# Our District's Approach to Long Term Conditions

**Chiquita Hansen** 

Chief Executive





#### **OUR ROHE**

We have a population of

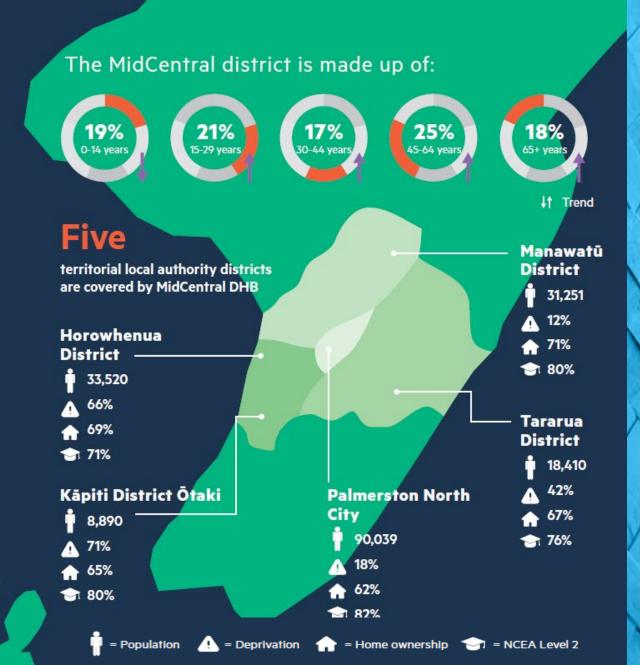
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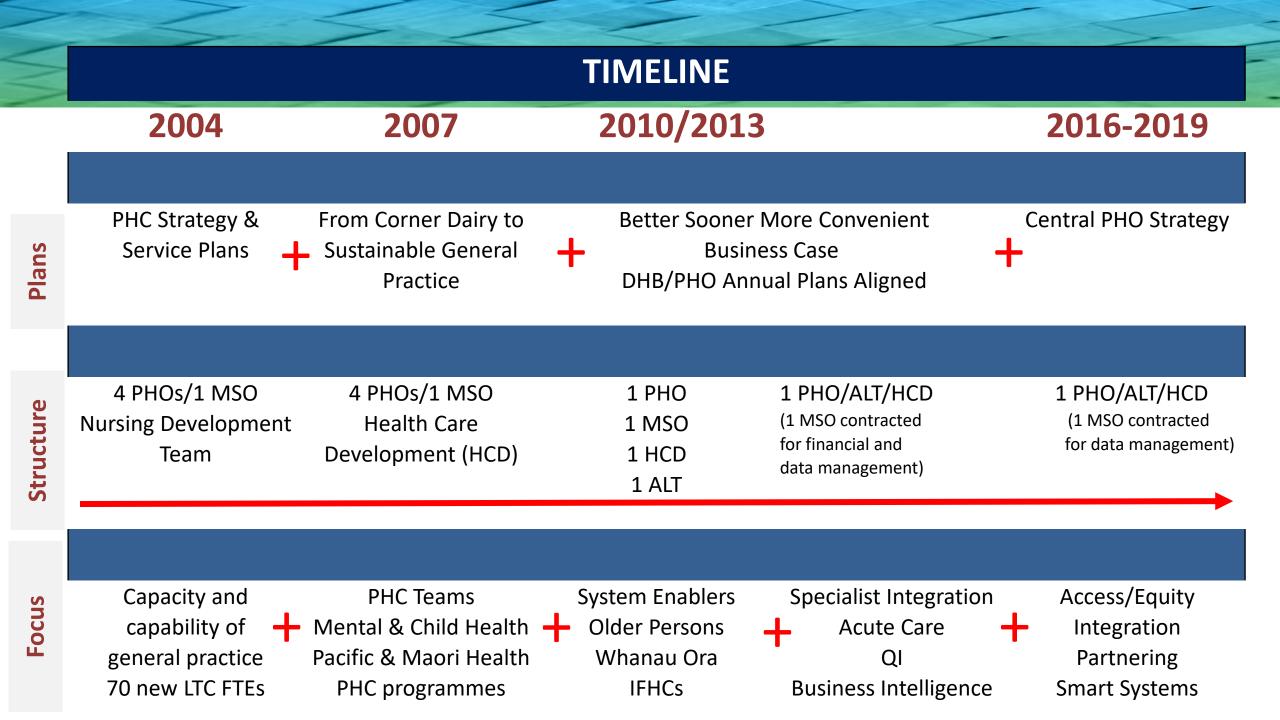


which is estimated to rise to **186,040** by 2023/24

As a district, we have a higher proportion of Māori compared to the national average







