with CALD sector organisations, thanks largely to the organisation's Multicultural Liaison Officer, introducing new projects is not something that can be rushed if it is to be effective. Organisations which work with vulnerable and marginalised populations are naturally protective of their members and clients. As such, developing a new consumer engagement project and expecting to obtain access to an array of vulnerable populations within a two-month timeframe is not feasible.

The central methodology of the project also acted as a constraint in the CALD context. A number of organisations indicated that a facilitated discussion/focus group approach would not be appropriate for their members/clients. Some key informants indicated one-on-one interviews, such as the identified consumer interviews discussed above, would be more appropriate, but encounter the same barriers as facilitated discussions, in terms of building relationships in a time-limited scenario. Other key informants noted that feedback mechanisms implemented by a person external to the organisation would not be able to reach a number of marginalised members/clients.

The limits of the timeframe and the choice of consumer engagement mechanism are highlighted by interactions with the Hazara community. As indicated in section 2.6, contact was made with a representative of the ACT Hazara community with regard to organising a facilitated discussion. This representative indicated that it would be better to obtain feedback in a survey context, as it would be difficult to get people together at the same time. An online survey was developed and sent to the representative of the Hazara community, with a suggestion that it could be translated into Farsi or Hazaragi. However, despite a number of follow ups, this survey gained no respondents. This could be due to the limited time in which feedback was required, as well as a lack of a well-developed relationship with the community representative.

The chosen consumer engagement mechanism also proved challenging for the groups from the West Belconnen Child and Family Centre. The coordinators for both the South Sudanese Mothers Group and the Aboriginal and Torres Strait Islander Strong Women's Group indicated that a "formal" facilitated discussion would not be appropriate for these women due to the format of the groups.[1] Additionally, the

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[1] A community development worker at the West Belconnen Child and Family Centre has recently conducted some interviews with Aboriginal and Torres Strait Islander clients around the Closing the

Translating and Interpreting Services was unable to supply an onsite Dinka interpreter for the South Sudanese group, limiting the kinds of questions that could be asked effectively. Ultimately, HCCA used less formal and structured approaches with the groups which did not strictly adhere to the discussion guide.

In addition, while the consumer interviews proved a valuable source of information, the method behind identifying participants was ad hoc and relied on consumers already directly (or indirectly) connected to HCCA's networks. As such, participants do not necessarily represent a broad spread of demographics and do not strictly adhere to the target groups outlined above.

The demographic composition of the consumer interview and facilitated discussions participants also required examination. There were a number of biases demonstrated by participants in this project which need to be noted:

- the length of time lived in Canberra – most participants indicated that they had lived in Canberra for more than six years, while evidence from other sources points to the continuing transient nature of Canberra's population;
- the gender spread – the majority of consumer participants in this project were women; and
- access to transport – most participants indicated that they had adequate access to private transport which enabled them to physically access services, while evidence from other sources, including passed on anecdotally to HCCA, emphasises that lack of adequate public transport remains an access issue for people without private vehicles.

The feedback contained in this report should be considered in light of these limitations. It would be prudent to further explore these issues in a less time-limited manner, with an understanding of appropriate methods and flexibility in mechanisms for gathering feedback in marginalised and vulnerable groups, and more in-depth consideration of the demographics of interview participants.

Gap initiative. A brief summary of the themes collected during these interviews was kindly provided to HCCA, and can be found at Appendix 5.

5. Feedback from consumer interviews and facilitated discussions

5.1. Navigating the system and identifying the right service

Most key informants indicated that their clients or members are simply not aware of the kinds of services that are available to them, and what assistance they might be eligible for. The under- or non-utilisation of after-hours services like healthdirect and the Walk-in Centre is not due to a rejection of these models, but rather indicates that people do not know where they are located or how to access them.

Most consumers we spoke to either indicated that navigating the health system proved one of the most troubling barriers in regards to access to care. Consumers across all ages groups often found it difficult to determine where to seek care when they required it.

> *"There are so many options…it's difficult to know where to go for what: you don't want to go from pillar to post looking for services."* (Ali)

> *"I think that's the biggest barrier: not lack of need, but lack of information."* (Kieran)

> *"Unless you know who to go to…unless you can get contact with the right person [it's almost impossible]…it hasn't got any better…you have to go to them and ask 'Can you help me?'."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

Many consumers still rely on their GP to assist in the coordination of the primary health care needs. Ainslie Village residents accessed few services outside of their GP, and so are reliant on their doctor to be able to manage their often complex needs. Older people in the A Gender Agenda, Lung Life ACT, and Pain Support ACT sessions, and women in the South Sudanese Mothers Group session also tended to seek information about service coordination from their GPs.

> *"I just go straight to the source [to the GP]."* (Participant, A Gender Agenda older members session, 10 October 2013)

However, the ability of the GP to be able to perform the role of service coordinator adequately was questioned throughout this project, in both "corporate" and "family" general practice settings, and especially when continuity of care was lacking.

> *"The GP didn't explain anything [about] how to get my blood taken, where to go, how much it would cost, or when I would get the results. I felt blind."* (Antonia)

In particular, people we spoke to felt that GPs did not have a good understanding of health and support services provided in the community, which would be of benefit to their patients.

> *"GPs don't know about really good organisations in the community, like Arthritis ACT and the RSI Association…they should be referring people to these organisations for the support they get. My GP has never referred me to any of these organisations, I've had to find them on my own."* (Participant, Pain Support ACT session, 22 October 2013)

Several participants felt that their GPs did not refer them to appropriate services.

> *"My GPs were not helpful…they did not appear to be aware of any pain services. I found out about The Canberra Hospital Chronic Pain Clinic myself and asked my GP to refer me to it."* (Pain Support ACT survey respondent)

In the case of Rebecca, she accessed social work services for post-natal depression, but was only aware of this service after a recommendation from a friend, rather than a referral from her GP or another health professional.

In particular for older people, many participants noted that GPs do not have a good understanding of how community support programs, such as Home and Community Care funded services, actually function in reality. Most participants felt that GPs did not fully appreciate the limitations of services provided in the community, and were often not able to provide advice about how to access alternative services. There was agreement that GPs should keep themselves informed of changes to do with the provision of aged care services in the community, so that they can effectively assist in coordinating care.

> *"GPs need to know the changes in policy and direction so that they can help direct their patient care."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

Younger people we spoke to were more reliant on the Internet than on GPs for finding out information about health and health care services.

> *"If I have a question, I usually try to ask the Internet."* (Participant, Dickson College students session, 25 September 2013)

The Internet was a particularly important source of information for young people in the A Gender Agenda session, whose concerns can often not be addressed by GPs with a minimal understanding of the kinds of gender issues they face. Internet forums provided support and non-judgemental advice regarding transgender issues for these young people, as well as contact to a community of people experiencing similar issues.

> *"I had no information about non-binary genders until I found the Tumblr page."* (Participant, A Gender Agenda young people session, 10 October 2013)

Young members of A Gender Agenda also noted that the organisation itself plays a crucial role in providing face-to-face support and advice for transgender people attempting to navigate the system.

> *"AGA is life-saving. Before AGA, transitions happened in other people's lounge rooms. Once you get to the other side [of a transition], you don't always want to stay as a trans person, so you move away from it and don't necessarily want to be available to give others advice. That's why we need a hub like AGA."* (Participant, A Gender Agenda young people session, 10 October 2013)

In general, young people also tended to prefer talking to their family and friends, rather than seeking information from health professionals. Most of the young people we spoke to indicated that they felt more comfortable discussing health concerns with people they knew and trusted.

> *"[I] talk to mum…I'd much rather talk to friends and family…I feel safer with someone I know…I trust them…I like what I know."* (Amy)
>
> *"No-one really wants to talk to their parents about it [sexual health]…I mean, you might talk to your friends, but apart from that, it can be difficult to find someone."* (Martina)

Young people sharing information by word-of-mouth can potentially be problematic, as misdiagnoses by friends and inappropriate treatment can result. It is also telling that a trusted relationship is key in enabling access to primary health care services for young people. Many young people seek care only episodically, minimising their chances of developing a relationship with a practitioner and allowing for the exchanging of high quality and verified health advice.

During the session with Dickson College students, there was a consensus that things like how to navigate the system and how to manage physical health are not taught enough in high school and college.

> *"In school, it's mainly mental health and sexual health that they focus on; they don't really talk about physical stuff – I feel like there needs to be more education."* (Participant, Dickson College students session, 25 September 2013)

Some young people also experienced barriers in terms of the administrative side of primary health care access, i.e. the Medicare system. One young person we spoke to (Amy) explained that she still lives at home and is registered on her parents' Medicare care. When she wants to use a service that requires the presentation of a Medicare card, she has to borrow a card from one of her parents. While she is aware that she can register for her own Medicare card, she does not have the time during the week to visit a Medicare office to complete this process, as she works full-time and has limited flexibility in her working day to go to Medicare. Amy noted that many of her friends are in a similar situation.

> *"A lot of my friends don't have [their own] Medicare cards…it's just a matter of finding the time to go in and do it."* (Amy)

The difficulties young people associate with accessing care, including presenting a Medicare card, can deter them from seeking help. As Natalie Oliver from the Youth Coalition noted during our key informant interview,

> *"If access to care is difficult or time consuming, many young people don't bother."* (Natalie Oliver, the Youth Coalition of the ACT)

Several people we spoke to over the age of 25 also used the Internet for information about services available to them, usually in conjunction with GP advice. There was a general consensus that information provided on the Internet was not necessarily reliable, and that a measure of self-filtering was required from consumers. Many people also commented that it was frustrating that sources of information were not available in one location, and that there was a lack of localised health service information.

> *"You have to be careful what websites you go to."* (Caroline)

> *"There's a lot of misinformation out there…everything's just cancer."* (Kendall)

In addition to traditional 'webpage' type information, some of the mothers of young children we spoke to reported using social media pages associated with local, national or international bodies to access health information and support, such as the "Canberra Mums" and the Hyperemesis Education and Research Foundation Facebook pages. One young mum, Georgina, also indicated that she used free smartphone apps for pregnancy information – "What to Expect and "Pregnancy WebMD". These tools were all remarked upon favourably, giving women access to information and shared experiences, without having to leave their homes.

"The Canberra Mummies Facebook page is really useful…the amount of times I've seen photos on there of different coloured poo and mums asking if it was normal…" (Participant, Playgroups ACT Canberra Mummies session, 25 November 2013)

"There's also an Australian Breastfeeding Association person on there, who you can tag in questions and send messages to, and she responds really quickly." (Participant, Playgroups ACT Canberra Mummies session, 25 November 2013)

5.2 Coordination and fragmentation

A large number of the people we spoke to raised issues of the fragmentation within the health system and the lack of coordination in the community, and especially at the interface of primary and tertiary care. This disconnection between levels and settings of care presented a barrier to consumers accessing appropriate care in a timely manner, and was particularly an issue for people in vulnerable populations, including Aboriginal and Torres Strait Islander people, CALD people, older people, young people, and people dealing with gender issues – people who don't necessarily possess the skills to fight for or coordinate their own care.

Older people we spoke to generally spoke positively about staff working in frontline services, but emphasised that dysfunctional administrative systems presented barriers to getting the care they needed, when they needed it.

> *"[It's] good people, lousy systems."* (Participant, ACT Aged Care Consumer Reference Group, 4 October 2013)

Fragmentation within key primary health care services was problematic and frustrating for older consumers. In one example, a woman we spoke to tried to organise for her wheel-chair bound husband to be weighed:

> *"We tried to get [him] weighed, and that simple thing became so complicated…. because they didn't have the right clinicians around."* (Participant, ACT Aged Care Consumer Reference Group, 4 October 2013)

Referrals for services also presented an issue for people with complex needs, sometimes barring them from being able to access the services or equipment that they needed.

> *"Someone need[ed] bed blocks, Friday afternoon, went to the ELS, equipment loan service…they had them…only to be told, 'We can't issue them, because we need an OT referral'…where do you get that on a Friday after 3 o'clock?…they had to go and buy a set of blocks."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)
>
> Similar concerns were raised with community nursing and access to speciality clinics.
>
> *"It's getting the referral…they've got the systems in place to expedite things, but you get tripped up at first base."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

Coordination and connection between primary and tertiary health care was also presented as an issue of concern by the consumers we spoke to. One woman recounted the story of a friend, in which she was unable to receive community nursing support in the ACT for a frequent injection she was unable to perform herself, despite this being requested by a specialist interstate. As a result, this person has to drive to her GP in a different suburb three mornings per week in order to receive this injection.

In addition, Aboriginal and Torres Strait Islander and South Sudanese women we spoke to also had concerns about the coordination of care when transitioning from the hospital into the community. There was a general consensus that support provided at this juncture was not adequate, and that it was sorely needed:

> *"[After coming out of hospital] there was no support. If my family wasn't around, I wouldn't have been able to cope."* Participant, Aboriginal and Torres Strait Islander Women session, 25 October 2013)

> *"[I need] someone to help me work out my care, and someone to talk to if I'm upset and don't know where to go for something."* (Participant, South Sudanese Mothers Group session, 30 October 2013)

> *"[trying to find someone to help you is like] banging your head against a brick wall…there's just so many hoops to jump through."* Participant, Aboriginal and Torres Strait Islander Women session, 25 October 2013)

Aboriginal and Torres Strait Islander women we spoke to firmly emphasised the need for more support for them within the health system. While they spoke positively about the Aboriginal Liaison Officer at the Canberra Hospital, they noted that *"…one is not enough, there needs to be more of them."* Participant, Aboriginal and Torres Strait Islander Women session, 25 October 2013)

People spoke to wanted to see the introduction of an enhanced, or more accessible, liaison service to ease the transition out of the hospital, by coordinating services required for the move back into the community.

Similar concerns were raised about the lack of adequate communication between GPs, specialists and other health care providers. People with chronic conditions involved in this project agreed that it was important to be *"in charge"* of their own health so that they could maintain these linkages between different levels of care, because the system was unable to do so.

> *"I always add my GP for diagnostic testing results, as well as my specialist…I don't know if they read them, though…if there was a problem I don't even know if someone would get in touch with me."* (Participant, Lung Life ACT session, 26 September 2013)

> *"I said to my specialist, 'Can you please write to my GP and tell her what she should be doing?, [in terms of managing her chronic condition]'."* (Participant, Lung Life ACT session, 26 September 2013)

People with chronic conditions who were required to be *"in charge"* of their own health care management felt that their years of personal experience in dealing with a chronic condition made them "experts" in their own health. They also noted that there was limited, if any, recognition of this.

> *"After a while, you know what to do, it's just something you learn, it's not because you're clever or anything, it's just over the years…"* (Participant, Lung Life ACT session, 26 September 2013)

This expert status is a result of ongoing self-management, in addition to a (well-founded) perception that people with chronic conditions need to retain control of their own health, as GPs, specialists, and pharmacists are not in good communication and often make mistakes. This lack of recognition of the consumer's self-knowledge is also echoed in the experiences of consumer dealing with the Equipment Loan Service, which requires a referral to obtain access, not accepting the autonomy of the consumer to define and understand their own needs.

> *"The individual knows what they need…they wouldn't be asking for a wheelchair if they only needed bed blocks."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

A number of key informants expressed a desire to see general practice work more closely with pharmacy to deliver training, education, and monitoring. This enhanced relationship would benefit people who have chronic conditions and ongoing medication needs, enabling better management of initial prescription, side-effects, and drug interactions. The Home Medicines Review program could be better promoted through general practice, giving people the information to be able to request this service. The quality use of medicines was indicated as an issue of particular importance for CALD organisations, as there are many people with chronic conditions, who only recognise their medications bye size and colour, as they are unable to read the information on the packaging.

5.3 Finding the right provider for your needs

Most of the people we spoke to stressed the importance of finding the "right" kind of GP, a practitioner who suits the needs of themselves and/or their family.

> *"…[it's difficult] trying to find a new doctor who suits our needs, and who we get along with…who we like. [we tried one but] she didn't know anything about Nikolai [her one year old son]…she didn't really care…I thought, 'this is crap'…there was no 'Can I help you with anything else?'."* (Kendall)

> *"I've spent many years trying to find the perfect GP…but she's very hard to get into, so I don't often see her."* (Krissy)

Desirable attributes for GPs included an open attitude towards exploring other options, an appropriate knowledge base, availability, and open communication.

Effective communication skills were of key concern to many people we spoke to, often defining the quality of the GP consultation.

> *"I have low expectations [of GPs]…I feel like doctors go to a class of how not to carry on a conversation...the GP I have now is the first one that has talked about differential diagnosis."* (Angela)

> *"My GP doesn't like to be questioned…people don't have the training to question their [the GP's] views."* (Garry)

> *"I never feel that I can ask all the questions I want to…I never have enough time…there's always more that I wanted to say."* (Georgina)

Availability of appointments was again raised as a concern, especially in connection to urgent health issues. Most people we spoke to who indicated that they had a "preferred" or "regular" GP were unable to get appointments with their doctor within a reasonable timeframe. As such, most participants chose to see a different doctor within their usual medical practice or go to one of the corporate medical practices.

> *"I see a different doctor every time…I'm aware that this is less than ideal, but I've just adapted. I would love to have my own GP, but if you get sick suddenly, this isn't always an option."* (Dee)

> *"My doctor only works part-time and so I have to make appointments with her weeks in advance. If something else comes up, I have to just see another GP at the same practice. This GP doesn't really know my history...I don't have good continuity of care."* (Georgina)

> *"[At a Canberra Medical Centre] it feels like Russian roulette every time you go to the doctor…you see a different doctor every time…they don't know my history, there's no rapport, and there's no follow up care…they're not prepared to listen to what you say."* (Tracey)

The search for the "right" kind of GP becomes crucial for consumers with specific and complex needs, such as those with conditions like chronic pain, and for people dealing with gender identity issues. In this context, the "right" GP needs to possess both adequate knowledge and sensitivity to assist them in treating/managing their condition and navigating through the system.

Older participants particularly valued their long-term relationships with their GPs. Once people in this category found a GP they liked, they tended to maintain the relationship for as long as possible. Having an equal, partner-type relationship was important for older people, with health care feeling less like a transaction and more like a two-way conversation.

> " *My GP's very good, he doesn't argue with me! He listens to me, and I listen to him, and then make up my mind whether I agree with what he's got to say. He accepts the fact that if there is something wrong, I will come and tell him."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

However, even when consumers had a regular GP, they indicated that it was not always possible to see their preferred provider, due to the lack of available appointments.

> *"You have to be sick a month in advance!".* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

There was general agreement that while GPs are capable of dealing with straightforward or basic issues, their skills in other, more specific or emerging issue areas may be lacking.

