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Consumer Perspectives Informing Primary Care Responses to Chronic Health Conditions in WA : Results from WAPHA'S Naïve Inquiry Part 2

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Contents

Acknowledgments

Acknowledgement to people and country

WA Primary Health Alliance, Health Consumers Council and Curtin University acknowledge the Traditional owners and Elders of the county in which we work and live and recognises their continuing connection to land, waters and community. We pay our respects to them and their cultures and to Elders both past and present.

Acknowledgment to participants

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Introduction and background

Chronic health conditions are well recognised as presenting a significant burden to Australia in terms of impacts on individuals, the health system and the economy. Chronic health conditions are diverse, being defined by their longer-term nature and covering a spectrum including genetic disorders, mental illnesses, injuries and disabilities.[1] Chronic conditions vary in severity but can impact on a person's functional capacity and quality of life. Half of all Australians are living with a chronic condition (arthritis; asthma; back pain and problems; cancer; cardiovascular disease; chronic obstructive pulmonary disease; diabetes; and mental health conditions), with nearly a quarter of Australians suffering from two or more of these chronic conditions.[2] Those living with at least one chronic condition are more likely to die prematurely, and those living with multiple long-term conditions (comorbidities) have poorer overall health outcomes and higher rates of engagement with health services and healthcare costs, including potentially preventable hospitalisations. [2,3] More than a third of direct health expenditure is estimated to be spent on just four chronic conditions.[4]

The 2015 report of the National Primary Health Care Advisory Group, *Better Outcomes for People With Chronic and Complex Health Conditions,*[5] described the current response to chronic condition care by primary health as being poorly connected with the wider Australian health system, and restricted by current clinical payment arrangements. It detailed a range of recommended improvements both within and external to primary care, centred on a "Health Care Home" model of patient centred team care for those patients with multiple and complex chronic conditions.

The Health Care Home model has been drawn from models of General Practice developed in the US. It will be trialled at a number of sites around Australia from 2017, [6] with the key features being:

- General practice providing a "home base" to manage and coordinate care and support
- Flexible, accessible team-based care provision supported by changed funding arrangements
- Partnership with patients, families and carers to support increased self management
- Use of data to support improvement

The Royal Australian College of General Practitioners has also described a model of Health Care Homes, called Patient-Centred Medical Homes, which sets standards for care of all patients of General Practice.[7] In Western Australia, the WA Primary Health Alliance has drawn on these models and other work nationally and internationally to support a local response to the challenges to equity and health outcomes, including chronic health conditions.[8] The Naïve Inquiry study, commenced in 2016, its purpose is to inform this response.

The main aim of this short paper is to report on the findings from the Naïve Inquiry (NI) Part 2, a qualitative study which involved speaking to health consumers around their chronic conditions and their interactions and experience of the WA health system. The report begins by introducing the concept of the Naïve Inquiry and providing a brief overview of NI Part 1, before moving on to focus on Naïve inquiry Part 2. The final section brings together findings from NI 1 and 2 and provides some thoughts on next steps for service delivery and research.

Naïve Inquiry Approach

The Naïve Inquiry approach is exploratory in nature and focuses on gathering stakeholder views and experiences, without providing systematic representation or linking to a pre-determined theory about expected outcomes. Thus, it does not try to impose an existing theory or view, but rather uses a bottom up approach to understand a problem from the view point of those most closely aligned to the area of interest. In this study the problem is the response to chronic disease, those most closely aligned to this problem are health care professionals, patients and carers.

The inquiry had two discreet phases: **Part 1** involved discussion with general practice staff and **Part 2** involved discussions with consumers suffering from chronic health conditions.

Naïve Inquiry (NI) Part 1: Consultation with General Practice Staff [11]

A collaboration between WA Primary Health Alliance (WAPHA), Curtin University, WA General Practice Education and Training (WAGPET) and The Royal Australian College of General Practitioners (RACGP). NI Part 1 explored WA General Practice staff (GPs, practice nurses, practice managers) views and perceptions on the following:
Current provision and models of care for patients with chronic disease:

- Current provision for patients with chronic and complex co-occurring conditions;
- Explore how GPs and practice staff currently manage the tri-morbid patient cohort;
- Identify how GPs undertake risk stratification for tri-morbid patient cohort.

GP understanding of the PCMH model including:

- The value and appropriateness of the PCMH model for the WA context;
- The barriers and facilitators to the adoption and implementation of PCMH model in WA;
- Identify the most appropriate outcome measures to enable quantification of effectiveness of the PCMH model.

A summary of 'ingredients' for success is below (with further findings in the NI Part 1 report):[11]

- a holistic approach to care that centres around the patient;
- coordinated team care approach;
- role clarity for team, which includes the patient;
- an individual that takes overall responsibility for co-ordination;
- patients empowered to take responsibility and understand their role in self-management and working with GP to achieve positive outcomes;
- having appropriate robust systems to manage patients (including recall) and record activity;
- placing more priority on patients with chronic conditions, with greater recognition of the value of this support to the wider system;
- patients need continuity in terms of practice and GP.

