TALKING ABOUT HEALTH

Long term conditions study

2016-2018

Brief patient results 2016

Purpose of the report

This report provides a brief summary of the 2016 patient findings from the Talking about Health: Long term conditions study 2016-2018. Some recommendations based on the findings are included within the sections and a fuller list is presented at the end. The full report is available on the PHO website for those wanting more detailed results. A separate report presenting results for Māori participants is also available.

Background

Long term conditions (LTCs) are those defined as being ongoing, requiring regular involvement with the healthcare system and having a significant impact on quality of life. As very little time can be spent with health practitioners, the main burden of care responsibility lies with the individuals, their families/whānau and friends. As such it is important that people with LTCs are given the knowledge, skills and confidence to manage their conditions on a day to day basis and to know when they need help from a health professional.

With this longitudinal study we have recruited 569 people aged 18 years or older with at least one LTC who have had a comprehensive health assessment done in general practice over the last few years. They have consented to take part by completing a questionnaire annually for three years. The study explores the patient experience of living with a long term condition, and care provided within the general practice setting to support their long term condition management. This report provides the findings from the patient questionnaire data collected in 2016. Some comparison of results based on participant subgroups (i.e. sex, ethnicity, age, income) has been included, with greater detail being provided in the full report.

Demographics

Participants are predominantly New Zealand or other European (82%), 15% are Māori and less than 1% are Pacific. As in previous years it has been difficult to engage Pacific people despite oversampling for Māori and Pacific and sending out a second invitation to these groups. An alternative approach to data collection has been used with Pacific people and this work is currently underway. Just over half of the sample is female (56%) and the majority (62%) are aged between 65 and 84 years. Around a third (31%) of the participants were living alone at home and 17% indicated they had insufficient income to meet their daily needs.

Health status

The number of LTCs ranged from 1 to 11, the average being 3.3. Only 13% reported having a single condition. The main conditions reported were hypertension (54%), chronic pain (61%), diabetes (50%) and a respiratory condition (35%). It was notable that 24% of Māori and 18% of non Māori indicated they experienced depression/anxiety related to having a long term health condition. Utilisation of the Massey University Health Conditions Psychology Service is highly recommended as it is

Health in general

- Excellent — 1.8
- Very good — 18.3
- Good — 43.7
- Fair — 30.6
- Poor — 5.7
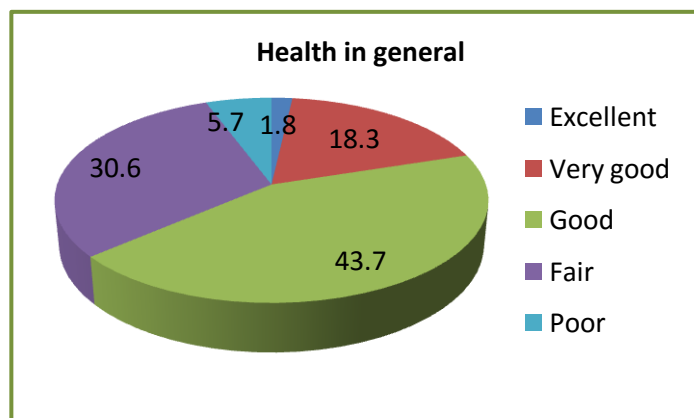
well documented in the literature that feelings of anxiety and depression can be addressed using self-management training, cognitive behaviour therapy, counselling and other related therapies[1]. Health status was measured using the 10-item global short form Patient-Reported Outcomes Measurement Information System (PROMIS) to assess mental and physical health as well as health in general. Self-reported health in general ranged from poor (6%) to excellent (2%) the average being fair to good. More positive ratings were found amongst those with more income and a higher level of education.

Physical and mental health scores are standardized so that a T-score of 50 represents the mean (M) for the US population with a standard deviation (SD) of 10. The Global Physical health T-scores for the patient sample (N=549) ranged from 23.5 to 67.7 with a mean of 42.5. The Global Mental health T-scores ranged from 21.2 to 67.6 with a mean of 46.3. Mean scores in relation to participant demographics are presented in Table 1 on the following page. In summary, physical health scores were slightly higher with more education, older age, living with a partner, increased income and fewer LTCs.   Mental health scores were higher for non Māori, people with school qualifications or higher, older age, living with a partner, a higher level of income and fewer LTCs.

