Consumers Health Forum OF Australia

Patient Activation in Australians with Chronic Illness – Survey Results

October 2019

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Consumers Health Forum of Australia is funded by the Australian Government as the peak healthcare consumer organisation under the Health Peak and Advisory Bodies Programme

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Summary

The aim of this national patient activation survey was to get a better understanding of the level of activation of health care consumers to ascertain how receptive they might be to models of service delivery that require them to be more involved in their own care. Often lack of engagement - or activation - is cited as a barrier to increasing self-management and shared decision-making and hence better experiences of care and health outcomes.

Patient self-management or activation is a patient's knowledge, skill and confidence to take on the role of managing their health and healthcare (Hibberd and Gilburt, et al 2005).

The Consumers Health Forum (CHF) utilised the Patient Activation Measure (PAM®) tool across a national sample of 1703 respondents to determine levels of patient engagement in Australia for adults with two or more chronic illnesses to inform better policy and strategies to support patient self-management. CHF had access to the PAM® tool under licence for research purposes. The PAM tool describes four levels of activation with Level 4 being consumer behaviours which show they are engaged with their own health care and Level 1 being consumers who are disengaged and feel overwhelmed by their condition.

Over one-quarter of respondents were classified as Level 4 (having adopted behaviours to support their health) with a further 41% of respondents classified as Level 3 (acting but lacking skill and confidence). This research project found that Australians with chronic illnesses with high levels of patient activation as measured by their PAM® level had better self-reported outcomes and experiences in the healthcare system. However, the overall proportion of Australian's with chronic illnesses who reported having these high levels of activation, 68% in total, was lower than the level of high activation measured in the general Australian population, 85% in total, in a previous study. This suggests that Australians with chronic illnesses are less activated than their healthy counterparts which may be a contributing factor to their generally worse health outcomes.

The findings suggest that should health policy and practice systemically incorporate measures designed to improve levels patient activation, the overall health outcomes and experiences of Australians with chronic illnesses could be improved. Investing in measures to assist general practices and patients leverage patient activation to navigate the range of services they need to exercise choice and control in their healthcare as part of a comprehensive national primary health care reform strategy would deliver high value care for those with chronic illnesses. Measures should include shared decision-making practices, tools and resources to support shared-decision-making, evidence-based self-management services, workforce development in the form of practice-based health coaches and service coordinators and a social prescribing scheme.

Background

Improving patient outcomes is a constant and critical aspiration of the health sector, and there are many initiatives and methods in use which seek to improve the lives of people affected by health conditions. Health practitioner initiatives which encourage patient involvement and shared decision-making can be important for empowering individuals to take greater interest and ownership over their health.

The Government's current wave of reforms are to focus on strengthening primary health care to ensure it is more prevention oriented and that the general practice setting is bolstered with coordinated multidisciplinary teams to provide modern, convenient, continuous and coordinated care particularly to Australians with chronic conditions. This is in response to Australia's growing rates of chronic disease, risk factors such as obesity and avoidable hospital admissions. A key measure to date has been to implement patient and family-centred medical home models of care starting with the Health Care Home Programme to be followed by a similar measure announced in the 2019 Federal Budget of voluntary-practice based enrolment and flexible practice payments to support the coordinated care of Australians over 70 years of age.

A key consideration for the reforms will be evidence regarding what works in patient self-management, and specifically identifying what programs, services and patient and clinician education could support patients with chronic conditions to manage their conditions better.

Patient self-management, or 'patient activation', is a patient's knowledge, skill and confidence to take on the role of managing their health and healthcare (Hibbard et al, 2005). Patient activation is recognised internationally as a means of achieving desirable patient outcomes as well as resource efficiency in the health sector (Hibbard and Gilburt, 2014; NHS, undated). High levels of activation enable patients to understand their role in the care process and feel capable of fulfilling that role (Hibbard and Gilburt, 2014). In addition, those with long-term illnesses are likely to engage in positive health behaviours which result in more effective management of their health conditions (Hibbard and Gilburt, 2014). Furthermore, evidence suggests that a chronic illness self-management program that promotes patient activation can improve health status while reducing hospitalisation (Lorig et al, 1999).

It is important to note that patient activation is a related but distinct concept from 'health literacy'. Health literacy refers to an individual's ability to derive meaning from health related text and tables, thus it is a skills-based concept (Insignia Health, 2014). Patient activation is a broader construct that refers to an individual's knowledge, skill and confidence for managing their health and health care (Insignia Health, 2014). Studies that investigate both have found that the level of patient activation is a stronger predictor of health outcomes than health literacy levels (Insignia Health, 2014).An individual's level of patient activation can be determined using the validated PAM® tool (Hibbard et al, 2004; Hibbard et al, 2005; Prey et al, 2016). This is a licenced tool for clinicians (and researchers) which attributes one of four levels of patient activation. Levels range from Level 1 'starting to take a role', to Level 4 'maintaining behaviours'. The PAM® considers activation as a continuum, and evidence suggests that with effective

interventions, individuals can improve their activation scores over time (Hibbard and Gilburt, 2014). A summary of PAM® tool levels is included below.

LEVEL 1	Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
LEVEL 2	Individuals may lack the knowledge and confidence to manage their health.
LEVEL 3	Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
LEVEL 4	Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

The Commonwealth Department of Health contracted the CHF to conduct a national survey utilising the PAM® tool across Australia to determine levels of patient engagement in Australia for adults with two or more chronic illnesses to inform better policy and strategies to support patient self-management. CHF had access to the PAM® tool under licence for research purposes.

This research was undertaken to examine the PAM® tool results in an Australian context to inform whether patient activation could support the Department's reforms and influence patients with chronic illnesses to self-manage better. By understanding the levels of activation of patients with chronic disease in an Australian context, these findings will contribute to the evidence base and provide important insights about how patients can be best supported to self-manage chronic illnesses by determining levels of patient activation, attitudes and practices to self-management and barriers to self-management.

For the purposes of this research project, chronic illnesses comprised: arthritis or osteoporosis; asthma; cancers (such as lung and colorectal cancer); heart or circulatory condition (such as coronary heart disease and stroke); chronic obstructive pulmonary disease; diabetes; mental health conditions; including depression or anxiety; long-term injury (such as back pain or back problems); and "any other long-term health condition".

Method

This research projects survey tool was developed by CHF with assistance from the Department of Health. Insignia Health's 13 question PAM tool was augmented by drawing on previous surveys into consumer health measures including the *South East Sydney LHD PAM Survey Report 2015*, the *ABS Patient Experience Survey 2017-18* and the *CHF Consumer Sentiment Survey 2018*. Deakin University's *Health Literacy Questionnaire* tool was considered for inclusion but ultimately rejected due to a desire to keep the survey completion time under 10 minutes.

Dynata was engaged to run the final survey tool through their online market research panel, which targeted respondents to recruit a sample that was representative of the Australian population in terms of gender, age and geographic location based on Australian Census 2011 data. Potential respondents were excluded if they were under the age of 18, did not reside in Australia, did not possess two or more chronic illnesses or were not eligible to be given a PAM score based on their responses. This resulted in a sample of n=1703 respondents completing the survey.

Data analysis was undertaken by Urbis Pty Ltd under commission to CHF. Descriptive analysis was used to understand the level of patient activation, care utilisation, care experience and health literacy amongst Australians with two or more chronic illnesses. Additionally, basic cross tabulations and Chi-square testing was used to map PAM categories against key measures to determine if patient activation affected the health stays and healthcare experience of Australians with two or more chronic illnesses.

Policy analysis was undertaken by CHF.

Limitations

The primary limitation of this survey is the potential representativeness of the sample. For example, the proportion of people from a culturally and linguistically diverse background (1.4 per cent of the sample) is substantially lower than the proportion in the 2016 census (16 per cent (ABS, 2016)). There would be merit in doing a survey targeted at culturally and linguistically diverse communities to see what the level of activation is for this group.

Only 16.5% of respondents reported themselves to be in excellent or very good health, significantly lower than the national average of 56.4% (ABS 2018). Conversely respondents were more likely to report being in poor or fair health (46.8%) compared to the national average (14.7%) (ABS, 2018). To some degree this variance should be expected given the respondents comprised those with two or more chronic illnesses.

