

Alleviating the Burden of Chronic Conditions in New Zealand (The ABCC NZ Study)

Executive Summary: New Zealand Experts' Perspectives, Generic
Stocktake Analysis and Disease Specific Stocktake Analysis

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CONTENTS

INTRODUCTION	2
EXPERTS' PERSPECTIVES ('MOVERS AND SHAKERS')	2
GENERIC STOCKTAKE – CCM DIMENSIONS	4
GENERIC STOCKTAKE - PRIMARY CARE QUESTIONNAIRE	6
General Primary Care Provision	8
GENERIC STOCKTAKE - HEALTH INEQUALITIES QUESTIONNAIRE	9
Health inequalities at the DHB / PHO macro-strategy level	10
<i>Barriers to access into programmes for people with chronic conditions</i>	10
<i>Cultural safety training</i>	10
Health inequalities at the PHO macro-strategy level.....	10
<i>Barriers to access into programmes for people with chronic conditions</i>	11
<i>Cultural safety training</i>	11
DISEASE SPECIFIC STOCKTAKE.....	12
Summary of evidence-based CVD service provision by DHB size	12
Summary of evidence-based CHF service provision by DHB size.....	13
Summary of evidence-based COPD service provision by DHB size	14
Summary of evidence-based stroke service provision by DHB size	14
GENERIC STOCKTAKE: OVERALL COMMENTS	15
DISEASE SPECIFIC STOCKTAKE: OVERALL COMMENTS	17
ARE OUR FINDINGS VALID?	20
THE FUTURE.....	20

INTRODUCTION

This document summaries three aspects of the ABCCNZ study also published in full and précis form: [1] Semi-structured interviews with 29 New Zealand based experts in chronic conditions management (CCM) on aspects of CCM pertinent to NZ practice and existing programmes; [2] A generic stocktake questionnaire submitted to all DHBs¹ in October 2007 (15 respondents) to determine extent of CCM practice in Cardiovascular Disease (CVD), Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD) and Stroke (representing a DHB {not PHO} perception of CCM); [3] A disease-specific questionnaire submitted to all DHBs¹ in October 2007 (15 respondents) of evidence-based service provision for the above conditions.

EXPERTS' PERSPECTIVES ('MOVERS AND SHAKERS')

Twenty-nine individuals were interviewed - with a range of roles including CEO, GP, chronic care nurse, clinical adviser, and service manager. They represented a range of organisations including general practice, Primary Health Organisations, District Health Boards, Maori Health Providers, Ministry of Health, PHARMAC, and service providers. Interviews were transcribed and coded by themes as they aligned with dimensions already determined by the ABCCNZ study, and detailed in our Literature Review.

Conceptual understanding of CCM: There appear to be a number of perceived inhibitors to CCM uptake that relate to the system as currently structured. These relate to issues of professional identity and autonomy, and limited opportunity for education and support in primary care. The enablers all seem to relate to either additional resource being allocated or current resource re-channelled.

Patient/Whanau self management: Considered key but underdeveloped; includes effectiveness at encouraging patient/whanau behaviour change; enhancers - needs systematic approach, train the trainers (especially lay people), financial support.

Appropriate levels of collaboration: Working closely together with consistent goals and actions, underpinned by trust and buy-in, communicating across health sectors is enhanced by face-to-face meetings, systematic structure and coordination across agencies, good information sharing and a multidisciplinary approach. Interaction (community/family/whanau, between general practices, primary/secondary care, general practice/allied health, primary care/social services) is a key enabler. However, such interactions are limited by lack of formal structural support.

Active engagement of leadership: Leaders and champions are essential; not many are needed, but they need to be present at several levels, the more levels the better (community, practice, PHO, and DHB). Structures to identify/nurture leaders and champions are lacking. Thus, any programme championship results from passion, and individuals committing extra time and effort. This approach is not sustainable. Programme championship needs formal recognition through focused funding.

Appropriate development of sustainable community links: Patients/families should be included from the start as part of the workforce; you can't for example design a Maori programme and put it into Maori territory, you must employ the existing organic infrastructure; lay people are invaluable for

¹ DHBs classified by size: Small: C, G, Q, Medium: D, B, L, K, H, F, Large: E, A, I, M, N and P

In this and other ABCCNZ reports the absence of any alphabetic code in the graphs and discussion indicates absence of response from that DHB pertaining to that analysis.

reaching 'hard to reach' groups. Enhancers comprise opportunistic behaviours - likely to result from presence of a passionate leader. The development of formal infrastructure and incentives to support community linkages will help institutionalise sustainable community linkages.

Focus on reducing health inequalities: Reducing health inequalities has typically not been designed into programmes as a key element and is threatened by the large number of eligible people not enrolled in programmes. The problem cannot be addressed without accurate data collection and data management focussed specifically to address inequalities. We need to encourage more Maori providers. Too often the perceived solution within existing programmes seems to be to put more resources into enrolling patients. However a major reason Maori don't enrol (or adhere) is because the health system is structured and/or delivered in a way that is culturally foreign. The other significant barrier in general practice is the consultation fee. Putting more resources into getting people to attend will not address these issues.

Decision support: Integrated, preferably electronic, patient notes are essential; systems for bi-directional sharing of information between primary and secondary care are required; their current lack is a major barrier to continuity of care; ongoing training is needed; there is a relative lack of decision support systems. The poor access/use of performance data helps explain the current limited collaboration. Good data provides information that motivates collaboration.

Appropriate delivery system design: A systematic approach is needed - people working in a team, sharing the same clinical issues and the same data; a generic approach is preferable to a disease-specific approach; culturally sensitive approaches are important; the biggest inhibitor is lack of capacity /capability of staff - often due to problems of recruitment/retention. Enhancers - skills of brief opportunistic intervention, flexible processes, ethnic specific workers, outreach, information management between primary and secondary care, multidisciplinary teamwork, patients involved in programme development, funding encouraging inter-sector integration, the key is structured care.

All these issues require a reframing of the 'work' of general practice and wider primary care (as well as secondary care). The changes needed however are quite vast. It might thus be worthwhile to consider the development of district based CCM clinics to work in partnership with general practices/PHOs.

Knowledge transfer: Disease registers, storing and extracting data in a timely manner; quick feedback is more effective than delayed feedback; access to specialist knowledge quickly. Much of the discussion around knowledge transfer relates to the need for access to good information – either via accessible 'experts' or a robust database (see decision support section above). It may well be that people see the two as one and the same. However, access to good information alone will not create knowledge transfer. E.g. simply knowing there was a population change in HbA1c does not mean that you know why. In other words, a process needs to be resourced in which providers can examine changes (e.g. in KPIs), access evidence to link changes to interventions, and communicate this to other providers.

Adherence to clinical guidelines: Good quality, evidence-based guidelines are valued; in fact some of these have probably driven the development of CCM programmes; a good guideline provides key information on structure and best practice - however practitioners want process-orientated, step-by-step guidelines; nonetheless, guideline implementation in NZ is critical and currently lacking.