Quality of life

This was measured with three questions, all rated on a 0 to 10 point scale. They concerned the level of control participants felt they had over their lives (M=7.0), their life satisfaction (M=6.6) and the effect their LTC/s had on their quality of life (M=5.8). Overall people were more satisfied with life, felt more in control of their lives and felt that their conditions had less impact on their quality of life if they were older (65+), living with a spouse or partner and had enough or more than enough income.

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[1] Clarke, D.M., & Currie, K.C. (2009). Depression, anxiety and their relationship with chronic diseases: A review of the epidemiology, risk and treatment evidence. Medical Journal of Australia, 190 (7) S54-S60.

Table 1: Mean global physical and mental health scores according to demographic characteristics		
	Physical Health mean (N)	**Mental Health mean (N)**
Sex		
Male	42.8 (236)	46.2 (236)
Female	42.2 (306)	46.3 (307)
Ethnicity		
Māori	41.8 (79)	44.4 (78)
non Māori	42.6 (470)	46.6 (473)
Educational qualifications		
No school	41.5 (193)	44.7 (195)
School	41.5 (115)	47.3 (113)
Post school	43.2 (141)	46.8 (142)
University	44.7 (78)	47.9 (79)
Age		
<55	41.4 (56)	42.5 (57)
55-64	40.4 (102)	43.4 (101)
65-74	43.7 (179)	47.3 (179)
75+	42.6 (200)	48.0 (201)
Living situation		
With partner	43.3 (308)	47.4 (310)
Not with partner	41.6 (222)	45.0 (221)
Income adequacy		
Not enough	37.3 (90)	39.9 (87)
Just enough	41.6 (186)	45.8 (189)
Enough	44.4 (191)	48.5 (193)
More than enough	46.4 (67)	49.7 (66)
Number of LTCs		
1LTC	47.4 (74)	51.1 (72)
>1 LTC	41.6 (472)	45.5 (476)

Healthy behaviour

Generic healthy lifestyle questions were provided for all participants asking them how many days a week, on average, they performed specific behaviours (Figure 1).
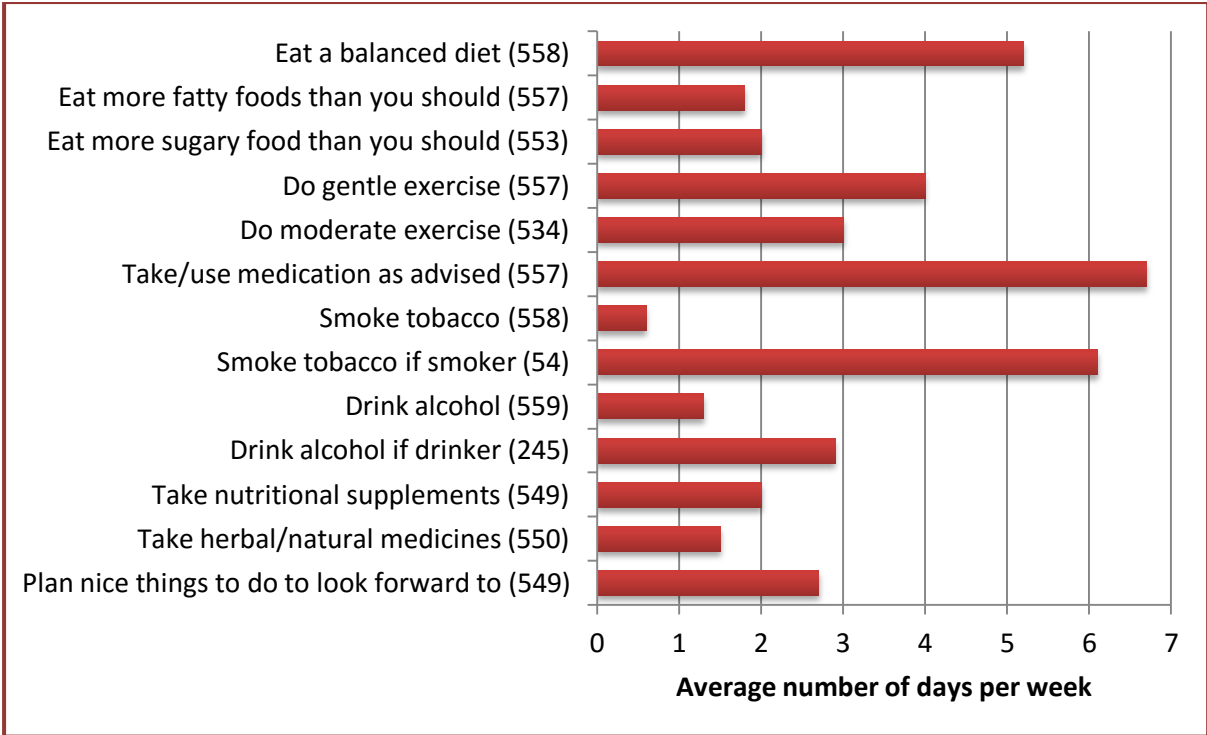
Figure 1: Number of days health related behaviours are carried out on average per week

