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REPORT TO THE WELL DUNEDIN TRUST

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**PATIENT AND HEALTH PROVIDER
PERSPECTIVES ON THE PROVISION OF
CHRONIC ILLNESS CARE IN THE
SOUTHERN REGION**

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EXECUTIVE SUMMARY

This project sought to gain an understanding of the views of general practitioners, practice nurses and patients regarding the provision of chronic illness care in the Southern region.

All general practitioners and practice nurses in the region (302 PNs and 335 GPs) were mailed a self-report survey. Of these, 32% responded. Five hundred patients with multiple long term conditions enrolled on the Care Plus programme were also mailed the same self-report survey. In addition to the survey a group of 8 patients completed a daily diary for two months. They recorded their experiences of interactions with health care services and their daily experiences of living with multiple chronic conditions.

Analysis of the returned surveys identified the existence of differences in perceptions of the provision of chronic care management as assessed by survey. Areas of significant difference related to patient activation and the provision of follow-up and coordinated care. Both these elements are pivotal to effective chronic illness care and consequent health outcomes.

Analysis of the text data from the diaries highlights the unique and fluctuating needs of those living with multiple chronic conditions. As well as coping with the management burden of multiple chronic conditions, these individuals described the importance of maintaining functional ability. The significance of social participation was also emphasised, as was the importance of maintaining a sense of self.

Recommendations for the Southern District Health Board and the Southern Primary Health Organisation are presented for consideration.

PROJECT BACKGROUND

In November 2011, the Director of the Centre for Health Systems responded to an Expression of Interest (EOI REF 1070) by Well Dunedin Trust. The proposal's focus was the study of chronic illness care provision in the Southern region, with the key aim being to study the provision for chronic illness care from a patient and provider perspective. The proposal was accepted and funded. This report represents the culmination of the project.

PROJECT AIM AND OBJECTIVES

Aim

To study the organisation and coordination of chronic illness care in the Southern region from the perspective of patients and primary health care providers.

Objectives

1. To design and conduct a survey of patients to gather quantitative data on chronic illness care provision and care coordination from the patient perspective;
2. To design and conduct a survey of practitioners to gather quantitative data on chronic illness care provision and care coordination from the provider perspective;
3. Design, recruit participants and conduct a patient tracking study to gather qualitative data on how systems of care function from a patient perspective.

DELIVERABLES

The project included the following milestones:

1. Completion of a cross-sectional patient survey in the Southern region;
2. Completion of a primary health provider survey in the Southern region to encompass all general practitioners (GPs);
3. Completion of a patient tracking study in the Southern region, involving the tracking of twenty patients living with chronic conditions for a period of up to six months, with the aim of mapping the pathways and processes of care the patients engage in.

Overview of deliverables

Surveys

The patient population of interest for this project were patients with chronic conditions. The patient survey was sent to a random cohort of 500 patients enrolled in Care Plus.^A Care Plus

^ACare Plus is a capitated funding stream introduced in 2004 to provide additional finance to primary care to enable it to offer extended consults to those with high health care needs.

evolved from a proposal from the Independent Practice Association Council (IPAC) in 2002 to address the disadvantage some people with high health needs may face resulting from the newly established funding formulas for Access and Interim Primary Health Organisations (PHOs).

The health provider population of interest was all GPs working in the Southern Region. However, due to the significant contribution practice nurses (PNs) make to chronic illness care provision, this health provider group was also surveyed. The research team felt that this was crucial to gain a clear understanding of chronic care provision within the region's primary care services.

An extensive search was made of the literature to identify the most appropriate survey instrument. The Patient Assessment of Chronic Illness Care (PACIC) was chosen as the survey tool for both population groups of interest.(1) This is a well validated survey instrument. A recent study comparing 37 questionnaires considered it one of the top two most applicable questionnaires for use with this population group.(2) However, the research team were interested in the possibility of directly comparing the responses from health professionals with those from patients, enabling the comparison of views between the two groups on the same components of care. To this end, the modified version of the PACIC was used. (3) The modified version was developed by researchers from Massey University for use in New Zealand and had previously been used to compare responses between health provider and patient groups.(4) The questionnaire utilises a Likert Scale, with the following ratings and scores: none of the time = 1; a little of the time = 2; some of the time = 3; most of the time = 4 and always = 5.

In concordance with postal survey best practice, multiple follow up surveys were posted, incentives were also employed with both groups and a stamped addressed return envelope provided.(5-7)

Patient tracking

Following consideration of various ways to map the pathways and processes of care patients living with long term conditions interact with, such as, clinical audit of primary and tertiary care notes, or health care process mapping,(8) it was decided to use solicited participant diaries. Solicited patient diaries allow for the recording of healthcare interactions, as well as the day to day lived experience of managing multiple chronic conditions in real time.(9-11) Solicited participant diaries are written with the research topic in mind. The participant completes the diary to reflect issues of interest to the researchers and with the knowledge that the diary will be read and interpreted by another person.(11) This data collection method acknowledges that the patient is the only person who experiences the full course of a health

care issue and all the interactions and management strategies that accompany it. Diaries, therefore, enable researchers to get close to the contemporaneous experiences of the patient. While a novel data collection approach, this method has many advantages, including:

- The data reflects the patient's point of view;
- Reduced recall error;
- Reporting of acute and chronic episodes that do not require medical attention;
- Provide a more comprehensive view of people's lived experiences with chronic conditions, as well as their health behaviours.(10, 11)

Obstacles also exist in relation to this data collection method, including:

- Participants must have certain abilities, e.g. reading and writing ability, physical capacity to complete the task;
- Reporting burden on participants;
- Time burden of data collection;
- Complexity of data analysis.(10)

In view of the information gleaned from the literature regarding reporting burden and time burden, it was decided to limit the data collection period to two months of daily diary entries and the research area to Dunedin-Mosgiel and surrounds. All survey respondents from this area (n=59) were contacted by phone to ask if they would consider being part of the diary study. Fourteen agreed to look at an information pack and of this group eight agreed to take part. The eight participants comprised four men and four women; had a mean age of 75 years; age range 58-94 years; and all had multiple morbidities.

Participants received an initial visit from the research assistant (RA) during which time they were familiarised with the diary, the areas of research interest – everyday situations and contacts with health care providers and services, and the requirement to record their self-rated health daily. The RA answered any questions the participant had and asked them to complete the COOP/WONCA questionnaire, a 6 item questionnaire which measures the following dimensions of functional health status: physical fitness, feelings, daily activities, social activities, change in health and overall health.(12) This questionnaire was also completed at the study midpoint and completion. When the RA collected the completed diaries, an interview also took place with the participants to ask them about the experience of keeping a diary for a research study. The interview schedule can be seen in Appendix one.

KEY PERFORMANCE INDICATORS

The key performance indicators laid out in the contract were as follows:

KPI number	Description	Process	Measurement	Completed
1	Complete patient survey	Suitable patient survey identified via literature search	Data collected & analysed	✓
2	Complete provider survey	Suitable health provider survey identified via literature search	Data collected & analysed	✓
3	Complete patient tracking study	Literature search identified novel process for collecting this information	Data collected & analysed	✓
4	Design a model of care	Analysed data recommended a model of care	Model delivered	✓

RESULTS

Surveys

A data analysis framework was developed. Based on this, data from the surveys were analysed using SPSS version 19.

One hundred and ninety-eight health professionals (32%) and 259 patients (52%) responded. The following two tables provide an overview of the characteristics of the health provider and patient responders to the surveys, with additional related information presented under each table.

TABLE 1: CHARACTERISTICS OF HEALTH PROFESSIONAL RESPONDENTS

Variable	Frequency	Percent
Practice nurse	104	52.3%
General practitioner	94	47.2%
Female	149	74.9%
Male	47	23.6%
Solo practice	31	15.6%
Multiple practice	160	80.4%
Location of practice		
Central Otago/Lakes	22	19.1%
Southland/Gore/Invercargill	27	29.7%
Dunedin/Clutha/North Otago	77	50.2%
Multiple locations	1	0.5%

The mean age for health professionals was 49 years, with a standard deviation of 10.6 years

Seventy-seven percent of practices responded to the survey by returning a minimum of one survey. Although the 32% response rate from GPs and PNs was somewhat disappointing, it is in line with contemporary survey response rates from GPs. Cook et al found that GPs in the US, Canada, Australia and New Zealand were lower responders to surveys,(13) while a recent Australian study using two approaches found response rates of between 25.8% and 32.5%.(14)

TABLE 2: CHARACTERISTICS OF PATIENT RESPONDENTS

Variable		Frequency	Percent
Male		122	47.1%
Female		137	52.9%
Ethnicity			
Maori		18	7.1%
NZE		226	88.6%
Samoan		2	0.8%
Cook Island Maori		2	0.8%
Chinese		1	0.4%
Other		6	2.4%
Self rated health			
Excellent		4	1.6%
Very good		44	17.3%
Good		120	47.2%
Fair		74	29.1%
Poor		12	4.7%

The mean age of patient responders was 71.5 years, with a standard deviation of 12.5 years. The age range was 31-97 years. Generally respondents were married (57.2%), 18% were single and 8.6% were widows or widowers. The majority were retired (65%), with

26.6% in either full or part-time employment or self-employed. Just under a third of this cohort reported they had no formal qualification, with 11.6% reporting they had a university degree. The majority (64.4%) were living on a household income of \$35,000 or less, with only 7% having access to a household income of \$80,000 or more. Data analysis identified an inverse statistically significant relationship between self rated health and age, ($P=0.043$) and a trend towards statistical significance in relation to household income and self-rated health ($P=0.564$).

