

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
 - o Team Leaders: Brian Mupangure, Denise Small
 - o South Sudanese Group Facilitators: Khuyen Tran, Rebeca Gonzalez
 - o 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.

Demographic information for the interviewees can be found at Appendix 3. Interview summaries can be found at Appendix 6.

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

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 by 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 Wanniasa 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 an 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 it if 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. Its 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)

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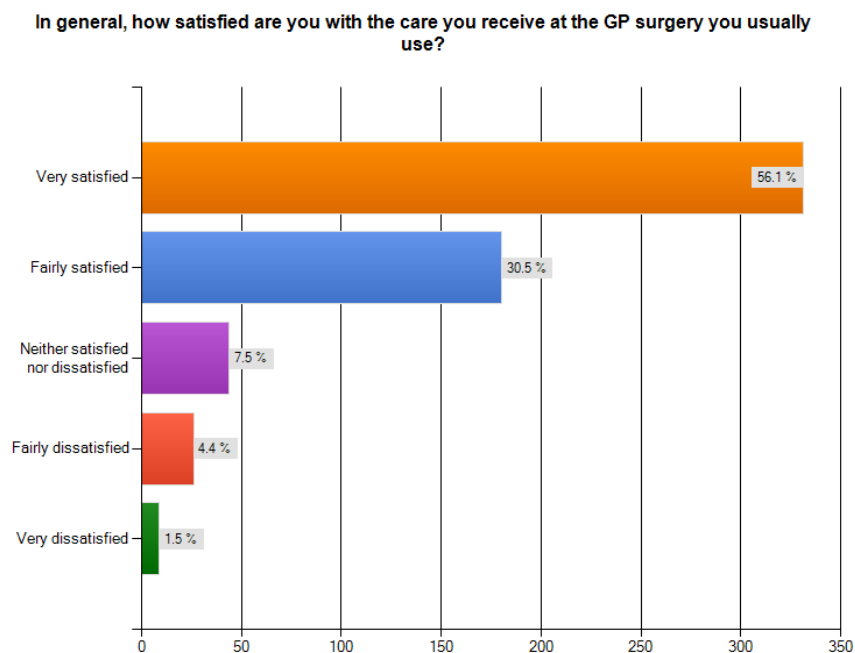
Belconnen	135 (24)	122 (24)	13(23)
Gungahlin	34 (6)	31(6)	3(5)
Inner North	108 (19)	93(18)	15(27)
Inner South	28 (5)	25(5)	3(5)
Woden	55 (10)	50(10)	5(9)
Weston Creek	61(11)	54(11)	7(13)
Tuggeranong	121(21)	113(22)	8(14)
Surrounding NSW	25(4)	23(5)	2(4)

This table shows that since *GP Snapshot 2009*:

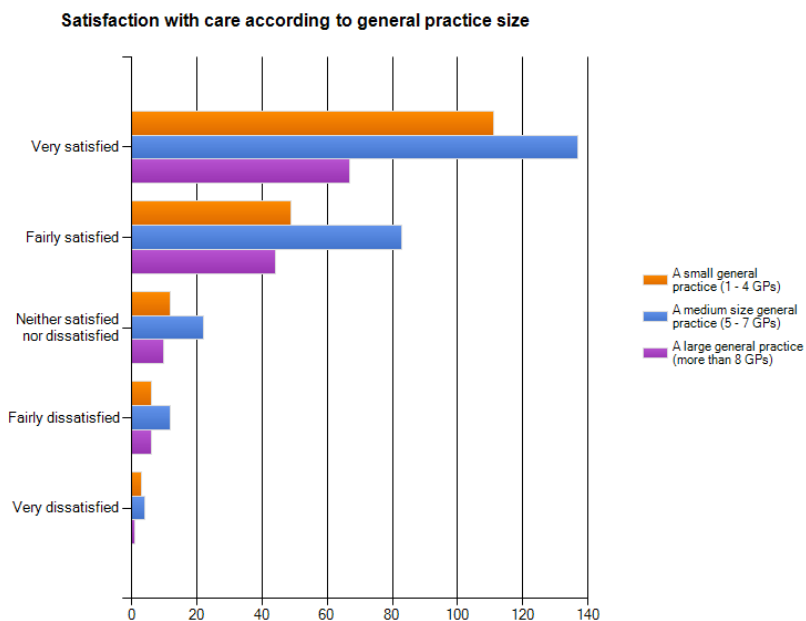
- There is an overall improvement from 106 respondents not having a regular GP to now only 56 respondents;
- Respondents living in Belconnen are more likely to have a regular GP and those in Weston Creek are less likely to have a regular GP; and
- The biggest growth area – Gungahlin – has less respondents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

Satisfaction with current GP services

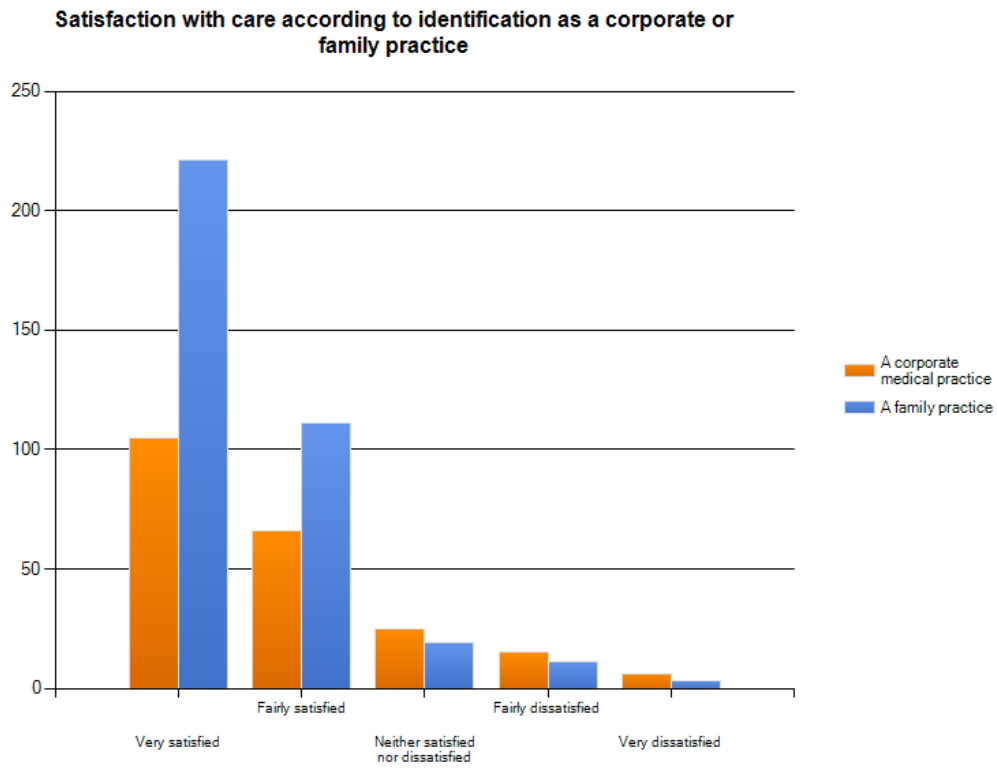
Eighty-seven percent of respondents to *GP Snapshot 2013* are satisfied with their GP. It is encouraging to note an increase of 7% in satisfaction levels from *GP Snapshot 2009*.



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



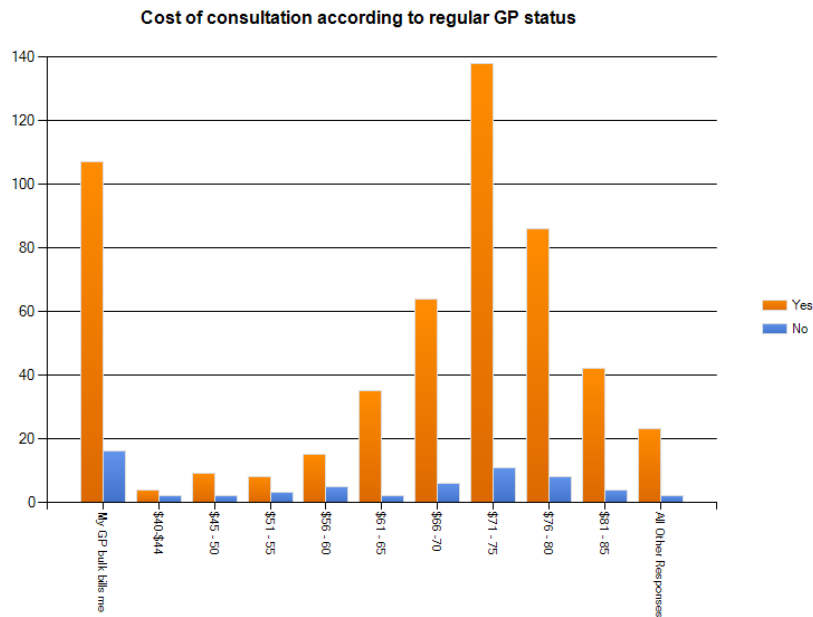
Respondents who used family practices (91%) were more likely to be satisfied than those using corporate practices (79%).



Cost

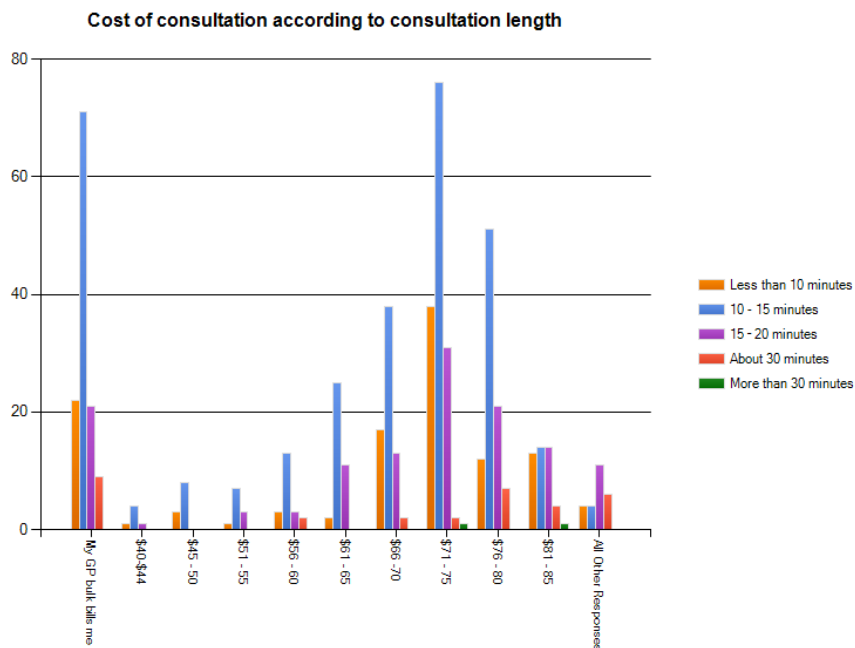
GP Snapshot 2013 supports the issue of there being limited bulk billing practices. Only 21% of survey participants have a GP who bulk bills them. This is less than the 27% in 2009. On the other hand 67% pay \$61 or more per consultation; considerably more than the 50% in 2009.

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

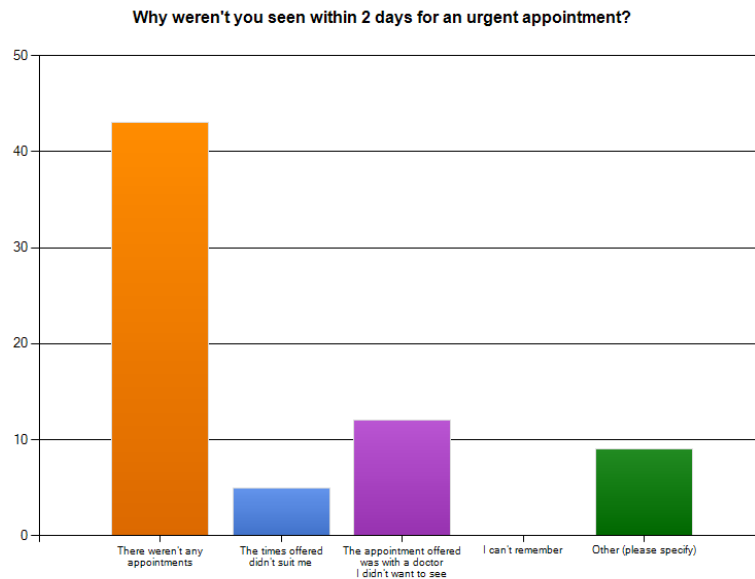
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Urgent access

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 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.

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 Australia 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 on GPs to assist them in 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.

Appendix 3: Project participant demographic information

Consumer interviews

Alex

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Inner North	More than 10	Very Good	Male	No	Yes

Ali

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-44	Tuggeranong	More than 10	Very Good	Female	No	Yes

Amy

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Inner North	More than 10	Very Good	Female	No	Yes

Angela

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
35-44	Weston Creek	3-5 years	Excellent	Female	No	Yes

Antonia

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Weston Creek	1-2 years	Very Good	Female	Yes	No

Caroline

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
35-44	Tuggeranong	More than 10	Good	Female	No	Yes

Cassandra

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Tuggeranong	6-10	Very Good	Female	No	Yes

Ciara

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
65-74	Woden	More than 10	Fair	Female	No	Yes

David

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Belconnen	More than 10	Excellent	Male	No	No

Dee

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Belconnen	3-5	Very Good	Female	No	Yes

Garry

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
55-64	Inner North	More than 10	Excellent	Male	No	Yes

Geoffrey

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
35-44	Inner North	More than 10	Very Good	Male	No	Yes

Georgina

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Inner North	More than 10	Excellent	Female	No	Yes

Harlee

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP	ATSI
45-54	Inner South	More than 10	Fair	Female	Yes	Yes	Yes

Martina

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
12-17	Weston Creek	More than 10	Very Good	Female	No	Yes

Jorge

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Belconnen	More than 10	Excellent	Male	Yes	Yes

Julia

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Tuggeranong	More than 10	Very Good	Female	No	Yes

Kendall

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Weston Creek	6-10	Very Good	Female	No	Yes

Kieran

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Woden	More than 10	Excellent	Male	No	Yes

Krissy

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
35-44	Inner North	More than 10	Very Good	Female	Yes	No

Lulu

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
35-44	Belconnen	More than 10	Good	Female	Yes	Yes

Marg

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
55-64	Woden	More than 10	Good	Female	No	Yes

Markus

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Inner North	More than 10	Very Good	Male	No	No

Mick

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
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25-34	Belconnen	More than 10	Very Good	Male	No	No
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Paul

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
18-24	Inner North	More than 10	Good	Male	No	Yes

Reagan

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
65-74	Belconnen	More than 10	Fair	Female	No	Yes

Rebecca

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
25-34	Inner North	3-5 years	Very Good	Female	No	No

Robyn

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
55-64	Inner North	6-10	Very Good	Female	No	Yes

Tracey

Age	Location	Years in Canberra	Health rating	Gender	LOTE	Regular GP
45-54	Inner North	More than 10	Fair	Female	No	No

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 decline³. 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

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 presentations 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 hospital⁴. 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 patients⁵. 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

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 problems⁶.