> *"I think GPs are not coping well with some of the new diseases, for example, mental health. I'm not sure they're well trained enough to cope with mental health…in many cases depression can be managed at the GP level. Similarly with chronic pain, and some of the other chronic conditions. I don't think it's too much to expect the GPs to upskill to deal with some of these conditions."* (Participant, ACT Aged Care Consumer Reference Group session, 4 October 2013)

The lack of GP knowledge about particular issues is demonstrated by the experience of Cassandra, who suffers from *hyperemesis gravidarum*, a conditions which requires careful and considered treatment in the general practice setting.

> *"[With my previous GP] I just really felt like she didn't understand what I needed at all…she only gave me enough ondansetron for a day. She wasn't a bad GP, she just didn't give me the right support. I need someone that is going to take me seriously."* (Cassandra)

People with chronic pain are similarly underserved in the general practice setting. A number of people we spoke to discussed their GP's resistance to validate and seek appropriate interventions for their chronic pain.

> *"GPs dread the person with pain. My [previous] GP said to me: 'We only provide one referral.' I think she thought I was a bit of a nutter; she wouldn't give me a referral. Later, when she [her physiotherapist] said 'They think you're looking for drugs', my jaw just dropped."* (Marg)

Several participants had tried to find different GPs to better suit their needs, but found that there was a prejudice around "interviewing" other practitioners.

> *"They labelled her [his wife who experiences chronic pain] a 'doctor-shopper' and a 'drug seeker'. Doctors don't understand what the patient is saying."* (Participant, Pain Support ACT session, 22 October 2013)

There was a perception that GPs are automatically inclined to consider people describing pain as "delusional" or as "drug-addicts".

> *"Their default position is not to believe you. Their default position is you're a bit nutty, or you want something, and it's all in the mind. And you start talking about the*

> *history…but they don't really want to listen…they ask you, but they don't want to listen."* (Participant, Pain Support ACT session, 22 October 2013)

Other people we spoke to who experience chronic pain felt that GPs did not have a good understanding of chronic pain or how it should be treated.

> *"They [GPs] don't know the modern approach, which is multidisciplinary. Educating the consumer to self-manage and understanding that all of these things like exercise, and psychological understanding, and understanding of the condition itself, will help. I think people do have a right to find out and understand what is happening to them, and I think GPs, certainly mine, had no idea and didn't know what to do with me."* (Participant, Pain Support ACT session, 22 October 2013)

There was a perception that GPs had failed many chronic pain sufferers in terms of coordinating care. As GPs are often the first point of contact for someone experiencing pain, they have a responsibility to be aware of services available to assist in management.

> *"People find themselves with chronic pain suddenly and they don't know there's [a specialist clinic]. Their GPs don't know…my GP never referred me to the pain clinic. I went there another route, from the psychologist I saw. I don't think she [her GP] knew about it."* (Participant, Pain Support ACT session, 22 October 2013)

People we spoke to who were thinking about or undergoing gender transitions also spoke about how difficult it was to find an appropriate GP. While this is a small cohort of people in the Canberra community (thought to be around 250), they have clear needs of their health professionals in primary health care. For transgender people, the GP is the gatekeeper to the very first elements of their transition, usually access to hormone therapy. However, A Gender Agenda members we spoke to generally found their experiences with GPs uncomfortable, frustrating and judgemental.

> *"You're often on the receiving end of a GP's moral view. I badly wanted chest surgery, but I was told I could not have chest surgery until I'd had a hysterectomy. I did not need that. It affected my energy levels and took me a long time to recover enough to be able to return to work. It was all born out of ignorance and discrimination."* (Participant, A Gender Agenda younger members session, 10 October 2013)

> *"The only issue is that the GP still uses my PTSD to question whether I am genuine about transitioning. It's very invalidating."* (Participant, A Gender Agenda younger members session, 10 October 2013)

> *"It took me two years to access hormones at the same GP [because] I was under 18. She had worked with trans people before, but thought she could decide what was best for me. She said I needed a note from a psychiatrist or specialist. I had to go through four psychiatrists before I found one that would help me. My GP also ignored several letters from psychiatrists, so I had to find one she would accept."* (Participant, A Gender Agenda younger members session, 10 October 2013)

> *"There is often a lack of information about transitioning even though GPs are the gatekeepers. When there's a lack of knowledge, a consultation becomes a voyeuristic experience."* (Participant, A Gender Agenda younger members session, 10 October 2013)

A Gender Agenda members also found it difficult to locate mental health services that suited their needs.

> *"There is appalling access [to mental health services]. they're the same as GPs but more entitled, like everything is their decision."* (Participant, A Gender Agenda younger members session, 10 October 2013)

> *"We're scared of mental health services; one told me I wasn't a true transsexual and also told my family."* (Participant, A Gender Agenda younger members session, 10 October 2013)

Young people also sought providers and services that catered to their needs, specifically they looked for practitioners who were open-minded and youth-friendly.

> *"Gender is less important than finding someone with the right attitude…they have to actually listen to you, without judging…[you need] someone who caters to the needs of young people, and fosters relationships with them...my family GP doesn't do this"* (Julia)

Young people were generally satisfied with the care received from their family GPs, unless their needs involved sexual or mental health issues. In this context, the dissatisfaction was hypothetical – young people preferred not to see GPs with whom they've had a long relationship, and who their family members might still see, for more sensitive health issues.

> *"I had a suspected STD and I thought, 'I'd rather not see my family GP about this'."* (Alex)

> *"I wouldn't want to see him [for a mental health issue] because I've known him so long."* (Paul)

When seeking treatment for mental health or sexual health issues, most young people we spoke to used "corporate-style" medical practices, such as the Phillip Medical Centre, or youth-specific services like The Junction. A theme that emerged during our discussions with young people is that there seems to be a general reluctance to talk about sexual health issues, but that specific services aimed at youth have been helpful.

> *"I know a lot of my friends have found the people from SHLIRP [the Sexual Health, Lifestyle and Relationships Program] really, really lovely and completely non-judgemental."* (Martina)

Several younger respondents made a distinction between GP interactions in a "family practice" setting as opposed to a "corporate practice" setting. The reduction in the comprehensiveness of care in a "corporate" setting meant that young people had to be aware of their needs and to be able to articulate them to the GP.

> *"[The Medical Centre is] a bit too laid back…the way my friend puts it is they're kind of doctors who didn't make it to private practice sort of thing…they don't actually sit down and talk to you. These ones go 'What's wrong? Ok. Bye'…[a good consultation is] when they sit there and take time to find out what's wrong, to the extent of what's wrong, rather than being like 'Oh, you've got a tickle in your throat? It's a cough'. Unless you actually turn around and go 'No, I need something more', they go, 'Ah well, try this and see how it works'.* (Amy)

Due to their socio-economic status and social isolation, Ainslie Village residents do not have the freedom of choice in GP that other consumers have.

> *"I've been thinking about changing GPs but it seems a bit hard. My current GP won't give me my own x-rays."* (Participant, Ainslie Village residents session, 10 October 2013)

> *"I would look at changing GPs but my main concern would be finding someone who respects patient confidentiality. I don't want to play snakes and ladders."* (Participant, Ainslie Village residents session, 10 October 2013)

The difficulties encountered by the consumers we spoke to in trying to access appropriate GP care demonstrate a number of concerns. Firstly, not enough GPs possess the skills and knowledge deal with issues like chronic pain and gender transitions, which can be managed effectively in the primary health care setting. Secondly, consumers do not know where to go to find out which GP will be suitable for their needs. A number of people we spoke to suggested the creation of a register of GPs which lists their interest/"speciality" areas, allowing consumers to make informed decisions about the general practice. GP education about emerging health issue for consumers, and enabling informed choice for consumers in regards to GPs, are areas which would benefit from further exploration and action.

5.4 Understanding the scope of practice of health services

Some of the people we spoke to indicated some reluctance to access certain services due to their lack of knowledge about what could be seen to by each service. This attitude was particularly prominent when speaking with young people.

Rebecca indicated that she doesn't seek advice from the pharmacist because she is unsure about what is within their scope of practice.

> *"I feel like I shouldn't ask pharmacists too much, because they might get into trouble."* (Rebecca)

Other people we spoke to drew distinction between "retail" and "community" pharmacies and their respective scopes of practice.

> *"It's great to have a yarn with a chemist in a place that's not a shop, but a community service…I went into a pharmacy in the mall…I left without a sense of understanding…a community pharmacy provides full care."* (Ali)
>
> *"If we want good advice, we go to Wanniassa pharmacy…[but we buy] Ondansetron at Chemist's Warehouse."* (Cassandra)

Young people tended to only use the pharmacy for the dispensing of prescription and pharmacist-only medications, rather than for seeking advice. Dickson College students noted that they felt that pharmacists did not tend to be as professional as GPs, with some discussion of judgemental behaviour regarding the dispensing of the morning after pill.

Attitudes like these demonstrate and absence of understanding and promotion of pharmacist's skills and their scope of practice, as well as perhaps a need for further pharmacist education about providing services in an appropriate way.

Similarly, while Kieran was familiar with the Walk-in Centre and indicated that he would use if it required, he did flag his confusion about how the Centre complemented the rest of the primary health care system.

> *"I'm not entirely sure what they [the Walk-in Centre] would [treat]."* (Kieran)

Paul put his lack of more frequent visits to the GP down to perception of what general practice should be for:

> " *Not going to the GP for cold/flu is also more because I don't feel they're worth the doctor's time - he probably has more important cases."* (Paul)

When consumers, especially young people, are not in possession of the information about a service's scope of practice, they are less likely to take full advantage of what the service can offer them, and which might assist in treating conditions before they reach a crisis point.

6. Barriers to access

6.1 Cost

Cost is one of the most persistent barriers for consumers in obtaining timely access to primary health care interventions. In this project, cost was of most acute concern to members of vulnerable populations, such as Ainslie Village residents, A Gender Agenda members, and people living with chronic conditions.

Cost was raised as an issue for organisations which have contact with people on low incomes and financially disadvantaged people (West Belconnen Child and Family Centre, The Youth Coalition, Karralika ACT, Canberra Multicultural Community Forum, ACT Hepatitis Resource Centre).

People undergoing a refugee determination process are not eligible for some services and are unable to access Medicare rebates, making cost a significant barrier for them to be able to access care for themselves and their children.

The low rate of bulk-billing services is an issue even for those people who are able to access the Medicare system. While there are a number of bulk-billing hubs, such as Winnunga Nimmityjah and medical centres, access to affordable services outside of these services is more difficult.

Key informants indicated that there are high / prohibitive costs associated with, medications and community pharmacotherapy, dental services, mental health services, and after-hours services like CALMS.

6.1.1 GPs

Bulk-billing GPs were acknowledged as enabling access for a number of people, especially those on low incomes, and with children.

> *"Bulk-billing plays a big part…[it impacts on my ability to] see the GP as frequently. If the doctor says, 'come back in 2 weeks', and I was at another practice [that didn't bulk-bill], I wouldn't be able to do that."* (Harlee)

In one area, residents continued to see a GP with whom they were dissatisfied, as he both bulk-billed and was located close to their residence. The lack of other bulk-billing services in this area impacts on the ability of Ainslie Village residents to seek appropriate care, as they do not have the resources to seek care further afield or seek alternative non-bulk-billed services close by.

Several people we spoke to also raised issues with the financial and time costs associated with the search for the "right" GP.

> *"One of the challenges is that you're basically always paying out of pocket for a GP…and so to find a GP and work out if you sort of get along well and they're the kind of GP you're looking for…that can be a bit hit and miss and it can cost you quite a bit of money if you don't find what you want straightaway…because it's not like you can have one visit with them and make a decision."* (Cassandra)

Additionally, Georgina and Cassandra both mentioned that they have to go to the GP quite regularly when pregnant, so the consultations "*add up to quite a lot of money*". However, Georgina is reluctant to go to a bulk-billing general practice as she has had poor experiences with these in Canberra. Similarly, Cassandra wants to remain with her current GP because she had a good understanding of her condition.

6.1.2 Medication

A number of people we spoke to, especially people with chronic conditions or complex needs, found that the cost of medicines contributed substantially to their healthcare related financial burden, particularly if these medications were not subsidised through the PBS.

> *"If you have to buy medicine…if you don't have a health care card, you have to pay so much."* (Participant, Pain Support ACT session, 22 October 2013)

> *"I've found the cost of one of my medications, which has been the most effective for me, was extraordinarily high. It wasn't on the PBS list. There's been a battle and I think it's now on."* (Participant, Pain Support ACT session, 22 October 2013)

One woman we spoke to raised concerns about the PBS Safety Net thresholds, and disadvantages for a single person.

> *"[Before my husband died] when we were two of us, you know you get up to 58 scripts a year, and then you go onto the Safety Net…but now, he's not here, I still have to reach that same amount of scripts for only one person."* (Participant, Lung Life ACT session, 26 September 2013)

Medication costs also became a concern for people when they developed a new condition, which they had not had to previously manage. Caroline noted that while cost is not usually an issue for her, using an array of services and treatments (especially medications not subsidised by the PBS) can "add up".

> *"Sometimes, you weigh things up…whether to pursue treatment or not."* (Caroline)

Cassandra, who suffers from *hyperemesis gravidarum*, noted that the cost medication she requires to maintain her quality of life is substantial, especially over the course of a pregnancy.

> *"My ondansetron costs $200 per fortnight."* (Cassandra)

The high cost of this medication is due to its listing for specific management of nausea related to cancer, rather than for *hyperemesis.*

A Gender Agenda members experience similar difficulties with accessing subsidised medicines, especially when the drug was only subsidised for use by a particular gender or for a particular reason.

> *"It costs $150 per testosterone injection, which is difficult when you're unemployed. It wasn't covered by Medicare because I was still a female on my parent's card."* (Participant, A Gender Agenda young people session, 10 October 2013)

In another example, a person undergoing a transition was prescribed an expensive anti-androgen prior to gender reassignment surgery. In order to have the medication covered under the PBS, this person had to be classified as a sexual deviant.

6.1.3 Dental services

Dental services were often only mentioned by people we spoke to in relation to high costs.

Women in Aboriginal and Torres Strait Islander session agreed that dental care for themselves and their children is prohibitively expensive. Several women had been to the Community Health Centres for subsidised/public dental care, but were not satisfied with the thoroughness and quality of the examination.

South Sudanese women in the Mothers Group expressed similar concerns. One woman indicated that she has had ongoing teeth problems for six years, but simply does not have the financial resources to seek private dental care. One woman required dental examinations every six months, but was unable to afford the cost of this monitoring. Another woman has had a cavity since 2010, but as the cost of the initial consultation was $300, she fears that she does not have the money to have the cavity filled in a second consultation.

6.2 Waiting times

Waiting times were raised by a number of people we spoke to as an inconvenience and a barrier to accessing timely care.

When attempting to access services in large, corporate medical centres, many people spoke negatively about the length of waiting times. Lung Life ACT members felt that the long waiting times contributed to a *"dreadful"* experience.

> *"At Ginninderra Medical Centre you have to wait up to two hours to be seen."* (Dee)
>
> *"The biggest problem is having to wait."* (Participant, Dickson College students session, 25 September 2013)

Young people spoke favourably about the introduction of an electronic system where the patient could be notified by SMS when they were going to be seen. In this way, consumers would not be required to stay in the waiting room for unreasonable lengths of time. The young people we spoke to acknowledged that long waiting times, and the perception of them, can deter young people from seeking care at all.

Women in the Aboriginal and Torres Strait Islander session felt that waiting times for children's dental services, even through Winnunga Nimmityjah were not tenable, and meant that she was forced to find care for her children elsewhere.

> *"Kids should be a priority [for dental care]."* (Participant, Aboriginal and Torres Strait Islander Women session, 25 October 2013)

Pain Support ACT members discussed difficulties experienced by themselves, and people in their networks, in finding timely treatment for chronic pain. The public system is unresponsive and the private system can be quite expensive.

> *"Accessing public health services [for pain] is difficult…there are long waiting periods. It takes ages to get into the public pain clinic here. It's something like 18 months at the moment. Which misses the three-month opportunity to actually stop the chronic pain continuing. Which is such a waste of public money and so terrible for those people. They just have to wait and make do. And it's pretty hard to make do if you're in chronic pain…people are pretty heavily reliant on medication, which is not the only way to manage pain…access is very poor."* (Participant, Pain Support ACT session, 22 October 2013)

The issue of chronic pain management in the ACT is compounded due to the long waiting period to access the Pain Clinic at the Canberra Hospital. This makes it very difficult for consumer who require the support of a tertiary service, and also for general practitioners who may not have an adequate understanding of pain, and yet are left to meet the demands in the community. This is an area which requires further investigation by the ACT Medicare Local.

Similar issues are experienced by people with hepatitis. For example, Caroline was referred to the Liver Clinic by her GP, for treatment for Hepatitis C. Caroline called the Clinic through the switchboard – her call was not answered, and so she left a message. Staff from the Clinic/switchboard failed to call Caroline back, even after 2 months. Caroline attempted to make contact about 3-4 times, with the same result. She also faxed in her referral, and received no response. After a period of no treatment for hepatitis, Caroline is keen to take up some new treatment methods, but is unable to do so because she cannot access the Liver Clinic.

While the Liver Clinic is an acute service, the difficulties faced by consumers in attempting to access the service mean that there is more pressure on general practice to meet the needs of consumers like Caroline. GPs require increased knowledge around liver disease and blood-borne viruses like hepatitis. It is also worth considering the role of general practice in monitoring access issues when referrals are made.

6.3 Transport

While transport did not feature heavily as a barrier for most of the people we spoke to, those who were affected tended to be marginalised and of lower socio-economic status.

Harlee indicated that transport was an issue for her when accessing non-GP services, as Winnunga provides transport for general practice consultations. She doesn't drive and is not eligible for community transport. She noted that some bus journeys can take hours.

At Ainslie Village, the residents listed transport as one of the main issue preventing them from accessing care. Distance from health services often meant that residents were more likely to just *"sit it out"* or try to treat themselves.

> *"Transport is the major thing. It takes half an hour to walk to the city and I can't walk back up the hill. Buses come every half hour and the nearest stop is Chisolm Street."* (Participant, Ainslie Village residents session, 10 October 2013)

Older people with chronic conditions also struggled with getting access to transport as options for those with limited mobility can be few and far between. Lack of viable transport options often means that people forgo treatment.

> *"My friend needed to go to the GP because she was unwell. She doesn't drive. She's on a pension and can't afford a taxi. Buses are difficult for her because her mobility is impaired. In the end, that lady just stayed at home."* (Participant, Pain Support ACT session, 22 October 2013)

A member of the ACT Aged Care Consumer Reference Group stressed that older people are not a homogenous group – the transport needs of a 65 year old are different from those of an 85 year old. This needs to be considered when planning for services.

While the issue of transport did not come through strongly in this project, its impact on the ability of people to access care should not be downplayed. It relative absence from this feedback can be attributed to the demographic bias of some of the feedback components, which are discussed in the limitations of the project, in section 3.

6.4 Language and interpreters

Anecdotally, HCCA is aware that access to interpreters is an ongoing issue for culturally and linguistically diverse Canberrans.