THE ABOVE DATA SUGGESTS FIVE INTERACTING ISSUES FOR ATTENTION -

- a need for connection within and across providers,
- a 1^o and 2^o care attitude that widens focus from acute care to include chronic care,
- investment in ongoing education and workforce development (inc. champions)

- greater focus on addressing health inequalities using appropriate strategies
- infrastructure to support quality improvement in primary care for CCM

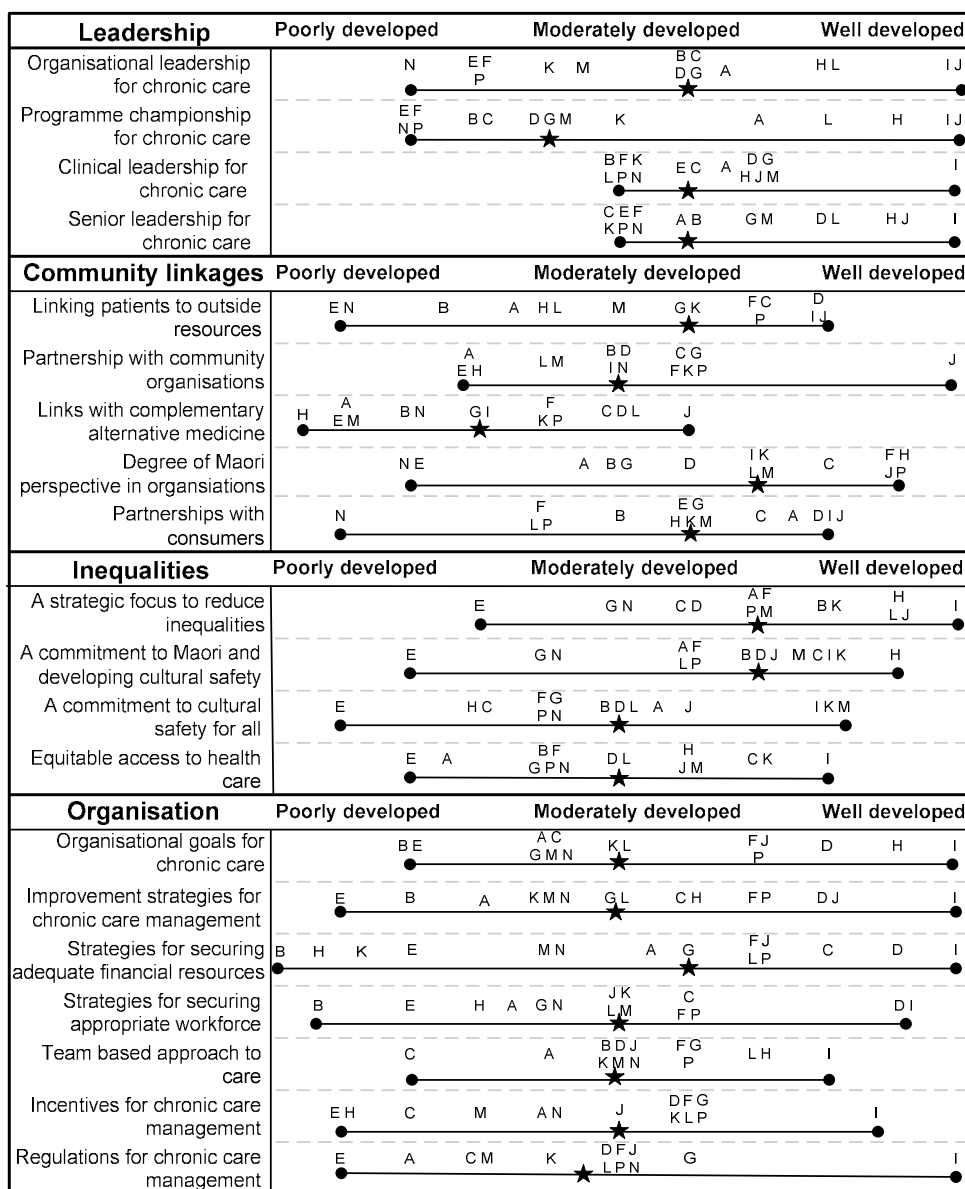
Responding to these themes will require a refocus of resources and investment in change management that motivates behaviour change. The challenge of change is significant, but so is the problem faced.

GENERIC STOCKTAKE – CCM DIMENSIONS

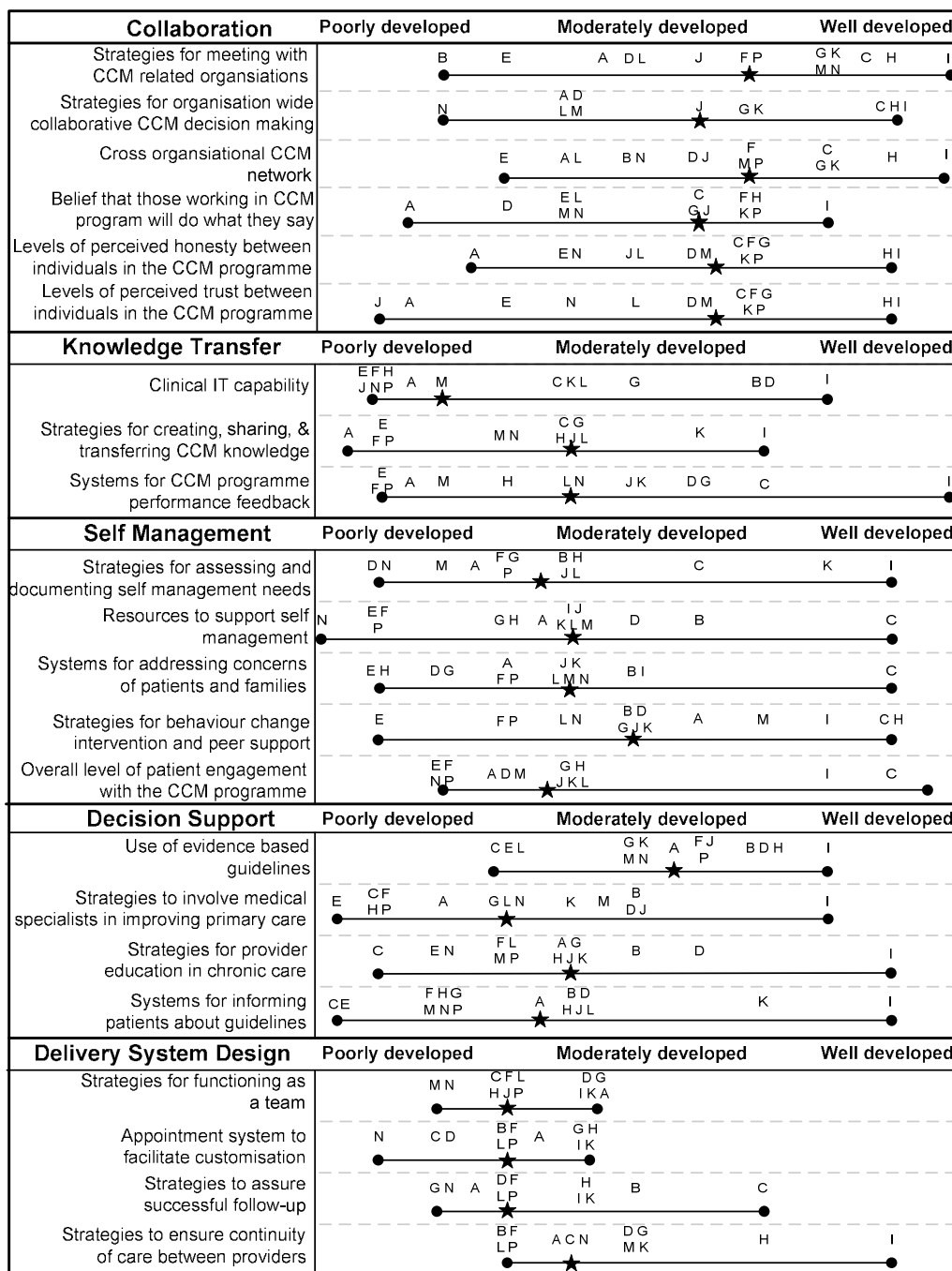
Here we focussed on generic CCM features identified by predefined **dimensions** above. DHBs were asked to express views on statements re. CCM dimensions on a Likert scale (0-11, 11=variable described is fully implemented and the DHB gives maximal support for the statement). Figures below summarise responses, (DHBs indicated by confidential alphabetic codes²). The most important findings are:

- Those DHBs that rate themselves poorly/highly tend to consistently do so.
- DHBs have, to a moderate level, developed strategies for responding to chronic conditions.
- Across most dimensions, practice ranged from poor to highly developed
- Two of the dimensions relating to change management (knowledge transfer and system design), are rated noticeably lower than other dimensions
- Strategies focusing on patients as the centre of the system are less developed relative to those placing providers at the centre of the system.

² DHBs classified by size: Small: C, G, Q, Medium: B, L, K, H, F, Large: E, A, I, M, N and P



KEY: ★ = median score A B . . N = DHB ●—● = range



KEY: ★ = median score AB..N = DHB ●—● = range

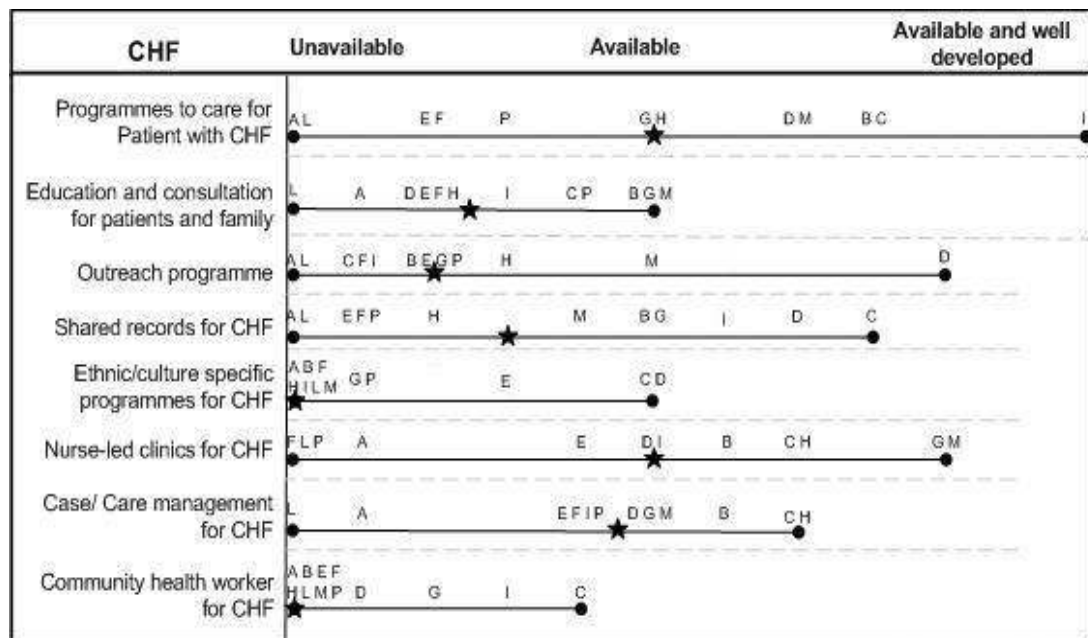
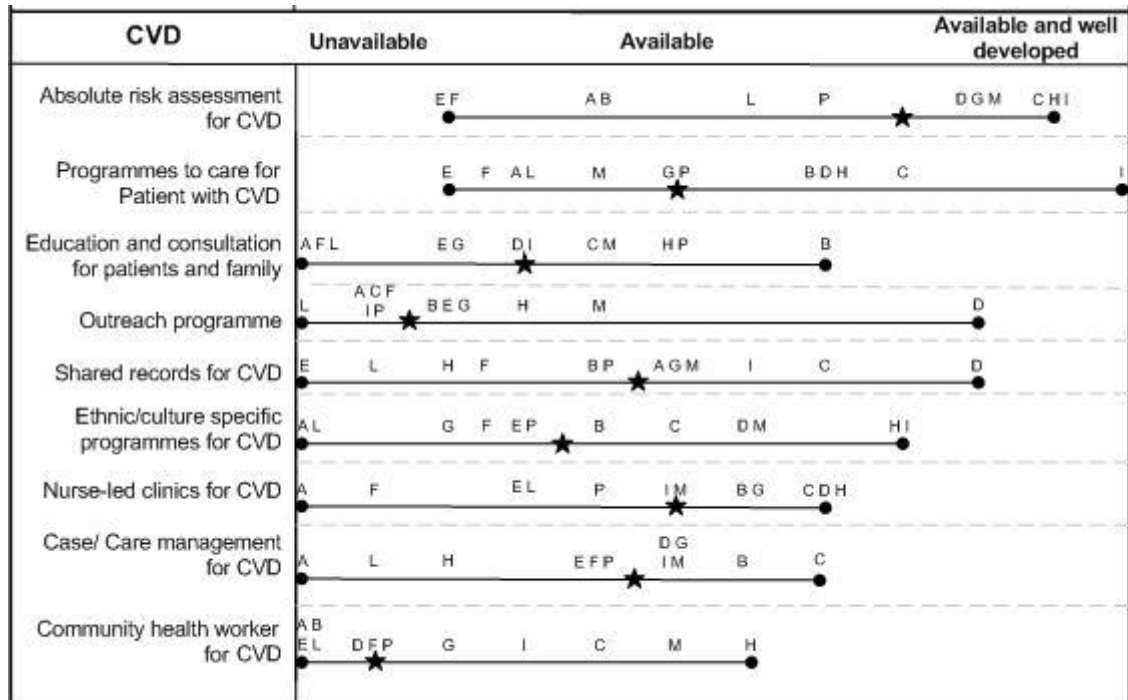
GENERIC STOCKTAKE - PRIMARY CARE QUESTIONNAIRE