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 ED⁷. 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 from 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

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 Kings Fund.

caregiver burden has found a strong significant correlation with increased mortality and even mortality in older patients⁸.

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 aging⁹ 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 consumers¹⁰. 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

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 functionality¹¹. 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

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

Appendix 6: Interview and facilitated discussion summaries

Population Health Needs Consumer Interview – Alex

4 October 2013

Alex is 18 years old and has lived in Canberra for more than 10 years. He currently lives with his mother and stepfather in the Inner North. He describes his health, in general, as “very good”.

Alex described primary health care as dental, regular check-ups with the GP and other services like the physiotherapist. Alex feels like there is not enough of a focus on preventative health initiatives, especially for young people.

Alex has had his regular GP for 6-7 years. He mentioned that he followed this doctor from a previous practice. Alex described this GP as his “family GP” as his mother still sees this doctor as well. There are around 10 GPs at this practice. Alex’s mother covers his medical expenses.

Alex goes to the GP if he is generally “sick” with things like a “swollen, sore throat” or “chest pain”. He described his interactions with the GP as sometimes “awkward”. Alex noted that his mother still comes with him to the doctor, but that he is the one who interacts with the GP. However, he believes that it is easier to talk to his GP than to his parents.

Alex doesn’t always see his family GP. For a suspected sexually transmitted infection, Alex went to the Junction Youth Health Service. For matters of this nature, Alex noted, “I’d rather not see my family GP”. He also mentioned that it was easier to get an appointment at the Junction, and that he was satisfied with his interaction and would go back.

In terms of other services, Alex has had contact with a social worker at the Junction Youth Health Service and has also been to see a youth worker at Headspace. When connecting with Headspace, Alex noted that some of his friends had been there, and that his mum also mentioned it as an option for him. After making contact with Headspace, the youth worker suggested that he get a mental health plan from his GP. However, Alex didn’t follow up on this because he didn’t feel like he needed it. Alex does not go to the pharmacist for advice because he “doesn’t really need it”. He has heard of CALMS but never used it.

Alex’s interactions with his GP are “okay”. He feels that he would be welcome to ask questions if he wanted to. He also noted that his mother “studied science” and so is able to explain conditions and treatments to him as well.

Alex works infrequently in a casual position and does not own a car. His grandparents sometimes provide transport for him to access services. Catching buses can sometimes be frustrating, with waits of 30 minutes to an hour between services.

For health information, Alex uses the Internet, specifically Wikipedia and Googling. He also asks his mother for advice.

Key quotations

“[primary health care is] the health care that matters to you the most.”

On how much a consultation costs: "I'm not really sure, it's my mum that would know these things."

On why he goes to the GP: "...normally, I'll just go to get some antibiotics to make me feel better."

On his interactions with the GP: "It's awkward at first because I'm not used to telling the GP what's wrong with me, because I've been there with my mum so much and she's the one that talks to the GP."

On some mental and sexual health issues: "I'd rather not see my family GP about this."

"It's easier to talk to my friends or GP than my parents."

On why he didn't follow up on obtaining a mental health plan: "I felt like I didn't need it."

On the Walk-in Centre: "I've heard of it, but I don't actually know what it is."

Population Health Needs Consumer Interview – Ali

19 September 2013

Ali is 43 years old and has lived in Canberra for more than 10 years. She is the mother of triplets, aged 6 years. Ali and her family currently live in Tuggeranong.

When asked to define primary health care, Ali described it as the “main parts of health care”. Ali said that she thinks that access to doctors and dentists currently works quite well, but that she had recently had a poor experience with diagnosis at the GP level. Ali spoke highly of the pharmacy in this context, saying that she’d had “amazing support from the chemist” which “added an extra edge” to her primary health care journey. Ali marvelled at “how engaged they [the pharmacist] became with me”.

In terms of accessing GPs, Ali said that she goes to her general practice for “run of the mill” health concerns, prescriptions for “basic” illnesses and doctor’s certificates. However, Ali noted that she recently discovered that pharmacists can provide sick certificates as well, and that she would be inclined to do this in the future, “if I remember”.

Ali noted that she has a good relationship with her GP, and that her doctor explains things to her in a way that she can understand. While she prefers to see a specific GP, Ali said that sometimes she does see other doctors within the same practice when her preferred doctor is not available. Ali mentioned that she “adores” her practice’s online booking system, as it allows her to book in a time even when the practice is closed.

Ali drives to her GP, and there is sufficient parking with a good turnover of carparks. Her GP doesn’t generally bulk-bill, but she did ask for bulk-billing on one occasion which was granted. When all three of her children have health issues at the same time, the GP will bulk-bill. There is a practice nurse at her general practice, and her children have used this service for vaccinations.

Discussing referrals, Ali mentioned that she had recently received a referral that she didn’t follow up on, as it was connected to a misdiagnosed condition. However, Ali noted that she usually does follow up on referrals.

In terms of other services, Ali has used a chiropractor (2 times per year), osteopath (regularly earlier in the year) and dentist. She has used the pharmacist for advice quite often over the years, and has recently realised that she doesn’t always need to see a GP for some health concerns. Ali spoke positively about “having a yarn with the chemist” in a setting that is “not a shop, but a community service”. Ali made a distinction between more retail focused pharmacies, and “community” pharmacies, explaining that she had been to a pharmacy in a mall, and that she left “without a sense of understanding”, whereas a community pharmacy provides “full care”.

Discussing after-hours services, Ali demonstrated that she is aware that her general practice is extended hours – 8am-8pm during the week, and 8am-6pm on the weekends. Ali recounted one experience of going to the Phillip Medical Centre for stitches. She also demonstrated some awareness of the nurse-led Walk-in Centre at the Canberra Hospital, but wasn’t sure about function. Talking about specific health-related phone lines, such as HealthDirect, Ali said that “in a panic” she wouldn’t think to “look these [services] up”.

Ali did not know about the "Know Your Options" awareness campaign, and noted that she doesn't really watch television, and doesn't take notice of "unsolicited" mail, and so wouldn't take any information in that way.

When asked to define "urgent" and "emergency", Ali didn't make a marked distinction between the two concepts, describing them as something resulting in "lots of blood" or "lack of breathing" and requiring immediate medical attention.

Ali noted that there are "so many options" for health care, and often it is difficult to know where to go for what: "you don't want to go from pillar to post looking for services". She mentioned that she would be more inclined to use a phone line if it was a "one stop shop" kind of service, which was able to direct people to different services.

When looking for health information, Ali said that she will often Google for particular information, and then pick a few key sites. She also seeks information through the pharmacy.

Population Health Needs Consumer Interview – Angela

13 September 2013

Angela is aged between 35 and 44 and lives in Weston Creek. She works in the public service and has lived in Canberra for between 3 to 5 years. Angela has two children, aged 5 years old and 1 year old.

When asked to define primary health care, Angela described it as including doctors, nursing clinics, pharmacies and allied health practitioners.

Angela noted that in the current primary health care landscape, she believes the Walk-in Centre is working well and wished that they could see children under 2 years old for basic care, and for the issuing of carers certificates for herself or her partner. She also mentioned that she liked the extended scope of pharmacists in their ability to issue sick certificates. On a less positive note, Angela spoke about her difficulties in finding a GP that was taking new patients when she first arrived in Canberra in 2007.

Angela and her family currently have a “regular” GP, whom they have been seeing for less than a month. This GP operates from a new practice in Weston Creek, close to where Angela lives, enabling her to walk or take a short drive to see the doctor. Previously, Angela and her family used a general practice in Tuggeranong.

Angela described herself as “relatively healthy” and so noted that she most often goes to the doctor for her children, but even this is infrequent. She has been to the GP in the past for her children’s chesty coughs or ear infections, for treatment if necessary and for carers certificates so that she can stay home from work and look after them. For herself, Angela has visited the GP for confirmation of pregnancy and monitoring of her iron levels. Her current GP does not bulk-bill for her appointments or for her children, however, Angela noted that cost is less of a concern to her than convenience and ease of access.

In the past, Angela found that her GPs have not explained treatment options and diagnoses to her in a clear way, and have not invited questions. Angela said that she “feel[s] like doctors go to a class about how not to carry on a conversation”. Angela said that her current GP is an improvement on previous doctors, noting that he is only one in her experience that has explained to her about differential diagnosis.

When discussing the referral process, Angela noted that she had been referred by a GP to other services on several occasions, including for fertility issues and pregnancy. She found the process “normal” and straightforward. Angela has visited a practice nurse, usually for immunisations and other regular check-ups for her children.

In terms of after-hours access, Angela was not sure about the arrangements for her current general practice. She did note that the general practice in Tuggeranong does have some extended hours. Angela was also aware of CALMS, as it is not promoted by GPs. As noted above, Angela is aware of, and uses, the Walk-in Centre. In reference to HealthDirect, Angela said that it “sounds familiar” but wasn’t too clear on its function. After a brief explanation, Angela indicated that she would be interested in using this service in the future. Angela hadn’t heard of the ACT Medicare Local’s “Know Your Options” after-hours awareness campaign.

Discussing the definitions of “urgent” and “emergency”, Angela described urgent as something that “requires attention immediately”, while emergency was a “life-threatening” situation. Angela spoke about an urgent health issue for her daughter, who developed a severe ear infection on a Sunday night, which was eventually treated in the hospital – after a long wait in ED – with intravenous steroids.

Angela was aware of the PCEHR, but has not signed up for one. She explained that she could see the value in the non-duplication and sharing of records between service providers, but is concerned about the breach of privacy it could represent.

In terms of accessing health information, Angela noted that she would contact HCCA for information and to ask questions about services. She also said that she uses the Internet to obtain some information, tending to trust organisational websites such as those from the Cancer Council, medical journals and representative organisations. She has also previously Googled symptoms and conditions for further information. Angela said that she doesn’t often look for specific services, as she is confident that she knows where to go, but noted that this is not the case for all people.

Angela noted that her main focus on health is usually diet-related and is not defined solely by Western medicine. In this context she follows “self-directed learning”, speaking to naturopaths, homeopaths and spiritual healers.

Key quotations

On the Walk-in Centre: "I really love the Canberra Hospital nursing clinic."

On trying to find a GP in 'closed book' practices: "People were really rude, that we would even think to ask."

On quality of GP interactions: "This is the first GP...that's talked about differential diagnosis."

On quality of GP interactions: "I feel like doctors go to a class of how not to carry on a conversation."

On quality of GP interactions: "I have low expectations [of GPs]."

On the PCEHR: "I really like the organisational value of it."

On navigating the system: "I'm pretty confident that I know where to go."

Population Health Needs Consumer Interview – Julia

26 September 2013

Julia is 22 and has lived in Canberra for more than 10 years. She currently lives in the Tuggeranong area and studies at ANU. Julia identifies as a lesbian.

Julia described primary health care as “basic services” such as a GP, pathology and physiotherapy, noting that she has accessed physiotherapy services relatively frequently in connection to sports related. Julia has her own Medicare card, something she organized when she “started doing things [she] didn’t want her parents to know about”.

Julia spoke positively about her experiences with the ANU Medical Centre, noting that she preferred it to her family general practice, as the GPs at ANU “cater to the needs of younger people” and have staff who are able to “foster relationships with students”. Julia noted that she feels as though her family GP does not listen to her and validate her concerns as well as the GPs at the ANU Medical Centre.

Julia visits her family GP for ongoing management of health conditions, such as asthma. Despite her dissatisfaction with some elements of care at her family GP, she maintains this relationship as there is a long professional history, and the practice has her full medical record. Julia prefers to use the ANU Medical Centre for concerns related to more personal issues, such as lactose intolerance or sexual activity. Her GPs at the ANU have explained diagnosis and treatment options to her effectively, without medical jargon, and have provided sufficient take-home information. She spoke positively of the approach of the ANU GP who suggested an option and outlined its mechanism, rather than just saying “here, try this, see if it works”. Julia is aware that there are practice nurses operating at the ANU Medical Centre, but she has never used their services.

Julia noted that the gender of her GP is less of a concern for her than finding someone with the “right attitude”. While her male GP does not appear to have the capacity to listen and assess her concerns, Julia acknowledged that this may be a personal failing, rather than indicative of his gender as a whole. Julia also mentioned that often young people like herself avoid going to the GP due to waiting times, and the difficulties associated in seeing the same doctor on each visit.

Due to her GP’s mode of interactions with her, Julia is reluctant to discuss mental health or sexuality issues with her family GP. Julia does not believe that her GP would address these issues in a constructive way. She noted that he is of a different ethnic/cultural background to herself, so there may be some cultural elements at play in his interactions as a GP. She noted that the GPs at ANU are “much more open minded, as there is lots of diversity in sexuality on campus...they are very accepting, and if they lack knowledge, they ask me questions.” However, Julia did note that “it would be nice if they were more informed...they could attend a course on diversity and how to speak to people and what terms to use – I know this is especially important for transgender people.”

In terms of access, Julia noted that she would find it difficult to access her family GP in Kambah if she didn’t have a car. She mentioned that access by public transport to the ANU is more feasible. Julia explained that a number of her friends access GP services at the Phillip Medical Centre because it is close to the Woden town centre. Julia also mentioned that if she were unable to access bulk-billing services, cost would be a big issue for her, as “[she’s] the kind of person to go to the GP to check things out.”

Julia has used an extended-hours GP in the Tuggeranong area for the treatment of tonsillitis. She has also visited the Walk-in Centre and was aware of HealthDirect. Julia did not know about CALMS and was not aware of the "Know Your Options" campaign. Her family GP is open until 7pm.

For accessing health information, Julia noted that she rarely seeks this online. As her mother is a nurse, she generally asks her for advice in the first instance. However, she has used the Livestrong and Better Health Channel websites in the past.

Population Health Needs Consumer Interview – Caroline

8 October 2013

Caroline is 42 years old and has lived in Canberra for more than 10 years. She currently lives in Tuggeranong. Caroline described her health as, in general, "good". Caroline has hepatitis C, a condition for which she is not currently receiving treatment.

Caroline described primary health care as either the "GP or the Emergency Department". She has had the same GP for about 10 years. Caroline goes to the GP for any issue, on an episodic basis, for conditions like sinus and chest infections. About once per year, her GP provides her with pathology requests for liver function tests. All together, she visits the GP about 10 times per year. Caroline feels that her GP listens to her and respects her point of view.

