



CANCER AND CHRONIC DISEASE:

A SERVICE REVIEW

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Executive Summary

Cancer, Cardiovascular Disease, Respiratory Disease and Diabetes were all identified as key focus areas within the TDHB District Strategic Plan due to the considerable burden this range of conditions has in terms of mortality, morbidity and health expenditure. Furthermore, significant inequalities exist in terms of the disproportionate burden this range of conditions has on Maori health, and addressing these inequalities was also identified as a key priority area.

The report provides a review of cancer and chronic disease services in Taranaki, as well as in-depth consideration of international evidence and outcomes from alternative service models. An assessment of the relevance of these models for Taranaki has been undertaken, leading to a range of recommendations for service development and reconfiguration.

The international evidence suggests that significant potential exists to improve health outcomes, quality of life, and satisfaction with health services, whilst also decreasing the burden on the acute sector, by configuring services revolving around the patient with a strong focus on the integration of care and removal of barriers which may exist between primary and secondary services.

Due to the nature of chronic disease, supporting patients in terms of self management of their condition is an integral component of service delivery and a strong evidence base exists for the effectiveness of appropriate education programmes.

Currently, patient education for chronic disease is offered by numerous providers within the community, although secondary nurse specialists and educators provide education services for a high proportion of patients. Primarily, this education is provided for people with established disease, or who have suffered an acute episode. Further support is available through individual NGO's.

The current service offered by Case Managers involves undertaking assessment and coordinate care of patients who have been admitted to hospital, and aims to arrange timely discharge. However, there is less focus on coordination with primary care, or with ongoing follow up or management.

In terms of cancer, a multidisciplinary team approach, coordinated by a specialist nurse, is established for patients with breast cancer, but not for any other types of cancer.

Duplications in service have been identified, such as the risk factor modification and coping strategy education which is common across several education programmes, whilst gaps in services have also been identified, such as the need for greater access to psychosocial services for patients with cancer / chronic disease.

Whilst elements of current services are excellent, opportunities exist for further development which can potentially provide significant benefit in terms of delivering a more coordinated and seamless service, based on the holistic needs of the patient, and underpinned by more consistently high standards of care.

Current services should be reconfigured to more closely align with the needs of patients, recognising the reality that two thirds of these people have multiple conditions and therefore require a more holistic approach to their care. As systematic screening develops to identify those who are 'at risk' of developing chronic disease, these programmes must provide a relevant pathway in terms of earlier interventions these people.

These programmes should incorporate strong involvement with psychological specialists in order to overcome the current lack of psychosocial support which is available to chronic disease and cancer patients, despite the high prevalence of stress, anxiety and depression associated with these conditions. Likewise, provider education in this field should be strengthened to improve the ability of non-specialists to recognise and understand psychological comorbidity in chronic disease patients, in order for them to be managed appropriately and receive the necessary support.

In light of supporting evidence from abroad, educational programmes should be developed which are culturally adapted to meet the specific needs of Maori.

Due to significant commonality between certain cancer types and chronic diseases in terms of risk factors, education needs, psychosocial support requirements, and focus on coordination, chronic disease services should be accessible for those patients with cancer for whom they are appropriate.

A full multidisciplinary team approach should be adopted for the full range of cancer types in accordance with national and international recommendations of best practice.

Primary care should provide the driving force for chronic disease as it presents a more appropriate setting for the majority of education services, however these must be established under an independent service which spans all primary providers.

For this shift towards primary care to be achieved, effective mechanisms for integration and communication between providers across primary and secondary services are essential. System Design aims to ensure that the full range of services are accessible and are sufficiently coordinated to provide a seamless service for patients. Central to this, once again, is shifting the focus of services towards earlier interventions and preventions of acute episodes and deterioration.

Whilst mechanisms and structures are important, it is the communication and engagement of health care professionals that are central to the shifts in focus being achieved. The role of specialists should be to care for the most complex patients, whilst supporting other health care professionals to care for the majority of patients.