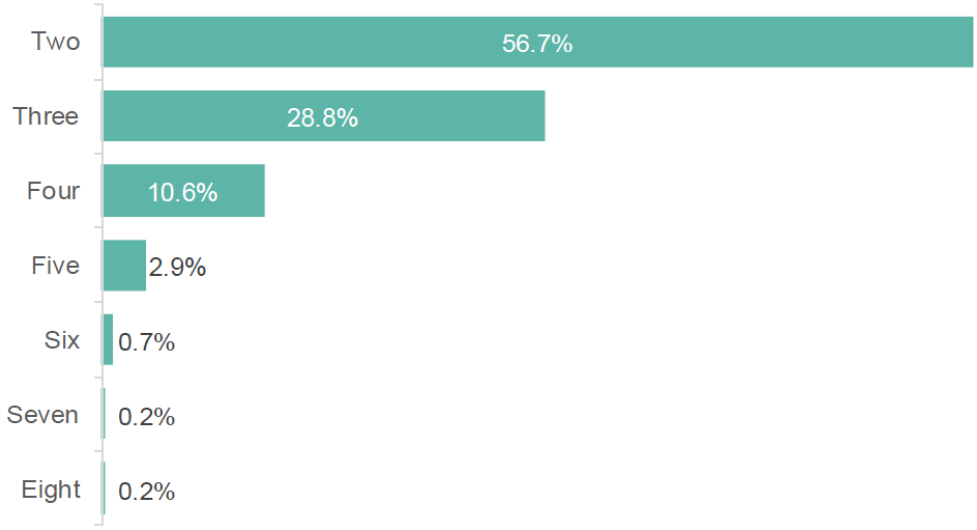
The recruitment method, an online recruitment panel, may have also limited the generalisability of the findings as participants were proficient enough with internet usage to complete an online survey and potentially more engaged when compared to the general population given their active participation on research panels.

Results

1. Overview of chronic illnesses

As shown in Figure 1, over half of survey respondents (56.7%) indicated that they currently have a combination of any two of the listed chronic illnesses. It was rare for respondents to indicate they have six or more chronic illnesses, with approximately 1% of all respondents selecting between six and eight illnesses.

Figure 1 – Number of chronic illnesses per respondent



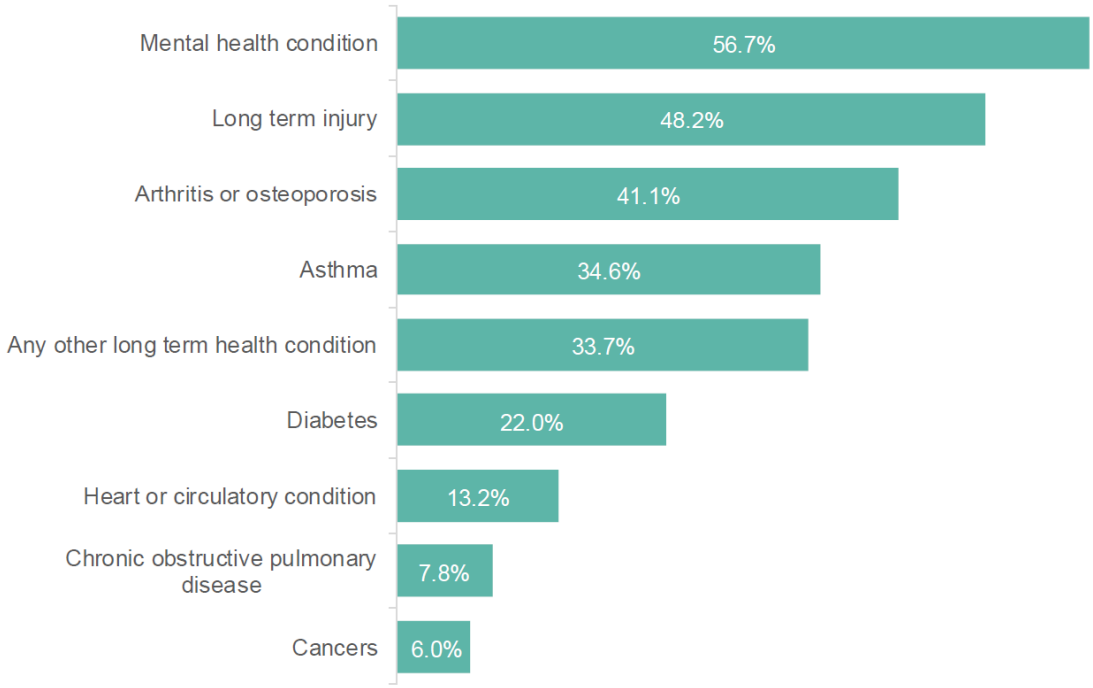
Base n = 1,703 Question 1: At the moment, do you have any of the chronic illnesses listed that have lasted, or are likely to last, for six months or more? Is so, please select which ones.

Survey results suggest that mental health conditions are the most common chronic illness amongst Australian health consumers, with almost six in ten (56.7%) respondents reporting that they are currently experiencing a mental health condition which has lasted, or is likely to last, for a period of six months or more (see Figure 2).

Long-term injuries, such as back pain or problems, were another prominent issue highlighted by the survey, with almost half of all respondents (48.2%) indicating that they are currently experiencing some type of long-term injury.

Cancer was the least common chronic condition identified, with only 6% of respondents reporting they have this illness.

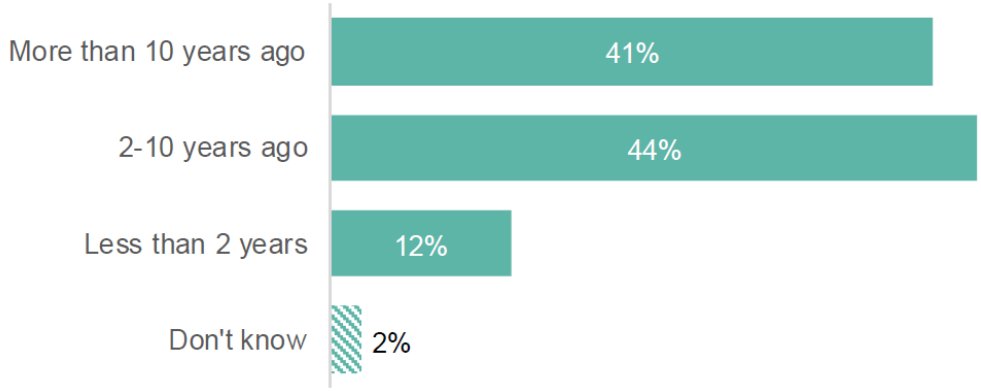
Figure 2- Proportion of respondents that reported having each chronic condition



Base n = 1,703 Question 1: At the moment, do you have any of the chronic illnesses listed, that have lasted, or are likely to last, for six months or more? Is so, please select which ones.

Forty-one (41)per cent of respondents indicated that they have been living with their chronic illness(es) for more than 10 years. A further 44% of respondents reported that they were diagnosed in the last 2-10 years, while only one in ten of respondents (12%) had been diagnosed in the last two years (Figure 3).

Figure 3- Number of years since respondent's chronic illness diagnosis



Base n = 1,703 Question 2: How many years ago were you first diagnosed with a chronic illness?

2. Health service utilisation and literacy

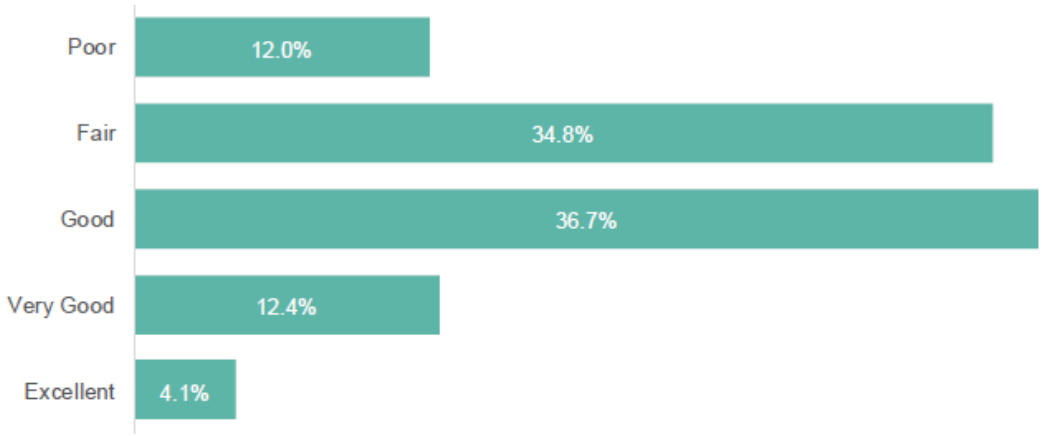
Broadly speaking, the survey results suggest a high level of engagement with the health system amongst consumers with two or more chronic illnesses. Almost all respondents (98.5%) reported engaging with a General Practitioner (GP) at least once in the past 12 months while over half (57.5%) of all respondents reported that they had attended a GP six or more times in the past 12 months. Further, one in three respondents (32.9%) identified that they had visited a pharmacist more than 12 times in the last 12 months.