DHBs were asked to describe district levels of CCM service they believe currently exists within primary care on a Likert scale (0-11, zero = no provision, 11 = full provision). Five sub-sections related to CHF, CVD, COPD, stroke, and to general primary care provision. The following figures summarise DHB responses in relation to their perception of CCM service for our index conditions, (DHBs indicated by confidential alphabetic code³). The most important finding are:

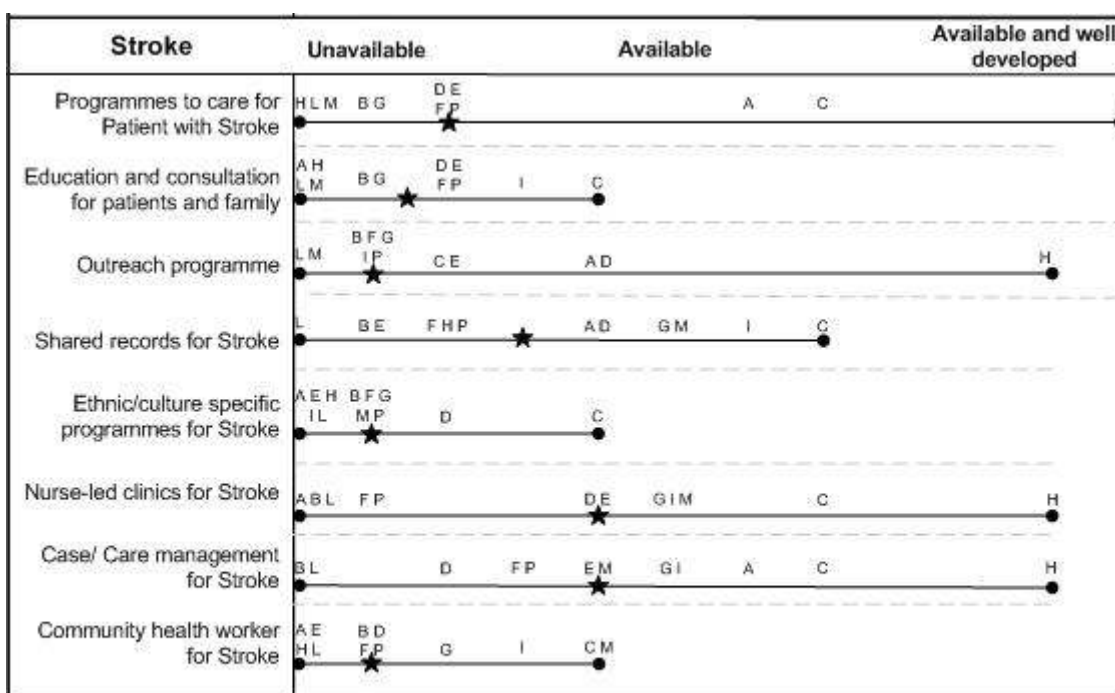
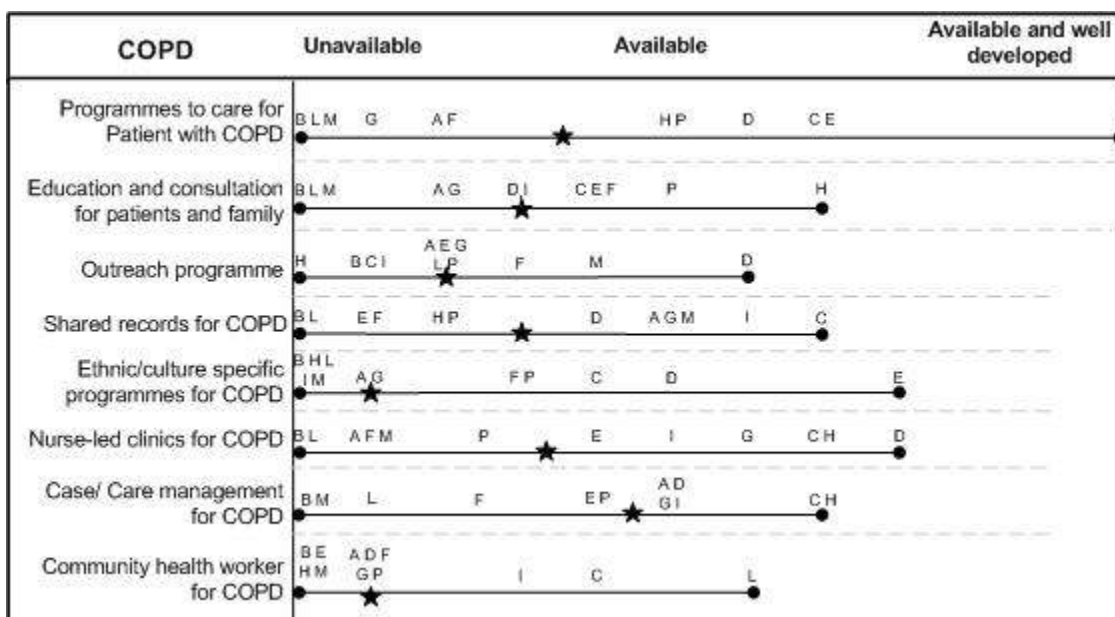
³ DHBs classified by size: Small: C, G, Q, Medium: B, L, K, H, F, Large: E, A, I, M, N and P

DHBs classified by size: Small: C, G, Q, Medium: B, D, L, K, H, F, Large: P, E, A, I, M and N

- Those DHBs that rate themselves poorly/highly tend to consistently do so.
- DHBs collectively have developed strategies in some areas to a low or moderate level only.
- Only a minority of services in a minority of DHBs were ‘available and well developed’.
- Overall, provision for CVD is rated better than that for CHF, COPD and Stroke.
- Outreach, community workers and cultural initiatives seem particularly poorly developed.