In relation to adopting healthy general self management behaviours, it is surprising to find 91% of the sample reporting that they take their medicines every day as advised. Medicine non-adherence has been identified as a major self-management issue both within the literature and in clinical practice. The second highest general health behaviour was healthy eating, with 29% of people reporting that they eat a healthy diet every day. This number may be influenced by people's perception of what equates to a healthy diet as the question defined it as including plenty of fruit and vegetables and was followed by queries about fat and sugar intake. Therefore things such as having an occasional treat or a takeaway may have meant people reported eating a healthy diet less often. When we looked at the figures for people reporting that they eat a healthy diet at least 5 days per week, the proportion increased to 73%. Slightly more Māori than non Māori were smokers and they were more likely to smoke on a daily basis than non Māori. Fewer Māori than non Māori drink alcohol.

A Healthy Behaviours scale was created by combining responses to questions about eating a balanced diet, eating fatty and sugary foods (reverse coded), doing gentle exercise, taking medication as advised and planning nice things to look forward to. Mean scores (N=519) ranged from 2 to 7 with an overall mean of 4.8. Comparisons by demographics revealed that healthy behaviours were reported with greater frequency by participants who were non Māori, better educated or older and by those with more income.

Self-management of specific conditions

Sets of questions were developed to explore the way in which people manage specific conditions at home. These included, pain, respiratory, angina, heart failure, diabetes, renal failure and chronic kidney disease. The consent form asked people to indicate the conditions they had and

questionnaires were individualised according to their responses. It is recommended that clinicians with expertise in diabetes, cardiac conditions, respiratory conditions, renal care and pain read the relevant sections of the full report related to self management, and identify key ways in which patient self management could be better supported from a health system perspective.

Pain

Pain was identified as a LTC by 57% of the sample but only 16% of the participants indicated they had experienced no pain in the previous week and 49% reported taking regular pain medication. Pain management was explored by asking how well a set of 16 behaviours were managed: 'not well managed' (scored as 1), 'fairly well managed' (2) and 'well managed' (3). Those managed best were avoiding caffeine, and other sleep disrupting behaviours before bedtime, and taking prescribed and additional 'when needed' pain medication. Conversely, the behaviours managed least well were good sleep, relaxation breathing and remaining socially active. A Pain scale was calculated for all participants who had answered at least 14 of the 16 questions. Mean scores ranged from 1.2 to 3 out of a possible 3 with an overall scale mean of 2.2. Using an 11 point rating scale ranging from 0 to 10, participants with pain rated their overall management of pain at home as 7.1 on average. The two measures of pain were moderately correlated (r=.52) with each other.

As pain was the most frequent health condition reported by patients in our study, and the most common response to 12 of the 16 questions was 'fairly well managed', there is room for pain management programmes/education in the community to support patients to improve their self management.