Naïve Inquiry (NI) Part 2: Consultation with Health Consumers

NI Part 2 commenced in 2017 and involved a collaboration between WA Primary Health Alliance (WAPHA), Curtin University and the Health Consumers Council (HCC).

The aim of NI Part 2 was to gain insight into the experiences of adults with multiple chronic conditions who receive management support through primary care centred in general practice. These insights will help inform the ongoing development of care models and support to primary care services.

Methods- what did we do?

Consumer perspectives on chronic condition management within Primary Care were captured through a series of Focus Groups, a qualitative research method which elicits rich information from participants through a facilitated topic discussion within small groups. The research team analysed the data obtained from the focus groups and found a number of key recurring and contrasting themes raised by participants. The method is not intended to constitute community consultation, and recruited participants are not a representative sample of the population of people with multiple chronic health conditions.

Areas explored with participants

A number of key areas where explore with participants these included their views and perceptions on the following:

- current provision and models of care for patients with multiple (>1) chronic conditions;
- preferences and expectations around health literacy education and self-management support
- the patients (their) role in care management;
- what works well for them around chronic condition management in the community and broader health system;
- what could be improved around chronic condition management in the community.

Four target regions of the metropolitan area were identified by WAPHA based on previous population needs assessments – Armadale, Midland, Rockingham/Mandurah and Wanneroo.[8] Each region is located peripherally to the metropolitan area, with relatively higher levels of disadvantage and rates of chronic conditions.

Three regional locations were initially identified, aligning with the Naïve Inquiry 1 locations; however, it was only possible to conduct groups in the localities of Bunbury and Albany due to time limitations and concurrent regional activities.

Ethical approval for the study was obtained from Curtin University ethics committee.

Recruitment

Target participants were consumers with at least one chronic health condition, supported in their chronic condition management by a GP Care Plan. Participant recruitment was conducted by HCCWA, primarily through distribution of a flyer through electronic media:

- Emailed directly through HCCWA membership and promoted through electronic and printed newsletters, Facebook page and at information events;
- Distributed through HCCWA and WAPHA staff personal and professional networks;
- Distributed through targeted contacts identified through the Connect Groups website; a platform which provides a central database of self-help and other support groups
- Distributed through WAPHA's clinical and community engagement networks;
- Promoted to participants of chronic condition self-management and similar programs by WAPHA-contracted providers.

Participants- Who got involved?

Forty six participants were involved in the study, 76% of participants were female, with two of the metropolitan groups including one male only, and one regional group being exclusively female.

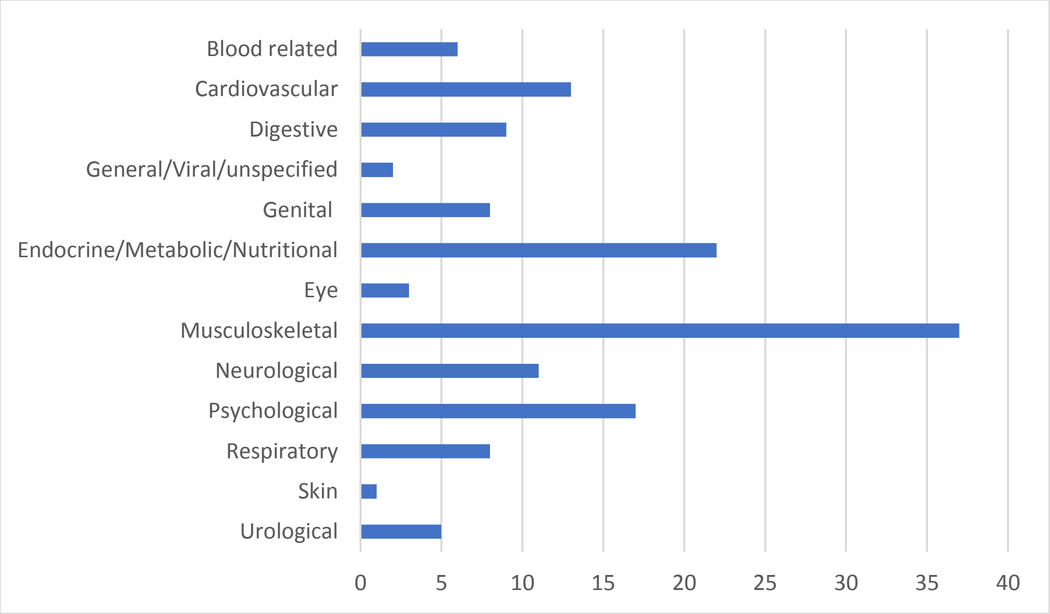
Table 1 below summarises collected data on characteristics of the group participants, showing diversity both within and between groups. All participants who met the criteria of having more than 1 chronic condition and being able to participate in a group setting were invited to a group, if they were able to travel to the closest planned group location.