Participant diaries

All eight participants completed their daily diaries. One participant found diary writing challenging. However, he agreed to complete an audio-recorded semi-structured interview.

FINDINGS

Survey findings: health professional

Univariate analysis of the independent variables within the health professional survey which included age, gender, professional role, number of years working in general practice, type and location of practice, revealed that professional role, GP v PN, drove the majority of statistically significant results. Nurses were statistically more likely to state they provided the components of chronic illness care listed below, most of the time or always, compared to general practitioners.

Domain: Patient activation

- Question 4: Asked patients if they ever have difficulty understanding information provided to them related to their medical condition/s, ($P=0.005$).

Domain: Delivery system

- Question 1: Provide a written list of things they should do to improve their health, ($P=0.009$).
- Question 3: Show them how what they do to take of themselves influences their condition, ($P=<0.001$).

Domain: Goal setting

- Question 1: Ask them to talk about their own goals in caring for themselves, ($P=<0.001$).
- Question 2: Help them to set specific goals in caring for themselves, ($P=<0.001$).
- Question 3: Give them a copy of their treatment plan, ($P=0.0020$).

- Question 4: Encourage them to attend a specific group or class to help them cope with their illness, ($P < 0.001$).

Domain: Problem solving

- Question 1: Consider their values and their traditions when recommending treatments, ($P = 0.002$).
- Question 3: Help them to plan ahead so they can take care of themselves even in hard times, ($P = 0.003$).
- Question 4: Ask them how their chronic illness affects their life, ($P = 0.023$).

Domain: Follow up/coordination of care

- Question 1: Contact them after a visit to see how things are going, ($P = 0.004$).
- Question 2: Encourage them to attend a programme in the community that could be helpful, ($P < 0.0010$).

Domain: Cultural sensitivity

- Question 1: Appropriately involve the whanau/family in the care and management of their condition, ($P = 0.001$).
- Question 2: Gather information or feedback from the whanau/family members, ($P = 0.001$).
- Question 3: Educate the whanau/family on prevention of the chronic condition where appropriate, ($P = 0.013$).
- Question 5: Alter or modify your care due to their ethnicity, ($P < 0.001$).
- Question 6: Offer another culturally appropriate service if there is one available, ($P = 0.002$).
- Question 7: Ask them if there are any cultural or ethnic issues that you need to be aware of, ($P < 0.001$).

General practitioner gender did drive one statistically significant result. Male GPs were more likely to state they felt satisfied they were doing a good job organising their patients' chronic illness care, most of the time or always, compared to their female counterparts ($P = 0.022$).

No statistical relationship was identified based on age, years of working in occupation or type of practice, or solo versus multi-partner practice.

It is perhaps unsurprising that PNs rated their provision of chronic illness care higher than their GP colleagues. During the roll out of Care Plus funding there was a concerted focus on highlighting the potential role primary care nurses could play in the provision of chronic care

management.(15) Care Plus has overwhelmingly been considered an initiative led by PNs and a 2006 evaluation of the roll out of Care Plus found that of the practices surveyed, half reported the “programme” was either driven by nurses or was an exclusively nursing service.(16)

Using the goal setting domain as an example, a consideration of why PNs generally scored their chronic illness care provision higher than GPs is provided. Goal setting is a component of a care plan and developing a care plan is a task generally undertaken by PNs. Care planning is an important component of chronic illness care, supporting improved self-management skills via the processes of shared decision making, goal setting and action planning. A personalised care plan ensures the patient receives care that reflects their needs, preferences and lifestyles.(17) In the 2006 review of Care Plus it was noted that, “patients were treating their Care Plans as an important record of events.(16)

Overall, the questions where the PNs score was statistically higher than that of the GPs generally reflects 2 factors: 1) PNs are generally delivering Care Plus therefore making use of the extended appointments which enable them to provide the aspects of care outlined by the questions and especially in relation to the aspects where they scored themselves higher; and 2) nursing is underpinned by a more holistic and less bio-medical framework than medicine.

The returned survey forms contained multiple comments. These comments were entered into NVivo 10 to assist with data management, then analysed and coded using a general inductive approach.(18)

The key categories that emerged following the inductive analysis were:

1. Frustrations
2. Challenges to chronic care management
 - a. Patient challenges
 - b. Time
 - c. Misunderstanding
 - d. Lack of continuity/coordination and linkages
3. Enablers of chronic care management
 - a. Teamwork
 - b. Care plus
4. Areas for improvement

This next section provides a selection of quotes illustrating the categories listed above.

Frustrations

“In an ideal world we might say that all of these things are important and that this type of care (follow up) should be provided. However, this is not an ideal world and we do the best we can, within the time and financial constraints”. M GP

“We live in a far from perfect world. Our resources to provide care are limited and the demands upon services are great. In a perfect world we would be able to do a lot more, and to a higher standard”. M GP

“Questions cannot readily be answered when we are working in such a critically pressurised environment”. F GP

Challenges to chronic care management

Patient challenges

“The patient will want their funny mole, turned ankle looked at, in the same slot you have earmarked for their chronic condition. (They think it is just a repeat of my pills). Hospital specialists in outpatient clinics can dodge the above by saying, “ask your GP about that”. F GP

Time

“Time constraints have a large impact on helping the client organise their care”. F PN

“I don’t always do as good a job as I’d like because of time constraints”. F GP

Misunderstanding

“While patients value what I say, if it is backed up by the GP, then they really value it”. F PN

“Those with chronic conditions usually have several chronic conditions, are often on a limited income and are less able/willing to attend frequently. This results in cramming a lot into one consultation, limiting the provision of items like written lists and instructions, checking full understanding etc or seeking their views/barriers etc. Most of these consults take 20-30 minutes in a 15 minute slot with no additional funding – Care Plus does not meet the need. M GP

Lack of continuity/coordination and linkages

“We don’t always know about appointments with other health professionals”. F PN

“There are some good cultural agencies here, but no feedback, unless insisted upon. Community resources must be at a high functional level”. F PN

“I encourage groups if available in the area, but often not available”. F PN

“Sometimes services are lacking or overlooked”. F PN

Enablers of chronic care management

Teamwork

“Depending on the condition/s other team members include: pharmacists, continence nurse, Arthritis/Alzheimer’s/Parkinson foundations, cardiac or pulmonary rehabilitation etc. F GP

“We use the Care Plus booklet (to provide written list) and the nurse will discuss and document exercise goals etc. I provide them with a written list of their medication changes and annotate the script so the chemist knows what changes I have made”.
F GP

Care Plus

“We send out three month recall letter to Care Plus patients inviting them to come in for a Care Plus visit at a reduced fee of \$15. We alternate GP/PN (same ones) which provides continuity of care and builds relationships. Patients can phone their nurse case manager between visits if concerned”. F PN

Areas for improvement

“I probably should ask them if they ever have difficulty understanding information provided to them related to their medical condition/s”. F GP

“Re show them how what they do to take care of themselves influences their condition, I should start to tell them”. F PN

“Ask them how their chronic illness affects their life, I should definitely ask more often”. F GP

Discussion of thematic analysis

The comments contained within the survey point to a high level of dissatisfaction within the sector in relation to the provision of chronic illness care, especially amongst GPs. Previous studies have highlighted similar dissatisfaction, and a recent paper stated that in primary care “Joy is in short supply”.(19) Skinsky and colleagues emphasise that burn-out has been linked to lower patient satisfaction and reduced compliance to treatment plans and as such, dissatisfaction of health providers should be of concern.(19) In a recent paper by Entwistle and colleagues, the importance of how health service staff are feeling is illustrated by the following quote which is a synthesis of their conceptual framework regarding which experiences matter to patients.

The characteristics and actions of health care services and staff, and the ways they relate to patients, have implications for patients’ experiences of being enabled (or not) to feel, be and do what they value feeling, being and doing – in the course of their health care contacts and beyond. Experiences of health care delivery matter because they shape and represent capabilities that are key to how well people’s lives can go.(20)

The first three sub-themes (patient challenges, time and misunderstanding) encompassed within the theme, challenges to chronic care management, suggest a misunderstanding of what Care Plus is and confusion around the roles of the GP, PN and patient.

Care Plus was launched by the Ministry of Health in 2004 with one of its four specific aims being to improve management of chronic conditions.(21) Care Plus is a funding stream of

additional capitated funds to target enrolled patients with the highest health needs. The eligibility criteria can be viewed in Appendix two. Care Plus funding was to provide:

- Low or reduced cost access to nurse and/or doctor expertise and time
- Continuity of care that includes a Care Plan jointly developed with the patient and on-going support through pre-planned regular reviews
- Advice on improving health outcomes through better self-management, with support to identify and meet realistic personal health goals

Care Plus is not a model of chronic illness care; it is an enabler of chronic illness care via the provision of additional funding.(22) The comments appear to indicate that GPs do not generally make use of the extended appointment times offered by the additional Care Plus funding; some patients are not clear about the function of the extended consult; extended consults appear to be considered a “thing nurses do”; and the role of the nurse in chronic care management is not recognised, with even nurses downplaying their valuable contribution to chronic illness care, compared to that of their medical colleagues. A recent U.K. study found that patients with chronic conditions frequently frame their preferences and expectations of their chronic illness care within a biomedical paradigm, which the authors suggest may influence their experiences of nursing input into their care.(23) Wilson and colleagues conclude that autonomous nursing practice requires support and endorsement to society generally, if there is to be a shift in societal expectation and trust in the nurses capacity and capability to deliver chronic disease management care.(23)

Another challenge to providing effective chronic illness care was the provision of continuous and coordinated care, as well as the lack of functional linkages or in some cases the absence of linkages to community based services.