KEY: ★ = median score AB, MP = DHB ●—● = range



KEY: ★ = median score AB..MP = DHB ●● = range

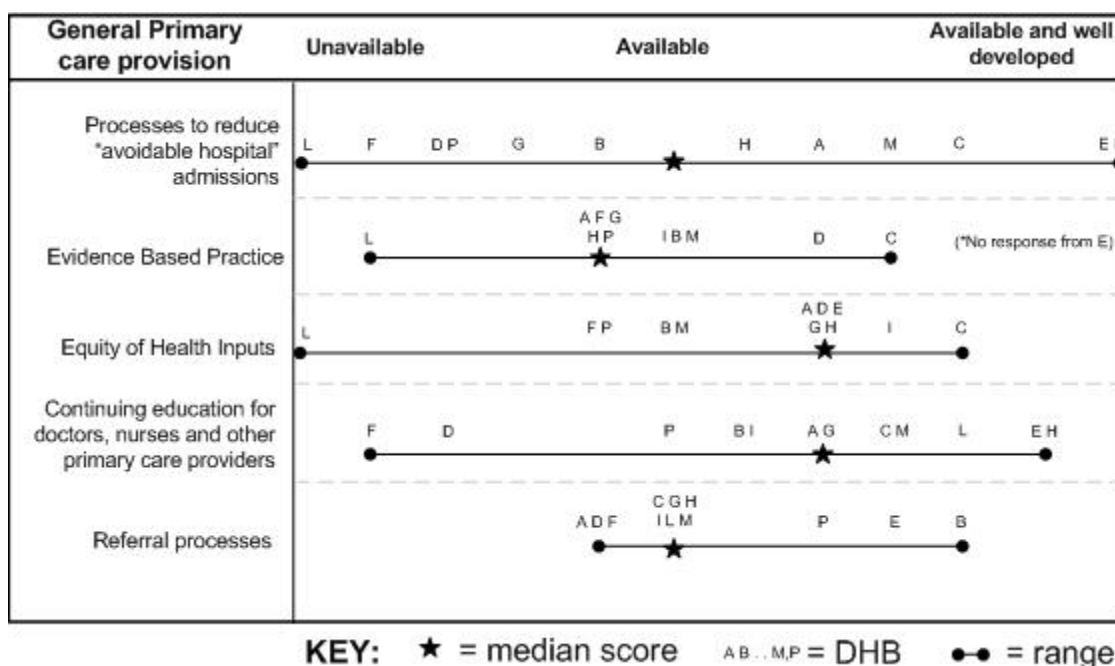
General Primary Care Provision

The figure below summarises DHBs' responses in relation to their perception of primary care CCM provision (DHBs indicated by a confidential alphabetic code). The most important findings are:

- Wide range of perceived provision (all variables) - largely dictated by a minority of outliers.
- DHBs collectively have developed strategies to a moderate/high level in these areas.

DHBs classified by size: Small: C, G, Q, Medium: B, D, L, K, H, F, Large: P, E, A, I, M and N

- The DHBs' previous tendency to consistently rate themselves poorly/highly was less marked.



GENERIC STOCKTAKE - HEALTH INEQUALITIES QUESTIONNAIRE

This questionnaire sought macro-strategy answers at DHB and PHO level. Data are presented in tables below. (DHBs represented by confidential alphabetical code).

Responses for questions relating to addressing health inequalities at population health level

Processes for addressing health inequalities	Percentage of response	DHB codes for those DHBs with relevant processes/tools/plans
Have tools for tackling health inequalities	14 /14 DHBs (100%)	Some DHBs use HEAT tool and some use other tools
Have strategic inequalities plan	2 /14 DHBs (14%)	A, H
Have plans/framework developed to address health inequalities		
Maori Health Plan	13/14 DHBs (93%)	A, B, C, D, E, F, G, H, I, J, K, M, P
Pacific Health Plan	7/14 DHBs (50%)	B, D, E, H, I, L, K
Asian Health Pan	Nil	
Refugee and Migrants	1/14 DHBs (7%)	B
Other	2/14 DHBs (14%)	B, J

DHBs classified by size: Small: C, G, Q, Medium: B, D, L, K, H, F, Large: P, E, A, I, M and N

Summary of the response to questions relating to disadvantaged groups

Outcomes for groups at greatest disadvantage	Percentage response and DHB codes of those responding in the affirmative	Nil response (and DHB code)
Have committed resources for groups at greatest disadvantage	12/14 DHBs (86%) A, B, C, D, F, G, H, I, J, L, M, P	1/14 DHB (7%) J
Have data on estimated numbers in district by ethnicity and quintile with:		
COPD	4/14 DHBs (29%) B, D, K, M	1/14 DHB (7%) J
CHF	2/14 DHBs (14%) A, K	1/14 DHB (7%) J
CVD	4/14 (29%) A, I, K, M	1/14 DHB (7%) J
Stroke	4/14 DHBs (29%) A, D, K, M	1/14 DHB (7%) J

Health inequalities at the DHB / PHO macro-strategy level

Processes and programmes DHBs use to identify ethnicity and SES demographic characteristics of their population for the four disease specific areas: Four or five of 14 DHBs (depending on index condition) said they had no processes to identify affected individuals by ethnicity or SES. Of those reporting they *did* have such processes, many cited acute admissions and outpatient/rehab/outreach which only identify the already diagnosed. See full report for details.

Barriers to access into programmes for people with chronic conditions

Problem of access into programmes, and procedures used to discover if barriers are reduced or eliminated: Three DHBs (E, G, H) said they did not identify/quantify access problems. One (P) did not respond. See full report for details.

Cultural safety training

Cultural safety training in relation to Maori: Nine DHBs (C; D; F; G; H; I; J; L; M) said they required employees to undertake Maori cultural safety training. Four (A; B; E; K) said that such training was not compulsory. One (P) did not respond. Four said the number of employees who had undertaken Maori cultural safety training was unknown. Two did not respond. Only three provided a figure (see full report).

Cultural safety training in relation to working with people who have disabilities, belong to different ethnic groups, religious groups, and people with different sexual orientations: Eleven of 14 DHBs (A; B; C; D; E; F; G; H; J; K; L and M) reported they did not require employees to undertake cultural safety training detailed above. Two (H and F) reported that none of their employees had undertaken such training.

Health inequalities at the PHO macro-strategy level

We also asked DHBs about service provision at the PHO strategy level. Only 7 DHBs responded. A DHB with a high Pacific load did not have programmes targeted at the Pacific population. All respondent DHBs (with one exception for Stroke) said they had PHO strategy level processes/programmes to manage care of people with COPD, CHF, CVD and Stroke by ethnicity and by SES. DHB size did not appear to affect number of programmes / services provided. Among the respondents, Care Plus was commonly used at PHO level for our index conditions.

Barriers to access into programmes for people with chronic conditions

Identifying problem of access into programmes: Five of seven respondent DHBs reported how their PHOs had quantified issues of access into programmes for people with chronic conditions. Two did not.

Programmes or services to address recognised barriers to access: Five DHBs commented; of these, two said they had SIA funding to address access barriers at PHO strategic level. Other processes cited are detailed in the full report.

Procedures employed to discover if barriers are reduced or eliminated: See full report. DHB size did not appear relevant.

Cultural safety training

Cultural safety training in relation to Maori: Six DHBs said that their PHOs required employees to undertake cultural safety training in relation to Maori. Three said the proportion who had undertaken training was unknown. Two said that all PHO staff had undertaken training, and one that they had only just begun training. One did not respond.

Cultural safety training in relation to working with people who have disabilities, belong to different ethnic groups, religious groups, and people with different sexual orientations: Four DHBs reported that PHOs required employees to undertake disability training, two said employees were required to undertake training in relation to working with diversity of people and one did not know. Six could not quantify the proportion who had undertaken training.

