

TALKING ABOUT HEALTH

Long term conditions study:
2016-2018

A comparison of patient results
across the years

Claire Budge & Melanie Taylor

Contents

Executive summary	4
Health status.....	4
Self-care challenges.....	4
Healthy behaviours.....	4
Patient Activation	5
General practice interactions	5
Care planning and goal setting	6
Abbreviations	6
Main report	7
Demographics.....	7
Care giving	10
Three year comparison group results	11
Social contact.....	11
Long term conditions.....	13
Impact of conditions.....	14
Self-care challenges.....	16
Impact of long term conditions on quality of life.....	17
Health status.....	17
General self-management behaviours	20
Self-management behaviours related to specific conditions.....	22
Pain.....	22
Respiratory	32
Patient Activation	41
Patient Activation level and self-management at home.....	43
Patient Activation and demographics	45
General self-efficacy	45
Interactions with General Practice	47
Main source of support	48
General Practitioners.....	49
Nurses.....	50

What would people change if they could?	55
Other practitioners.....	57
Care planning and goal setting.....	58
Health education	60
Medicines	60
Advice for others	64
Conclusion and recommendations.....	65
APPENDIX A: Correlations between the number of listed LTCs, ratings of General Health, Satisfaction with Life, Control over Life and Effect of LTCs on QOL in 2016 and 2018.....	68
APPENDIX B: Mean scores on health and general practice interaction variables by PAM level with ANOVA results	69
APPENDIX C: Numbers of general practice team members consulted during the study period by Māori/non Māori and male/female subgroups.....	70
APPENDIX D: Additional information regarding Health Care Home and standards for care to people with long term conditions	71
APPENDIX E: Numbers of participants consulting practitioners outside the general practice team across the three study years.....	72

Executive summary

This report summarises and compares the three years of Talking about Health patient data that was collected from 2016 to 2018. For full details on how the study was implemented please refer to the 2016 full patient report available on the Central PHO website. The number of participants dropped from 569 in 2016 to 376 in 2018, with the greatest decrease taking place in the younger rather than older age groups. There was a slight drop off in male respondent numbers compared to female; a 29% decrease in non Māori ethnicity and a 56% decrease in Māori. The few Pacific participants we managed to recruit remained part of the study throughout. Demographic information is provided in Tables 1 and 2 for the participants across the three years with a separate column for those who took part in every year (N=349). It is this group that the majority of the report is based on in order to look at change over time within the same group of participants. Overall the results were relatively stable.

Health status

Ratings of general health over the three years were stable overall, the largest group of participants indicating their health was good, rated as 3 on a 5-point scale from poor to excellent. A slight decrease in numbers indicating their health is good was offset by a similar increase in those defining their health as poor. No differences were found between Māori and non Māori ratings of general health.

There was some deterioration in physical and mental health, on average, as could be expected from a sample of predominantly older people with one or more long term conditions. This was more evident in mental than physical health as measured by the PROMIS. The self-reported conditions experienced most commonly were pain, hypertension, diabetes and respiratory conditions. There was an apparent increase in chronic pain, for both ethnicities, and in hypertension and mental health issues for Māori and renal failure for non Māori. A slight decrease in the number of non Māori with hypertension was observed. Based on a list of 13 main conditions (see Table 3) Māori had significantly more conditions on average than non Māori in 2018 (mean= 3.5 cf 2.8). The number of listed conditions experienced was correlated with ratings of general health, satisfaction with life as a whole, control over life and the effect of LTCs on quality of life.

Self-care challenges

In 2018, when the question was asked, the self-care challenges experienced by the largest number of people were home and garden maintenance, experienced by 52.7%, sleeping (46.2%), mobility (44.5%), pain (43.1%) and exercise (42.8%). When asked about the *main* challenge or challenges related to living with their long term condition(s), the top ones were described as home/garden maintenance (17.0%), mobility (18.1%), pain (14.4%), being overweight (12.4%) and sleeping (11.0%). The number of challenges faced ranged from none to 17 with an average of 4.6. More challenges were indicated by Māori (5.6) than non Māori (4.5), by women (4.9) than men (4.1) and by those with less income.

Healthy behaviours

A scale was formed combining ratings of how many days per week participants eat a balanced diet, eat too much fatty food and sugary food (both reverse coded), do gentle exercise, take medication as advised and plan nice things to do. Average scores remained very similar over the three years and did not differ according to sex

or education. In 2018 non Māori scored higher than Māori (4.9 cf 4.4) and across all years older people scored higher than younger people. Also, those with more income scored higher than those with less income.

Patient Activation

Measured by the Patient Activation Measure (PAM), patient activation is defined as “an individual’s knowledge, skill, and confidence for managing their health and health care” (Hibbard et al., 2005)¹. Thirteen statements are provided and respondents are asked to rate their agreement with each on a 4 point scale ranging from ‘disagree strongly’ (1) to ‘agree strongly’ (4). Scores are weighted and summed to produce an overall score and to classify each score into one of four levels. Previous research has found patient activation to be associated with clinical outcomes, rates of hospitalisation and satisfaction with health services.

The number of participants at each PAM level remained fairly consistent; 12-14% at Level 1, 15-17% at Level 2, 41-47% at Level 3 and 26-30% at Level 4. However, there was movement of individuals between the levels with only a third remaining at the same level throughout the study. In 2016, a pattern of means was found such that scores on a range of health and general practice interaction variables were higher for those at a higher level of patient activation and vice versa. Despite the movement between levels described above, this pattern remained within the 2017 and 2018 data.

General practice interactions

Overall, General Practitioners (GPs) are seen regularly by nearly all of the patients, and practice nurses are seen by around three quarters. Between 20 and 30% have seen CCN:LTCs and specialist nurses/Nurse Practitioners. For all practitioners, the number of people seeing them during the previous 12 months appears to have decreased slightly across the study period. Most people cite their GP as the source of most support for their LTC care, followed by practice nurses, GP and practice nurses combined and then home. The slight drop in number citing their GP was balanced by an increase in those citing home as their main source of support in 2018.

Interactions with GPs were assessed using a set of 16 aspects of the consultation which were rated according to how good their doctor is at carrying them out. Response options ranged from ‘very poor’ (1) to ‘excellent’ (6). Mean scores were calculated and from these it is clear that there is not a lot of difference for each of these different aspects of the consultation. One aspect remained in the top 5 across all three years; ‘making you feel comfortable about your physical exam ($M=4.9$)’. Two remained in the bottom 5; ‘knowing about you as a person not just a patient ($Ms=4.4/4.5$)’ and ‘learning about and helping with your social support needs’ ($M=4.2$). The same questions were asked about interactions with nurses in the general practice environment and the ones staying in the top 5 were ‘listening to what you have to say’ ($M=4.9$) and ‘making you feel comfortable about your physical examination’ ($Ms=4.9/5.0$). The same two as for GPs remained in the bottom five for all three years; ‘knowing about you as a person not just a patient ($Ms=4.4/4.5$)’ and ‘learning about and helping with your social support needs’ ($Ms=4.3 - 4.5$). The latter question was not seen to be applicable to the General Practice Team (GPT) role by a number of participants, highlighting a need for education as patients may not be aware that if they need additional support (financial, physical, environmental) they should raise it during a

¹ Hibbard, J. H., Mahoney, E. R, Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the Patient Activation Measure'. *Health Services Research*, 40(6), 1918–1930.

consultation. An overall rating of support from the general practice team was provided using a 0 - 10 scale and mean ratings were a consistent 7.9 in 2016, 8.0 in 2017 and 7.9 in 2018.

Care planning and goal setting

With the change from the Enhanced Care+ Programme to the Long Term Conditions programme, the practice requirement for people with long term conditions to have a standardised, comprehensive health assessment (CHA) and collaborative care plan developed and provided to them has been removed. Therefore the continued use of a range of care planning tools is promoted but is no longer monitored. This may have impacted on the finding that over the study period the number of people indicating that they had a written care plan decreased slightly from 18 to 16%. There were no sex, ethnicity or income differences in the reported incidence of written care plans.

The number of people saying that a health practitioner provided them with support for their health goals also dropped marginally from 51 to 48%. The number stating that they had no health goals increased over the study period from 30 to 35%.

In 2016 it was found that people with written care plans, on average, had higher patient activation scores and rated their interactions with doctors and nurses and their support from the GPT more positively than those without a care plan. These differences did not remain significant throughout the study. However, having practitioner support for health goals was consistently linked to higher ratings of GP and nurse interactions and GPT support.

Abbreviations

ANOVA	Analysis of variance	NP	Nurse Practitioner
CCN-LTC	Community Clinical Nurse - Long Term Conditions	ns	non significant
CKD	Chronic kidney disease	PAM	Patient Activation Measure
GPT	General practice team	PN	Practice Nurse
IFHC	Integrated Family Health Centre	PROMIS	Patient-reported outcomes measurement system
LTC	Long term condition	T1	Type 1 diabetes mellitus
M	Mean/average	T2	Type 2 diabetes mellitus
N	Number of responses when using the total sample	Y1, Y2, Y3	Year 1, Year 2, Year 3 of the study: 2016, 2017, 2018
n	Number of responses when using a subset of the total sample		

Main report

This report presents and compares the findings across the three years of patient data collection for the longitudinal ‘Talking about Health’ Long Term Conditions study. There is a practitioner report presenting results from the 2018 practitioner arm of the study available on the CPHO website. Interviews carried out with 32 patient participant volunteers are being written up separately and a publication is planned based on the findings. However, the conclusions and recommendations in this report encompass some of the interview findings as well. After each section, findings of note are presented in a text box. Reports on the findings from Māori, Pacific and pain participant interviews are still underway.

Demographics

The following tables present the demographics for the Talking about Health study participants across the three study years (2016 - 2018) referred to as Year 1 (Y1), Year 2 (Y2) and Year 3 (Y3). The final column provides information at Y3 about the group of participants who completed all three questionnaires and consequently appear in all three data sets.

Over the study period Table 1 shows that there has been a 24% drop in participant numbers from Year 1 to Year 2 and another drop of 14% to Year 3. The age distribution was always skewed towards those aged 65+, as could be expected for a population with multiple long term conditions; however it is notable that the three oldest age groups are the ones with the least drop in numbers. From Year 1 to Year 3 we retained 68% of those aged 65 - 74 years, 76% of those aged 75 - 84 and 90% of those aged 85 and over. There was a slight decrease in male respondent numbers compared to female and a greater decrease in Māori than non Māori participant numbers. The few Pacific participants remained part of the study throughout. The distribution of participants across education level remained constant over the three years of the study but employment status altered slightly, in line with the earlier finding of retaining more of the people of retirement age in the study.

Table 1: Demographics

	2016	2017	2018	3 year comparison group
Sex	N (%)	N (%)	N (%)	N(%)
Male	246 (43.9)	185 (42.6)	155 (41.3)	142 (40.7)
Female	315 (56.1)	249 (57.4)	220 (58.7)	207 (59.3)
Total	561	434	375	349
Age				
25 - 34	2 (0.4)	0 (0.0)	0 (0.0)	0 (0.0)
35 - 44	10 (1.8)	7 (1.6)	2 (0.5)	2 (0.6)
45 - 54	47 (8.4)	26 (6.0)	26 (6.9)	22 (6.3)
55 - 64	103 (18.4)	73 (16.9)	54 (14.4)	52 (14.9)
65 - 74	185 (33.1)	143 (33.2)	126 (33.5)	118 (33.8)
75 - 84	164 (29.3)	138 (32.0)	125 (33.2)	115 (33.0)
85+	48 (8.6)	44 (10.2)	43 (11.4)	40 (11.5)
Total	559	431	376	349
Ethnicity				
Other	472 (84.6)	379 (87.3)	335 (89.3)	313 (89.7)
Māori	82 (14.7)	51 (11.8)	36 (9.6)	32 (9.2)
Pacific	4 (0.7)	4 (0.9)	4 (1.1)	4 (1.1)
Total	557	434	375	349
Highest educational level				
No school qualifications	204 (37.4)	143 (34.3)	124 (33.8)	116 (33.9)
School qualifications	116 (21.2)	94 (22.5)	83 (22.6)	77 (22.5)
Post school/polytech/trade	146 (26.7)	115 (27.6)	104 (28.3)	97 (28.4)
University qualification	80 (14.7)	65 (15.6)	56 (15.3)	52 (15.2)
Total	546	417	367	342
Employment				
Employed	104 (19.2)	78 (18.3)	60 (16.3)	55 (16.0)
Unemployed	75 (13.9)	44 (10.3)	39 (10.6)	36 (10.5)
Retired	362 (66.9)	304 (71.4)	270 (73.2)	252 (73.5)
Total	541	426	369	343

Table 2: Demographics continued

	2016	2017	2018	3 year comparison group
Location	N (%)	N (%)	N (%)	N (%)
Alone at home	178 (31.9)	149 (34.6)	128 (34.7)	120 (35.2)
At home, sometimes alone	20 (3.6)	14 (3.2)	8 (2.2)	8 (2.3)
At home with others	354 (63.4)	265 (61.5)	229 (62.1)	209 (61.3)
Residential care	6 (1.1)	3 (0.7)	4 (1.1)	4 (1.2)
Total	558	431	369	341
Living with partner/spouse				
All of the time	320 (57.3)	238 (55.3)	209 (55.9)	194 (56.1)
Some of the time	9 (1.6)	6 (1.4)	8 (2.1)	8 (2.3)
No	229 (41.0)	186 (43.3)	157 (42.0)	144 (41.6)
Total	558	430	374	346
Income adequacy				
Not enough	92 (16.7)	69 (16.2)	54 (14.6)	48 (14.0)
Just enough	195 (35.3)	145 (34.0)	126 (34.1)	116 (33.9)
Enough	198 (35.9)	161 (37.8)	140 (37.9)	132 (38.6)
More than enough	67 (12.1)	51 (12.0)	49 (13.3)	46 (13.2)
Total	552	426	369	342
Housing issues *				
No problems	388 (71.1)	305 (72.3)	253 (69.1)	235 (69.1)
Repairs needed	86 (15.8)	75 (17.8)	75 (20.5)	70 (20.6)
Pests	36 (6.6)	25 (5.9)	14 (3.8)	12 (3.5)
Too small	15 (2.7)	7 (1.7)	9 (2.5)	9 (2.6)
Damp	36 (6.6)	23 (5.5)	17 (4.6)	16 (4.7)
Hard to keep warm	88 (16.1)	50 (11.8)	53 (14.5)	50 (14.7)
Total	546	422	366	340

* Percentages add to more than 100 as a number of respondents indicated there was more than one housing issue (range 0-5).

Care giving

In 2018 we included a question about being a caregiver as we are aware that many people who have long term conditions and receive care are themselves in a caregiver role. Of the 335 people responding, only 19.1% said they provided no care for others. Family were the greatest receivers of care (55.8%) followed by friends (45.1%), neighbours (32.2%) and others (4.5%). Note that these percentages add to more than 100 as many people provided care to more than one other category of person. The people listed as being in receipt of care other than family, friends and neighbours were: through Age Concern; as a caller for St John; at church; elderly/bereaved in the community; at the marae and an employer. When asked about how being a caregiver for somebody else impacted on their own health and well-being, 41.7% said it had no effect, 4.2% said it made it worse 2.6% said both better and worse and 32.7% said it had a positive impact. Some of the reasons provided to explain responses were as follows.

Positive impact	<ul style="list-style-type: none">• “It feels good to help others. Whilst I cannot help financially I can offer companionship, listening etc”• “Great feeling to help a friend get groceries, chemist, library etc that can't drive”• “I enjoy being able to give back to people what they have given me”• “It keeps me active body and mind”• “It makes me feel useful and worthwhile. I enjoy contact with others”• “Helping others is something I get personal satisfaction from on a mental level”• “Makes me appreciate that some others are much worse off than I am, many of whom never complain”
Negative impact	<ul style="list-style-type: none">• “I help my 91 year old mother and I find this can make me fatigued and foggy but she is my mum and needs me”• “Can become breathless if anything physical required”• “Back pain and anxiety”• “Feel obliged to do things for relatives that means I have little time to myself on weekend”
Both positive and negative impact	<ul style="list-style-type: none">• “Helping helps socially and mentally - pain usually increases but treat it with medication, rest etc”• “Makes me feel good just to help others most time it has no impact but if I start to feel over committed it has an effect on my health”• “Generally improves it however sometimes it is draining”

A comparison between those who indicated they were caregivers and those who did not found no differences according to age or sex but Māori were more likely to be caregivers than non Māori (97.5% cf 87.0%).²

² $\chi^2 = 7.53$, p=.006

Main demographic findings

- Around half of the respondents have less than enough or only just enough income to meet daily needs
- 81% of respondents provide some form of care for others, and many find that it improves their own well-being and quality of life

Three year comparison group results

The remainder of the report presents information that is based on the 349 participants who took part in all three data collection points throughout the study. This enables us to look at what has changed for these individuals over the study period and to compare the results for the same set of people - those in the final columns of Tables 1 and 2. The exceptions to this are where we introduced a few new questions in Y3 of the data collection and the responses to these questions are provided for all who answered them (the 2018 column in Tables 1 and 2). Where this applies, the different sample is identified as being the '**full set**' in the text.

Social contact

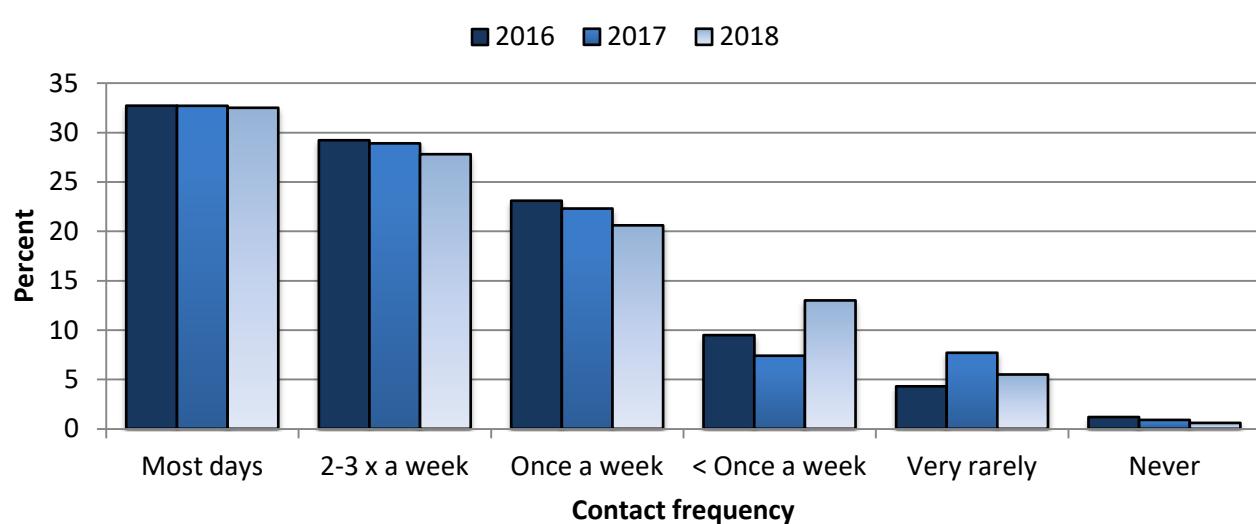


Figure 1: contact frequency with family/whānau/fanau outside the home

The amount of contact participants have with family members/whānau/fanau who do not live with them has remained fairly stable, but it appears that for those who see whānau weekly or less, the level of contact has decreased slightly over the three years. Most people felt that the amount of contact they have with whānau outside the family home is the right amount and this did not really change across the three years (79.9%, 77.4%

& 77.7% respectively). The next largest group (18.7%, 19.1% & 20.2%) were those who felt they had too little contact.

Engagement in social activities outside the home was measured using questions from the Te Kupenga Māori Quality of Life survey. A list of social activities was provided and respondents were asked to state whether they were involved in them at least once a month (yes/no). The results are provided in Figure 2. Again these results have remained consistent suggesting that people have continued to visit people, attend clubs and engage in paid or voluntary work to a similar extent throughout the study period.

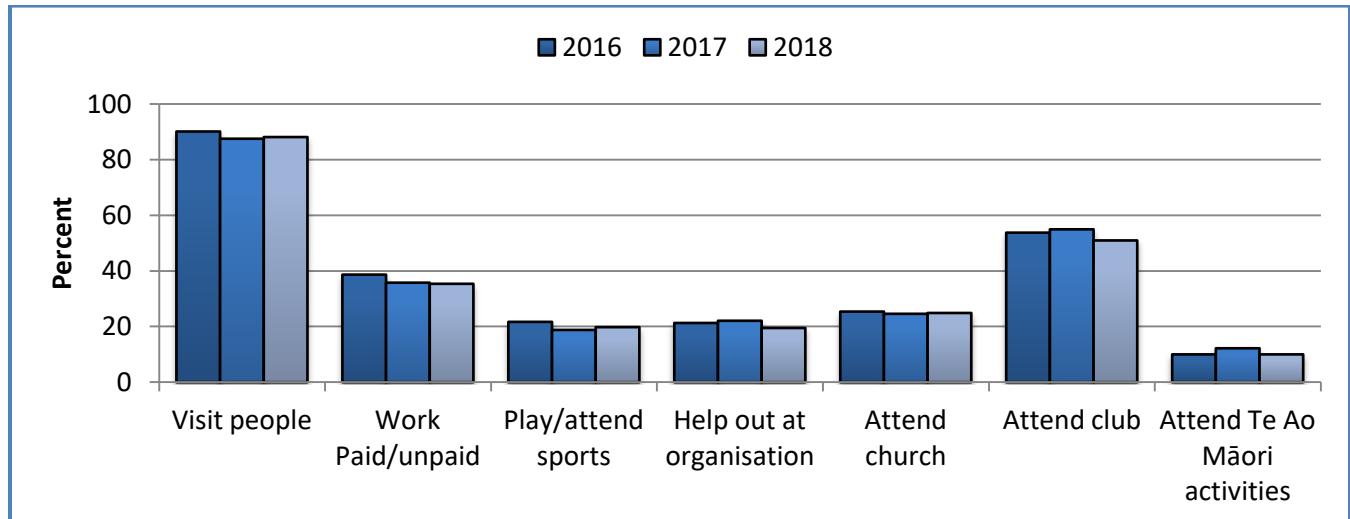


Figure 2: Monthly involvement in activities outside the home

The first six of these items were combined into a Social Activity scale with scores ranging from 0 to 6. The number of activities engaged in across the study period is depicted in Figure 3.

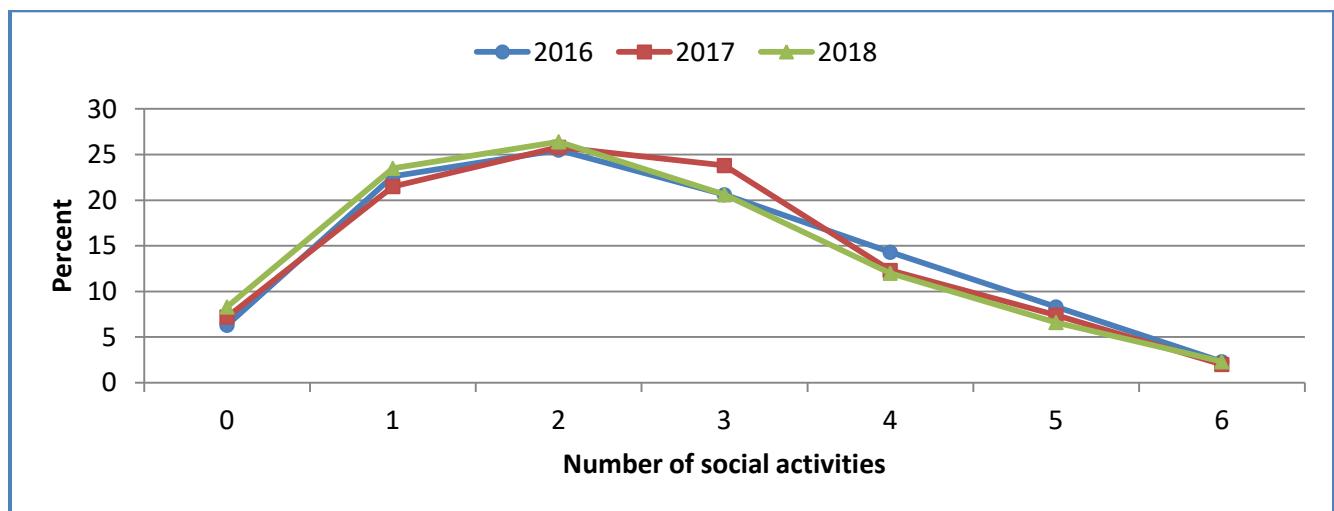


Figure 3: The number of social activities people were engaged in at least monthly.