Fragmented health care services which are dislocated from related support services, such as social services, can contribute to poor health outcomes,(24) especially for vulnerable individuals with multiple chronic conditions whose needs are part medical, part psychological and part social.(25) However, addressing fragmentation and improving coordination of care is a complex task. Coordination needs to occur horizontally at an organisational and systemic level, but also vertically, frequently reflecting disease progression.(24) Strategies to address our fractured health system need to address financing and planning as well as service delivery.(26) Notwithstanding attempts to address fragmented health care in New Zealand, integration remains a vision. Kodner and Spreeuwenberg(25) compiled a continuum of strategies from macro to micro which can be used to foster integration of care, as outlined in table three below. Many of these strategies are in place in pockets across New

Zealand, but the spread is not uniform and no one location has uniformly implemented all the suggested strategies.

TABLE 3: CONTINUUM OF INTEGRATED CARE STRATEGIES

Domain	Strategy
Funding	Pooling of funding (at various levels)
	Repaid capitation (at various levels)
Administration	Consolidation/decentralisation of responsibilities/functions
	Inter-sectoral planning
	Needs assessment/allocation chain
	Joint purchasing or commissioning
Organisational	Co-location of services
	Discharge and transfer agreements
	Inter-agency planning and or budgeting
	Service affiliation or contracting
	Jointly managed programmes or services
	Strategic alliances or care networks
Service delivery	Consolidation, common ownership or merger
	Joint training
	Centralised information, referral and intake
	Case/care management
	Multidisciplinary/interdisciplinary teamwork
	On-call coverage
Clinical	Integrated information systems
	Standard diagnostic criteria
	Uniform, comprehensive assessment procedures
	Joint care planning
	Shared clinical records
	Continuous patient monitoring
	Common decision support tools
	Regular patient/family contact and on-going support

Linkages to non-governmental organisation and community services that could assist primary care teams to support individuals develop their self-management skills appear to be lacking or absent. With the current workforce challenges it is important the health system looks outside itself to community programmes and resources that can assist in enhancing the care it provides to chronically ill patients and avoid duplication of service delivery. Sometimes, these services are present; however, as alluded to in one of the quotes, these community resources can be overlooked. Research has demonstrated that some of the reasons underpinning the lack of referral to community based services is fear of further

fragmentation of care, concern as to whether or not the programme/service adds value to the usual care and concerns regarding continuity of care.(27)

The text data also pointed to enablers of chronic illness care, namely, teamwork and the additional capitated funding known as Care Plus. Teamwork is central to primary health care and essential for effective management of chronic conditions.(28) Effective interdisciplinary team work improves coordination of care, enhancing the health care experiences of those with chronic conditions who frequently receive services and care from multiple providers.(29) The quotes related to teamwork reflected the partnership between GP and PN within general practice, as well as teamwork with those outside the physical structure of the general practice such as the community pharmacist and nurse specialists. A key challenge within the New Zealand health system is the misalignment of funding models which neither support nor promote interdisciplinary teamwork across health and social care sectors making it challenging to achieve.(28) It was notable that no quote explicitly mentioned the patient as part of the team, although primary care professionals may well implicitly consider this a given. However, in a recent study by Pullon et al., the role of the patient was perceived differently by GPs and PNs. General practitioners consider the patient as a recipient of care; nurses, however, viewed them as team members.(30) A partnership between patient and health professional is a vital underpinning principle of effective chronic illness care.(31) One of the original premises regarding the additional Care Plus funding was that it would facilitate increased opportunities to enhance partnerships between health provider and patient.(21)

Care Plus was also seen as an enabler of chronic illness care provision. When originally launched in 2004, the additional funding was expected to enable improved access to primary care for those with the highest health needs; enhanced continuity of care and partnership working between health provider and patient, as well as between health professionals; and improved self-management skills through the development of a jointly agreed care plan.(21) Care Plus was therefore envisaged as an enabler of chronic care provision. It is not however, a model of chronic care, but a component of a chronic care approach.(22) There is perhaps a perception within the healthcare community that Care Plus is a chronic care management model, and this perception may be stymieing the need to develop a more coordinated approach to the provision of health and social care to those living with chronic conditions. The absence of a robust longitudinal evaluation of Care Plus is a significant gap in our understanding of the impact of the provision of these additional funds to the sector for those with highest health care needs. Current PHO data only provides information regarding the uptake of the funding; there is no tracking of associated health outcomes.

Survey findings: Patients

No statistical relationships of significance were identified between on any of the demographic variables collected from individuals and the domains of the M-PACIC. Significant differences were, however, identified between the combined mean scores of the two health professional groups and those of the patient group. Table four provides an overview of the mean scores of each health professional group and patients. Appendix three contains the frequency of response tables.

TABLE 4: COMPARISON OF MEAN SCORES BETWEEN GROUPS

		Patient activation score*	Delivery system score	Goal setting score	Problem solving score	Follow up score*	Cultural sensitivity score*	Overall mean
Practice nurse	Mean	3.89	3.49	3.33	3.80	3.50	3.32	3.6
	N	101	104	99	100	103	97	
	Std D	.68	.60	.74	.76	.65	.83	
GP	Mean	3.84	3.21	2.81	3.42	3.24	2.79	3.2
	N	93	94	88	91	89	88	
	Std D	.55	.52	.55	.62	.51	.65	
Patients	Mean	2.61	3.17	2.53	3.02	2.15	1.57	2.5
	N	242	243	239	230	227	202	
	Std D	1.26	1.21	1.21	1.36	1.13	0.95	

Highly statistically significant differences were detected across the following domains:

- Cultural sensitivity: $P < 0.001$ (mean score difference of 1.5)
- Patient activation score: $P < 0.001$ (mean score difference of 1.25)
- Follow up score: $P < 0.001$ (mean score difference of 1.22)
- Goal setting score: $P < 0.001$ (mean score difference 0.5)
- Problem solving score: $P < 0.001$ (mean score difference 0.61)

In relation to delivery system there was a statistical difference detected ($P = 0.0432$) but the mean difference in scores was only 0.19.

The returned survey forms contained multiple comments. These comments were entered into NVivo 10 to assist with data management and analysed and coded using a general

inductive approach.(18) The findings from the thematic analysis will be presented later in this report. The following section considers the key differences in the mean scores.

Discussion of mean score differences

This next section will focus discussion around the three domains where the mean score differences were greater than 1.0, namely: cultural sensitivity; patient activation and follow up.

- Cultural sensitivity: $P < 0.001$ (mean score difference of 1.5)
- Patient activation score: $P < 0.001$ (mean score difference of 1.25)
- Follow up score: $P < 0.001$ (mean score difference of 1.22)

Cultural sensitivity

When modifying the PACIC for use in New Zealand, Carryer et al.,(3) added in a set of questions related to the provision of culturally sensitive care. These questions were developed by the research team in collaboration with Maori nurses. These questions did not appear to work well with either health professional or patient respondents. Many patients scored the questions included in this domain very low. However, comments were frequently added by patient respondents that they did not feel the question was applicable to them as they were New Zealand European. Health professionals frequently expressed annoyance the questions in this domain especially the question asking whether they altered or modified their care due to a patient's ethnicity. Comments were frequently documented around not providing different care based on a patient's ethnicity. One GP did understand the intent of the question, documenting that he did not alter the care he provided but delivered it differently based on a person's ethnicity. Although the findings from the analysis of the cultural domain questions are debatable, the finding from the question already included in the PACIC around consideration of values and traditions does suggest that this aspect of delivering care is not always provided in a satisfactory manner. Sixty-one percent of health professionals responded that they considered a patient's values and traditions most of the time or always, yet only 48% of patients perceived that their values and traditions were considered in the provision of their care.