Table 1 : Characteristics of focus group participants by focus group location

	Focus group location						
Characteristics	All groups	Albany	Armadale	Bunbury	Midland	Rockingham	Wanneroo
Number of participants	46	7	8	8	9	8	6
Gender (% female)	76.1	100.0	62.5	75.0	88.9	87.5	50.0
Age (Average [range])	48.1 [20:75]	62.0 [55:75]	58.4 [38:73]	55.0 [20:69]	55.3 [33:74]	55.3 [41:74]	53.0 [31:71
Disability - self identifed (%)	52.2	52.2	62.5	50.0	33.3	62.5	66.7
Carer status (% with a carer, % identify as carer)	23.9, 26.1	14.3, 42.3	25.0,12.5	25.0, 12.5	44.5,0	25.0,50.0	33.3,50.0
Income (%Centrelink)	54.3	85.7	37.5	62.5	33.3	75.0	33.3
Number of reported chronic conditions (Average [range])	3.3 [2:6]	2.1 [2:3]	3.4 [2:6]	3.6 [2:6]	2.8 [2:6]	3.5 [2:6]	3.5 [2:6]
ED presentation in past year (% of participants)	43.5	71.4	37.5	37.5	44.4	50.0	33.3

The reported chronic conditions for all participants are summarised by ICPC-2 group[9] in Chart 1 below. Fifty nine percent of participants reported at least one musculoskeletal issue making this the most frequent category, however diabetes mellitus was the most commonly occurring specific condition (experienced by forty one percent of participants).

Chart 1 : Self reported chronic conditions – all focus group participants (N=46)



Over 23% of participants listed fibromyalgia as one of their chronic conditions, with at least one participant in each group reporting this condition. The participation of consumers with chronic conditions which are less common, and which may have less clearly defined diagnostic and treatment pathways than the more frequently identified chronic conditions, provided breadth to the discussions and highlighted the challenges faced by primary care in providing comprehensive care.

Participants- What did they tell us?

The main emergent themes identified are presented below, mapped against the areas of interest. An overall generalisation of the themes is given in bullet points, representing the most frequent and intensive perspectives identified. Three illustrative quotes have been selected to provide further voice to the theme descriptions; where quotes have been abbreviated for clarity and specificity, "…" has been used.

Current provision and models of care for patients with multiple (>1) chronic conditions

Current provision and models of care includes disease care and management services provided within general practice, specialist services and the wider primary care services including pharmacists, primary care-based nurses, and allied health services accessed through current Medicare arrangements.[10] The focus group participants discussed these care contexts, as well as the wider contexts of care delivered through on-line support, and care in Western Australia.

General Practice and General Practitioners

- ***GPs are central to chronic condition care***
- ***Trust and confidence develop in long-term relationship between patient and GP***
- ***Patients value and seek out GPs who listen***

The GP was identified as the main provider of health care and support by most participants, although some participants described a primary relationship with medical specialists. There was limited mention of contact with other staff within General Practice except for reception staff. Eighty five percent of participants stated that they always attended the same GP; in many cases describing relationships lasting more than a decade. A key theme was the building of trust and confidence within a long term relationship with a GP.

“If you’re on a lot of medications, I think seeing the same GP – they know what you’re on, they know how you’ve reacted to medications and that in the past – and you’re safe…and you’re not drug seeking.”

“But the other thing is, with my conditions : they can look at you, and they know how you were last time, and the time before that, and they go ‘you’re not well, are you?’.”

“I stuck with one GP for almost 9 years, and then I ended up getting really sick and he said I wasn’t sick, I needed treatment with psychologist, so everything was in my head. And I couldn’t go any further with him….it was a really bad experience. Once I have my new GP that I have at the moment, he ended up finding out all the issues that I have and the problems that I have, everything went through a good path but I’m still afraid if he goes away, going to someone else I don’t trust.”

GP listening skills were identified by participants as being very important, with several indicating that they had previously changed GPs due to this issue. The extra time involved in receiving care that includes “good listening” was acknowledged.

“I’ve been in [other participant’s] position with doctors over the years – I’ve seen plenty of them – and what I do if…they’re not listening and I don’t feel like I’m getting the help I need, I will move on and find someone until I do. I’ll just keep going, until I do.”

“That’s why my doctor is always late, because he’s very thorough [with everyone].”

“I feel lucky ‘cause the practice I’ve got, all the doctors seem to – and the important thing is – listen. They don’t talk over you, they’ll actually sit there and also they’ll explain stuff so they’re never rushing you and I just feel that’s one of the most important things out.”