Survey results also suggest that the public hospital system is accessed more frequently than the private system, with more than half of respondents (56.8%) indicating that they had accessed public hospital services at least once in the past 12 months. In contrast, only around one in four respondents (24.6%) indicated that they had accessed a private hospital in the past 12 months.

Further, survey results highlight that mental health services delivered by a counsellor or psychologist had relatively low levels of access and utilisation, with 64.1% of respondents reporting that they had never accessed these services. However, a small number of respondents indicated a high frequency of visitation, with 16.3% of respondents reporting that they had sought mental health services six or more times in the past 12 months. Similarly, community-based healthcare services also appear to have low engagement, with only around one in four respondents (25.1%) indicating accessing these services in the past 12 months.

Respondents typically rated their health status as good (36.7%) or fair (34.8%), however, only 16.5% rated their health as very good or excellent (Figure 4). In addition, respondents identified as having high levels of health literacy with 77% of respondents indicating they rarely or never need assistance when reading instructions, pamphlets, or other written materials from their doctor or pharmacist.

Figure 4- Current self-rating of health status by respondents

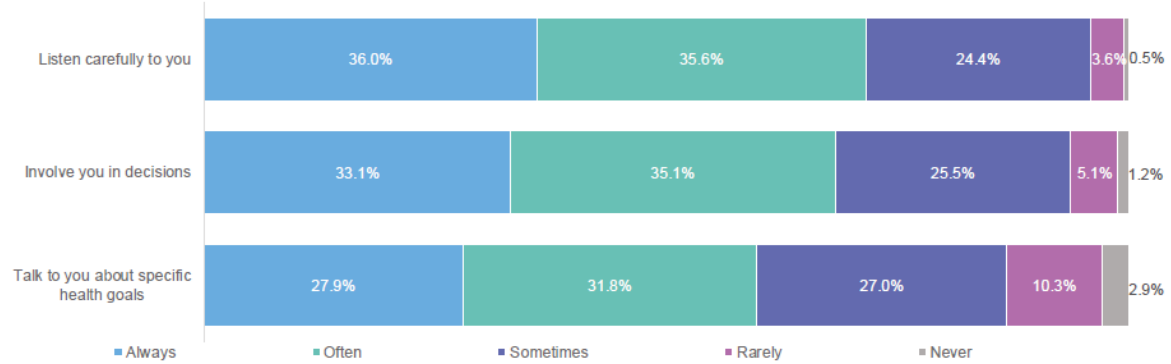


Base n-1703. Question 5: How do you rate your current health status

As shown in Figure 5, respondents also reported high levels of practitioner involvement. One in three respondents (33.1%) reported always being involved in decision-making with their

practitioners, and a further 35.1% identified that they were often involved in decision-making. However, while a majority of patients were involved in the decision-making process, the co-coordination of specific health goals was less common: for instance, only 27.9% of respondents noted that their practitioner always discussed health specific goals while 37.3% indicated they were rarely or never involved in this process.

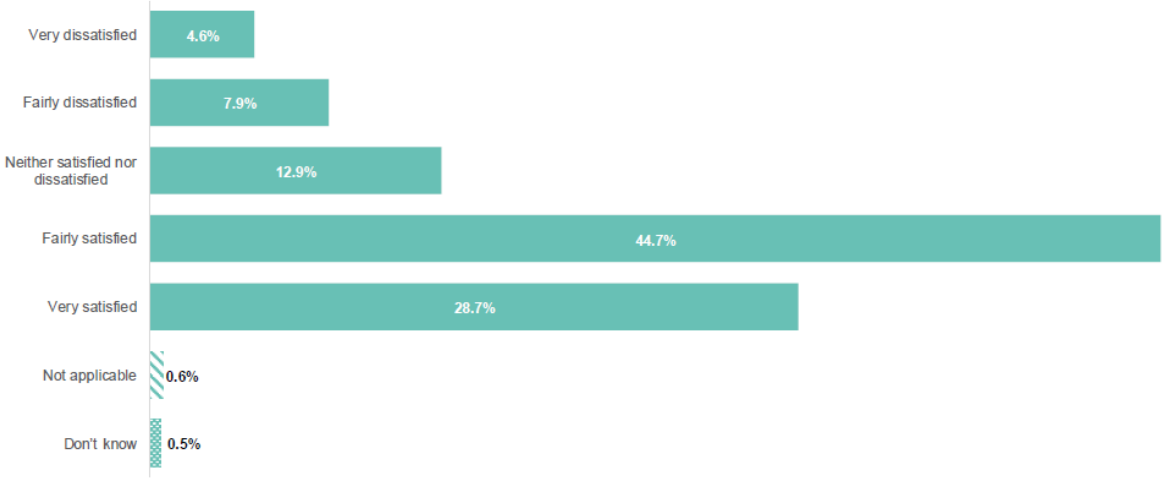
Figure 5- Health practitioner level of involvement with respondent



Base n= 1703. Question 9: Thinking about all the health providers you have seen in the last 12 months, how often did they listen carefully to you, involve you in decisions and talk to you about specific health goals?

Finally, respondents were typically satisfied with the healthcare they had received in the past 12 months, with 73.4% of respondents indicating that they were either fairly (44.7%) or very (28.7%) satisfied (Figure 6).

Figure 6- Respondents reported level of satisfaction with healthcare

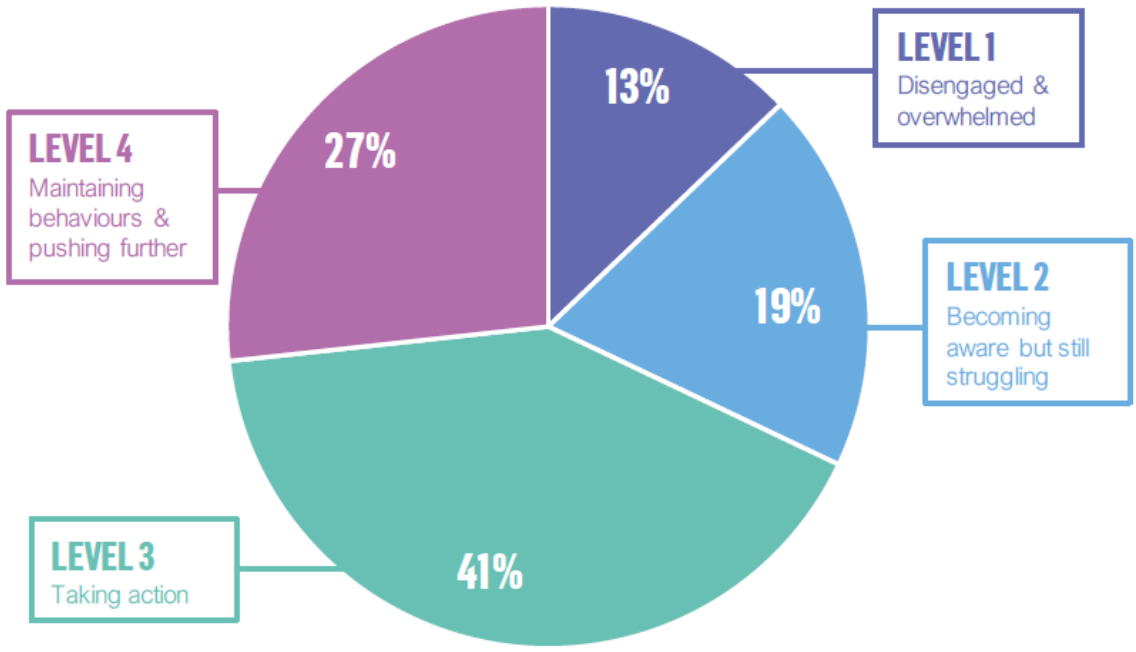


Base n= 1703. Question 10: Overall, how satisfied are you with the care you received in the last 12 months.

3. Summary of PAM® activation segments

Over one-quarter of respondents were classified as Level 4 (having adopted behaviours to support their health) with a further 41% of respondents classified as Level 3 (acting but lacking skill and confidence). Around a third of respondents were classified as Level 1 (12.9%) or Level 2 (19.2%).

Figure 7 – PAM® segment sizes



Base n = 1,703

Table 1 maps each PAM® segment against key demographics of respondents. Table 2 maps service utilisation and healthcare experience against the PAM® segment subgroups of respondents.

There was no association between PAM® levels and any demographic characteristic. This includes gender, age, state of residence, CALD status, level of education, income level, private health insurance status, healthcare card/concession status, the specific chronic illness; or the specific number of chronic illnesses. This suggests that no particular demographic subgroup of Australians with chronic illness have a systematically lower level of involvement in their healthcare.