DISEASE SPECIFIC STOCKTAKE

Separate questionnaires covered provision for each index condition. Between 13 and 15 DHBs (depending on condition) completed all/part of each questionnaire. DHBs were grouped by size according to MoH breakdown by population: three small (C, G, Q) six medium (B, D, L, K, H, F) and six large DHBs (E, I, A, N, M, P). The tables below summarise provision (non-responders excluded). For details of results by DHB (confidentially coded) see full report

Summary of evidence-based CVD service provision by DHB size

	Small DHBs (%) positive response	Medium DHBs (%) positive response	Large DHBs (%) positive response
Overall Leadership in Cardiology	0	80	100
Protocols/guidelines for ACS management	33	100	100
Echocardiography	67	100	100
Coronary Angiography	0	40	80
Percutaneous coronary intervention	0	0	80
Coronary Artery bypass grafting	0	0	60
Hospital or community based cardiac rehab	100	100	100
Post-rehab exercise programme	0	33	60
Ongoing (post-rehab) support	100	67	80
Cardiac rehab audit or quality improvement programme	100	50	60
Smoking cessation service	67	100	60
Smoking cessation audit or quality improvement programme	0	0	Nil response
Dietician service for cardiac patients	100	100	80
Dietician service audit or quality improvement programme	0	0	33
Cardiac patient self-management and education programme	67	80	60
Self management programme audit or quality improvement programme	0	50	0
CVD Case management	33	60	40
Case management audit or quality improvement programme	0	50	100

Summary of evidence-based CHF service provision by DHB size

	Small DHBs (%) positive response	Medium DHBs (%) positive response	Large DHBs (%) positive response
Audit/Quality Improvement for Patients admitted with CHF	0	60	60
Leadership in CHF	0	40	33
Protocols/guidelines for CHF management	50	60	50
Echocardiography	67	100	100
Hospital at home teams for acute CHF exacerbations	33	40	0
Discharge planning for CHF patients	33	40	83
Audit/quality improvement programme for discharge planning	Nil response	Nil response	100 (only 1 DHB responded)
Outpatient based CHF management service	33	100	100
Audit/quality improvement programme for outpatient CHF service	0	0	40
CHF self-management education programme	50	60	83
Audit/quality improvement programme for CHF self management	0	0	25
CHF Case management	50	80	50
Audit/quality improvement programme for CHF case management	Nil response	Nil response	100 (only 2 DHBs responded)
Palliative care for CHF patients	50	100	83

Summary of evidence-based COPD service provision by DHB size

	Small DHBs (%) positive response	Medium DHBs (%) positive response	Large DHBs (%) positive response
Audit/ Quality Improvement for COPD admissions	0	33	50
Overall Leadership in COPD	33	50	67
Protocols/guidelines for COPD management	33	83	50
Spirometry	100	100	100
Spirometry audit/quality improvement programme	50	33	60
Pulmonary Rehabilitation (PR)	100	83	100
Ongoing home-based exercise programme	0	33	60
Ongoing (post-rehab) support	100	100	40
Other rehab community based service	0	100	40
PR audit or quality Improvement Programme	50	67	100
LTOT Service	100	100	100
Service lead for LTOT (large 'nil response' rate)	50	75	50
Written guidelines for LTOT	100	100	100
LTOT Audit / quality improvement programme (large 'nil response' rate)	50	0	75
Non-invasive ventilation (NIV) for stable COPD (large 'nil response' rate)	0	0	60
NIV for COPD exacerbation (NB. large 'nil response' rate)	50	75	80
Hospital at home teams for COPD exacerbation	0	17	0
Smoking Cessation	100	100	100
Audit or quality Improvement Programme for smoking cessation (NB. large 'nil response' rate)	50	0	0
COPD Self management / education programme	67	67	50
Audit / quality improvement programme for COPD self management (poor response rate)	0	0	100 (only 1 respondent)
COPD Case management	33	67	50
Audit / quality improvement programme for COPD case management (NB. large 'nil response' rate)	0	100	100

Summary of evidence-based stroke service provision by DHB size

	Small DHBs (%) positive response	Medium DHBs (%) positive response	Large DHBs (%) positive response
Audit Process/Quality Improvement for acute stroke	33	67	80
Overall Leadership in Stroke	67	100	80
TIA Clinic	0	67	60
IV thrombolysis for stroke	0	50	100
Acute inpatient (IP) Stroke Unit	0	50	60
IP Stroke rehab facility for patients <65yrs	33	0	75
IP Stroke rehab facility for patients ≥65yrs	0	17	75
Stroke-specific MDT for rehab patients	33	50	75
Stroke-specific early discharge programme	33	17	40
Day Hospital rehab	50	17	40
Outpatient (clinic) rehab	33	50	80
Community or home-based rehab	67	67	100
Routine audit: patient level	33	17	100
Routine audit: service level	33	17	100
Use of guidelines	67	83	100
Routine follow up of all patients post discharge	67	33	40

GENERIC STOCKTAKE: OVERALL COMMENTS

Our first concern revolves around the response rate of DHBs. We do not suggest that an incomplete response may mean that the data may be to some extent unrepresentative of the national picture (though we acknowledge this possibility), but that, particularly for a study commissioned by DHBNZ, lack of engagement of some DHBs must call to question the priority given to CCM development in those districts. The commonest reason provided for absent or incomplete response was lack of DHB resource, though we also recognise the phenomenon of ‘survey fatigue’. Nonetheless, engagement in any initiative may be crucially dependent on the priority accorded to the issue in question.

Perhaps the most striking overall finding in the current survey is the **wide variability in perception of provision, processes etc between DHBs**. Such geographical disparity has been termed a ‘postcode lottery’, and such a situation, if genuine, must be cause for concern. The first question therefore must be whether the impression of a postcode lottery is a true reflection of the current situation around CCM (for CVD, CHF, COPD and Stroke in particular) in New Zealand. Given our concerns (see below), regarding the possibility of variability in DHBs’ awareness of primary care/PHO provision this is a valid question. However, in very many cases, even if minimum perceived provision underestimated actual provision by a factor of 2 or 3, variability would still be marked. It is also noteworthy, and perhaps of even greater concern, that in addition to the overall pattern of variability discussed above, those DHBs that rate themselves poorly/highly tend to consistently do so across the spectrum of dimensions.

Inequalities: We were disappointed with some of the DHBs’ responses around the strategies and initiatives that both they and PHOs have in place for health equalities, and how they monitor the success of these initiatives. Very few DHBs reported that they had reliable estimates of the demographics of these conditions by ethnicity or by quintile, and others relied on opportunistic discovery, only able to identify patients with significant symptomatology necessitating specialist help. DHBs’ responses on whether access barriers had been reduced or eliminated were more reassuring, though there was a tendency to rely on process monitoring and on improvements in rather blunt outcome measures. We recognise, however that this is an extremely difficult area. It would also appear that the situation regarding cultural safety training, particularly the monitoring of the uptake of such training, has considerable room for improvement in both DHBs and PHOs. In contrast, the results of the inequalities dimension, taken in isolation, make reassuring reading. There was a reasonable degree of congruity between those DHBs reporting that they possessed data by ethnicity and by SES on the demographics of our four index conditions and the scores DHBs accorded to the inequalities dimension i.e. the two sets of data appeared to validate each other. However there was less apparent congruence between DHBs’ impressions of their commitment to cultural safety and either their requirement for employees to undertake cultural safety training in relation to Maori or to other ethnic groups, or their ability to provide data on the proportion of employees who had undertaken such training. Overall these findings suggest that there needs to be greater effort in terms of recognition of the Treaty of Waitangi and inequalities for Maori. They also suggest need for improved efforts around other ethnic groups and minorities.