CALD key informants noted that many service providers do not provide interpreter services for their clients. Often CALD people require assistance to make appointments and support during their consultations. Many GPs do not use the telephone interpreter service, even though it is free, with anecdotal reasons for this being that it limits their time with clients.

In the context of this project, women in the South Sudanese Mother's Group indicated that while they are offered interpreter services, and that interpreters are provided for consultations, often these interpreters do not speak the right language. Members of this group speak Dinka, with many members also speaking Juba Arabic. However, interpreters organised for them by their general practices spoke Middle-Eastern dialects of Arabic, which are not intelligible with Juba Arabic.

Antonia also shared her experience of interpreter services in Canberra. While her English is now proficient, when Antonia first arrived in Australia she did not speak any English. When asked about accessing services during this time, Antonia said that she had luckily been able to locate a GP who was able to speak with her in her native language – something she saw as integral for understanding her condition and treatment options. On another occasion, the Red Cross hired an interpreter to attend a consultation with her. While Antonia was aware of the phone interpreter service, she preferred the security of having an on-site interpreter.

HCCA has collected feedback from CALD consumers about their access to interpreter services in Canberra, as part of our work on the Health Infrastructure Program. A selection of this feedback can be found in section 8.

7. After-hours primary health care experiences

7.1 healthdirect

Many people we spoke to said that they hadn't accessed suggested healthdirect simply because they didn't know it existed.

> *"I would definitely have used [healthdirect] if I'd known about it."* (Participant, Dickson College students session, 25 September 2013)
>
> *"I would use healthdirect if you put the word out. People would get on board if it was advertised properly."* (Participant, Ainslie Village residents session, 10 October 2013)
>
> *"I wish I'd known about it a couple of weeks ago, I had hay-fever and got nose bleeds from the sneezing. I went to the GP and he just answered my question straight away. I had to pay the full cost [of the consultation] when I could have just called the phone line."* (Participant, Dickson College students session, 25 September 2013)

Reponses about healthdirect from people who had used the service were variable.

For example, Krissy received advice from healthdirect prompted her to go to the GP twice. The GP advised that no treatment was necessary and that the condition would resolve itself in a few days, which it did. Krissy spoke about the "stress" involved with the healthdirect procedure and that she has adopted a "should I bother calling?" mentality about the service, due to less than ideal outcomes in the past.

> *"They take a long time taking your details, which can be stressful in an urgent situation. In this situation you're nervous, stressed and really worried…you don't want to spend time giving your address to someone on the phone."* (Dee)

Some people we spoke to raised concerns that healthdirect was not locally adapted, meaning that they did not refer people to the Walk-in Centre or CALMS, when these options may have suited consumer needs.

> *"I called [healthdirect] and they told me to go to the Emergency Department."* (Georgina)
>
> *"[healthdirect is] sometimes useful although the nurses seemed to play it safe in recommending further medical attention, which was a little alarmist."* (Playgroups ACT survey respondent)

However, Georgina did still see some value in the service:

> *"It's good for reassurance in the middle of the night."* (Georgina)

Others spoke very positively about healthdirect.

> *"[healthdirect] is really, really helpful…they gave me immediate advice on the spot I didn't feel like it was just one person's opinion…it's an informed, step-by-step process, but it does feel tailored to your situation".* (Rebecca)
>
> *"The few times I have accessed this service have been terrific. Very reassuring about when to worry and when not to worry. Very professional, caring and easy to understand people made it well worthwhile."* (Playgroups ACT survey respondent)

Both Ali and Lulu indicated that calling a phone line would not occur to them during a stressful health care episode.

> *"In a panic, I wouldn't think to look [healthdirect] up."* (Ali)
>
> *"Where I come from, we don't have it so we don't use it. I didn't think to use it."* (Lulu)

7.2 CALMS

Almost half of the consumers interviewed were aware of CALMS or had accessed this service. Kendall spoke highly of CALMS, saying that she had used it a number of times *"usually after a long night"* of dealing with illness.

Interactions with GPs at CALMS were not always of the highest quality.

> *"I'm fairly happy [with CALMS], but the lady on the front desk was grumpy and the GP wasn't great with kids…and he didn't make my son feel comfortable…but he did get better as it [the consultation] went along."* (Rebecca)

Cost remains an issue for consumers on low incomes in the after-hours period. Several participants indicated that they would not use CALMS due to the costs associated with the service.

> *"I wouldn't use CALMS because I don't have the money. I'd wait at ED."* (Harlee)

Young people were reluctant to access CALMS, commenting that they thought the services would not be as personal and that it would be better to see someone who knew their background.

> *"The other day my friend's mum said just to wait until during the week, because those GPs are more likely to care."* (Participant, Dickson College students session, 25 September 2013)

7.3 Pharmacy

Very few people spoke specifically about using a pharmacy in an after-hours context. Tracey indicated that this would be her first choice, and she believes that the Inner North is well-served in regard to late-opening pharmacies. Marg also spoke about what she action she would take in an after-hours situation, noting that if she runs out of medication she speaks to the pharmacist who will provide her with an advance – a benefit of developing a relationship within community pharmacy.

Several people we spoke to didn't have the confidence to judge what was appropriate to ask a pharmacist for advice about.

> *"I feel like I shouldn't ask them [pharmacists] too much because they might get in trouble."* (Rebecca)

7.4 The Walk-in Centre

A number of participants displayed some confusion between the Walk-in Centre and no-appointment medical clinics, like Phillip Medical Centre. People who had not used the Walk-in Centre indicated a lack of understanding of the service's scope of practice.

> *"The Walk-in Centre is not on our [her family's] radar".* (Cassandra)
>
> *"I'm not entirely sure what they [the Walk-in Centre] would treat."* (Kieran)
>
> *"Is it [the Walk-in Centre] for regular check-ups?"* (South Sudanese Women's Group)

Almost half of the consumers interviewed indicated familiarity with the Walk-in Centre. While there was reasonable awareness of this service, less than a quarter of people interviewed had actually accessed services at the Walk-in Centre.

Women in the Aboriginal and Torres Strait Islander session expressed some frustration that this service was not available to children under two years old.

People who rely on public transport continue to struggle to be able access some services in the after-hours period. While most participants in the project had access to private transport, young people and people on low incomes needed found it more difficult to go outside of their local area for services.

> *"I wouldn't be able to get to the [Walk-In Centre at] TCH by myself."*
> (Participant, Dickson College students session, 25 September 2013)

Although they had heard of the Walk-In Centre, older A Gender Agenda members had not used the service before. One person said they might consider using the Walk-In Centre for very minor conditions. Another person (with multiple chronic conditions) commented:

> *"My issues are too complex for the Walk-In Centre."* (Participant, A Gender Agenda older people session, 10 October 2013)

This attitude is consistent with anecdotal evidence received by HCCA from consumers with chronic conditions. The Walk-in Centre is not designed for people with more complex needs, and thus there remains a gap for people in this category in the after-hours space.

Additionally, interviewees reported that sometimes the "sick certificates" issued by the Walk-in Centre are not accepted by university lecturers.

8. Relevant findings from the "GP Snapshot 2013" survey

Between 5 September 2013 and 4 October 2013, HCCA ran a survey designed to capture a snapshot of consumer experiences and expectations of general practice in the ACT. It explored issues about consumer experience with GPs (e.g. the quality of the interaction and waiting times) as well as other ways that people access health information and demographic material.

The survey was publicised through HCCA members and networks, and social media. Publicising the survey involved a snowballing technique that identified highly engaged individuals and organisations and asked them to spread the word and encourage people in their networks to participate in this important survey. There were 617 responses which demonstrate a strong interest in the community around this issue.

This is the second such survey undertaken by HCCA – the first was *GP Snapshot 2009*. These are two cross-sectional surveys which capture snapshots in time.

The differences in demographics between *GP Snapshot 2013* respondents and the ACT population highlight the limitations of this survey method. It is noted that (a) respondents self-select and (b) they may not always be referring to their personal experiences, but maybe of family members or someone for whom they provide support. The percentages reflect the membership of HCCA and other Canberra based community boards. The demographic sample shows:

- There was a disproportionate number of women (78%) compared to the ACT figures (50%)
- Almost 50% of the respondents were 55 and over (the ACT population is approximately 25%)
- The representation of the 35-54 age groups responding to *GP Snapshot 2013* has decreased by one-third from *GP Snapshot 2009*
- The proportion of indigenous people was approximately one third that of the ACT population
- The proportion of people who speak a language other than English at home was approximately one half of the ACT population, although double the figure of 2009
- Eleven percent of respondents said that they usually visit the GP for their children
- Forty-seven percent of respondents said that they had seen a GP in the past 12 months with someone that they cared for or supported

HCCA has completed preliminary analysis of the data collected from the survey, a sample of which can be found below. HCCA will further interrogate this data in 2014.

Regular GP status

The majority 546 (89%) of respondents to *GP Snapshot 2013* have a regular GP (n=613). This is 8% higher than reported in *GP Snapshot 2009*.

Table 3: Regular GP in Relation to Place of Residence

Place of residence	Respondents n=570 (%)	Have a Regular GP n=511 (%)	Do not have a Regular GP n=56 (%)

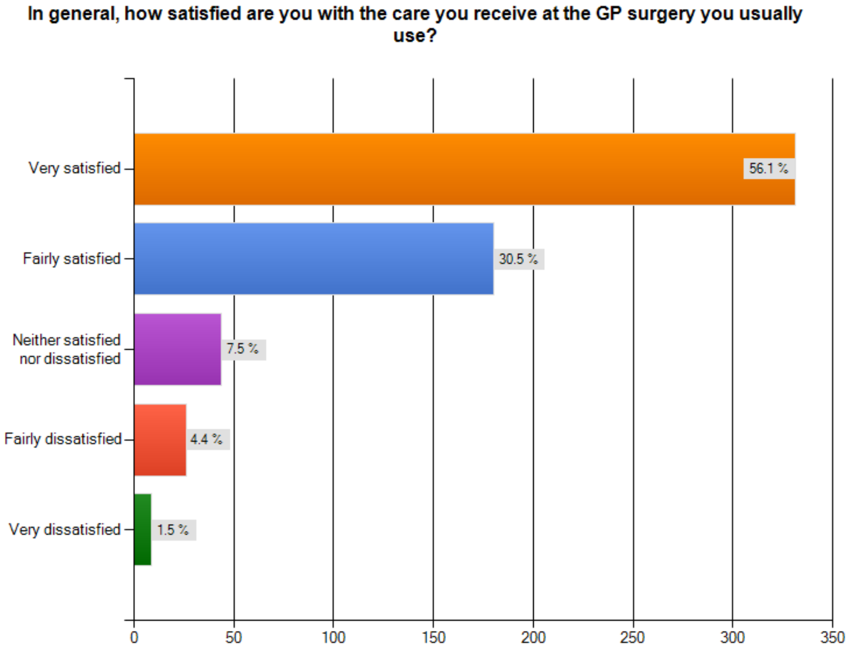
Belconnen	135 (24)	122 (24)	13(23)
Gungahlin	34 (6)	31(6)	3(5)
Inner North	108 (19)	93(18)	15(27)
Inner South	28 (5)	25(5)	3(5)
Woden	55 (10)	50(10)	5(9)
Weston Creek	61(11)	54(11)	7(13)
Tuggeranong	121(21)	113(22)	8(14)
Surrounding NSW	25(4)	23(5)	2(4)

This table shows that since *GP Snapshot 2009*:

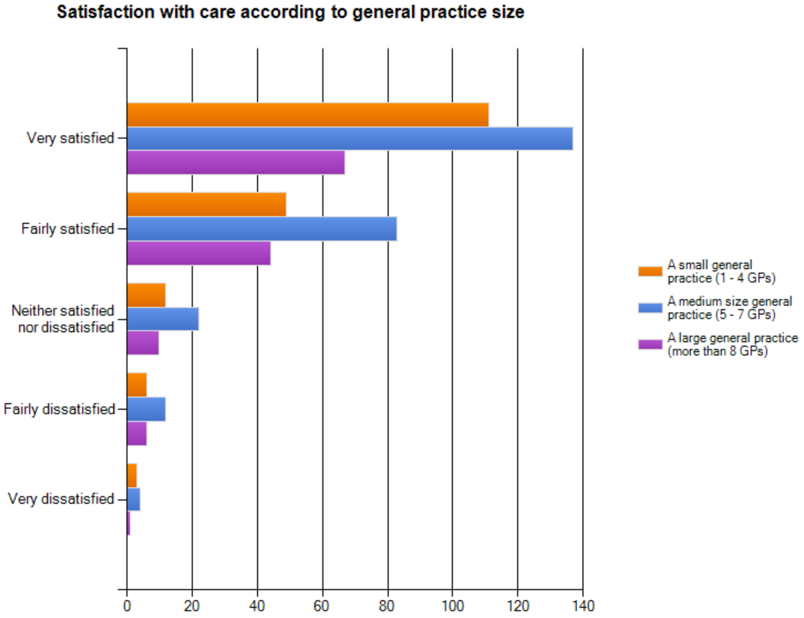
- There is an overall improvement from 106 respondents not having a regular GP to now only 56 respondents;
- Respondents living in Belconnen are more likely to have a regular GP and those in Weston Creek are less likely to have a regular GP; and
- The biggest growth area – Gungahlin – has less respondents than in 2009.

Satisfaction with current GP services

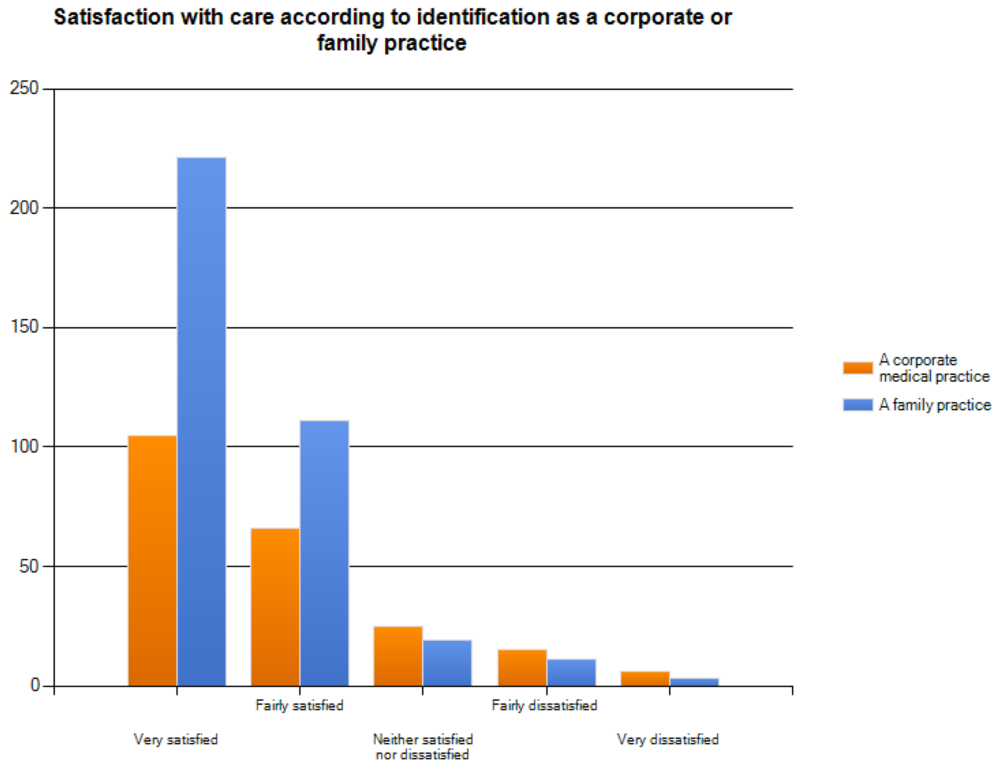
Eighty-seven percent of respondents to *GP Snapshot 2013* are satisfied with their GP. It is encouraging to note an increase of 7% in satisfaction levels from *GP Snapshot 2009*.



Respondents showed similar levels of satisfaction (very satisfied or fairly satisfied), according to whether the practice was small (88%), medium (85%) or large (87%).



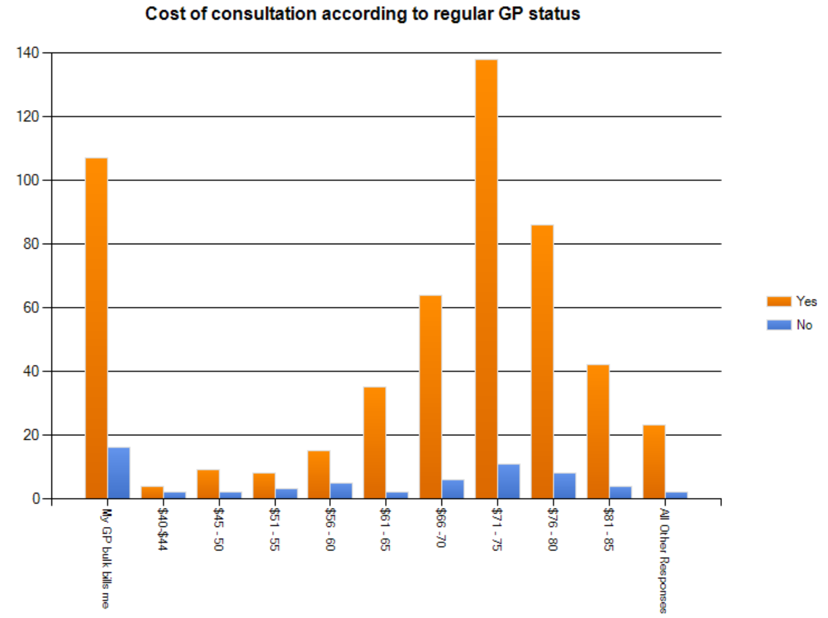
Respondents who used family practices (91%) were more likely to be satisfied than those using corporate practices (79%).