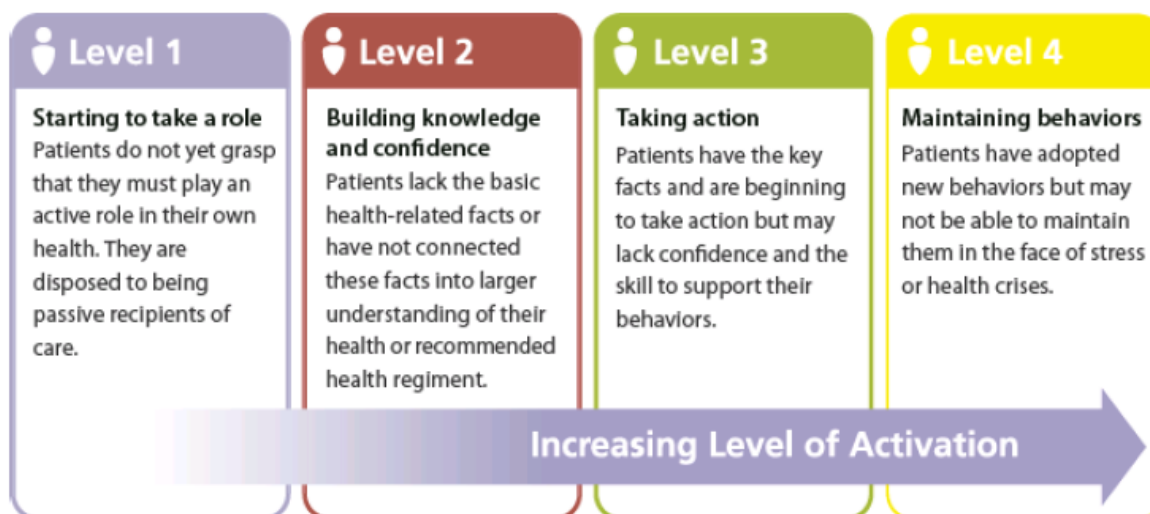
Patient activation

The difference in patient activation mean scores between health professional responders to the survey and patient responders is concerning. Patient activation refers to a person's willingness to engage in and their capacity to take independent actions to manage their health and healthcare.(32) Effective chronic illness care requires patients to be informed and active in the management of their conditions.(31) Developed by Judith Hibbard and colleagues at the University of Oregon, the Patient Activation Measure (PAM) assesses people's knowledge, confidence and skills for self-management; essentially gauging their

understanding of their role as manager of their own health and health care. The measure assesses activation at four stages:

- **Stage 1 – Believes Active Role Important:**
Taking an active role in my own health care is the most important factor in determining my health and ability to function.
- **Stage 2 – Confidence and Knowledge to Take Action:**
I am confident that I can follow through on medical treatments I need to do at home.
- **Stage 3 – Taking Action:**
I am able to handle symptoms of my health condition on my own at home.
I have made the changes in my lifestyle like diet and exercise that are recommended for my health condition.
- **Stage 4 – Staying the Course Under Stress:**
I am confident I can figure out solutions when new situations or problems arise with my health condition.
I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.(32)

FIGURE 1: DEVELOPMENTAL STAGES OF ACTIVATION



Source: J.Hibbard, University of Oregon

For patients in levels 1 and 2 action plans focus on knowledge, beliefs, awareness of their role in managing their health, while in levels 3 and 4 action plans focus on the initiation of new behaviors and maintaining other health promoting behaviors. This is illustrated in the figure below.

FIGURE 2: PATIENT ACTIVATION SUPPORT GUIDE

Level 1	<p>Develop Basic Knowledge, Self-Awareness, & Confidence</p> <p>Individual becomes self-aware of own behaviors and symptoms. Focus coaching on the relationship between symptoms and behaviors, building self-confidence and awareness. The individual should choose the area(s) they want to work on.</p>
Level 2	<p>Increase in Knowledge, Initial Skills Development</p> <p>Individual develops the knowledge, skills and confidence needed to master new self-management competencies. Coaching should focus on helping the individual learn to monitor symptoms, behaviors and adverse triggers - and adjust accordingly. Focus on taking small steps.</p>
Level 3	<p>Initiate New Behaviors</p> <p>Individuals initiate new health promoting behavior(s) and work to further refine techniques to monitor and adjust. Coaching should focus on providing encouragement, noticing successes, and problem solving.</p>
Level 4	<p>Maintaining Behaviors & Techniques to Prevent Relapse</p> <p>Individual strives to maintain desired health-related behaviors over time and learn to anticipate difficult situations that will arise. Coaching should focus on the issues that make it hard to stick to correct behaviors and to help the individual trouble-shoot.</p>

Using findings from their national survey, Hibbard and colleagues identified cut-off points for the four stages of patient activation. These are:

- Stage 1: believes patient role important (PAM score 47.0 or lower);
- Stage 2: confidence and knowledge to take action (PAM score 47.1 to 55.1);
- Stage 3: taking action (PAM score 55.2 to 67.0);
- Stage 4: staying the course under stress (PAM score 67.1 and above).

Multiple studies of patients with a range of conditions, across various countries and from a variety of socioeconomic backgrounds have empirically demonstrated the association between a higher patient activation score and the following:

- Engagement with more preventive health care behaviour such as, participation in regular screenings and immunisations;
- Engagement in more healthy behaviours, such as eating a healthy diet and participating in regular physical activity;
- Engagement in more health information seeking behaviours, such as seeking information on their health conditions;
- Improved health outcomes such as blood pressure, HbA1c and lipids levels within normal ranges;
- Improved health care experiences.

Patients with lower patient activation scores are three times more likely to have unmet health needs, and twice as likely to delay seeking medical care.(32)

A diabetic patient’s level of activation has also been shown to predict health care utilisation and health outcomes two years into the future.(33)

FIGURE 3: PATIENT ACTIVATION ASSOCIATION WITH HEALTH CARE UTILISATION AND HEALTH OUTCOMES TWO YEARS INTO THE FUTURE FOR DIABETICS.

	% change for a 1 point change in PAM Score	10 Point Gain in PAM Score 54 (L2) vs. 64(L3)	<i>P</i>
Hospitalization	1.7% decline	17% decreased likelihood of hospitalization	.03
Good A1c control (HgA1c < 8%)	1.8% gain	18% greater likelihood of good glycemic control	.01
A1c testing	3.4% gain	34% greater likelihood of testing	.01
LDL-c testing			

Levels of activation have been found to vary by age, income, education groups, and chronic condition.(34). The table below illustrates the variation of patient activation by chronic condition from a recent U.K. study. Table 5: variation in patient activation levels by chronic condition(34)

PAM score	Arthritis (n=930) %	High blood pressure (n=893) %	High cholesterol (n=607) %	Chronic pain (n=605) %	Angina (n=348) %	Depression (n=376) %	Lung disease (n=314) %
Stage 1	14.2	11.8	13.3	19.8	11.8	20.6	13.5
Stage 2	37.2	33.4	31.1	38.5	35.1	36.8	35.8
Stage 3	32.3	34.3	37.7	26.5	39.9	28.5	36.1
Stage 4	16.3	20.4	18.0	15.2	13.2	14.1	14.5
PAM score	Diabetes (n=260) %	Digestive problems (n=291) %	Bowel problems (n=169) %	Bladder problems (n=213) %	Cancer (n=109) %	Stroke (n=68) %	
Stage 1	8.9	19.9	8.9	15.7	6.3	12.1	
Stage 2	30.5	39.1	39.1	35.6	41.4	32.8	
Stage 3	37.9	25.6	34.3	34.0	35.1	43.1	
Stage 4	22.7	15.4	17.8	14.7	17.1	12.1	

Health coaching plays a significant role in patient activation yet the survey highlighted different perceptions of how frequently this was occurring. In the survey 65% of health professionals reported they showed patients how what they do to take care of themselves influences their condition, most of the time or always. Whereas only 46% of patients reported

that they were shown how what they did to take care of themselves influences their condition.

In summary health goals and targets will not be reached without efforts to improved patient engagement in managing their health and health care. This is also key to ensuring a sustainable health care system.

Follow up and coordination of care

The perceptions of health provider responders to the survey and patient responders regarding the provision of care coordination and follow up differed significantly. However, given that the concept of coordinated care is neither clearly defined nor well understood, perhaps this is not too surprising. The term is used concurrently and interchangeably in relation various aspects of care, including: structural aspects of care delivery (what care is provided and when); the process of care delivery (how care is delivered); the philosophical aspects of care delivery (why care is delivered in a particular manner), and the interpersonal aspects of care delivery (who delivers care to whom).(24) The recent review by Ehrlich sought to identify and examine the key attributes of coordinated care. The components of care coordination they identified as key uncovered a complex matrix of activity underpinning care coordination. Partnerships, networking, collaboration, knowledge transfer, person-centred practice and self-management support were all identified as vital to care coordination. The authors' emphasised the role of effective support for self-management, as the individual with complex care needs is the single constant element in a backdrop of frequently changing health needs and confusing health care delivery structures.(24)

The term care coordination is common within the healthcare lexicon, and this familiarity has perhaps resulted in the understanding that it is simple to achieve and as a result the underlying complexity has been overlooked. It is not clear what elements of the matrix illustrated in table three are essential, or if all have to be in place to accrue gains. Within the Southern region some are already in place, some require enhancement and some will need to be implemented. The new directive from the Minister of Health regarding “alliance contracting” provides an opportunity to improve coordination of care for those in the region with the highest health care needs.

Thematic analysis of comments from the patient survey responders

The key categories that emerged following the inductive analysis were similar to those from the health professional analysis:

1. Frustrations
2. Challenges to chronic care management

- a. Time
 - b. Misunderstanding
 - c. Lack of continuity/coordination and linkages
3. Enablers of chronic care management
- a. Care plus

Frustrations

“I would like to be treated as a whole person, not just a particular problem like a pain somewhere. Being sent to a specialist is Ok but my whole self is affected by whatever is being treated. Often my Care Plus visit does not deal with everything. My doctor is good but tends to get stuck on one problem when other things are bugging me as well”. F78 yrs

“I feel like medical care deals with the immediate problem presented to the doctor, but a long term holistic approach is needed to seek solutions to improve my quality of life”. F 75 yrs

Challenges to chronic care management

Time

Under the Care Plus programme too much emphasis is put on time and the lack of it. A lot of things are going on for me but everytime, “we’ll deal with it next time”, and it never gets done. F 62 yrs

Misunderstanding

Comments within the patient survey suggested a misunderstanding or lack of understanding regarding the role of practice nurses as well as confusion regarding the purpose of Care Plus funding.