#### **THINK Hauora** Strategic Aims





Rangatiratanga Self-Managing



**Kōtahitanga** Whānau Cohesion



**Hauoranga**Living Healthy
Lifestyles



**Tuakiritanga**Participating in Te Ao
Māori



**Tiaki Taiao**Responsible Stewards
of Living & Natural
Environments



**Pāporitanga**Participating in Society



**Pukenga Rawa**Economic Security &
Wealth Creation



# "HEARING THEIR VOICES"

THE VIEWS OF PEOPLE WITH LONG TERM
CONDITIONS ON HOW BEST TO PROVIDE
SELF-MANAGEMENT SUPPORT

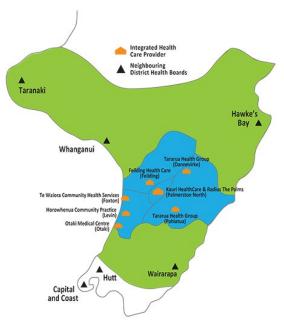
Melanie Taylor, Claire Budge & Chiquita Hansen

## **TODAY'S PRESENTATION**

- Overview of the Talking about Health study
- Demographics
- Some of the main findings incorporating key messages for health practitioners relating to:
  - People's experiences of 'living with a LTC'
  - Interactions with the general practice team and how they could be improved
  - Medication use
  - Patient activation
- Practice points



#### **'TALKING ABOUT HEALTH'**



A three year observational study of people with long term conditions in the MidCentral region and their primary care doctors and nurses. The focus was on their health status, how they manage their conditions and the support they receive through general practice to self-manage/manage at home on a daily basis.

#### **METHOD**

- Patient sample recruited through Compass Health using documented comprehensive health assessment (CHA) data.
- 2730 invitations and consent forms were sent out (unknown how many were received)
- Consent forms asked for information about which long term conditions people had
- Over 700 responded and were sent questionnaires including relevant self-management questions
- Paper and online questionnaires (SurveyMonkey) were made available
- 569 returned completed questionnaires in Yr 1: response rate ~21%
- 32 non-Māori volunteers were interviewed in Yr 2 (Māori interviewed by Massey University researchers)

#### **ANNUAL QUESTIONNAIRES INCLUDED MEASURES OF:**

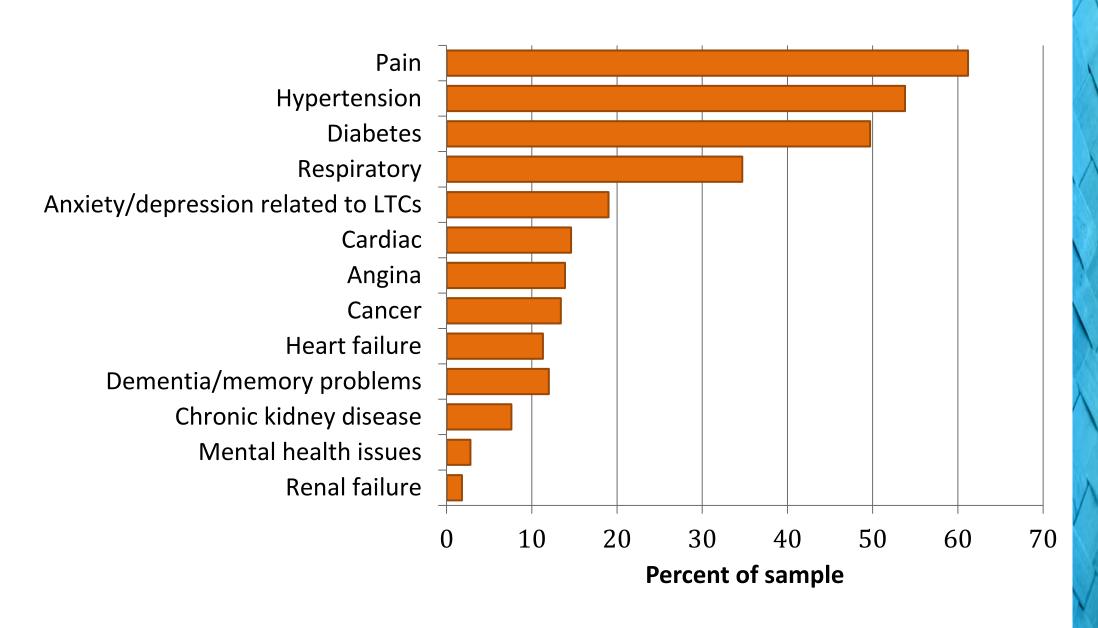
- Health status general, physical and mental health (PROMIS; Hayes et al., 2009)
- Healthy behaviours
- Self-management of specific conditions
- Patient activation (PAM; Hibbard et al., 2004)
- Experiences with GPs and nurses in primary care (productive interactions) – NZ version of GPAQ (Zwier, 2013)
- Care planning and goal setting
- Medication use
- Demographics