In terms of referrals, Caroline has been referred to an Ear, Nose and Throat specialist for her chronic sinus problems. She has also been referred to the Liver Clinic by her GP, for treatment for Hepatitis C. The process of trying to access this service, however, was less than satisfactory. 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. She hasn't mentioned this issue to her GP, but may do so in the future.

Caroline has asked other services with the community, including Sexual Health and Family Planning ACT and pharmacies. She spoke positively about both, and in particular, Caroline finds the pharmacy useful for management of her hayfever, as she noted, "they know me and know my condition" and the staff are "quite knowledgeable".

While Caroline mentioned that usually she does not experience discrimination due to hepatitis, on one occasion she was bumped from the top of a surgery waiting list due to her condition. Caroline has also experienced, and heard of others' experiences, discrimination in relation to obtaining the morning after pill from pharmacists.

Caroline noted that cost is not usually an issue for her, but that lots of different medical consultation and treatments can "add up". As Caroline noted, "you weigh things up...whether to pursue treatment or not". As an example, for her chronic sinusitis Caroline was prescribed a steroid-based nasal spray. This spray costs \$60 and is not subsidised under the PBS. Caroline uses 1 bottle per month. Contraception costs also contribute to Caroline's medical financial burden, particularly when the PBS subsidy is low and private health insurance does not cover the gap.

In the after-hours context, Caroline has used CALMS and the Walk-in Centre, as a patient and carer respectively. Caroline noted that her GP has started to open on Saturday mornings, and to stay open later on Friday evenings.

When looking for health information, Caroline uses the Internet as a starting point for a diagnosis, but she does worry about the accuracy of the information – as she notes, "you

have to be careful which websites you go to". She also Googles medication side-effects and noted that the official Consumer Medicine Information can be found online.

An improvement that Caroline would like to see is an increase of publically funded dental services.

Population Health Needs Consumer Interview – Amy

19 September 2013

Amy is 20 years old and has lived in Canberra for more than 10 years. She is currently working as a childcare assistant and lives in the Inner North with her parents and sisters.

When asked to define primary health care, Amy described it as “where I go first”, a service she knows “is always going to be available”. She included hospitals and general check-ups in her definition.

Amy spoke about the difficulties experienced by herself and her friends in accessing services that require the presentation of a Medicare card. Amy is still listed on her parents’ Medicare card, and there is a limit of 2 cards per household. As such, Amy must borrow her parents’ card if she wants to access particular services. While she is aware that she can register for her own Medicare card, Amy does not have the time during the week to visit a Medicare office to complete this process, as she is working full-time in the Inner North. A friend of Amy’s has experienced similar trouble with Medicare, as neither the friend nor her father had a Medicare card.

Amy has a regular GP, whom she described as her “family GP”. She last visited this GP 5-6 years ago. During high school, she visited the GP more regularly for treatment of recurrent bronchitis and circulation problems. In terms of managing her bronchitis now, Amy noted that her mum buys over the counter medication for her to treat the condition at an early stage.

While she has not seen her family GP for more than 5 years, Amy has had recent experience with a no-appointment GP clinic. Amy has visited the Phillip Medical Centre for a minor health concern, resulting in bloods being taken for examination. On another occasion she visited the Phillip Medical Centre to have a sub-dermal contraceptive implant fitted. When asked why she visited this service instead of her family GP, Amy explained that she simply “had the opportunity” to visit the medical centre as she was in the area. She found this service easy to access, with waiting times not excessive (30 minutes). Amy noted that they bulk-billed her for her most recent visit.

Amy also spoke about the distinction she makes between centralised medical centres and suburban general practices. For her, medical centres [are] “not a GP clinic”, as the doctors “don’t sit down and talk to you”.

In terms of transport, Amy sometimes has access to a family car and on other occasions catches the bus, which is generally efficient during the week. If she were accessing services at her family general practice, she could walk or ride her bike.

Discussing other services she uses, Amy noted that she hasn’t used the pharmacy recently, but has accessed it in the past for the dispensing of the morning after pill. Amy said that she feels comfortable at her local pharmacy, as she is familiar with the pharmacist and pharmacy assistants. While she has had good interactions with her local pharmacy, Amy recounted a couple of instances in which her friends had poor interactions with pharmacists due to moral judgements or condescending lectures about behaviour. Amy also noted that she hasn’t had a dental check-up for 2-3 years as it is “easy to put off” unless she has a specific issue.

Amy didn't know of many after-hours care options, and wasn't aware of the "Know Your Options" awareness campaign. Amy suggested some good advertising methods to reach young people, including advertising on FM104.7 and providing other promotional materials like bumper stickers and balloons. She hadn't heard of the Walk-in Centre (WiC), but after a brief explanation indicated that she would be happy to use this model if she needed it, also noting that the city would be a good location for another WiC. Amy was also unaware of HealthDirect, but similarly indicated that she would be interested in using it in the future.

When looking for health information, Amy indicated that she does use the Internet and does Google symptoms. She was more inclined to trust websites with simple text and without images, saying "the less colourful, the better". In order to verify the accuracy of the information, Amy checks several different sites and compares the information. She also mentioned that she uses the library if she is in the vicinity, and that she trusts scientific and medical books.

Amy also receives informal referrals, advice and suggestions from friends. She mentioned that she "doesn't like to do anything new", and so seeks recommendations from her peer group about which services are appropriate and effective. Amy mentioned that she doesn't have concerns about seeing her family GP for sexual health or mental health concerns.

Describing good GP care, Amy noted that a "good" GP "takes the time to make a diagnosis". Speaking about a friend, Amy explained that she had to go back to the Phillip Medical Centre a number of times due to a misdiagnosis. While the GPs at the Phillip Medical Centre do not "take their time" with patients, Amy believes that she hasn't had poor experiences there because she is very clear about her symptoms and suspected diagnosis, and she gives the GP appropriate medical history. Amy would consider getting her "own" GP "in the long run", but noted that she is "too lazy" at the moment and sees the GP too infrequently to make it worthwhile.

Speaking about health eating and exercise habits, Amy emphasised that while the concept of "5 serves of vegetables a day" was "drilled in [her]" during school, now that she earns her own money, she stated, "I buy pizza for dinner".

Key quotations

On seeing a GP: "I think it's really easy...you can do it on the spot."

On Medicare cards and getting to medical appointments: "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."

"I don't get sick."

On why she didn't visit her family general practice: "I couldn't remember who I had to ask for."

On knowing where to access emergency contraception: "My friend told me."

On her first steps when she is unwell: "[I] talk to mum...I'd much rather talk to friends and family...I feel safer with someone I know."

On good locations for Walk-in Centres: "The city wouldn't be a bad idea either."

On navigating the system: "I know where I'd go...I trust them...I like what I know."

On seeking advice about a health issue: "I would automatically go to my friends."

On when she goes to appointments and undertakes health errands: "Lunch breaks."

On what a good GP consultation looks like: "Just 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!'"

On how to ensure good care at Phillip Medical Centre: "Unless you actually turn around and go 'No, I need something more', they go, 'Ah well, try this and see how it works!'"

On bad experiences with GPs: "I've never had one. When I've sat down and said, 'Yeah, you know, this is what I want', they've all been quite good."

Population Health Needs Consumer Interview – David

4 October 2013

David is a university student who currently lives in the Belconnen area.

David has used several services for GP care, including the Ginninderra Medical Centre, the UC Medical Centre. He has taken his 4-year-old son to the Ginninderra Medical Centre when he fractured his arm. David described the UC Medical Centre as “free and quick”, and appointments that can “fit him in a couple of days”. He has also taken his children to the UC Medical Centre. They generally see a different GP on every visit. The Ginninderra Medical Centre is open extended hours during the week and on the weekend, while the UC Medical Centre is only open standard hours during the working week.

He finds these GPs easy to talk to, and that things are explained to him clearly. However, David noted that he does not really feel comfortable in asking questions. His father is a GP, so often he asks him for advice about his children’s health, but not his own health.

In terms of other services, David uses the pharmacy for prescription and pharmacist-only medications, and rarely seeks advice from the pharmacist. He spoke positively about the Consumer Medicine Information leaflet included in drug packaging. David hadn’t heard of the Walk-in Centre, CALMS or HealthDirect.

For health information, David uses the Internet in general, and the Canberra Hospital website in particular, when he is looking for information about services. He also undertakes Google searches but worries about the accuracy of the information. David would be more inclined to trust information from peer-reviewed journals. Usually, David would not “self-diagnose” but would look for more information once he had received a diagnosis from a GP.

Discussing improvements that could be made to the system, David had a few ideas. He suggested more of a focus on health literacy, and communication between doctors and patients. David believes that GPs could benefit from education and training around communicating effectively with their patients. He also suggested other methods of delivering health/service information to the community, such as information packs for new students at universities listing options in the ACT.

Population Health Needs Consumer Interview – Dee

2 October 2013

Dee is aged between 25 and 34 and has lived in Canberra for more than 5 years. In general, she describes her health as “very good”. Dee has a 3 year old son.

Dee described primary health care as GPs, nurses, Nurse Practitioners, medical centres, and “non-specialised” care.

Dee has had positive experiences with GPs at the Ginninderra Medical Centre, but indicated that the waiting time of 1.5-2 hours was less than ideal. She also spoke about a medical centre near her home that she has used in the past, but mentioned that she no longer uses this service as it does not offer bulk-billing and she was less than satisfied with the quality of her interactions with the doctors. Dee has also used the ANU Medical Centre, but often found it difficult to get an appointment in less than a week.

While Dee had a “regular” GP at the ANU Medical Centre, due to waiting times Dee often saw a different doctor, noting, “I’m aware that this is less than ideal, but I’ve just adapted”. For access to an immunologist for her son, Dee mentioned that she had to make appointments months in advance. At the Ginninderra Medical Centre, Dee “doesn’t expect” to see the same GP, and for her, “the waiting time is more of a concern” than the ability to see the same doctor. Dee does want the continuity of care that seeing a regular GP can provide, but knows that this “isn’t really possible” as she only goes to GP episodic care. As Dee said, “I would love to have my own GP, but if you get sick suddenly, this isn’t always an option.”

Dee goes to the GP for management of her son’s allergies, viruses and urgent illnesses. For her son, Dee visits the doctor between 6 and 10 times per year. For herself, Dee visits the GP about twice per year.

Dee also spoke about her experiences when first living in Canberra – she had little information about what kinds of services were available and where they were located. Now that she has lived in Canberra for several years, she “knows Canberra better” and she knows “where to go and where not to go”.

Dee was referred for treatment for gestational diabetes at the Canberra Hospital during her pregnancy. At this time, she was living in the Inner North and did not have access to a car. As such, she found it necessary to catch taxis in order to make her appointments at the Canberra Hospital. Dee has also been referred to a paediatrician and immunologist for her son’s allergies. For herself, she has been referred to gynaecologist. These referrals were all straightforward processes, but expensive ones, with a gynaecologist appointment costing more than \$300. She has used Belconnen Medical Centre and ACT dieticians in civic and was generally happy with getting appointments in time and the level of service.

When discussing what constitutes a good GP consultation, Dee mentioned that she approves of GPs who “delve deeper” and “ask lots of questions”, but also invites the patient to ask questions. She also wanted a doctor who “takes you as a whole person” and “takes their time with you”. For Dee, a poor GP consultation is one that is “rushed”, where “time is tight”, like the “10 minute appointments” at the ANU Medical Centre. One GP in particular at the ANU Medical Centre refused to answer Dee’s questions, and ended up misdiagnosing her

son's allergies. As Dee was born in a tropical area, the doctor explained her son's skin rash as eczema caused by "not being used to a dry environment", assuming that the child had been born in the same place as Dee – in reality, her son was born in Canberra and had never been to a tropical location. Dee explored other potential diagnoses and suspected a food allergy, something that was confirmed by a dietician. Dee was disappointed and frustrated that the GP did not suggest this in their diagnosis of her son's condition. She spent months (incorrectly) treating her son for eczema following GP advice.

In terms of barriers to accessing care, Dee spoke about her experiences as a spouse of an international student in Australia. During this time, it was difficult for her to find GPs that worked with international student health insurance and cost the least amount of money. Dee mentioned that with this insurance, "you get very little back for what you pay".

In the context of after-hours services, Dee has used HealthDirect, but was less than satisfied with her experience. "They take a long time taking your details," she said, "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 is also aware of the Walk-in Centre, and while she hasn't used it, she would consider using it in the future. She has also heard of CALMS, but never used it. Dee was not aware that pharmacists can issue sick certificates.

For health information, Dee looks online – "I Google it". She also uses the "Canberra Mums" Facebook page. Dee suggested that there could be more interactive health information website, more localised services, or a "one stop shop" type of site.

In terms of general improvements, Dee spoke about long waiting times and referrals. As Dee said, "1-2 hours is a long time to wait, and lots of families can't take this kind of time off, or only really need a 5 minute consultation to get a medical certificate". She also spoke about the frustration she's felt around not being able to see a specialist without a referral, and referrals "not being valid after a one year...you usually need a follow up appointment in 12 months."

Population Health Needs Consumer Interview – Garry

24 September 2013

Garry is aged between 55 and 64, lives in Canberra's Inner North and has lived in the ACT for more than 10 years. Garry works as a public servant and described his health, in general, as "excellent".

Garry described primary health care as "GP-type" care, the first point of contact within the system. Garry also included Nurse Practitioners in his definition.

When discussing elements of the system that were working well, Garry indicated that until a few days prior to the interview, he was satisfied with his primary care: he was able to see his GP when required / within a reasonable amount of time. Recently, Garry suspected that he and his son had contracted whooping cough and made efforts to seek a professional opinion. However, his regular GP was on leave, and a receptionist at the practice told him that "there's no-one here that can help you, go to CALMs, you need to see a GP immediately". Garry was also surprised that this receptionist did not suggest any other alternatives, such as a "walk-in style" general practice like those in Phillip and Belconnen. Garry felt like his, previously functional, relationship with the system fell apart when his regular GP was not there to act as a coordinating point. He mentioned that he would raise this issue with his regular GP when he returned from leave.

Usually when Garry visits the GP, it is for management of minor illnesses and his mild hypertension. He visits the GP about 2 times per year. Garry rated his interactions with his GP as "good", but mentioned that they do "debate some issues". While he feels he is able to discuss issues with his GP, Garry also feels as though his doctor "doesn't like to be questioned" and that other people "don't always have the skills to be able to question GPs".

Garry's GP used to be located in a practice close to home, but has since moved to a practice in the city. A consultation costs about \$80 before the Medicare rebate. While Garry's GP doesn't bulk-bill him, Garry is aware that he does offer this to health-care card holders.

Garry also spoke positively about the ACT ambulance service, which he had used during a suspected heart attack. He also felt that the ambulance service should be "brought back into the health system".

In terms of other services he and his family access, Garry mentioned that he had been to physio once for treatment of some back pain. While he tends not to go to the pharmacy for advice, Garry explained that his wife recently had visited the pharmacist for advice regarding her daughter's closed earring-hole. Garry was aware of the Walk-in Centre and HealthDirect, but has never used them – his wife, however, has used both services.