Consumer experience appears associated with the level of patient activation. Respondents who reported greater satisfaction and involvement in decision-making with their health practitioners typically scored a higher PAM score.

There was a significant relationship between patient activation and overall health status, with Level 1 respondents being disproportionally likely to rate their health status as "Poor" while Level 4 respondents were disproportionally likely to rate their health as "Excellent". Similarly, Level 1

patients were disproportionally likely to resort being “Very dissatisfied” with the care received in the previous 12 months while Level 4 respondents were disproportionally likely to report being “Very satisfied”.

The only health engagement measures with a significant association with PAM® level were the frequency of use of private hospitals and frequency of visits to a counsellor or psychologist in the previous 12 months. There was no significant association with visits to GPs, GP nurses, dentists, pharmacists, specialist doctors outside of hospitals, community based health services, allied health services, alternative therapies or usage of public hospitals.

There was a significant association between PAM® level, health literacy and the need for assistance to understand written materials provided by a GP or pharmacist, with Level 4 respondents disproportionally reporting “Always” needing assistance.

There was a significant association between PAM® level and how often respondents reported health providers listening carefully to them, with Level 1 patients disproportionally reporting “Never” being listened to.

There was a significant association between PAM® level and health providers involving respondents in healthcare decisions, with Level 1 patients disproportionally reporting “Never” and Level 4 disproportionally reporting “Always”.

There was a significant association between PAM® level and health providers talking about specific health goals with respondents, with Level 1 patients disproportionally reporting “Never” and Level 4 disproportionally reporting “Always”.

Table 1 – Summary of levels by demographic characteristics

Lowest Value	Highest Value

Demographic characteristics		Level 1	Level 2	Level 3	Level 4	Chi square	Commentary
Gender							
	Male	45.20%	48.60%	49.30%	51.40%	χ^2 (6, N=1,703) = 4.856, p = 0.562	▪ Level 4 has the highest proportion of males and the lowest proportion of females. ▪ The converse is the case for Level 1 which has the highest proportion of females and the lowest of males.
	Female	54.80%	51.40%	50.30%	48.40%		
	Other	0.00%	0.00%	0.40%	0.20%		
Age							
	18-24	9.60%	9.20%	6.10%	5.50%	χ^2 (15, N=1,703) = 24.345, p = 0.059	▪ Level 4 has the highest proportion of males and the lowest proportion of females. ▪ The converse is the case for Level 1 which has the highest proportion of females and the lowest of males.
	25-34	18.70%	14.70%	19.10%	16.70%		
	35-44	20.10%	20.50%	23.20%	17.60%		
	45-54	19.60%	14.40%	16.10%	17.40%		
	55-64	12.80%	18.70%	14.10%	17.80%		
	65+	19.20%	22.60%	21.40%	25.10%		
State							
	ACT	1.40%	1.20%	1.70%	1.10%	χ^2 (21, N=1,703) = 15.774, p = 0.782	▪ Level 3 has the highest number of respondents from ACT, NT, Queensland and SA. ▪ Level 4 has the highest representation of Tasmanians. ▪ Level 2 has the highest proportion of Victorians while Level 1 has the highest representation of respondents from NSW and WA.
	NSW	32.40%	29.10%	28.80%	27.90%		
	NT	0.00%	0.30%	0.70%	0.20%		
	Qld	21.00%	21.70%	22.50%	21.10%		
	SA	6.40%	9.80%	10.50%	9.70%		
	Tas	3.70%	2.10%	2.10%	4.20%		
	Vic	24.20%	27.20%	24.10%	27.00%		
	WA	11.00%	8.60%	9.50%	8.80%		
CALD status							
	CALD	1.80%	0.30%	1.70%	1.50%	χ^2 (3, N=1,703) = 3.650, p = 0.302	
	Not CALD	98.20%	99.70%	98.30%	98.50%		

	Highest Level of Education						
	Primary school	0.00%	0.60%	0.40%	0.90%	χ^2 (18, N=1,703) = 15.024, p = 0.660	▪ Level 4 has the highest number of respondents with a postgraduate university degree while Level 3 has a high proportion of respondents with an undergraduate university qualification. ▪ Level 2 has the highest proportion of respondents with a TAFE or trade qualification or who did not complete high school. ▪ Level 1 has the highest proportion of respondents who completed high school.
	High school (not completed)	14.20%	16.50%	13.10%	12.30%		
	Highschool (completed)	21.50%	20.20%	18.50%	19.60%		
	TAFE/Trade	33.80%	35.50%	33.80%	34.70%		
	University (undergraduate)	20.10%	21.40%	23.80%	21.50%		
	University (postgraduate)	10.00%	5.20%	10.00%	10.50%		
	Prefer not to say	0.50%	0.60%	0.40%	0.40%		
	Income (weekly)						
	Under $700	23.70%	30.90%	26.60%	28.40%	χ^2 (15, N=1,703) = 15.303, p = 0.430	▪ Level 1 has the highest proportion of low to middle income respondents while Level 2 has the highest proportion of very low income earners. ▪ Level 4 has the highest proportion of high-income respondents.
	$700-$1,399	33.30%	30.60%	32.80%	29.20%		
	$1,400-$2,399	21.50%	19.90%	21.10%	20.40%		
	$2,400+	9.60%	7.00%	8.70%	11.00%		
	Don't know	2.70%	5.50%	4.00%	2.60%		
	Prefer not to say	9.10%	6.10%	6.80%	8.40%		
	Health insurance						
	Yes	42.50%	42.20%	43.30%	42.90%	χ^2 (6, N=1,703) = 0.853, p = 0.991	
	No	56.60%	57.20%	56.30%	56.50%		
	Don't know	0.90%	0.60%	0.40%	0.70%		
	Health care card						
	Pensioner Concession Card	39.70%	39.10%	41.30%	44.20%	χ^2 (18, N=1,703) = 27.622, p = 0.068	▪ Level 4 has the highest proportion of respondents with Pensioner Concession Cards and Level 3 contains the highest proportion of those without any health care card
	Health care card	23.30%	17.10%	17.20%	14.10%		
	Commonwealth Seniors Health Card	5.90%	5.50%	3.40%	5.50%		
	Veterans' Health Card	2.30%	2.40%	2.00%	1.50%		
	Other	0.50%	2.10%	0.40%	0.70%		
	Don't have a health card	26.50%	33.00%	34.20%	33.00%		
	Don't know	1.80%	0.60%	1.40%	1.10%		

	Region						
	Major city	73.50%	70.30%	70.70%	70.80%	χ^2 (15, N=1,703) = 11.537, p = 0.714	▪ Level 3 has the highest proportion of respondents from inner regional, remote and very remote respondents. ▪ Level 1 has the highest proportion of respondents from major cities or inner regional areas.
	Inner regional	22.80%	21.70%	22.80%	22.20%		
	Outer regional	3.70%	8.00%	5.70%	6.80%		
	Remote	0.00%	0.00%	0.40%	0.20%		
	Very remote	0.00%	0.00%	0.30%	0.00%		
	Condition						
	Arthritis or osteoporosis	37.40%	41.60%	38.20%	47.00%		▪ Level 4 has the highest proportion of respondents with arthritis, osteoporosis, cancer or a long-term injury. ▪ Level 3 has the highest proportion of respondents with asthma or a heart condition. ▪ Level 1 has the highest proportion of respondents with chronic obstructive pulmonary disease or mental health conditions.
	Asthma	36.10%	31.20%	36.50%	33.60%		
	Cancers	6.80%	6.10%	5.10%	7.00%		
	Heart or circulatory condition	10.50%	13.10%	14.20%	13.00%		
	Chronic obstructive pulmonary disease	9.60%	8.60%	7.80%	6.40%		
	Diabetes	22.40%	23.20%	20.50%	23.10%		
	Mental health condition	61.60%	59.30%	57.80%	50.50%		
	Long term injury	45.20%	48.30%	47.30%	51.00%		
	Other	35.20%	35.80%	33.30%	32.10%		
	Number of conditions						
	Two	56.60%	54.70%	60.40%	52.30%	χ^2 (18, N=1,703) = 26.198, p = 0.095	
	Three	28.30%	28.70%	25.80%	33.80%		
	Four	10.50%	12.20%	9.10%	11.60%		
	Five	3.20%	3.70%	2.80%	2.20%		
	Six	0.90%	0.30%	1.30%	0.00%		
	Seven	0.50%	0.00%	0.30%	0.00%		
	Eight	0.00%	0.30%	0.30%	0.00%		
Length of diagnosis							
	Less than 2 years	12.30%	11.30%	12.30%	13.00%	χ^2 (9, N=1,703) = 3.920, p = 0.917	▪ Level 4 has the highest proportion of respondents who have been diagnosed within the past 2 years.
	2-10 years	45.70%	46.20%	42.70%	44.60%		
	More than 10 years	40.60%	39.80%	42.60%	40.90%		
	Don't know	1.40%	2.80%	2.40%	1.50%		