Respiratory

Respiratory self-management and knowledge questions were answered by 35% of the sample. The respiratory management behaviours best managed were related to medication; both using regular medications/inhalers as prescribed and using additional medication when needed. Poorer management was related to continuing to exercise when breathless, with only 28% saying this was well managed. 'Flu vaccinations were reported by 85% of the people with respiratory conditions. Knowledge levels were good overall but over 10% of this group reported not knowing when they have a fever or what do to about it and not knowing when a cold has become a chest infection. The responses to the self-management and knowledge questions were combined to form a Respiratory scale, one missed response in each of the two sets was allowed when forming the scale. The pulmonary rehabilitation attendance question was left out due to it applying to less than a third of the group. The possible range of scores was from 1 to 5, the actual range was 3 to 5 with a mean of 4.2. Overall management of respiratory health at home was rated on an 11 point scale (from 0 - 10). Scores ranged from 1 to 10 with an average rating of 7.8. These two measures of the management of respiratory health were moderately correlated (r=.54).

Angina

Angina was experienced by 14% of the sample. Three-quarters of them indicated that they understood the cause and it appears that it slightly more often results from emotional upset than from exercise. The strongest self-management behaviour is stopping exercise if angina occurs, 38 of the 39 affected individuals saying they do. Almost all of the people with angina indicated they knew the signs and symptoms of a heart attack and how to use their nitrolingual spray. However a few did

not know which is a concerning finding for people with angina, particularly as nearly half of them say they never or only sometimes stop and take medication if they experience pain while exercising.

Ratings of how well they manage their angina at home (n=75) ranged from 1 to 10, the average rating being 8.1. No difference in ratings of angina self-management were found between men and women or when comparing Māori with non Māori.

Heart failure

Heart failure questions were answered by 11% of the patient sample, and most reported taking their medications on a daily basis. However other self-management behaviours were not so well done; only half of the people who had been advised to limit their fluid intake reported doing so on a daily basis. About three quarters said they checked for shortness of breath and leg swelling every day, a few saying they never did. Daily weighing is done by just over a third of those with heart failure, but 9% indicated they never weigh themselves at home. Overall self-management ranged from 3 to 10 and the average rating was 8.2. No difference was found according to sex or ethnicity.

Diabetes

Close to half of the patient group (49%) had diabetes and three quarters of them test their blood glucose levels (BGLs) at home. Of these, around 80% keep a record and take their records to appointments with health professionals. A similar number reported understanding what their BGLs mean but fewer (70%) knew what their targets for their BGLs were. The frequency with which they test is quite varied, with the largest subset (38%) testing 2-4 times per day. Over half (59%) test their levels at least once a day. Just under half (47%) of the participants with diabetes use insulin and 91% said they use it as advised. Fewer than half titrate their own doses with most of those that do (92%) thinking about their BGLs when making adjustments, 61% factoring in activity levels and 58% thinking about carbohydrate intake. Of those taking tablets for their diabetes (n=204), 96% indicated they take them as advised and 76% understand how they work. Although it is recommended that people with diabetes check their feet on a daily basis only two thirds of the participants with diabetes said they checked their feet regularly. Fewer than half of the people with diabetes (44.1%) indicated that they knew what their target HbA1c was, and some of those reported target levels that were clearly not right. This suggests a need for further education and, given the technicality of the term and what it represents, may highlight a health literacy issue. The average rating of diabetes management at home was 7.5 (range 0 to 10).

Chronic kidney disease

This group was quite small at 7% of the sample, and over half also had diabetes. Self management was quite variable; most said they had not been asked to restrict their fluid intake, but those who had been asked generally did. Weighing at home was done by 72% and 46% stick to a low salt diet every day. Most reported checking their legs for swelling but generally not every day. Diuretics were prescribed for 70% of this group but close to a third of them didn't take them. Nearly half (43%) reported never seeing a dietitian. Self-management was rated as 7.3 out of 10 on average, scores ranging from 0 to 10. No differences in these ratings of self-management of CKD were found in relation to sex or ethnicity.

Renal failure

Only 10 patients indicated they had renal failure (1.8%) and of these, 6 were on haemodialysis with 3 having it as often as prescribed. Peritoneal dialysis applied to 5 people, 3 of whom reported doing all

their exchanges each day. Four had had a kidney transplant and 3 of these reported taking their medication as advised. Overall management of their renal failure at home was rated from 0 to 10, the mean score being 6.4, the lowest of all the specific condition management scores.