ABCC Dimensions: The overall perception of only limited CCM dimension development was particularly evident in **decision support, self-management support, knowledge transfer** and in some aspects of **delivery system design**. Two of these dimensions (**knowledge transfer** and **system design**), relate particularly to change management. Indeed this may also speak to a difficulty *accepting* the need for

change as also evidence by the fact that strategies which focus on the patient as the centre of the system are underdeveloped relative to measures placing the healthcare provider at the centre of the system. That DHBs perceive most of their systems aimed at promoting self-management as being at basic level is particularly worrying in the light of the fact that **self-management support** is fundamental to current understanding in CCM. **Decision support** and **knowledge transfer** (both underdeveloped in relation to many other dimensions) relate to IT provision, an area also highlighted as weak in other aspects of our project - particularly in the 'movers and shakers' interviews. The inability of many DHBs to provide data in other areas of the stocktake, together with (again in many DHBs) the lack of processes to improve patient access to evidenced based programmes may also be, at least in part, a consequence of inadequacies in IT support. Provision of evidence based guidelines was reported as being generally good. However, there was little evidence that DHBs supported their guidelines by provider education or reminders.

The low scores given to aspects of **delivery system design** such as the appointment system and follow-up, and the extremely low scores provided in the inter-related dimension of **knowledge transfer** are disappointing given the likely relatively small level of investment (vs. for example recurrent salary costs) that would be needed to produce more responsive, patient integrated systems. Such integration is an essential component of any system which aims to increase 'fidelity' to a CCM programme.

Within the **leadership** dimension perceptions were more encouraging, and variability less marked. Disappointingly however the lowest score for any aspect of this dimension was for championship. This suggests that one of the challenges for New Zealand is how to encourage/facilitate clinical leaders to become champions. These results align well with the impressions of our 'movers and shakers'.

Most self-rated scores within the dimension of **community linkage** were reassuring. The exception was the area of links with traditional healers and complementary therapy. Within the **collaboration** dimension it was gratifying to find that honesty and trust between individuals are perceived strengths. Within the dimension of **organisation of the health care delivery system** scores were perceived as moderate in all areas. However 'moderate' actually translates as: 'marginal workforce, not projected to increase'; 'team discussions dominated by lead clinicians'; 'no encouragement for self management'; 'need to fight to retain financial resources'. These are not encouraging descriptions. The workforce issue is of particular and major relevance in New Zealand.

Primary Health Care Questionnaire – Disease Specific: The perception within DHBs of provision by and/or within primary care of CCM services is not encouraging. Best provision seems to be for CVD. However even here perception is of almost an absence of patient education, community workers and outreach and only limited provision of cultural specific programmes and nurse-led clinics. This latter again contrasts with DHBs' assertions around cultural safety. DHBs believe that primary care is performing much better in risk assessment and moderately in terms of CCM programmes for CVD in primary care, the sharing of records, and single-disease focused case management.

Provision for CCM for CHF in primary care is believed by DHBs to be poor. Though DHBs acknowledge CCM programmes exist in primary care, the ratings provided for patient education, outreach programmes, shared records, culturally specific programmes, and provision of community health workers were very low. There was also little provision for nurse led clinics and case management was regarded as having single-disease focus, rather than an integrated approach cognisant of co-morbidity and patient centeredness. In terms of provision of CCM for COPD within primary care, DHBs perceive

the situation to be even worse than that for CHF. Whilst DHBs acknowledge some CCM primary care programmes for COPD do exist, the mean rating for this variable indicates a low level of provision. Ratings for provision of support groups, outreach programmes, shared records, culturally specific programmes, nurse led clinics, single-disease specific case management, and community health workers were perceived as poor or very poor. These findings largely accord with the results of a survey by the New Zealand Branch of the Thoracic Society of Australia and New Zealand (TSANZ) conducted in 2006, which found that only 10 DHBs had implemented *any* aspects of a CCM strategy for COPD, and only 12 reported cooperation in *any* COPD service provision between primary and secondary care providers. In terms of Stroke the picture is similar to that for COPD. In common with DHBs' perception of overall CCM, the DHBs' perceptions of diseases-specific CCM services within primary care, if accurate, suggest a "post code lottery" of perceived provision.

Primary Care Questionnaire – General: DHB perception of CCM in primary care in terms of processes to reduce avoidable hospital admissions, use of evidence-based practice, referral processes, equity of health inputs, and continuing education for healthcare professionals is reassuring. Though variability in these areas between DHBs was perceived to exist, it was largely influenced by a small minority of DHBs who perceived very low provision. Furthermore, the tendency for some DHBs to rate themselves relatively high in all areas, and for other DHBs to rate themselves consistently low, seen in other parts of the current report, was considerably less marked in this area. These factors suggest more equity of provision across the nation than do the results of other aspects of the current survey.

Methodological Constraints: Our results / interpretations depend on accuracy of DHB perceptions of CCM in primary care. Questionnaires were completed by Funders and Planners in cooperation with lead clinicians in relevant areas. If however DHB perceptions are inaccurate we may have overestimated, or (more likely) underestimated primary care provision. If this were so however it would suggest a systemic problem of intersectoral understanding which would militate against effective CCM provision almost as much as would the limited levels of provision highlighted in the report assuming their accuracy. This is particularly true in relation to patient experience at the primary-secondary interface, especially around acute hospital admission for exacerbation of a chronic condition. Though only a tiny proportion of the life journey of a person with a chronic condition, these acute events are crucial and life changing (and expensive). Thus intersectoral awareness is also crucial. If DHBs' perceptions are accurate there is much to be done; if inaccurate the same is true.

DISEASE SPECIFIC STOCKTAKE: OVERALL COMMENTS

There is general agreement that chronic conditions management (CCM) should largely take place within a primary care and community context. We strongly endorse this view. However, getting things right in primary care is no excuse for poor provision in secondary care:

- The evidence base that has led to the view that CCM must be largely a primary care concern has been formulated and gathered in healthcare systems with effective and reasonably comprehensive secondary care service provision.
- Evidence of the need for effective primary/secondary interfaces in CCM is strong.
- The remaining evidence base and guidelines are largely in the secondary care field and in the ABCCNZ study we were looking for initiatives based on evidence.

- Though only a very small proportion of the life journey of a person with a chronic condition, secondary care events are crucial and life changing (and expensive).
- Hospital episodes can be an index event on which to base further contacts.
- In New Zealand, many patients pay for primary care access and not for secondary care. Thus failure to improve secondary care CCM provision as a priority will at the very least perpetuate existing inequality of access to CCM.

The main purpose of the disease-specific stocktake was thus to evaluate secondary-care-based CCM provision and its links with primary and community care.