For health information, Garry spoke positively about Norman Swan's Health Report as a good source of new information. Garry was not convinced of the utility of the Internet, as he feels that "there is too much information to filter". By way of an example, Garry Googled whooping cough when he has suspected he had contracted it – there were more than 4 million page results. While Garry thinks that the Internet can be a risky resource, he did indicate that he would be inclined to trust government websites for health information.

Key quotations

On general practice administration: "Often they'll put inexperienced and cheap people on the front desk."

On giving blood: "...[it's] a mini health check."

On attending a GP consultation: "My biggest problem is remembering all the things I wanted to see him about."

On interacting with the GP: "People don't have the training to question their [the GP's] views."

On the Walk-in Centre: "We need more of 'em!"

On finding health information: "If you look up whooping cough on Google, you get 3 million hits. What's meaningful and what's not?"

On men's health: "Men don't talk about their health. It's just not done."

Population Health Needs Consumer Interview – Georgina

26 September 2013

Georgina is 25-34 and has lived in Canberra for more than 10 years. In general, she describes her health as “excellent”. Gemma has a young son who is almost 3 years old, and she is currently pregnant.

Georgina described primary health care as her GP, local hospital and other services like physiotherapy and pharmacy. She also included complementary therapies in her definition, such as osteopathy and acupuncture.

Georgina feels that her access to GP services “could be better”. While she is satisfied with her general practice’s location and her preferred GP’s service, this doctor only works part-time and appointments with her need to be made several weeks in advance. As such, Georgina often has to see another GP at the same practice, if she has urgent or unexpected issues. This GP is not familiar with her medical history, and so she does not have good continuity of care. A consultation at her local practice costs around \$70, before the Medicare rebate.

Georgina mentioned that she has to go to the GP quite regularly while she is 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 in this context. She mentioned that her access to GP services was much better in Melbourne, where previously lived. In Melbourne, Georgina saw a regular GP in a clinic that bulk-billed, had 30 minute waiting times and appointments available within a week.

Georgina is also somewhat dissatisfied by the general approach of most GPs she has seen, which is “have a prescription to solve it [your health issue]”. For Georgina, medication is a last resort, and she would prefer more advice about treatment and strategies for managing conditions without pharmacological assistance. The provision of information sheets or website suggestions from GPs would be much appreciated by Georgina. Georgina spoke favourably about advice and treatment options she’d received from her physiotherapist regarding joint pain related to pregnancy.

In terms of interactions with GPs, Georgina is relatively satisfied, but she noted “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 has considered changing general practices, but this process presents some difficulties for her right now, as she recently developed some complex health issues and would prefer to stay with a practitioner who is familiar with her story. In addition, Georgina has heard that a lot of other general practices have “closed books”.

Georgina expressed some frustration with the maternal and child health nurse in Canberra, as there is a lack of continuity of care. In the ACT, Georgina and her son saw a different nurse every time, all of whom have different styles and give different advice, resulting in what Georgina described as “mixed messages”.

For urgent, after-hours problems, Georgina has used several services. On one occasion she called HealthDirect on the weekend when her child developed a bad fever. The HealthDirect operator instructed her to go to the Emergency Department, and did not suggest an after-hours GP like CALMS. However, she would use this service in the future, as it provides some

“reassurance” in the middle of the night, which is very important with young children. Georgina has used CALMS once, for a suspected chest infection on a Sunday afternoon.

Since August, Georgina has been experiencing seizures, which is not a condition she has previously had. On the first occasion, her husband called an ambulance and she was taken into the hospital through the Emergency Department. At the ED, she was advised to “go home, and get a GP referral to a neurologist within 2 days”. After discharge, she was unable to see a GP within this timeframe. When she was eventually able to secure an appointment, it was with a new GP who didn’t know Georgina or her history. Ultimately, a doctor in the ED provided her with a referral to a neurologist, noting that she would “get in faster this way”.

Georgina spoke about her journey through the health care system since first experiencing seizures. She noted that she has spoken to “11 doctors” to whom she has to tell the same story every time, always in a “slightly rushed fashion” so that “no-one gets the full story”. As Georgina said, “I have to keep the full story in my head...I have a lot of conversations that are really one-sided”. Fortunately, Georgina’s husband wrote down her case history so that she can refer back to it when required. One doctor discussed details of Georgina’s condition with her husband, and then told him “not to talk to her [Georgina] until she’s had some rest”. Handover while in Calvary was also poor – despite being prescribed some intravenous fluids and electrolytes, Georgina did not receive this as her cannula was removed as it had ‘tissued’. Another cannula was not inserted so that Georgina could receive hydration, and the nurse advised her to “just drink water”.

Georgina also experienced difficulties in being transferred to Canberra Hospital, after initially being admitted at Calvary. Senior staff told her that they “couldn’t make a case” for transferring her, even though she needed to be seen by a neurologist, but was being seen by a gastroenterologist. Eventually, Georgina discharged herself with the help of some supportive staff and a junior doctor, and made her way by car to Canberra Hospital. “It was like a jailbreak”, Georgina said.

Regarding transport to health services, Georgina usually drives or rides her bike. However, since the commencement of seizures, Georgina has been advised not to drive. Her neurologist works at the Canberra Hospital, and Georgina lives in the Inner North, so it will become difficult for Georgina to make this trip without a car.

For health information, Georgina uses Google and Google Scholar to find journal articles. Online, Georgina uses the Better Health Channel website, Wikipedia, specific organisational websites and the Raising Children Network site. She also speaks to a GP friend for informal advice, as well as friends, family and her midwife. Georgina is also connected to several Facebook groups which provide advice and information, such as the Australian Breastfeeding Association. She also uses free smartphone apps – “What to Expect” and “Pregnancy WebMD” – for information about pregnancy.

Post interview email:

I forgot to mention that one of my big concerns about the ACT health system is that the options for having a home birth here are extremely limited. My comments on this subject are below.

There are 2 midwives that I know of who provide private services for Canberra women. While I am glad this option exists, the disadvantages include: these midwives live outside of Canberra (the closest is 1 hour away in Goulburn) which is not ideal for someone expecting a quick labour; it costs around \$5000 to hire a private midwife which is not usually covered by health insurance or Medicare; and there is no insurance for the labour and birth at home. There are publicly funded home birth programs available now in NSW, VIC, WA, NT and SA, so why aren't women in the ACT given the same care options?

When I was living in Melbourne I had my first child through the Sunshine Hospital home birth program which was fantastic as I was able to have access to all of the hospital's facilities (for antenatal tests etc) and one on one midwifery care. 2 midwives from the hospital (my primary midwife and another midwife from the team whom I had also previously met) attended my birth at home which went absolutely brilliantly and the outcomes for the baby and me couldn't have been better. I always had the option of transferring to the hospital if necessary, while retaining the same midwives the entire time. I would like to use the same model of care for this pregnancy and I'm very frustrated that it's not available to me in the ACT.

Population Health Needs Consumer Interview – Geoffrey

3 October 2013

Geoffrey is 35-44 and has lived in Canberra for more than 10 years. He currently lives in the Inner North with his wife and two young children, a girl aged 3 and a boy aged 5. Geoffrey rates his health as generally “very good”.

When discussing the positive and negatives of the current primary health care landscape in Canberra, Geoffrey suggested that “not using the health system works well”. He explained that neither her nor his wife had a regular GP in Canberra until his wife became pregnant. Geoffrey described trying to find a GP as “difficult” and “annoying”, forcing him, as the consumer, to “beg for business”. Prior to this, Geoffrey did not see a GP for about 10 years.

When Geoffrey does go to the GP, it is often for his children, although he acknowledged that his wife often performs this role. Geoffrey noted that “one of the kids has to go to the GP at least once a month”.

Before going to the GP, Geoffrey will seek advice from other services within the community, such as the chemist or the Walk-in Centre. When he does see the GP, he is subjected to a wide variety of tests, as Geoffrey explained, “when you’re a male, and you actually make it in to the GP’s office, they want to do everything to you”. In the 10 year period that he did not see a GP, Geoffrey did give blood at least once per year, something that worked as a “free health check” for him.

Geoffrey also spoke about the importance of “professional reassurance” when you are a parent. By way of example, Geoffrey spoke about his interactions with the Maternal and Child Health nurses, one of whom mentioned to Geoffrey and his wife that their child had “the biggest head” she had ever seen. This statement prompted a sense of anxiety in Geoffrey and his wife; as he noted, “deviations from normal are scary”. The follow process involved a visit to the GP, and a referral to a paediatrician, who, for a consultation fee of \$150 reassured them both that their child’s head size was not a health concern.

In terms of referrals to other services, on one occasion Geoffrey was referred to a gastroenterologist after his GP expressed some concerns about his bowel. Geoffrey was provided with a list of 4 gastroenterologists from which he could choose. However, there were 8 week waits for these specialists, and as Geoffrey noted, “I just got too busy”. When asked why he didn’t eventually follow up, Geoffrey explained that he “never saw it [the GP’s concerns] as an issue” for him, as he “never felt sick...and had no immediate symptoms”. Geoffrey also referred to the specialist follow-up process as a “money pit” and something that could be a “hobby”, indicating that the diagnostic testing and specialist appointments are very time consuming.

Geoffrey’s family are a “one car family”, which can be problematic when urgent issues arise. In one instance, his wife injured herself with a kitchen appliance and was unable to drive herself to the hospital. Geoffrey had to run home from work and drive her himself.

In the context of after-hours services, Geoffrey is aware of CALMS, but believed that it was a service only for children. Geoffrey also mentioned that any phone-lines, such as HealthDirect, seem like counselling services.

For health information, Geoffrey spoke positively about the Better Health Channel website. He also indicated that he would be unlikely to trust the information provided by US, UK or industry websites. On one occasion, Geoffrey's child was diagnosed with slap-cheek by the GP. Geoffrey then Googled this condition for more information – the information he found online did not match up with his child's experience. Geoffrey was disappointed that the GP didn't provide him and his wife with more information about slap-cheek.

Geoffrey also expressed some frustration with the management of unwell children in child-care. In this context, child-care workers cannot administer paracetamol without parental consent. However, Geoffrey feels that often staff wait too long to make the phone call to the parents, prompting a worsening of the child's condition and necessitating their removal from the child-care facility.

Key quotations

On finding a GP: "We've had to trade GPs 3 times in the last 3 years. I found that annoying, where you have to go 'round and almost beg for business, when it should be the other way 'round."

On what works well for him and his family: "Not using the health system works well. Every day that we don't have to go to the health system, I think that's good."

On his wife becoming pregnant: "Oh crap, we need a GP."

On attending the Walk-in Centre: "I went to the Walk-in Centre for man flu. I self-diagnosed myself with man flu."

On getting a GP appointment: "Whenever I've rung the GP for an urgent appointment, it's normally between 2 and 7 days."

On the urgency of a health issue: "When I'm ringing for health, I think it's urgent because I don't go to the doctor."

On being male and going to the GP: "Every time you go to the GP as a male, they just love the fact that you're there and so they do absolutely everything."

On his period (10 years) without a GP: "In the period that I didn't see the GP, I would give blood once a year, and it was like a health check...it was my proxy for it."

On not following up on a specialist referral: "I never saw it as an issue...I didn't feel sick...it's a money pit that proves worthless."

On waiting for appointments: "It sets up that power imbalance. It's like 'my time is important, yours is not'."

On transport: "When you've got kids, public transport is more difficult."

On using CALMS: "One time I left wishing I had gone to the chemist."

On what kind of health information he access: "Any service I access on the internet before ringing...we'd look there [Better Health Channel] before trying to access anything."

Population Health Needs Consumer Interview – Harlee

5 September 2013

Harlee is an Aboriginal woman aged between 45 and 54 years old. She has lived in Canberra for more than 10 years and currently resides in the Inner South. She has 5 children, ranging in age from 27 to 12.

Harlee described primary health care as a general doctor and other allied health practitioners, such as dietitians. She also noted that specialists should be included in the scope of primary health care, but that she understands they aren't.

When asked to give a broad overview of what she thinks is working well in the ACT primary health care system at the moment, Harlee replied that the holistic approach to care she receives from her GP at the moment is very positive. She also spoke positively about the collocation of different services, such as GPs, physiotherapists and dentists. When discussing what is not working well currently, Harlee spoke about waiting times for different services, the lack of coordination of some times of care, particularly when transitioning between different levels/settings of care, and access to after-hours services in the Canberra region.

Harlee has a regular GP that she has been seeing for about 12 months. She has been generally happy with this GP, and would consider moving with her to a different practice, providing she continued to bulk-bill. Harlee said that she goes to the GP "for everything". In the past year, she has visited the GP quite regularly, for management of a number of issues, including diabetes, a heart condition and a thyroid condition. Previously, she only visited the GP on a needs basis for things like colds/flu and psychological support. Out of her 5 children, Harlee still attends the GP with three of them, for treatment of colds and flu and for regular monitoring for hearing, which occurs every 8 weeks.

Harlee said that her GP sometimes explains things in a way that she can understand, and that when something is unclear, she feels comfortable to ask questions.

When asked about GP home visits, Harlee outlined a situation when she would have wanted a home visit from a GP had it been available. In this example, Harlee was unable to walk and so couldn't get herself out of the house to physically access a GP. Harlee spoke favourably of the after-hours home visit model which operates in Townsville, and would like to see a similar service introduced in the ACT, with a particular emphasis on affordability.

Access to the GP is convenient for Harlee as it is located close to where she lives. She also noted that the general practice offers transport services to its clients, which can assist people in getting to their appointments.

In terms of accessing other services, Harlee said that this can be more problematic. Harlee doesn't drive, and some bus routes don't provide easy access to services that she needs to access. Travelling by bus also takes a significant amount of time. Harlee is not eligible for community transport.

The physical structure of buildings can also be a barrier. There are no ramps to access some buildings, there are often lots of stairs, and if there are lifts they are normally very small. Harlee also spoke about signage as an issue, mentioning that directions to services are often unclear.

When discussing cost, Harlee noted that if her GP didn't bulk-bill, she would not be able to go as frequently to manage for follow up care and monitoring of her conditions. Cost is also a factor in Harlee's ability to access other services. Costs associated with transport, diagnostic tests, medication and specialist consultations impact on Harlee's decisions to follow up on referrals. In one instance, Harlee did not follow up with a gynaecologist due to the out-of-pocket costs associated with the consultation.

Harlee is aware that her general practice is not open after-hours or on the weekend. When asked about other after-hours services she was aware of, Harlee mentioned the Emergency Department, the Walk-in Centre and HealthDirect. Harlee noted that she wouldn't use CALMS or the Phillip Medical Centre because they were expensive. She mentioned that her daughter had used HealthDirect, and believes that it is something she would potentially use in an emergency situation. Harlee also noted that she had only heard of the Walk-in Centre via HCCA.