The number of people engaging in none of these activities ranged from 6.3% in 2017 to 8.3% in 2018. Around 70% of the participants across all three years were involved in one to three different forms of social activity each month. The average number of activities engaged in was 2.5 at Y1, 2.4 at Y2 and 2.3 at Y3.

Long term conditions

We enquired about the long term conditions people have in Y1 and again in Y3. The main conditions and the numbers of Māori and non Māori participants living with them are presented in Table 3.

Table 3: Percent of Māori and Non Māori participants with specific conditions in 2016 and 2018

	2016	2018		
	Non Māori	Māori	Non Māori	Māori
Diabetes	143 (45.1)	19 (59.4)	145 (45.7)	18 (56.3)
Pain	200 (63.1)	20 (62.5)	219 (69.1)	25 (78.1)
Respiratory	100 (31.5)	15 (46.9)	96 (30.3)	15 (46.9)
Hypertension	185 (58.4)	15 (46.9)	171 (53.9)	19 (59.4)
Angina	46 (14.5)	3 (9.4)	54 (17.0)	3 (9.4)
Heart failure	36 (11.4)	1 (3.1)	34 (10.7)	2 (6.3)
Other cardiac condition	55 (17.4)	4 (12.5)	34 (10.7)	4 (12.5)
Chronic kidney disease	18 (5.7)	2 (6.3)	16 (5.0)	3 (9.4)
Renal failure	3 (0.9)	2 (6.3)	10 (3.2)	2 (6.3)
Dementia/memory problems	42 (13.2)	6 (18.8)	46 (14.5)	6 (18.8)
Anxiety/depression related to LTC	56 (17.7)	12 (37.5)	58 (18.3)	11 (34.4)
Cancer	35 (11.0)	3 (9.4)	36 (11.4)	3 (9.4)
Mental health issues	10 (3.2)	2 (6.3)	13 (4.1)	5 (15.6)

Based on these self-reported conditions, it can be seen that the percentage of participants with specific conditions is relatively stable over time. Of concern is the high number of people reporting chronic pain and anxiety and depression related to their LTC over the three year period. There was an apparent increase in chronic pain, for both ethnicities, and in hypertension and mental health issues for Māori. A slight decrease in the number of non Māori with hypertension was observed and an increase in those with renal failure. Pain, hypertension, diabetes and asthma/COPD remain the predominant conditions. It is important to note (a) the low

numbers for several of the listed conditions, and (b) that this data was self-reported meaning that conditions could be over or under represented.

The number of these particular conditions each participant had at Y1 and Y3 (Table 3) was calculated and the range was 0 to 9 in Y1 ($M=3.0$) and 0 to 8 in Y3 ($M=2.9$). A comparison between the mean number of conditions for Māori and non Māori showed that Māori reported having more of these listed conditions at Y1 (3.3 cf 2.9) and at Y3 (3.5 cf 2.8) than non Māori and the difference at Y3 was statistically significant³. No difference in the number of listed conditions reported was found according to sex or age group.

Correlations between the number of conditions people had (0 - 9) and ratings of General Health, Satisfaction with Life, Control over Life and effect of LTCs on QoL were calculated and all were significant at Ys 1 and 3 and in the expected directions (see Appendix A). Therefore the people with more LTCs were likely to report poorer general health, less satisfaction with and control over life and indicated their LTCs had a greater impact on their quality of life in comparison to those with fewer LTCs.

Impact of conditions

In Year 3 we included an additional question about whether one condition had more of an impact on life than others as we wanted to gain insight into the challenges people experience with their self management. Approximately three quarters of the full set of participants said that one condition *did* have more of an impact, or that the conditions interacted to have a greater impact. Explanations about which conditions had the most impact and how they affected people could be summarised as follows.

Responses related to body system, condition, disability, incidents or symptoms

- Some people categorised a body system to identify what was problematic. Cardiac, renal, respiratory and vascular were the categories used.
- Over 40 different LTC conditions, 6 disabilities⁴ and a small number of incidents (such as falls, unwanted treatment side effects i.e. loss of bowel control post radiation treatment, previous trauma) were reported.
- Many participants chose to focus on symptoms that were problematic. Over 15 different symptoms were identified with pain, breathlessness, difficulty standing or mobilising, fatigue and anxiety being more common. Less common were symptoms such as feeling down, incontinence, cognitive blocking, tremor and insomnia.
- As expected, diabetes, heart conditions, chronic lung conditions, chronic pain, mental health, cancer and arthritis were the LTCs cited as being the most problematic with greater frequency than others. This was to be expected as a higher proportion of people in the study are living with these conditions. Stroke, multiple sclerosis, depression, vertigo, back pain, osteoporosis and diverticulitis are examples of the other long term conditions identified. Others reported LTCs that were unpredictable such as a flare up of fibromyalgia or, in one person's case, terminal cancer.

³ Ethnicity difference $t=2.14$, $p=.023$

⁴ Disabilities included sight or speech challenges, paraplegia, hemiplegia, and autism.

- A few participants described how treatment for one of their LTC conditions affected the management of their Type 2 diabetes, with blood glucose levels being raised.
- Some acute conditions were also identified (regular urinary tract infections (UTIs), heart attack, cellulitis) with one participant explaining that an ingrown toenail was particularly problematic at the time. Others talked about acute phases of their long term condition such as recent treatment for cancer.
- A few said it was the condition that required regular medical intervention that affected them the most. Examples included participants with renal failure requiring dialysis, anaemia requiring regular transfusions, and a person who has frequent UTIs needing frequent GP visits. People described how this contributed to their fatigue.

Impact of condition or restrictions imposed by it

- Some people mentioned having to use wheelchairs and aids or needing help for everyday living such as showering.
- Many said that mobility was an issue, and for some this included standing, maintaining balance, walking, physical activity or exercise. This was particularly problematic for participants with arthritis, chronic pain and COPD.
- Memory loss and mental health conditions appear to be particularly problematic for affected participants. One person said that depression had an impact '*as it leaves me with no energy and not wanting to interact with family and friend*' but also anxiety '*because It's worse when I'm around people and in groups and being out for an hour can make me sleep 3-4+ hours*'
- A large number of people shared that they could no longer do things that they previously enjoyed because of their LTC. Examples related to being able to do handcrafts, exercise, socialise or undertake home maintenance. Pain was frequently mentioned as the causative factor, one participant saying '*pain; affects every part of my life*'.
- Fatigue often accompanied pain, shortness of breath, anxiety or depression and conditions that affected people's mobility.
- There was a range of emotional responses; fear, fear of being judged, feeling down, lonely, and having a short temper were some of the responses described. Some people felt frustrated and their frustration was directed either at the condition, or at the health system's lack of ability to provide co-ordinated care. Others had lived with the emotion for a long time with one participant with a stoma talking about his fear that it would leak, which meant that he had been unable to go on holiday for the last 30 years. Another participant felt that his marriage break up was directly related to his LTC.

Modifying life

- A number of participants shared information about how they have modified their life in order to work around the restrictions placed on them by their LTC. Many said that they take things a little slower, 'paced' their activities and ensured they have enough rest. A few had opted to work part-time instead of full-time.

- Pain, hypertension, diabetes and respiratory conditions were the most commonly experienced throughout the study
- There was an increase in chronic pain over the three years
- The majority of participants reported having two or more LTCs indicating that multimorbidity is common
- Māori reported having significantly more LTCs than non Māori by 2018
- People with more LTCs were likely to report poorer general health, less satisfaction with and control over life and indicated their LTCs had a greater impact on their quality of life in comparison to those with fewer LTCs
- LTCs impacted on people's lives in a variety of different ways and around three quarters of the respondents said one had more of an impact than others. For some there was an interaction between two or more conditions
- The emotional response to having a LTC was evident in the comments

Self-care challenges

In the final year of the study we also asked the participants to indicate which of a list of potential challenges they found to be challenging in caring for themselves and then to tell us which was the main challenge or challenges. The following results emerged (Table 4).

Table 4: Number (percent) of Y3 participants reporting specific self-care challenges and main self-care challenges

Challenge	Main challenge/s		Challenge	Main challenge/s	
	N (%)	N (%)		N (%)	N (%)
Pain	153 (43.1)	51 (14.4)	Friends or family/whānau/fanau not understanding	38 (10.7)	6 (1.7)
Breathing	84 (23.7)	30 (8.5)	Social isolation	44 (12.4)	9 (2.5)
Sleeping	164 (46.2)	39 (11.0)	Taking medication	34 (9.6)	4 (1.1)
Being overweight	122 (34.4)	44 (12.4)	Lack of money	85 (23.9)	27 (7.6)
Mobility	158 (44.5)	64 (18.1)	Communication with health professionals	52 (14.6)	9 (2.5)
Healthy eating	67 (18.9)	11 (3.1)			
Health monitoring	36 (10.1)	5 (1.4)			
Not smoking	26 (7.3)	7 (2.0)	Housework	126 (35.5)	28 (7.9)
Exercise	152 (42.8)	36 (10.2)	Home/garden maintenance	187 (52.7)	59 (17.0)
Anxiety/depression	91 (25.6)	24 (6.8)			

In descending order, the most frequent challenges participants in 2018 indicated that they face in looking after themselves were home/garden maintenance, sleeping, mobility, pain and exercise. Each of these was experienced by more than 40% of this group. The main challenges they indicated experiencing were mobility, home/garden maintenance, pain and being overweight.

All of these challenges were presented as a list for the participants to respond to but they were also asked to describe any additional challenges they faced. These included: caring for others; eyesight and hearing problems; fatigue; motivation; travel/transport issues; dressing/undressing; toileting and access to GPs. Travel, hearing, caring for others, motivation, access to GP and toileting were also listed as main challenges.

The number of challenges individuals faced ranged from 0 to 17 with a mean of 4.6. A comparison between demographic groups found there to be no difference according to educational level however women faced more challenges than men on average (4.9 cf 4.1)⁵ and Māori faced more challenges than non Māori (Ms=5.6 cf 4.5)⁶. People who lived alone reported facing more challenges on average ($M=5.1$) than those who lived with others ($M=4.3$). This difference was significant.⁷ There were also differences according to income adequacy; means being 6.4 for those with insufficient income, 5.0 for those with just enough; 4.0 for those with enough income and 3.0 for those with more than enough income to meet their daily needs⁸. Post hoc contrasts revealed that all of the mean income differences, except the difference between enough and more than enough income, were significant.

- The most frequent challenges people indicated that they face in looking after themselves were home/garden maintenance, sleeping, mobility, pain and exercise. Each of these was experienced by more than 40% of respondents
- More self care challenges were faced by Māori, women, people who lived alone and those with lower incomes

Impact of long term conditions on quality of life

The overall impact of long terms conditions on quality of life was measured on an 11 point scale ranging from 'no effect' to 10 'very large effect'. The results were remarkably stable, ranging from 5.6 in Y1 to 5.7 in Y2 and Y3.

Health status

Health status was measured using the 10-item global short form Patient-Reported Outcomes Measurement Information System (PROMIS) to general overall health status as well as physical and mental health. General health is measured with a single item which asks participants to rate their health in general on a 5 point scale (Figure 4).

⁵ Gender $t=2.49$, $p=.013$

⁶ Ethnicity $t=2.16$, $p=.031$

⁷ Living situation $t=2.28$, $p=.023$.

⁸ Income adequacy $F=16.86$, $p<.001$

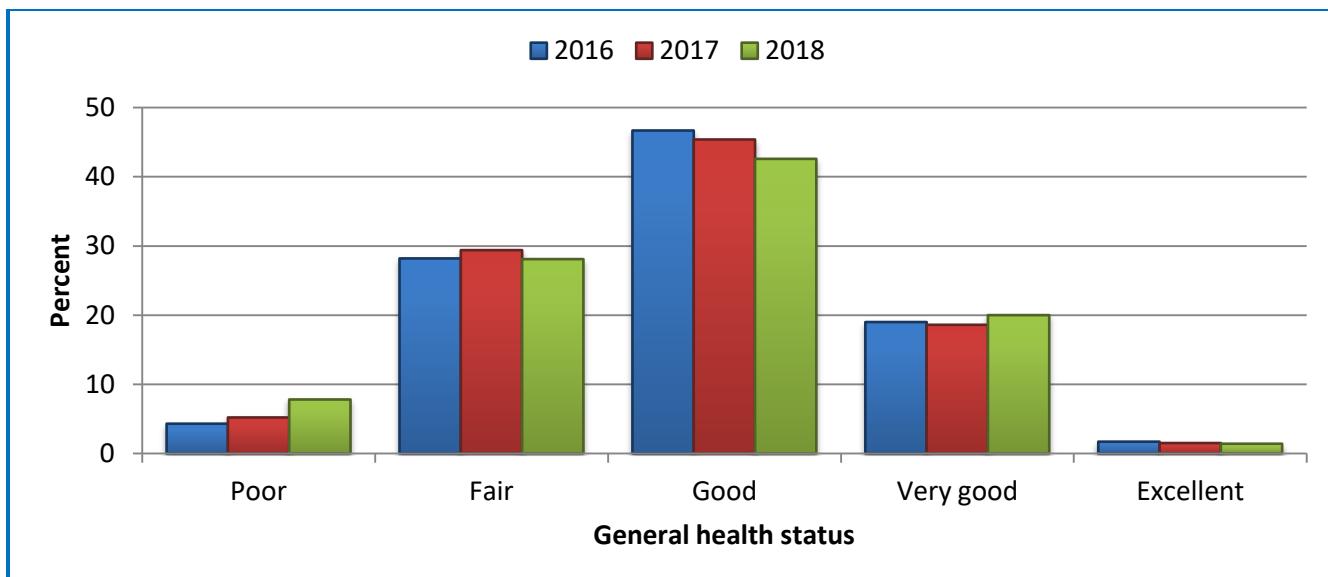


Figure 4: Ratings of general health status for the three year comparison group

This shows stability overall, a slight decrease in the number of people indicating their health is good being offset by a similar increase in those defining their health as poor. No differences in Māori and non Māori ratings of general health over the three study years were found.

The physical and mental health scales are generated by combining subsets of the PROMIS items. Responses are scored, summed and standardized so that a T-score of 50 represents the mean for the US population with a standard deviation (SD) of 10. The Global Physical and Mental health T-scores for the three year comparison group are graphed in Figure 5.

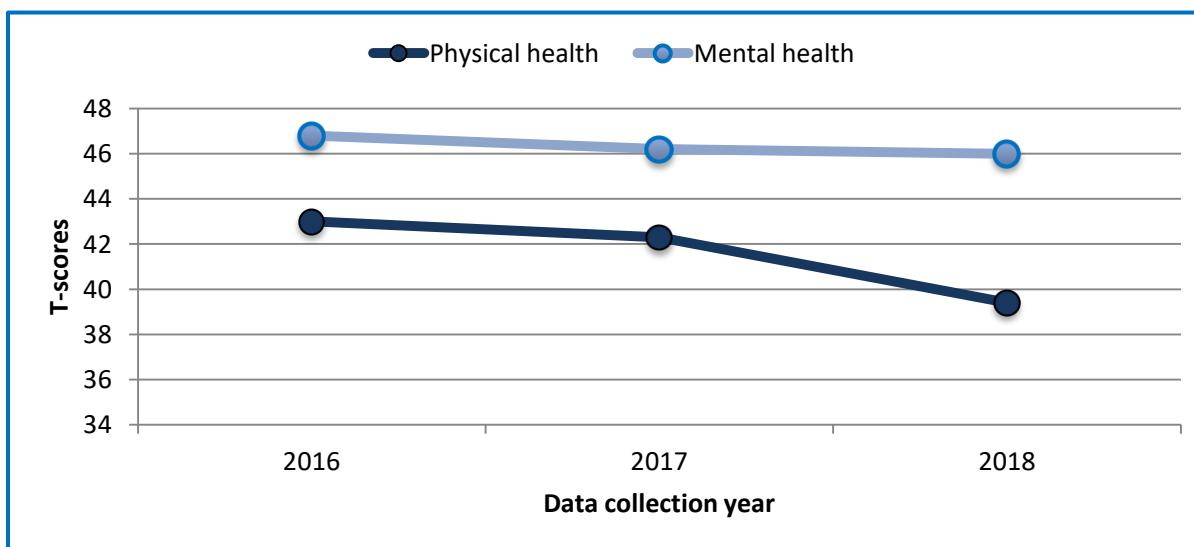


Figure 5: Mean physical and mental health scores for the three year comparison group

These results show that while mental health scores have remained more or less the same there has been a slight decrease in physical health, particularly from Y2 to Y3. A paired samples t-test identified this drop to be statically significant⁹.

Table 5: Mean global physical and mental health scores according to demographic characteristics

	Physical Health mean scores			Mental Health mean scores		
	2016	2017	2018	2016	2017	2018
Sex						
Male	43.5	42.9	39.6	46.7	46.4	45.8
Female	42.7	41.9	39.3	46.8	46.1	46.1
Ethnicity						
Māori	41.1	41.3	37.0	44.0	44.5	43.9
non Māori	43.2	42.5	39.7	47.1	46.4	46.2
Educational qualifications						
No school	42.0	41.1	38.7	45.1	45.2	44.5
School	42.2	42.4	39.7	48.0	46.9	47.1
Post school	43.2	42.1	39.0	47.4	46.3	46.3
University	45.6	45.9	41.5	47.6	47.9	47.3
Age						
<65	41.1	41.4	38.4	43.4	43.8	43.3
65-74	43.9	42.9	40.1	47.5	46.6	46.0
75+	43.7	42.4	39.4	48.6	47.3	47.4
Living situation						
With partner	44.1	43.4	39.8	48.2	47.4	47.2
Not with partner	41.9	41.1	38.9	45.0	44.8	44.3
Income adequacy						
Not enough	36.9	36.9	36.6	39.2	40.1	41.0
Just enough	42.3	41.8	38.3	46.5	46.0	44.5
Enough	44.9	43.4	40.3	49.0	47.2	47.2
More than enough	47.7	47.8	42.9	51.3	51.8	51.0
Number of listed LTCs						
0-1 LTC	48.5	-	45.2	52.4	-	49.2
2-3 LTCs	43.7		40.0	47.2		47.7
>3 LTCs	39.0		35.6	43.3		41.4

⁹ Physical health comparison t=8.25, p<.001.

A comparison of mental and physical health scores by selected demographics was performed and the results are presented in Table 5. Here we can see that physical health scores were slightly higher for non Māori, amongst those with more education, of older age, living with a partner, higher income and fewer of the listed 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. The overall pattern of mental health scores staying fairly constant and physical health scores decreasing was also evident within the demographic contrasts. An exception was that there was less of a decrease in physical health scores for those without a partner than for those with.

General self-management behaviours

A set of self-management behaviours considered to be important to all people with long term conditions, and for health in general, were measured by asking respondents to indicate how many days each week, on average, they were carried out. The mean responses across the three years are presented in Figure 6. The results are remarkably consistent across the study period with medication use and eating a balanced diet being the positive behaviours achieved most often. The number of smokers decreased from 28 in Y1 to 22 in Y2 and 25 in Y3 with the average number of days per week that tobacco was smoked also dropping slightly. The number of alcohol consumers changed from 158 in Y1 to 151 in Y3 and 149 in Y3; a third drinking one day a week on average across the three years.

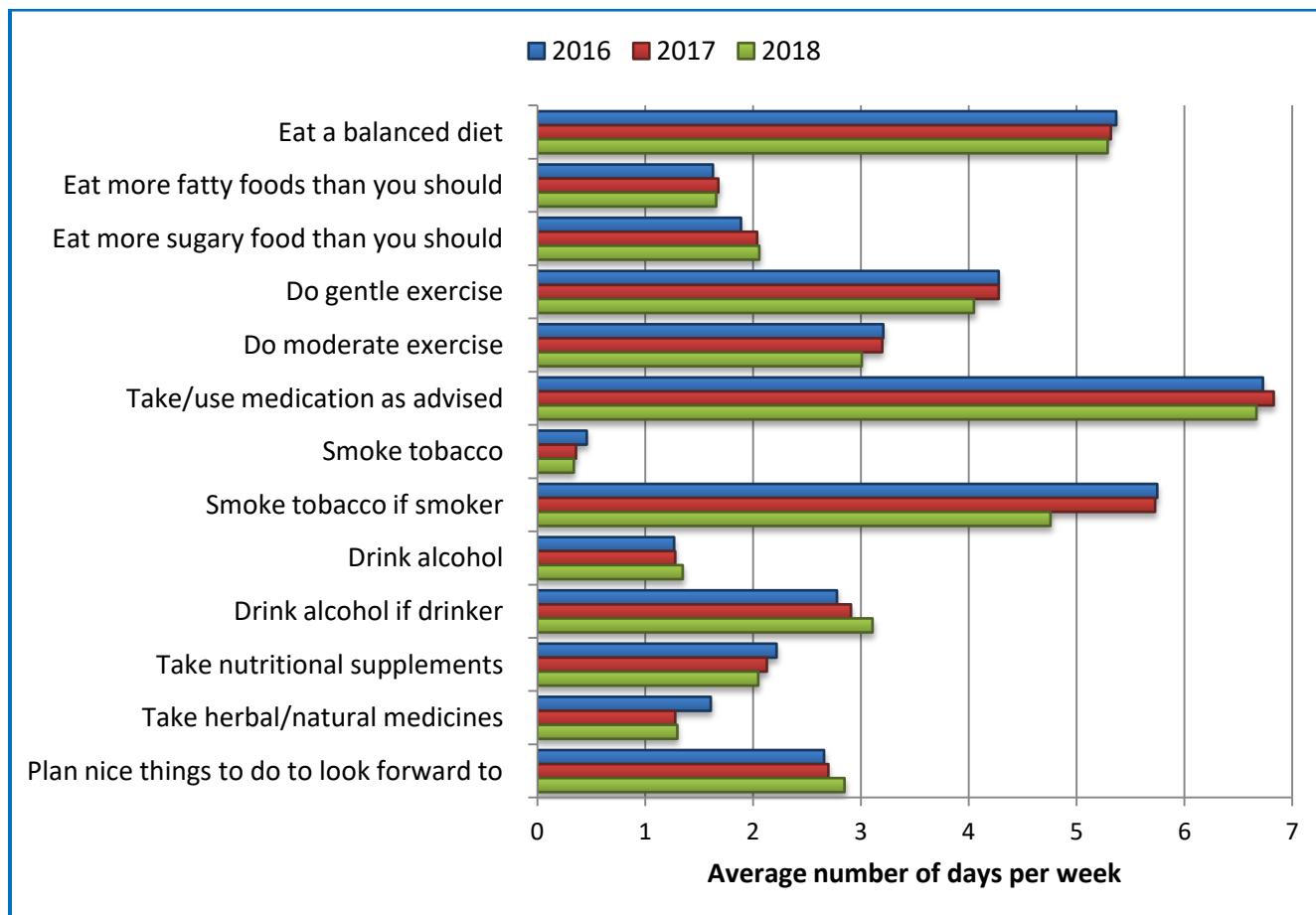


Figure 6: Number of days health related behaviours are carried out on average per week

A Healthy Behaviours scale was created by combining responses to questions about eating a balanced diet, eating fatty foods and sugary foods (both reverse coded), doing gentle exercise, taking medication as advised and planning nice things to look forward to. Mean scores were very consistent across the three years (Y1 4.9; Y2 4.9; Y3 4.8). A comparison of scores by demographics found no difference according to sex or education. For ethnicity the only significant difference was found in Y3 where the score for non Māori participants ($M=4.90$) was higher than that found for Māori (4.35)¹⁰. An analysis of variance (ANOVA) identified a difference for the three age groups across all years such that older participants scored higher on the Healthy Behaviours scale¹¹. ANOVA results for income and healthy behaviour were also significant across all three years and suggest that on average, those participants with more income engaged in healthier behaviours.¹² The mean age group scores are plotted in Figure 7 along with the income adequacy means.