### PARTICIPANT DEMOGRAPHICS - YEAR 1 (N= 569)

- Sex: Female 56%; Male 44%
- Ethnicity: Maori 15%; Pacific 1%; Other 84%
- Age: <55 11%; 55-64 18%; 65-74 33%; 75+ 38%
- Education: no school qualifications 37%; school 21%; post school 27%; university 15%
- Employment: employed 19%; retired 67%
- Living situation: alone 32%; with others 67%; in residential care 1%
- Income adequacy: Not enough 17%; just enough 35%; enough 36%; more than enough 12%
- Housing issues: none 71%; 1-2 24%; 3 or more 5%
- LTCs: range 1-11, mean 3.3, 86.6% had 2 or more indicating multimorbidity

#### **LONG TERM CONDITIONS**



#### **INTERVIEWS**

- O How people live with their LTCs:
  - Self-care challenges
  - Support from others whānau/friends/community/support agencies
- Experiences of care:
  - The general practice consultation
  - Balancing advice with lifestyle and LTC limitations
  - Conflicting advice
  - Areas for improvement in general practice experiences
  - Interactions with community pharmacy



#### PARTICIPANT DEMOGRAPHICS (N)

- Sex: Female (20); Male (12)
- Ethnicity: predominantly NZ European, Australian, (1); Samoan (1)
- **Age:** <55 (5); 55-64 (10); 65-74 (9); 75+ (8)
- **Employment:** employed (7); unemployed (7); retired (17); student (1)
- Living situation: alone (8); with partner (16); sometimes with partner (2); with other people (6)
- Income adequacy: Not enough (13); just enough (10); enough (5); more than enough (4)
- Effects of LTC on Quality of life: range 0 (no effect) to 10 (very large effect); mean
   6.8
- Support: 10 had no non-medical support, others a range of sources including family, friends, neighbours, organisations, agencies and church
- LTCs: range 1-7; mean 3.7. Diabetes (20), chronic pain (19), and chronic respiratory conditions (9)



#### **KEY THEMES**

#### Acceptance

- Of their LTCs and the limitations they impose
- Of support
- Of advice

#### Making life work

- Home life
- Keeping safe and pacing yourself
- Working with the health system
- Personal control
- Forward planning

#### Work with me

Know me, listen to me, believe me & partner me



#### **ACCEPTANCE**

"I wouldn't call myself recovered. I think it is something I've learned to live with... I think I'm a very different person to what I was before and I've got to accept that"

"I'm too ... stubborn. I don't wear socks, or if I have to I'll get down on my bum and I'll do it myself"

...The thing is its unsolicited advice 9 times out of 10. I mean if I ask for advice then I'll listen to people obviously. But most of the time it is unsolicited advice and you think "oh...I'm dealing with enough...at the moment and I don't need this on top of it"

#### **MAKING IT WORK**

"I make my own decisions, the recommendations that the doctor or nurse give me I take on board but at the end of the day I make the decision whether they're something I can do or not. A lot of it depends on time"

"Usually I prepare and he cooks, it doesn't matter. If he is sick I do the cooking and if I am sick he does"

"When my head's like it is today, full of cotton wool, I wouldn't drive my mobility scooter today"

"I'd ask them for the results, like the creatinine, ask them what it was because I don't like doctors having the power because it's not their health...It's not the doctor's health, its mine"

#### **WORK WITH ME**

"I would really like to be listened to, listened to properly, I'd like to be actually heard rather than acknowledged if you like"

"When we do chat he generally asks me the same questions over and over again like he's never asked them before. I suppose sometimes he says, I suppose he has to ask them but, I don't think that he remembers what I say to him anyway. Really, I'm just what's up on the screen at a particular time. I don't expect much more from doctors, they've got too much to do anyway"

#### **SELF-CARE CHALLENGES**

Challenge	Percent	Challenge	Percent
Home/garden maintenance	52.7	Breathing	23.7
Sleeping	46.2	Healthy eating	18.9
Mobility	44.5	Communication with health professionals	14.6
Pain	43.1	Social isolation	12.4
Exercise	42.8	Family/whānau /friends not understanding	10.7
Housework	35.5	Health monitoring	10.1
Being overweight	34.4	Taking medication	9.6
Anxiety/depression	25.6	Not smoking	7.3
Lack of money	23.9		



EXPERIENCES
WITH THE
GENERAL
PRACTICE TEAM

#### PARTICIPANT ADVICE

"Have a good relationship with your GP and the staff at the medical clinic"