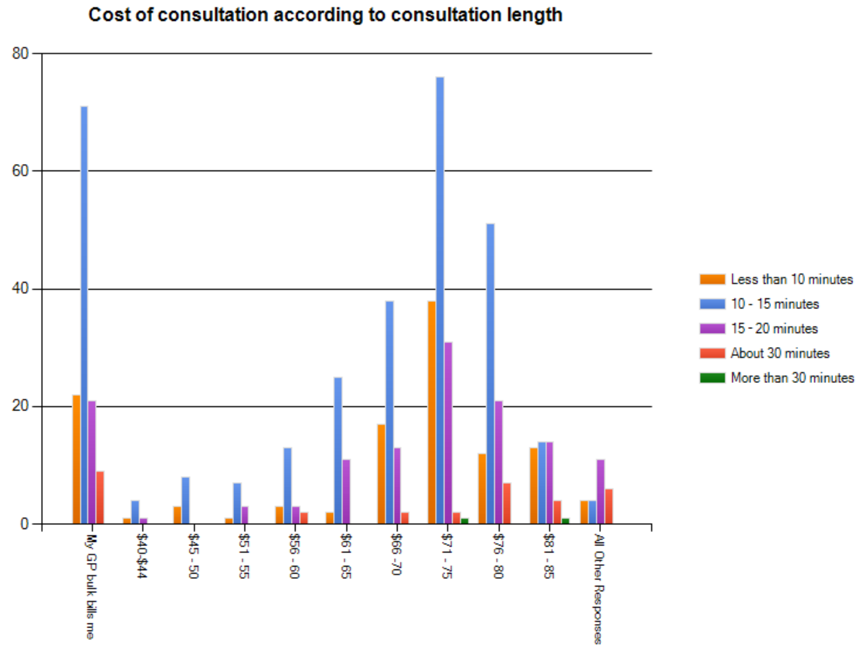
Cost

GP Snapshot 2013 supports the issue of there being limited bulk billing practices. Only 21% of survey participants have a GP who bulk bills them. This is less than the 27% in 2009. On the other hand 67% pay $61 or more per consultation; considerably more than the 50% in 2009.

37% of consumers reported that they did not follow up on referrals to other primary health care practitioners including podiatrists, physiotherapists, dieticians, psychologists and occupational therapist as the cost is prohibitive. 40% did not follow up on referrals to specialists and 21.4% did not follow up on referrals for diagnostic tests because of the cost.



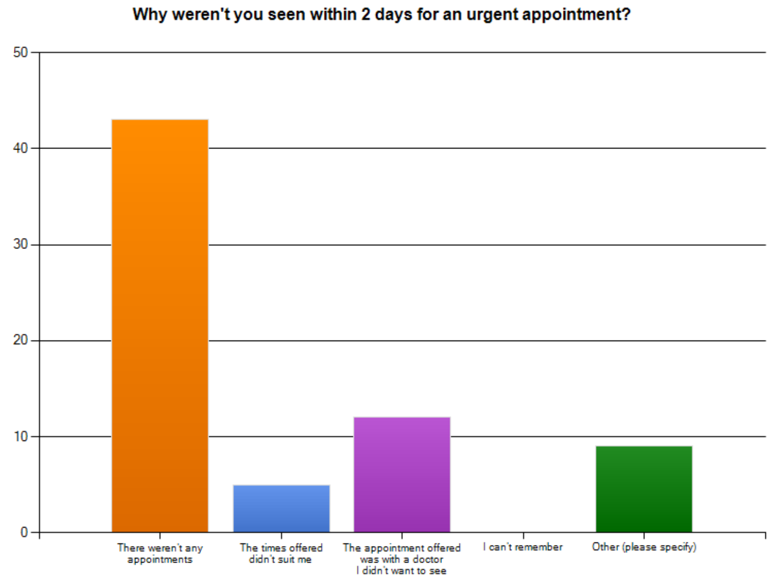
Respondent d 15 minutes. Length of consultation did not increase with out-of-pocket expenses.



Urgent access

When urgently needing to see a GP, 46% of respondents to GP Snapshot 2013 were able to make an appointment on the same day. Another 24% could make an appointment on the next day, 16% within 2 days, 6% within 3 days and 7% longer than 3 days. These are similar to figures reported in 2009. 62% thought that it was reasonable to be seen on the same day, with another 28% on the next day and 8% (2009:16%) within 2 days. This time expectation is reduced from 2009 when more than 80% thought that they should be seen on the same day.

87% of respondents who were unable to receive an urgent appointment were not able to make an appointment as there were no appointments available. This is more than double the percentage reported in 2009.



Waiting times

GP Snapshot 2013 asked respondents about their experiences of waiting in the practice.

Waiting Times in GP Practices

TIME	USUAL EXPERIENCE WITH APPOINTMENT n= 578 %	USUAL EXPERIENCE WITHOUT APPOINTMENT[2] n= 563 %	EXPECTATION n=581 %
No wait	3	1	3
Up to 15 minutes	25	0	50
Up to 30 minutes	32	1	37
Up to 45 minutes	16	1	4
Up to an hour	16	2	5
More than one hour	6	4	1

The figures for usual experiences are similar to 2009.

While most respondents (54%) expect that the wait should be less than 15 minutes, only 27% indicated that they are usually are seen within that time. This is significantly worse than 2009 figures. 5.9% of respondents indicated that they usually wait more than an hour.

Contact with the GP

Consumers were asked in *GP Snapshot 2013* if they have had email contact with their GP in the last 12 months. Only 5% of respondents indicated that they had been in email contact. However, when asked if they would like to have email contact with their GP two thirds of consumers responded *yes.*

Would you like to be able to email your GP?

	Small Practice n=177(%)	Medium Practice n=255 (%)	Large Practice n=127 (%)
Yes	**114(65)**	**171(67)**	**86(68)**
No	63(35)	84(33)	41(32)

As stated in the report on *GP Snapshot 2009*, given the high reliance on email and other web based medium for contact both personal and professional use, it is reasonable to expect that GPs could make themselves available in this way.

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[2] 91% answered not applicable as their GP only takes appointments.

9. Feedback from other HCCA community engagement mechanisms

Commencing in 2012, HCCA has conducted a series of information sessions about the Health Infrastructure Program. These sessions include a question and answer component, during which participants raised a number of issues relevant to this project.

Epilepsy ACT

Participants in this session raised a number of issues regarding access to primary health care, including transport, practitioner knowledge about epilepsy, stigma and discrimination, access to treatment, and transitions between different levels of care.

People with uncontrolled epilepsy are generally unable to drive, restricting their ability to get around and participate within society. Community transport are reluctant to take people with "uncontrolled" seizures, and people with epilepsy only qualify for the taxi subsidy scheme if they have a certain number of seizures per year.

A number of participants spoke about the lack of awareness, demonstrated by health professionals, and the wider community, about epilepsy. Participants indicated that sometimes their seizures have been interpreted by staff as violent behaviour or mental illness, resulting in people being taken to police stations or treated in a mental health facility.

Epilepsy often remains undiagnosed for a long time. There are many different causes/presentations of epilepsy, making it difficult to uniformly treat or diagnose – the condition requires very tailored diagnosis and treatment. It is hard to generalise about epilepsy because of this. GP education around epilepsy appears to be generally poor, and misdiagnosis at the primary health care level is a concern – one person was diagnosed with epilepsy, had a seizure at the hospital and was treated as a psychiatric patient. A second diagnosis for this person was "complex headaches" rather than epilepsy.

The quality use of medicines is a key issue for people with epilepsy – interactions between the suite of medications used to treat epilepsy can be adverse when not monitored appropriately.

Participants indicated that if they have an interaction with the hospital, sometimes they are discharged inappropriately, either when they have no support at home, when they are inappropriately attired and don't have transport to return home, or when their medical condition is very serious.

Carers ACT Chinese Group

Participants noted that often interpreter services were not offered to patients when required. There was no introduction of the Translating and Interpreting Service during initial patient contact in primary health care.

Participants were also keen to see more information about health and services provided in Chinese.

Issues of transport were of concern to this group as well. Out of 18 members in this group only 2 or 3 people drive. This issue had a high impact in this group as they use mainly public transport, which can make it difficult to access services in a timely and stress-free way.

Carers ACT Greek Group

Participants noted that interpreters are not always offered or provided by health services. Additionally, there are consumers who cannot read English and so require written information in Greek.

Participants commented that limited consultation time and minimal information provided to patients made it difficult to fully understand treatment programs. It is important that clinicians take the time to ensure that their patients understand the course of action, especially for migrants who have limited English language skills. Many participants noted that clinicians do not have appropriate cultural awareness when communicating with them.

Carers ACT Indian Group

Dental care was very important issue for this group, but was difficult to obtain due to the costs associated with private treatment and the waiting times in the public system.

Carers ACT Spanish Group

Several participants spoke highly of the Walk-in Centre, saying that the service was "fantastic" and "very effective". Other participants had not heard of the service, and suggested that it be advertised more broadly.

Participants in this group tended to use friends or family members as interpreters during medical consultations, particularly when they were not offered assistance by the health service. Some participants had used TIS services, but had found these unreliable.

Carers ACT Tongan Group

Dental care was of concern to participants, particularly in relation to long waiting times for older people, costs of private services, and a perception of the low-quality of service. One participant had a filling treatment performed, however after a short while the filling fell out. Another participant organised a dental appointment in the public system, but had to wait more than six months. Due to the severity of the pain, the patient had no other option than going to a private dentist but could barely afford it.

English proficiency in this group varies from limited to functional. Some participants used family or friends to translate during medical appointments, while other participants simply made do. Participants would be keen to see a doctor who speaks their language, but were unsure about how to find one.

Most of the members in this group depend on public transport and community transport to take them to medical appointments. Many participants had mobility issues, but continued to use public transport as the community services are oversubscribed.

Carers ACT Vietnamese Group

Participants raised the issue of a shortage of doctors in residential aged care, and the difficulties in obtaining GP attention for residents.

Participants also noted concerns about the qualification of some overseas trained GPs. Some participants found that the patient interaction of some overseas trained doctors was poor and that often they had to be prompted to perform basic tasks such as hand washing and blood pressure monitoring. One participant noted concerns about medication management and the provision of a medication which caused an adverse reaction – despite this, the medication regimen was not altered.

Southside Community Services Bingo Group

Participants raised the issue of poor public transport access in Tuggeranong, noting that sometimes they have to take three buses to get to appointments.

Southside Community Services Croatian Group

One woman raised the issue of expensive allied health services. Even with a rebate from Medicare, often the fee is too expensive for those on low incomes.

Participants agreed that television is the most effective way to communicate with this group. Hearing is also an issue for this group, so written information was another popular format.

Southside Community Services Spanish Group

Members of this group expressed that language was a major issue for them when attending primary health care consultation. Some participants were unlikely to trust the TIS telephone service, as there was a perception that they do not interpret well and do not have all of the details.

There was also a distrust of interpreters who learnt Spanish as a second language. For example, a woman requested onsite interpreter for her GP appointment. The interpreter was a non-native Spanish speaker and did not possess the right vocabulary to interpret medical information accurately. As a result, the consumer became confused about the requirements for taking her medication. Participants were also keen to see more information about health and services in Spanish.

Access to adequate public transport remains an issue for the community in general. Many of these participants did not leave near transport hubs, making it difficult to access relatively isolated services, such as Village Creek.

Communication tools came across as missing part for this group in any context of the health system. This group has missed out on important information due to the lack of communication provision particularly in their language. There was a lack of awareness of changes happening in the health system due to some people not able to have access to technology hence missing the access to other information. The majority of people this group were not aware of the information that was provided in regards to HIP developments.

Participants also spoke about their concerns regarding dental services, such as the long waiting times and expensive fees. Several participants indicated that it was difficult for them to eat due to the severity of their oral health problems. However, they simply do not have the money to pay for private treatment.

Brindabella Women's Group

Attendees raised the point that many women, and mothers, are socially isolated and financially disadvantaged and will need outreach support in order to be able to access services.

There was some uncertainty about the Walk-in Centre and questions were raised in connection to doctors. Participants at the session seem to be presenting at the Emergency Department because they are unaware of what other services are available. One attendee reported that she had waited at the ED for 5 hours for a suturing for her child. A comment was also made about not knowing the limitations of the Walk-in Centre scope of practice – one attendee had presented at the Walk-in Centre and was then referred to CALMS, which was both frustrating and time consuming. Discussion took place about the need for the provision of better information around the Walk-in Centre scope of practice.

Issues were raised about the quality of interactions with internationally-trained doctors, such as an absence of hand-washing. Another participant also noted that after taking her child to see the GP, the doctor told her not to bring her other two children to the next consultation.

Canberra Multicultural Community Forum SMILES Group

Some members of this group expressed concerns about the lack of information available about TIS services and how members of the CALD community can they access this service. Other questions were raised around the extent of languages and associated costs.

Majura Women's Group

In connection to mothers using the "Sleep and Settling Service", which only allows the baby and mother to be present, attendees commented that this is impractical for mothers with more than one child. There is a need for assistance in relation to looking after other children during appointments. Some mothers find it difficult to attend appointments for themselves if child-minding is not available. Additionally, the cost of child-minding can be prohibitively expensive for some families. The group suggested including child-minding services next to the clinic.

Some women in this group felt that the Health Direct line takes too long to provide advice.

Weston Creek Community Council

Predominantly, the issues raised at this Council meeting centred on the lack of services in the Weston Creek area. While the Community Health Centre and Walk-in Centre model were seen as positive developments by participants, there were concerns that no such services are forthcoming in the Weston Creek area, especially in relation to the projected population increase due to a number of suburban developments. There have been difficulties for Weston Creek residents in accessing community health services at the Tuggeranong and Phillip Centres due to waiting lists and “out of area” issues. GP services are also in short supply and participants in this session expressed a desire for governmental incentives for the establishment of private practices. Participants were also keen to see the consideration of a Walk-in Centre for the area. In addition, there were some concerns raised about the lack of services for men provided by the Community Health Centres.

10. Opportunities for further exploration

Access to GPs

As outlined in previous sections above, generally, people had adequate access to GP services when they needed them. Some participants retained a perception that GPs have "closed books" despite an increase in the number of GPs serving the ACT population – this may reflect the different ease of access to services in different geographical areas. As the ACTML's Population Health Commissioning Atlas notes, the ratio of GPs to population rose between 2009-2010 and 2011-2011. However, many participants still reported that they struggled to see their preferred GP when they needed to. Additionally, the Atlas notes that in Canberra, rates of visits by GPs to Residential Aged Care Facilities are considerably lower than the national average, something that is echoed by the findings of this project. As a participant in the ACT Aged Care Reference Group facilitated discussion noted:

> *"GPs, I feel, would prefer not to continue on [with older patients]…they don't make house calls or go to residential aged care facilities…even if you're in your 80s or whatever, they still expect you to be able to go to them."*

Issues of primary health care for older people are expanded on in Appendix 4.

Education, training and awareness

One of the key concerns raised by participants with specific and/or complex needs was the lack of available GPs with the requisite knowledge to undertake diagnosis and ongoing condition management. While the Atlas discusses the prevalence of neurological disorders like dementia and Parkinson's Disease, it fails to address rates of other disorders like epilepsy (estimated to affect 3-3.5% of Australians at some point in their lives) and chronic pain (estimated to affect 20% of Australians at some point in their lives, or more than 30% of Australians over 65). Other specific issues around gender and alcohol and other drug use are not treated as comprehensively in general practice as they could be, due to a lack of practitioners with adequate skills to deal with these issues in a sensitive and effective way. In addition, CALD, Aboriginal and Torres Strait Islander, and young participants require access to care that was culturally/age-appropriate and suitable for their needs.

The Atlas also fails to address the prevalence of hepatitis B and C. Left untreated, hepatitis can cause serious liver disease, resulting in liver failure and liver cancer, which can be fatal. Prevalence of Hepatitis C has been estimated by the ACT Government to be as high as 5000 people. One half of hepatitis B infections are undiagnosed, around 110000 people nationally. One quarter of those infected will die without treatment. Currently, only between 3% and 10% of those who could benefit from treatment are currently receiving treatment. High-risk groups for hepatitis B are overwhelmingly composed of migrants to Australian who were born overseas in high prevalence regions (especially in Southeast and Northeast Asia, sub-Saharan Africa and Pacific nations).

Cost

As the Atlas notes, 15% of respondents to a survey indicated that cost was a barrier in accessing primary health care services in Canberra, compared to 8% in "Metro One" areas.

This is certainly reflected through the information gathered in interviews and facilitated discussions for this project. While access to GPs has improved in Canberra over the past few years, rates of bulk-billing have not. Additionally, there was a reported perception that clinics which did bulk-bill provided a lower quality of care and a "herding cattle" mentality, when compared to a "family-style" general practice.

Navigating the system and coordination of care

Many participants reported that the main stumbling block for them to access timely care was working their way through the system. Few people had a comprehensive idea of what kinds of services were available to them, instead relying in GPs to assist them to recommending services and coordinating care. However, participants with complex needs often felt that their GPs had not provided them with enough information or the right kind of support, due to their lack of knowledge in dealing with particular issues. While some people sought out information for themselves, this can prove difficult if it is not consolidated, or available in the right format and language.

Effectiveness of community engagement models

As outlined briefly in section 3, there were some issues with employing this model of community engagement to gather feedback. The interviews conducted and facilitated discussions held yielded a great amount of high quality feedback. Mechanisms like these are useful for two main reasons: one, they provide the opportunity to collect information at a grass-roots, service user level; and two, they give people the opportunity to have their say, and also a feeling that they have been heard by the system. As such, facilitated discussions and semi-structured interviews remain valid tools for gathering feedback.

However, the employment of these methods in the CALD sector is not always appropriate, at least not initially. There are potentially cultural sensitivities around discussing personal information in a group context, or speaking to a stranger. While some of these sensitivities can be eased through the building of a relationship over time, this was not possible in the context due to the short timeframe of the project. Accordingly, further exploration of issues with CALD consumers should be undertaken over a longer period of time, allowing for the establishment of enabling relationships with group/community leaders.

Finally, the consumer interviews, not initially included in the scope of the project, provided a rich source of information for this project. However, due to the slightly ad hoc nature of their employment, the selection of participants was not as structured or diverse as it should have been. As such, if this method is to be employed again (which would be recommended), it would be necessary to develop a system of finding/selecting participants in order to ensure a broad spread of demographics and life experiences.

Appendix 1: Discussion guide

General

- When I say the phrase “primary health care”, what does that mean to you?

        - After their explanation, give the scope of primary health care, e.g. it can include things like GPs, physiotherapists, nurses and pharmacists and other services that you can access without a referral.
- What services do you think are working well/not working well with primary health care at the moment?

About the GP

- Do you have a regular GP? Why/why not?
- If you don't have a regular GP, do you have a regular general practice? Can you explain a bit about what it's like?
- What kinds of things do you go to the GP for?
    - Prompt if required: coughs, colds, regular appointments for condition management.
- Does your GP explain things to you in a way that you understand? Does your GP make you feel like you can ask questions?
- Has there ever been an occasion when you wanted a home visit from a GP? What were the circumstances?
- Do you get referrals from GPs to other service providers? Do you understand the referral process? Do you act on these referrals? Why/why not?

Other services

- Do you use allied health services like physiotherapy, pharmacy and podiatry?
- Do you know what a practice nurse is? Use practice nurse services?

Access

- What barriers exist that could prevent you from accessing services?

        - Prompt if required:
            - Cost
            - Transport
            - Location
            - Access to interpreter
            - Physical accessibility of the building – lots of steps, parking located far away
- Have you had any problems in getting to health services when you have needed them? If so, what was the problem?