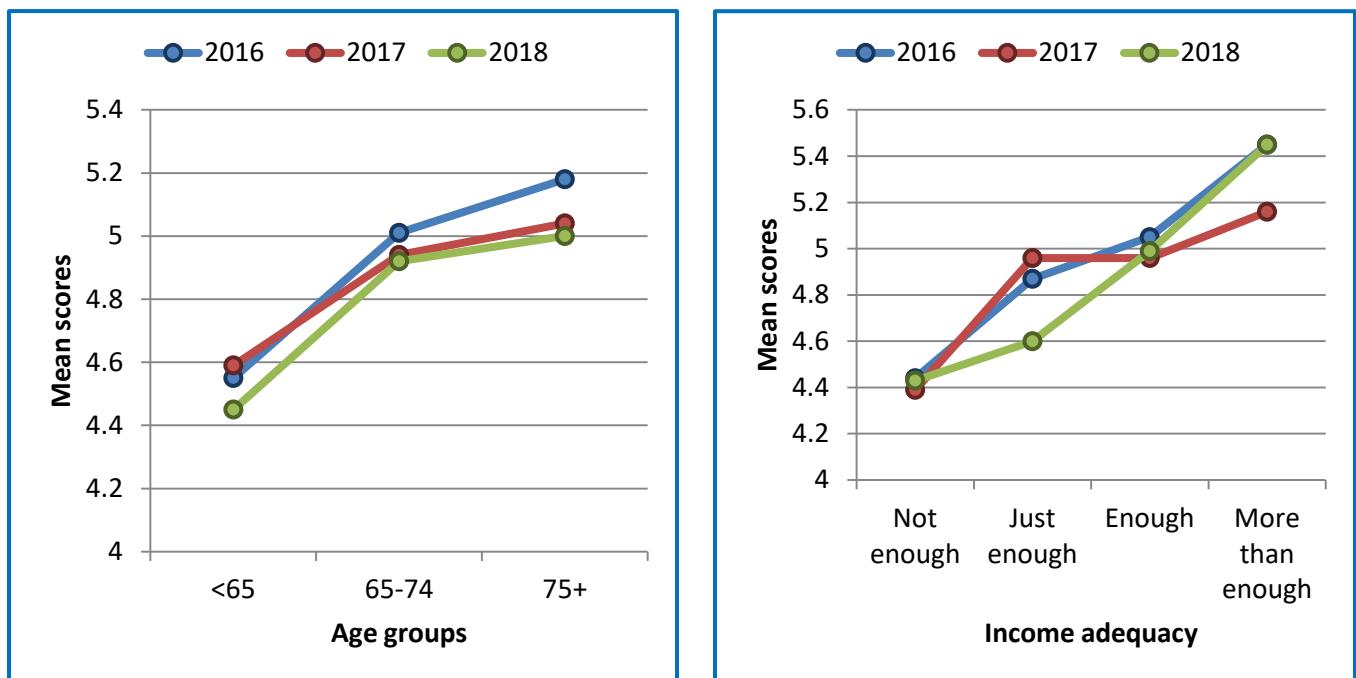


Figure 7: Mean Healthy Behaviours scores according to age group and income adequacy

¹⁰ Ethnicity results: Y3 $t=3.03$, $p=.003$.

¹¹ Education results: Y1 $F=12.23$, $p<.001$; Y2 $F=5.74$, $p=.004$; Y3 $F=8.58$, $p<.001$.

¹² Income adequacy results: Y1 $F=9.24$, $p<.001$; Y2 $F=6.46$, $p=.004$; Y3 $F=13.22$, $p<.001$.

Self-management behaviours related to specific conditions

Sets of questions were developed to explore the way in which people manage specific conditions at home. Not all conditions were covered, those that were included: diabetes, pain, respiratory, angina, heart failure, chronic kidney disease¹³ and renal failure. On their study consent form participants were asked to indicate which conditions they had and questionnaires were individualised by including the relevant self-management item sets. This section provides the results of the self-management questions for these conditions. For some (e.g. diabetes) the results are presented simply as response frequencies, as the questions did not all apply to each person and were consequently difficult to combine into meaningful sets of items or scales. Others, such as pain and respiratory, have been combined into scales as well as being presented as individual items.

Pain

The first pain question was part of the PROMIS and enquired about the level of pain experienced in the previous week. Following this, participants were asked if they regularly used pain medication (yes/no) and if so what their average pain score (0-10) was once they had taken their pain medication. A summary of the responses to these questions for the three years is provided in the following table.

Table 6: Information about pain prevalence, scores and medication

Pain in last week			No pain (0 on scale)	Regular pain medication taken		
	Range	Mean	N (%)	Yes N (%)	Pain score in last week	Pain score after meds ¹⁴
2016	0 - 10	3.6	56 (16.1)	168 (48.6)	5.3	-
2017	0 - 10	3.9	51 (14.8)	162 (48.8)	5.4	4.0
2018	0 - 10	4.0	61 (17.1)	174 (50.7)	5.5	4.1

Pain was experienced by around 63% of this group with average pain levels in the last week increasing slightly over the study period. Around half of the participants take regular medication for pain relief and when we focus on these people, the average pain score is in the mid 5s out of 10, again with evidence of a slight increase by year. The rating of pain severity once pain medication has been taken is slightly lower which suggests that for some people at least, their pain relief is not working all the time, or perhaps has not been taken in such a way as to maximise its effectiveness.

Among those people with pain, high levels of arthritic pain were reported (71.8%) and 15.7% had another type of pain as well. Given this high prevalence, it is unfortunate that Arthritis New Zealand no longer has a regional base and is consequently less accessible and less able to provide on the ground support for people living with this debilitating condition.

¹³ Note that the low numbers of people having CKD (19, 5.4%) and renal failure (6, 1.7%) make a three year comparison difficult so self-management results for participants with these conditions have not been included.

¹⁴ We discarded the year one score as the wording of the question was ambiguous and had clearly been interpreted in different ways within the sample. It was clarified for Y2 and Y3.

A comparison of people with arthritis related pain, another type of pain or both types of pain was made with respect to general health, pain in the last week and pain once medication had been taken. The means for these three groups are plotted in Figure 8. For all three indices it is apparent that people with both arthritis and another type of pain are worse off followed by those with 'other' pain and then those with arthritis. ANOVAs found these differences to be significant overall.¹⁵

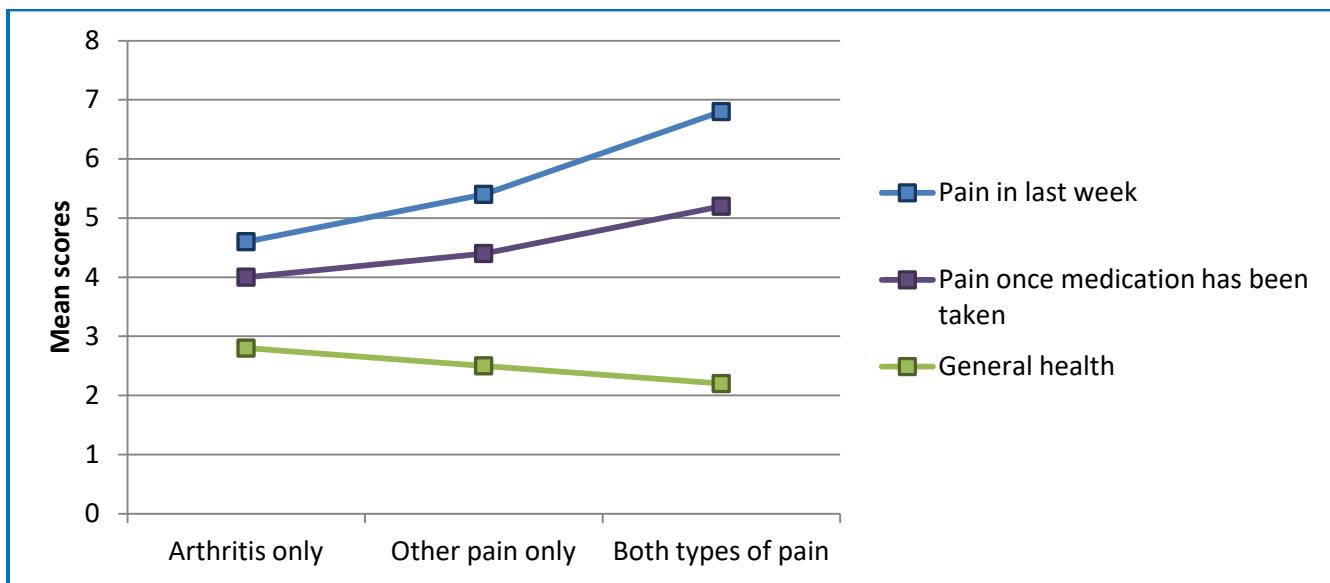


Figure 8: Mean pain and general health scores for three groups of pain participants

A set of 16 self-management questions was included for the 213 (61%) participants who indicated on the enrolment form in Y1 that they experienced chronic pain. They were asked to rate how well they managed each of a list of things people can do to help manage their own pain. A three point response scale was provided ranging from 1 'not at all well managed' through 2 'fairly well managed' to 3 'well managed'. Responses to the items across the three years are presented in Figures 9 and 10.

The overall pattern of results is very similar across the three years and there were only minor variations in mean scores across the 16 items. It is clear that use of everyday and extra 'when needed' medication is reported to be managed best followed by the avoidance of exercise, heavy meals and exercise before bed.

¹⁵ Pain in last week ($F=14.34$, $p<.001$); Pain when medication has been taken ($F=4.00$, $p=.020$); General health ($F=8.39$, $p<.001$).

Organise your home/work to make physical jobs easier to achieve and put less stress on your body.

Pace yourself - take breaks while doing things or split tasks into small achievable pieces

Change activities to avoid repeated movement

Drink plenty of fluid to stay hydrated and avoid constipation

Sleep well

Put a good bedtime routine in place

Avoid caffeine after 5pm

Avoid heavy meals, alcohol and exercise just before bed.

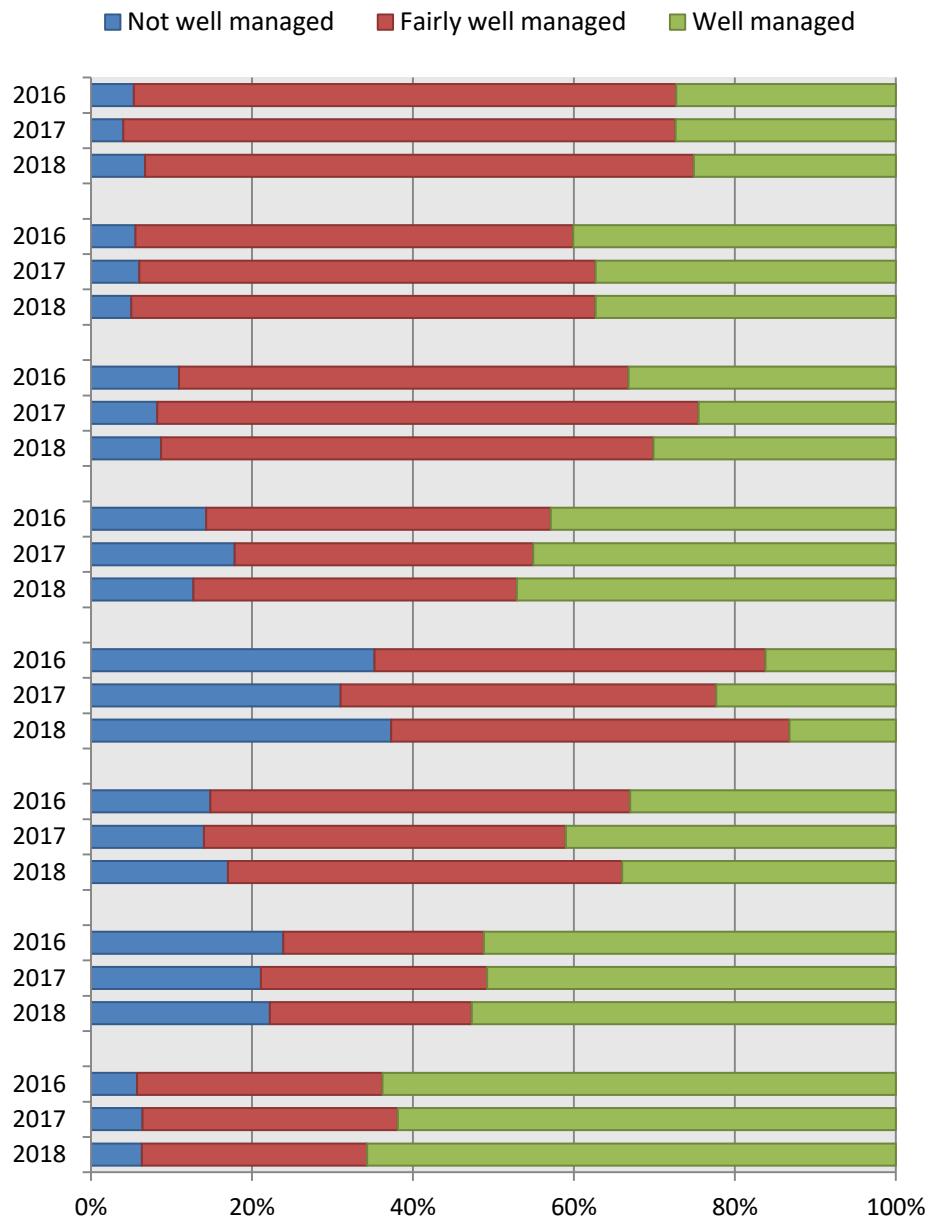


Figure 9: Responses to items 1 - 8 of the Pain Scale across the three study years

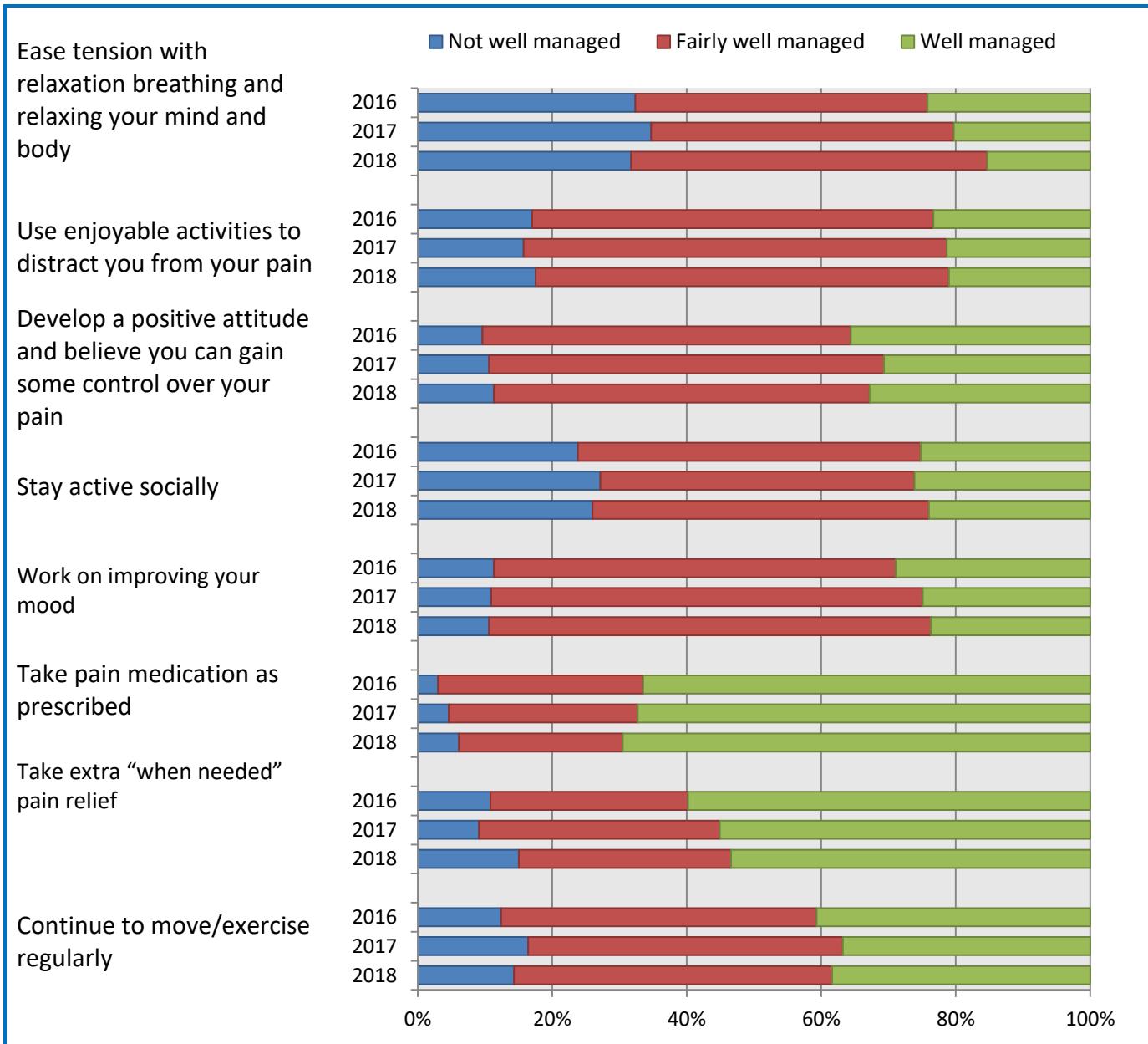


Figure 10: Responses to items 9 - 16 of the Pain Scale across the three study years

A Pain Management score was calculated based on summed scores for all participants who had answered at least 14 of the 16 questions. Mean scale scores were found to be very similar over the three years (2.23 at Y1, 2.20 at Y2 and 2.21 at Y3), however, mean scores do not capture the variation in individual participants' scores and correlations were calculated to see how closely they were related across the three years. Pearson's correlations were Y1 with Y2 ($r=.65$), Y2 with Y3 ($r=.71$) and Y1 with Y3 ($r=.66$) suggesting that although they were moderately to strongly correlated there was some change in scores within individuals during the study period. As an example, there were 43 people at Y1 with Pain Management scores of less than 2 and by Y3 15 of the 43 (34.8%) had scores of 2 or greater suggesting an improvement in managing the pain control strategies.

After completing the pain management behaviour questions participants were asked to provide an overall rating (0-10) of how well they felt they were managing their pain at home. Mean scores were 7.1 at both Y1 and Y2 and 6.6 at Y3. A paired samples t-test found this difference to be significant ($t=2.54$, $p=.012$) suggesting that perceptions of management of pain at home had decreased significantly over time. Correlations between the Pain Management scale and Pain Management at Home scores were $r=.51$ at Y1, $r=.44$ at Y2 and $r=.37$ at Y3. All correlations were highly significant ($p<.001$).

T-tests and ANOVAs were performed to see if there were any differences in scores on Pain Management and Pain Management at Home according to sex, ethnicity or age. No sex or Māori/non Māori differences were found. However with Pain Management at Home scores a trend for age was found across all three years such that participants aged 65 years and over scored higher than those aged under 65.¹⁶

Results of correlations between the pain scale and pain management at home with other study variables are provided in Table 7.

Table 7: Correlations between Pain Scale (PS) scores and pain management at home (PMH) scores and other study variables

	2016		2017		2018	
	PS	PMH	PS	PMH	PS	PMH
Overall health	.21	.32	.31	.40	.30	.26
Physical Health	.29	.43	.33	.44	.30	.37
Mental Health	.46	.38	.44	.45	.42	.45
Life satisfaction	.35	.30	.34	.41	.46	.49
Control over life	.39	.45	.38	.43	.41	.48
Effect of LTC on QoL	-.24	-.35	-.31	-.31	-.28	-.25
Healthy Behaviours	.43	.33	.45	.24	.38	.16
Average pain in last week	-.19	-.41	-.19	-.26	-.21	-.28

¹⁶ Y1 <65 (M=2.04) 65 - 74 (M=2.29), 75+(M=2.32); F=12.60, p<.001

Y2: < 65 (M=2.09), 65 - 74 (M=2.22), 75+ (M=2.31); F= 7.55, p=.001

Y3: < 65 (M=2.12), 65 - 74 (M=2.23), 75+ (M=2.29); F=3.36, p=.037

Almost all of these weak to moderate correlations were significant; the one exception is the weak relationship between healthy behaviours and mental health in 2018 (in italics in the table). In general, the strongest relationships are between the pain self-management behaviours and healthy behaviours as well as between mental health and both measures of pain management. The other apparent pattern is the stronger correlations between the three health variables (general, mental and physical) and the pain management variables in Y2 (2017) in comparison with the other years.

New pain questions

In 2018 (Y3) we added to the questions about pain as we had previously found it affected so many people. We asked about pain locations, the effect of pain on participants' lives and the health professionals they sought help from in managing it. This section is therefore based on the **full set** of those with pain who took part in Y3 (N=234, 63.2% of the full sample). The location of the pain they experience is presented in Table 8 (N=215). Note that the percentages add to more than 100 as most people indicated they had pain in more than one location. The number of sites ranged from 1 to 11 ($M=3.9$, mode=3).

Table 8: Location of chronic pain

Location	N (%)	Location	N (%)	Location	N (%)
Hip	95 (44.2)	Shoulders	98 (45.6)	Internal	28 (13.0)
Knee	113 (52.6)	Elbows	27 (12.6)	Head	24 (11.2)
Lower back	152 (70.7)	Wrists/hands	97 (45.1)	Neck	88 (40.9)
Upper back	39 (18.1)	Ankles/feet	83 (38.6)	Leg*	5 (2.3)

* Leg pain wasn't on the initial list but 5 people added it in. It is therefore likely to be an underrepresentation of pain in that location

To explore the times at which people experience pain we included the pain items from the Nottingham Health Profile¹⁷ which requires respondents to answer yes or no according to whether or not they have particular pain experiences. The results are presented in Figure 11.

¹⁷ Hunt, S. M., & McEwan, T. (1980). The development of a subjective health indicator. *Sociology of Health and Illness*, 2, 231-246.

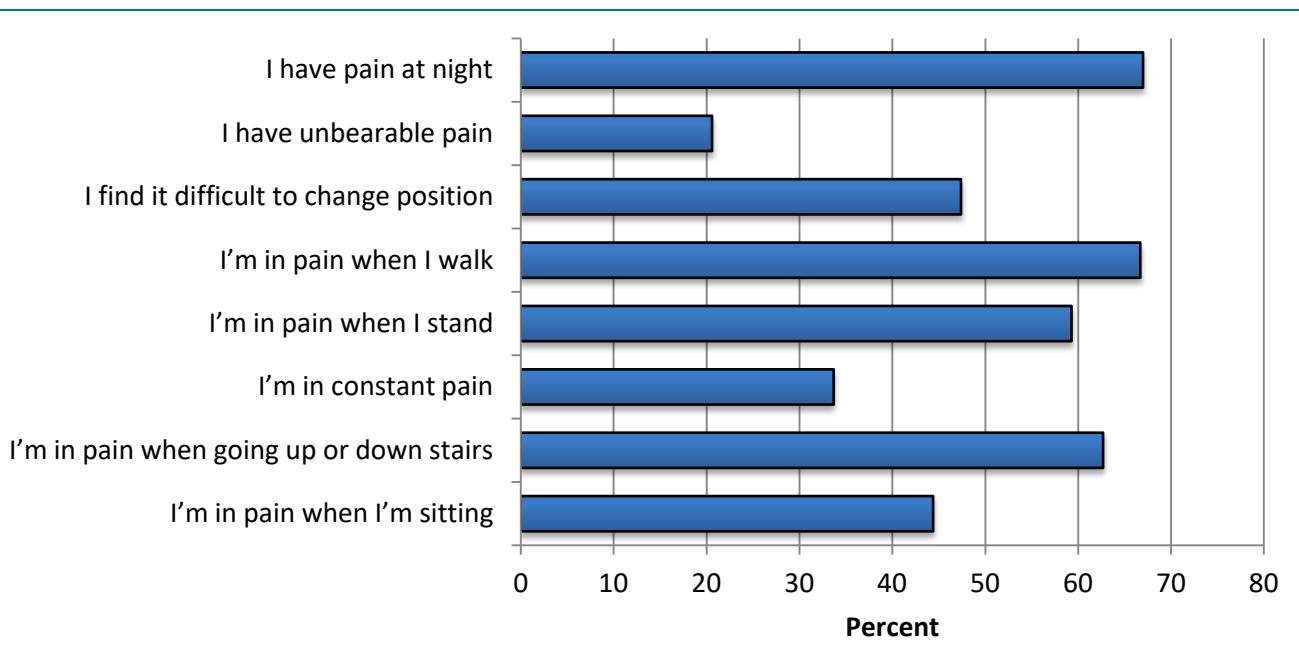


Figure 11: Percent of 'yes' responses to the Nottingham Health Profile pain questions

Pain is experienced most often at night, when walking and when going up and down stairs - all of which affect approximately two thirds of the pain participants. A third of this group said they experience constant pain and a fifth indicated that their pain was unbearable.