“Too often a visit to the doctor’s results only in time with the practice nurse, with no doctor consultation. This leaves a feeling of, if they don’t care why should I?” M 81 yrs

“My participation in the programme is a 3 monthly visit to my doctor, for medication for hypertension and diabetes”. F 77 yrs

Lack of continuity/coordination and linkages

“My doctors always change. GPs come and go”. F 68 yrs

“Here are X we see many different doctors, some only once”. M 91 yrs

“I feel the uncertainty of what doctor I will see next time I visit makes it very hard to build up a good working relationship with them. In X we have had numerous doctors here, none of which stay long enough to build up a rapport with which makes it very hard”. M 75 yrs

Enablers of chronic care management –

Care Plus

“I visit my doctor 3 monthly. At this time we discuss any problems or if any other treatment is required”. M 86 yrs

Discussion of thematic analysis

Within health care today, there is an onus on bio-medicine and evidence based care. Appropriate as these elements of health care are, they have the potential to overshadow the ability of the clinician to care for the patient and affect the facility of the patient to be cared for as an individual.(35) Modern medicine has become profoundly disease focused and organ specific, with specialisation and sub-specialisation resulting in an increasingly fractured health system.(36) The limitation of these approaches is well illustrated by the two above quotes illustrative of the frustration theme. The 2010 study by Carryer et al.,(4) also found that patients are not entirely satisfied with the provision of support to assist them manage their long term conditions. Today’s disease focused health service is divergent from the concept of person centric health care, especially for those living with multiple chronic conditions.

The needs of those with multiple chronic conditions are variable and various; and for some patients even the extended Care Plus consult was not deemed to be long enough.

Getting enough time in the consult is well established as a patient priority (37) and certainly one the extended consults in Care Plus sought to address. Balancing patients' demands with medical needs within the consultation is challenging, further exacerbated by multimorbidity.(38) For patients with multimorbidity the tension between patient needs and professional response can lead to logistical inconvenience for the patient, contested priorities within the priorities (as illustrated by the both the time and frustration quotes) and low importance placed on multimorbidity specific issues such as treatment challenges and opportunities for therapeutic synergies, such as the benefit of exercise across multiple conditions (heart disease, diabetes and depression).(38) Bower et al.,(38) highlight the findings from various studies which suggest a care planning process sympathetic to the needs of those with multimorbidity may help deal with the competing tensions, ensuring that multimorbidity per se and the needs related to the various individual disorders could be met.

Care plans are living documents and need to be responsive to the fluctuating needs of those with multiple chronic conditions. It is possible that this is not occurring in a consistent fashion across the region as illustrated by the following quote.

“Having a care plan since 2006 I conclude that the only advantage of this (Care Plus) appears to be some financial savings”. M 82 yrs

“My action plan I have had for the last few years...” F 85 yrs

As discussed previously, there is an apparent misunderstanding regarding the capabilities of nurses in primary care and their role in the provision of chronic illness care management. This finding is similar to that of Carryer et al.,(39) who also found limited patient awareness of the nurse’s role in general practice. In her opinion piece, McKinlay draws attention to the significant contribution primary care nurses can make to the interdisciplinary care for those with chronic conditions.(22) Henty and Dickinson suggest that patients take time to appreciate the new role of nurses in the provision of chronic illness care.(15) While primary care nurses have a significant role to play in the provision of chronic illness care, other research identified, suggests that many primary care nurses (and GPs) have low self-efficacy around the provision of chronic care management and more specifically the provision of effective self-management support.(40) The provision of chronic illness care is and will compromise the majority of the primary care workload into the foreseeable future.(41) It is essential that the primary care workforce is supported to ensure they feel confident in their ability to provide this form of care. In addition, effective linkages with non-government agencies such as Arthritis Foundation New Zealand, who provided generic self-management training based on the well validated Stanford Model, (42) and other community organisations need to be developed. Partnering with organisations in the community primary care can enhance self-management support for its patients, avoid duplicating effort and reduce its own workload.(31)

Several responses from patients indicated that their view of the extended Care Plus consult was limited to receipt of their medications. One GP noted, “They think it is just a repeat of my pills”. The review of the implementation of Care Plus identified limited perceptions regarding what Care Plus was, as did Julia Ebbett in her thesis, “What are patient perceptions of the nursing contribution through the Ministry of Health funded semi-structured programme currently known as Care Plus?” (21, 43) It is essential that patients referred to Care Plus or a chronic care programme understand the intent of the programme and their role in it.

Lack of continuity of care was referred to frequently within the patient feedback comments. To be more specific, the comments related to longitudinal relationship continuity. In the U.K., a recent survey identified that preference for seeing a specific GP rose from 52% of adults

aged 18-24 years, to over 80% for those aged 75 years and over. There is, however, an innate tension in general practice and that is the tension between prompt access on the one hand and continuity of care on the other. In relation to chronic care management many appointments can be planned in advance. However, even people with chronic conditions have acute episodes. In an effort to address relational continuity within larger practices, Bodenheimer suggests the concept of the teamlet within primary care settings.(44) Although teamwork is an underpinning principle of primary care,(28) a teamlet is only made up of a dyad. In the example given by Bodenheimer this was a family physician and a health coach, but could equally be the doctor and the practice nurse. Patient would have continuity with their teamlet within the practice, as opposed to a single clinician.

Within the patient comments there were a couple alluding to Care Plus as a facilitator of chronic care provision as illustrated above. In the quote above, the use of the personal pronoun, “we”, is significant. It suggests that for this patient the consult with their GP is based on a partnership. The role of “partnership” is fundamental to the provision of effective chronic care,(31) and in this instance clearly valued.

The survey findings identify differences between health care providers (GPs and PNs) and patients in their self-reported perceptions of the provision of chronic care in the Southern Region. Inductive analysis of the comments of both groups identified significant similarities regarding the obstacles and barriers to the effective provision of chronic illness care within the setting of primary care.

The next section provides an overview of the analysis and findings from the solicited participant diaries.

Solicited diary findings

Text data was entered into NVivo 10 to assist with data management and a general inductive approach was taken to analysing the text data. A typology of varying health profiles emerged from the analysis of the text data.

- Life as expected: older respondent, multiple illnesses, grown used to them;
- Life interrupted: younger, experience of a sudden unexpected event;
- Life altered: typically degenerative, but also related to health of partner.

Individuals did not necessarily stay static within a category during the two months of the study, nor did they necessarily inhabit just one category at any one time.

Below are some quotes that illustrate the categories within the typology.

Life as expected: older respondent, multiple illnesses, grown used to them

Female, 94yrs; NZDepQ3; CHF, angina, glaucoma, vertebrobasilar insufficiency . Daily self-rated health score range: 8-9

“The weather was bright today which makes it easier for me to see. Hate the dark days, everything is too dark and I get stressed out not being able to see. However, I am lucky to see as much as I can”.

“Not very well today. Had a bit of angina in the night. So taking it easy to-day. Another shower day today, so did a small wash and got it ironed and put away. Feel lucky to still be able to do that for myself”.

Life interrupted: younger, experience of a sudden unexpected event

Male, 59yrs, NZDepQ 2; obese, pre-diabetic, hypertensive, chronic depression, then major cardiac event (VT-dilated cardiac myopathy), with pre-diabetic status converting to type 2 diabetes. Daily self-rated health range; 3-7

“Feel frustrated at length of time until clinic, in limbo”.

“Feeling very tired at work, also low – other people seem to have so much energy and enthusiasm! Plod on.....”.

“Number of pills doubled since heart problem. Bought a pill box (\$10) put out medication for next week. Previously I could remember which pills to take daily”.

“Continue to be fascinated by defibrillator inside me. Most times I forget about it, but when I do remember I often rub (caress?) the skin above it”.

“As it happened, the diagnosis of diabetes took priority over any other topics I would have liked to bring up.... No mention though of the long term management of diabetes or heart failure”.

Life altered: typically degenerative, but also related to health of partner.

Male, 82yrs , NZDEPQ3, toxic goitre, thyroid disease, mitral and aortic stenosis, CVD, thyroid nodule, and valve replacement. Daily self-rated health range; 7.5-9

“The writer wishes it to be known that due to the fact that this wife is making a slow recovery from operations there are inevitably times when the consequences of the situation bear heavily on the events of the day”.

Female 73yrs , NZDEPQ4: rheumatoid arthritis, ulcerative colitis and cancer of the cervix.

Daily self-rated health range; 5-8

“Did some baking made fruit loaf and choc cake, creaming the butter and sugar is very hard on my hand and my arms. That night I had to get my husband to help me undress for bed as my shoulders are so sore. I put voltaren on but I didn’t sleep very well every time I turn over I woke up”.