While the numbers of people with CKD and renal failure were small, the CKD self management behaviours were varied amongst this group with a number not appearing to know about fluid restrictions, and limiting salt intake. A few patients reported that some medications were not taken, and less than half of the people taking diuretics knew how to adjust the dose. In renal failure, patients were divided into groups according to of dialysis type and renal transplant. Interestingly in each dialysis group, some patients reported not having the treatment as often as recommended. There were some patients who reported not taking their medicines regularly and some did not know who to contact if they became unwell. Whilst specific renal care is not covered in the Living a Healthy Life (LHL) (Stanford) Programme, general self management is, and attendance at one of these programmes may provide necessary information, skills and confidence that will benefit patients with these conditions. Another recommendation is that people with CKD or renal failure are encouraged to see a dietitian as part of their package of care.

Self-management across different LTCs

A comparison of health status, quality of life and ratings of self-management for people with just one versus more than one of the highlighted conditions was made. It appears that people with only one of the LTCs tended to report having more positive experiences than those with more than one. This included; better health status, more control over life, more life satisfaction, and reporting that their condition had less impact on their quality of life. Healthier behaviour was also reported by those with only one of these conditions. There were a few people with each condition who reported managing poorly (score less than 5 out of 10) at home. Interestingly the proportion was slightly higher amongst those with a single condition and it may be that having more than one condition encourages people to become better self-managers as there is more to do or perhaps the significance of having more than one diagnosis encourages people to take their conditions more seriously.

It is recommended that clinicians promote the generic Living a Healthy Life Programme (Stanford) with patients, specifically targeting people with pain and CKD. Central PHO should also consider diversifying the way the Stanford programme is delivered in the region by offering specific pain and diabetes programmes.

Interactions with general practice

Almost all participants (97%) had seen a general practitioner (GP), and most (73%) had seen a practice nurse (PN) during the last 12 months. Similar numbers had seen a Community Clinical Nurse - Long Term Conditions (CCN-LTC) and a specialist nurse/Nurse Practitioner (27% and 29% respectively). Ratings of GPs and practice nurses with respect to a range of aspects of the patient/practitioner consultation were sought using a 6-point scale ranging from 'very poor' (1) to 'excellent' (6). **For GPs** the highest ratings (M=4.9) were associated with making people feel comfortable during their physical exam and knowing about patients' medical history and treatment. Lowest ratings were for knowing patients as people (M=4.4) and learning about and helping with social support needs (M=4.2). The combined items generated a score of 4.7 out of 6 overall.

When you see **the doctor** at your General Practice, how good are they at ...		Mean	Excellent/very good %	Poor/very poor %
TOP	• Making you feel comfortable about your physical examination	4.9	67.1	2.0
	• Knowing about your medical history and current treatment	4.9	67.7	3.4
	• Introducing themselves and asking you to introduce yourself	4.8	66.9	4.7
	• Listening to what you have to say	4.8	65.2	4.0
	• Explaining your problems or any treatment you need in a way you can understand	4.8	65.4	3.9
BOTTOM	• Spending enough time with you	4.5	56.0	6.7
	• Involving family/whānau/fanau in decisions about your care	4.5	55.4	11.6
	• Knowing about you as a person not just a patient	4.4	53.2	10.7
	• Learning about and helping with your social support needs	4.2	44.7	12.4

For nurses, the highest scored aspects were making people feel comfortable during their physical exam, listening to what patients have to say, asking fully about symptoms and feelings and introductions (all Ms=4.9). Things rated least well were including whānau in care decisions (M=4.5), knowing patients as people (M=4.5) and learning about and helping with social support needs (M=4.4). The combined items gave a score of 4.8 out of 6 overall.

When you see **the nurse** at your General Practice, how good are they at ...		Mean	Excellent/very good %	Poor/very poor %
TOP	• Making you feel comfortable about your physical examination	4.9	69.6	1.5
	• Listening to what you have to say	4.9	69.1	1.3
	• Asking fully about your symptoms and how you are feeling	4.9	68.0	1.9
	• Introducing themselves and asking you to introduce yourself	4.9	68.5	2.7
BOTTOM	• Involving family/whānau/fanau in decisions about your care	4.5	58.1	9.4
	• Knowing about you as a person not just a patient	4.5	55.5	8.7
	• Learning about and helping with your social support needs	4.4	51.2	9.2