The results of the pain measurement can be calculated in two different ways, the first being a count of the number of items the participants responded positively to. This revealed that the range of scores was 0 to 8 out of a possible 8 and the mean score was 3.9. The scores are plotted in Figure 12.

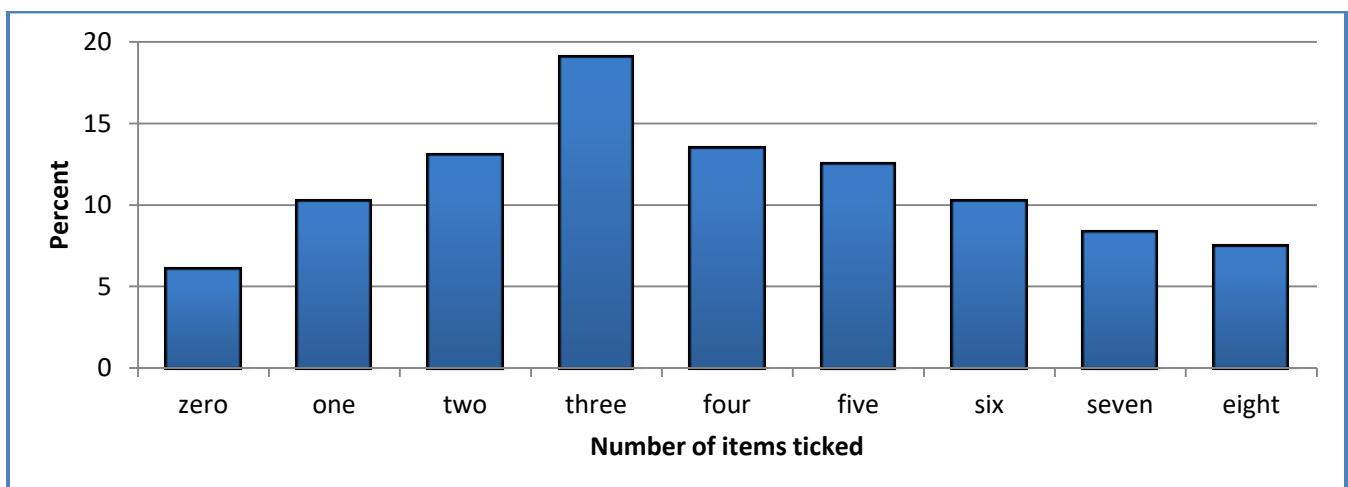


Figure 12: Number of pain questions receiving 'yes' responses

The second calculation involved assigning predetermined weights to the ‘yes’ responses and summing them to create a pain score where 0 represents good and 100 represents poor health. With our data this resulted in a set of scores ranging from 0 to 100 with a mean of 44.0 ($SD=28.4$). As a comparison, the scale developers conducted a validation study using four different respondent groups, one of which involved 59 people with at least one chronic illness. The average pain score for this group was around 30. Another study reported NHP pain scores collected from people with rheumatoid arthritis at two time points, the second being after a three month period of self-reported improved health. Average scores were 35.4 and 24.9 respectively. These comparisons suggest that the current sample was experiencing slightly higher levels of pain than had been measured previously. However within an earlier MDHB study of chronic illness care¹⁸ the mean score for 54 people living with chronic pain was 58.7 ($SD=31.7$).

The pain participants in Y3 were also asked to tell us which health professionals they had consulted about their pain during the last 12 months. Twenty participants (9.2%) indicated that they had not consulted any health professionals. The number of people consulted ranged from 0 to 9, the average being 1.8 (mode = 1). The individuals consulted N (%) were:

- | | |
|--------------------------|------------|
| • General Practitioner | 186 (85.7) |
| • Practice Nurse | 57 (26.3) |
| • Physiotherapist | 46 (21.2) |
| • CCN:LTC | 33 (15.2) |
| • Massage therapist | 13 (6.0) |
| • Chiropractor | 12 (5.5) |
| • Osteopath | 10 (4.6) |
| • Specialist pain doctor | 10 (4.6) |
| • Specialist pain nurse | 9 (4.1) |
| • Acupuncturist | 4 (1.8) |
| • Orthopaedic surgeon | 3 (1.4) |
| • Rheumatologist | 2 (0.9) |
| • Nurse Practitioner | 2 (0.9) |

Other clinicians mentioned by one participant each were: neurologist; Ora Kinetics clinic; podiatrist; urologist; Wellington Hospital; occupational therapist; hospital; kidney specialist; oncology; lymphoedema practitioner, orthotics and vocational therapist.

The final question asked about whether people had a plan, agreed with their doctor or nurse, to help them manage their ongoing pain. Seventy five (35.0%) said yes, 102 (47.7%) said no and 37 (17.3%) were unsure.

Discussion

With the exception of the 20% of people consulting physiotherapists, the small numbers of people seeing a practitioner outside of their general practice team suggests that pain is generally being managed within the

¹⁸ Carryer, J., Budge, C., Hansen, C., & Gibbs, K. (2010). Improving care for people with chronic illness. Round 2 report. MidCentral DHB.

practice rather than referrals to pain specialists being made. However since the start of the Talking about Health study the pain team at MidCentral has been restructured and is now only available to inpatients thus limiting the availability of specialists to refer to within the DHB. However, a project is currently underway to assess unmet pain needs. The MidCentral scenario reflects the national lack of pain specialists identified by the recent Sapere report¹⁹. Recommendations of the report include New Zealand learning from the Australian National Pain Strategy and its three key principles:

- “Knowledgeable, empowered consumers and carers: There is good evidence, from both within the pain area and outside it, that having consumers, carers, and other supporters armed with knowledge can reduce health care costs and the impact of illness. For example, there is solid evidence that the use of mass media to deliver health messages to the general community works as a preventative health strategy, and can be much more cost effective than strategies that focus on individual patients or health care professionals. The self-management approach encourages patients and their carers or other supporters to take an active part in the management of their conditions.
- Skilled professionals and evidence-based care: The following research and experience show that upskilling health professionals improves outcomes: – systematic reviews of randomised controlled trials, especially multidisciplinary approaches – evidence-based guidelines – recent experience with Medicare changes for psychological treatment of depression/anxiety.
- Multidisciplinary care at all levels: There is solid evidence of the benefits of multidisciplinary care from experience internationally and in Australia. Controlled trials show that integrated medical, physiotherapy, and psychological interventions using cognitive-behavioural methods can be more effective than usual care in limiting the impact of recent onset back pain, especially in selected cases where psychological and social risk factors are present. Multidisciplinary pain clinics are essential for dealing with more complex and chronic cases for a short period only. Then care should be returned to the local community level (and the individual patient) for maintenance” (pp. 24-25).

Link between pain, health and quality of life

Working with the three year comparison sample we compared the people who indicated they have pain to those who did not with respect to ratings of general health, quality of life, physical health and mental health. Figures 13 and 14 clearly demonstrate that people with pain experience a poorer health status according to all of these measures.

¹⁹ Moore, D., & Davies, P. (2018). The Problem of Chronic Pain and Scope for Improvements in Patient Outcomes. Sapere Research Group.

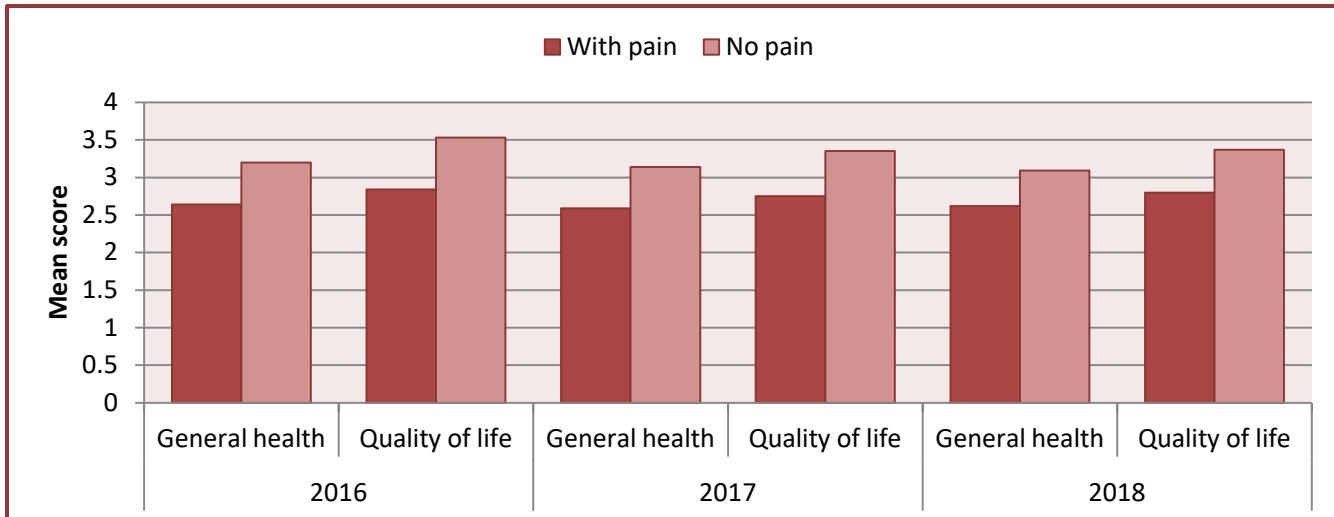


Figure 13: Mean general health and quality of life scores for participants with and without pain

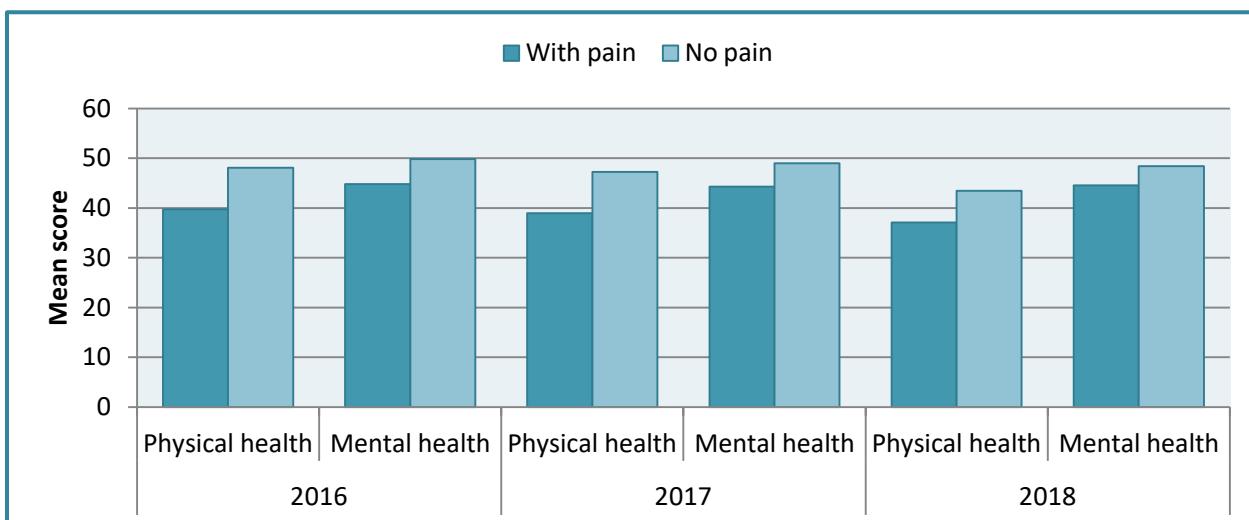


Figure 14: Mean physical and mental health scores for participants with and without pain

- Pain was the long term condition most commonly experienced
- Lower back pain was a problem for 71% of people with chronic pain
- Of the people with chronic pain, a third of the group said it was constant, and a fifth said it was unbearable
- Those with pain indicated they had poorer health and quality of life than those without pain
- People over 65 appear to engage better with self-management activities and rate their overall pain management more positively than younger age groups

Respiratory

The respiratory questions were answered by 116 people, 33.2% of the total sample. Two types of question were included, one related to self-management behaviours which were framed in the same way as the pain questions with three response options of 'not well managed', 'fairly well managed' and 'well managed'. The second set was mostly knowledge questions. The self-management behaviour questions and their response frequencies across the three years are provided in Figure 15 and the mean scores in Figure 16.

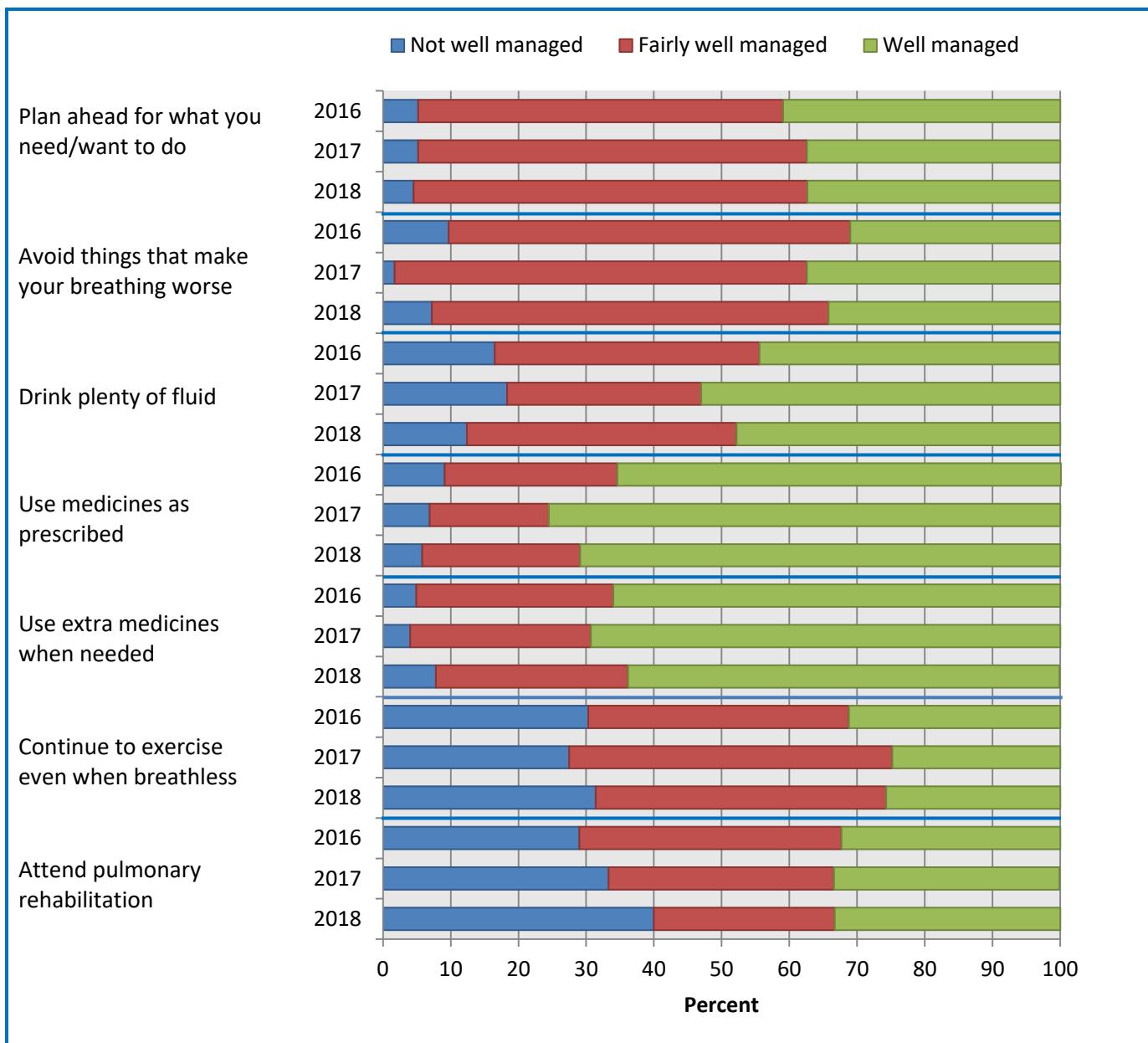


Figure 15: Participants ratings of how well they do with specific respiratory management behaviours across three years

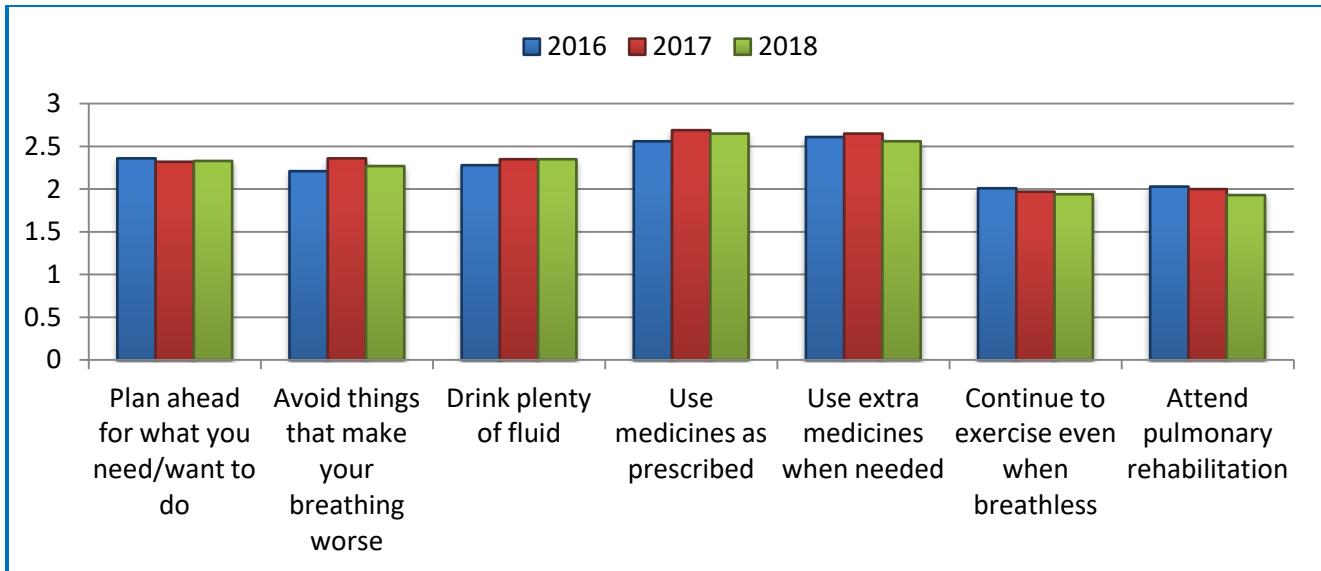


Figure 16: Mean scores for respiratory management questions across the three years

Firstly it is notable that there is a marked consistency across the study period. By looking at the mean scores and the percentages of people indicating they were managing well we can see that the respiratory management behaviours achieved best 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 (25 to 31% saying it was well managed) and attending pulmonary rehabilitation (33% of those it applied to saying it was well managed).

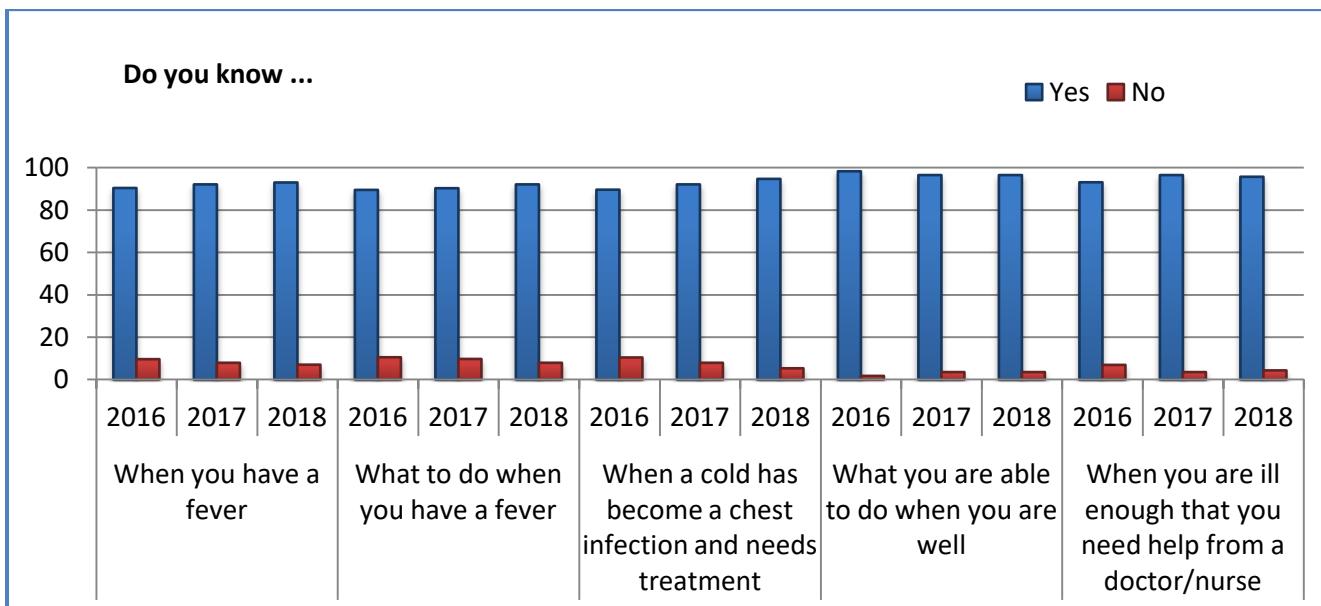


Figure 17: Participants ratings of their knowledge of specific respiratory management behaviours

Figure 17 presents the responses to the knowledge questions which were accompanied by ‘yes’ and ‘no’ response options. Self-reported knowledge related to respiratory concerns would appear to be high amongst this group of patients and to have marginally improved over the three years.

These 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 self-management scores (3-point scale) and the knowledge scores (2-point scale) were combined and averaged making the possible range of scores 1 to 5. Mean scores on the Respiratory Scale were 4.25 in Y1, 4.32 in Y2 and 4.30 in Y3, so again little change. Pearson’s correlations were Y1 with Y2 ($r=.50$), Y2 with Y3 ($r=.34$) and Y1 with Y3 ($r=.45$) suggesting that although they were moderately correlated there was change in scores within individuals during the study period.

Overall management of respiratory health at home was rated on an 11 point scale (from 0 - 10). Scores ranged from 4 to 10 in Y1, 2 to 10 in Y2 and 1 to 10 in Y3. Means were 7.7, 7.9 and 8.0 respectively.

T-tests and ANOVAs were run to see if there were any differences in scores on the Respiratory Scale and Respiratory Management at Home according to sex, ethnicity or age. No Māori/non Māori differences were found and only two sex and age differences were found. With respect to the Respiratory Scale score in 2016; participants aged 65 to 74 years performed better ($M=4.73$) than those who were younger ($M=4.09$) or older ($M=4.25$).²⁰ Regarding Respiratory Management at Home, women ($M=8.3$) scored higher than men ($M=7.49$) in Y1 only.²¹ Correlations with health and quality of life variables are provided in Table 9.

Table 9: Correlations between Respiratory Scale (RS) scores and Respiratory Management at Home (RMH) scores and other study variables						
	2016		2017		2018	
	RS	RMH	RS	RMH	RS	RMH
Overall health	.24	.35	.31	.39	.19	.31
Physical Health	.26	.34	.27	.29	.21	.37
Mental Health	.28	.36	.26	.33	.24	.40
Life satisfaction	.16	.27	.24	.28	.18	.34
Control over life	.26	.34	.31	.26	.18	.34
Effect of LTC on QoL	-.22	-.32	-.01	-.24	-.08	-.30
Healthy Behaviours	.42	.11	.37	.19	.25	.16

Most of these correlations are weak but significant, those in italics are not significant. The strongest correlations were found between Respiratory Scale scores and Healthy Behaviours in Y1 (2016) and between mental health

²⁰ Age difference $F=3.21$, $p=.044$.

²¹ Gender difference $t=2.76$, $p=.007$.

and Respiratory Management at Home in Y3 (2018). Overall, the ratings of Respiratory Management at Home were more strongly related to the health and the satisfaction, control and QoL variables than the Respiratory Scale scores. The exception is Healthy Behaviours where Respiratory Scale scores are more strongly associated. This suggests that what is being captured by the set of questions about self-management behaviours is not the same as what is being captured by the single item overall rating of management at home. This conclusion is supported by the correlations between the two measures Respiratory Scale and Respiratory Management at Home) which were $r=.49$ at Y1, $r=.54$ at Y2 and $r=.27$ at Y3.