“My shoulders and my left hand are very painful and my right foot is very sore on top. I have never had pain there before. I have put voltaren all over everything it’s getting me down this time”

The use of solicited patient diaries did not result in significant learnings regarding the coordination of care. What did emerge was a plethora of rich, descriptive text data regarding the challenges of daily living with multiple conditions. As well as the typology, other key aspects emerged which were consistent across typologies: the need to maintain maximal functional capacity, the importance of social participation and being valued and striving to maintain a sense of self. The importance of social participation can be seen in the following quote.

“Felt quite a bit better today. The choir were singing at Iona church Port Chalmers this morning. I always feel a lot better when I am with the choir; seems to help me a lot”. Male 88 yrs, NZDEPQ2, cardiovascular disease, osteoarthritis and allied disorders, history of myocardial infarction. Daily self-rated health range 5-9

“Lovely day again. Haven’t spoken to anybody since Saturday feel a bit isolated. Decided to go and visit an ex neighbour in a rest home. Spent about one hour with her”. Female 74 yrs,

NZDEPQ4, Vitamin B12 deficiency, aortic aneurysm, type 2 diabetes. Daily self-rated health range 4-9

The desire to maintain functional ability was also evident.

“I would like to do a bit more around the house but just can’t at the moment”. Next day, “I think I am coming right; did all my dusting and we had a hot meal at lunch time”. Female 73yrs, NZDEPQ4: rheumatoid arthritis, ulcerative colitis and cancer of the cervix. Daily self-rated health range; 5-8

The following quote, from the gentleman who participated in an audio recorded interview, illustrates the importance of maintaining a sense of self. This gentleman had led an active life and been employed in physically demanding jobs. Now his functional ability is severely limited due to poorly managed pain from his osteoarthritis. When asked why he did not let his general practitioner know that the currently prescribed analgesia were no longer effective, he replied:

‘I don’t like people thinking I can’t do this and I can’t do that’. M 73yrs, NZDEPQ4. Osteoarthritis, type 2 diabetes, emphysema and obesity.

This novel methodology highlighted some key learnings regarding the needs of those living with multiple chronic conditions:

- Chronic illness impacts in multiple ways and is fluid in nature. Individuals could inhabit more than one typology or move across typologies during the course of the study;
- A perception of self is not static when living with multiple chronic conditions. Therefore keeping a sense of your own identity can be challenging;
- Consults need to address patient concerns as well those considered to be priorities by health providers;
- Individuals strive to maintain independence and not be seen as a burden;
- Social participation/interaction is important to this group;
- Care needs to be viewed as important, as treatment.

The diaries highlighted that these eight individuals had unique and fluctuating needs and their priorities, especially in the case of a life interrupted but also across all typologies changed frequently. Life appeared to be a constant balancing act, deciding which condition

to prioritise as well as working out how to satisfy the need for social participation and meeting what potentially they view as a moral obligation to look after themselves so they could maintain their ability to live independent lives.

In summary this mixed methods study highlighted a divergence in the perceptions of chronic illness care in the region between primary health professionals and patients. Key areas of concern were patient activation and follow up and care coordination. Both of these concepts are fundamental to effective chronic illness care and therefore require attention.

Analysis of responders' comments within the survey identified barriers and facilitators of chronic care provision, as well as providing an explanation for the numerical data. Within the domain of patient activation several patients described problematic interactions with primary care professionals, including instances of not being listened to. The need to feel "cared for" as an individual and not just a collection of diseases was evident in the comments. Suggesting a need to balance the cure and care foci of the health care system. Lack of continuity of care emerged as another key patient concern and the quote provided illustrates how lack of care continuity impacts on patient activation levels.

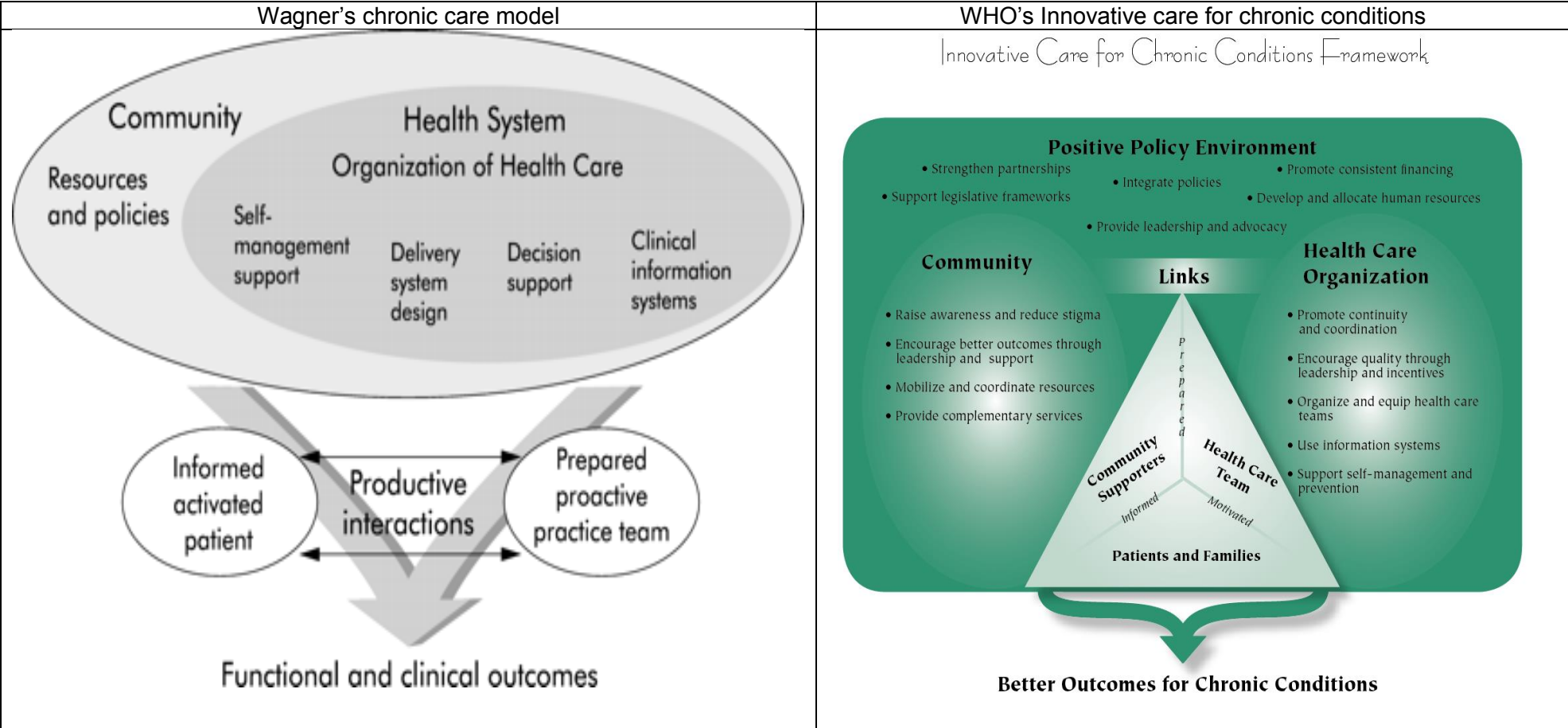
Health professionals also had issues. Overall reading the comments provided a sense of general frustration at not being able to provide the care the questions alluded to. While some general practitioners were clearly taking the opportunity to use the Care Plus extended consults with patients, many appeared not to be. The quotes within the frustration challenges domains from health professionals align with research of general practitioners experiences of multimorbidity management in primary care. This suggests a level of validity in the analysis. Teamwork and the ability to provide extended consults via Care Plus funding were seen as enablers of effective chronic care management.

The solicited participant diaries illustrate the varied needs of those living with multiple chronic conditions as well as the strategies they used to address these. Across the typologies that emerged was the consistent presence of three key factors: the desire to maintain a level of functional capacity that enabled independence or at the very least the ability to manage some level of self-care; the importance of social participation and being valued; and the need to maintain a sense of self.

Models do exist which can be used as a framework to guide the provision of effective chronic illness care as illustrated below.