When asked about her understandings of 'urgent' and 'emergency' care, Harlee said that to her urgent meant "life-threatening" while emergency meant "needing attention right away". Harlee gave an example of an "emergency" situation: when her son split his lip, and she took him to the Emergency Department.

In terms of accessing health information, Harlee said she looked for information online, through disease-specific groups and from the GP (if they are approachable). When looking for information online, Harlee focuses on Australian websites as she believes they are more reliable, and it is a plus if they have been endorsed by a recognisable body. Harlee noted that she regularly uses the Better Health Victoria website However, her rule for Internet searches is "I don't take it as gospel".

Key quotations

On big clinics with co-located services: "Everything's there, you don't have to go from one end to the other."

On 'the system': "It's knowing how to navigate through it."

On costs: "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."

On specialist costs: "Every consultation was a hundred and something dollars, and on top that the pathology, which I thought was bulk-billed...and I had to get medications that wasn't under Closing the Gap."

On not following up on a referral: "I didn't follow up with a gynaecologist [because of the] cost."

On after-hours services: "I wouldn't use CALMS because I don't have the money. I'd wait at ED."

On information online: "I don't take it as gospel."

Population Health Needs Consumer Interview – Ciara and Reagan

4 September 2013

Ciara is around 70 years old and has lived in the ACT for over 30 years. Reagan is over 70 and has lived in Canberra for around 20 years. Ciara lives in the Inner South and Reagan lives in Belconnen. Both women have a chronic lung condition.

Ciara's understanding of primary health care is that it is the "first steps" you take when you are sick, and indicated that a GP would often be a first point of call. Reagan expanded on this definition, adding that the GPs act as a coordinating point for further care from other specialists.

Both women have a "regular" GP. Ciara's GP operates out of a large corporate medical practice, which she moved to from a suburban practice. While her GP's current practice does not take appointments, Ciara is able to line up to see her preferred GP. However, the waiting time for accessing her GP can be extensive. On a "good day" Ciara noted that the wait is about an hour to see any doctor. Ciara described this extended waiting time as "horrible".

Reagan has seen her GP for 11 years, noting that she "followed" him from one practice to another. Her GP currently practices in a corporate medical practice that accepts appointments.

Ciara visits her GP about once every six months. She mentioned that she avoids going to see her GP due to the waiting times associated with the corporate medical centre in which he practices. Ciara visits her GP to obtain her regular prescriptions including prophylactic prescriptions for antibiotics, which she can use to treat minor upper respiratory tract infections, without a separate visit to the GP. These infections can exacerbate Ciara's chronic condition, and so it is important that she has the ability to treat them quickly. While she was positive about being able to access these prescriptions, Ciara noted that the process at the corporate medical centre she uses is time-efficient: the doctors "don't take their time" and follow up with patients in the way that a "traditional" GP would.

Reagan sees her GP once every three months for management of several chronic conditions. Reagan noted that she does sometimes see her GP in between these regular visits if she has "urgent" issues.

Both women felt that their GPs explained things in a way that they could understand. Reagan noted that with "some GPs, you can only say 3 words and you've got to go", but found her experience with her current GP much more positive. Both women drive to their GPs and find the parking and physical access to the building adequate.

In terms of after-hours coverage, Ciara was aware that her general practice was open 7 days per week with extended hours. She also noted that there is a range of other services available within the facility, such as physiotherapy, dental and nurses. Ciara was positive about having these services collocated. She also said that she had been to see the general practice's nurse for some of her care needs.

Reagan was not aware if her general practice had after-hours or extended-hours arrangements. She mentioned that at night, her first thought would be to use the

ambulance. Reagan described the other services that are available at her general practice, which include flu vaccinations, blood tests and specialty skin cancer treatment.

Ciara had heard of the Walk-in Centre, but had not used it. Reagan had not heard of the Walk-in Centre and was unfamiliar with the concept. Both women had heard of CALMS, and Ciara spoke positively about the "24-hour mediline" (probably HealthDirect). Reagan noted that she used a diabetic-specific phone line, and that it had been helpful in terms of the advice given. Ciara had a "Know Your Options" after-hours fridge magnet, but was unsure about how she had obtained it.

Both women noted that they had visited pharmacies for treatment advice. In Ciara's case, the pharmacist ultimately suggested an expensive cream, so she decided to manage the minor condition at home instead. Ciara noted that if the condition had persisted, she probably would have waited until her next scheduled GP appointment to seek treatment, instead of making another appointment. Reagan spoke positively about advice given to her by the pharmacist about managing an allergic reaction.

Both women mentioned that they had received "permanent referrals" from their GPs to other specialists, meaning that they don't require renewal. Both women were very positive about this process.

In terms of other primary health care services, Reagan visits a physiotherapist, podiatrist, psychologist and dentist. Reagan was positive about her "GP referral plan" which enabled her to access 5 psychologist appointments with a Medicare rebate. She suggested that many people don't know about this process. Ciara mentioned that she hadn't heard of the "GP referral plan", and that her GP had never spoken about it. Ciara said that the referral process is "often confusing", with patients not knowing what to ask for.

For emergency care, Reagan's preference is to phone for an ambulance, as her chronic conditions are complex and could cause her to deteriorate rapidly. She is aware that there are costs associated with accessing ambulances, but she doesn't have to pay due to her concession status.

Ciara spoke about access to oxygen, particularly after-hours. There is a phone line for domiciliary oxygen support, but most of the services that attend to the needs of oxygen dependent people shut at 5pm although there is an emergency number. In one case, Ciara needed a part for her oxygen device on a Friday night – the part didn't arrive until the following Tuesday. Ciara noted that if she was dependant on oxygen during that period, the outcome could have been poor, although she could have gone to the Emergency Department.

In terms of cost, Ciara noted that pensioners are bulk-billed at her general practice. Reagan said that her GP used to bulk-bill routinely but now doesn't. She also mentioned that some of her visits, particularly if they are related to diabetes management, are bulk-billed and that she's "not sure when [she's] going to have to pay or not".

With regard to accessing health information, both women spoke positively about connecting with peers, as this is a good way of finding out information "first hand". When using the Internet, Ciara mentioned that she has a propensity to trust websites that represent a "national body". Both women have an ehealth record, so are aware of its function. Ciara

noted that a lot of their knowledge comes through information disseminated by Lung Life ACT.

Population Health Needs Consumer Interview – Jorge

24 September 2013

Jorge is a 21-year-old man who lives in the Belconnen area and speaks Spanish at home. He describes his health as "excellent". Jorge has lived in Canberra for more than 10 years.

Jorge said he goes to the GP for flus, colds and other viruses, but also mentioned that he "stays healthy" and "[doesn't] waste time" on going to the GP. He visits the GP 6 times per year, on average. Jorge feels that his GP explains things clearly to him, and that he would feel comfortable to ask questions, if he had any. Jorge's GP bulk-bills, and is easily accessible by car from home or by walking over from work.

Jorge had a referral from his GP to see "some sort of surgical specialist" about a cluster of capillaries in his hand. He did not follow up on this referral, as he "[didn't] think it was an issue".

Jorge uses the pharmacy for over the counter medications like Strepsils, and sometimes to fill prescriptions for antibiotics. He does not ask the pharmacist for advice. He was unsure if there is a practice nurse at his general practice.

In terms of after-hours services, Jorge's GP is open on the weekend, but does not have extended hours during the week. He had some awareness of the Walk-in Centre at the Canberra Hospital, mentioning that his girlfriend had used it when she experienced pain after a tonsillectomy. Jorge was also aware of the Medicare Local campaign, having seen posters and television advertisements, but wasn't sure of the details. Likewise, Jorge had heard of HealthDirect but didn't have many details. After a brief explanation, Jorge indicated that he would be inclined to use this service in the future, if he needed it.

For health information, Jorge uses the Internet and occasionally checks books. Jorge uses Google first, and then often goes to Wikipedia. He mentioned that he is sceptical of information he reads on the website, until he can verify it on a "medical website". However, Jorge mentioned that he rarely needs to look up medical issues anyway.

Population Health Needs Consumer Interview – Cassandra

23 September 2013

Cassandra is aged between 25 and 34 and lives in the Tuggeranong area. She has lived in Canberra for between 6 and 10 years, and describes her health as, in general, “very good”. Cassandra has a young daughter (~2 years old) and is currently pregnant.

Cassandra defined primary health care as the first point of contact within the health system, including GPs and some “allied health” services within this context, such as physiotherapy.

When discussing the positive and negative aspects of the ACT’s primary health care system, Cassandra mentioned that when she was living in the “inner” part of Canberra, it was difficult to find a GP that was taking new patients. Cassandra noted that this had improved now that she had moved to a different suburb, further from the city centre. Cassandra also spoke about the fact that she is almost “always paying out of pocket” for a GP consultation.

Recently, Cassandra has found a “good” GP with whom she gets along. She mentioned that that it is “time consuming and expensive” to “interview” GPs in order to find one that meets your needs. Cassandra also feels that “the best GPs” seem only to work part-time.

Cassandra has been seeing her current regular GP for 3 months. Prior to this, Cassandra saw a different GP at a practice in Kingston, which is a 20-minute drive from her house. Cassandra suffers from *hyperemesis gravidarum*, meaning that during pregnancy she is very unwell with nausea and vomiting. As such, the 20-minute drive to her Kingston GP was no longer practical for Cassandra to undertake on her own, and her husband works full-time and so wouldn’t always be available to provide transport.

Cassandra also changed GPs due to her new health care requirements. Cassandra experienced *hyperemesis gravidarum* during her first pregnancy and so is aware of her health care needs around managing this condition. Her previous GP was not able to effectively assist her in managing her condition. She mentioned that she had tried to have conversations about her medication requirements with her GP, but with little effect. In one instance, Cassandra’s GP provided her with a prescription for ondansetron – a powerful antiemetic drug – but only prescribed enough for one day’s use. Cassandra said that she was “disappointed” that her GP didn’t meet her needs and didn’t “respond to her concerns”. Despite her disappointment, Cassandra noted that her previous doctor “wasn’t a bad GP” but just “didn’t give the right support”.

When she became pregnant for the second time, Cassandra decided to look for a GP closer to home, and tried her current practice on recommendation from a friend who also suffers from hyperemesis. Her current practice is a 5 minute drive from her house.

Cassandra noted that she was looking for a doctor that would “take [her] seriously for hyperemesis”. Her current GP is very committed to providing effective care for Cassandra’s condition, as this doctor also experienced the hyperemesis during her pregnancy. The new GP explores alternative treatment options and has connected with other professionals for advice in helping Cassandra manage the hyperemesis. Cassandra mentioned that her current GP is very “empathetic” and she and Cassandra “click” well in terms of personality.

Currently, Cassandra visits the GP about one to two times per week. When she is not pregnant, Cassandra sees the GP about one time every 3-4 months, either for herself or for

her daughter. She mentioned that this infrequent, episodic use of GP services, in normal circumstances, makes it difficult to find a good GP who suits her needs – “you don’t go to the GP to interview someone if you are unwell”.

Cassandra has been to the practice nurse at her GP clinic on several occasions for the administration of intravenous fluids. On one occasion, Cassandra was too dehydrated for this procedure to be performed in the primary health care setting and so she was admitted for a one-day stay in Calvary John James Hospital. This admission was organised through Cassandra’s GP and obstetrician.

Cassandra’s GP has visited her at home on several occasions, to administer intravenous fluids, and to provide her with pathology requests and prescriptions. Her GP also calls her to check on her condition. In the weeks following this interview, Cassandra will be receiving Vitamin B injection several times per week, with one injection to be delivered in her own home.

Cassandra is seeing a private obstetrician for her pregnancy, and related her disappointment that midwives are not better integrated into the private system.

While most services leave Cassandra out of pocket, she mentioned that some consultations and services at her current practice are bulk-billed, something she asserts wouldn’t have happened at her previous practice in Kingston. Non-bulkbilled costs are \$75-\$80, and \$90-\$95 on the weekend. Cassandra noted that she could spend up to several thousand dollars each month on medication, GP / obstetrician appointments, diagnostic / monitoring tests, and acupuncture. Cassandra’s supply of ondansetron alone costs around \$200 per fortnight.

In terms of accessing urgent primary health care, Cassandra noted that she and her daughter are able to access GP services on the same day as an appointment is requested, or the day after. Cassandra said that her husband continues to use GP services in Belconnen, about 20-30 minutes’ drive away.

When discussing after-hours primary health care services, Cassandra mentioned that she has used CALMS and has rung HealthDirect. She also tried to use the Walk-in Centre for her daughter, but was unaware of the service’s age limit. Despite not being able to use the Walk-in Centre, Cassandra demonstrated a fairly good understanding of the service’s scope of practice. Cassandra also gave an indication that the Walk-in Centre is “not on our [her family’s] radar” and would try the GP first in an urgent situation. Cassandra also related a positive experience with CALMS, wherein the GP stitched up a wound, noting that there is “reluctance” by some GPs to do stitching.

Cassandra has also had poor interactions with after-hours services in the Canberra Hospital. During her first pregnancy, Cassandra was vomiting so frequently that she became severely dehydrated, and so went to the Emergency Department at night. She waited for three hours, and Cassandra said that there did not appear to be a “policy or protocol around hyperemesis” and some staff seemed to consider it “just morning sickness”. Some staff in the prenatal unit also displayed little sensitivity, telling Cassandra that “if you can’t deal with it, you can terminate the pregnancy”. Cassandra felt that there was not much effort made to connect with patients and to assist with treatment options. Cassandra’s poor experience in the hospital could have been avoided if there were appropriate community-care services in place, like the SilverChain Home Hospital which operates in Western Australia.

For health information, particularly about *hyperemesis gravidarum*, Cassandra uses Internet resources, including a Facebook support group and HelpHER, the website of the US-based Hyperemesis Education and Research Foundation. There is a lack of locally-based information about hyperemesis. The network of people represented by HelpHER and the Australian Facebook group do their best to link up women with “hyperemesis-friendly GPs” and to provide resources for women to take to their GPs and pharmacists, such as the hyperemesis protocol of the Royal Women’s Hospital in Melbourne.

Population Health Needs Consumer Interview – Kendall

19 September 2013

Kendall is part-time public servant aged between 25 and 34. She is the mother of a one-year-old boy named Nikolai. Kendall has lived in the ACT for 6-10 years and currently lives in Weston Creek.

When asked to define primary health care, Kendall described it as “my doctor”, who caters to her individual needs and those of her family. Kendall also included dentists, physiotherapists and community nurses in her definition.

Kendall mentioned that the community nurse check-ups for Nikolai work very well. On a less positive note, Kendall explained that she lost her regular GP about 6 months ago, as the doctor moved to Sydney. She spoke about the difficulties associated with trying to find a new GP with whom she can get along and who meets the needs of her and her family.