"Keep asking questions, you need good answers"

"Seek medical help and 'get on with life' "

"Go and see your doctor every three months, whether he/she wants to see you or not"

"Don't stop asking questions until someone listens"



#### INTERACTIONS WITH THE GENERAL PRACTICE TEAM

- 14 statements describing health practitioner behaviours
- Participants asked to rate performance of doctor/nurse at the general practice using a scale from very poor (rated as 1) to excellent (6)
- Example: "When you see the doctor at your general practice, how good are they at spending enough time with you?"
- Other behaviours included introductions, listening, knowing you as a person, knowing your medical history and treatment, asking fully about your symptoms and how you are feeling, involving the patient/family in decision making, explaining problems/treatment in a way the patient can understand, being patient and building a trusting relationship
- Doctors and nurses were rated separately



#### RATINGS OF GPT INTERACTIONS ACROSS THE 3 YEARS

#### **Consistently highest ratings**

#### Operation Doctors:

- making people feel comfortable about physical exams
- Knowing about their medical history and current treatment
- Explaining things clearly

#### • Nurses:

- Being a good listener
- Making people feel comfortable during physical exams

#### **Consistently lowest ratings**

#### Operation Doctors:

- Knowing patients as people
- Learning about and responding to support needs
- Spending enough time

#### • Nurses:

Involving whānau in decision making

# CARE PLANNING AND HEALTH GOAL SUPPORT YEAR 1 PARTICIPANTS

- 19% indicated they had a written care plan 23% of Māori and 18% of non Māori
- 66% did not and 16% were unsure
- Of those with care plans:
  - 89% said they had contributed to developing it
  - ❖ 71% used it for day-to-day health management
  - 84% said a practitioner reviewed it with them: 38% quarterly, 30% annually or less often
- 51% said they had practitioner support for health goals 56% of Māori and 50% of non Māori
- 29% said they had no health goals 25% of Māori and 29% of non Māori

#### CARE PLAN VERSUS NO CARE PLAN: MĀORI AND NON MĀORI

Māori		Non Māori			
	Care plan	No care plan		Care plan	No care plan
Physical health	41.8	41.8	Physical health	43.8	42.2
Mental health	45.4	44.0	Mental health	47.1	46.5
Effect of LTCs on QoL	6.1	6.1	Effect of LTCs on QoL	5.7	5.7
Patient activation	70.3	62.4	Patient activation	67.1	62.2
GPE:GP	5.2	4.4	GPE:GP	5.0	4.6
GPE:N	5.5	4.4	GPE:N	5.0	4.7
GPT support	9.1	7.5	GPT support	8.5	7.8

# SUPPORT VERSUS NO SUPPORT FOR HEALTH GOALS: MĀORI AND NON MĀORI

	Māori			Non Māori	
	Support	No support		Support	No support
Physical health	42.5	40.9	Physical health	44.1	41.0
Mental health	46.2	42.3	Mental health	47.5	45.7
Effect of LTCs on QoL	5.9	6.4	Effect of LTCs on QoL	5.5	6.0
Patient activation	66.2	61.7	Patient activation	65.5	60.6
GPE:GP	5.0	4.0	GPE:GP	5.0	4.4
GPE:N	5.1	4.1	GPE:N	5.0	4.5
GPT support	8.6	7.1	GPT support	8.6	7.2

### **CHANGES TO GENERAL PRACTICE CONSULTATIONS (N=174)**

- Time and 'busyness' of the practice
- Costs
- Treating me well and personalising my care
- The wider general practice team and setting



#### TIME AND 'BUSYNESS' OF THE PRACTICE

- Being rushed and feeling like 'a nuisance'
- Insufficient time
- Practitioner preparation for the consultation
- Wasting of patient time
  - Long wait for appointments especially to see 'your' doctor sometimes weeks rather than days
  - Huge wait in the waiting room

#### **COSTS**

 Excessive costs associated with consultations, other services general practices provide, repeat prescriptions and collecting medicines

 Need for longer or double appointments to get the extra time needed for a long term conditions consultation

A different funding system needed for LTC care

#### GENERAL PRACTICES IN THE THINK HAUORA REGION (JANUARY 2020)

- 30 general practices across Horowhenua, Manawatu, Tararua and Kapiti Coast
- 7 currently enrolling patients, only 1 in PN city
- Costs for an adult without a CSC \$18.50 to \$50 per consultation
- 15 have a lower fee for adults aged >65 years.
   Decreases range from \$1-12