MODELS OF CARE THAT SUPPORT EFFECTIVE CHRONIC ILLNESS CARE PROVISION

FIGURE 4: TWO FRAMEWORKS THAT SUPPORT THE PROVISION OF CHRONIC ILLNESS CARE

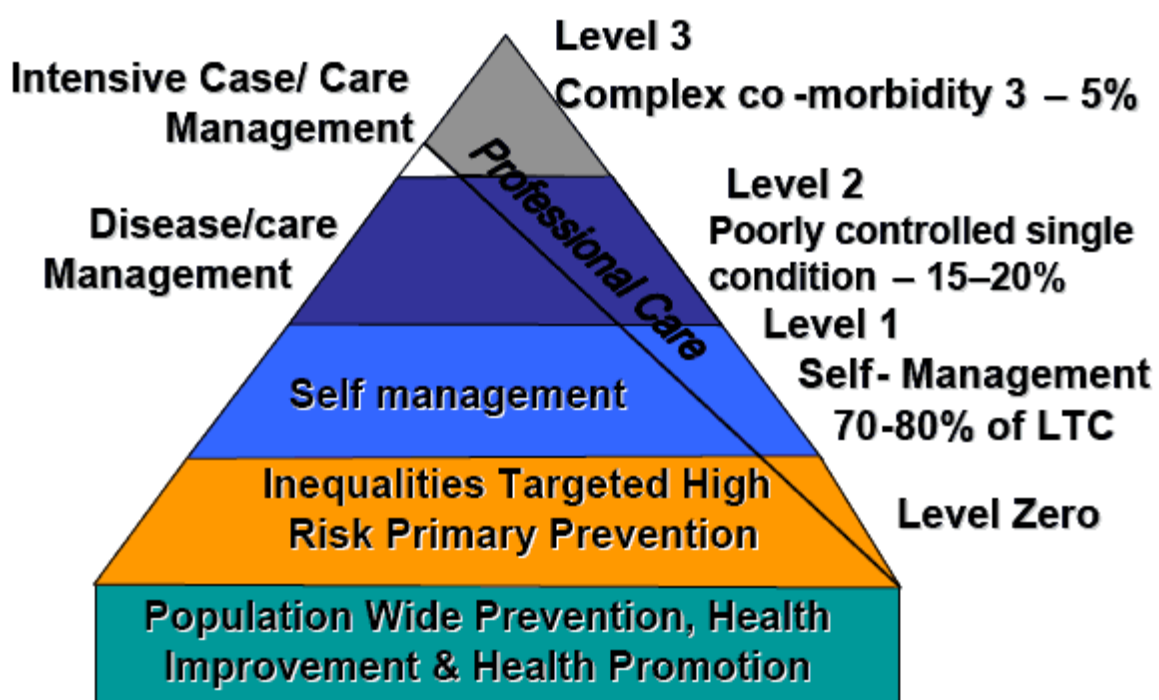


The chronic care model (31) is the most widely referenced chronic care model and it is has guided the work of leaders in New Zealand of chronic care provision, such as Counties Manukau District Health Board. A second significant model of chronic care management is WHO's Innovative Care for Chronic Conditions (ICCC).(45) This model has a stronger emphasis on the roles of the policy environment and community engagement.

Either of these models would provide a suitable framework to guide improvements in the three key areas of partially met need: patient activation, care coordination and community linkages and the provision of care reflective of the values and traditions of patients.

Within the framework use of the Kaiser Model of Stratified Care, according to patient need would provide a model for practices to estimate their caseload of patients requiring complex care, compared to those who are capable self-managers. The schema below provides an overview of the approach.

FIGURE 5: KAISER MODEL OF STRATIFIED CARE



In addition the Southern Primary Health Organisation could use the suggested percentages to generate potential chronic care funding models that allocated dollars based on clinical need. This would ensure that general practice was appropriately compensated.

PROJECT SUCCESSES AND LIMITATIONS

Project strengths

1. The research team was supported by a cross-sectorial reference group comprising representatives from stakeholder groups, as well as research team members. This group provided guidance to the research team. Establishment of the group generated the forming and development of relationships across sectors, which have produced further fruitful collaborations. See Appendix Four for group members.
2. Employing a mixed methods approach enhanced the opportunities for the research team to answer and understand the complexity of care provision for and life with chronic illnesses, in a manner that was efficient, valid and generalizable.(46)
3. The researchers did not have institutional proximity to the evaluated process and had received independent funding, factors identified as being important when evaluating chronic care interventions.(47)
4. The study findings reflect the findings from similar New Zealand studies,(4, 39) suggesting the study findings are valid.

Project limitations

1. The health professional response rate to the survey was disappointing in view of the relevance and topicality of the subject area to primary care. It is well established that personalising postal surveys has a positive impact on response rates.(48) Therefore, the decision that the provider surveys should not be personalised potentially effected the response rate to the survey.
2. A common challenge in evaluating chronic condition management approaches is the reluctance of providers to engage in evaluation. The rationale for this can be due to a variety of factors, for example, general lack of an evaluation culture, the focus of the evaluation not resonating with the participant, and the additional administrative burden.(47)
3. The number of individuals completing the diary study component was less than hoped for. Nevertheless, the researchers gained extensive, rich, informative text data.

RECOMMENDATIONS FOR CONSIDERATION

Southern DHB

1. Review of funding models to enable the establishment of integrated care, vertically and horizontally.

Southern PHO

1. Establish the routine measurement of patient activation for those enrolled in Care Plus. This will provide greater awareness of who needs support, enable greater individualisation of patient care as support and information can be targeted to patient need, will strengthen the patient's understanding of their role in managing their health, and ensure more efficient use of resources by targeting the greatest level of support to those who need it most.
2. Provision of collaborative learning opportunities to primary health care staff regarding the following:
 - a. The chronic care model
 - b. Health coaching
 - c. Care planning
3. Promote the role of the practice/primary health care nurse to the community so they understand the capabilities and skills inherent in this health professional group.
4. Complete a stock take of community resources that could support patient self-management. Inform primary care of the resources in its locality and update this information on at least an annual basis.
5. Work with non-government organisations known to provide self-management training to patients, such as the Arthritis Foundation to ensure courses are provided throughout the region.
6. Promote an understanding of the role of evaluation and research in relation to supporting optimal care and improved health outcomes, by involving those in primary care as partners as well as participants in the process.

These recommendations provide a suggested direction of travel for both organisations. How and if the recommendations are actioned remains the responsibility of either organisation.

APPENDICES

Appendix one

Final interview schedule

1. How have you found the process of diary keeping?
2. Has it increased your awareness about any aspect of your health, behaviour or life in general?
3. Did you find any benefits to keeping the diary?
4. Were there any negatives to keeping the diary?
5. Was the length of time we requested you keep the diary, too long, too short or just right?
6. Would you have been willingly to keep it for longer?
7. If so, how long do you think would be reasonable

Appendix two

Eligibility criteria for Care Plus

1. Is assessed by a Practitioner who usually delivers their First Level Services as being expected to benefit from .intensive clinical management in primary health care. (at least two hours of care from one or more members of the primary health care team) over the following six months; and either
2. Has two or more chronic health conditions so long as each condition is one that:
 - i. is a significant disability or has a significant burden of morbidity; and
 - ii. creates a significant cost to the health system; and
 - iii. has agreed and objective diagnostic criteria; and
 - iv. continuity of care and a primary health care team approach has an important role in the management of that condition; or
3. Has a terminal illness (defined as someone who has advanced, progressive disease whose death is likely within twelve months); or
4. Has had two acute medical or mental health related admissions in the past twelve months (excluding surgical admissions); or
5. Has had a total of six First Level Service and/or casual general practice consultations and/or emergency department visits within the last twelve months; or
6. Is on active review for elective health services

Appendix three

Comparison of frequency tables from the surveys of primary health care professionals and individuals living with long term conditions

Domain one: patient activation

Q1: Ask for their ideas when making a treatment plan/asked for your ideas when making a treatment plan

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	4 (2%)	16 (8.1%)	50 (25.3%)	88 (44.4%)	40 (20.2%)
Patient	85 (34.1%)	37 (14.9%)	45 (18.1%)	46 (18.5%)	36 (14.5%)

(10 patients did not answer this question)

Q2: give them choices to think about regarding treatment/ given choices to think about regarding treatment

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	3 (1.5%)	6 (3.0%)	25 (12.6%)	106 (53.5%)	58 (29.3%)
Patient	97 (38.6%)	36 (14.4%)	36 (14.3%)	40 (15.9%)	42 (16.7%)

(8 patients did not answer this question; 1 health professional did not answer this question)

Q3: asked them to talk about any problems with their medicines and their effects/asked to talk about any problems with your medicines and their effects

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	0	5 (2.5%)	27 (13.6%)	104 (52.8%)	61 (31%)
Patient	58 (23.1%)	41 (11.3%)	42 (16.7%)	52 (20.7%)	58 (23.1%)

(8 patients did not answer this question; 2 health professionals did not answer this question.)

Q4: asked them if they ever have difficulty understanding information provided to them related to their medical conditions/asked if you ever have difficulty understanding information provided to you related to your medical conditions

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	5 (2.5%)	25 (12.6%)	68 (34.2%)	68 (34.2%)	33 (16.6%)
Patient	132 (53.2%)	19 (7.7%)	32 (12.9%)	32 (12.9%)	33 (13.3%)

(11 patients did not answer this question)

Domain two: delivery system/practice design

Q5: provide a written list of things they should do to improve their health/provided a written list of things to do to improve your health

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	15 (7.5%)	70 (35.2%)	78 (39.2%)	33 (16.6%)	3 (1.5%)
Patient	106 (42.2%)	27 (10.8%)	39 (15.5%)	26 (10.4%)	53 (21.1%)

(8 patients did not answer this question)

Q6: feel satisfied that you are doing a good job organising their care/feel satisfied with the organisation of your care

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	0	11 (5.5%)	50 (25.1%)	131 (65.8%)	7 (3.5%)
Patient	17 (6.8%)	22 (9.8%)	42 (11.6%)	76 (30.5%)	92 (36.9%)

(10 patients did not answer this question)

Q7: show them how what they do to take care of themselves influences their condition/shown how what you do to take care of yourself influences your condition

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	2 (1.0%)	11 (5.5%)	57 (28.6%)	101 (50.8%)	28 (14.1%)
Patient	57 (23.0%)	31 (12.5%)	45 (18.1%)	56 (22.6%)	59 (23.8%)

(11 patients did not answer this question)

Domain three: goal setting/tailoring

Q8: ask them to talk about their own goals in caring for themselves/asked to talk about your own goals in caring for yourself