Finally, the number of people with respiratory conditions who indicated they had a flu vaccination in the previous year remained fairly stable, 86.2% in Y1, 86.3% in Y2 and 84.3% in Y3.

- Flu vaccinations are an important aspect of managing respiratory conditions and ideally all people should be having annual vaccinations.

Angina

A series of self-management behaviours to assist with angina were presented to the 45 (12.9%) individuals who reported having it. These took the form of statements with 'yes', 'sometimes' and 'no' response options. If a specific cause of angina was indicated, a second question explored the patient's response to that trigger and the responses are based on these people only. For example if they identified exercise as causing angina they continued to answer a question about whether they attempted to manage their exercise. The percentage of respondents responding 'yes' or 'sometimes' to each of the behavioural questions and 'yes' to the knowledge questions is graphed in Figure 18.

The results suggest that there has been little change over the three years. However slightly more people are saying that they understand what causes their angina as time has gone on. Similarly a few more indicated that exercise is a trigger for their angina over the study period but self-management has increased in line with this change. The strongest self-management behaviour is stopping exercise if angina occurs, all of the affected individuals saying they do. Emotional stress appears to have become less of a trigger.

By 2018 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 and self-reported knowledge levels appear to have improved slightly.

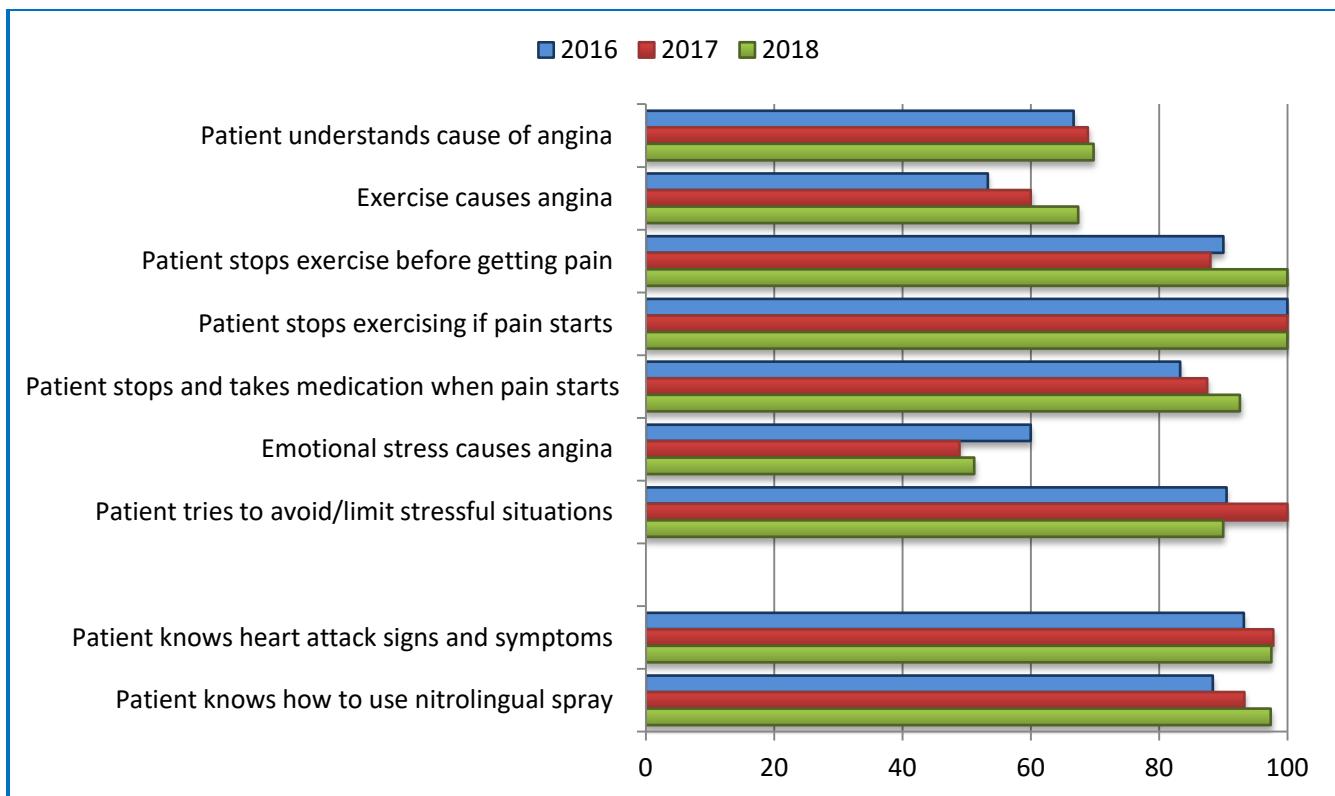


Figure 18: Positive responses to angina self-management and knowledge questions

Ratings of how well they manage their angina at home were again measured using a 0-10 point scale. Angina Management at Home scores ranged from 4 to 10 in Ys1 and 2, and 5 to 10 in Y3. Mean scores were 8.2, 8.4 and 8.1 for each year respectively. Slight differences in Angina Management at Home were found for men and women in Y1 and Y3 with women indicating they managed better, but only at Y3 was the difference statistically significant.²² No Māori/non Māori differences were found but only three of the people with angina were Māori. Correlations with other study variables are presented in Table 10.

²² Female mean = 8.6, male mean = 7.7 ($t=-2.07$, $p=.046$)

Table 10: Correlations between Angina Management at Home (AMH) scores and other study variables

	Angina Management at Home		
	2016	2017	2018
Overall health	.34	.24	.34
Physical Health	.35	.21	.43
Mental Health	.48	.37	.44
Life satisfaction	.21	.13	.10
Control over life	.07	.25	.49
Effect of LTC on QoL	-.03	-.03	-.14
Healthy Behaviours	.16	.07	.26

Fewer of the correlations between Angina Management at Home and the other study variables are significant than were found for pain and respiratory. However this is partly due to the much smaller number of people with angina than with the previous two conditions covered.

The magnitude of the correlations is generally lower though, suggesting that they are weaker associations. Overall, Angina Management at Home scores were moderately correlated with Mental Health scores in all three years as well as with Physical Health in Ys 1 and 3 and Control over Life in Y3.

- Although there was some improvement, 30% of people with angina still said they didn't understand what caused it
- People's knowledge of how to use their Nitrolingual spray and the signs and symptoms of a heart attack improved over the study period

Heart failure

Thirty five (10%) patients indicated that they had heart failure at Y1 and this number had increased to 39 by Y3. Responses to five questions regarding frequency of specific self-management behaviours are provided in Figure 19.

The bar graph again shows a fairly strong degree of consistency across the years but with a slight decrease in the number of people with heart failure carrying out recommended self-management behaviours on a daily basis (pink sections). The behaviour carried out by almost everyone was taking their prescribed medications every day, although even this decreased over the three years. However there was a considerable range in response to how often other, potentially helpful, self-management behaviours were performed. For example, of the people who had been advised to limit their fluid intake less than 60% 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 about 40 percent of this group, but several indicated they never weigh themselves at home.

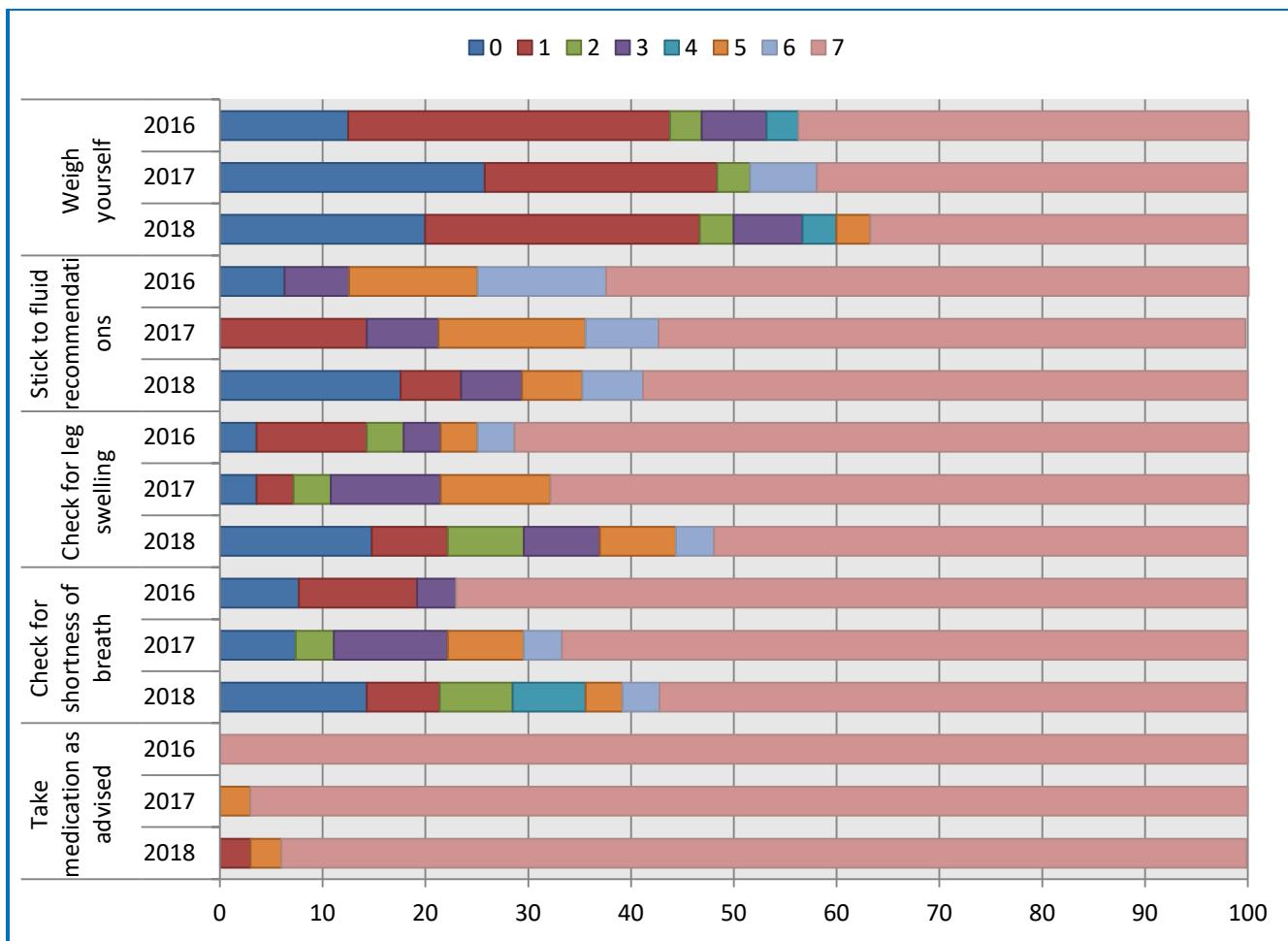


Figure 19: Number of days per week people with heart failure engage in relevant self-management behaviours

Overall Heart Failure Management at Home (0-10 scale) was rated on average as 8.3 in Y1 (range 5-10), 7.7 in Y2 (range 6-10) and 8.4 in Y3 (range 5-10). No difference was found according to sex or ethnicity. Correlations with health and quality of life variables appear in Table 11.

Table 11: Correlations between heart failure management at home scores and other study variables

	Heart failure management at home		
	2016	2017	2018
Overall health	.33	.17	.32
Physical Health	.33	.34	.31
Mental Health	.41	.31	.29
Life satisfaction	.18	.02	.01
Control over life	.30	.40	.11
Effect of LTC on QOL	-.10	-.25	-.05
Healthy Behaviours	.40	.19	.31

Again the small number of people with heart failure will have affected the significance of the correlations found but overall there are few moderate strength correlations between Angina Management at Home and the other variables. The strongest associations were found with Mental Health and Healthy Behaviours in Y1, and with Control over Life in Y2. Looking at the pairs of variables over time it seems that the link between Angina Management at Home and Mental Health is most consistently the strongest.

- Self management behaviours to manage heart failure were at odds with their overall rating of managing their condition at home. Over the study period, self management behaviours that were expected to be done daily decreased rather than increased.

Diabetes

163 participants (46.7%) indicated they had diabetes, the majority having type 2 (94.7%). Responses to diabetes self-management questions are provided in Table 12. Note that the percentage responses to question about blood glucose levels (BGLs) are calculated using the number of testers as the denominator rather than the total number of people with diabetes. The same logic applies to questions about use of tablets and insulin.

Table 12: Diabetes knowledge and self management behaviour expressed as frequency of positive responses

Behaviour	'Yes' percent			Knowledge	'Yes' percent		
	2016	2017	2018		2016	2017	2018
Test own blood glucose levels	74.5	71.4	72.6	Know target BGLs if self test	86.0	91.5	89.9
Keep a record of BGLs if self test	80.2	74.1	74.3	Know target HbA1c	47.9	49.3	57.9
Take record of BGLs to health appointments	72.4	71.7	76.7	Understand what BGLs mean	79.3	93.2	84.2
Check feet regularly	66.9	72.8	72.8	Know when to seek help based on BGLs	87.3	87.8	87.9
Take tablets as advised	95.8	95.1	92.2	Understand how tablets work	81.2	76.4	81.5
Use insulin as advised	86.8	93.0	97.3				
Adjust own insulin doses	48.4	53.6	45.9				
Think about BGLs when adjusting insulin	83.3	91.9	96.9				
Think about activity when adjusting insulin	55.2	73.0	57.6				
Think about carbohydrate intake when adjusting insulin	50.0	64.9	60.6				

These results suggest there has been a marginal decrease in numbers of people who test their own blood glucose levels at home and in the numbers of people keeping a record of the levels if they do test. However a slight increase has occurred in numbers taking their records to appointments with practitioners.

The frequency with which the people who test their own BGLs do so (Figure 20) is quite varied, with the largest subset (36% in Y1 to 41% Y3) testing 2-4 times per day. Over the three years, the number testing at least twice a day has risen from 42.7% in Y1 through 50.5% in Y2 to 54.9% in Y3.

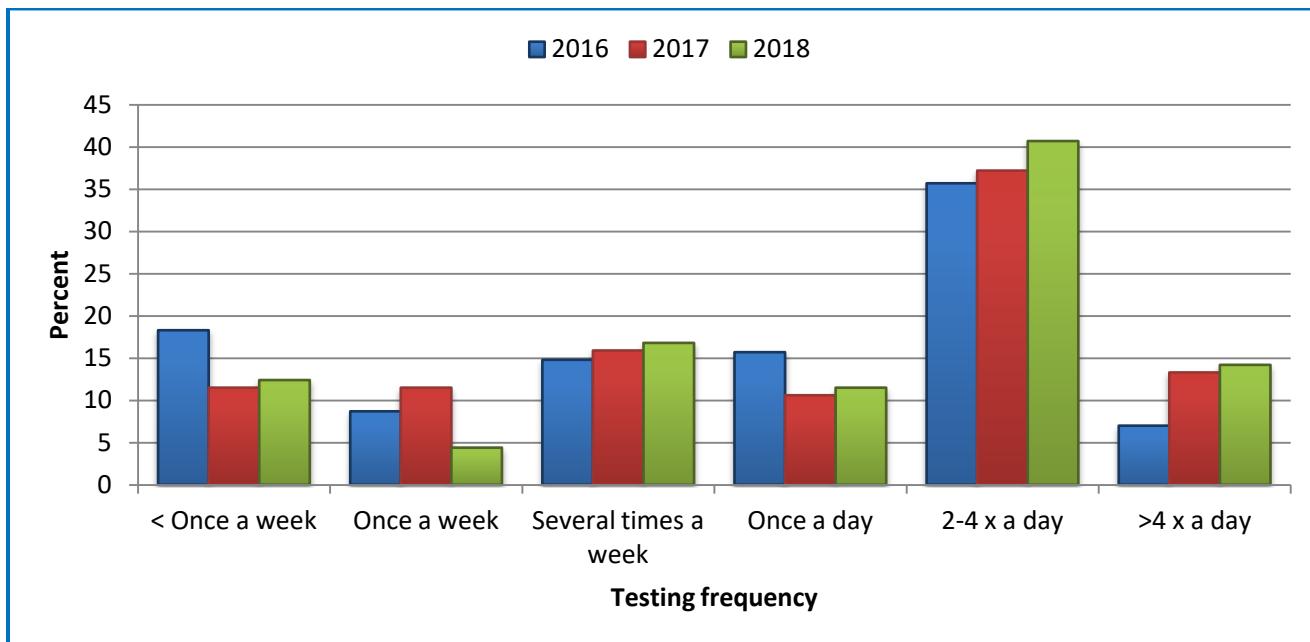


Figure 20: Frequency of blood glucose testing

Most of those who test their BGLs indicated that they know what their target levels are. However while the number of people knowing what HbA1c they are heading for has increased over the three years, it is still only just over half. This highlights a possible health literacy issue. The number of people who take tablets saying they take them as advised has decreased slightly and the number of people who use insulin saying that they use it as advised has increased slightly. Although there has been a little change in the number of people who titrate their own insulin doses, it increased and then decreased so the Y1 and Y3 data are similar. However of those who do their own titration, there has been a slight increase in the number of factors considered when making decisions about dose adjustments. The mean numbers of factors individuals take into consideration has changed from 1.8 (Y1) to 2.2 (Y3). The number or people considering all three increased from 40.0% in Y1 to 48.5% in Y3.

The number of people regularly checking their feet has marginally improved with close to three quarters of this group saying they do so in Y3. However it is recommended that all people with diabetes check their feet on a

daily basis²³. Diabetes Management at Home was recorded on the same 11-point scale used for the other conditions. Scores ranged from 0 to 10 ($M=7.6$) in Y1, from 2 to 10 ($M=7.5$) in Y2 and from 0 to 10 ($M=7.6$) in Y3. Correlations with the same set of health and quality of life variables as was used with the other conditions are presented in Table 13.

Table 13: Correlations between diabetes management at home scores and other study variables

	Diabetes management at home		
	2016	2017	2018
Overall health	.18	.29	.25
Physical Health	.21	.27	.18
Mental Health	.19	.37	.27
Life satisfaction	.26	.34	.25
Control over life	.19	.46	.40
Effect of LTC on QoL	<i>-.09</i>	<i>-.18</i>	<i>-.06</i>
Healthy Behaviours	.42	.30	.23

The number of significant correlations relates to the larger sample size. The magnitude of the correlations suggests that most are relatively weak. However moderate strength correlations are evident between diabetes Management at Home and Healthy Behaviours in Y1, and Control over Life in Ys 2 and 3. Only two were not significant, those in italics in the table.

No differences in self-management ratings were found for the different sexes or ethnicities in any of the three years.

- Less than 60% of people with diabetes reported knowing what their target HbA1c was
- Over the study period, there was an improvement in people who titrate their own insulin using their knowledge to consider multiple factors prior to administering their insulin dose

Patient Activation

Patient activation is described by Hibbard and colleagues²⁴ 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.

²³ http://www.diabetes.org.nz/about_diabetes/complications_of_diabetes/feet

²⁴ Hibbard, J. H., Mahoney, E. R, Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the Patient Activation Measure'. *Health Services Research*, 40(6), 1918–1930.

According to Hibbard and Cunningham²⁵, 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
- 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.

Hibbard and colleagues developed a measure of patient activation known as the Patient Activation Measure®. It consists of a set of 13 statements and respondents are asked to indicate their level of agreement with each using a four point scale ranging from 'disagree strongly' to 'agree strongly' scored as 1 to 4. A not applicable option is also included. Scores are calculated for all respondents who answer at least 10 of the 13 questions using a spreadsheet provided by the licensing authority (Insignia Health LLC). This produces scores ranging, theoretically, from 0 to 100, with most falling between 39 and 95²⁶.

Scores are divided into four levels of activation which describe the progression as follows:

- 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 PAM® scores and levels for the three years of the Talking about Health study are presented in Table 14.

²⁵ Hibbard JH, Cunningham PJ (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.

²⁶ Greene J, Hibbard JH (2011). 'Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes'. *J Gen Intern Med* 27(5):520–6.

Table 14: Number and percent of participants at each level of patient activation

	2016		2017		2018	
	Mean PAM score	N (%)	Mean PAM score	N (%)	Mean PAM score	N (%)
Level 1:	43.4	41 (12.1)	43.8	46 (13.4)	43.1	46 (13.6)
Level 2:	51.2	50 (14.8)	51.2	53 (15.4)	51.5	56 (16.6)
Level 3:	61.0	159 (47.0)	60.2	142 (41.3)	60.2	157 (46.4)
Level 4:	85.1	88 (26.0)	83.9	103 (29.9)	84.7	79 (23.4)
Total	63.7	338	63.7	344	62.3	338

Looking at the percentage of people at each of the four PAM levels, these results look reasonably stable across the three years. However correlations between the PAM scores across the years tell a different story. The correlation between scores at Y1 and Y2 was only .29 and between Y2 and Y3 was .34. The correlation between scores at Y1 and Y3 was slightly stronger ($r=.54$). Closer examination revealed that only 11 people remained at Level 1 throughout the study, 6 remained at Level 2; 53 remained at Level 3 and 40 at Level 4. Overall when differences from Y1 to Y3 were calculated it was found that 52.6% stayed at the same level, 27.3% dropped in level and 20.1% rose in level. Chi-square tests found that these changes were not associated with the sex or ethnicity of the participants.

In 2016, a pattern of means was found such that scores on a range of health and general practice interaction variables increased as level of patient activation increased. Despite the movement between levels described above, this pattern remained within the 2017 and 2018 data. The mean scores are presented in Appendix B.

Patient Activation level and self-management at home

Participants' ratings of how well they are managing their conditions at home were compared across the three years according to their level of Patient Activation. Three conditions for which there were sufficient numbers to draw comparisons were selected, and the pattern of mean scores for these (diabetes, pain and respiratory) are presented in Figures 21 to 23.