After-hours access

- What does "urgent" mean to you? What does "emergency" mean to you?
- Have you ever needed access to "urgent" or "emergency" primary health care services? What were the circumstances and where did you go?
- Do you know what after-hours services are available and how to access them? Have you heard of the "Know Your Options" after-hours awareness campaign?
- Do you know about / have you accessed

  - the Walk-in Centre?
  - healthdirect?
  - Canberra Afterhours Locum Medical Service (CALMS)?

- Do you know if your GP is open after-hours or on the weekends / do you use a GP that is open after-hours or on the weekend?

Health information

- Do you access health information online or from other non-GP sources? Where do you go? If the Internet, what specific sites do you use?
- Have you heard of the Personally Controlled Electronic Health Record?

Final

- Are there any other system improvements you can think of that would make your access to health services easier?

Appendix 2: Facilitated discussion group background statements

A Gender Agenda

A Gender Agenda is a community support organisation for transgender and intersex people in the ACT. It represents a group of people within our community who are often marginalised and socially isolated. They have specific issues that relate to their gender, many of which health professionals are not aware. The expertise of transgender and intersex people needs to be recognised if they are to experience good care and have better health outcomes. In addition to their gender issues, young members of A Gender Agenda also face many of the barriers experienced by other young people.

Lung Life ACT

Lung Life ACT is a self-help group for people with ongoing, chronic respiratory conditions and their carers/families. They have a high level of insight into their illness and what they need to maintain their health and wellbeing. They know their bodies well enough to know when to take action and seek intervention.

Pain Support ACT

Pain Support ACT is a self help group for people living with chronic and persistent pain. Their needs have been overlooked until recently where there has been effective advocacy from a range of organisations at the local and national including HCCA, the Australian Pain Management Association, and Pain Australia.

South Sudanese Mothers Group

This group is facilitated by the West Belconnen Child and Family Centre and is designed for Sudanese families with children from birth to 5 years. The group aims to build links with the community and improve access to parenting information and services.

Aboriginal and Torres Strait Islander Strong Women's Group

This group is facilitated by the West Belconnen Child and Family Centre and is designed for Aboriginal and Torres Strait Islander women. The group provides information and activities for participants to learn new skills.

Dickson College students

This group comprised year 12 students from Dickson College, a co-educational institution located near the HCCA offices.

Ainslie Village

Ainslie Village is a facility which provides medium-term and crisis accommodation for homeless men and women. Currently, the Village has over 200 residents. Many residents have alcohol and other drug issues and dependencies, as well as mental health concerns and custodial histories.

Playgroups ACT Canberra Mummies Group

This group is hosted by Playgroups ACT, and comprises women from 25-40 who are stay-at-home mums or are employed part-time and their babies. The group is an unstructured play session held on Monday afternoons.

Facilitated discussions

A Gender Agenda young people

Participant	**Age**	**Location**	**Years in Canberra**	**Health rating**	**Gender**	**LOTE**	**Regular GP**
1	18-24	Woden	Less than 1	Good	Transgender	No	Yes
2	18-24	Gungahlin	More than 10	Fair	Male	No	Yes
3	18-24	Tuggeranong	More than 10	Very Good	Transgender	No	Yes
4	45-54	Inner North	1-2	Fair	Transgender	No	Yes
5	Did not disclose	Did not disclose	Did not disclose	Did not disclose	Did not disclose	Did not disclose	Did not disclose

A Gender Agenda older people

Participant	**Age**	**Location**	**Years in Canberra**	**Health rating**	**Gender**	**LOTE**	**Regular GP**
1	55-64	Belconnen	More than 10	Good	Transgender / Intersex	No	No
2	65-74	Weston Creek	More than 10	Good	Transgender	No	Yes

Dickson College students

Participant	**Age**	**Location**	**Years in Canberra**	**Health rating**	**Gender**	**LOTE**	**Regular GP**
1	12-17	Inner North	More than 10	Very Good	Male	No	Yes
2	12-17	Inner North	6-10	Very Good	Female	No	Yes
3	12-17	Inner North	6-10	Excellent	Female	Yes	Yes
4	12-7	Inner North	More than 10	Very Good	Female	No	Yes
5	18-24	Inner North	More than 10	-	Female	No	Yes
6	18-24	Inner North	6-10	Very Good	Male	NO	Yes

Lung Life ACT members

Participant	Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
1	65-74	Woden	More than 10	Fair	Female	No	Yes
2	65-74	Tuggeranong	More than 10 years	Fair	Female	No	Yes
3	65-74	Weston Creek	More than 10 years	Fair	Female	No	Yes
4	85+	Woden	More than 10 years	Fair	Female	No	Yes
5	65-74	Weston Creek	More than 10 years	Good	Female	No	Yes
6	80-84	Inner North	More than 10 years	Poor	Male	No	Yes

Pain Support ACT members

Participant	Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
1	65-74	Belconnen	More than 10	Fair	Female	No	Yes
2	75-79	Woden	More than 10	Very Good	Male	No	Yes
3	65-74	Woden	More than 10	Very Good	Female	No	Yes
4	75-79	Belconnen	More than 10	Fair	Female	Yes	Yes
5	55-64	Woden	More than 10	Good	Female	No	Yes

ACT Aged Care Consumer Reference Group members

Participant	Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
1	65-74	Woden	More than 10	Good	Female	No	Yes
2	65-74	Woden	More than 10	Fair	Male	No	Yes
3	75-79	Surrounding area, NSW	More than 10	Excellent	Female	No	Yes
4	75-79	Inner South	More than 10	Good	Male	No	Yes
5	65-74	Weston Creek	More than 10	Very Good	Female	No	Yes
6	55-64	Woden	More than 10	Good	Female	No	Yes

Ainslie Village residents

Participant	Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
1	65-74	Inner North	More than 10	Very Good	Male	Yes	Yes
2	45-54	Inner North	6-10	Fair	Male	No	Yes
3	45-54	Inner North	More than 10	Good	Male	No	Yes
4	55-64	Inner North	More than 10	Good	Male	No	No

West Belconnen Child and Family Centre South Sudanese Mothers Group

8 participants. Further data was not collected as this was an informal session.

West Belconnen Child and Family Centre Aboriginal and Torres Strait Islander Women's Group

5 participants. Further data was not collected as this was an informal session.

Playgroups ACT Canberra Mummies Group

15 participants. Further data was not collected as this was an informal session.

Appendix 4: The need for more coordinated and comprehensive primary health care for older consumers

Introduction

Acute care services in the ACT, as well as across Australia, face the monumental task of enhancing their service delivery to cater for an aging population living with increasingly complex, multi-organ conditions. We are strongly encouraging the ACT Medicare Local (ACTML) and the Primary Health Care sector to recognise and take up their role in reducing the number of older patients being admitted to acute care via the emergency department (ED) and improve patient outcomes.

This snapshot report provides a brief overview of research findings from Australia and around the world that demonstrate the need to take action in the primary health care sector to reduce the burden on acute care services and support older consumers to stay healthier for longer. The literature covered demonstrates a strong correlation between inadequate health care in community and primary care settings and increased hospitalisations and mortality rates in older patients. In particular, lack of coordination and integration between services across different levels of care has been identified as a major risk factor.

In this context, we then present some of the findings from our own investigation into consumer experiences of primary health care in the ACT to identify ways in which the ACTML can work to improve the care of older people in our community; to ensure that they can stay healthy, out of hospital, and independent for as long as possible.

Poor care of older people in acute settings and the ED

In 2012, Melbourne based advanced trainee Registrar Dr Karen Hitchcock wrote an essay for The Monthly magazine discussing the problems with treating elderly patients suffering from undifferentiated general decline[3]. These are the patients who have deteriorated to the extent that they cannot have their care needs addressed in primary health settings but are not at immediate risk of dying and so are considered only a low priority in the ED. In addition, these elderly consumers are likely to be suffering from multiple chronic conditions, which can also make it difficult for the ED to determine which team should take responsibility for the patient.

Unfortunately, older consumers suffering from undifferentiated conditions and requiring urgent care have nearly no option other than presenting to the ED. Often, their health has deteriorated in the community or in aged care settings due to inadequate support from the primary care system. Recently, one of our members has had difficulty accessing a medicines review for their father, who lives in a Residential Aged Care Facility (RACF). Ultimately, the RACF had to send her father to the ED in order to get him admitted as an inpatient. This has been highly traumatic for both our member and her father, who has deteriorated significantly as a result of the delay in accessing care.

Speaking about the essay in a Radio Interview on ABC's Radio National, Dr Hitchcock commented that we are beginning to see a gradual shift towards a revival of 'general

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[3] Hitchcock, (2012). Last Resort: How the rebirth of general medicine will save lives. The Monthly Magazine. http://www.themonthly.com.au/how-rebirth-general-medicine-will-save-lives-last-resort-karen-hitchcock-5619

medicine' and a more holistic approach to acute care. However, there is a phenomenal amount of work still to be done in order to ensure that Australia's health system will be able to meet the needs of its aging population.

On the other hand, older consumers who are admitted to the ED with immediately life-threatening conditions are often required to undergo costly and invasive procedures that involve a long and difficult recovery process. It is also highly unlikely that they will be able to regain their former level of daily functioning and continue living independently. While some of these cases are unavoidable, the significant costs and consequences associated with urgent ED presenations mean that reducing the demand for ED and acute care services needs to be a top priority for the primary care system.

Deterioration and re-admission following hospital admission

Many older people who are admitted to hospital for an acute illness will have some form of co-morbid mental illness or cognitive impairment. This has been found to have a significant impact on patient outcomes. One recent study followed the recovery of 250 patients aged over 70 years with some form of cognitive impairment after they were admitted to an English acute general hospital[4]. It was found that 31% of patients died during their initial hospitalisation, 42% were readmitted and 24% of community-based patients needed to move into Residential Aged Care Facilities (RACFs) within the next six months. In addition, less than half of the older patients were able to return to their previous level of daily functioning following discharge. The researchers concluded that a coordinated approach across a wide range of community services was required to better meet the needs of this people, both in terms of preventing hospitalisation and better supporting older consumers following hospitalisation for an acute illness.

Another study conducted in a Victorian public teaching hospital focused specifically on unplanned hospital re-admission rates for older patients[5]. The researchers conducted semi-structured interviews with older patients who were re-admitted to the hospital within 28 days of their initial discharge along with family members, caregivers, and health professionals. The participants interviewed reported positive experiences with regard to the treatment of their acute illness. However, there was a widely held perception that patients and family members left the hospital with little understanding of the underlying health problems and were ill prepared for further health problems. This was considered to have contributed to the patients' declining health and need for re-admission.

The findings from both studies show that many older consumers are likely to face significant deterioration following admission to hospital and that the acute care system is ill-equipped to handle this problem on its own. Both research papers called for a more coordinated and comprehensive approach from the primary and community care sectors to support older consumers to manage their overall health and well-being.

The role of primary health care in preventing avoidable hospitalisations

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[4] Bradshaw, et al., (2013). Six-month outcomes following an emergency hospital admission for older adults with co-morbid mental health problems indicate complexity of care needs. *Age and Ageing, 42*, 582-588.

[5] Slatyer, et al., (2013). Early re-presentation to hospital after discharge from an acute medical unit: perspectives of older patients, their family caregivers and health professionals. *Journal of Clinical Nursing, 22*, 445-455.

By improving the quality of and access to primary health care for older consumers, the number of elderly consumers admitted to hospital could be drastically reduced. This has the potential to significantly reduce the financial burden of our aging population and to improve the quality of life for a large proportion of our community.

Consumers agree that in some situations, hospitalisation is necessary and unavoidable. However, research has clearly indicated that particular factors in community settings significantly increase the risk of hospitalisation and subsequent deterioration for older consumers. This is also the case for residents in RACFs, where access to primary health care services is often limited. This lack of effective health care has been linked with avoidable hospital admissions, poorer quality of life, loss of physical functioning and mental health problems[6].

The remainder of this report is dedicated to identifying key aspects of primary health care that need to be addressed in order to better meet the needs of older consumers.

Findings from the literature

Comprehensive and coordinated services

A recent Kings Fund report on older people accessing EDs in the UK has identified a major need for improved coordination of primary care services to reduce the cost of unnecessary admissions to the ED[7]. The report found that if primary health care services across the whole of England were able to perform as effectively as the top 25% of the country, the number of hospital beds required would be reduced by 7000. Moreover, effective integration of primary, community and acute care services were associated with lower bed use by older people.

While the statistics may not necessarily reflect the health care situation in the ACT, the general findings from the Kings Fund Report are highly applicable to any health system looking to meet the needs of an aging population. The message is clear: primary health care providers need to work with both the community and acute care sector to provide more coordinated care of older consumers to improve health outcomes and reduce unnecessary expenditure. In addition, a coordinated health system makes it easier for consumers to navigate the system and access the care they need, rather than having to wait until things get bad enough that they end up in the ED.

Supporting carers

When an older person becomes unwell, it is often their spouse or next of kin that takes on the responsibility for their care. This is a major commitment that can take up considerable time and resources, in some cases to the detriment of the carer's health. Without adequate support form community and primary health care services, the caregiver burden can increase to the point where the carer is no longer able to care for their loved one. This in turn can result in the older person having to be admitted to an RACF prematurely or in inadequate care that leads to hospitalisation and more serious health issues. Research investigating

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[6] Australian General Practice Network. (2010). *Australian General Practice Network submission to the Productivity Commission inquiry into caring for older Australians.* Pg 5.
[7] Imison, et al., (2012). *Older people and emergency bed use: exploring variation*. The Kinds Fund.

caregiver burden has found a strong significant correlation with increased mortality and even mortality in older patients[8].

Primary health services need to ensure that carers are adequately supported in their role as well as assist them to maintain their own health and well-being. While part of this effort will involve recognising and responding to the needs of carers, it is mainly about developing services that enable consumers' to access the right care in a timely manner. Consumers and carers need to know where to go and be supported by coordinated services that facilitate effective navigation of the primary health system.

A holistic approach to health and well-being

Keeping people out of hospital is about more than just responding to acute illness as soon as it arises. Primary Health Care also has a key role in promoting healthy lifestyles and preventing illness. For consumers who already have chronic conditions, it can be particularly difficult for them to stay healthy and prevent other health problems from developing.

The Australian Longitudinal Study on Women's Health (ALSWH) research on women, health and aging[9] found that more than half of the women surveyed over the age of 70 years were living with one or more chronic conditions. The more chronic conditions the women had, the lower they tended to rate their own quality of life. Crucially, the ALSWH reported that the women living with chronic conditions were less able to engage in healthy lifestyle behaviours such as physical activity in order to prevent health issues such as obesity and reduce the risk of having a fall.

Older consumers are highly likely to have ongoing contact with particular primary health professionals, providing the unique opportunity to work with the consumer to monitor and maintain their overall health and prevent health problems from deteriorating to the extent that they require an escalation in care beyond the capacity of the primary care system.

Working with pharmacists

Research has also found that involving pharmacists in medication reviews as part of ACAT assessments can lead to more timely detection of medication related problems in older consumers[10]. This is just one way in which primary health care could develop a more coordinated approach to treating older consumers in order to improve health outcomes.

The CareWell–primary care program

The CareWell program is a primary health care initiative being trialled in the Netherlands aimed at providing integrated and complex care for elderly consumers in the community. A study into the efficacy and cost-effectiveness is currently underway to determine whether this type of primary care intervention is able to successfully reduce the hospitalisation of

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[8] Kuzuya, et al., (2010). Impact of Caregiver Burden on Adverse Health Outcomes in Community-Dwelling Dependent Older Care Recipients. *American Journal of Geriatric Psychiatry, 19*, 382-391.

[9] Australian Longitudinal Study on Women's Health, (2011). Major Reports: Women, Health and Aging. *Annual Report,* pg 15-17*.*

[10] Elliott, et al., (2012). Pharmacist-Led Medication Review to Identify Medication-Related Problems in Older People Referred to an Aged Care Assessment Team. *Drugs & Aging, 29*, 593-605.

older consumers and prevent deterioration and loss of functionality[11]. HCCA is very interested to see the findings of this research and would like to bring the program to the attention of the ACTML.

Findings from the Primary Health Care report

In conducting the research for the 'Primary Health Care in the ACT: Consumer Experiences' Report, HCCA conducted a number of one-on one interviews and facilitated group discussions with a range of older consumers. Some of the participants reported being in relatively good health and were satisfied with the primary care services available to them. However, older consumers living with a number of chronic conditions commented that they often found it frustrating trying to access the care they needed. These participants felt that GPs didn't always have a good understanding of complex chronic conditions such as chronic pain or mental health issues, which meant they were less able to provide useful advice to the consumers and direct them to appropriate services.

Participants also felt as though not enough was being done in the primary care sector to address gaps in services for older consumers in community settings:

"You'll get the HACC services in but then the GPs don't deal with the minimalist care that's coming in… there are major problems with delivering the aging in place policy."

Both older consumers and their carers found that one of the most difficult and frustrating aspect of the health system was the disconnect between different services and levels of care. When coupled with unhelpful administrative systems, the result is that older consumers are left with the responsibility of coordinating their own care but without the necessary resources and support. Many participants described instances where they knew exactly what they needed but ended up running around in circles trying to locate the right 'gatekeeper' in order to access the service. For instance, one participant with a chronic lung condition needed to replace part of their oxygen equipment on a Friday afternoon. They were told that they could not access equipment services without a referral from an Occupational Therapist, which would be impossible until the next week. They mentioned that if they had been dependent of oxygen at that point in time, they would have had no choice but to go to the ED.

However, most participants wanted to stress that this was a systemic failing, rather than a failure of individual health professionals:

"good people, lousy systems."

Other consumers mentioned that their GP had given them a permanent referral to access a specialist for their chronic condition. They were very happy about this practice and thought it could be more widely applied.

Another concern was that GPs were often reluctant to continue on with older consumers, and that many refused to make home visits or go to RACFs. This could result in older

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[11] Ruikes, et al., (2012). The CareWell-primary care program: design of a cluster controlled trial and process evaluation of a complex intervention targeting community-dwelling frail elderly. *BMC Family Practice, 13*, 115-123.

consumers ultimately becoming cut off from quality primary care services and the practitioners they know and trust.

Consumers with a disability or chronic condition that prevented them from driving also spoke about difficulties arranging transport to different specialist appointments. Public transport was often too infrequent or inappropriate for the consumers' condition. One participant mentioned that if they needed to access health care straight away, they would have to call an ambulance simply because they had no means of getting to any other service. Community transport services in the ACT have been raised as an issue by many of our members in the past, and we are aware that there are restrictive eligibility criteria that prevent many consumers from accessing this vital but limited service.

One of the interesting findings from HCCA's GP Survey 2013 was that 74% of respondents over the age of 65 had conducted a Google search in the past 12 months. Older consumers who were interviewed often commented that while they would take all health advice from the Internet with a grain of salt, they tended to trust government websites or sites run by reputable health organisations. This offers a cost effective opportunity to provide older consumers with additional information and resources to stay healthy for longer and access appropriate primary care services before a more serious condition develops.