#### THE WIDER GENERAL PRACTICE TEAM AND SETTING

- Care continuity seeing your own doctor or nurse makes a huge difference
- Importance of follow-up shows that somebody cares how you are getting on and can provide the motivation to keep going with the medication/weight loss/exercise/monitoring
- Receptionists' attitudes and helpfulness
- Prescription and billing errors
- Suggestions:
  - Improve the physical environment
  - Get an answer phone
  - Provide a 'full check-up' option within the booking system
  - Have more appointment times for urgent needs
  - ❖Bigger/combined practices are not better







#### PARTICIPANT ADVICE AND COMMENTS

"My main problem is remembering to take medication at the right time"

"Accurate and relevant medication is important"

"With asthma medication my life is normal"

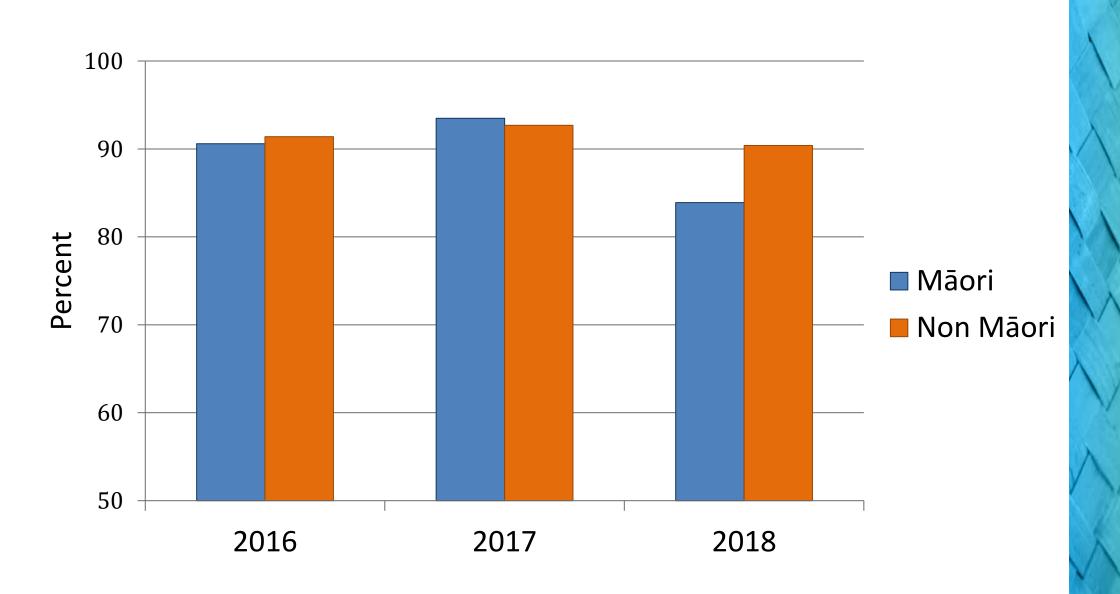
"Follow the medication instructions correctly and if you are unsure ask a professional"

"Meds can have side effects I am not warned of by GP"

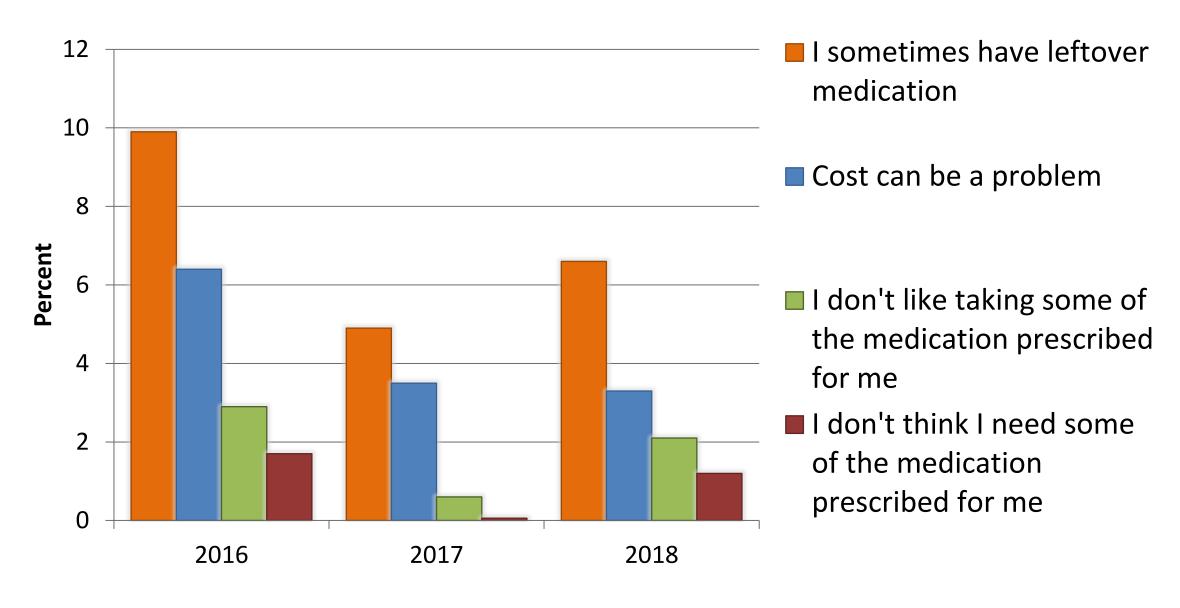
"Always be aware of what medications and treatment you are receiving"