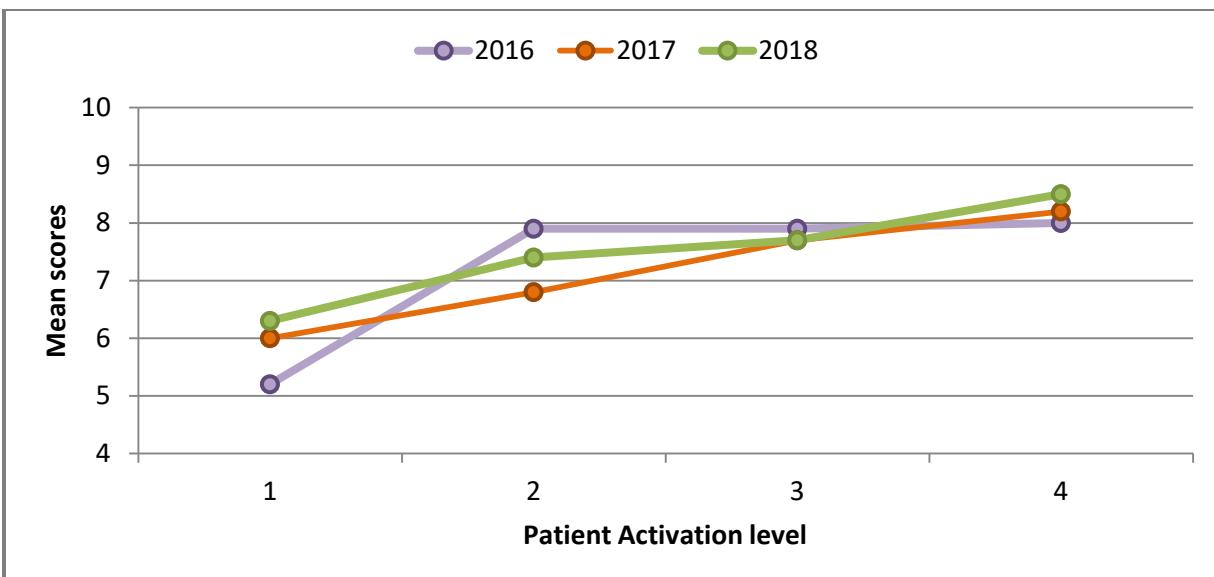


Figure 21: Diabetes self-management at home according to PAM level

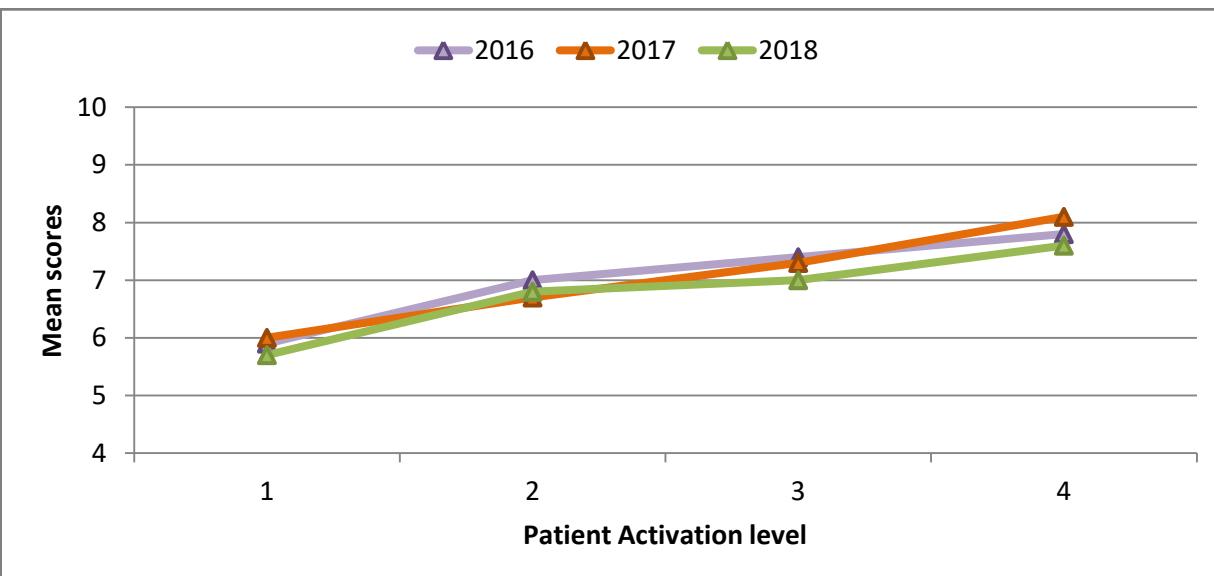


Figure 22: Pain self-management at home according to PAM level

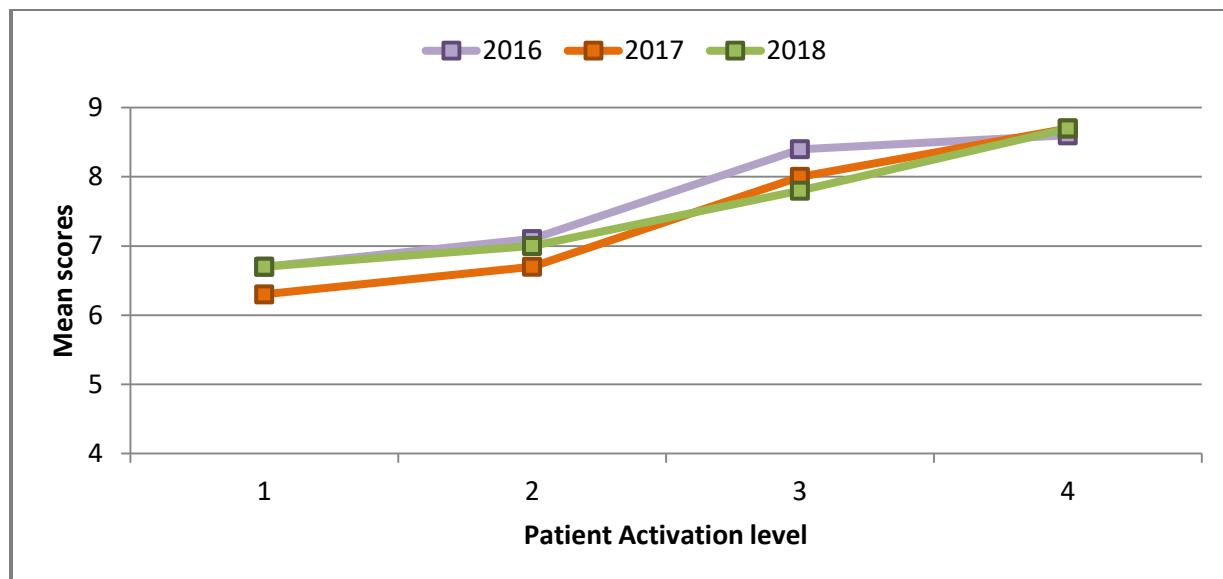


Figure 23: Respiratory self-management at home according to PAM level

Patient Activation and demographics

Patient activation scores have not generally been found to vary according to demographic characteristics such as age, sex, education or income. In the current study independent samples t-tests found no difference in mean PAM scores according to sex or ethnicity. However ANOVAs found income adequacy to be related at Y2 and Y3 such that more income was associated with higher scores (Y2 $F=2.8$, $p=.040$; Y3 $F=9.4$, $p<.001$) and education at Y3 ($F=3.0$, $p=.029$), those with higher educational achievement levels having higher activation scores on average.

- Although the number of people at the different levels of activation remained about the same, there was individual movement between the four levels
- Higher levels of activation are significantly associated with: higher ratings of condition management; better general, mental and physical health; more positive ratings of general practice interactions and support from the GPT; higher ratings of life satisfaction and control over life; and, less effect of LTCs on quality of life.

General self-efficacy

In 2018 we introduced a short set of questions to measure self-efficacy as it was thought that this general trait might help to explain self-management of health conditions and might also be related to health activation. The construct of self-efficacy “refers to the belief that a person is able to control challenging environmental demands by taking adaptive action” (Romppell et al., 2013, p. 4). Although self-efficacy may be explored within a

particular domain or aspect of life, it can also be thought of more generally as representing a broader and more stable confidence in your own ability to deal with demanding situations.²⁷

The General Self-Efficacy short form was selected (GSE-6)²⁸ consisting of 6 items from the General Self-Efficacy (GSE) Scale developed by Schwarzer and Jerusalem. Each of the six items takes the form of a statement and respondents are asked to indicate how true each statement is for them. Response options are: 'not at all true' (coded as 1); 'hardly true' (2); 'moderately true' (3); and 'exactly true' (4). Scores are summed to make a total GSE score ranging from 6 to 24. The range was 6 to 24 for the full set of Talking about Health participants, with a mean score of 17.3. Independent t-tests and ANOVAs were run to look for demographic relationships with self-efficacy. No sex, ethnicity, age or education differences were found. The ANOVA for self-efficacy and income adequacy was significant overall ($F=4.37$, $p=.005$) and post hoc comparisons found the difference to be between those with just enough income to meet their daily needs ($M=16.7$) and those with more than enough income ($M=18.6$).

Correlations between self-efficacy and other study variables at Y3 are provided in Table 15.

Table 15: Pearson's correlations between General Self-Efficacy and health, patient activation, GPT interaction and self-management scores			
Measure (N)	Correlation (p value)	Measure (N)	Correlation (p value)
General health (345)	.31 (<.001)	Diabetes mgmt @ home (161)	.33 (<.001)
Physical health (335)	.36 (<.001)	Pain mgmt @ home (199)	.39 (<.001)
Mental health (335)	.44 (<.001)	Respiratory mgmt @ home (116)	.29 (.003)
Patient activation (341)	.46 (<.001)	Angina mgmt @ home (40)	.37 (.020)
GP Interactions (337)	.19 (.001)	Heart failure mgmt @ home (36)	.28 (.101)
Nurse Interactions (319)	.17 (.003)	CKD mgmt @ home (14)	-.03 (.918)
GPT support (340)	.21 (<.001)	Kidney failure mgmt @ home (4)	.59 (.412)

While most of these correlations are significant, some due to the relatively large sample size, the strongest are moderate correlations with kidney failure management at home, patient activation and mental health. The weakest correlations are with CKD management at home and with the three productive interaction variables (see the next section).

²⁷ Schwarzer R, Jerusalem M. Generalized Self-Efficacy scale. In: Weinman J, Wright S, Johnston M, editors. Measures in health psychology: A user's portfolio. Causal and control beliefs. Windsor, UK: NFER-NELSON; 1995. p. 35-7.

²⁸ Romppel, M., Herrmann-Lingen, C., Wachter, R., et al. (2013). A short form of the General Self-Efficacy Scale (GSE-6): Development, psychometric properties and validity in an intercultural non-clinical sample and a sample of patients at risk for heart failure. *GMS Psycho_Social_Medicine*, 10, ISSN 1860-5214.

Interactions with General Practice

Participants were asked which members of their general practice team (GPT) they had consulted during the previous year. In all years the most common combination of practitioners seen during the previous 12 months was GP and practice nurse, accounting for 41% (Y3) to 46% (Y2) of participants. The results by sex and ethnicity across the three years are presented in Figures 24 to 26 and in Appendix C.

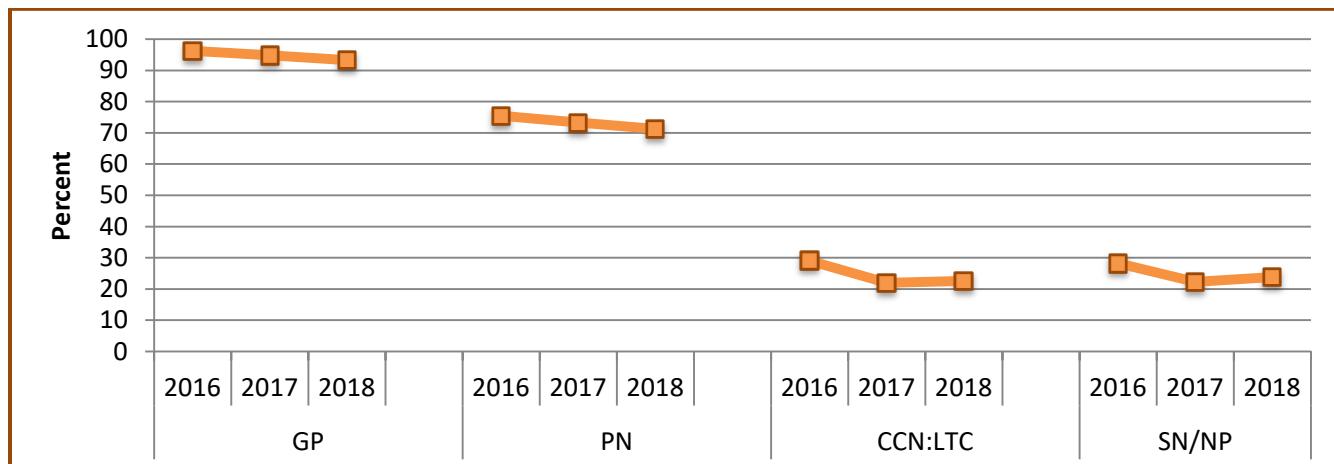


Figure 24: Numbers of general practice team members seen by year

The overall results show that GPs are seen by nearly all of the patients, and practice nurses are seen by around three quarters. Between 20 and 30% have seen CCN:LTCs and specialist nurses (SN) or Nurse Practitioners (NP). For all practitioners, the number of people seeing them during the previous 12 months appears to have decreased slightly.

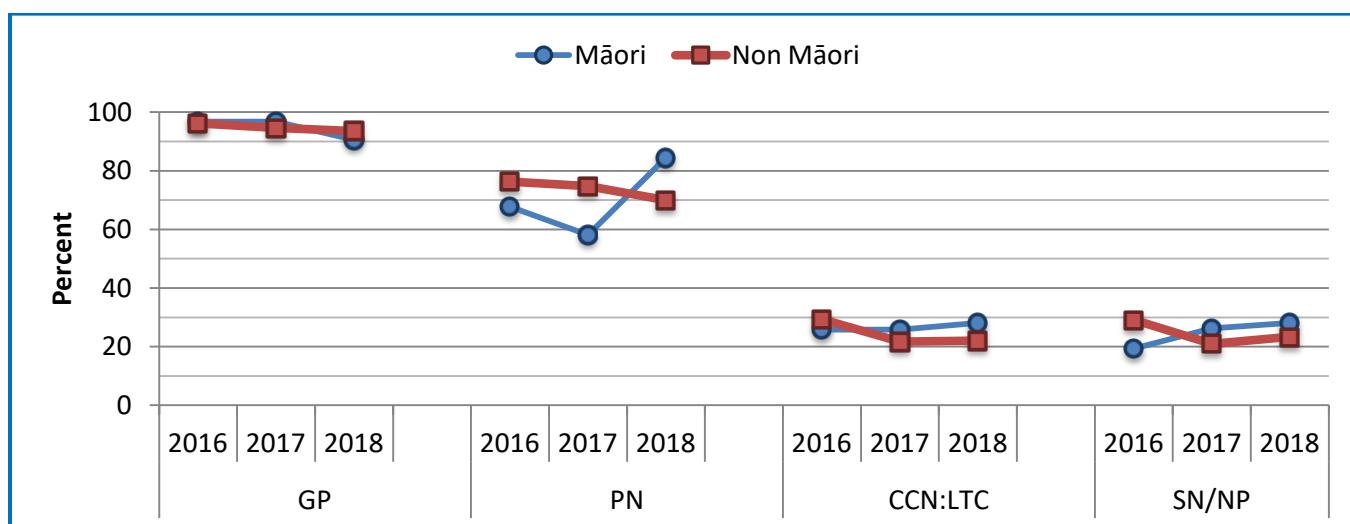


Figure 25: Number of practitioners seen by year for Māori and non Māori

Comparing Māori with non Māori reveals that the number of Māori participants consulting practice nurses has notably increased over the study period. The number seeing CCNs and specialist nurses or Nurse Practitioners has also increased but less dramatically.

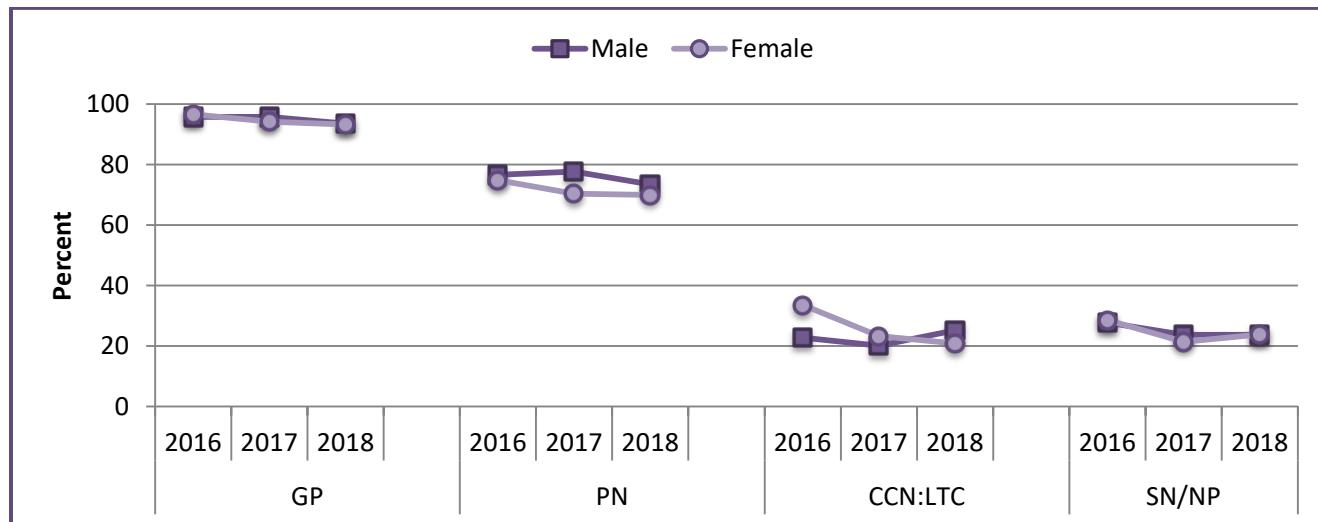


Figure 26: Number of practitioners seen by year for men and women

The main difference between GPT consultations for men and women appears to be the decrease in appointments with CCN:LTCs for women from Y1 to Y3.

Main source of support

The number of people selecting their GP, practice nurse, both GP and PN or home as the greatest source of support for managing their LTCs is presented in Figure 27. The remainder (Y1 5.6%, Y2 5.6% and Y3 9.6%) mentioned other sources such as the hospital, specialists or a combination of more than one other source. The number selecting their practice nurse as the main source of support (18%) has increased from the very few (3.0%) who were chosen as the ‘main health professional’ in the 2007 “Improving Care for People with Chronic Illness” study carried out in the region.

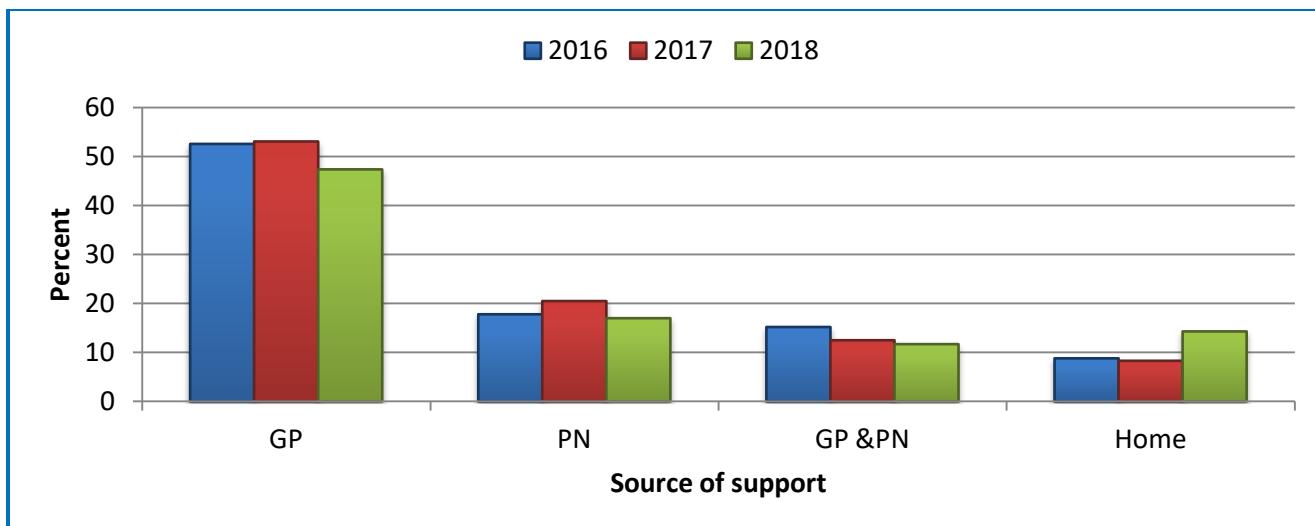


Figure 27: Main sources of support for managing long term conditions across the three years

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).

General Practitioners

The mean ratings of interactions with GPs (based on the 1 to 6 ratings) across the three years are presented in Table 16. The lowest three scores each year are presented in blue font and the highest in red.

There is reasonable consistency across the three years, with learning about social support needs and knowing patients as people rated the lowest in all three years and comfort around physical examinations rated high in all three years. It is clear though that there is not a lot of difference in mean scores for each of these different aspects of the consultation.

Table 16: Mean ratings of interactions with GPs across the three years

When you see the doctor at your General Practice, how good are they at ...	2016	2017	2018
Introducing themselves and asking you to introduce yourself	4.8	4.8	4.8
Asking fully about your symptoms and how you are feeling	4.7	4.7	4.8
Listening to what you have to say	4.8	4.8	4.8
Making you feel comfortable about your physical examination	4.9	4.9	4.9
Involving you in decisions about your care	4.7	4.8	4.8
Involving family/whānau/fanau in decisions about your care	4.5	4.5	4.8
Explaining your problems or any treatment you need in a way you can understand	4.8	4.8	4.9
Spending enough time with you	4.5	4.5	4.6
Being patient with your questions or worries	4.7	4.7	4.8
Checking that you understand what is being talked about	4.6	4.6	4.7
Building a trusting relationship with you	4.7	4.8	4.8
Learning about and helping with your social support needs	4.2	4.2	4.2
Knowing about your medical history and current treatment	4.9	4.9	4.8
Knowing about you as a person not just a patient	4.4	4.5	4.5

A scale was formed by summing the item scores. If participants had answered 12 or more of the 14 questions they were included, if not they were discarded from the calculation. The scale was called GP Interaction and mean scores ranged from 1.4 to 6 in Y1, 1.2 to 6 in Y2 and 1.7 to 6 in Y3. The overall mean across all years was 4.7. Independent t-tests demonstrated that total GP Interaction scores did not differ according to sex or ethnicity.

Nurses

The same ratings were carried out with respect to consultations with practice nurses and the results appear in Table 17. Again, the lowest three scores each year are presented in blue font and the highest in red.

Table 17: Mean ratings of interactions with nurses across the three years

When you see the nurse at your General Practice, how good are they at ...	2016	2017	2018
Introducing themselves and asking you to introduce yourself	4.8	4.9	4.9
Asking fully about your symptoms and how you are feeling	4.8	4.9	4.9
Listening to what you have to say	4.9	4.9	4.9
Making you feel comfortable about your physical examination	4.9	5.0	5.0
Involving you in decisions about your care	4.8	4.8	4.8
Involving family/whānau/fanau in decisions about your care	4.5	4.6	4.8
Explaining your problems or any treatment you need in a way you can understand	4.8	4.9	4.9
Spending enough time with you	4.8	4.8	4.8
Being patient with your questions or worries	4.8	4.9	4.9
Checking that you understand what is being talked about	4.8	4.8	4.8
Building a trusting relationship with you	4.7	4.8	4.8
Learning about and helping with your social support needs	4.3	4.5	4.4
Knowing about your medical history and current treatment	4.6	4.7	4.7
Knowing about you as a person not just a patient	4.4	4.5	4.5

As with the ratings of GPs there is a consistent pattern across the three years with learning about and helping with social support needs and knowing people as people and not just as patients scoring lowest and listening and making people feel comfortable with physical exams scoring highest. The range in mean scores is again relatively limited. These scores were combined, allowing two to be missing as before, to make a Nurse Interaction score. These ranged from 1.0 to 6 in Y1, 1.5 to 6 in Y2 and 1.0 to 6 in Y3. Mean scores were 4.7 in Y1 and 4.8 in Y2 and Y3. Again they did not differ according to sex or ethnicity.

The range of mean GP Interaction and Nurse Interaction scores was divided into three groups, those less than 4 out of 6, those in the 4 range and those of 5 or more. Results across the study period for GPs and nurses appear in Figure 28.

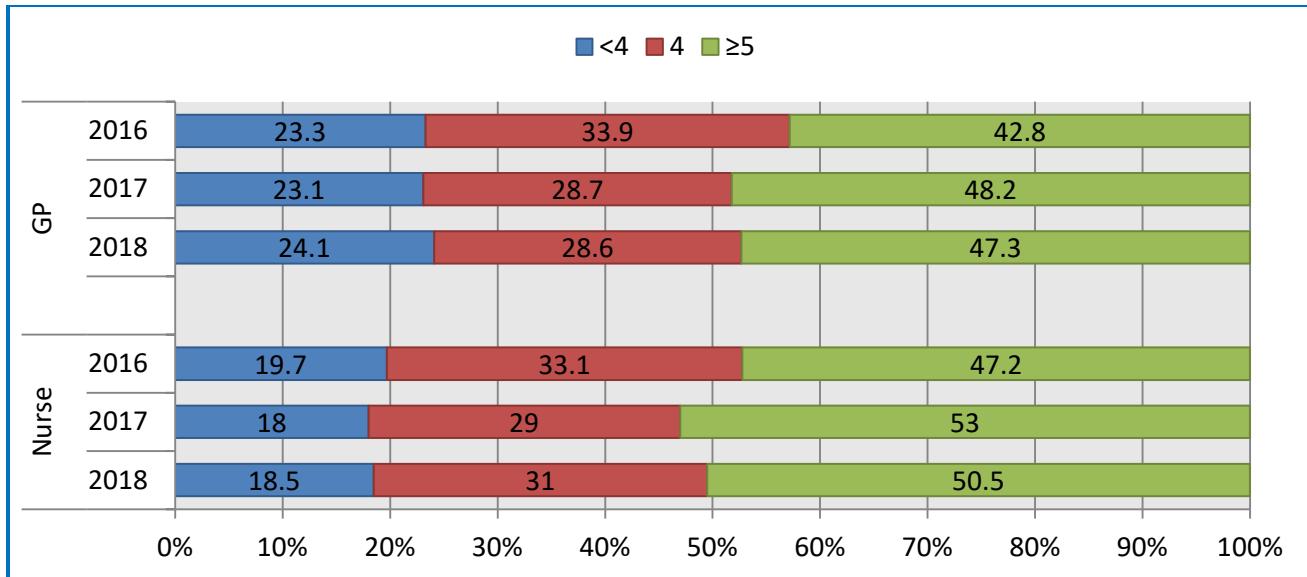


Figure 28: Mean GP and Nurse Interaction scores for the three years

These data suggest that nearly half the sample were rating their interactions with General Practitioners as very good to excellent on average, and around half were similarly rating nurses at the general practices. This number has risen slightly from Y1 to Y3. However, a quarter of the respondents rated their interactions with their GP, and close to a fifth rated their interactions with nurses, as less than good. This number has risen marginally for GPs and dropped marginally for nurses.