Although nearly half the sample were rating their interactions with General Practitioners and nurses at the General Practice as very good or excellent on average, a quarter of the respondents rated their interactions with their GP, and a fifth rated their interactions with nurses, as less than good.
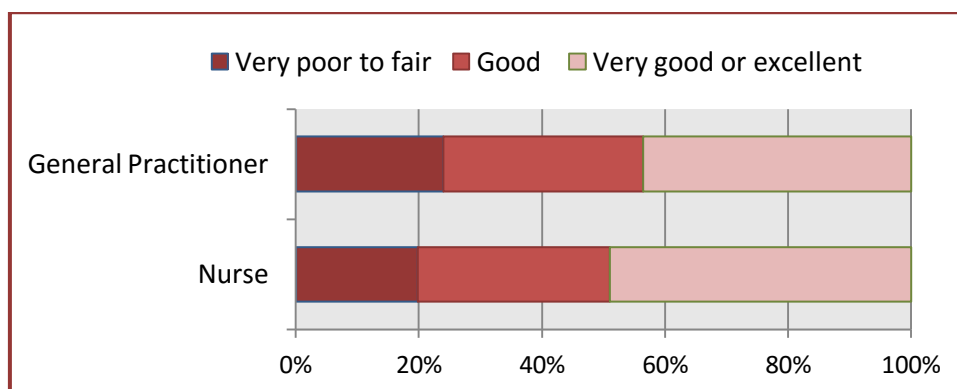
Figure 2: Score distributions for GP Interaction and Nurse Interaction scales

Reception staff were rated in a similar way and the areas in which they are doing best are in enabling appointments to be made at suitable times (M=4.8), listening to what patients are saying (M=4.7) and being friendly and welcoming (M=4.7). The things that are not being managed so well

are: knowing the patients as people (M=4.0); and enabling private conversations (M=3.9) - 39% of respondents said this was less than good.

Overall support from the GPT was scored from 0 to 10, with a mean of 7.9. Although these ratings were generally high overall, there were differences according to demographics - older people, those with no school qualifications and those with adequate income provided more positive ratings.

Firstly, it is recommended that Central PHO continues to support and promote practitioner and general practice team cultural competence, and secondly that the PHO informs the sector of the top and bottom rated items in the Interaction with General Practice tool. The bottom scores highlight the need for a greater focus on holistic care, social support and involving family and whānau in care decisions. However it is important that these be integrated generally into patient consultations rather than addressed as independent aspects of care.

Care planning

Only 19% of patients were sure that they had a written care plan and compared to those who did not, they were more active self-managers (see patient activation section) and reported more positive interactions with doctors and nurses in primary care as well as perceiving themselves to get more support from the general practice team. A greater proportion of Māori then non Māori said they had written care plans (23% cf 18%). Separate to care planning, half the sample said that a health professional regularly checked on how they were getting on with their health goals and slightly more (51%) indicated they received support from a health professional to reach their goals. A further 26% indicated they had no goals. Those who reported that a practitioner checks on or supports them in reaching their health goals were found to have better physical and mental health, to be better self-managers and to report more positive general practice interactions. Based on these findings it is recommended that clinicians promote the use of client are planning and/or goal setting in practice. Goal setting is particularly relevant to people with only one LTC, a combination of relatively mild LTCs, and/or require lifestyle modification. Greater emphasis should be placed on care planning with people who have: moderate or complex LTCs; multiple co-morbidities: high needs (including Māori and Pacific People); poor self-management skills; or complex social needs.

Other practitioners

The number of practitioners seen, other than the GPT, ranged from none to seven the average being 1.3.
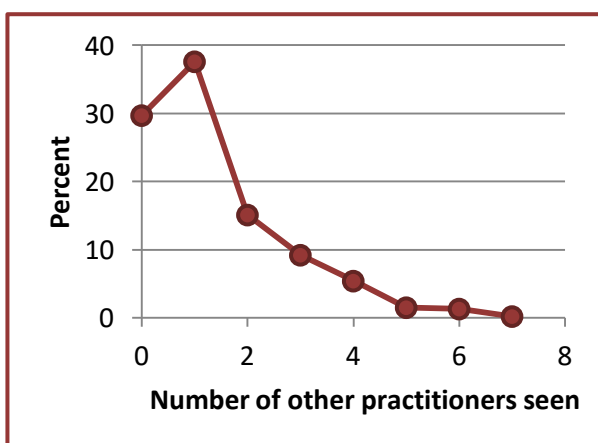
The other practitioners most commonly seen were specialist doctors (37%), podiatrists (20%) and specialist nurses (15%). Results demonstrated that more than 65% of this patient group are reliant on their GPT alone, or their GPT with the addition of one other health practitioner, for LTC care thus positioning the burden of care strongly in the primary practice arena.