Table 2 – Summary of levels by health engagement, experience and literacy measures

Health engagement, experience or literacy measure		Level 1	Level 2	Level 3	Level 4	Chi Square	Commentary
Current health status							
	Excellent	4.60%	2.10%	2.60%	7.50%	χ^2 (12, N=1,703) = 60.518, p = 0.000	▪ Level 4 has the highest proportion of respondents who report their health is good, very good or excellent. ▪ Level 2 has the highest proportion of respondents who rate their health as fair. ▪ Level 1 has the highest proportion of respondents who rate their health as poor.
	Very good	11.00%	9.80%	13.20%	13.80%		
	Good	26.50%	35.20%	38.00%	40.70%		
	Fair	37.40%	37.60%	35.80%	30.10%		
	Poor	20.50%	15.30%	10.40%	7.90%		
Have a GP							
	Yes	91.80%	90.20%	93.00%	92.10%	χ^2 (3, N=1,703) = 2.436, p = 0.487	
	No	8.20%	9.80%	7.00%	7.90%		
Visits to GP in last 12 months							
	0	2.30%	2.10%	1.00%	1.30%	χ^2 (9, N=1,703) = 5.911, p = 0.749	▪ Level 1 has the highest proportion of respondents who had not been to a GP at all or who had been 6-12 times. ▪ Level 3 has the highest proportion of respondents who have visited their GP more than 12 times.
	1-5	37.90%	42.50%	40.00%	43.10%		
	6-12	39.70%	36.10%	38.30%	35.20%		
	More than 12	20.10%	19.30%	20.70%	20.40%		
Times used public hospital service in last 12 months							
	0	38.80%	40.10%	45.40%	44.40%	χ^2 (9, N=1,703) = 11.609, p = 0.236	▪ Level 4 has the highest proportion of respondents who have used a public hospital more than 12 times. ▪ Level 3 has the highest proportion of respondents who had not used a public hospital service in the past 12 months.
	1-5	50.20%	49.50%	44.90%	43.70%		
	6-12	7.80%	7.30%	7.50%	7.00%		
	More than 12	3.20%	3.10%	2.10%	4.80%		

	Times used private hospital in last 12 months						
	0	72.60%	76.10%	76.10%	74.90%	χ^2 (9, N=1,703) = 18.797, p = 0.027	▪ Level 4 has the highest proportion of respondents who have used a private hospital more than 12 times. ▪ Level 3 has the highest proportion of respondents who had not used a private hospital service in the past 12 months.
	1-5	18.70%	21.70%	20.20%	20.40%		
	6-12	7.80%	1.20%	2.80%	3.50%		
	More than 12	0.90%	0.90%	0.90%	1.10%		
	Visits to GP nurse in last 12 months						
	0	48.40%	44.30%	47.40%	45.30%	χ^2 (9, N=1,703) = 5.170, p = 0.819	▪ Level 4 has the highest proportion of respondents who had visited a GP nurse more than 12 times. ▪ Level 1 has the highest proportion of respondents who had not visited a GP nurse at all in the last 12 months.
	1-5	43.80%	46.20%	44.90%	44.60%		
	6-12	5.50%	8.00%	5.70%	7.30%		
	More than 12	2.30%	1.50%	2.00%	2.90%		
	Visits to dentist in last 12 months						
	0	38.80%	40.70%	38.60%	41.80%	χ^2 (9, N=1,703) = 9.859, p = 0.362	▪ Level 4 has the highest proportion of respondents who had not visited a dentist at all in the last 12 months. ▪ Level 1 has the highest proportion of respondents who had visited a dentist either 6-12 or more than 12 times.
	1-5	52.10%	53.80%	54.30%	50.30%		
	6-12	6.40%	4.30%	6.40%	5.90%		
	More than 12	2.70%	1.20%	0.70%	2.00%		
	Visit to pharmacist in last 12 months						
	0	5.00%	4.90%	3.80%	3.70%	χ^2 (9, N=1,703) = 9.725, p = 0.373	▪ Level 4 has the highest proportion of people who had visited a pharmacist 6-12 times. ▪ Level 1 has the highest proportion of respondents who had not visited a pharmacist at all in the past 12 months.
	1-5	28.80%	28.40%	30.10%	27.00%		
	6-12	30.10%	30.00%	35.20%	37.60%		
	More than 12	36.10%	36.70%	30.90%	31.60%		

	Visit to specialist doctor outside of hospital in last 12 months						
	0	32.00%	34.90%	40.30%	40.00%	χ^2 (9, N=1,703) = 13.363, p = 0.147	▪ Level 3 has the highest proportion of respondents who had not visited a specialist. ▪ Level 1 has the highest proportion of respondents who had visited a specialist either 6-12 or more than 12 times.
	1-5	50.20%	52.00%	48.30%	45.10%		
	6-12	12.80%	9.80%	8.00%	11.40%		
	More than 12	5.00%	3.40%	3.40%	3.50%		
	Visit to counsellor or psychologist in last 12 months						
	0	55.30%	61.50%	66.00%	67.30%	χ^2 (9, N=1,703) = 26.330, p = 0.002	▪ Level 4 has the highest proportion of respondents who had not visited counselling services. ▪ Level 1 has the highest proportion of respondents who had visited a counselling service either 1-5 or more than 12 times.
	1-5	26.00%	20.80%	17.10%	19.60%		
	6-12	9.60%	13.10%	13.00%	9.00%		
	More than 12	9.10%	4.60%	4.00%	4.20%		
	Visit to community-based health service in last 12 months						
	0	73.10%	74.30%	74.50%	76.70%	χ^2 (9, N=1,703) = 11.888, p = 0.220	▪ Level 4 has the highest proportion of respondents who had not visited a community-based health service at all. ▪ Level 1 has the highest proportion of respondents who had visited a community-based health service 6-12 or more than 12 times.
	1-5	15.50%	18.70%	18.40%	15.40%		
	6-12	5.50%	4.90%	5.00%	4.60%		
	More than 12	5.90%	2.10%	2.10%	3.30%		
	Visit to allied health service provider in last 12 months						
	0	35.60%	44.30%	41.20%	44.20%	χ^2 (9, N=1,703) = 12.549, p = 0.184	▪ Level 4 has the highest proportion of respondents who had accessed allied health services either 6-12 or more 12 times. ▪ Level 2 has the highest proportion of respondents who had not accessed allied health services at all over the past 12 months.
	1-5	49.30%	42.50%	42.90%	37.80%		
	6-12	10.00%	8.30%	11.50%	11.90%		
	More than 12	5.00%	4.90%	4.40%	6.20%		

Policy Implications

The aim of the research was to get a clearer understanding of how engaged Australian consumers are in their own health care. This could then inform the design and implementation of different models of care that move consumers from being passive recipients of care to more active partners in their own care.

One of the barriers to introducing more active care model has been the belief amongst some clinicians and policy makers that consumers are not interested in their own health care and do not want to the responsibility for self-management or even to be involved in shared decision-making processes. This survey dispels that view.

Given that two thirds of respondents fall into PAM® Level 3 and 4, those patients and healthcare practitioners should be well placed to incorporate treatment management and communication strategies such as shared decision-making, referral to self-management supports and services and social prescriptions that utilise this activation to improve both healthcare outcomes and satisfaction with healthcare. This is particularly the case if practices designed to shift PAM® Level 3 respondents (41%) to Level 4 are adopted.

However, the overall level of patient activation in Australians with chronic illnesses appeared to be lower than their healthy counterparts. Those who fall into PAM Level 3 or 4 are typically defined as having 'high' levels of activation. The overall proportion of Australian's with chronic illnesses who reported having a high level of activation was 68% in this study. This was lower than the level of high activation of 85% found in the general Australian population in a previous study by the South Eastern Sydney Medicare Local (SESML, 2015). This suggests that Australians with chronic illnesses are less activated than their healthy counterparts which may be a contributing factor to their generally worse health outcomes.

The results suggest that chronically ill patients with the highest levels of patient activation have improved healthcare experiences and outcomes compared to those with the lowest patient activation levels. This supports the idea that putting more effort into increasing activation amongst the nearly one third of patients with chronic illness who have low PAM® levels would pay dividends in improving their currently lower levels of relative health status and healthcare satisfaction.