An overall rating of support from the general practice team was provided using a 0 - 10 scale and means were 7.9 in Y1, 8.0 in Y2 and 7.9 in Y3. Scores were divided into groups and frequencies are graphed in Figure 29.

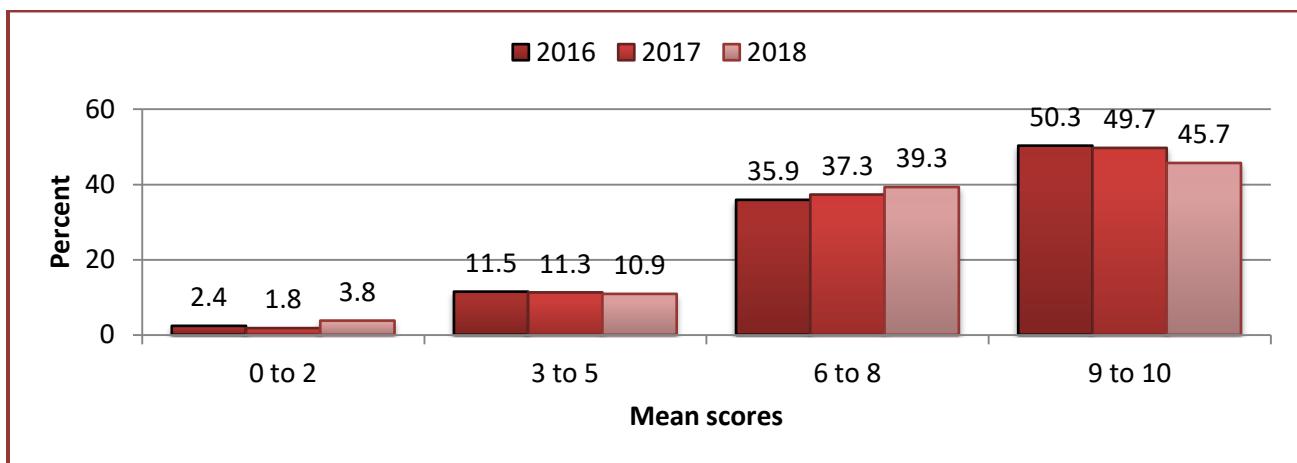


Figure 29: Mean scores of overall support from the general practice team for long term conditions

The pattern is reasonably consistent again, the only differences being a slight increase in the number of scores between 6 and 8 with a concomitant decrease in scores of 9 to 10.

A comparison of mean overall support scores across different demographic groups is provided in Table 18.

Table 18: Mean general practice team (GPT) support scores according to demographic characteristics				
		2016	2017	2018
Sex	Male	8.1	8.2	8.2
	Female	7.8	7.9	7.6
	<i>t-test result</i>	<i>ns</i>	<i>ns</i>	<i>t=2.19, p=.03</i>
Ethnicity	Māori	7.8	7.8	7.9
	Non Māori	7.9	8.0	7.3
	<i>t-test result</i>	<i>ns*</i>	<i>ns</i>	<i>ns</i>
Education	No school	8.1	8.3	8.3
	School	7.3	7.6	7.8
	Post school	8.1	8.0	8.1
	University	7.5	7.4	7.4
	<i>ANOVA result</i>	<i>F=3.16, p=.025</i>	<i>F=3.11, p=.027</i>	<i>F=3.24, p=.023</i>
Age	<65	7.1	7.7	7.6
	65-74	8.0	7.9	7.6
	75+	8.5	8.3	8.1
	<i>ANOVA result</i>	<i>F=14.42, p<.001</i>	<i>ns</i>	<i>ns</i>
Income adequacy	Not enough	7.5	7.4	7.0
	Just enough	7.8	7.7	7.7
	Enough	8.1	8.4	8.1
	More than enough	8.4	8.6	8.5
	<i>ANOVA result</i>	<i>ns</i>	<i>F=5.00, p=.002</i>	<i>F=4.87, p=.002</i>

*ns= not significant

Here it can be seen that there were no ethnicity differences but with respect to sex, men rated their support from GPTs higher than women and this difference was significant in Y3. On average, older patients rated their GPT as providing better support than younger patients, a significant trend in Y1. Educational achievement was related to ratings of GPT support with significantly higher ratings coming from those with no school qualifications when compared to those with university degrees. Those participants with enough or more than enough income gave higher ratings of GPT support than those with insufficient income; this trend was significant in Ys 2 and 3.

Discussion

There has been very little change over time in the participants' perceptions of where they receive most of their support for the long term conditions. A few more are saying that their main source of support is provided at home and slightly fewer indicated their GP was their main support source. As was noted in the 2016 report this

is perhaps surprising as general practices have in recent years made efforts to develop the role of nurses in LTC management and consequently we might have expected more people to be seeing a practice nurse or a LTC nurse on a regular basis. The transition from the Enhanced Care+ programme to the Long Term Conditions programme may have impacted on appointments with nurses as the number of people indicating they have consulted a PN or a CCN:LTC has decreased, but not hugely so (about 5% over the study period). Integrated Family Health Centres (IFHCs) receive LTC funding through high trust agreements and are participating in Health Care Home²⁹, which has four domains: ready access to urgent and unplanned care; proactive care for those with more complex needs; better routine and preventive care; and improved business efficiency and sustainability. General practice teams not involved in IFHCs receive additional funds to provide LTC care within a framework of standards³⁰ based on the Chronic Care Model. More information about the Health Care Home domains and the standards for delivering care to people with LTCs³¹ can be found in Appendix D.

Another interesting finding was that older people tended to rate the support they receive from general practice more positively than younger people but this effect diminished over time. The only demographic comparison that remained significant across all three data collection years was related to education, with the highest scores found amongst those with no school qualifications. The people indicating they had inadequate income generated lower mean scores than those with enough or more than enough. These apparently contradictory findings suggest that there is a less than obvious link between educational achievement and disposable income.

The higher rated aspects of care, related to physical exams for both disciplines and listening for nurses, are not unexpected as they are key components of professional daily practice. One of the lowest rated aspects of LTC care was learning about and helping with social support needs and it was also one that was not seen to be applicable to the GPT role by a number of participants. This highlights a need for education or promotion as patients may not be aware that if they need additional financial support by way of a disability benefit, home help or changes in their physical environment (ramps, handrails, bed/chair raisers etc) they should be discussing it with their doctor or nurse. Knowing the person as an individual, not just a patient, is important for building trusting relationships and for continuity of care. We know from the interviews that this is important to people but also that it is difficult to achieve when there is a shortage of time and practitioners.

²⁹ <http://www.healthcarehome.co.nz>

³⁰ Service Delivery Guide: Population health and long term condition management 2017/2018. Available on the CPHO provider portal

³¹ Service Delivery Guide: Population health and long term condition management 2017/2018. Available on the CPHO provider portal

- Average ratings of various aspects of consultations with doctors and nurses in primary care were all in the 4 out of 6 range which equates to 'good' as a qualitative description.
- Questions considered to be of least relevance to respondents was the involvement of family/whānau in discussions and learning about and helping with social support needs
- A comparison based on demographics found that higher ratings were found amongst those with no school qualifications in comparison with other educational groups
- Ratings of overall support from the general practice team decreased very slightly over time, around 15% rated them as less than 6 on a 0-10 scale in 2018.

What would people change if they could?

In 2018 we added a question at the end of the GPT ratings to ask what, if anything, they would change with respect to their experiences with their doctor or nurse at the general practice. This open response format question generated a broad range of answers. A large number of people (50) indicated that the question was not applicable, that they were unsure of what they would change, or said they were happy with the service provided. Some participants observed that they only regularly see a nurse or a Nurse Practitioner and not a GP. The other participants' responses have been summarised in the box below.

Themes	Description and examples
Access	<ul style="list-style-type: none"> • Many participants said that the waiting time for getting an appointment was too long, many having to wait for weeks rather than days. This was particularly problematic when they wanted to see their own Doctor.
Time and busyness	<ul style="list-style-type: none"> • People identified the busyness of general practice as being a problem. Some people noted that they felt 'rushed' and others felt they were being a 'nuisance'. • One person said "I have answered fair to many of the questions re the doctor because I feel she does not have enough time to spend with each patient. Her practice is so big and she would be trying to see many people. I know she is a good and caring doctor but time is not on her side". • More allocated time per consult was requested as 15 minutes was not perceived to be enough. Others commented that they would like the full 15 minutes rather than being dismissed early. • Participants expected that practitioners would read their notes and be 'prepared' for their consult, and that they would record the consult accurately in the notes for future reference. • 'Wasted patient time' was an issue for a lot of people. This included the time in the waiting room before being seen and times when a referral wasn't deemed necessary such as being sent to the Emergency Department and later sent home as hospital care was not required.

Cost	<ul style="list-style-type: none"> The cost of general practice; consultations, repeat prescriptions and collecting medicines was frequently recorded. One patient said “The cost. In four weeks I have spent \$280 on visits”. One person commented that her Community Services Card made very little difference to the cost of being seen or collecting medicines. Others commented about the costs mounting up, particularly when practitioners collaborated resulting in both a Doctor and Nurse consult charge. One patient was upset that s/he gets charged a double fee for a double appointment despite being unable to do so as s/he is always financially “backpedalling”. A couple of people suggested that LTC care be funded, with one participant suggesting that “long term illness should not have a charge”.
Treating me well and personalising my care	<ul style="list-style-type: none"> Participants expected to be treated well in the consultation. They expected; practitioners to have a pleasant approach, and to feel concern and interest; to be shown respect; to be heard; and to be accepted (not judged). They also wanted time within the consult to express their own thoughts and ideas. Patient centred care was requested with individuals asking for the following: practitioners to ask about their general wellbeing, not just the issue that required a consult; to be informed about options; to be asked about their preferences; and awareness of individual limitations and needs. One patient’s request was “Listen to me and my needs”. A holistic approach to care was also desired. Some practices restrict the consult with a ‘one or two problem rule’. Patients disliked this as it didn’t enable them to talk about things that were important to them and one reported feeling anxious about forgetting an important question, knowing they wouldn’t have a second opportunity to ask it. A few patients shared that they felt that either their doctor was too focused on medicine management, or on referring them to see others, rather than addressing their needs. A group of participants pointed out that they were enjoying seeing a nurse or nurse practitioner for the bulk of their care. Practitioners who focused on the computer rather than the patient, lack of privacy during the consult, and practitioners who stood or sat at different levels than the patient when communicating were identified as some of the physical barriers encountered.
The wider general practice team and setting	<ul style="list-style-type: none"> Participants wanted care consistency and having your own GP or nurse for the consultation was very important. Extended wait times often meant that patients had to see other practitioners or locums. In this case patients wanted their own practitioner to provide input. Follow up was important, as it showed participants that the practitioners cared about their progress. Passing on test results was also highlighted as being important. One participant suggested that nurses develop more skills. Receptionists were commented on, one person saying they would change the receptionist “who thinks booking appointments for three months is a waste of time!” Another wanted them to be more helpful in making appointments and getting repeat prescriptions. Ongoing prescription errors appeared to be particularly problematic for some individuals. Billing issues also caused significant frustration. Purchasing an answer phone and improving the physical setting were two suggestions for improving the practice work space. Other service improvement suggestions were;

	<p>re-designing the appointment system so that more spots are available to be responsive to urgent demand; improving front of house interactions namely with the reception area; and enabling a full check up option within the suite of general practice services.</p> <ul style="list-style-type: none"> One person commented on the IFHC structure saying “four GP Practices built one new clinic – big is not better.”
Health system	<ul style="list-style-type: none"> One person asked for better coordination of care saying “I am on Shared Care Programme for psychiatric illness. Haven’t seen a Psychiatrist for a number of years even though there have been changes in my mental health”. Another urged that primary and secondary IT be integrated.

Other practitioners

A list of 14 practitioners beyond those seen at the general practice was provided for participants to indicate who they had consulted during the previous 12 months. The list included specialist doctors, specialist nurses, dietitian, podiatrist, social worker, community pharmacist, physiotherapist etc. Frequency data regarding how many of the 14 listed practitioners were seen over the study period is provided in Appendix E. An ‘other’ option was also provided so that more could be added. The number of practitioners seen ranged from none to seven in Ys 1 and 2 and none to eight in Y3 (Figure 30). The average was 1.4 in Ys 1 and 2 and 1.5 in Y3, indicating little change overall. The graph also shows little change in numbers seen by this group of patients and there was little difference in how many consulted different types of practitioner, specialist doctors and podiatrists being the ones most often mentioned.

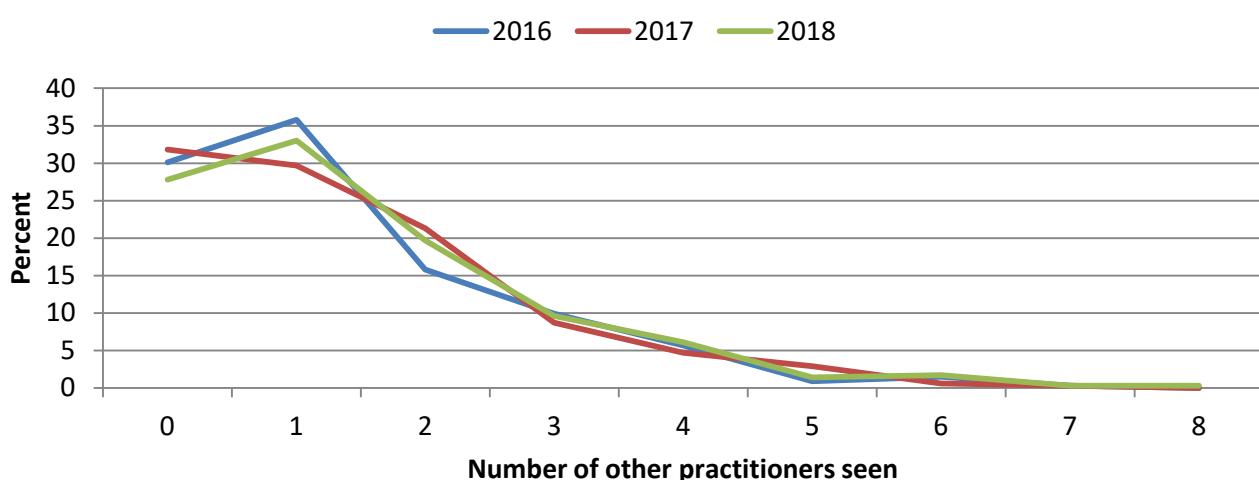


Figure 30: Numbers of practitioners other than the GPT seen

These results suggest that over time slightly more people are consulting practitioners beyond their GPT members. In Y1 34.1% saw at least two practitioners in addition to their GPT, a figure which rose to 38.5% in Y2

and 39.2% in Y3. On average, Māori saw more other practitioners ($M=2.0$) than non Māori ($M=1.4$)³² but there was no difference in the number seen by men and women or according to income level or educational achievement.

Care planning and goal setting

The number of people indicating that they had a written care plan decreased slightly during the Talking about Health study as did the number saying that a health practitioner provided them with support for their health goals. The number stating that they had no goals increased over the study period. These results appear in Figure 31. There were no sex or ethnicity differences in the reported incidence of written care plans.

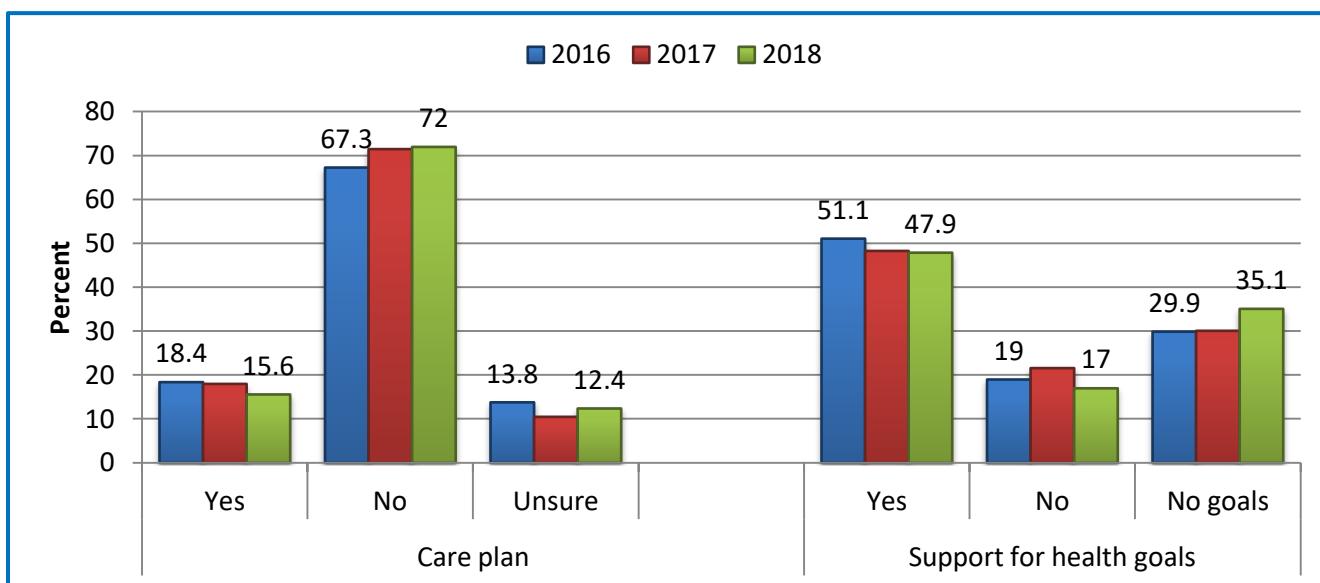


Figure 31: Number of participants with written care plans and receiving support for their health goals

Patients were divided into two groups according to whether or not they had a written care plan (yes and no/unsure). A series of independent t-tests were conducted to see if there were differences in patient activation, health or perceptions of general practice interactions based on care planning. The results are presented in Table 19 with means that are significantly different according to independent t-tests in blue font.

³² Ethnicity difference $t=-2.29$, $p=.022$

Table 19: Mean score comparisons according to care planning done or not and health goals support or not

	2016		2017		2018	
Care planning	Yes	No/unsure	Yes	No/unsure	Yes	No/unsure
Patient activation	67.5	62.8	64.3	63.4	63.5	61.9
Physical health	44.1	42.7	41.0	42.7	37.8	39.6
Mental health	47.3	46.6	46.0	46.3	45.8	46.1
GP Interaction	5.0	4.6	4.7	4.7	4.8	4.7
Nurse interaction	5.0	4.7	4.9	4.8	4.9	4.8
GPT support	8.6	7.8	8.4	7.9	8.2	7.7
Health goal support	Yes	No/unsure	Yes	No/unsure	Yes	No/unsure
Patient activation	65.9	58.6	66.2	62.9	65.5	60.1
Physical health	43.8	40.3	43.0	40.9	39.7	39.0
Mental health	47.5	43.8	47.0	45.1	45.9	46.5
GP Interaction	5.0	4.0	5.0	4.1	5.1	4.1
Nurse interaction	5.0	4.1	5.1	4.2	5.1	4.0
GPT support	8.6	6.4	8.6	6.6	8.5	6.0

With respect to care planning in Y1 it appeared that, on average, people were better off if they had a written care plan. They were more active self-managers and reported better interactions with doctors and nurses in primary care as well as perceiving themselves to get more support from the general practice team. These results were not supported by the Y2 and Y3 data. The trend for having practitioner support for health goals was even stronger in Y1 as support was associated with better mental and physical health as well as better experiences and perceptions of overall support from the general practice team. The same pattern of results was evident in Ys 2 and 3 although fewer of the differences were significant. Overall it seems that even if a written care plan is not in place it may be as important, if not more so, to have support for a practitioner for achieving health goals.

Repeatedly we hear that time pressures affect care delivery in general practice. Not only does this influence who gets a care plan or is supported with their health goals, but the provision of self management support in general.

- Reaching health goals is an important part of self management yet around a third of participants said they had no health goals
- Practitioner support for health goals has positive links to patient wellbeing
- In 2016 it was found that patients were better off when they had a care plan

Health education

In all three years we asked about the health related education that our participants had attended during the last 12 months. In 2016 42.7% of the participants indicated they had attended some sort of education, a figure which dropped to 30.9% in 2017 and 20.7% in 2018. Given the self-management focus of the study we were particularly interested in how many had taken part in the Stanford Living a Healthy Life programme (which was renamed My Health myself part way through the study period) as it is specifically designed to support better self-management for people with long term conditions. The numbers attending this programme remained fairly stable; 7.8% in Y1, 7.1% in Y2 and 6.4% in Y3.

- There was a considerable decline in the number of people indicating they had attended education related to their LTCs over the three year study period

Medicines

A number of questions addressed medication related issues including use, understanding, prescriptions and consultations with community pharmacists.

Participants were asked how many days a week they take their medications as advised and the average number of days per week was very similar across the three years (Y1=6.7, Y2=6.8, Y3=6.7). The responses are summarised in Table 20.

Table 20: Percent of participants taking their medication as advised 0 to 7 days a week

Year (mean)	0	1	2	3	4	5	6	7
2016 (6.7)	1.7	0.0	0.9	0.9	0.6	1.2	3.5	91.3
2017 (6.8)	0.0	0.3	0.6	0.9	0.9	1.4	3.2	92.8
2018 (6.7)	2.3	0.3	0.3	0.6	0.9	2.9	2.9	89.8

Based on adherence to medication figures reported in the literature the number indicating they take medication correctly on a daily basis appears high. A comparison of Māori and non Māori participants was made and the percentage of each ethnicity taking their medication as advised less often than daily, is displayed in Figure 32.

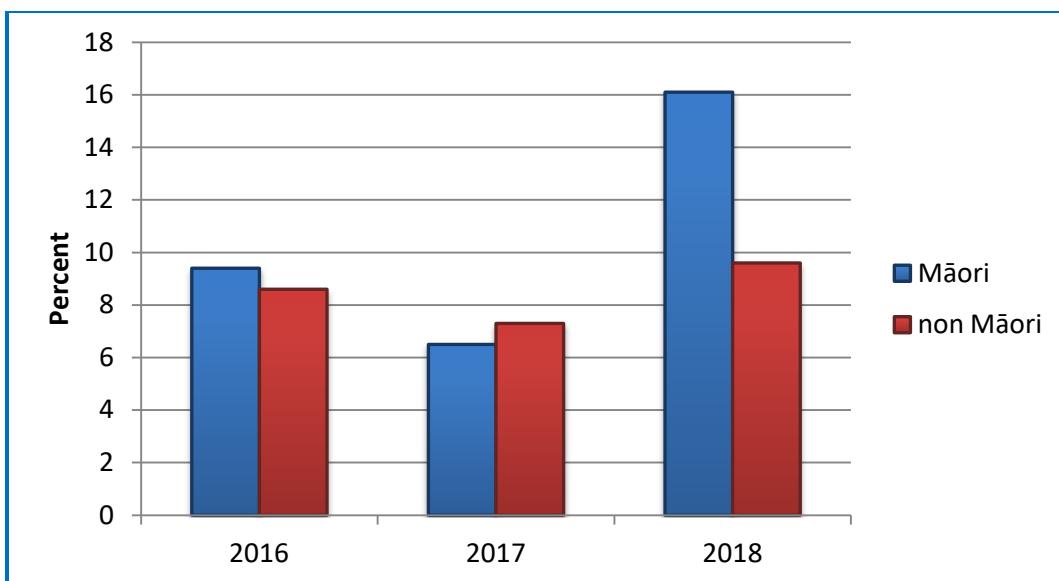


Figure 32: Percentage of Māori and non Māori taking medication as advised less often than 7 days a week.