The impacts of not feeling listened to were highlighted by one group:

> *"What does that do to you in terms of an individual when you feel unlistened to or dismissed?"*
> (Researcher)

> *"Well, it just enhances your grief. Because …you don't feel like you're ever going to improve."*
> (Participant 1)

> *"I feel as if I'm being a nuisance".* (Participant 2)

> *"You lose the will to fix yourself."* (Participant 3)

> *"And I think you lose confidence in telling people, too."* (Participant 4)

Pharmacists

- ***Pharmacists are important, accessible and give appropriate advice***
- ***Pharmacists can protect patients from medication errors***
- ***Trust built through long term relationship with Pharmacist***

A strong theme which emerged from the discussions was that, through their central dispensing role and medication expert knowledge, pharmacists can protect patients from medication errors that can occur in transitions of care. Another theme was that pharmacists provide fast, free and appropriate health advice.

> *"He knows what I can take, and that's very important. So we stay…been with the same one for 30 years. So, he knows our, my health better than my doctor, because I've had to change doctors."*

> *"Instead of asking my GP sometimes, I head off to the pharmacist. He prints me out a patient information sheet or something like that…I sort of think that to have the same pharmacist is almost as important as having the same GP."*

> *"Ours has been very good at monitoring, especially the mixes and matches along the way and potential side effects. She's very good at highlighting 'look, this is what you need to, you need to look at this, you need to look at that, and you need to monitor yourself or what you're actually looking at'."*

Allied health providers and care provided through care plans

- ***Care plans are not well promoted***
- ***Access to allied health services under Medicare is appreciated, but 5 services are not enough***
- ***Allied health services can involve long assessment processes and are not individually tailored***

A broad range of experiences of care plan access and services were discussed. A key theme identified from participant discussions was concern that care plans are not well promoted, and eligible patients miss out on accessing a resource which would be of benefit.

> *"I think they're important. A lot of people, I don't think know about them necessarily, so I think it's an information thing that your GP needs to tell a patient that's maybe... just been diagnosed with different stuff. Because, being on a care plan, um lets you access more things through Medicare."*

> *"My girlfriend is a nurse, so I'm very lucky, because she told me about [care plans], so I told the doctor about it so that I could get better access to physio."*

> *"I only started on one at the beginning of this year. Before that, I was eligible for one, but no GP ever told me I was eligible for one, for like 7 years. So, yeah I find it really helpful, so far. It's mainly just me and the GP organising appointments with the specialist, but…I'm really glad she told me about it, otherwise I wouldn't have known."*

Another key theme was expressed frustration with the limit of five sessions per year which was viewed by most participants as being too low.

> *You can have 5 visits to someone, so if I needed to go and see a podiatrist for diabetes – I can't see the podiatrist because I've used my 5 visits up on the chiropractor…I know its good that I get 5 free visits for that year, but the system doesn't seem to work."*

> *"Yeah, you have to nominate one thing for that care plan and then that's it."*

> *"Me personally, I don't need a podiatrist – but if I have got back problems and I do need a podiatrist as well, you're pretty well stuffed. Its going to have to come out of your pocket, or private health, because you sign up to your care plan…to get your 5 visits, but then you have to, you can't swap them. You can't swap it over to the podiatrist."*

Related to the sense of allied health funded services as being a rare resource, many participants across the groups indicated a sense of frustration and waste when they attended a session that they did not find useful. Two issues were repeatedly mentioned as being associated with a waste in allied health sessions:

(1) time-consuming assessment processes, and

(2) generic information formats that do not account for individual preferences.

Dietetics advice was discussed critically in many of the groups, with participants expressing a preference for sessions involving a “hand’s on”, clinical therapy rather than education and advice.

> *“I’m not saying that dietitians and physiotherapists and whoever else don’t know what they’re doing, I’m saying that a lot of that stuff I can find out for myself like dietary advice and diabetic advice I can find out for myself. So, I want to choose what I feel does me good and that was the podiatrist. But the other ones…I could find out most of the stuff.”*

> *“Most of the first visit to any of these people is taken up just gathering information which they’ve already got anyway…its just that they re-gather it to take up the time.”*

> *“I went down to the swimming pool, and I’m supposed to do leg exercises and everything like that. And they threw me a plastic – one of these cards. But – you look at it, and you leave it at the side of the pool…I thought it was going to be a group thing, that we could all have a bit of a laugh and exercise…it done my head in, and I said ‘well I’m out of here’.”*

Perth context

- ***Perception through internet and social media research that Perth doctors and services are not up-to-date***

There was a recurring theme relating to rarer conditions and latest diagnostic and treatment availability in Perth. Many metropolitan participants expressed the opinion that there are care options readily available in other states or other countries that cannot be accessed in Perth. Knowledge of these options had come through internet research and social media-based support group networks.