Attention needs to be paid to supporting clinicians to more easily identify patients with low activation and a graduated response is needed to engage them in their own care. The survey results showed there were no significant associations between PAM® level and any demographic characteristics, there is no easy way to identify people with chronic illnesses with lower levels of patient activation who require additional support. Two practices in the Health Care Homes trial used the PAM® tool and others have considered it. Some of the Primary Health Networks have seen it as a useful tool for promoting more patient-centred care and are looking at facilitating its use but the cost is seen by some as prohibitive. It may be that GPs and those they work closely with on team care arrangements such as practice nurses need to be encouraged, and reimbursed, for using this with patients, particularly those who with chronic conditions who are not doing as well as expected.

Given that people in Level 1 report being overwhelmed simply providing more information is not the solution: specific action is needed to address not only their levels of activation but also their health literacy. People who are Level 1 may need one-on-one support to understand their condition and to gradually see the way forward to taking control and managing it. There are existing approaches that provide this kind of support such as diabetes educators who work with people with diabetes to understand their condition and to look at ways to manage it. The introduction of specialist nurses such as rheumatology and Parkinson's nurses are other examples of this tailored approach.

The results suggest health literacy resources such as *Choosing Wisely Australia's* 'Five Questions to Ask Your Doctor' and the Australian Commission for Safety and Quality in Healthcare's *Question Builder* are likely to be valued and utilised by patients with high activation, but less likely to be used by those with lower activation. Either way, more needs to be done to promote awareness and utilisation of such resources.

It was observed that the most common chronic illness in respondents was mental illness, which is also the most common chronic condition in the general Australian population (ABS, 2018). It was also noted that the engagement of respondents with chronic illness with counsellors or psychologists was low (35.9%). There are many reasons why this might be the case. One is cost as the current funding model only allows a small number of referred psychologist visits to attract the MBS rebate. In addition, most psychologist consultations are not bulk billed and so there are out-of-pocket costs for patients. There are also questions to be asked in relation to how and who is the Better Access in Mental Health Care program targeting and whether this program needs to be reviewed.

A potential explanation for this finding may be the reported high level of engagement with GPs, as previous research has found that GPs were the first port of call for mental health issues and 12.4% of all GP encounters were mental health related (AIHW, 2018). With nearly all respondents seeing a GP in the last 12 months and a majority (57.2%) seeing a GP six or more times, chronically ill Australians with mental health problems may be obtaining treatment through GPs for those conditions. The survey results also showed a significant association between a respondent's increased PAM® level and their reduced engagement with those health services although causality has not been established. What is clear is that there needs to be a more active model of engagement for people with mental health, particularly those with physical and mental health co-morbidity.

Finally, investing in measures to assist general practices and patients to navigate the range of services they need to exercise choice and control in their healthcare as part of a comprehensive national primary health care reform strategy would deliver high value care for those with chronic illnesses. Measures could include greater use of shared decision-making tools, evidence-based self-management services, social prescribing and service navigators and coordinators.

The *Ask Share Know* GP network has been doing extensive work on the development of shared decision-making tools for GPs and encouraging GPs to embed these into their practice. This survey shows many consumers are ready to participate in that process and so more attention needs to be given to GP and practice team education on what tools are available and encouraging their use.

For consumers who are engaged with their own care, social prescribing can assist in helping them make lifestyle changes that have a positive impact on their health status and reduce their risk of developing chronic conditions in the first place, developing additional chronic conditions or their existing chronic conditions worsening. In addition, social prescribing can help address other factors in their lives that can determine their health and wellbeing. There needs to be support for clinicians to know what to prescribe and for consumers to access appropriate services.

As the possible service offerings cover both the health and community services areas many people will need some help in finding the right mix of services for them. Patients with higher levels of activation are likely to feel confident about determining what services they need but may still need help finding the services they need. There is merit in looking at service navigator roles and tools to assist those groups. The aged care system is trialling aged care navigators to help people find the right service and this model could be extended to people with complex and chronic conditions. Such a measure would also help strengthen their health literacy: we know from the recently released ABS data that Australians have a positive view of their own health literacy, but that, in general, people with chronic illness or psychological distress are less likely to feel positive about their health literacy.

People with lower levels of activation would need more active assistance to establish what they need and how to get it and so may need someone to help coordinate them to access the services. Any such service coordination should have, as an indicator of success, working to increase activation so people move from Level 1 to higher levels as they gain an understanding of how the system works and what their needs are.

In conclusion, the findings from the national survey of patient activation reinforce the primacy of a high performing primary health system and the need to take a comprehensive and systemic approach to strengthening our primary care arrangements so they are fit-for-purpose for 21st century care.

This requires not only changes to the way in which primary care services are funded and delivered, but also consideration of other essential elements of primary care to facilitate high performance. The 10 building blocks of high performing primary care (Bodenheimer et al, 2014) is a useful framework to use as a guide because it illustrates how important the patient-team partnership is. This partnership recognises the expertise an activated patient brings and the need for investment in measures to support patients to be activated and involved in managing their condition.

The findings are also a reminder that policy, future system design and care models need to be much more integrated when it comes to better management of people with physical and mental health comorbidity. The way we think about primary care and mental health policy and programs in the future need to change.

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Acknowledgements

The Consumers Health Forum of Australia would like to acknowledge the following for their assistance with this research project:

Insignia Health: providing the PAM® tool

Department of Health: input to the survey tool and project funding

Dynata: recruitment of participants

Urbis Pty Ltd: initial data analysis and report drafting

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Appendix 1: Demographics of respondents

Figure 7- Respondents by age (n=1703)

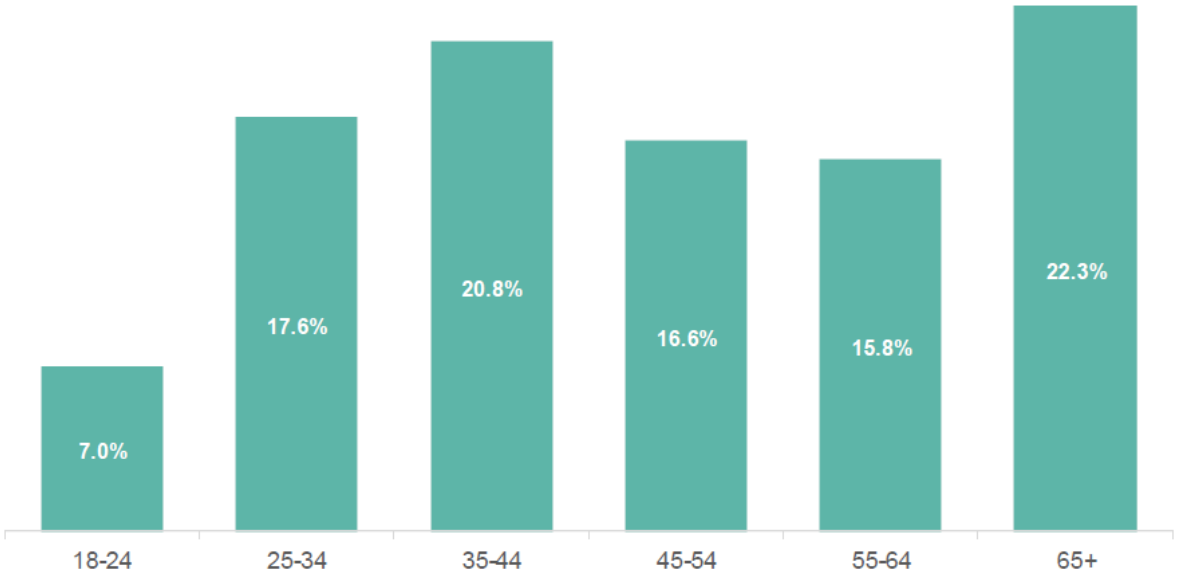


Figure 8- Respondents by state (n=1703)

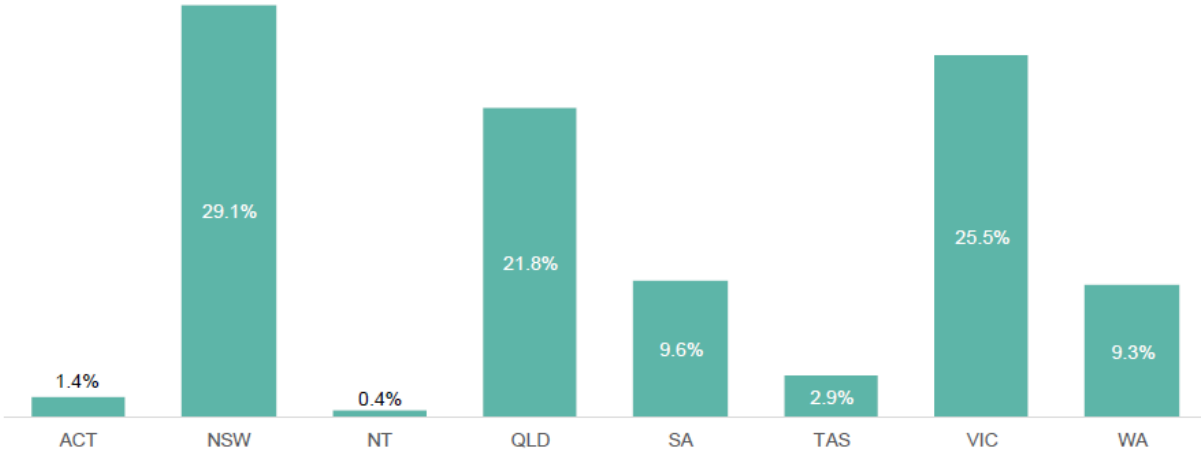


Figure 9- Respondents by regionality (n=1703)