Conclusions

The perspectives and experiences of older consumers in the 'Primary Health Care in the ACT: Consumer Experiences' report indicate that more effort is needed to improve the coordination and integration of health care services in the ACT. This is particularly imperative based on literature from around the world linking problems with primary health care and care coordination with excess hospitalisations and poor health outcomes for older consumers, including increased mortality. In addition, the number of older consumers living with multiple and complex chronic conditions is set to increase significantly.

As gatekeeper to the health system, the primary care sector has a significant role to play in meeting the needs of our aging population. Innovation and improvement in primary health care can help to prevent and manage illness, reduce avoidable hospitalisations and lessen the financial burden for both consumers and the health system itself.

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Appendix 5: Key themes from West Belconnen Child and Family Centre Closing the Gap interviews

Time

- “I need a good doctor with appointments”
- Need quick waiting times
- “I can wait 3-4 hours at Winnunga, which is a problem”
- 12 month wait for dentist at Winnunga
- Time at Winnunga a problem – “…could be the whole day”

Cost

- Winnunga is a one stop shop – no cost even if referred to in-house specialists
- Local GP too expensive, use “normal” GP.
- Good to have access to a bulk-billing psychologist
- “What if I’m on a single income with no health care card?”
- Access to cheap massage, nutrition, gym would be good
- Need bulk billing
- “I want a family doctor who treats us all the same”

Transport

- Transport to doctor hard
- Winnunga provides some transport
- A mobile service would be good, especially for older people

What we use

- “I go to AMS so I don’t have to shop around for a GP who has a clue about Aboriginal health”
- Use local “walk-in” style practice – Ginninderra Medical Centre
- Use local doctor
- Local doctor – West Belconnen Health Co-Op
- Use Winnunga
- Originally Winnunga, followed my GP from there
- Use a combination of local GP and Winnunga
- Use Winnunga
- Use Headspace

Aboriginal and Torres Strait Islander Community

- Health centre is a chance to connect the Aboriginal and Torres Strait Islander community and “see what’s going on”
- BBQs and events are good at Winnunga

How we stay healthy (from the kids)

- Healthy Food

- Sports
- Help from home makes it easier
- Water
- Exercise

Information

- Hard to find GPs if you're not from here
- Not enough information on Closing the Gap
- "I would use the Co-Op if it had Closing the Gap…my GP doesn't do it."
- No info about Closing the gap
- "I find out information through medical centres"

Identity

- Winnunga take Aboriginal and Torres Strait Islander and non-indigenous people, raising questions of priority?
- Anxious about identifying as Aboriginal or Torres Strait Islander – "They treat me differently"
- People question Aboriginality if the kids are lighter. Some anxiety about using Winnunga if kids are lighter – "They look at me because the kids are too white"
- I don't know if I would be accepted.
- Important to advertise if services are Aboriginal and Torres Strait Islander friendly

My family needs

- Hearing
- Braces
- Coughs and colds, episodic treatment
- Dental treatment
- Condition management, asthma

Mental health

- No structure for Mental Health at Winnunga
- Need Aboriginal and Torres Strait Islander Mental Health Team
- Need Health checks at school
- Mental health and wellbeing should be provided at school for teens

Facilitated discussion – ACT Aged Care Consumer Reference Group

4 October 2013

What is primary health care?

Participants defined primary health care as access to a GP or other frontline health staff. One participant also included disability equipment services in her definition.

"OT, physio, those sorts of outsources…ILC [the Independent Living Centre], all of that."

Another participant described primary health care as *"care that requires minimal interventions, making it possible for people to stay home, so that they don't require high level care…in hospital…care that is delivered in a community setting that removes the stress from the hospital."*

Barriers to accessing care

The need for referrals

Participants discussed a number of barriers, foremost the need for referrals to access many services that they perceive as "primary health care."

"There are some issues around emergency type support services. The classic was, someone needing bed blocks, Friday afternoon, went to the ELS, equipment loan service…they had them…only to be told, 'We can't issue them, because we need an OT referral'…where do you get that on a Friday after 3 o'clock?…they had to go and buy a set of blocks."

There was some frustration expressed that services, like the Equipment Loan Service, can only be accessed via a referral, and do not accept the autonomy of consumers to define and understand their own needs.

"The individual knows what they need…they wouldn't be asking for a wheelchair if they only needed bed blocks."

Similar concerns were raised with community nursing and access to speciality clinics.

"It's getting the referral…they've got the systems in place to expedite things, but you get tripped up at first base."

Navigating the system

Participants also discussed the difficulties encountered in navigating the system, particularly in knowing which service to access for which particular need.

"Unless you know who to go to…unless you can get contact with the right person [it's almost impossible]…it hasn't got any better."

"It's almost like saying, 'Oh, we don't really want you'…it took 12 months to get [a response saying] 'Oh, we can't help you'."

"[the hardest thing is] knowing about them [particular services]…you have to go to them and ask "Can you help me?'."

Staff and systems

Emphasis was also placed on the need to have appropriate trained and supported staff, particularly in residential aged care facilities and the aged care sector generally, in order to ensure the best experience for consumers. Participants agreed that workforce needs to be appropriately trained, waged and provided with acceptable working conditions.

While participants generally spoke positively about the staff working in frontline services, disconnection between levels of care and unfriendly administrative systems were also cited as barriers to accessing timely care, causing one participant to remark that the context was one of *"good people, lousy systems."*

On one occasion, a participant had tried to make an appointment at a Community Health Centre in person, only to be told that appointments had to be made over the phone. In another example, one participant attempted to organise for her wheelchair-bound partner to be weighed:

"We tried to get [him] weighed, and that simple thing became so complicated ... because they didn't have the right clinicians around."

In another example of a lack of coordination between tertiary and primary care, one participant recounted a friend's story, in which she was unable to receive community nursing support in the ACT for a frequent injection she was unable to perform herself, despite this being requested by a specialist interstate. As a result, the participant's aged friend must drive to her GP in another suburb three mornings per week in order to receive this injection.

Several participants also raised the lack of locally located pathology collection centres, as an issue, especially for people whose mobility is restricted. However, one participant mentioned, on a positive note, that his pathology is now collected from him at home by a community nurse, immensely simplifying the process.

General practice

All participants indicated that they had a regular GP, for varying lengths of time. All participants were generally satisfied with the care that they received, however one participant noted: *"prevention, they should be trained with that in mind"* and indicated that a greater focus on general health, instead of simply treating illness, would be welcomed. The participant continued"

"The older GPs are good at that [taking care of needs]...those clinics with multiple doctors are more worrying..."

Participants spoke positively about the appropriate use of practice nurses in a general practice setting, and indicated that they liked being able to use practice nurse services when a visit to the GP was not necessary.

Participants valued their relationships with their GPs, some of which had been developed over more than 10 years.

"My GP's very good, he doesn't argue with me! He listens to me, and I listen to him, and then make up my mind whether I agree with what he's got to say. He accepts the fact that if there is something wrong, I will come and tell him."

However, while participants were satisfied with their regular GPs, there was some frustration that appointments for their preferred practitioner had to be made weeks in advance. One participant remarked: *"You have to be sick a month in advance!".* When asked what course people take when their preferred doctor is unavailable, one couple said:

"We go to A and E, or the Walk-in Centre...or we have a back up doctor at a different clinic."

While there was a reluctance to refer to multiple-GP practise as corporate, (*"I wouldn't call it corporate because that has a cold, hard feeling about it."),* these larger practices were generally viewed favourably:

"There seems to be a proliferation of GPs coming together in groups...and I think that's a positive thing...our son has now established contact with the local clinic...they have dental and other ancillary services within the same practice...you can usually get in on the day."

There was general agreement that while GPs are capable of dealing with straightforward or basic issues, their skills in other, more specific or emerging issue areas may be lacking.

"I think GPs are not cooping well with some of the new diseases, for example, mental health. I'm not sure they're well trained enough to cope with mental health...in many cases depression can be managed at the GP level. Similarly with chronic pain, and some of the other chronic conditions. I don't think it's too much to expect the GPs to upskill to deal with some of these conditions."

In particular for older people, many participants noted that GPs do not have a good understand of how community support programs, such as HACC funded services, actually function in reality. Most participants felt that GPs did not fully appreciate the limitations of services provided in the community, and were often not able to provide advice about how to access alternative services. There was agreement that GPs should keep themselves informed of changes to do with the provision of aged care services in the community, so that they can effectively assist in coordinating care.

"GPs need to know the changes in policy and direction so that they can help direct their patient care."

Additionally, there was a perception that GPs do not do enough to prepare their patients for necessary lifestyle changes, such as moving to a residential aged care facility.

"There's a misconception in some people's minds that regardless of what infirmities or incapacities they have that they'll be able to stay in their home...and GPs don't say to them, 'You've got six steps at the front, six steps at the back, how will you get out to put your washing out?' and then they say 'You'll get the HACC services in' but then the GPs don't deal with the minimalist care that's coming in...there's major practical problems with delivering the ageing in place policy."

Participants also discussed the lack of responsiveness to the access needs of older people by GPs.

"GPs, I feel, would prefer not to continue on [with older patients]...they don't make house calls or go to residential aged care facilities...even if you're in your 80s or whatever, they still expect you to be able to go to them."

Accessing other services

One participant spoke positively about her experience with a new dentist, praising in particular his upfront style and clear explanation of treatment options for an ageing person.

"I went to a new dentist and the first question he asked was 'How long do you expect to live' and I thought, 'Well, this is a change, a new concept in dentistry'… and he said 'Well the reason why I ask it is, we are trying to get your teeth and gums into the condition that as you age you will still be able to eat your food, and it will not be impinging on your general health'."

After-hours services

Only a couple of participants indicated that they had a good understanding of the afterhours options available in Canberra. A couple of people mentioned the Walk-in Centre as an option, as well as CALMS ("If you can get there"), highlighting the difficulties in obtaining transport for mobility-impaired people. Only two participants were aware of HealthDirect.

One participant summed up the lack of general awareness about afterhours options: *"It's the old adage, 'If it doesn't affect me, why be interested?'."*

Several participants indicated that the afterhours they would call an ambulance as "there's no other way" to get both transport and health care services.

When discussing ways to improve community awareness about these options, one person noted: *"In the ageing population, forget about putting it into computers and email systems…they're not good users of that…"*

Another participant suggested, *"…they should produce a booklet…that could be given out with the renewal of driver's licences…which could include a sweep of services and how to access them, in a summary format."*

Facilitated discussion – A Gender Agenda (older members)

10 September 2013

What is primary health care?

Group members understood primary health care to mean the first place you go to receive care. They talked about secondary care as being any treatment received in the hospital or services that need a referral.

Satisfaction with current GP

One person had previously seen the same GP for 20 years but no longer had a regular GP. They were relatively satisfied with the practice but did not think it had a particularly caring environment.

'In the past, the practice was really caring, now I feel like I'm just a financial transaction'

Another person had been going to the same GP for the past 20 years but saw different doctors. They commented that they used to be able to ask their GP about anything, but now it was becoming difficult.

'Now, unless you assert yourself, you're just a bloody number, you really have to jump up and down'

However, they had no problem getting an appointment and there was a practice nurse available that could provide the same services as the Walk-In Centre. The nurse could then get the GP if necessary.

Overall, group members thought there was a lack of bulk-billing in Canberra and that it was excessive to have to pay for a full consultation just to get a prescription renewed. This was a significant issue for group members, as each one required ongoing hormone therapy.

Attitudes towards transgender persons

'I always tell people straight up that I'm transgender so they can tell me straight away if they don't want me, but I haven't had a problem with the GP'

None of the group members had experienced any negative attitudes from their GP, but did have stories about other health professionals who had been very uncomfortable treating a transgender patient.

'One psychiatrist in Calvary was not okay with me being transgender…the feeling I got was total disdain, I felt like something the cat had dragged in'

'I ended up having to go to Melbourne to find someone who was really specialised in transgender issues – this was the first time in my life it felt like someone was listening to me as a person, because nobody else did'

Managing multiple chronic conditions

One of the group members was living with multiple chronic conditions, including Diabetes. They had also suffered two strokes and two heart attacks. They attended wound nursing twice a week, but commented that the nurses were able to come to them when they weren't able to drive.

"I'm a regular customer because I'm on so many medications, it's like a meal"

They felt that their diabetes was well managed between their GP and the staff at TCH.

Pharmacy

One group member had spoken to their pharmacist in the past to ask about their medications and if there were any alternatives. They had even had a pharmacist come to their home for a 'home medicines review'. At this time, the person was advised to stop taking Mobic to protect their. After trying Panadol-osteo for a short time with little pain relief, they had to go back to their GP to change the prescription back to Mobic.

"At the age I am, I just take what I need to relieve my pain regardless of the side effects. I don't care anymore, I've lived my life."

Hormone management

One of the group members commenced hormone treatment in 1997. At this time, they needed to get a referral to see an endocrinologist in Sydney as there were none available in the ACT who specialised in gender transitioning. Further discussions with other members indicated that this is still the case.

Prior to surgery, the anti-androgen they were taking was very expensive. In order to get the prescription covered under the PBS, they had to be classified as a sexual deviant. Post-surgery, the person still needs to see their GP every 12 weeks for a new hormone prescription.

Urgent care

The group members considered 'urgent' to mean a condition like a heart attack or stroke or anything that required an ambulance (any life or death situation). They considered an emergency to mean something like a broken arm.

After hours care

Group members had heard of CALMS, the Walk-In Centre and Healthdirect. One of the members had taken their wife to CALMS as they were going travelling the following morning. Although it cost twice as much as seeing their regular GP, they thought it was a good service and put their minds at ease.

Another group member said they had heard about Health direct from their children, who used the service for anything to do with their own children.

"My children speak highly of Healthdirect, they say it's very comforting"

Although they had heard of the Walk-In Centre, none of the group members had used the service before. One person said they might consider using the Walk-In Centre for very minor conditions. Another person (with multiple chronic conditions) commented:

"My issues are too complex for the Walk-In Centre"

Health information

All group members said that their preferred source of information was their GP

"Just go straight to the source"

PCEHR

One person mentioned that they liked the sound of the PCEHR, as they thought it would make it easier to take their medical information with them to a new GP that provided bulk-billing. They also thought it might things easier if they ended up being admitted to hospital in a different state. However, they were a bit concerned about how much information would be stored on it and who would have access.

Facilitated discussion – A Gender Agenda (younger members)

10 September 2013

What is primary health care?

Group members commented that they were a bit confused by the term 'primary health care' and didn't know if it included things like hospital and emergency services.

Satisfaction with current GP

Many of the group members were seeing a GP they had heard about through A Gender Agenda (AGA). However, there were still a number of issues with GPs regarding their knowledge of and attitude towards trans issues.

"You're often on the receiving end of a GP's moral view. I badly wanted chest surgery, but I was told I could not have chest surgery until I'd had a hysterectomy. I did not need that. It affected my energy levels and took me a long time to recover enough to be able to return to work. It was all born out of ignorance and discrimination."

Other group members described more positive experiences of GPs who had been accepting of their wishes, but still had limited knowledge of trans issues.

"The only issue is that the GP still uses my PTSD to question whether I am genuine about transitioning. It's very invalidating."

"At my first visit, I asked for someone who was trans-friendly and got in without hassle."

Access to Hormones

Most of the group members were young adults who had either recently transitioned or were in the process of transitioning. This meant that issues such as access to hormone treatments were of high significance.

One group member aged around 20 years spoke about how difficult it had been to get their GP to support them to begin hormone treatments. Other members had similar stories, with GPs often refusing to believe that the person was a 'real' transgender person.

"It took me two years to access hormones at the same GP [because] I was under 18. She had worked with trans people before, but thought she could decide what was best for me. She said I needed a note from a psychiatrist or specialist. I had to go through four psychiatrists before I found one that would help me. My GP also ignored several letters from psychiatrists, so I had to find one she would accept."

Often, people intending to transition were forced to go and see multiple mental health specialists in order to prove that they genuinely wanted to transition.

"You need to find a GP who's happy to work with you and find the right information. You don't need a specialist, just a mental health officer that is capable of declaring you mentally sound. Then you can get a prescription straight from your GP."

Many people at AGA have found that the difference between a good and bad experience with a GP often depends on how they present themselves. They need to be confident, armed with information, and sure of what they want. While this is valuable knowledge, this fact does not bode well for people who are not aware of their options and are relying on their GPs to provide them with advice.

"I told them exactly what was going to happen instead of asking, so I got what I wanted straight away."

Medicare gender classifications

A number of group members had had difficulty getting their medications and treatments covered by Medicare purely because of the gender registered on their Medicare account.

"It costs $150 per testosterone injection, which is difficult when you're unemployed. It wasn't covered by Medicare because I was still a female on my parent's card."

"I had a similar problem with the surgery: If I changed my paperwork to male, I was worried that a hysterectomy wouldn't be covered."

However, one person had managed to sort things out:

"Medicare works well for me now, they don't hassle me anymore about what my gender is regarding whether my surgery should be covered."

Awareness of transgender issues

One of the biggest problems for the group members when accessing health services was finding a GP or a psychiatrist with a good understanding of transgender issues as well as the processes and protocols involved in transitioning to another gender. Many of the group members had experienced difficulty finding the information they needed from health professionals and had to turn to online forums and AGA.

"We want people to know what they're talking about – there needs to be more education about trans issues in medical training."

"There is often a lack of information about transitioning even though GPs are the gatekeepers. When there's a lack of knowledge, a consultation becomes a voyeuristic experience."

"It's very different going from female to male and male to female. People don't know how to deal with androgyny."

Support during gender transitions

The group members who had recently transitioned had found that there was little support in the general community. They found they had no option but to leave their job and also faced a lack of understanding from their family and friends. While not a reflection on health services, these experiences highlight the importance of ensuring that health professionals are understanding and supportive of transgender people and not further contributing to the discrimination they face in the community.

"I tried to transition on the job; it was a very bad idea. I really had no other option but to quit. I haven't worked since then."

"Prolonging the process is very traumatic and very expensive. It makes it hard to find the right support. A lot of us are unemployed, so financial barriers are really serious."

Mental health services

Almost every group member needed to access mental health services for support with their transition. While a couple of members had had positive experiences, most found the mental health services in Canberra were extremely lacking.

"There is appalling access [to mental health services]. they're the same as GPs but more entitled, like everything is their decision."

"We're scared of mental health services; one told me I wasn't a true transsexual and also told my family."

Some group members were happy to say that they had found a good psychologist/psychiatrist, but still found a lack of awareness of trans issues.

"The psychologist I saw was good because she admitted she knew very little and offered to learn. There was no sense of voyeurism, which is rare in Canberra."

AGA has been an important source of mental health support, but is struggling with the demand for services.

"AGA's psychologist is very good, but snowed under."

Acute care services

When primary health services are not able to meet consumer needs, the consumer can end up in acute care. For transgender people, this can be a particularly traumatic experience. They don't know how staff and other patients are going to react to them. One group member had experienced a particularly traumatic incident at the mental health units at TCH and Calvary, where staff showed very little understanding of their situation. For the entire time they were in hospital, they felt powerless and had no access to hormones.