Support from others

Information about whether any help or support was received from family/whānau members, neighbours, friends or local organisations was sought (Table 2), and it was found that most support came from family/whānau followed by friends. A quarter of the patients indicated that they receive help from nobody other than health practitioners.

Table 2: Help or support received by study participants	
	Number (%)
Family	277 (53.7)
Friends	194 (37.6)
Neighbours	98 (19.0)
Other	68 (13.2)
None	127 (24.6)

Medications

Participants were asked how many days a week they take their medications as advised and 2% indicated they never did, 91% said every day and the remaining 7% indicated they did 2 to 6 days a week. In addition, 35% take nutritional supplements and 27% take herbal/natural remedies. Almost all (90%) collect all their prescribed items from the pharmacy, reasons for not doing so included cost (6%), having leftover medication (5%) not liking some of the medication prescribed (2%) and feeling that they did not need some of the medications prescribed (1%). Additionally, 19% indicated they had not used some of their collected medication, the main reasons being: having some leftover (8%); not liking to take some of the medication (5%); thinking they don't need it (3%); and because of side effects (2%). One-on-one consultations with community pharmacists were reported by 13% of participants.

Patient activation

This term was coined by Hibbard and colleagues and is defined as 'an individual's knowledge, skill, and confidence for managing their health and health care'. The authors state that people with high levels of activation not only understand their role in the care process and feel able to fulfil that role, but are more likely to engage in positive health and self-management behaviours. Previous research has found patient activation to be associated with clinical outcomes, rates of hospitalisation and satisfaction with health services.

According to Hibbard and Cunningham[2], people with low levels of health activation:

- feel overwhelmed with the task of managing their health
- have little confidence in their ability to have a positive impact on their health
- misunderstand their role in the care process
- have limited problem-solving skills

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[2] Hibbard, J.H., & Cunningham, P.J. (2008). How engaged are consumers in their health and health care, and why does it matter? Health System Change Research Briefs, no 8, pp 1–9.

- have had substantial experience of failing to manage their health, and have become passive in managing their health
- say that they would rather not think about their health.