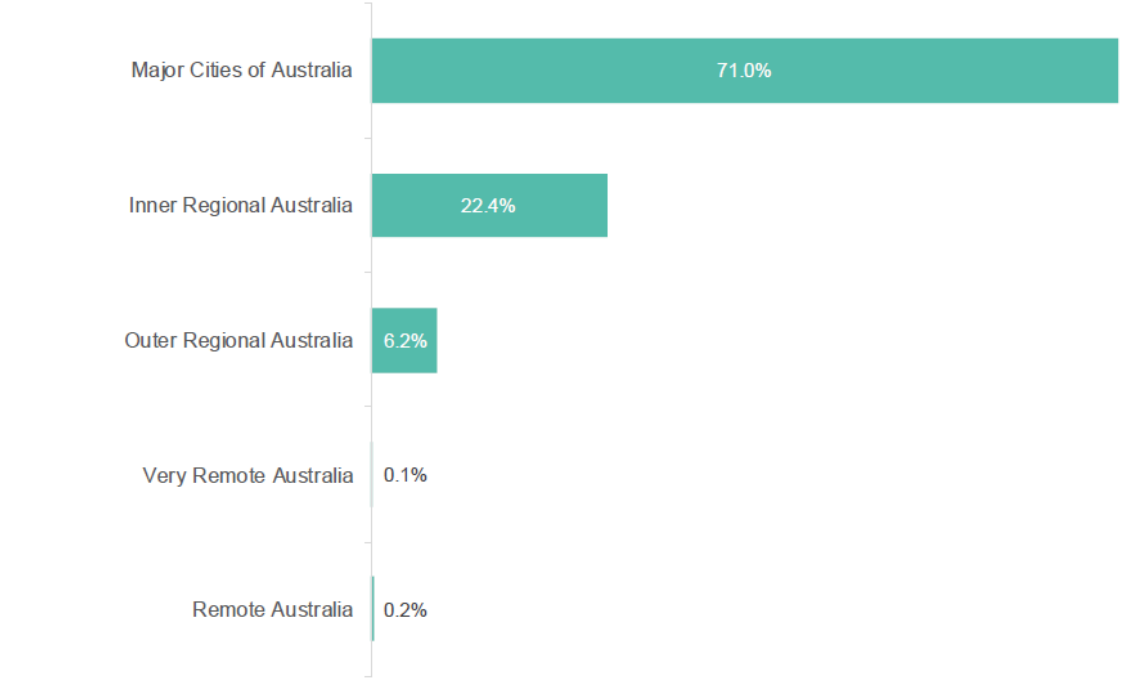


Figure 10- Respondents by education level (n=1703)

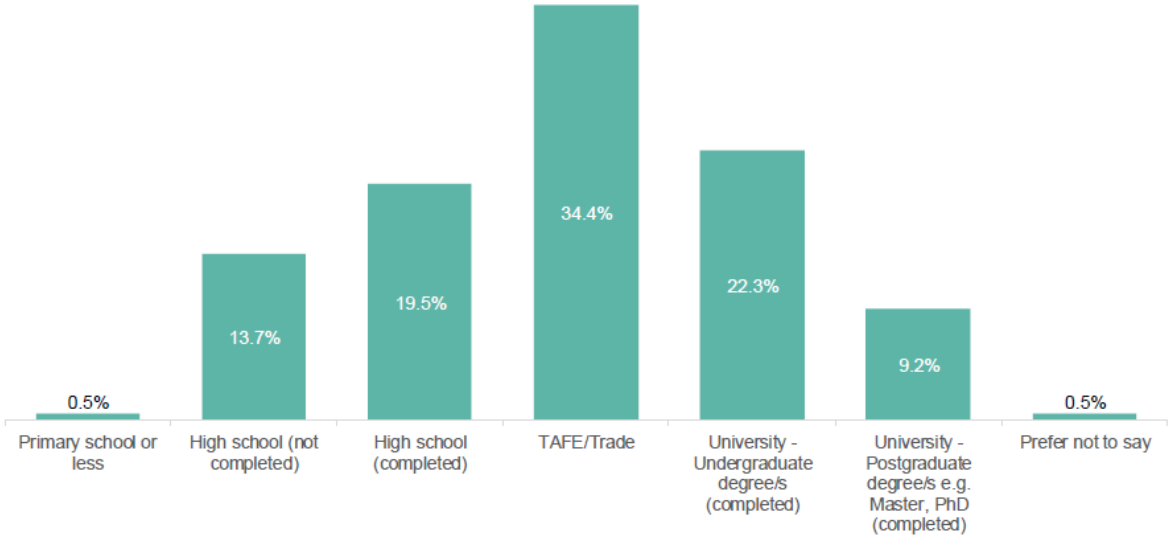


Figure 11- Respondents by household income (n=1703)

Figure 12- Respondents by language spoken at home (n=1703)

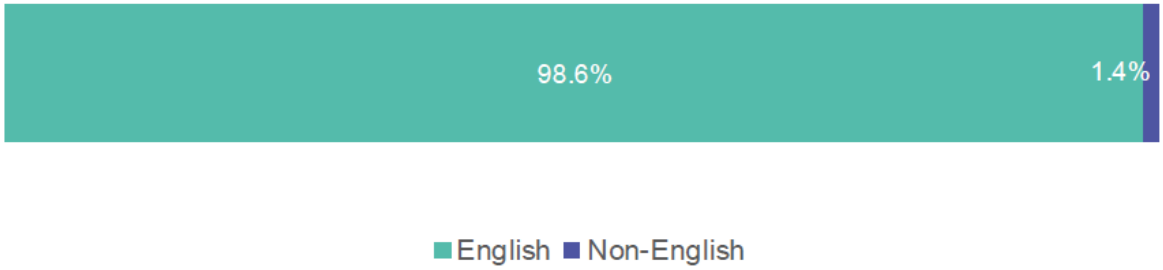


Figure 13- Respondents by private health cover (n=1703)

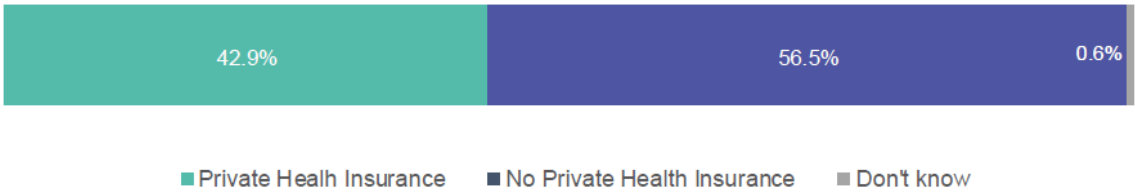
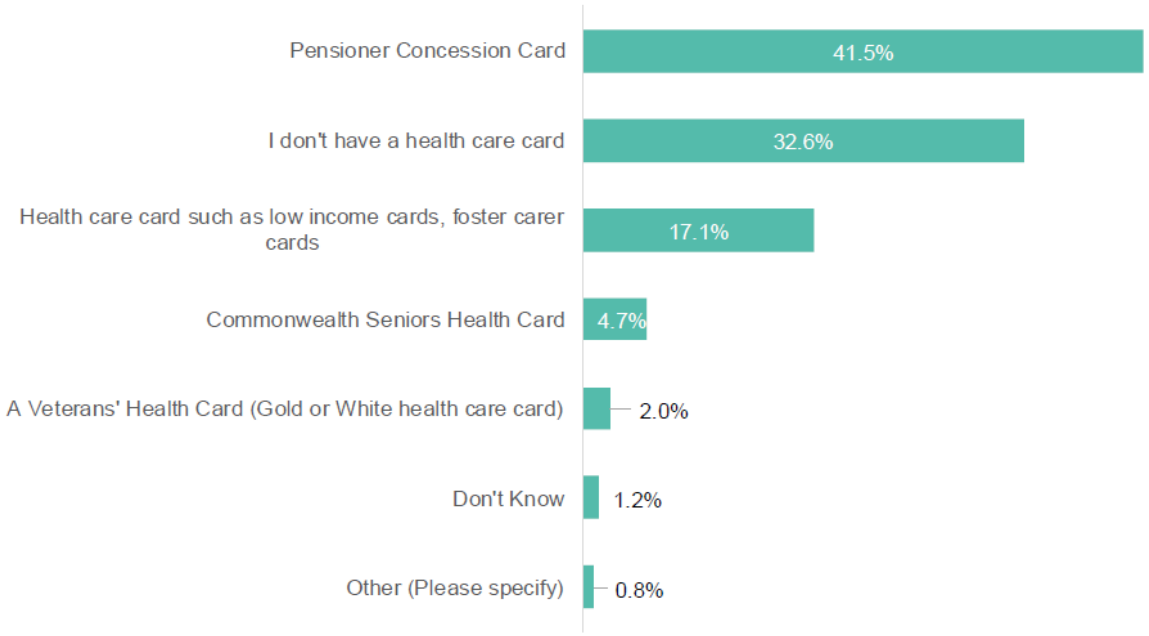