Her previous GP was located in the Inner South, and after her GP left, Kendall went to see another GP at the same practice. Kendall described this as a very poor interaction, saying that she had a “5 minute consultation” and thought, “this is crap” because “she [the GP] didn’t even know anything about Nikolai”. During the interaction, the GP didn’t encourage questions or seem interested in continuing the conversation about potential follow-up care. Kendall tried to see another GP in Weston Creek, but this practice was not taking new patients.

Kendall has since visited another practice at Majura Park, with which she is relatively satisfied for the minor concerns she has had. It is fairly easy to drive to this practice either from work or home, and parking is ample. This GP bulk-bills for children under 5, something that Kendall noted gives her the “freedom” to be able to “investigate” Nikolai’s health issues. Kendall emphasised that this was particularly important for her, as Nikolai is her first child.

Kendall usually visits the GP for colds and flus, and has visited for the confirmation of pregnancy and some care during pregnancy. She visits the GP about 3 times per year. Kendall spoke highly of her previous regular GP at the Inner South practice, noting that when she was pregnant and experiencing morning sickness, the GP rang her at home to check on her. Kendall also mentioned that while she was experiencing morning sickness she would have appreciated a home visit from the GP, as the nausea and vomiting made it difficult to leave the house.

In terms of other primary health care services, Kendall has used an osteopath, and a physiotherapist while she was pregnant. She also uses the pharmacy relatively regularly, and noted that she would “go there first” before going to see the GP. She asked her local pharmacist for advice regarding a rash Nikolai had, and was recommended a cream that alleviated the condition.

Discussing after-hours access to services, Kendall was aware that the general practice at Majura Park was open some extended hours, noting that she had used it on the weekend for follow-up care. Kendall spoke highly of CALMS, saying that she had used it a number of times “usually after a long night” of dealing with illness. She also mentioned that she goes to no-appointment Medical Centres if she is “desperate”, but that the long waiting times are very difficult to manage with a baby. One of the reasons Kendall likes CALMS is because you

have an appointment at a specific time. Kendall also noted that cost is not an issue in accessing care at CALMS. She was also aware of the Walk-in Centre, saying that her partner had used it for treatment for a cut on his head. Kendall also knew about HealthDirect, and has friends who have used it. She said that she wouldn't use it herself, as her sister is a nurse and so she goes to her for advice first.

When asked to define "urgent" and "emergency", Kendall described urgent as something that you are "concerned" or "worried" about, but that is "not an emergency". She included fevers that don't break, or prolonged periods of illness in this context. Kendall described emergency as "something that I couldn't control", and spoke about "choking" or "not breathing" as conditions that would prompt her to seek emergency care, and to call an ambulance.

Kendall is aware of the ACT Medicare Local (ACTML), but doesn't have a good understanding of what it does. She mentioned that she had had a good interaction with someone from the ACTML at a stall in a shopping centre. Kendall hadn't heard of the "Know Your Options" awareness campaign.

Both Kendall and her partner have signed up for Personally Controlled Electronic Health Records, noting that having an electronic system is "easier" and saying, "I don't understand why it doesn't just happen".

In terms of accessing health information, Kendall speaks to her sister (who is a nurse), and also seeks advice from other friends with babies and young children. Kendall also goes to the pharmacy and GP for advice. She mentioned that she tries not to use the Internet for health information, as "there's a lot of misinformation out there" and "everything's just cancer". However, Kendall conceded that she does use the Internet for more minor things that don't require GP attention. For services, Kendall uses Google. She hadn't heard of the Find a Health Service directory, but indicated that she may use this in the future.

Key quotations

On finding a new GP after the departure of her previous GP: "...[it's difficult] trying to find a new doctor who suits our needs, and who we get along with...who we like."

On a poor experience with a GP: "She didn't know anything about Nikolai...she didn't really care...there was no 'Can I help you with anything else?'."

On home visits: "There were times during my pregnancy when I would have like a home visit...but I thought it was an old school thing, or only happens in country towns."

On the first point of care: "Often I'll go to the pharmacist first, before going to a GP."

On her GP's after-hours arrangements: "It's something I never even think of."

On what constitutes an emergency health situation: "Something that I can't control."

On finding health information: "I'll talk to my friends with babies."

Population Health Needs Consumer Interview – Kieran

10 September 2013

Kieran is a 23 year old full-time university student who lives in the Woden area and has lived in Canberra for more than 10 years. In addition to studying full-time, Kieran also works full-time in an administration position at night. Kieran currently lives with his parents.

When asked to define primary health care, Kieran described it as “doctors, hospitals...anything on the front line” to do with treating sickness and providing care. He also included nurses, specialists and surgeons in his definition.

Giving a broad overview of what he thinks is working well and not working well in primary health care in the ACT, Kieran spoke positive about the ACT ambulance service and the ease of access to GPs. On the negative side, Kieran was less happy about the communication between different levels of care, for example from the GP to the hospital and vice versa. Kieran also mentioned the old-fashioned processes involved with transferring patient data – faxes and hardcopies – and suggested that this could be accomplished more effectively through an entirely electronic system.

Kieran has a regular GP that he has been seeing for more than 10 years. He visits the GP for minor illnesses such as colds, and to obtain medical certificates for work. He has also attended in the past for sports injuries. Currently, he visits the GP about twice per year.

When asked about his interactions with his GP, Kieran spoke positively about his GP’s clear explanations and encouragement of questions. Kieran’s GP practice is located close to home and he often walks, which takes 10 minutes. His GP does not bulk-bill, and noted that the cost for a standard consultation was around \$76. Kieran also said that cost is not a barrier for him.

Kieran has had referrals to for other diagnostic tests from his GP, including an ECG and an x-ray. Both of these tests were bulk-billed and he found the referral process very straightforward, with the GP providing sufficient explanation. However, Kieran noted that the referral was done in hardcopy and then faxed, something which struck him as peculiarly inefficient.

Discussing other primary health care services, Kieran said that he had visited a physiotherapist more than five years ago, and that he had never used the pharmacy for advice. He believes that he has received an immunisation from a practice nurse.

In terms of after-hours access, Kieran knew that his GP was not open extended hours or on the weekend. He mentioned that he had used the CALMS clinic at the Canberra Hospital, just before going overseas. Kieran noted that this wasn’t an emergency situation, but that he needed advice but had left it too late to get an appointment with his regular GP.

When asked about the difference between “urgent” and “emergency”, Kieran described urgent as something that “needs to be done right away”, while emergency is a “bad thing that is urgent”, adding that “urgent doesn’t have to be negative, emergency does”. For Kieran, after-hours services he was aware of included the Emergency Department, CALMS and the Phillip Medical Centre. Kieran knew of the Walk-in Centre but mentioned that he felt he didn’t know enough information about what the Centre can treat in order to be comfortable in presenting there. He wasn’t aware of the “Know Your Options” campaign.

Kieran also hadn't heard of HealthDirect, but after an explanation indicated that he would potentially use it in the future.

Discussing access to health information, Kieran joked that he uses WebMD with the diagnosis always being "you have cancer". Joking aside, Kieran explained that he uses the internet for accessing the majority of health information. Giving an example, Kieran had a "weird eye tic" and he researched this online, with his conclusion backing up his initial thoughts about the cause. He acknowledged that it is difficult to ensure the accuracy of information, unless it is a "medical journal", but that he is inclined to trust sites verified by external sources, such as Better Health Victoria.

Population Health Needs Consumer Interview – Krissy

25 September 2013

Krissy is a 35-44 year old woman who describes her health as generally “very good”. She is currently living in the Inner North and has lived in Canberra for more than 10 years. Krissy comes from a non-English speaking background and speaks a language other than English when she visits her parents.

Krissy described primary health care as “day to day health”, encompassing services like the GP, as well as emergency services for things like broken bones, or other non-ongoing health issues.

Krissy has a regular general practice but she does not use one specific GP for all of her health concerns. She mentioned that she has “spent many years trying to find the perfect GP” and has found one with whom she is satisfied at her current general practice. However, this particular GP is “quite sought after” and only works one day per week, so it is often difficult to secure an appointment with her, particularly for urgent matters. Appointments generally need to be made about a month in advance. As such, when an urgent issue arises, Krissy uses whichever GP is available at the same practice. Her general practice is located closer to work than home, which was a priority before she had a child. Now it is more difficult to access her practice as it is in the city, and parking can be difficult to come by. Her general practice does not bulk-bill, and consultations cost around \$70 before the Medicare rebate.

Krissy goes to the GP for herself about once per year, usually for help managing chronic migraines, general illness, regular testing and check-ups (such as pap smears), and for monitoring of her gestational diabetes during her pregnancy. For her 18 month old daughter, Krissy has visited the GP about 6 times since her birth, for things like fever and sleeping issues. Krissy spoke about how important this was for “reassurance” so that doesn’t “freak out” about her “new parenting worries”.

Krissy also spoke about her experience with maternal and child health (MACH) nurse services, which she has used for regular development checks for her young daughter. The MACH clinic is located close to home for Krissy, and it provides a “drop-in” Q&A service on Mondays, which Krissy has found helpful.

Quality interactions with service providers are particularly important to Krissy, particularly for her daughter’s health care. She mentioned that her daughter can perceive when nurses and doctors are “child friendly” – these practitioners allow her daughter to “get comfortable” in the environment before attempting to undertake a physical examination. A quality interaction is one in which her daughter is put at ease by the provider, and that the doctor or nurses demonstrates that “they understand your situation” and that you are “not feeling rushed to get out of there”. Krissy has had a poor experience with a MACH nurse in this context. The nurse, whom Krissy described as “strict” and someone who didn’t allow any “pussy-footing around”, did not put her daughter at ease, and actually physically forced the child down in order to take her measurements. Understandably, Krissy’s daughter didn’t take this well and became quite upset, while the nurse seemed to have little comprehension of what she had done wrong.

Krissy's daughter was referred to the QEII Family Centre for help with sleeping issues. Krissy described this process as one of providing reassurance, "to have the experts confirm everything" with her. Like with the MACH nurses, her experiences with the staff were variable, and her daughter responded better to some than others. Krissy spoke about how difficult it was for her in the early stages to let the nurses know that their style was off-putting for her daughter. Krissy didn't feel as if there was a culture of "you know best" as the mother of the child.

In terms of other services, Krissy has used HealthDirect, but was not entirely satisfied with her interactions. On one occasion, 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. Krissy also spoke positively about massage that she had received during her pregnancy. She described this as a "holistic approach" which took into account her general physical health and involved a detailed patient history. Krissy also used the pharmacy during her pregnancy, and received a lot of information about potential impacts of medications on her child. She has also taken her daughter for advice about a skin condition. Krissy is also aware of the Walk-in Centre, but didn't know about the service's age restrictions.

For after-hours care, Krissy's general practice is open until 12pm on Saturdays. She has also used CALMS, for a possible reaction to an immunisation and long-lasting fever for her daughter. Krissy again spoke about how this reassurance from the GP was important for her as a new parent. She has also visited the ED with her daughter, when she and her partner feared that their child was experiencing breathing difficulties. Ultimately, it turned out that Krissy's daughter had just learned to make a new noise, rather than a respiratory condition. Krissy was relieved that the ED staff did not make her and her partner feel as though they had wasted their valuable time, and legitimised their concern and course of action.

When accessing information about health conditions and services, Krissy uses the Better Health Channel website, as well as a mother's group on Facebook. For advice about medication, she speaks to a pharmacist. On the internet, Krissy is more inclined to trust Australian government websites. She mentioned that she does use Google for things like finding out what a normal and high temperature range is. Krissy also conducts research for her mother, who doesn't speak English well. Her mother was not receiving sufficient advice from her GP, and so Krissy supplemented this information with her own research. By doing this, Krissy was able to facilitate an ACAT assessment and the introduction of mental health services for her mother.

Additional comments, made by email 16 October 2013

Thanks for the summary, most of it looks good but I've just remembered that I didn't tell you that I suffer from endometriosis too. Because of this I've been endometriosis clinic at the Canberra hospital as an outpatient and for memory I've had 2 appointments there. I was on the triage waiting list for some time (for memory it was like 6 months, and then it was rescheduled too) I was also kept in the waiting room for a number of hours, even though I had an appointment on both occasions. In saying this, the care was wonderful and very detailed and that's what's important to me. The parking was stressful and I also was running late for work, but because I knew what to expect on my second appointment I was more prepared and ended up taking a day off work.

Also, when I was pregnant the results for my gestational diabetes went missing and I wasn't notified for about a month. One of the G.P's at the practice I go to rang me on a Saturday to say they had found some test results at the bottom of their in-tray and they weren't sure if I had been informed that I had gestational diabetes. This was very stressful for me as I was worried that it had gone untreated for that amount of time and the impact it would have on my un-born baby. In the end all was fine, but this was an unnecessary stress and I think the communication between the G.P and midwife could have been better (as I was on the continuity care program so my midwife was looking after by prenatal care).

Key quotations

On primary health care: "[it's] my day to day health...my GP."

On finding a GP: "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."

On a good GP interaction: "It's quite obvious with my daughter, she doesn't like going to the GP at all...she can tell people's natures, and if they're sort of, kid-friendly...[the good GPs] don't get straight in there, and let her get comfortable...[when this doesn't happen] she freaks out and it becomes a really stressful experience."

On using MACH nurses: "[my daughter] didn't want to get measured, and the MACH nurse was quite forceful...I felt a bit awkward about the whole thing, like my daughter was behaving in a way that wasn't normal."

On multiple GP appointments for a minor issue: "I spent \$140 for something that could have been done over the phone. I don't want to spend \$140 on a freak out."

On why she goes to the GP for her daughter: "Deep down, I sort of knew that it was okay...it comes down to the reassurance, especially as a new mum, for the experts to say, 'Oh, you don't need to freak out'."

Population Health Needs Consumer Interview – Martina

13 September 2013

Martina is 17 years old and is a full-time college student. She has lived in Canberra for more than 10 years. Martina currently lives with her parents and is covered by their private health insurance.

When asked to define primary health care, Martina described it as services that are used on a more regular basis, "general, rather than specific". Martina included mental health and hospitals in her definition, and excluded specialists.

Discussing the positive aspects of the current primary health care system in the ACT, Martina said that she found that the mental health referral system had worked well for her, matching her up with a provider who meets her needs. She noted that she needed someone who was "gentle and easy going" to work with her on mental health. Martina also said that the treatment of young people by health service staff is generally good. On a less positive note, Martina related the story of one of her friends who has cystic fibrosis, and had to wait a long time for a hospital bed when they were acutely unwell. Martina also noted that cost can be a barrier in accessing some health services.