> *“…when it comes to these diseases that I have that aren’t well recognised in WA – Eastern States, they’re miles ahead of us with their trials, what their doctors know, compared to our doctors here.”*

> *“If you jump on Facebook, you’ll get everyone’s opinion, and tests you can ask for WA doctors to run – the doctors won’t do the tests unless you ask for it”*

> *“What isn’t helpful is when I’ve gone to, say my back specialist and said : ‘Do you know anything about…platelet-rich blood spinning and injections, to decrease inflammation?’ No idea. ‘What about the effects of cryotherapy?’ No idea. ‘What about stem-cell research, stem cell injections’ No idea. So all of these things, which are available on the East coast, which are available in other countries, that I know about, that I’ve researched, that is medically documented and in published PubMed studies, they don’t know about and they’re the specialists.”*

Preferences and expectations around health literacy education and self management support

The internet as a source of health information

- ***“Dr Google” is a primary source of information***
- ***Awareness that there are risks associated with using the internet to provide health information***
- ***Empowering for patients to use information accessed from the internet in their contact with health providers***

Across all groups, participants identified the internet as a primary point of access to information about their condition and management options. Accessing medical information from the internet was commonly referred to as “Dr Google”. Participants indicated that they are cautious about the information available on line, being aware of inaccuracy and risks of creating unnecessary health anxiety.

> “You’ve just got to be careful. And the GP said “just do the…PubMed. Try and use that, and use ones that …it’s actual doctors papers that you’re reading, and not somebody’s opinion’. So, you’ve just got to be a bit more educated… ”

> *“When you’re looking for things that you don’t know, it’s kind of hard to get a focus on how you kind of follow a thread of information, and then you realise : ‘oh that’s actually rubbish’. So you kind of, you don’t know what you don’t know.”*

> *“Unless you’re very very clear about what you put into Dr Google, it spits out everything. You’ve got to be really specific what you put in, and very very clear, otherwise you get loads of shit given back to you and it becomes extremely confusing.”*

Participants discussed internet research as a tool to empower their working relationship with their doctors and their self-management.

> *“My doctor is willing to listen to things [information found on the internet] and do research on it if she feels it is something that, you know because GPs cannot be 100% on every single thing.”*

> *“[GP] is very open to any, you know any new information herself, which I find is great…she’ll then have a look herself and say ‘agree’, or give me more information and point me in another direction.”*

> *“When I see my doctors, and I get all this paperwork with results, I come home and I will go to Google and I look up the words [that I don’t know]…its only through me doing my own research I now know what I actually have.”*

The patients (respondents) role in care management

Responsibility for care management

- ***The patient is responsible for their care***
- ***Self management skills include being confident to ask questions***
- ***Recognising the need to take responsibility is enhanced when something goes wrong***

There was a strong theme in all groups around the ultimate responsibility for care management sitting with the patient. Stories shared described participants’ active journeys through the health care system to arrive at points of diagnosis, effective treatments and care partnerships. Probing with regards to determining specific strategies used had limited responses; several participants mentioned use of a diary to track symptoms.

> *“What I have found is that you’ve got to be assertive, and say : ‘look, I take responsibility for my condition, you’re here to help me’ and whether its GP or a nurse podiatrist, dietitian, whatever it is …and I think that can assist that process.”*

> *“You’ve got to rely on yourself, more than anybody. Because, no one can tell you how you feel, can they? You gotta, you’ve got to own it yourself.”*

> *[following education on chronic pain management] ”As soon as the brain starts to understand things by themselves, obviously you get better outcomes, better how to manage it, how to control it…it’s nice to know what is wrong with you, but also nice to know how you deal with it.”*

Several participants described a development of awareness and acceptance of the need to take personal responsibility for their own care, facilitated by experience of poor health events and through changing stages of life.

> *“A couple of months ago, my kidney collapsed because of the diabetes…and I thought: ’this is ridiculous, I really must start being more careful’ .“*

> *“I always have been [very involved in my care] but the mismanagement [experienced in hospital] really ingrained it in me that I really need to be far more responsible.”*

> *“I mean like, I was working full time, it was just you know more and more drugs and treatments after work and then I gradually had to reduce work more and more as the pain got worse, but that also then gives you more time to look into different types of treatment, seek out different things…I feel more in control, and sort of recognise in yourself, when to stop, or when…if I do that now I know I’m going to be in that much more pain… ”*

What works well and what could be improved around chronic condition management in the community

Support with the costs of care

- ***People with chronic conditions are burdened financially***
- ***Care choices are impacted by costs***

Bulk-billing was discussed in all groups, and a majority of participants indicated that this is an essential factor in their care. Participants explained that as chronic patients, they had high costs associated with medications and were limited in their capacity to work. Some participants described changing practice when bulk billing was withdrawn.

> *"… when you have a personal issue and you have built a relationship with a doctor [loss of access to bulk billing] can really significantly impact on your health, because – sometimes I won't even go to the doctor and worry about it"*

> *"My doctor…chose not to bulk-bill me, so it does make me consider how often I need to go, I think twice before I make an appointment."*

> *"I've had to change from good doctors when they've stopped bulk-billing, so – I can't afford to. With the amount of times I have to go with medications and things I have to go to a bulk-billing doctor so that's been something that has stopped me seeing good doctors in the past, when they have gone private."*

Other financial burdens of care were raised within discussions about bulk-billing practices. Many participants indicated that they had previously decided against seeing a recommended specialist due to up-front and gap costs incurred.