This suggests that the number of Māori in particular not taking medications as prescribed has increased during the Talking about health study period.

In response to the question of whether all items on the prescription were collected from the pharmacy, the majority said ‘yes’ (90.4 to 92.2%). Four possible reasons for why people might not get all the items on a prescription were provided for people to indicate why they didn’t collect all their medication, plus an ‘other’ option was provided with space for comment. The reasons provided by those who said ‘no’ are provided in Figure 33.

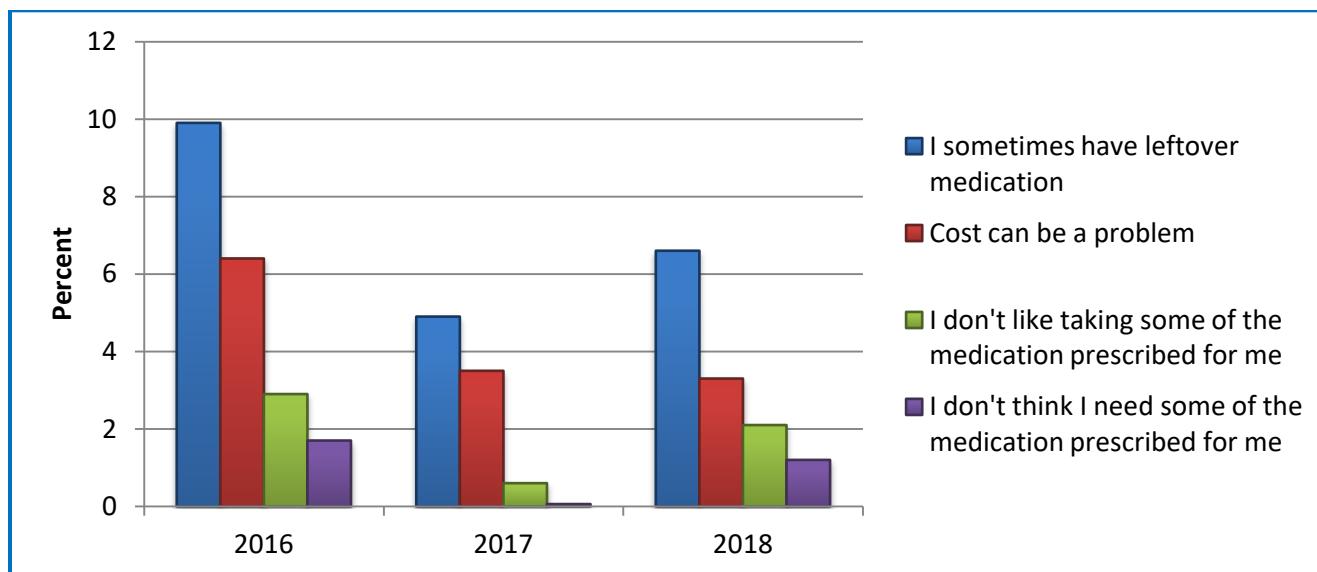


Figure 33: Reasons for why participants do not collect all their medication from the pharmacy

This shows that for the people who don't collect all their medicines (8-10% of the patient group) the main reason is that they have medications left over. This may be due to them not being taken as regularly as they are prescribed but it may also include people who have 'in case' medication - such as additional pain medication to be taken if needed - and they have counted this as leftover. However this scenario would apply better to the next question regarding medications that are collected from the pharmacy but not used (Figure 34).

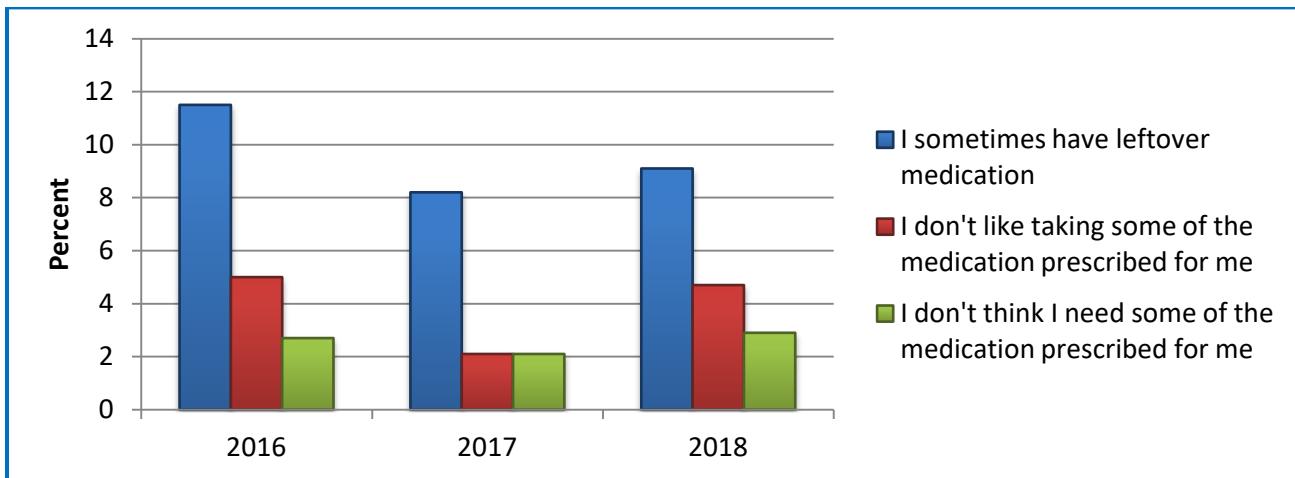


Figure 34: Reasons for why participants collect but do not use all their medication

Again the main reason indicated was that leftover medication was available to take followed by people not liking some of their prescribed medication but they collected it anyway.

Additional comments provided some context and further insight into why people do not use medications as intended. The themes reflected in the comments along with some examples, in italics, were:

- Improvement in health, condition settled
- Preference for other options
- Incorrect prescription
- Incorrect information led to wrong/unnecessary prescription,
- Hospitalisation results in their medications not being used
- Prescribed medication is too difficult to use - '*if I use the cream at night it sticks to my sheets*', '*I live on my own so have no one to help me apply the cream*' '*I find it hard to take pills*'
- Patient choice to stop taking regularly or altogether - '*I don't take morning meds if I have had alcohol the night before*', '*I heard bad things about it so I didn't take it*', '*I don't take my Frusemide if I am going out in the morning*'
- Medicine impacted on other aspects of patient health i.e. interfered with BGL
- Medicines not working
- New doctor co-ordinating care prescribes different medicines
- Doctor overzealous in prescribing medicine
- Cost - '*I hold over medicine so I don't have to go to the doctor so often as it is costly*'

- Doctor prescribes too much
- Fear of consequences - '*I don't want to build an immunity to antibiotics'*
- Trying to use less pain medicine i.e. opiates, take substitutes or uses alternative therapy such as attending physiotherapy to improve pain management
- Acknowledgement of underuse - '*I don't always recognise how bad my asthma is until it is serious... I should probably take my blue inhaler earlier*'.
- The doctor didn't explain why they needed a new drug so they didn't take it.

Thus it appears that some patients have issues with managing their medication regime, either due to it not fitting in with their way of life or because of side effects or concerns about the medication. There is also evidence of some patient/doctor communication breakdown with respect to prescriptions and amounts prescribed. Improving patient understanding of the importance of regular medication and of how, for example, antibiotics and pain medications work would be beneficial. In addition, encouraging them to talk about their experiences of taking specific medications, and why they may not like them, will assist with adherence and open up collaborative discussion to benefit both patient and practitioner. Promotional work across the region to inform patients about pharmacy's ability to put prescribed medicines 'on hold' when not required at time of collection could significantly reduce wastage.

A comparison was made regarding the number of Māori and non Māori participants who indicated they did not collect all their medications from the pharmacy or did not use all the medications they had collected. The results across the three study years are presented in Figure 35 showing that Māori were slightly more likely than non Māori to not collect or use their prescribed medications. The greatest difference was for use of collected medications in Y3.

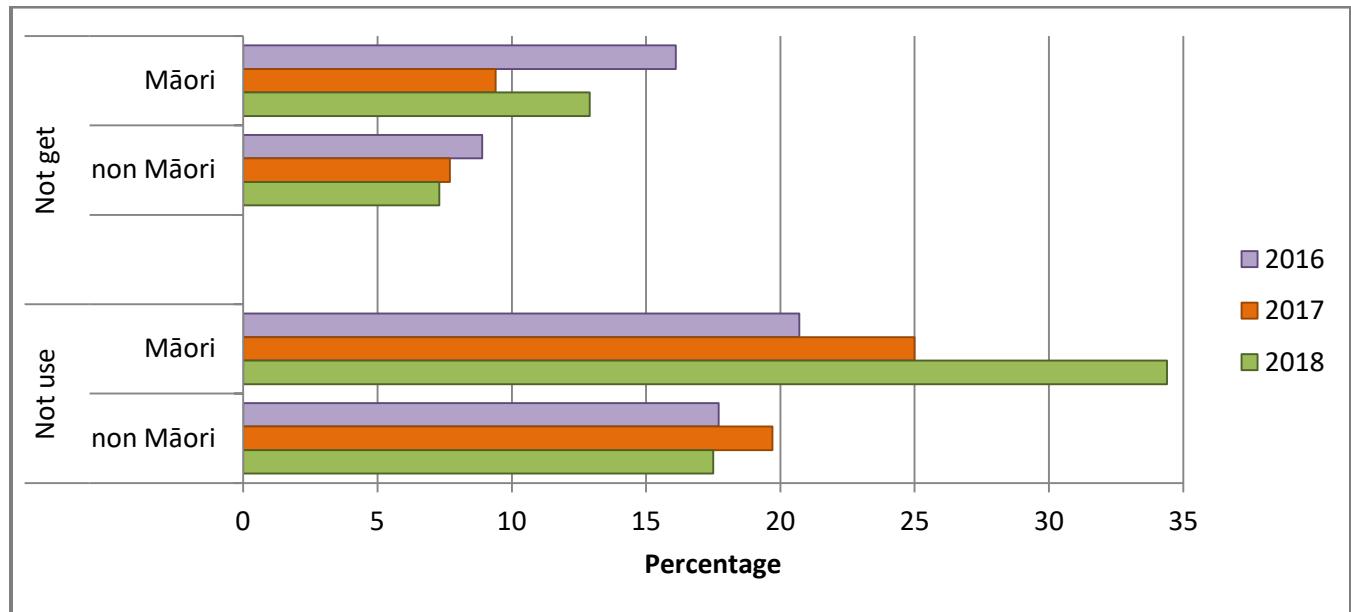


Figure 35: Māori/non Māori differences in collection of medications from the pharmacy and use of collected medicines

Figure 35 indicates that Māori participants were more likely than non Māori to get only some of their prescribed medication and were also more likely to not use the medication they had collected from the pharmacy. This was particularly pronounced in 2018.

When we asked about consultations with a range of other health professionals we discovered that the number of people seeing a community pharmacist for a one-on-one appointment was relatively low. For non Māori the consultation percent was 12.9 in Y1, 11.0 in Y2 and 11.4% in Y3. For Māori there was an increase across the years from 3.1% in Y1 through 12.5% in Y2 to 15.6% in Y3. Note however that the overall number of Māori participants involved in the study across all years was only 32, so 15.6% equates to only five individuals.

- Participants reported that taking their medicines was a self care activity that they did well, with 89.8 - 92.8% percent of participants taking their medicines as advised 7 days a week. This finding differs from current literature which reports the non-adherence rate to be much higher
- Māori were less likely to follow their medicine regime daily and by 2018 the number had increased
- About 20% of people collect their medicines from the pharmacy but do not use them, and this applies more to Māori than non Māori. Promotional activities across the DHB to inform people about the 'on hold' capacity may help reduce the level of wastage.

Advice for others

When we interviewed some of the study participants we identified a broad range of experiences highlighting ways in which people managed their conditions, their home environment and their interactions with health practitioners. From this we made a list of ideas which we felt would be beneficial to people living with long term conditions. To supplement this we added a question into the final (2018) questionnaire asking for any advice that they felt would assist somebody else living with a long term condition. Responses were many and varied and the intention is to write them up and present them as a booklet which could be made available through general practice in the region.

The sorts of things people proposed were:

- Accept your condition ...
- But don't let it define you: "Don't make your health your identity"
- Keep moving and exercising: "Have a good reason to exercise; a beach is a great reason to go walking. A tricycle provides a great way to get to the dairy but is also great exercise"
- Have a hobby: "If you can no longer do a certain activity then find others that you can do. Never sit around and do nothing".
- Try to remain positive, keep a sense of humour: "The main thing that works for me is attitude - a sense of humour is vital for it distracts you from your symptoms"
- Keep talking to people; friends, family and health professionals: "When dealing with busy medical folk, ensure that they fully understand all of your symptoms and problems. I find that some don't take you seriously if you have multiple issues but I make sure they have heard me"

- Set goals and try to achieve something each day
- Get professional advice and follow it: “[Adhere to the doctor’s recommendations](#)”
- Ask for and accept help
- Recognise the importance of sleep
- Take one day at a time: “[Each morning when you wake, take a deep breath and remind yourself this is a marathon not a sprint](#)”
- Pace yourself: “[Some things have to be done at an appointed time but others have to be done at a pace you can handle and may have to be moved back in time if you are unwell. Do not take much notice of what other people think, they do not have your problems. You have to adjust your lifestyle to give the best deal for you](#)”.
- Prepare for doctor/nurse visits: “[make sure you have everything you want to discuss written down when you visit your GP. Don’t be afraid to ask - no matter how silly it seems](#)”
- Take a second person with you: “[it’s good to have a second pair of ears in case you miss something](#)”
- Rearrange your home environment to make things easier: “[It \(the pain\) is not going to get better so things need to be set up for later disability i.e. walk in shower, hand rails, aids for the kitchen](#)”

Conclusion and recommendations

The findings presented in this report add to the region’s earlier research and regular evaluation activities undertaken on LTC management in primary health care. Overall the results show that little has changed over the two-year study period (2016 - 2018) for the Talking about Health study participants. Within general practice, changes to policy and practices have occurred during this time. Of relevance is the discontinuation of the EnhancedCare+ Programme (a package of LTC care offered through General Practice to a targeted group of people with LTC, with the aim of improving their clinical and self-management). Good assessment and care planning was at the core of this programme. General practice teams now receive additional funds to provide LTC care through a high trust agreement. The Health Care Home initiative has since been introduced and has a quality improvement component aimed at improving LTC management. To date, four practices (all IFHCs) are participating in this project.

When compiling recommendations we have thought about results from this report, the 2016 and 2018 Practitioner component of the study and the rich data gained from the 32 participant interviews completed in 2017. A number of publications are currently underway which focus on particular aspects of the research. Sharing our findings with the sector is a vital part of the research process and integral to improving patient experience. In addition to the brief list of recommendations below, interesting findings have been summarised throughout the report with the intent that the reader will reflect on these and draw their own conclusions. Whilst some high level recommendations are made, we have also included simple practice options, aimed at improving the experience of people living with a long term condition in the region.

Recommendations

- In accordance with the region's strategic plans, priority should be given to improving the LTC management (clinical management and self management) of Māori.
- Self-management support should be targeted with LTC funding; a priority being to support people to reach their health goals (preferably with a written care plan).
- If self-management support is not able to be provided through general practice due to lack of time or expertise, consideration needs to be given to how this could be provided by other health services and resources in the community; i.e. the establishment of a hub of Health Coaches to assist with lifestyle change support.
- Improving the health of people with chronic pain should be a priority given the number of people experiencing it. Arthritis-related pain is particularly prevalent among our participants. Promoting the chronic pain version of the self management programme (My Health myself), provision of patient and provider education, and partnering with Arthritis NZ to find some solutions are some ideas to improve both the clinical management and self management required to 'live well' with this condition.
- Mobility and social assistance such as help with home maintenance and housework was highlighted as a significant self care challenge for a lot of participants, yet many people did not perceive it to be part of the practitioners' role to ask about and assist with this. This finding reinforces the need for regular holistic assessment to be undertaken and for practitioners to connect patients to necessary services such as Support Links and occupational and physiotherapists in the community.
- Managing pain, sleeping, exercise and being overweight were also found to be significant challenges, and whilst managing pain has been raised as a recommendation, supporting patients with their sleep and exercise and nutrition also warrants attention. All of these topics are covered in the My Health myself self-management programme, with a version for people with chronic pain having just been launched in the region. Additional resources have been secured to assist with recruitment and the provision of programmes across the region.
- Managing breathing was a specific self care challenge for 23.7% of the cohort and may indicate that educational material or resources should be targeted to support people with breathing difficulties.
- Health literacy continues to be problematic for some participants; as an example, less than 60% of people with diabetes know what their target HbA1c is. Initiatives to further develop practitioners and patient health literacy are recommended.
- People with higher incomes and higher education scores (on average) had higher PAM scores, indicating that they were better self-managers. Self-management support targeted at priority populations is vital to improve peoples' knowledge, skills and confidence to self manage, and to improve overall health, wellbeing and quality of life.
- Fewer than 20% of people in the study had a written care plan and the figure declined over the study period. A care plan is the gold standard for LTC care and attention to improving this important component of care should be a practice priority.
- Support by practitioners for the participants to reach their health goals was rated higher (around 50%) but this also declined over the study period. A large group of people also said that they had no goals and this increased over the study period. Patient goal setting is an integral part of LTC management and should be a key component of the care package.
- Learning about social support needs and knowing patients as people were aspects of the consultation that were rated the lowest in all three years. Whilst the scores were still relatively high on average, real

health gains can be made by addressing unmet need, especially since the self-care challenges most commonly experienced related to mobility and social support services.

- If it were possible to find a way to give people with long term conditions some sort of reduced fee it would be really appreciated. They basically have a series of revisits as they need regular check-ups and prescriptions which have a huge financial impact.
- There is a notable decline in the number of participants reporting that they have attended education relating to their LTC in the last 12 months. Patient education is necessary for good self management and hence it is recommended that the PHO review how patient education is promotes within primary care across the region.

APPENDIX A: Correlations between the number of listed LTCs, ratings of General Health, Satisfaction with Life, Control over Life and Effect of LTCs on QOL in 2016 and 2018.

2016	General Health	Satisfaction with life	Control over life	Effect of LTC on QOL
Number of LTCs	-.31	-.24	-.29	.34
General Health		.43	.35	-.51
Satisfaction with Life			.66	-.37
Control over Life				-.35
2018				
Number of LTCs	-.37	-.26	-.23	40
General Health		.45	.46	-.52
Satisfaction with Life			.72	-.42
Control over Life				-.47

APPENDIX B: Mean scores on health and general practice interaction variables by PAM level with ANOVA results

Health and General practice variables	2016 PAM level					2017 PAM level					2018 PAM level				
	1	2	3	4	F	1	2	3	4	F	1	2	3	4	F
General health	2.3	2.7	2.9	3.1	9.6	2.3	2.5	2.8	3.2	15.8	2.3	2.6	2.8	3.3	15.7
Physical health	37.5	40.8	43.4	46.2	12.7	36.0	40.3	42.7	45.7	18.3	35.0	37.9	39.6	43.7	11.9
Mental health	40.8	45.0	47.6	49.3	11.6	40.4	44.1	46.5	49.8	18.4	40.4	44.5	46.0	50.7	17.3
Healthy behaviour	4.4	4.8	4.9	5.3	7.9	4.2	4.7	4.9	5.3	18.8	4.4	4.6	4.7	5.4	16.3
GP Interaction	4.2	4.4	4.7	4.9	6.1	4.1	4.4	4.8	5.0	9.3	4.2	4.3	4.8	5.2	13.7
Nurse Interaction	4.2	4.5	4.7	5.1	9.5	4.5	4.5	4.8	5.0	4.7	4.4	4.5	4.8	5.2	8.5
GPT support	6.3	7.8	8.0	8.5	11.9	7.0	7.5	8.2	8.4	7.4	6.1	7.5	8.1	8.5	14.6
Life satisfaction	5.2	6.5	7.0	7.1	8.3	5.2	6.1	6.9	7.4	12.2	5.4	6.3	6.7	7.7	12.3
Control over life	5.5	6.8	7.2	7.9	12.4	5.8	6.4	7.2	8.0	15.6	5.5	6.3	7.2	8.1	19.3
Effect of LTCs on QoL	7.2	6.0	5.4	5.0	7.1	7.3	6.2	5.5	5.0	8.8	7.6	6.0	5.4	4.7	12.4

P values for all ANOVAs <.001 except Nurse Interaction Y2 where p=.003

APPENDIX C: Numbers of general practice team members consulted during the study period by Māori/non Māori and male/female subgroups

Table A1: Numbers of GPT members consulted during the previous 12 months by sex and ethnicity

Subgroup (n)	General practitioner	Practice nurse	CCN:LTC	Specialist nurse/ Nurse Practitioner
2016				
Male (141)	95.7	76.6	22.7	27.7
Female (206)	96.6	74.8	33.5	28.6
Māori (31)	96.8	67.7	25.8	19.4
Non Māori (306)	96.2	76.3	29.4	29.1
TOTAL (347)	96.3	75.5	29.1	28.2
2017				
Male (139)	95.7	77.7	20.1	23.7
Female (206)	94.2	70.4	23.3	21.4
Māori (31)	96.8	58.1	25.8	26.2
Non Māori (314)	94.6	74.8	21.7	21.0
TOTAL (345)	94.8	73.3	22.0	22.3
2018				
Male (139)	93.5	73.4	25.2	23.7
Female (206)	93.2	69.9	20.9	23.8
Māori (32)	90.6	84.4	28.1	28.1
Non Māori (313)	93.6	70.0	22.0	23.3
TOTAL (345)	93.3	71.3	22.6	23.8

APPENDIX D: Additional information regarding Health Care Home and standards for care to people with long term conditions

Health Care Home domains:

- **Ready access to urgent and unplanned care** - through quick access to a doctor/nurse in order to discuss care needs to get advice or decide together on the need for a face-to-face consultation
- **Proactive care for those with more complex needs** - the ‘year of care’ programme enables comprehensive collaborative health planning, involving the person/whānau and a multidisciplinary team, to schedule appointments, reviews, specialist and social care for the next 6 - 12 months. Care planning is led by appropriately trained practice nurses and involves self-management support.
- **Better routine and preventative care** - making use of: cheaper phone consultations; group consultations for self-management and peer support; the patient portal to enhance communication and access to results; goal tracking, ordering of prescriptions and booking of appointments.
- **Improved business efficiency and sustainability** - practices are supported to review their patient flow, systems, processes and facility design to improve efficiency and save time and money. The morning ‘huddle’, a 15 minute staff discussion, enables planning and task sharing for the day and review of performance quality with the aid of visual displays.

General practice teams not involved in IFHCs receive additional funds to provide LTC care within a framework of standards based on the Chronic Care Model. The six step approach taken to achieve productive interactions around LTC care involves:

- **Identification of the patient** - using the risk stratification tool and assessment of complexity
- **Completion of the appropriate assessment** - e.g. CHA or BPAC assessment forms
- **Identification of the care team** - a designated care coordinator, involvement of whānau/carers, input from other relevant practitioners
- **Completion of a care/action plan** - including collaboratively agreed health goals and actions and easily accessible to the patient and the care team
- **Monitoring of progress** - by patient and care coordinator, with follow up between appointments and communication of changes to the care team
- **Reviewing and updating** - care/action plan with patient/whānau and care team, use of collaborative case review if required, documentation of updated plans and progress.

APPENDIX E: Numbers of participants consulting practitioners outside the general practice team across the three study years

Practitioner	Percent		
	2016	2017	2018
Specialist nurse	13.8	15.8	18.6
Specialist doctor	37.2	35.2	40.4
Dietitian	11.5	11.5	6.9
Podiatrist	21.8	23.5	24.9
Social worker	2.0	1.7	3.7
Community pharmacist	12.0	11.2	11.7
Physical activity coordinator	8.6	4.6	6.3
Smoking cessation consultant	0.9	2.0	1.1
Counsellor	5.4	4.3	5.2
Traditional healer	0.3	0.0	0.6
Acupuncturist	2.0	1.7	1.1
Hypnotherapist	0.0	0.3	0.0
Physiotherapist	4.0*	13.5	13.5
Whanau ora Navigator	1.1	1.1	0.0

* Physios were not included in the list for Y1 but were added for Y2 and Y3.