"Throughout that month, not receiving hormones, AGA had to represent me until I was stabilised…It worries me that every time [a transgender person] is really struggling, they end up in an institution that knows nothing about their situation and has moral issues with trans people"

Other group members strongly agreed with these comments, saying that admission to hospital was among their biggest fears.

"Having to go to hospital is the worst thing I can think of. I don't know what I would do if I woke up in a women's ward or without testosterone"

They also raised smaller issues with acute care that, while appearing minor, could have a significant impact on their well-being and recovery. These included bringing the wrong type of bedpans and using the wrong gendered pronoun.

"I visited a friend in hospital once and not one nurse used the right pronoun. I told staff it would really help their recovery if they used the right one."

Of course, a major concern is also that, like any other patient, they will receive the care they need. One older woman commented:

"I don't care if they call me [X] or [Y]; I just want my knees done!"

Travel costs

Transgender residents of the ACT are often forced to travel interstate to access surgery and specialty mental health services. In addition to the time and inconvenience associated with this regular travel, this also creates a significant financial burden.

"For my chest surgery, I only got $2000 back. I had to have surgery over two sessions. The first session cost $6500 and the second session cost $8000. I had to go to a different city and wait one week [post-op] before I could fly. There is no surgeon in Canberra willing to do the operation."

It is also difficult for people living in regional areas around the ACT to access the care they need. They often have to travel to Canberra to get a referral to a service even further away.

"I was sent to someone in Canberra who said to go to the gender centre in Melbourne. I went there twice and it cost me $700 per trip including accommodation. I couldn't afford it. I've seen three doctors in Canberra; two were good but one wasn't helpful at all... I ended up importing hormones from overseas."

Financial barriers

Many of the group members talked about being unemployed as a result of their trans status. In most cases, they found that simply could not go on working in an unaccepting environment. The stress of transitioning without support often caused mental health problems that impact on work and education. As a result,

"Some people can't afford surgery, which can be a serious major health problem. It needs to be seen as a life or death issue"

Health Information

The younger group members all relied on internet forums for support and advice regarding transgender issues. They felt that this was the best place they could go to for non-judgmental support and to find other people with similar experiences.

"I had no information about non-binary genders until I found the Tumblr page"

AGA is also playing a crucial role in providing face to face support and advice for transgender persons and people looking to transition. They also provide advocacy for transgender people in vulnerable situations, such as when they are in acute care.

"AGA is life-saving. Before AGA, transitions happened in other people's lounge rooms. Once you get to the other side [of a transition], you don't always want to stay as a trans person, so you move away from it and don't necessarily want to be available to give others advice. That's why we need a hub like AGA"

Facilitated discussion – Ainslie Village residents

10 September 2013

Ainslie Village background

Ainslie Village is a facility which provides medium-term and crisis accommodation for homeless men and women. Currently, the Village has over 200 residents. Many residents have alcohol and other drug issues and dependencies, as well as mental health concerns and custodial histories.

What is primary health care?

Residents thought of primary health care as 'the first port of call'. They listed services including specialists, GPs, optical, dental, and pain management.

Satisfaction with GPs

Many of the residents had initially been referred to the Village by Samaritan House, where they were also referred to a GP that provided bulk-billing. Residents complained that a particular GP would not give them the referrals or prescriptions they needed, focusing instead on trying to convince them to attend his church. This was particularly frustrating for one resident, who had been diagnosed with Spina Bifida but could not get a referral to pain management services. Incredibly, his GP actually expressed frustration that the man had been told of his own diagnosis.

"It took me six months just to get some kind of pain relief. I can't take alkaloids or tablets. When it gets really bad, I have to move around on all fours"

"The only time he gave me some kind of an answer was when I had my phone out and he thought I was recording him."

"He's only really worried about getting me to join his church".

Prejudice and discrimination

Residents agreed that they also had trouble accessing pain medications, as GPs tended to assume that they were drug dependent. They had also faced similar difficulties when accessing acute care services.

"My current GP won't give me repeat prescriptions if I want to go travelling. I even asked if I could get him to renew my prescription over the phone to a pharmacist but he refused. I have to stay here."

"I had to get a flat mate to ring an ambulance for me. The ambos were great, really helpful with pain relief. But at the hospital the doctor didn't believe I had Spina Bifida and assumed I was drug dependent….I left with nothing but two panadol."

Financial barriers

In response to the feedback about the GP, we questioned whether they had ever considered or attempted to change GPs. Although most residents wanted to see a better GP, they felt disempowered and reluctant to move away from the security of bulk billing.

"I've been thinking about changing GPs but it seems a bit hard. My current GP won't give me my own x-rays"

"I would look at changing GPs but my main concern would be finding someone who respects patient confidentiality. I don't want to play snakes and ladders"

We also asked what would happen if the residents did not have access to bulk billing:

"Yeah, I definitely wouldn't be able to go to the doctor as much."

Medical centres

One of the residents had taken a friend to the Belconnen Medical Centre and was quite happy with the services.

"The doctors seemed familiar with all the patients at the centre and we only waited 30 minutes tops."

"They've never given me a bum steer."

"At Tuggeranong and Ginninderra it seems like herding cattle, but the waiting times and doctors are good."

Transport

The residents listed transport as one of the main issue preventing them from accessing care. Distance from health services often meant that residents were more likely to just *'sit it out'* or try to treat themselves.

"Transport is the major thing. It takes half an hour to walk to the city and I can't walk back up the hill. Buses come every half hour and the nearest stop is Chisolm St."

Residents wanted more frequent bus services that went directly to Civic and linked up better with other routes.

Urgent care

When asked about urgent care, the residents listed conditions that were life threatening and would require an ambulance. When we asked about other conditions such as persistent vomiting or deep cuts, the residents didn't see them as something requiring immediate care. Unless it was a life or death situation, they tended to just deal with it themselves. They also pointed out that some residents suffering from a drug overdose would refuse to get in an ambulance and none of the other residents could make a 'referral by proxy'.

"We just put up with it."

When asked about how they decide if something is a real emergency, one resident said:

"It's a pretty fine line, depends how well someone is able to gauge the problem."

One of the residents had earned their First Aid Certificate while in prison and was now the 'go to guy' for First Aid care. The resident was passionate about helping his neighbours but was concerned that he was running out of supplies and could not get a replacement kit.

Residents thought it would be unlikely that First Aid kits could be installed in the rooms at the Village as they would probably be stolen.

From our discussion, we got the impression that the residents at Ainslie Village have been neglected by a health system but are dedicated to taking care of one another. The resident with the First Aid kit became very emotional when he was talking about the injuries he had treated in the past. Some of them had been very serious and had obviously been traumatic to deal with.

Outreach services at the Village

In the past, specialists have come to the Village to provide testing, workshops and immunisations, but residents weren't always willing to access these services. The Hepatitis Resource Centre, in partnership with the Canberra Sexual Health Centre, had also run a BBV/STI screening clinic at the Village over three weeks in February where 15 residents presented for testing. Cases of hepatitis C were diagnosed and some were found to be un-vaccinated for hepatitis B. Hepatitis C is common in injecting drug users, but significantly underdiagnosed.

"GPs are not meeting this need."

Residents wanted to have a GP or nurse available that come to the village for regular appointments. They thought there would be a good uptake of this type of outreach service.

Health Direct and health information

The residents mainly relied on their GP for health information, which was problematic considering their current GP did not answer many of their questions. None of the residents had heard of Health Direct but thought it sounded like a good idea.

"I would use Health Direct if you put the word out. People would get on board if it was advertised properly."

Residents also called the poisons Information Centre to get help for other residents who were having a bad reaction to drugs.

Facilitated discussion – Dickson College students

25 September 2013

What is primary health care?

The group was not familiar with the term 'primary health care' but thought that it could mean anything that provides the first point of care, such as GPs, hospitals, medical centres, CALMS, or the Walk-In Centre. Specialists were not included in the list.

Satisfaction with current GP

Most of the group members were going to the same GP as their other family members and were quite satisfied with the services they received. Some mentioned that they always went to the same practice, but were happy to see whichever doctor was available. One person's family had moved to another practice in order to stay with a particular doctor.

The group commented that the General Practices they attended were friendly and family oriented. They also felt that their GPs took the time to answer questions and check up on their overall health. One person said that her mother always accompanied her to the GP so that she could ask questions as well.

'[My GP] always asks about my general well-being as well as what I've come to ask about'

In general, the group did not access health care very frequently. For minor illnesses, they were more likely to seek information online and either 'wait it out' or rely on non-prescription medications. The main reasons the group members visited their GP was to get a doctors' certificate or repeat prescriptions.

'I'll go if it's really serious ... the last time I went was when I had Glandular Fever'

When asked about practice nurses, most group members were unsure whether there were any at the GPs they attended, but one person said there was a practice nurse at her GP that just did immunisations.

While everyone was happy with their GP, most group members said they would not feel comfortable going to their GP for sexual health issues because the GPs knew them too well or they knew their family.

Medical costs

All the group members spoke highly of any health services that were provided free of charge. In particular, they praised the Sexual Health and Family Planning ACT (SHFPACT) for providing friendly and accessible services and useful advice without judgment.

While most group members were on their parents Medicare card and did not pay the additional charges themselves, they were frustrated about having to pay up to $80 just to renew a prescription. Group members wanted all appointments for prescription renewals to be bulk-billed. Alternatively, they talked about a phone or email service where GPs could approve prescription renewals for free.

'There should be a phone service to ask quick questions, or even an email service for my prescriptions'

One person had received a referral for both an immunologist and a dermatologist. While they had no trouble getting the referral, they found it annoying that they had to pay for the GP consultation when they already knew that they needed the referral.

Pharmacy

Most group members said that they didn't really think of the pharmacist as another person to go to for health advice. They also mentioned that they didn't think the pharmacists tended to be as professional as GPs, with one person talking about a pharmacist not wanting to prescribe their friend with the morning after pill.

Transport

Group members either caught the bus or had their parents drop them off at their GP appointments. Often they needed their parents with them to pay for the appointment, but some people just took their parents Medicare card and credit card with them. At another person's GP, they were able to go to their appointment and tell the receptionist that their mother would come by later to pay the bill.

Waiting

'The biggest problem is having to wait'

The group talked about experiencing long waiting times at both the ED and their GP. They felt that both facilities could use an electronic system where the patient could be notified by SMS when they were going to be seen. In this way, consumers would not be required to stay in the waiting rooms for unreasonable lengths of time.

Urgent and emergency care

Group members agreed that an 'emergency' meant that you were bleeding heavily or had some other serious condition that meant you were at risk of death. Requiring 'urgent' care was understood to mean that a person was in pain and in need of services. In both cases, some group members said that they would probably go to the ED, but understood they would need to wait longer if it was only urgent.

'I would still go to the ED, but would be happy to wait a bit longer'

Other group members said that they might try alternative services for urgent care, such as the 'Walk-In Centre', but would probably try their GP first. However, transport to these services would be problematic. They mentioned that unless it was serious enough to call an ambulance, they would have to rely on their parents to be available to drive them to their appointment.

'I wouldn't be able to get to the [Walk-In Centre at] TCH by myself'

'The only time I really need to access care, I had really, really bad stomach pains. I was able to get an appointment with my GP that afternoon; otherwise I probably would have gone to the ED'

Accessing after hours care

Group members were reluctant to access after-hours services such as CALMS, commenting that they thought the services would not be as personal and that it would be better to see someone who knew their background.

'The other day my friend's mum said just to wait until during the week, because those GPs are more likely to care'

Instead, group members were more likely to wait until normal practice hours unless it was very serious.

'If it was after-hours, I would probably just go to the ED, but only for extreme sickness, or if something was clearly not right'

Healthdirect

Only one of the group members had heard of and Healthdirect, and only because their parents had used in when they were a lot younger. When they were told about the service, all of the group members liked the idea and though they would use it in the future.

'I would definitely have used it if I'd known about it'

'I wish I'd known about it a couple of weeks ago, I had hay-fever and got nose bleeds from the sneezing. I went to the GP and he just answered my question straight away. I had to pay the full cost [of the consultation] when I could have just called the phone line'

Accessing health information

'If I have a question, I usually try to ask the internet'

All of the group members had used the internet in the past to find out additional information about health issues. They often used search engines such as Google or Yahoo Answers. However, they understood that this information was only supplementary and not necessarily credible.

'Normally I would just go to the internet for extra information – you never take a diagnosis from the internet seriously'

Group members commented that there was a lot of good quality mental health information online on properly accredited sites, such as Beyond Blue and Headspace. They thought it would be worthwhile having similar accredited websites for physical health issues.

Other suggestions for raising awareness about health information services like Healthdirect included Youtube advertisements and education sessions in schools.

'In school, it's mainly mental and sexual health that they focus on; they don't really talk about physical stuff - I feel like there needs to be more education'

Awareness of the ACTML

None of the group members had heard of the ACTML. They suggested that information about ACTML's after-hours projects could be advertised on flyer around schools or in bathrooms. Radio advertisements were also suggested as a means of reaching parents, who could then pass the information on to their children.

Facilitated discussion – Lung Life ACT

26 September 2013

What is primary health care?

Participants described primary health care in quite broad terms, including GPs, pharmacy, community nursing, dentists and other allied health professionals such as physiotherapists, dieticians, optometrists, and psychologists.

Remarking on how complete a list was generated from the discussion, one participant noted: *"..and I think I've used all of them, except for the psychiatrist!"*

General practice

Several participants raised problems that they had encountered in trying to find a suitable GP, particularly when their previous GP retires or moves interstate. Bulk-billing was considered by many participants as one of the indications of a practice's suitability.

"Well, GPs are a problem. One, it's a problem to find a GP who will take you, two, it's almost impossible to find a GP who bulk bills, unless you go to one of those dreadful clinic things, where you have to sit down for 3 or 4 hours waiting. So that's the choice: you either write off a day…or you pay 70 or 80 dollars…and for most pensioners, it's a lot of money if you have to go often."

"When my GP retired, I had terrible trouble finding one who would take me. I rang every practice in the inner north and inner south, and I think after about 20 or more calls, I finally found a practice that would accept me."

However, one participant recounted a more positive story about finding a GP in the wake of her GP retiring: *"…when they left, I got a list of doctors I could refer to, and I got in immediately. I was concerned about the doctor's closing down like that, because it left so many people out on a limb."*

Participants discussed difficulties which were sometimes experienced in terms of accessing timely care to their preferred practitioner, especially in light of reduced working hours as GPs age.

"When I ring for an appointment and can't get her, I know I could get one of the others, it's my choice to wait, but if it were urgent enough, I would go see one of the others."

Corporate-style medical centres were not viewed favourably by participants, with one participant describing them as *"dreadful"* (see above). Waiting times and GP interaction were the major concerns raised by participants, in particular the episodic nature of care. Participants preferred to have a regular GP in a family-style practice.

"The doctors treat what you're there for…so they're not treating the whole person, and not looking after you…it's nice to know that you have a doctor who thinks a little bit about you, who knows you."

Participants expressed anxiety about not being able to see their preferred or regular GP, as it means that they must be "on the ball" with regards to their condition and required treatment. Care in this situation is episodic, and often the GP is unaware of patient history, meaning that they can't serve as a prompt for diagnostic or treatment purposes. In one example, a GP asked a participant how many milligrams of a particular drug she was taking, as they did not have this information. The onus is on the patient to ensure that the GP has the correct information.

Barriers to accessing care

Cost

The cost of services, particularly general practice consultations, was raised as an issue of concern for participants. Few participants attended bulk-billing practices. As the group discussed, management of a chronic lung condition often requires frequent visits to GPs and other health care providers. One participant recounted her experience in caring for her late husband:

"I think a visit is about $79 dollars, they do 10 less for pensioners…when my husband was still alive, [the doctor said] I'll come and see him at home…and that was all fine…and then a few days later I had a bill for $135…and she [the doctor] said 'I'll come again next Friday' and I said, 'Please don't. I've got to get him up there because I can't afford the cost every week.'…and she said 'Oh, in future I'll bulk-bill for the home visits'."

Several participants remarked that they were surprised when specialist consultations cost less than GP visits.

"My ENT costs me less than the GP…and I have a good deal of time with him…how can they do that?"

Navigating the system

Participants in this group access a variety of health care providers to manage their chronic conditions. In general, participants found the communication between their GPs, specialists and other providers less than satisfactory. Participants agreed that it was important to be *"in charge"* of their own health so that they could maintain these linkages between different spheres of care.

"I always add my GP for diagnostic testing results, as well as my specialist…I don't know if they read them, though…if there was a problem I don't even know if someone would get in touch with me."

"I said to my specialist, *'Can you please write to my GP and tell her what she should be doing?, [in terms of managing her chronic condition]'."*

"When I went to hospital…they hadn't even heard of ehealth…in May 2013!"

One participant noted that she had experienced excellent follow up care after being discharged from hospital. Another spoke positively about her holistic and thorough treatment at the Falls Clinic.

However, most participants were less positive about the transition from hospital to the community. Participants were in favour of an enhanced, or more accessible, liaison service to ease this transition, by coordinating services required for the move back into the community. Even outside the hospital-community transition setting, most participants indicated that often in times of need, they simply didn't know what services were available.

Participants also agreed that managing a chronic condition over many years made them *"experts"* in their own health, but that there was only limited, if any, recognition of this.

"After a while, you know what to do, it's just something you learn, it's not because you're clever or anything, it's just over the years…"

This expert status is a result of ongoing self-management, as well as a (well-founded) perception that the participants in this group need to retain control of their own health, as GPs, specialists, and pharmacists are not in good communication and often make mistakes. Being an expert in your own healthcare is a stressful situation.

Pharmacy services

One participant raised concerns about the PBS Safety Net thresholds, and disadvantages for a single person.

"[Before my husband died] when we were two of us, you know you get up to 58 scripts a year, and then you go onto the Safety Net…but now, he's not here, I still have to reach that same amount of scripts for only one person. "

Participants sometimes visited the pharmacist for advice, but noted, *"it depends a lot on the chemist".* Most participants had preferred pharmacies for seeking advice.

Concerns were raised about the quality and safety controls employed by pharmacies when dispensing medications, particularly in relation to Webster-paks. The quality use of medicines is particularly important for those with chronic conditions who are often required to take a number of medications on a daily basis.

"I have Webster-paks. Twice now, the specialist has changed the medication. I've taken the prescription, told the pharmacist, 'this is a change'. Next Webster-pak, no change. Fortunately, I checked it, both times. And they're very apologetic and everything but it's just not good enough. The second one was really life threatening, if I hadn't picked it up it could have killed me…these people are professionals, they should do their jobs."

"Once I didn't get the right quantity [of medication]. Now I think 'Check it as soon as you get it.' Because that left me suddenly without tablets, and I sort of had to argue 'why haven't I got them'…sometimes it's the wrong medicine even."