> *"And it's not just an issue of, ok, driving up to Perth. After I've been in the car for like 3 hours, 3 and a half hours, I can't walk properly…and then you've got the expense of staying overnight, as well as you know the costs of the actual specialists."*

> *"The gap for referred specialists. That is massive. The referral that I got was $400, and I got, I think, $250 back – having anything coming back is good."*

> *"You're going for more expensive, you know, tests and that - you have to pay for that, up front. OK, you might get part of that back from the gap…but how are you supposed to pay?"*

Models of GP care delivery that accommodate the frequent contact needs of people with chronic conditions

- ***Flexible contact outside of clinic appointment model***
- ***Efficient appointment processes would reduce time spent in waiting rooms, which are potentially a source of further illness for people with chronic conditions***
- ***Separated waiting areas would reduce infection risk***

Accessing information and prescriptions from the GP without having face-to-face contact was valued by many participants, who felt that this indicated a relationship of mutual trust and a recognition of the skills of the patient as a manager of their own care. A perception was noted that GPs may be flexible, however clinic reception processes can be a barrier.

> *"We had some trouble…we had to get the doctor to speak to the reception staff to tell them…yes they do know what they are doing."*

> *"Very early on, [GP] gave me her mobile number, and I could ring at any time. And if I was desperate, I don't even need an appointment, I just rock up. And that has been brilliant."*

> *"[Receptionists] kind of treat you like – the general population. 'No, we can't give you blood results, you can't speak to your doctor' and its like – 'just please go and ask my doctor' and he's like "sure, no dramas…" but the reception staff are just got this like war-front against patients."*

A strong theme emerged from the discussions relating to risks to people with chronic health conditions that arise from long waiting times and exposure to contagious diseases in waiting rooms. Segregated waiting areas and time-efficient queue management strategies were suggested as solutions to this issue.

> "Cause sitting there for that long I tend to stiffen up, I can't sit for very long without having to get up and go for a walk. I'm worried about people who don't put their hands or their tissues over their mouths while they're coughing or they're sneezing…I feel like I want to walk around with a mask on..."

> *"[someone with the role to say] 'Hi, how are you doing, how are you feeling, are you on immune-suppressants? You sit over this side away from the sick kids'. Because there's people on immune-suppressants that will get the 'flu and end up in hospital with pneumonia."*

> *"We've got this on-line, booking thing that's happening now with our GP…which is good, because you don't have to ring , and wait and all this sort of thing, so that's good….They've also created this new…special line that you can ring in for your um reports, um your tests, your results. And basically, a doctor reviews these results all the time that come in, and if there's anything on those*

Condition-specific care pathways

- ***Standard conditions have clearly defined care pathways; rarer conditions do not***
- ***Mental health support in General Practice is limited***

As previously discussed, the focus group participants had a wide range of health conditions including conditions which are rare and/or not conditions that are commonly referenced in chronic condition management planning and policy literature. It was apparent and remarked upon in several groups that the health care experiences and needs of people with "standard" conditions that have clear diagnosis and care pathways (such as diabetes mellitus) are very different and perhaps less dependent on a strong relationship with general practice when compared to less common conditions (such as myalgic encephalomyelitis).

"Diabetes has a lot of funding too, so they know what they need to do now for diabetes. And if you do only have diabetes, its an easy path – not saying it is easy for you – …if you've now got a sore knee or you've now got a stomach problem it starts diverting, and then it's like the doctor looks at you like 'I know you're in pain and I can't deal with the emotional problem you have associated to the pain so I'm going to shut you out'."

"The doctor doesn't really know, there's no evidence for what's causing my issues…so he's sent me off for all of the tests that he knows about, they've all come back negative, he doesn't really know where to go from now because there's not enough research being done into what causes it."

"I just feel sometimes…because my condition is so rare, there isn't a lot of knowledge, even my GP doesn't have a lot of knowledge about it. So, sometimes I feel a little bit that they might not be following up properly on it, keeping tabs on it properly. And I don't really know too much about the future of this illness – I don't feel like I've been informed enough…its sort of up to me to ask questions, but sometimes I'm not really sure what to ask."

Care pathways for mental health conditions such as depression and anxiety were raised by participants as an area for improvement. Several participants discussed concerns that the level of mental health care that can be provided in General Practice falls short of need, particularly with regards to crisis support and access to specialist therapies.

"I was an outpatient with the mental health um clinic, and then that's gone completely when I was discharged, and now it's just my GP. But it's more serious than GP but not quite serious enough, so it seems like there's this no man's land in the middle…he's not a psychologist, he's dealing with all sorts of things so I get it, but yeah I can't afford $350 a consult every month for a psychiatrist. So I'm sort of – yeah I'm just getting by."

"I did see the GP (about mental health crisis) in the end…they just tripled my doses 'til I got up to a steady area now, and now I just sort of take my medication, and suck it up…when I was trying to find help, I couldn't find it."