A measure of patient activation has been developed by Hibbard and colleagues consisting of 13 statements with which respondents are asked to agree/disagree using a 4-point response scale. The total patient activation score did not differ according to age, ethnicity, education or income level but women scored higher than men. Scores are used to classify respondents into four different activation levels and 45% of the current sample was at level 3. Differences in self-management scores were found according to patient activation level as follows:
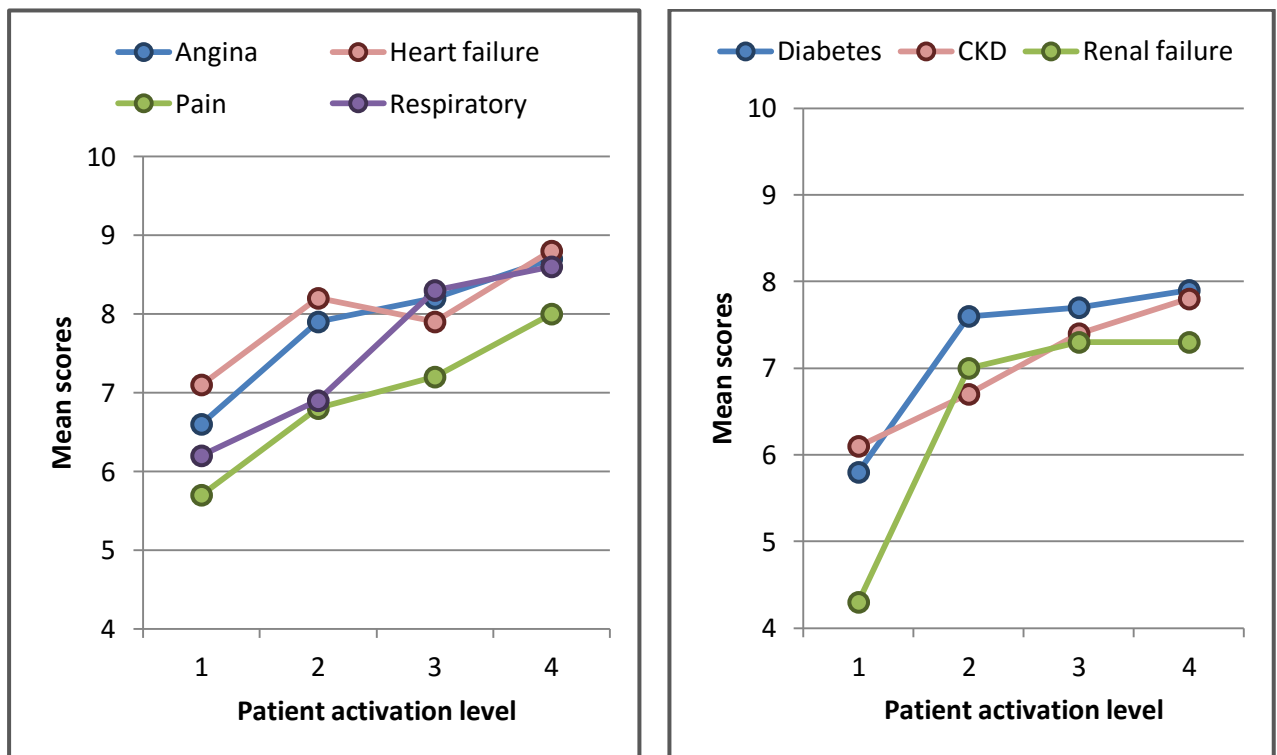
Figure 3: Mean self-management scores for people with specific conditions across the four levels of patient activation

Overall, higher levels of activation were linked to: better health; higher ratings of condition specific self-management; more positive interactions with general practice; higher ratings of life satisfaction and control over life; and perceptions that long term conditions were having less of an impact on quality of life. Therefore, patients should be encouraged to be active partners in health care decision making and management of their conditions.

Recommendations

Quality Improvement recommendations based on the research findings are an important part of the study. These recommendations give Central PHO an opportunity to introduce a change management process, and to address issues at the end of each research year, rather than waiting until the end of the three year study. A brief list of recommendations is provided here. For a fuller set of recommendations, including those for Māori, please refer to the full report.

- **Adopt and promote in the region an interpretation of self-management support that goes beyond disease state management.** This broader focus on helping people to live well with their long term conditions supports patient empowerment and self management.
- **Promote the generic Living a Healthy Life Programme (Stanford) and consider offering programmes specifically designed to meet the needs of people with specific conditions.** For example diabetes and chronic pain. Patients with CKD/renal failure should be targeted to participate in the generic LHL programme.
- **Raise awareness of health literacy concerns regarding patient understanding of care planning and setting of health goals.** Make use of education sessions and resources - for patients and practitioners. Development of a patient leaflet on care planning, health goals and action planning, based on health literacy principles, is highly recommended and could be provided to patients when a care package is implemented. Consider providing access to web based information such as Health Navigator.
- **Promote goal setting in practice for people with mild LTCs or who require lifestyle changes and care planning in practice for people with: moderate to complex LTCs; multiple co-morbidities; high needs - including Māori and Pacific people; those in greater need of self-management support; and patients with complex social needs**
- **People with CKD or renal failure should be encouraged to see a dietitian as part of their package of care.**
- **Continue to support and promote practitioner and general practice team cultural competence.**
- Inform sector of top and bottom scores given in the Interaction with General Practice tool. **The lower scores highlight a greater focus on holistic care, social support and involving family and whānau in care.**
- A significant proportion of participants reported having anxiety/depression related to their LTCs and **as Massey University has a dedicated Health Conditions Psychology Service this resource should be utilised for these people.**
- It is highly recommended that the findings about Māori access to care provided by a CCN:LTC and other specialist nurses be shared within the sector. These services are usually free and can often be provided at home. **Improving access to care is a fundamental part of addressing inequality in our region.**

The second questionnaire will be sent out later in the year and interviews will be held with participant volunteers to explore some aspects of the study in greater detail.