There are two themes common to the generic and disease specific stocktakes:

[1] As previously, our first concern is the response rate of DHBs. We acknowledge that in the disease specific stocktake many questions required demographic, continuous, and numerical information, and these aspects engendered the poorest response. However, engagement of only 13-15 DHBs in the *first phase* of the disease specific stocktake (which generally required only 'yes' or 'no' answers around service provision), was disappointing. We again however recognise the phenomenon of 'survey fatigue', and are aware of examples where aspects of our survey actually or almost coincided with other local or national surveys asking similar questions. An alternative (though equally important) explanation for paucity of data provision by some DHBs particularly in terms of questions relating to service uptake, access by ethnicity, waiting times and funding, is that DHBs' ability to easily access and manipulate their own data to the benefit of their services (and of their patients) is limited. The generic stocktake revealed problems with IT, data management, knowledge transfer and decision support; and the current paucity of information provided in some areas by some DHBs may be further evidence of this.

[2] Again, the most striking finding is the wide variability in perception of service provision between DHBs. It is of even greater concern that in many instances variability in disease specific service provision seems to relate to DHB size, larger DHBs having greater provision not only of 'technical' tertiary services, but also of standard care, leadership, patient education and self management, case management and audit. There are individual exceptions to this and a minority of areas where the converse pattern emerges. Nonetheless the overall picture is clear and in our view is a sad reflection on New Zealand healthcare provision.

We now address specific aspects of the disease specific results.

Leadership: There is a good level of clinical leadership in CVD and stroke with 69% and 86% of respondent DHBs indicating they had a clinical leader for these respective conditions. However only 29% have a clinical leader for CHF, and 54% report such a position/individual for COPD (40% for LTOT services). These results accord well with the opinions expressed by our 'movers and shakers'. DHBs' own impressions in the generic stocktake suggest that clinical leadership is perceived as reasonably well provided (probably true for CVD and stroke but demonstrably less true for CHF and COPD) but *programme championship* less so. For all index conditions there was evidence of greater provision of clinical leadership in larger DHBs.

Audit and Quality Improvement: The situation in respect of audit and quality improvement should be a major cause for concern. Again the situation was, with some exceptions, worse in smaller DHBs, but the failure to critically examine many aspects of service provision was seen across *all four* index conditions.

Some of the responses suggested that concepts of continuous quality improvement and of clinical indicators were misunderstood. Should this continue it would not bode well for CCM development, as without good, local evidence of access, workload and effectiveness, service design/redesign is a blind exercise. The Ministry of Health may also not be able to rely on DHB self reporting as a marker of the quality of services provided.

Use of protocols and guidelines: Guidelines for LTOT assessment in COPD were universally employed. With this exception, reported use of clinical guidelines/protocols in management can be described as dichotomous. Half of all respondent DHBs had no local guidelines in place for management of acute exacerbations of CHF, and 40% had none for acute exacerbation of COPD. The situation was much better for acute coronary syndrome and acute stroke, where 77% and 86% (respectively) of respondent DHBs employed local guidelines. This disparity between COPD and CHF on the one hand, and CVD and Stroke on the other may reflect the differences in clinical leadership in these areas. Again there was the suggestion of a trend for greater use of guidelines in larger DHBs though differences were less marked than for the use of audit. The limited use of guidelines in acute exacerbations of CHF and of COPD is particularly worrying as most patients with these conditions are admitted (not inappropriately) to general medical or geriatrics wards rather than to specialist units. Guidelines themselves are not ‘the answer’ to comprehensive patient management, but can be useful tools to facilitate quality improvement. They need to be in accessible, usable form, and the perceived failures in many cases in this regard, highlighted in the generic stocktake further emphasises the need for improvement in the availability and quality of (particularly IT based) decision support tools. Reinventing the guideline wheel in 21 DHBs has significant resource implications, emphasising the need for greater cooperation among DHBs in this area.

Self management and education: The evidence base around self management/education *as part of a comprehensively delivered CCM programme* is good. As stroke and TIA is generally an exception to this we did not ask about self management in stroke. In contrast with other areas, it appeared that self management and education (in CVD and COPD at least) was more widely incorporated into routine patient care in small and medium-sized rather than in larger DHBs. Overall 64% of respondent DHBs indicated they offered self management and education programmes in CHF, 60% in COPD and 69% in CVD. Though this variance needs further explanation these figures are reasonably reassuring, especially given the self-perceptions within the generic stocktake report that such programmes were not widely available and well developed. Nonetheless, reported staffing levels were, with few exceptions, disappointingly low.

Case management: For the same reasons as above, we did not enquire about case management in Stroke. However, case management provision in CHF, CVD and COPD was poor, with programmes in CHF in 57% of DHBs, in COPD in 47%, and in CVD in 46%, with again low staffing levels. We are aware from personal clinical experience that these services are expanding across New Zealand (reinforced by comments from DHBs around development plans – see full report), and we would encourage a diversion of available resources into this valuable area. There is large potential human resource available for nurse-led development here.

ARE OUR FINDINGS VALID?

The validity of generic and disease specific results is dependent on the accuracy and completeness of the knowledge of DHBs employees (clinicians and others). We had no control over who completed the surveys within individual DHBs (though we requested a wide variety of professional groups be involved). We are however, aware of the considerable efforts that DHBs employed to ensure delivery of information and thus as well as being deserving of gratitude, this reassures us of the reasonable accuracy of our report. We are further reassured by the 'internal' and 'external' consistency of our findings. Internally, our findings are reinforced by the consistency of information we obtained in the generic stocktake, the disease specific stocktake and the 'movers and shakers' interviews. Our exemplar analyses (reported separately) will further reinforce the stocktake findings. Externally, a variety of national surveys and audits have been conducted at around the same time. These have all produced similar results and conclusions (NZ Acute Coronary Syndrome audit, the survey of respiratory services by the NZ Branch of the Thoracic Society of Australia and New Zealand conducted in 2006, and a national survey of stroke rehabilitation conducted in 2007).

THE FUTURE

An extremely encouraging finding of the current stocktake is that even where services do not exist this does not appear to result from a lack of knowledge within DHBs about the drivers behind CCM and the structures and processes needed to implement it. In response to the questions around initiatives DHBs would like to implement, and around initiatives they had previously tried and failed (see full disease specific report), there was evidence of an excellent knowledge base, which was however confronted with the barriers of limited leadership, and lack of financial and staff resource and difficulties around decision support. Similar findings emerged in our exemplar visits and our national workshops. This provides a level of optimism for the future. The enthusiasm and knowledge base around CCM within DHBs should be cornerstones upon which future services can be built. We need to invest in structures at national/regional/local level that connect currently diverse parts of the system. This will enable interactions to focus on quality improvement initiatives linked to programme outcomes. Given the pervasive attitude that CCM is difficult, it is vital that individuals and agencies are incentivised to be part of this process, and important that regular feedback is given within and across networks. Construction of effective, available and equitable CCM is no small task. We believe however that as well as being essential it is eminently possible.