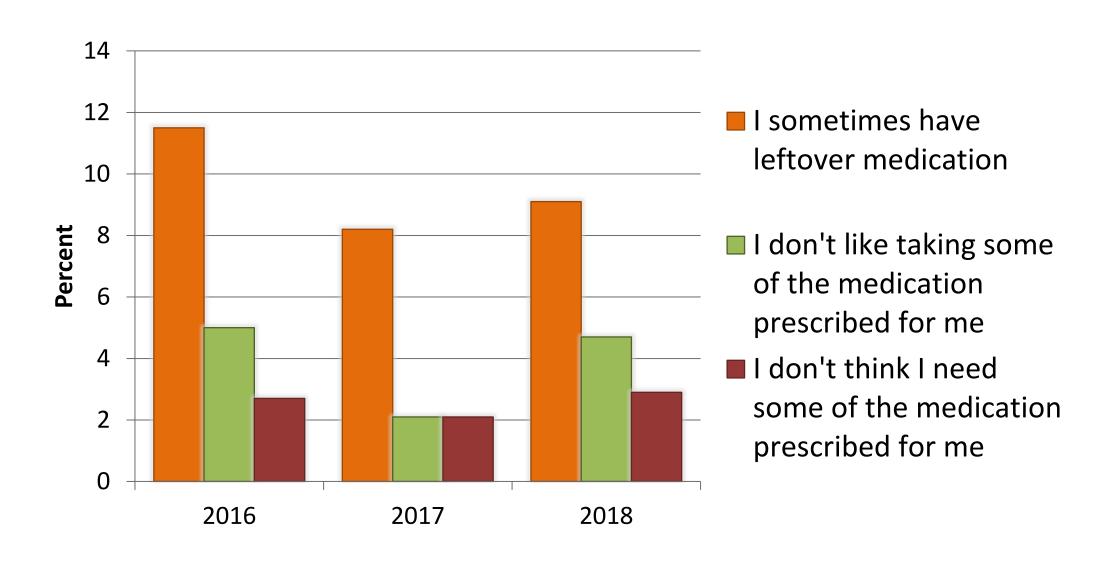
#### TAKING MEDICATIONS AS PRESCRIBED 7 DAYS A WEEK



#### MEDICATION COLLECTION



#### MEDICATION USE ONCE COLLECTED





#### PATIENT ADVICE AND COMMENTS

"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)"

"Feed good info to professionals"

"Get informed about your condition and ask questions"

"I used to eat fatty food, now I no longer want to. It took time and practice"

# PATIENT ACTIVATION MEASURE (PAM)

- 13 statements
- Respondents indicate their level of agreement using a 4-point scale ranging from 'disagree strongly' (1) to 'agree strongly' (4)
- A 'not applicable' option is provided
- O Scores (0 − 100) are calculated for respondents answering at least 10 of the 13 questions using a spreadsheet provided by Insignia Health who licence the PAM

# **LEVELS OF ACTIVATION**

#### • 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.

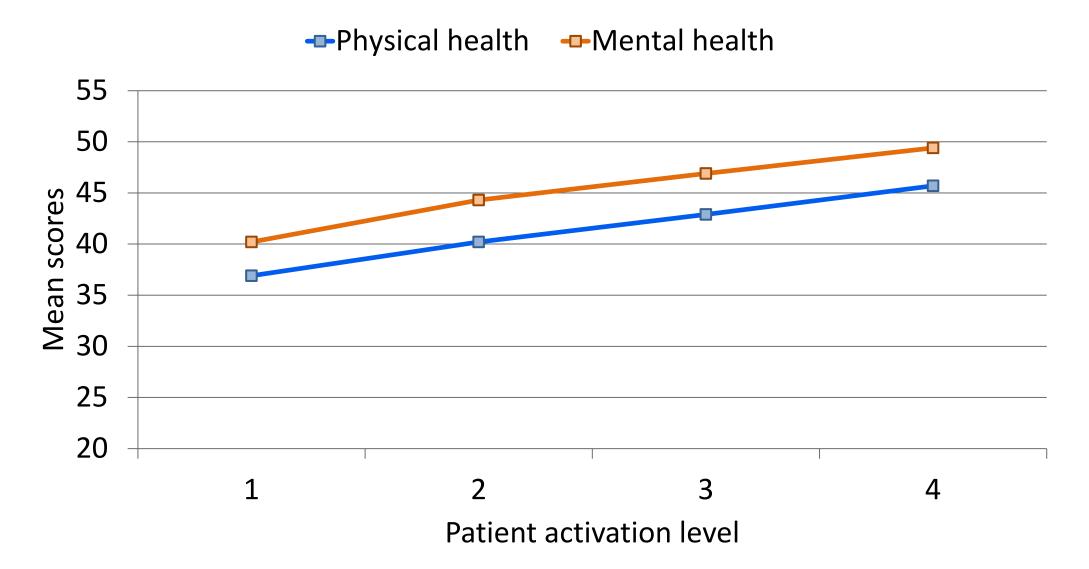
#### • Level 3:

Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.

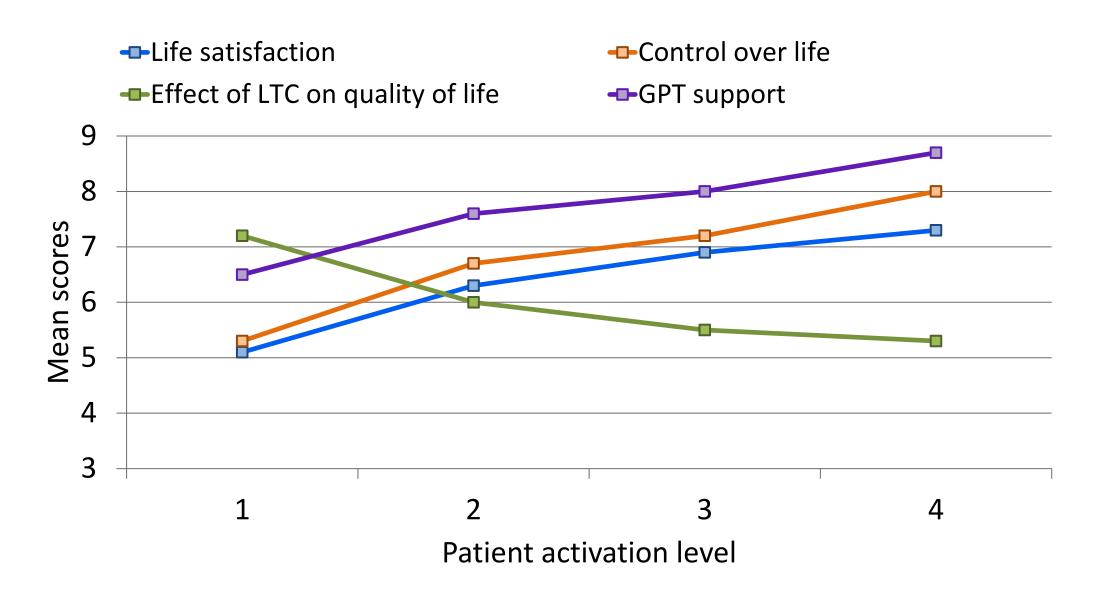
#### • Level 4:

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.