Martina has a regular GP whom she has seen "all [her] life". She explained that she goes to the GP if she has had health "troubles" for about a fortnight. Martina has also visited the GP to obtain a mental health referral, and returns for ongoing advice and management. She has a good relationship with her GP, whom she feels explains diagnosis and treatment options well. Martina described her GP as "gentle" and said she makes her feel "comfortable" and welcomes questions. Her GP bulk-bills, but Martina did say that cost is not so much of an issue as she has parental support for her health needs.

Martina's GP is easy to access, as it is located just down the road from her house, with walking time being between 5 and 10 minutes. It is slightly more difficult to access her psychologist, as it requires transport by car or bus, as it is in Deakin. Martina noted that the bus routes to Deakin are quite efficient. Before she obtained her provisional drivers licence, Martina did note that it was more difficult to arrange for her parents to pick her up and drop her off at various appointments.

In terms of other primary health care services she has accessed, Martina has seen a psychologist, physiotherapist and pharmacist. She visited the psychologist through a referral from her GP, and maintains this relationship. Martina noted that while her parents support her financially for psychologist appointments, some of her friends are unable to access treatment as they don't have this same kind of family support and simply can't afford it. Martina received some physiotherapy treatment for a neck issue, which cost about \$100-\$120 for the first appointment. Martina noted that there was a private health insurance rebate for this treatment, and that her parents covered the payment. Martina has also spoken to the pharmacist, who gave her advice regarding the appropriate kind of strapping tape for a sports injury. While she felt that this was a positive interaction during which she had received quality advice, Martina noted that it was disappointing that the local pharmacies close so early, at around 7pm.

When discussing the differences between "urgent" and "emergency" care, Martina described urgent as "almost emergency", something that "can't wait". On the other hand, Martina

described emergency as something that needs to be acted on “straightaway” something that is “causing distress” and “hurting health”. Martina recounted an experience where she had required urgent health care, when she had a severe virus. She phoned the local general practice and was able to be seen during an “emergency appointment” on the same day – usually there is a 2 week wait at her local general practice.

In terms of after-hours health services, Martina was aware of the Emergency Department, and also spoke about phone services such as Lifeline and Kids Helpline. When asked about HealthDirect, Martina indicated that she had heard of this service too. While Martina spoke about a “walk-in clinic”, she was not referring to the Walk-in Centre, but rather meant the no-appointment, GP-clinics like Phillip Medical Centre.

Martina joked that when she uses the Internet to find health information, the result is always “you’ve got cancer”. She also mentioned that she asks her brother for some kinds of information, as he has a medical science degree, and talks to her friends who have experienced similar conditions. Martina noted that she is often concerned about the accuracy of information provided online, and emphasised that even official organisational websites are lacking that “face to face” connection. Martina trusts information from organisations like Headspace and Beyond Blue in regards to mental health, but didn’t have any similar trusted sites for physical health.

Population Health Needs Consumer Interview – Marg

9 September 2013

Marg is a 64 year old woman who has lived in the ACT for more than 10 years. She currently lives in the Woden area. Marg lives with chronic pain that requires ongoing management. Marg is an informed health care consumer and is involved in a number of consumer organisations. She is aware of the Medicare Local and the role it plays in planning for primary health care services to meet the needs of the Canberra community.

When asked to define primary health care, Marg described it as the “first port of call” in the health care system, consisting of GPs and other experts that you can access without referrals, including physiotherapy and hospital outpatients services.

Marg gave an overview of what she thinks is working well and not working well within the primary health care system in the ACT. On the positive side, Marg thinks that the Medicare Locals present an “opportunity” to improve service delivery in the ACT. In addition, Marg spoke positively about the increase in the collocation of services in corporate clinics, such as dental and diagnostic services. She also mentioned identified the Walk-in Centre as a positive feature of the current primary health care landscape.

While public services are available, Marg believes that there is a perception that things “work better in the private system”. She noted that it was “sad” that she and others who cannot afford private services have to fund treatment for their chronic pain out of their own pockets or use the public system, which is not sufficiently responsive to their needs. Marg also identified the “variability of GPs” in terms of quality of practice and interaction as issue that needs to be addressed.

Marg has a regular GP whom she has been seeing for 3-4 years. The management of her chronic pain is now undertaken by a specialist, but Marg sees the GP for a number of health issues, including regular testing (e.g. breast examinations and pap smears) and injury (e.g. falling down the stairs). Marg described her interactions with her current GP positively. She feels that the GP explains things well, knows Marg’s interest areas and assists her in understanding some more technical aspects of treatment. However, Marg noted that there is little official recognition of chronic pain issues at an ACT-wide level. In her opinion, GPs are possibly aware of the extent of pain issues but many have little services or support to offer, meaning that ultimately many “GPs dread the person with pain”. There is a need for further education and training for GPs around pain – Marg spoke about an online accredited self-development course created by Pain Australia and the Royal College of General Practitioners that could be a useful tool.

Marg mentioned that when she first saw this GP it was something of a trial run, with her daughter describing it as her “interviewing the GP”. Marg said that she had “sacked” the last GP as she was unhappy with her interactions and ability to deal effectively with pain. Her previous GP provided her with a referral to a specialist. When Marg asked for a referral to another specialist in the same area, the GP refused to provide it on the grounds that one had already been given to her. Marg discussed this with her pain psychologist who said “they think you are doctor-shopping”, with Marg responding that she “felt like a consumer”.

The general practice Marg uses employs technology in an efficient way, with referrals and test results being processed electronically. The practice is located 10 minutes from home and has adequate, free parking. There is also a lift in the practice.

Despite her satisfaction with the care provided by her specialist and her GP, Marg noted that there is not good communication between her specialist and her GP. Often Marg has to prompt her specialist to send treatment information to her GP.

When asked about home visits by the GP, Marg described a situation in which she would have wanted one – she was in serious pain and had mobility difficulties, inhibiting her ability to access external services.

In terms of cost, Marg mentioned that some providers have assumed that she is unwilling or unable to pay for treatment. In her general practice, Marg is usually charged but occasionally bulk-billed, and she is aware that GPs in the same practice have a choice to bulk-bill or charge their patients. Surprisingly, Marg found that her surgeon did not charge her directly for a recent surgery.

When discussing other services, Marg noted that community pharmacy could be more proactive in noticing if there are changes in a person's medication, to prompt a discussion about this and to build a relationship with consumers. Marg is satisfied with her pharmacist as this does occur – they noticed the different kinds of medication she was taking and inquired about her condition. Marg also spoke favourably about her interactions with a psychologist, who played a key role in connecting support and care around her chronic pain issues. She said that the psychologist gave "great...practical" advice and had "expertise" in the area of pain. The psychologist also recommended an alternative physiotherapist who had an understanding of chronic pain.

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. Marg has also visited the Walk-in Centre for advice about a wound post-surgery. Marg noted that due to their narrow scope of practice, the Nurse Practitioner was unable to provide antibiotics, but did give a suggested diagnosis and referred her on to a GP. She has also used HealthDirect successfully for advice about the timing of medications. Marg was not aware of the "Know Your Options" campaign, and said that she was unlikely to have seen the advertisement as she rarely watches commercial television.

When looking for health information, Marg described herself as a "brochure grabber" collecting information from the GP, hospital and other services. She also looks online and has used the ACT Health website and the Find a Health Service directory. She is inclined to trust information from peer-reviewed journal, and government and university websites. Marg mentioned that she is "suspicious" of any websites that are "surrounded by ads".

Key quotations

On primary health care: "[it's] the first port of call for people who are in need of health care."

On GP care: "I think there's a lot of variability in GPs...people often have a good experience with their GPs...[and if they don't] they have the freedom to move, if there are other GPs available in their area."

On pharmacy: "Pharmacists are working well, and are perhaps underutilised."

On a good GP experience: "She wanted to know everything – everything – about my pain."

On connection between different levels of care: "I have to keep reminding my specialist to send copies to her [my GP]."

On referrals: "Sometimes I've been referred and then found that the person concerned has retired."

On 'doctor shopping': "I sacked a few doctors...in my pain drama."

On referrals: "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."

On 'doctor shopping': "When she [her physiotherapist] said 'They think you're looking for drugs', my jaw just dropped."

Population Health Needs Consumer Interview – Mick

1 November 2013

Mick is a 30 year old man who works for a sports-related community organisation in Canberra. He has lived in Canberra his whole life, and does not have a regular GP. Mick currently lives in the Belconnen area. He describes his health as “very good”.

Mick described primary health care as “the place where you seek most of your health care”. Mick does not have a regular GP at the moment. He noted that at university, “I had access to free doctors, so I just saw them.” Mick said that “time constraints” play a role in why he does not access GP services frequently, and why he doesn’t have a regular GP.

When he does have an issue that needs to be attended to by a GP, Mick “go[es] to wherever will be fastest...more often than not I usually go to the larger health clinics.” Mick is generally happy with his GP interactions, noting that they explain diagnosis and treatment to him adequately “every time”, even in the corporate style clinics.

Mick sees other services within the community, including physiotherapy and psychology. He noted that cost plays a factor in how often he can access these services, and specialist services. “Cost of specialists will definitely stop me. I currently go to a specialist maybe 4 times a year for various concerns, but if I had the money I would go once per month to either a sports doctor and/or a psychologist.”

Mick has accessed the Walk-in Centre at the Canberra Hospital – “I went there late at night once, so it was quiet...we were seen to quickly...it was fine.” Mick was not aware of CALMS or healthdirect.

When looking for health information, the Internet is Mick’s first port of call.

Population Health Needs Consumer Interview – Markus

25 October 2013

Markus is a 25 year old man living in the Inner North. He recently graduated from university and is currently working in the public service. Markus has lived in Canberra his whole life. He described his health as “very good”, and does not currently have a regular GP.

Markus described primary health care as “the main health care service that I use.” Markus noted:

“In recent times I have had very little interaction with any health care services, maybe that is the problem. I am stuck with the perception that it is difficult to access primary health care.”

Markus doesn’t have a regular GP or general practice because, as he notes, “I never really go to the doctor...I haven’t had the need.” The last time he went to a GP was more than 2 years ago. When dealing with the symptoms of colds and other viruses, Markus self-manages, and seeks the support of over-the-counter and pharmacist-only medications from the pharmacy. He does not seek treatment advice from the pharmacist, relying on recommendations from his friends and girlfriend as to which medications would be appropriate and effective.

Markus indicated some awareness of the Walk-in Centre, although he may have been confusing this service with the ‘no-appointment’ corporate clinics which operate in the ACT. Markus was not aware of healthdirect or CALMS.

Like most young people, Markus indicated that he would use in the Internet for health information:

“I just search what I’m looking for in Google...but I don’t really go looking for it [health information].”

Population Health Needs Consumer Interview – Paul

10 September 2013

Paul is 23 years old and lives in the Inner North. He has lived in Canberra for more than 10 years, and his father also lives in Canberra. Paul is a PhD student on a scholarship, and also tutors some undergraduate university classes. Paul has chronic asthma which can flare up on a seasonal basis.

When asked to define primary health care, Paul described it as “more important” health care, including GPs, doctors and dentists in this category. Paul mentioned other services like chiropractic, but did not include these in his definition.

Giving an overview of what is working well and not working well in primary health care in the ACT, Paul commented favourable on the attitude of GPs, noting that they are “professional” and “helpful”. On the negative side, Paul noted that it was difficult to get in to see a GP, and that he has to “book a long time in advance”. Paul also said that the dentist was very expensive.

Paul has had the same GP for his whole life. He visits the GP for episodic treatment for his asthma, including obtaining a prescription for an inhaler. Paul believes that his GP explains things well to him, is clear, understanding and invites questions. Despite his good relationship with his GP, Paul noted that he would be reluctant to see him for mental health issues because Paul has “known him so long”.

Paul’s GP is no longer close to his house, as he relocated from Weston Creek to the Inner North. He usually rides his bike to the GP or drives, and parking is adequate. Paul noted that his GP does bulk-bill him, but is not sure of the arrangements for other patients. Paul also said that the cost would not impact on his ability to seek care.

Paul noted that he self-manages coughs and colds as he doesn’t believe these are significant enough to warrant a visit to the GP. He also said that he has never had a medical certificate for illness, and that usually he just goes to work or school, even when he might be quite unwell.

In terms of other services, in the past Paul has visited an osteopath for scoliosis treatment, but mentioned that he found it difficult to reconcile the cost with the perceived benefit of the treatment. Paul also said that he has visited the university medical centre, and he may have seen a practice nurse there.

When asked about the difference between “urgent” and “emergency”, Paul described urgent as something that “needs to happen very quickly, something that can’t wait and needs medical attention”, while he described emergency as “more urgent than urgent” something “unexpected” that requires assistance.

Discussing his awareness of after-hours services, Paul mentioned “walk in clinics” where people “rock up” and are put on a waiting list to see a GP. Paul did not know about the Walk-in Centre, but confused the name with the no-appointment medical model outlined previously. Paul also thought that there might be 24-hour pharmacies, but he wasn’t sure. He also mentioned the hospital as an available after-hours service. Paul also wasn’t familiar with HealthDirect, but responded positively to the idea and mentioned that it would be something he’d consider using in the future.

Paul said that "Know Your Options" campaign "rings a bell" but that he wasn't too clear on what it was. After an explanation, Paul said that he didn't have a magnet, and that perhaps other methods of advertising might be more effective for his age group. He suggested the use of social media and online advertising, as opposed to traditional print- or television-based means.

When looking for health information, Paul said that he would do a Google search, look on the ACT Health website and search Wikipedia for symptoms and treatment. Jokingly, Paul noted that he would not use "Yahoo answers". He was aware of the limitations of seeking health information online, saying "I Googled some symptoms the other days and it told me I was pregnant".

Post interview comments from Paul, 16 September 2013, via email:

"I'm hoping that my confusion about the options helps highlight the need for more information and exposure. It made me realise that a lot of the time I don't use medical services because I don't know what's available, or I don't know what the best thing to do is, and so I do nothing (not the best practice, I'm sure). 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 (again, probably a bad line of thinking)."

Population Health Needs Consumer Interview – Rebecca

Rebecca is 33 years old and has lived in Canberra for 5 years. She currently lives with her husband and children in the Inner North. Rebecca's children are aged 3 years old and 1 year old. She describes her health, in general, as very good.

Rebecca described primary health care as the "first port of call for health care", including services like the GP, dentist, pathologist and other non-specialist services.

Rebecca does not currently have what she would call a "regular" GP. While there is a GP at her local practice whom she prefers to see, often this is not possible when required. Her preferred GP works part-time and is in high demand, making it difficult to get access to her for urgent issues. However, for urgent issues, Rebecca is able to see another doctor within the same practice, usually on the same day.

Easy access to a GP has not always been the case for Rebecca and her family, however. Previously when she had lived in the Inner North, her local general practice indicated that they "weren't taking any new patients", meaning that she had to seek care in a different suburb. Moving back to the same suburb in the Inner North, after some time in Gungahlin, Rebecca discovered that her local general practice, which previously had "closed books" had changed ownership and was now taking on new patients.