> *"I used to be under one of the hospitals mental health things and I had a case manager and all that sort of thing and now I'm not in that system – I've lost touch with what is actually available. So I was getting that information…my GP was quite happy to take over my care but I also felt like I was going to lose out here because now I'm not in the mental health system, I don't know what's available, I used to do a lot of art things and get access to, you know, different programs."*

Shared information between health professionals

- ***Shared health records make sense, would save time, and provide better quality care***
- ***Confidentiality of records is not a concern***
- ***Difficult/costly to transfer records between General Practices***

When discussing their experiences of communication between health professionals, the issue of centralised health records was raised by participants. Shared access to a central record was viewed as providing quality and safety, and saving time. Confidentiality of records was not a concern for participants when probed, although none of the participants were actively using eHealth records.

> *"It shouldn't be a privacy issue at all, because you know it's just information…it's for our own health….if you go to your Medicare, you know My Gov…they have a list of every single visit you've made. So if you've got a Medicare card they already know the number of visits you've made and the reasons."*

> *"I would have liked that to be linked to my Medicare card or something, where I could go in and I could tap it in to the system and I could see what is actually happening to me. Or, what my records are."*

> *"It's not just [for] yourself… there should be like a database for every medical practitioner, or medical professional that – they click a button, they know this is your problem. Not that every time you go somewhere you fill out the same bloody forms. It's the same forms, that take up so much time."*

Also relating to health records, participants spoke frequently of delays and difficulties experienced when they changed practices and requested transfer of their records. Fees charged for this service, stated to be in excess of $200, were seen to be unreasonable and to constitute a barrier to care. Personally controlled records were seen as a solution.

Advocacy and support

- ***People with chronic conditions require advocacy and support***
- ***Partners and relatives can provide this supportive role; people who don't have their own support network would benefit from a professional advocate***

Interpersonal support was identified by many participants as an important ingredient in their chronic condition management. Most participants discussed their primary advocate and care partner as being a spouse or relative, expressing concern for others in the community who may not have access to such support. A professional advocate role, sitting outside of the health system and provided by someone with psychosocial skills as opposed to medical skills and knowledge, was suggested in several groups. Participants in several groups mentioned the need at times for people with chronic health conditions to have "someone to hold your hand".

> *"I'm confident to access services…but sometimes, just to have that person on your side, because after a while it's like: 'I'm going to the doctor, I'm going to the specialist' – they must think I'm a hypochondriac, I'm just imagining this. Just to have that support there, if you need it."*

> *"You could have a family member that's going to support you. Or, you could be that person that has no one there for support."*

> *"[an advocate] could not just shepherd the person through the system, but they can also help the person feel a little more confident that someone else -who is not a doctor or a nurse, you know- to speak with them in simpler terms, explain the processes that sort of thing – or just sort of hold their hand, metaphorically speaking."*

Comparing Naïve Inquiry 1 and 2 responses

Eight key features considered by General Practice informants to be important in future models of care were identified in Naïve Inquiry 1.[11] These have been summarised in Table 2 below, with related consumer perspectives raised in Naïve Inquiry 2. There were similarities around the areas raised in port NI 1 and 2 and responses demonstrate the value and importance of the consumer voice in both defining terms and informing pathways to achieving outcomes.

Table 2 : GP and health consumer perspectives on recommended features of future care models

Holistic	Taking a holistic approach to care that centres around the patient - often at the expense of the business (financial model) - the holistic approach takes an investment of time and a practice philosophy that's aligned. **Consumer perspective:** patients wish to be listened to, respected, and have appropriate time made available to them. Sometimes they need someone in the system that can "just hold their hand".
Co-ordinated team approach	This involves multi-disciplinary skill base; good communication and relationships '*working closely together*' co-ordinated approach. **Consumer perspective:** sense of mismatch between service provided by GP and external allied health services – no sense of team care apparent. Limited information provided to allied health providers impacts on time available for therapy provision vs assessment
Role clarity for team – including patient	All individuals being clear on their role, the roles of other team members and understanding how their bit adds to the whole. This also involves patient being clear around their responsibility. **Consumer perspective:** patients see lower value in team members that provide standardised information; would prefer team members deliver more individualised care
Co-ordinator role	An individual that takes overall responsibility for co-ordination and relevant admin tasks - working closely with other staff and patients. **Consumer perspective:** System is confusing and patients would like more support to navigate and to receive reassurance. They worry about people who don't have a support network. A navigation/coordination role would not necessarily be provided by a clinical person, or based within the General Practice.
Patient empowerment and responsibility	Patients need to take responsibility and understand their role in self-management and working with GP to achieve positive outcomes. **Consumer perspective:** sometimes things have to go wrong for patients to realise their need to take responsibility. Patients feel empowered by access to other sources of information such as pharmacists, internet information and support groups. Health records are currently framed as a tool for clinicians and are not freely shared with health consumers.
Valuing patients with chronic conditions	This related to putting more priority to patients with chronic disease – and providing more transparency on what this costs the system. **Consumer perspective:** patients with chronic conditions feel that they have different needs to other patients who access GP less frequently, and would like to have different arrangements in place to meet these needs such as low-risk waiting areas/reduced waiting and flexible GP access. Bulk billing also important to facilitate regular appointments.
Good systems	Having appropriate robust systems to manage patients (including recall) and record activity. Making sure systems are used well - need to provide adequate training and support for staff. **Consumer perspective:** Patients report a range of recall systems. Attending an appointment for a care plan and not having other issues addressed in the same appointment is a frustration.
Continuity of care	Patients need continuity in terms of practice and GP. Patients need to access the same practice and preferably the same GP. **Consumer perspective:** Patients have a strong preference to stay with one GP once they find one that they are happy with. They will consider following a long term GP to a new practice in preference to getting another GP from the same practice. They agree with the concept of eHealth records that can be accessed by multiple providers, preserving an ongoing central health record that they can also have access to.