Figure 14- Respondents by health care card status (n=1703)



Appendix 2: Survey Tool

Qu #	Area	Question text	Answer options/format	Source
Preamble		- Purpose of survey, what CHF is - Chronic illness criteria - Potential benefits to participants - Expected time to complete - Data storage/security details - Contact details if participants have questions		
0	Consent	I have read and understood the information sheet provided and agree to participate in this research?	*Select one* - Yes - No	Inclusion criteria *LOGIC: If no, direct out of survey and exclude from sample*
1	Chronic Illness	At the moment, do you have any of the chronic illnesses listed, that have lasted, or are likely to last, for six months or more? If so, please select which ones	*Select as many as apply* - Arthritis or osteoporosis - Asthma - Cancers (such as lung and colorectal cancer) - Heart or circulatory condition (such as coronary heart disease and stroke) - Chronic obstructive pulmonary disease - Diabetes - Mental health condition, including depression or anxiety - Long term injury? (such as back pain or back problems) - Any other long-term health condition - No, none of the above	Inclusion criteria. Adapted from CSS and ABS Patient Experience Survey *LOGIC: If less than two options selected or "No, none of the above" selected, direct out of survey and exclude from sample*
2	Chronic illness	How recently were you diagnosed (with a chronic illness)	*Select one:* - Less than 2 years - 2-10 years ago - More than 10 years ago	Adapted from South East Sydney LHD PAM Survey Report 2015
PAM Questions			PAM preamble: "We would like to learn more about how you view your health so we can better tailor our interactions and care just for you. There are no "right" or "wrong" answers to this brief survey. Please answer these 13 statements with what's most true for you"	

Qu #	Area	Question text	Answer options/format	Source
			LOGIC: If three or more PAM question have "N/A" selected, direct out of survey and exclude from sample	
3	PAM Q1	I am the person who is responsible for taking care of my health	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
4	PAM Q2	Taking an active role in my own health care is the most important thing that affects my health	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
5	PAM Q3	I am confident I can help prevent or reduce problems associated with my health	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
6	PAM Q4	I know what each of my prescribed medications do	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
7	PAM Q5	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool

Qu #	Area	Question text	Answer options/format	Source
8	PAM Q6	I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
9	PAM Q7	I am confident that I can follow through on medical treatments I may need to do at home	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
10	PAM Q8	I understand my health problems and what causes them	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
11	PAM Q9	I know what treatments are available for my health problems	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
12	PAM Q10	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
13	PAM Q11	I know how to prevent problems with my health	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly	Insignia Health PAM Tool

Qu #	Area	Question text	Answer options/format	Source
			- N/A	
14	PAM Q12	I am confident I can figure out solutions when new problems arise with my health	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
16	PAM Q13	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	*Select one:* - Disagree Strongly - Disagree - Agree - Agree Strongly - N/A	Insignia Health PAM Tool
Service Utilisation, Patient Satisfaction, Other				
16	Self-assessed health status	How do you rate your current health status	*Select one:* - Excellent - Very Good - Good - Fair - Poor	Adapted from ABS Patient Experience Survey 2017-18
17	Service utilisation-regular GP	Do you have a regular GP or Family Doctor	*Select one:* - Yes - No	From South East Sydney LHD PAM Survey Report 2015
18	Service utilisation-types of service used	How many times have you used the following health services you have used in the **last 12 months**	*List of health services, select as many as apply:* - A public hospital - A private hospital - A general practitioner (GP) - A nurse who works in a general practice - A dentist or dental services - A pharmacist - A specialist doctor outside hospital (e.g. a cardiologist, surgeon, psychiatrist) - A counsellor or psychologist	Adapted from CSS and South East Sydney LHD PAM Survey Report 2015

Qu #	Area	Question text	Answer options/format	Source
			- A community-based healthcare service - An allied health service provider, such as a physiotherapist, dietician, optometrist, speech pathologist, occupational therapist, podiatrist etc - An alternative therapies practitioner e.g. acupuncture, naturopathy, herbalist etc *Each health service has the following options and can have one selected:* - None - 1 – 5 times - 6 – 12 times - More than 12 times	
19	Health Literacy Screen	How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?	*Select one:* - Always - Often - Sometimes - Rarely - Never	Adapted from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1435902/
20	Patient experience - communication	Thinking about all the health providers you have seen in the last 12 months, how often did they listen carefully to you?	*Select one:* - Always - Often - Sometimes - Rarely - Never	Adapted from ABS Patient Experience Survey (broadened from 'GPs' to 'health providers'
21	Patient experience – decision-making	Thinking about all the health providers you have seen in the last 12 months, how often did they involve you in decisions?	*Select one:* - Always - Often - Sometimes - Rarely - Never	Adapted from ABS Patient Experience Survey and RACGP Patient Feedback Guide (Communication)
22	Patient experience – goal setting	Thinking about all the health providers you have seen in the last 12 months, how often did	*Select one:* - Always - Often	Adapted from ABS Patient Experience Survey and CAHPS

Qu #	Area	Question text	Answer options/format	Source
		they talk to you about specific health goals?	- Sometimes - Rarely - Never	Patient-Centred Medical Home Item Set (PCMH4)
23	Patient experience – overall satisfaction	Overall, how satisfied are you with the care you received in the last 12 months?	*Select one:* - Very satisfied - Fairly satisfied - Neither satisfied nor dissatisfied - Fairly dissatisfied - Very dissatisfied - Don't know - Not applicable	Adapted from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060812/ and CSS.
Demographics				
24	Gender	What is your gender?	*Select one:* - Male - Female - Other - Prefer not to answer	Adapted from CSS
25	Age	In what year were you born? (enter 4-digit birth year; for example, 1976)	*Open ended four digit numerical*	Adapted from CSS
26	Location	What is your post code? (enter a 4-digit postcode; for example, 2000)	*Open ended four digit numerical*	Adapted from CSS
27	CALD- culturally and linguistically diverse	Do you speak English at home?	*Select one:* - Yes - No	Adapted from South East Sydney LHD PAM Survey Report 2015

Qu #	Area	Question text	Answer options/format	Source
28	Educational attainment	What is the highest level of education that you have completed? If you are currently studying, but have not completed a qualification, please answer with the highest level you have completed.	*Select one:* - Primary school or less - High school (not completed) - High school (completed) - TAFE/trade - University – Undergraduate degree/s (completed) - University - Postgraduate degree/s e.g. Master, PhD (completed) - Prefer not to say	Adapted from CSS and revised based on ABS Patient Experience Survey 2017-18
29	Socio economic status	What is your household income per week after tax? Note: Household income is the amount of money coming into the household from all sources including employment, government support schemes (e.g. Centrelink payments, unemployment benefits etc., for all household members)	*Select one:* - $2400 or more per week - $1400 - $2399 - $700 to $1399 per week - Under $700 per week - Don't know - Prefer not to say	Adapted from https://profile.id.com.au/australia/household-income-quartiles and https://www.ato.gov.au/individuals/income-and-deductions/.../low-income-earners/"
30	Private health insurance	Apart from Medicare, are you covered by private health insurance?	*Select one:* - Yes - No - Don't know	Adapted from CSS and revised based on ABS Patient Experience Survey 2017-18
31	Access to subsidised healthcare costs	Do you have a health care card, e.g. Health Care Card (including low income cards, foster carer cards) Commonwealth Seniors Health Card Pensioner Concession card A Veterans' Health Card (Gold or White health care card)	*Select as many as apply:* - Yes - No	Adapted from CSS and revised based on ABS Patient Experience Survey 2017-18