When she or her husband is sick, often they will wait several days before seeking medical attention. If one of her children is sick, and when it seems "a bit nasty", she will seek medical attention for them more rapidly. As her practice bulk-bills children, Rebecca is more likely to "get it [her children's health conditions] checked out" in order to get some professional reassurance. She remarked that bulk-billing for children was unusual to her, and she had never received this at any other practice. Rebecca goes to the GP for her children's colds and flus, ear and eye infections, and injuries, such as a poke in the eye.

Rebecca is generally satisfied with the interactions she has with GPs at her local practice. She described them as "very friendly" and believes that they "explain diagnoses and treatment quite well" and that she has never left the practice "thinking that they hadn't given [her] the full information". However, her experience of practice nurses hasn't always been as positive. Rebecca felt that on one occasion a practice nurse did not properly explain the vaccination process for one of her children. She has had better experiences with vaccinations with Maternal and Child Health nurses.

In terms of other services, Rebecca has accessed services through the Community Health Centres, including dental and a dietician, to assist in the management of her son's food intolerances. Rebecca and her family also frequently use the pharmacy, for prescription and pharmacist only medications. She has also sought pharmacist advice about a suspected case of conjunctivitis in her son – the pharmacist recommended a pharmacist only medication option. While she has sought out pharmacist advice, Rebecca mentioned that she "feels like [she] shouldn't ask them too much" as there may be legal implications for the pharmacist.

The main barrier to accessing care that Rebecca spoke about was simply knowing what services are available. Rebecca has accessed social worker services for post-natal depression, but only knew that this was available after a recommendation from a friend. Rebecca feels that information about services available is neither consolidated nor easily available.

In an after-hours context, Rebecca has used HealthDirect several times. She found this service "really, really helpful". Rebecca has used HealthDirect for urgent issues that are distressing, but which she knows don't "warrant a 000 call". HealthDirect gave her "immediate advice...on the spot" and gave her options about follow up care. Rebecca was

impressed by the HealthDirect process, saying "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 has used CALMS for her children's conditions (conjunctivitis, flu and fever) and was fairly satisfied with the service. However, she did not that the "lady on the front desk was grumpy" and that 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 was also aware of the Walk-in Centre but had not used it.

For health information, Rebecca has used the internet to find out more information about son's food intolerances, but also mentioned that she would be more inclined to find a practitioner she trusted and obtain information in this way. However, Rebecca did speak positively of the "FedUp" website, which contains resources and forums about uncommon food allergies. Rebecca noted that she also reads "people's opinions of providers" online, before she makes a choice about who to see.

Rebecca also discussed a general system improvement that would make a difference to her and her family: a more holistic approach by GPs, which incorporates complementary therapies and alternative therapies like homeopathy and naturopathy, instead of simply treating illness with medication.

Population Health Needs Consumer Interview – Robyn

Robyn is a 61 year old woman who has lived in Canberra for 9 years. She currently lives in the Inner North. Robyn has rheumatoid arthritis which causes frequent pain. She does not classify herself as a “chronic pain” sufferer.

Robyn defined primary health care as care that she receives from doctors, including her rheumatologist. Robyn has had a regular GP for 8 years, although she mentioned that when she has an urgent issue (which is rarely), she is happy to see another available GP at the practice.

Until about 2 years ago Robyn would visit her GP occasionally for blood tests, skin checks and other regular screening. In 2011, Robyn contracted whooping cough. Around this time, she also developed “incredibly debilitating” pain. Robyn believed that this pain was triggered by whooping cough – unfortunately, her pain was not alleviated when her whooping cough resolved.

Robyn’s GP explored a few diagnoses for the cause of the pain, during which time Robyn sought pain relief, both over-the-counter and prescription varieties. However, the prescription painkiller induced depression in Robyn so she quickly discontinued its use. Eventually, Robyn’s sister suggested that her pain might be caused by rheumatoid arthritis, a condition from which she herself suffers. Robyn was tested by her GP for this condition, but the results came back negative.

Despite testing negative for rheumatoid arthritis via her GP, 4 months after initially experiencing pain, Robyn requested a referral and attempted to access a rheumatologist through the public system in Canberra. The wait to see a public rheumatologist was another 6 months. Frustrated by this delay, and still experiencing intense pain, Robyn sought specialist assessment interstate. Her specialist confirmed the suspected diagnosis of rheumatoid arthritis and prescribed appropriate steroid treatment. Robyn did not have negative feelings towards her GP for missing her diagnosis, noting that she had tested negative (which is not uncommon) and adding, “You can’t expect a GP to know them all [symptoms] of all conditions”.

The steroid treatment for her rheumatoid arthritis has induced diabetes in Robyn, requiring further ongoing treatment. As such, Robyn now sees her GP for management of diabetes as well as the regular screening she would visit for previously.

Robyn feels that her GP explains diagnoses and describes treatments well, “sometimes more than what I want”. She mentioned that her GP is always running behind on her appointments because she “takes her time” with her patients. On several occasions, Robyn has waited an hour to an hour and a half after her allotted appointment time. However, Robyn understands this wait, as the GP “doesn’t make you feel hurried...you can deal with everything that you want to deal with”. Her GP doesn’t bulk-bill and a regular consultation costs about \$75.

In terms of other services, Robyn has used a range, including a naturopath to assist in treating her diabetes; shiatsu massage to alleviate pain caused by her rheumatoid arthritis; and an osteopath, during the pre-rheumatoid arthritis diagnosis phase. Robyn has a relatively good relationship with her pharmacist – the pharmacist always consults with Robyn about the administration and possible side-effects of new medications for treating her

rheumatoid arthritis. She did seek some pharmacist advice about pain relief during her undiagnosed phase, but the treatment suggested was not effective. Robyn is aware of the Walk-in Centre, HealthDirect and CALMS.

Cost is an important consideration for Robyn in her health care journey. While she has a low-income health care card, which means her medications are reduced in price, she has to travel to Melbourne in order to access specialist services, and her GP does not bulk-bill.

Fortunately, Robyn's specialist bulk-bills her as she comes from interstate. And while the lack of bulk-billing GP services can be frustrating for Robyn, she does not want to change practices as she is satisfied with her GP care, while not necessarily with the practice as a whole: "If it wasn't for [my GP], I wouldn't keep going to that practice". In fact, Robyn followed her current GP from a previous practice. When she first arrived in Canberra, Robyn had difficulty finding a GP, as most had "closed books". She attended another practice in the Inner North, but found these GPs "too conservative" and "unwilling to look at alternatives".

Population Health Needs Consumer Interview – Antonia

3 September 2013

Antonia is a 27 year old woman who works in the community sector.

Antonia came to Australia four years ago as a refugee, and has recently gained Australian citizenship. She has lived in Canberra for 15 months, in Weston Creek. Previously, she and her partner lived in Sydney.

Antonia's understanding of primary health care is that it is "basic healthcare" that "anyone can get". She gave examples of primary health care services which included the GP and community pharmacy. Antonia also noted the importance of basic dental services which she included in her definition of primary health care. She acknowledged that dental is often not considered a part of "primary health care" in the same way that a GP is, but she emphasised its importance to her health care.

Antonia described herself as young and "quite healthy". For these reasons, Antonia explained that she doesn't have a regular GP and doesn't visit the GP frequently. When she has been unwell, Antonia has attended a large corporate medical centre for GP care, at which she had poor experiences. On several occasions, Antonia had to wait 4-5 hours to see a GP for a 5 minute consultation. The quality of this interaction was also poor, as Antonia noted. The GP "didn't explain anything" to Antonia, especially in relation to the procedure around diagnostic testing. The GP provided her with a blood test request, but did not explain where to go to have the bloods taken, how much it would cost, or how Antonia would receive the results. "I felt blind", Antonia said, when describing her attempt at navigating the system.

On another occasion, Antonia was given a referral to see a specialist. After calling the specialist's office, Antonia was told that the initial consultation would cost \$300, plus the costs for subsequent consultations and treatment. The specialist's office did not explain to Antonia about Medicare rebates which would have reduced her out-of-pocket costs. Without this information, Antonia decided to forgo visiting the specialist, as the cost was prohibitive. During the interview, Antonia indicated that had she known about the Medicare rebate, this may have changed her decision not to visit the specialist.

When asked about other health services she accesses, Antonia spoke positively about pharmacies. Antonia demonstrated that she understood the difference between retail staff and pharmacy staff within the pharmacy. She also indicated that she had spoken to the pharmacist or pharmacy assistant about minor health issues ("skin rash", "cold and flu") and had been recommended medications or treatment by them. Antonia mentioned that she was aware of the Walk-in Centre and its scope of practice, but that she had not used it. She noted that for minor issues she visits the pharmacy or treats herself at home, and for more urgent or major issues she wants to see a GP.

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.

When accessing health information, Antonia uses the internet to find information about available services as well as for information about specific conditions. She noted that she is quite sceptical about the reliability of information that is available on the internet, but was not aware of websites that provided trusted information.

Population Health Needs Consumer Interview – Tracey

9 October 2013

Tracey is 50 years old and has lived in Canberra for 18 months, however between living in other places, she has previously lived in Canberra for about 20 years. She described her health, in general, as “fair”. Tracey has hepatitis C and is an intravenous drug user.

Tracey described primary health care as access to medical, dental and specialist care. Ideally, Tracey indicated, this should also include “complementary therapies” such as osteopathy, physiotherapy, herbalists and Chinese medicine – therapies that have “a basis in science”. She also noted that there should be better phone access to doctor and nurse advice/information.

Tracey has experienced difficulties in finding a general practice. The practices nearby to her house are “not taking new patients”, which has been the case for “5 years”. As such, when she needs GP advice, for flus/viruses and injuries, Tracey goes to Phillip Medical Centre, a corporate GP clinic. The quality of the care she receives at the Medical Centre is variable, as Tracey noted, “it feels like Russian roulette every time you go to the doctor”. Seeing a different doctor on every occasion means that “the doctors don’t know my history, there’s no rapport, and there’s no follow up care”. On several occasions she has been misdiagnosed. On one occasion in particular, the GP did not take an adequate medical history or ask her about the extent and duration of her symptoms. Tracey noted that the GPs at Phillip are “not prepared to listen to what you say”.

Tracey does not see anyone for regular management and monitoring of her hepatitis, or other conditions. She does not have breast exams or pap smears, as she does not feel this is appropriate in an environment that lacks continuity of care, like Phillip Medical Centre.

Tracey also spoke about her experiences of needle and syringe exchange services. She spoke positively about the ACT Hepatitis Resource Centre’s service (“respectful, knowledgeable and friendly”), but had less positive things to say about other services. Often, Tracey said, “you’re treated rudely, left ‘til last...some people treat you like a leper, like you’re disgusting...[they treat you] with contempt”. Tracey indicated there is a perception that people using the needle and syringe exchange service are “trying to scam people or steal things”. She felt that the best in-pharmacy service she had used was the Devlin’s Group pharmacy in Civic.

In terms of after-hours services, Tracey would use a pharmacy. She believes that the Inner North is well served in this regard, but that access in other areas of Canberra would be more problematic.

Tracey outlined some barriers to accessing services, including transport to services and cost. “Sometimes,” Tracey said. “You just can’t afford to [go to the GP]...it’s the doctor or feeding your children.” Tracey also spoke about the prohibitive costs that can be involved in prescription medicines, which are often recommended by GPs. Tracey explained that the situation is worse for low income earners who are not fully-supported by Centrelink payments, as these people do not have health care cards which entitle them to bulk-billing rates, but who might still struggle to pay for doctor’s visits.

Population Health Needs Consumer Interview – Lulu

3 September 2013

Lulu is a 42 year old woman. Lulu migrated to Australia 14 years ago from South America. She has two sons, aged 13 and 21. Lulu is a low-income earner and has a health-care card.

Lulu was unsure about what “primary health care” covered, saying that it was “the whole thing” including “GPs and emergencies and urgent care”.

Lulu has a regular GP that she has been seeing for 12 years. She noted that they have a very open relationship, and that she is not afraid to ask her GP questions or for clarification. Lulu has a chronic condition and visits her GP regularly to manage this. Lulu also visits the GP frequently with her youngest son, who suffers from asthma. She mentioned that she tries to “look after things...at home before going to the GP”, but that she knows her son’s asthma is serious and that if GP attention isn’t sought quickly, he can become very unwell.

Sometimes Lulu has to see a different GP when her regular doctor is on leave or unavailable. She commented favourably on one of these ‘fill-ins’, saying that he gave her a thorough examination, appropriate treatment and explanation of her condition, and good follow up care. Lulu noted that this GP also provided her with samples of medication to save her money. She commented on the different styles of different GPs, noting that some GPs, like the one mentioned above, treat you with “warmth and caring”, while her regular GP, although efficient, is sometimes curt and is often less comprehensive in his approach to care.

In the past 12 months, Lulu has received referrals to the physiotherapist, nutritionist, gynaecologist and urologist. Lulu did not follow up on the referral to the urologist due to the cost, which she was informed would be \$450 for the initial consultation, with apparently no Medicare rebate available. “I did ask about the rebate,” Lulu said. “...but they said there wasn’t one.” Fortunately, Lulu’s GP was able to refer her to another service within her local Community Health Centre to assist with managing her condition.

When discussing after-hours care, Lulu noted that her first instinct at night is to go to the Emergency Department, especially when her son is having an asthmatic episode. When her children were young, Lulu did not know where to go for after-hours services. She got some information from her son’s “Blue Book”, and these contacts were able to direct her to other services.

On one occasion, when her son had a sore stomach, Lulu rang the Canberra Hospital and asked for some information – she was transferred to a telephone help line (probably healthdirect). She spoke to a nurse that asked for a comprehensive list of symptoms and provided Lulu with advice about managing the condition at home, and when to escalate treatment. Lulu was happy with the quality of the advice she received, but noted that the idea of a medical telephone help line was alien to her: “Where I come from, we don’t have it so we don’t use it. I didn’t think to use it.”

Lulu said that her GP is open on Saturdays and Sundays, and that it employs a nurse to undertake some tasks. Lulu mentioned that she had seen the nurse for blood pressure tests and pap smears, but that she wasn’t 100% clear on what kind of nurse she was and how she fitted into the structure of the general practice.

When discussing where she goes for health information, Lulu gave a recent example of seeking out information. Her GP suggested a new treatment for one of her chronic conditions – however, he didn't provide her with comprehensive information about it. At home, Lulu looked up the new treatment on the Internet and found several journal articles about it, as well as a demonstration of the treatment on YouTube, providing her with enough information to decide to proceed with the treatment.

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 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."

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 unvaccinated 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 thought 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

Participants 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

Participants 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 upskilling 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 complaint.

"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 got 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 went 'Aah'. 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 bandaaid 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

Responses 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 haemorrhoids which her 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 not 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."