Summary

Participants provided insights into the experiences of life with chronic conditions and receiving related health services. In particular, the outcomes demonstrate the importance that many patients place on being able to choose and change their health providers to best meet their need for a workable relationship based on:

- trust;
- confidence;
- being heard; and
- being accessible in terms of time and cost.

They described a need for patients with chronic conditions to be managed differently to patients with occasional acute issues, through flexible access to information and prescriptions, and waiting processes that avoid exposure to community-based infections, which a view shared with many of the GP participants from NI Part 1.

There was a high level of interest and participation in this study from participants with rarer and/or harder to diagnose conditions. Many of these conditions are not included in prevalence data on chronic conditions; participants described feeling invisible and lost in the health system, aware that their GPs do not always have the expertise to diagnose and manage their condition. Stories shared demonstrated that these patients have positive experiences when they can access national and international support groups, learn about their condition and options through internet-based platforms, and work in partnership with a GP who is willing to also research their condition.

The concept of a GP-centred team that includes allied health services is a goal of primary care but not the current experience of focus group participants. Issues with the chronic condition care plan system raised by participants included:

- inconsistent promotion and use of care plans;
- limited apparent information hand over to allied health providers;
- perceived lack of choice and flexibility;
- unexpected out-of-pocket expenses; and
- an insufficient number of services provided to meet needs.

The Naïve Inquiry is limited at this stage to perspectives of general practice staff and consumers; the perspective of allied health and other care plan service providers would also be valuable.

A "navigator" role has been suggested as an appropriate future addition to primary care. Such a position would support linkage to appropriate services, and could potentially support more effective use of the care plan model. The participants of the focus groups were predominately people who had taken an active role in understanding the system and their entitlements – although several participants had not heard of care plans prior to their focus groups session – and saw the greatest value in an additional role that was primarily supportive on an interpersonal level.

The majority of participants had been living with chronic conditions for many years; the voice of people with a recent diagnosis was less strong. Although participants came from a range of ages and included some cultural diversity, the study did not attract participants representing linguistic diversity or hard-to-reach demographics, nor those who were not already engaged with primary health services.

Whilst the Naïve Inquiry only involved a small group of the WA community, the discussions and aspects raised demonstrate some key themes and areas for consideration by those involved in the planning and delivery of services. It is recommended that in further developing and refiningpriamry care responses a variety of stakeholder engagement processes continue to be incorporated.

Future directions

The findings from the Naïve Inquiry are being used to inform the work of all collaborating organisations.

WAPHA are using the information to inform a number of primary care and system wide based initiatives, that focus on the needs of patients and general practice.

Current WAPHA led and supported initiatives include:

Comprehensive Primary Care (CPC)

Comprehensive Primary Care is the WAPHA initiative that has been co-designed and developed with GPs. CPC builds capacity and capability in general practices to manage care for people with chronic health conditions. It is a whole of practice, whole of person approach.

Health Care Homes (HCH)

Health Care Homes is a Commonwealth Government initiative. HCH are existing general practices or Aboriginal Community Controlled Health Services which will provide care which is better coordinated and more flexible, for up to 65,000 Australians with chronic and complex conditions.

My Health Record

By the end of 2018 every Australian resident will have a My Health Record, unless they actively choose to opt out. WAPHA will be increasing engagement with health professionals and community members to support expansion of use of My Health Record, including training and information for health care providers and consumers on the benefits of My Health Record.

Health Consumers Council will use the findings to support its advocacy and lobbying activity. The study is also a demonstration of the collaborative nature of the Council and the importance it places on getting the consumer voice heard across the in policy, practice and research worlds.

Curtin University has presented the findings from this study at a number of national and international conferences. As a research organisation Curtin are keen to develop the evidence base to support future health care developments that can lead to improved health outcomes. The intention is to develop academic publications that can support the dissemination of the research to a number of important audiences (including policy makers, health professionals, clinicians and the broader research community). Curtin researchers recognise the importance of consumer involvement in research and will work closely with WAPHA, Health Consumers' Council, GP and Consumers in the evaluation of Comprehensive Primary Care models being developed across WA.

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