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	6 (3.1%)	43 (22.1%)	79 (40.5%)	51 (26.2%)	16 (8.2%)
Patient	79 (31.5%)	36 (14.3%)	39 (15.5%)	42 (16.7%)	55 (21.9%)

(8 patients did not answer this question; 4 health professionals did not answer this question)

Q9: help them set specific goals in caring for themselves/helped to set specific goals in caring for yourself

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	10 (5.2%)	27 (14.0%)	81 (42.0%)	57 (29.5%)	18 (9.3%)
Patient	66 (26.2%)	46 (18.3%)	42 (16.7%)	43 (17.1%)	55 (21.9%)

(7 patients did not answer this question; 6 health professionals did not answer this question)

Q10: give them a copy of their treatment plan/given a copy of your treatment plan

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	33 (17.3%)	52 (27.2%)	65 (34.0%)	29 (15.2%)	12 (6.3%)
Patient	123 (50.4%)	13 (5.3%)	22 (9.0%)	36 (14.8%)	50 (20.5%)

(15 patients did not answer this question; 8 health professionals did not answer this question)

Q11: encourage them to attend a specific group or class to help them cope with their illness/encouraged to attend a specific group or class to help you cope with your illness

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	13 (6.7%)	55 (28.2%)	88 (45.1%)	28 (14.4%)	11 (5.5%)
Patient	151 (60.6%)	27 (10.8%)	27 (10.8%)	22 (6.1%)	22 (6.1%)

(10 patients did not answer this question; 4 health professionals did not answer this question)

Q12: ask questions, either directly on in a survey about their health habits/asked questions either directly or in a survey about your health habits

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	6 (3.1%)	21 (10.8%)	57 (29.4%)	84 (43.3%)	26 (13.4%)
Patient	86 (33.7%)	40 (15.7%)	49 (19.2%)	40 (15.7%)	39 (15.3%)

(5 patients and health professionals did not answer this question;

Domain four: problem solving/contextual

Q13: consider their values and their traditions when recommending treatments/felt they considered your values and traditions when recommending treatments

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	2 (1.0%)	18 (9.2%)	35 (17.9%)	86 (44.1%)	54 (27.7%)
Patient	50 (21.0%)	21 (8.8%)	27 (11.3%)	61 (25.6%)	79 (21.8%)

(21 patients did not answer this question; 4 health professionals did not answer this question)

Q14: help them to make a treatment plan that they carry out in their daily life/helped to make a treatment plan that you can carry out in your daily life

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	6 (3.0%)	13 (6.7%)	57 (29.4%)	94 (48.5%)	24 (12.4%)
Patient	68 (36.8%)	26 (7.2%)	33 (13.6%)	42 (17.4%)	73 (30.2%)

(17 patients did not answer this question; 5 health professionals did not answer this question)

Q15: help them to plan ahead so they can take care of themselves even in hard times/helped to plan ahead so you can take care of yourself even in hard times

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	7 (3.6%)	30 (15.5%)	77 (39.7%)	61 (31.4%)	19 (9.8%)
Patient	89 (36.8%)	29 (12.5%)	28 (11.6%)	45 (18.6%)	51 (21.1%)

(17 patients did not answer this question; 5 health professionals did not answer this question)

Q16: ask them how their chronic illness affects their life/asked how your chronic illness affects your life

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	3 (1.5%)	18 (9.3%)	61 (31.4%)	75 (38.7%)	37 (19.1%)
Patient	74 (30.3%)	36 (14.8%)	38 (15.6%)	51 (20.9%)	45 (18.4%)

(14 patients did not answer this question; 5 health professionals did not answer this question)

Domain five: follow up/coordination

Q17: contact them after a visit to see how things are going/contacted after a visit to see how things are going

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	9 (4.5%)	57 (28.8%)	96 (48.5%)	29 (14.6%)	7 (3.5%)
Patient	127 (35.1%)	32 (13.1%)	37 (15.1%)	17 (6.9%)	32 (13.1%)

(14 patients did not answer this question; 1 health professional did not answer this question)

Q18: encourage them to attend programmes in the community that could be helpful/encouraged to attend programmes in the community that could be helpful

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	8 (4.1%)	37 (18.8%)	91 (46.2%)	54 (27.4%)	7 (3.6%)
Patient	143 (60.6%)	29 (12.3%)	20 (8.5%)	21 (8.9%)	23 (9.7%)

(14 patients did not answer this question; 2 health professionals did not answer this question)

Q19: provide referrals to other health professionals/given referrals to other health professionals

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	1 (0.5%)	8 (4.1%)	94 (47.7%)	60 (30.5%)	34 (17.3%)
Patient	150 (61.2%)	19 (7.8%)	25 (10.2%)	26 (10.6%)	25 (10.2%)

(21 patients did not answer this question; 2 health professionals did not answer this question)

Q20: tell them about how visits with other health professionals (other than GP) help with their treatment/told how visits with other health professionals helps with your treatment

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	3 (1.5%)	11 (5.6%)	80 (40.4%)	70 (35.4%)	34 (17.2%)
Patient	106 (44.5%)	34 (14.3%)	34 (14.3%)	30 (12.6%)	34 (14.3%)

(21 patients did not answer this question)

Q21: ask them how appointments with other health professionals are going/asked about how appointments with other health professionals are going

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	0	20 (10.2%)	67 (34.2%)	76 (38.8%)	33 (16.8%)
Patient	126 (52.5%)	26 (10.8%)	32 (13.3%)	17 (7.1%)	39 (16.3%)

(19 patients did not answer this question; 3 health professionals did not answer this question)

Domain six: cultural sensitivity

Q22: appropriately involve the whanau/family in the care and management of their condition/appropriately involved whanau/family in the care and management of your condition

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	3 (1.5%)	30 (15.3%)	78 (39.8%)	62 (31.6%)	23 (11.7%)
Patient	163 (69.1%)	17 (7.2%)	16 (6.8%)	17 (7.2%)	23 (9.7%)

(23 patients did not answer this question; 3 health professionals did not answer this question)

Q23: gather information or feedback from whanau/family members/gathered information or feedback from your whanau/family members

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	11 (5.6%)	55 (28.1%)	81 (41.3%)	38 (19.4%)	11 (5.6%)
Patient	140 (59.1%)	33 (13.9%)	23 (9.7%)	15 (6.3%)	26 (11.0%)

(22 patients did not answer this question; 3 health professionals did not answer this question)

Q24: educate the whanau/family on prevention of the chronic condition where appropriate/educated your whanau/family on prevention of the chronic condition where appropriate

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	10 (5.1%)	54 (27.6%)	77 (39.3%)	44 (22.4%)	11 (5.6%)
Patient	157 (68%)	19 (8.2%)	17 (7.4%)	14 (6.1%)	24 (10.4%)

(28 patients did not answer this question; 3 health professionals did not answer this question)

Q25: screen the family/whanau where appropriate – including risk factors/screened your family/whanau where appropriate

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	15 (7.7%)	53 (27.2%)	62 (31.8%)	55 (28.2%)	10 (5.1%)
Patient	182 (79.8%)	13 (5.7%)	7 (3.1%)	8 (3.5%)	18 (7.9%)

(31 patients did not answer this question; 4 health professionals did not answer this question)

Q26: alter or modify your care due to their ethnicity/alter or modified their care due to your ethnicity

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	18 (9.2%)	37 (19.0%)	67 (34.4%)	44 (22.6%)	29 (14.9%)
Patient	193 (88.9%)	5 (2.3%)	3 (1.4%)	5 (2.3%)	11 (5.1%)

(42 patients did not answer this question; 4 health professionals did not answer this question)

Q27: offer another culturally appropriate service if there is one available/offered another culturally appropriate service if there is one available

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	17 (8.8%)	39 (20.2%)	57 (29.5%)	50 (25.9%)	30 (15.5%)
Patient	191 (89.7%)	5 (2.3%)	1 (0.5%)	2 (0.9%)	14 (6.6%)

(46 patients did not answer this question; 6 health professionals did not answer this question)

Q28: ask them if there are any cultural or ethnic issues that you need to be aware of/asked if there are any cultural or ethnic issues that they need to be aware of

Group	None of the time n (%)	A little of the time n (%)	Some of the time n (%)	Most of the time n (%)	Always n (%)
Health professional	23 (11.8%)	51 (26.2%)	47 (24.1%)	44 (22.6%)	30 (15.4%)
Patient	189 (85.9%)	6 (2.7%)	3 (1.4%)	10 (4.5%)	12 (5.5%)

(39 patients did not answer this question)

Appendix Four: Members of the Reference Group

Dr Hywel Lloyd, GP and Chief Medical Adviser for BPAC

Ms. Adele Knowles, Portfolio Manager - Primary Care

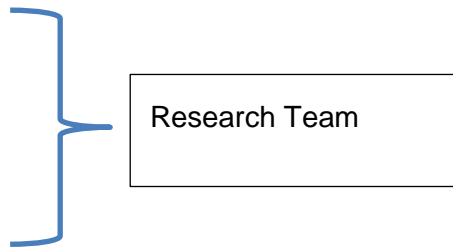
Ms. Megan Barrett, Southern Regional Manager, Southern PHO

Ms Claire Lord, Portfolio Manager - Health of Older People & Disability

Professor Robin Gauld

Dr. Debra Waters

Ms. Fiona Doolan-Noble



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