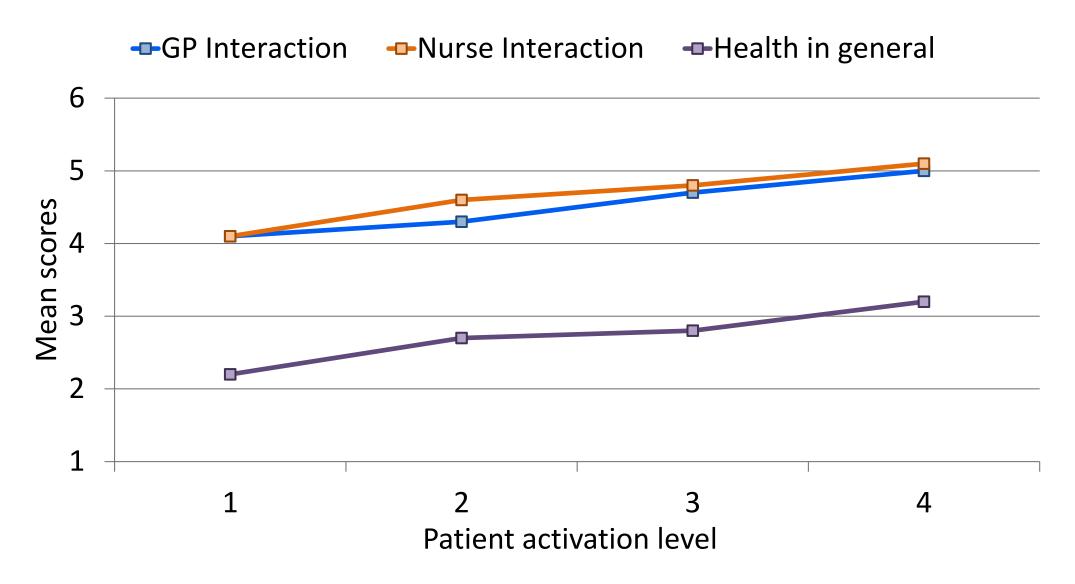
### **PHYSICAL & MENTAL HEALTH**



# **GENERAL PRACTICE TEAM SUPPORT & QUALITY OF LIFE**



### **INTERACTIONS WITH GPS AND NURSES & GENERAL HEALTH**





### **Self-management**

- Acceptance of a LTC influences people's ability to self manage and can take time. Good education to support understanding and accepting a diagnosis, and the provision of self management support (including meeting social needs) could influence people's thinking and movement towards 'making things work'.
- Start by asking 'what are the self care challenges you face?' Also consider more general challenges people face such as low income or family issues. This may identify areas of unmet need that you can act on.
- ❖ As many people with LTCs also have caregiving roles, enquire about this and how it impacts on their wellbeing.
- ❖ It is even more difficult to self manage when pain, sleep problems or anxiety/depression are experienced. Ask if these are present and develop an agreed plan to address these.
- \* People are more likely to accept advice if it is given by their health practitioner, and it is even more likely to be used when decision making is shared.



# **Self-management support**

- Ask people how they want to be included in their health-care decisions and in self management, and enable this to happen
- ❖ If we want people to self manage, practitioners and health services need to provide effective self management support as even the most activated people struggle in the face of life stressors.
- People with lower levels of activation need greater self management support. Good assessment, individualized care planning, tailored education, health coaching particularly for lifestyle change, and regular follow up are key to providing effective self management support.
- Medicines some medications are not being used and practitioners may not know about this. Useful discussions could be had around why meds are not being used and whether there are possible alternatives or discontinuations

## Health redesign

- ❖ People with LTCs are asking for more time and continuity of care. Whilst this is hard to provide from a service point of view, the cost and burden of LTC may continue to rise if we don't come up with innovative solutions.
- High costs of general practice fees for people with LTCs is problematic. Perhaps consider a reduced fee for repeat LTC related appointments.
- ❖ People want services and practitioners to recognize that their time is important too. Quality improvement activities aimed at reducing 'waiting' or better use of 'waiting' time is recommended.
- ❖ People appeared to be 'more activated' when an advanced nurse took a major role in their care

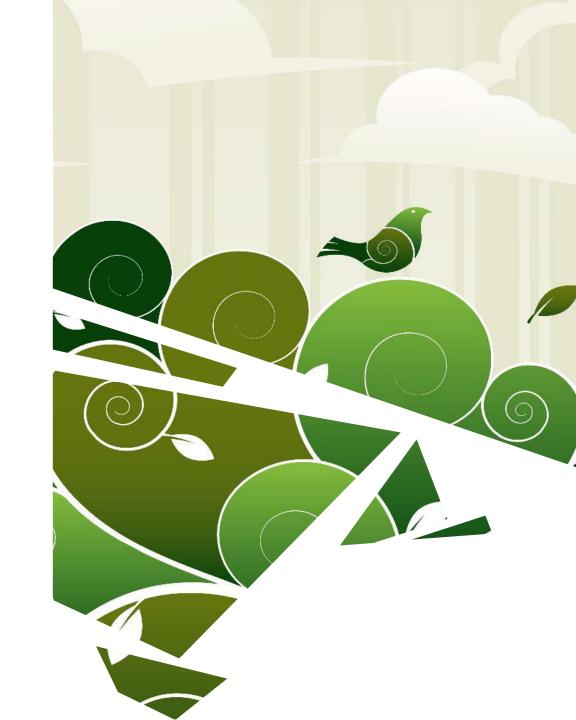


# Acknowledgements

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### **REFERENCES**

- Hayes, R.D, Bjorner, J. B., Revicki, D. A., Spritzer, K. L., & Cella, D. (2009).
   Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. Quality of Life Research, 18(7), 873-80.
- Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004).
   Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39, 1005-1026.
- Zwier, G. (2013). A standardized and validated patient survey in primary care: Introducing the New Zealand General Practice Assessment Questionnaire (NZGPAQ). The New Zealand Medical Journal, 126(1372), 47-54.
- Hunt, S. M., & McEwan, T. (1980). The development of a subjective health indicator. *Sociology of Health and Illness*, 2, 231-246.