Afterhours services

Two participants has used CALMS, and indicated that while it wasn't a wholly satisfactory experience, it was *"better than nothing".* For people with chronic lung conditions, one of the first responses would be to call an ambulance or seek transport to the Emergency Department. All participants had heard of the Walk-in Centre, but none had used it, and there was not a great deal of understanding regarding the kind of services it offers. Most participants had heard of HealthDirect, and indicated that it was a satisfactory service. One participant expressed some frustration that the HealthDirect advice was to call an ambulance. However, others noted that it provided *"reassurance"* late at night.

Health information

Participans used the Internet, support groups (like Lung Life) and their peers to find out information about conditions, treatments, services and practitioners. – especially Wikipedia.

In particular, people spoke positively about Lung Life meetings as a forum for sharing both information and experiences with others.

Key improvements

Particpants developed a list of key improvements that they would like to be made within the primary health care system:

- Better communication between GPs and the patient, and between different levels of care
- More affordable GP consultations and prescriptions
- Increased community support for people to care for themselves at home
- Increased support to reduce avoidable hospital admissions
- Better coordination when transiting between different spheres of care
- Increased awareness for GPs and patients about the range of services available and how these can be accessed
- Remove the need for a referral to see a specialist

Facilitated discussion – Pain Support ACT

22 October 2013

What is primary health care?

Participants described a broad range of health services that comprised primary health care for them, including GPs, dieticians, psychologists and pharmacists. Participants agreed that psychological health was equally as important as physical health in maintaining overall wellbeing.

"I've used the term a whole lot, but never really defined it in my head. The obvious thing is the healthcare you get from your GP for the most critical aspects of health care. I would have to include in there psychological wellbeing, because if you don't have that, it's just as a bad as having a serious physical condition. So I define it quite broadly…I'd include in there a healthy diet as well."

"The obvious family doctor service. Physical wellbeing…which becomes more important as we get older. We spend the first 60 years using our bodies and then the next 20-odd trying to keep them in one piece."

Barriers to accessing care

Availability of chronic pain services

Participants discussed difficulties experienced by themselves, and people in their networks, in finding appropriate treatment for chronic pain. The public system is unresponsive and the private system can be quite expensive.

"Accessing public health services [for pain] is difficult…there are long waiting periods. It takes ages to get into the public pain clinic here. It's something like 18 months at the moment. Which misses the three-month opportunity to actually stop the chronic pain continuing. Which is such a waste of public money and so terrible for those people. They just have to wait and make do. And it's pretty hard to make do if you're in chronic pain…people are pretty heavily reliant on medication, which is not the only way to manage pain…access is very poor."

While access to the public pain clinic is difficult at the outset, participants were more positive about the kind of services offered once you were accepted as a patient.

"The JUMP course about self-management is good…it's a little rushed to do it in one day though."

Participants discussed options for treating chronic pain, and one participant noted:

"At my private pain specialist, he mentioned that a lot of people are accessing his services, when their needs could be met by other services in the community. I think there's a change in attitude that's needed around treating chronic pain."

There was a perception that GPs had failed many chronic pain sufferers in terms of coordinating care. As GPs are often the first point of contact for someone experiencing pain, they have a responsibility to be aware of services available to assist in management.

"...people find themselves with chronic pain suddenly and they don't know there's [a specialist clinic]. Their GPs don't know...my GP never referred me to the pain clinic. I went there another route, from the psychologist I saw. I don't think she [her GP] knew about it."

There was also a perception that services were better once you'd had an experience with the hospital system.

"...there's a lot of things that you can't access unless you've been through the hospital system and they're organised on discharge...if you don't grab it at that moment, you don't get the services."

Discussing options for people with chronic pain while they are waiting for access to the pain clinic, participants indicated that the options were both limited and bleak.

"...people go without [treatment] or they struggle along with their GP. They get depression...they often become isolated...they lose connection...they are just so stressed and anxious with their condition, and they don't know what's going on with their body, and often it happens out of the blue. You can be healthy and then suddenly this dreadful thing starts."

Participants spoke about potential remedies to the long waiting times for the pain clinic and lack of similar services in Canberra. While more pain specialists were greatly desired, participants understood that there are other factors at play in increasing services in Canberra.

"We could do with another one or two pain specialists. But it is hard, across the country, to get pain specialists, because they're not training enough of them...but they don't have the capacity and funding to train enough...therefore it's hard for places like Canberra."

Lack of GP education and awareness about chronic pain

In general, participants felt that GPs did not have a good understanding of chronic pain or how it should be treated.

"They [GPs] don't know the modern approach, which is multidisciplinary. Educating the consumer to self-manage and understanding that all of these things like exercise, and psychological understanding, and understanding of the condition itself, will help. I think people do have a right to find out and understand what is happening to them, and I think GPs, certainly mine, had no idea and didn't know what to do with me."

Several participants had tried to find different GPs to better suit their needs, but found that there was a prejudice around "*interviewing*" other practitioners.

"They labelled her [his wife who experiences chronic pain] a 'doctor-shopper' and a 'drug seeker'. Doctors don't understand what the patient is saying."

There was a perception that GPs are automatically inclined to consider people describing pain as delusional or as drug-addicts.

"Their default position is not to believe you. Their default position is you're a bit nutty, or you want something, and it's all in the mind. And you start talking about the history...but they don't really want to listen...they ask you, but they don't want to listen."

"Our daughter was dealing with chronic pain, too. And her GP said 'It's all in your mind', so she sacked him and found a more appropriate GP."

"She [my GP] didn't respond at all well when I mentioned pain. As soon as I mentioned pain, she had that look of disbelief, and 'It's all in the mind', and she decided that obviously I had fibromyalgia without listening to what I'd said. And I sort of disputed it because I'd read a bit about it, and it just seemed to me that I didn't fit, it didn't match. And so the next thing was to send me off for a test for fibromyalgia…I've experienced an awful lot of that, being sent off for tests. It's like medicine by testing. 'Don't listen, just test, and then respond'."

Participants agreed that GPs required upksilling in terms of diagnosing and managing chronic pain in their patients, in order to be effective primary health care physicians.

"If only GPs could have a day of training in modern methods of treating pain. Actually, they would be a lot better off, because they dread people with chronic pain appearing at the clinic, because they don't know what to do with them. If only they could have a day of training, such a lot of problems would be solved. One in five people will have chronic pain of some kind, and one in three over 65. It's a huge drain on the people and on the resources."

Participant also felt that GPs also failed to provide patients with links to appropriate and helpful community organisations which can provide both support and services.

"GPs don't know about really good organisations in the community, like Arthritis ACT and the RSI Association. There are things they could learn from them, as much as they'd hate to admit it. The RSI Association does surveys periodically about what works…and that's really important information that doctors should know about…the second thing is, they should be referring people to these organisations for the support they get. My GP has never referred me to any of these organisations, I've had to find them on my own."

Cost

Cost was raised as an issue of concern by participants in terms of medications, and accessing private health services to assist in managing chronic pain.

"If you have to buy medicine…if you don't have a health care card, you have to pay so much."

"I've found the cost of one of my medications, which has been the most effective for me, was extraordinarily high. It wasn't on the PBS list. There's been a battle and I think it's now on."

"Things like massage…I mean I have private health insurance and massage doesn't cost an enormous amount, but I can't afford it anymore. The rebates are quite low from private health insurance."

Transport

Transport was raised as an issue of concern, particularly for older people with chronic pain, as transport options are often more limited than for younger people. Lack of viable transport options often means that people forgo treatment.

"My friend needed to go to the GP because she was unwell. She doesn't drive. She's on a pension and can't afford a taxi. Buses are difficult for her because her mobility is impaired. In the end, that lady just stayed at home."

Gender culture

A male participant raised the issue that men assess health very differently, and interventions, even at the primary health care level are only infrequently sought out. In particular, exercise and other preventative health measures appear to be undersubscribed by men.

"There's a social or cultural barrier that I've noticed, from attending exercise classes, is that I'm the only male. It seems that men are a bit disinclined to take on regular exercise."

Mental illness

Discussing the experience of her sons, one participant indicated that mental illness interferes with the ability and willingness of people to keep on top of their physical health. In addition, there is a perception that providers are unwilling or unable to look past the mental health concerns to assess and treat a physical complain.

"Serious mental illness is a major barrier. I have two sons with schizophrenia and one in particular has very poor physical health. His teeth are falling out, he doesn't eat…you name it, he's go it. But they always come a poor second to the psychiatric treatment…if you have a condition like that, he's not in a position to say 'Oh, there's something wrong with me' because they probably wouldn't believe him anyway…someone like my younger son doesn't live in our society. He's on another planet."

Physiotherapy as a key pain management service

While most participants were less than satisfied about their chronic pain care they had received from their GP, at least initially, they were more positive about physiotherapy.

"My psychologist suggested I go see a physio…and this guy, is possibly the best pain physio in Australia. So I was on a roll…I was very lucky. He listened. His experience of him listening…compared to the experience of what I'd had: 'We've got to get rid of this woman, she's a drug seeker, she's nutty'…his was to listen very carefully, and when I got to the bit where other GPs had been 'Oh it's a bit over the top.', he want 'Aaah'. So he was sufficiently knowledgeable about pain that he realised, he understood. But nobody else, including two specialists…did this. It was this huge burden was lifted. The relief was huge."

"My physio is the same…he listens, and he responds to you as an individual person. He doesn't take you in and stick you on a machine…as she rushes between multiple people on machines. If you have half an hour with him, you have half an hour. And he really takes careful note of everything you've got to say. It's the listening that's the most important thing."

Other issues

Over-servicing

Some participants raised concerns about over-servicing at the GP level, particularly in terms of diagnostic tests and appointment lengths.

"I said to my GP that I'd been having headaches for a couple of days, and she immediately sent me for a brain scan. Which was quite frightening and cost me a lot of money."

"My GP asked me to make an appointment to discuss blood tests results…there wasn't really anything there of substance. It could have waited until the next time I came."

"If I ask an extra question, my GP records it as a long consultation and I have to pay extra."

Afterhours services and health information

Most participants had heard of CALMS and several had used it. This was also the case for HealthDirect, although there was some frustration that the service often directed people to see a GP. Another participant felt that the HealthDirect process was very detailed and thorough, noting that *"they transferred over to me what a nurse or doctor might do to determine if it was a serious injury."* HealthDirect was also popular for their helpful website. The Walk-in Centre was familiar to most participants, but there was some concern about the long waiting times.

Facilitated discussion – Playgroups ACT Canberra Mummies Group

25 November 2013

Availability of GPs and finding the right provider

While most women in this group indicated that they had regular GPs, or a regular general practice, many still found it difficult to access care in a timely manner.

> *"It takes a week for me to be able to get an appointment at my local practice."*
>
> *"My clinic has urgent appointments that you can ring up for on the day, but by about 9am, they're all gone."*
>
> *"The real barrier for me is the lack of available appointments…how can I plan ahead for my baby to be sick in a week's time?"*

One woman spoke favourably of arrangements at her general practice:

> *"My GP keeps special emergency appointments for kids under two. This has been really helpful for us."*

Several women indicated that she had struggled with finding a GP that was right for the needs of her and her family, resulting in feelings of frustration.

> *"It was difficult for us to find a doctor that could look after our whole family. I saw 10 doctors before I found the one."*
>
> *"Sometimes the first doctor you see wants to give you a bandaid solution….if you go to one doctor and don't feel good about the interaction, you feel kind of stuck, you can't go back, but it's difficult to find someone else."*

Continuity and quality of care

When faced with an urgent issue, most women opted to see a different GP in their local practice or attend a multi-GP corporate-style practice. Some women raised issues with the lack of continuity of care, and poor interactions with GPs.

> *"We see a different doctor every time…the one we can get into. We don't have continuity of care."*
>
> *"At some of those big clinics, some of the GPs are quite hopeless…I've walked out a couple of times almost in tears about how I've been treated."*
>
> *"At those corporate clinics, it's like going to McDonalds, there's lots of just churning patients through."*
>
> *"I'm sure they take notes, but I've gone back and if there was a record of the last time I visited, they couldn't find it."*

Some women indicated that they were initially sceptical of the West Belconnen Health Co-Op model:

> *"We were worried about the doctors being a bit, you know, [gestures down], but once we actually went there, it was great. We love our doctor."*

While there was a general feeling that the corporate style clinics provided less complete care than a 'traditional' GP clinic, some women indicated that they were happy to use them in certain situations:

> *"I'll make a judgement call. If I know what we need, I'll go to a bulk-billing clinic. If I need a diagnosis, I'll go somewhere else to get it."*

After-hours care

Reponses about healthdirect were variable, with users of the service split between acknowledging its usefulness and decrying its reductive scope of practice.

> *"[healthdirect] is great. It lets me deal with things at home. The last thing I want is to have to drive around with a sick baby."*

> *"We've called healthdirect a few times, and they always just tell us to go to the ED."*

There was similar frustration with some corporate medical centres:

> *"Once, we had an urgent issue and went to the Ginninderra Medical Centre. They sent us to ED and we had to wait for hours, for something that really could have been seen by a GP."*

Three women in the group had used the Walk-in Centre, and there were positive comments about the extension of the service to Belconnen and Tuggeranong.

There was general consensus that CALMS was *"good, but expensive"*. One woman also noted:

"I don't know how it happens, but I always end up seeing the same GP at Calvary CALMS, so I have better continuity of care there!"

Women in this group were mostly positive about the role of the pharmacy in after-hours care, but many noted that their local pharmacies did not have extended hours.

> *"I would go to a pharmacy if there was one near me that was open late."*

Other services

Concerns were raised that the waiting time for Maternal and Child Health nurse services was jeopardising the wellbeing of babies:

> *"People have to wait so long for MACH services that it's past the immunisation time for their child."*

There were also favourable comments about the use of practice nurses within GP clinics:

> *"My doctor has nurses there to do immunisations…that's such a basic thing that every GP clinic should have."*

Another woman noted that in addition to advice and prescription medications from the pharmacy, she also uses services there:

> *"They weigh my baby at the pharmacy."*

Health information and reassurance

Participants spoke favourably about the Canberra Mummies Facebook page for sharing information with other parents and seeking reassurance about "odd" potential health issues in their children.

> *"The Canberra Mummies Facebook page is really useful…the amount of times I've seen photos on there of different coloured poo and mums asking if it was normal…"*
>
> *"There's also an Australian Breastfeeding Association person on there, who you can tag in questions and send messages to, and she responds really quickly."*

Facilitated discussion – West Belconnen Child and Family Centre South Sudanese Mothers Group

30 October 2013

GP services

Most women in this group had adequate access to GP services. Several participants described their GP as "very good" or "very helpful". Cost was not an apparent issue, with session participants either being bulk-billed or getting sufficient rebate from Medicare. Many women were also aware of "urgent appointments" available through their general practice, allowing them same-day access for urgent health issues.

When asked if they preferred to see female or male GPs, there was a consensus that the gender mattered less than the quality of service.

"I don't mind if it's a man or a woman, as long as it's the right kind of GP and the one I want to see."

Dental care

Women in this group agreed that dental care for themselves and their children is prohibitively expensive. Several women had been to the Community Health Centres for dental care, but were not satisfied with the thoroughness and quality of the examination.

One participant indicated that she has had ongoing teeth problems for six years, but simply does not have the financial resources to seek private dental care. One woman required dental examinations every six months, but was unable to afford the cost of this monitoring. Another participant has had a cavity since 2010, but as the cost of the initial consultation was $300, she fears that she does not have the money to have the cavity filled in a second consultation.

Access to interpreters

While women in this group indicated that they are offered interpreter services, and that interpreters are provided for consultations, often these interpreters do not speak the right language. Members of this group speak Dinka, with many members also speaking Juba Arabic. However, interpreters organised for them by their general practices spoke Middle-Eastern dialects of Arabic, which are not intelligible with Juba Arabic.

Pharmacy

While most women simply used the pharmacy to obtain prescription medications, a couple had sought advice from the pharmacist. One woman had chronic haemmorhoids which he GP described as "a normal condition". This woman sought advice from the pharmacist who suggested an over-the-counter treatment cream.

Other services

Participants also spoke about the need for a care coordinator, "someone to help me work out my care, and someone to talk to if I'm upset and don't know where to go for something."

Health information and health literacy

Some women indicated that they use the Internet to locate further health information. However, most participants preferred to seek this kind of information from their GP.

Many women in this group feed formula to their babies. While the rate of this has decreased since an information session delivered by a nutritionist, formula is still a significant presence in the group. In addition, many participants have limited English skills and low-literacy (if any) in written Dinka or Juba Arabic.

After hours services

Several women were aware of HealthDirect and had used it. One participant had used CALMS, but noted that it was an expensive service. None of the participants were aware of the Walk-in Centre, and there was confusion about its model, with some women asking, "Is it for regular checkups?".

Facilitated discussion – West Belconnen Child and Family Centre Aboriginal and Torres Strait Islander Strong Women's Group

25 October 2013

Access to services

Several women in this group used services available at Winnunga Nimmityjah Aboriginal Health Service and were satisfied with their access and care. Other women used "local" GP services in their own, or nearby, suburbs, and were generally satisfied with their access and care.

Dental care was discussed as an issue. The women who were clients of Winnunga Nimmityjah were reluctant to use dental services there as they had experienced "rough" treatment either for themselves or their children. Waiting times were also discussed as an issue in this context, with one woman indicating that the prolonged waiting time for dental procedures at Winnunga Nimmityjah meant that she was forced to find care for her children elsewhere.

"Kids should be a priority [for dental care]."

The cost associated with dental services also arose as an issue. While participants spoke favourably about services through the Community Health Centres, waiting lists were again discussed as a barrier to timely care, with one woman indicating that she had to wait four months for a simple cleaning. Seeking private dental treatment was often a huge expense for these women, but necessary in order to facilitate timely access, particularly for their children.

After-hours care

Several participants were aware of the Walk-in Centre. There was some frustration that this service was not available to children under two years old.

Coordination of care

One of the major concerns for this group was the coordination of care on transitioning between different levels of care, i.e. from the hospital into the community. One participant had undergone a traumatic mental health experience through the hospital system. However, on discharge, she did not feel as though she had been appropriately equipped to transition back into the community.

"There was no support. If my family wasn't around, I wouldn't have been able to cope."

This participant mentioned that "someone" from the health system came to her home "just to see if I was still alive", but there was no further follow up. She was no provided with numbers to ring or referrals to community mental health services after her discharge. This participant did not have any contact with an Aboriginal Liaison Officer.

In trying to access expanded care, one person noted that it was like *"banging your head against a brick wall…there's just so many hoops to jump through."*

All participants suggested that there should be more support for Aboriginal and Torres Strait Islander people within the health system. While they spoke positively about the Aboriginal

Liaison Officer at the Canberra Hospital, they noted that "one is not enough, there needs to be more of them."