Knowledge Management systems offer ways to encourage and embed this relationship between professionals, leading to an enhanced knowledge base in primary care and therefore a higher threshold for referral to specialist secondary services, whilst simultaneously improving communication and integration.

Knowledge Management, specifically Decision Support, aims to ensure that evidence based guidelines are consistently used in the management of chronic disease patients in order to provide standardised high quality care, based on the individuals specific needs and clinical situation.

In summary, the report provides a range of recommendations which aim to strengthen the ability of primary care to manage the significant majority of patients through community based services configured in such a way as to present packages of care relevant to the range of conditions they may have. This shift is enabled through the extension and formalisation of links between primary and secondary providers to break down these traditional barriers to integration.

Summary of Recommendations

This report includes a number of models and initiatives which may be considered for the development of services; the main recommendations of which are below:

Service and Workforce

Patient education services should be reconfigured to a community based model which sits within primary care, spanning the Primary Health Organisations.

Generic chronic disease education programme: Community based generic programmes focused on lifestyle, risk factor modification, coping strategies and self efficacy should be developed for patients with a chronic disease, or multiple chronic disease. These programmes should also be accessible to those patients identified as being at high risk of developing chronic disease, as well as those with established disease.

Group visits: To support the generic education, disease specific sessions run by specialist nurses / educators to provide education relevant to the particular condition should be established. These should also be community based services (where possible)

Case Managers: This function should be developed within primary care to work intensively with the highly complex and 'at risk' patients to prevent crises and unplanned admissions and to act as coordinators of care across various providers in primary and secondary services

Patient Held Care Plans: Patients should be empowered by taking ownership for care plans to help their understanding of their condition with information on their medication and treatment plans. This can also assist with coordination between providers and reduce the need to duplicate questions to the patient.

Psychosocial services: Psychosocial interventions should be included within the group education programmes, whilst further education and guidance should be provided to GP's and other health care professionals in order to recognise and manage these problems more comprehensively.

Knowledge Management

Effective mechanisms should be established to ensure the dissemination of knowledge from specialists to general practice. This will include the formalisation of processes and recognition and support of this within the specialists role.

Clinical Advisory Groups: Disease specific groups should be established to develop and promote evidence based practice guidelines to be adopted within primary care. This should include relevant direction towards local services.

Feedback to GP's: Inappropriate management of patients in primary care should be communicated to the GP in order to minimise re-occurrences.

Provider Education: Specialists roles should include a more formal focus on 'training the trainers' and provider education should be extended further in order to enhance the level of knowledge and expertise in primary care, whilst also improving communication and helping to remove barriers between integrated primary and secondary care.

Access to Specialist Advice: A web based posting system should be developed in order for specialists to respond to questions from GP's in situations where this may avoid an unnecessary referral.

Information Technology

Website: A TDHB chronic disease site, or micro-site, should be developed as a central point of reference with key services, contacts and links with accurate, validated and relevant information. Consideration should be given to supporting the NGO's in developing a collaborative resource centre for chronic disease.

Health Intranet: as well as the internet site as a resource for patients, a 'health intranet' or 'extranet' should enable integration with primary care providers. Functionality should include access to diagnostic results and appointments for tracking of patients.

Decision Support Tool. The success and effectiveness of the BestPractice decision support tool within Hawkes Bay DHB should be monitored with a view to implementing the tool within Taranaki. It offers full functionality to enhance the consistency and quality of care delivered by GP's. This must be led by the DHB and implemented across all PHO's.

Cancer Services

Integrate cancer / chronic disease services: Access to chronic disease services should be accessible to those cancer patients for whom it would be appropriate.

Extend Multidisciplinary Approach: A multidisciplinary team approach should be developed for patients with all types of cancer, in line with national and international recommendations of best practice.

Project Purpose

The purpose of this project is to review Cancer and Chronic Disease services within Taranaki.

The Taranaki DHB District Strategic Plan identified ten focus areas for the period 2005 – 2015 which include Cancer, as well as Cardiovascular Disease, Diabetes and Respiratory Disease.

Each strategic area was chosen on the basis that in focusing on these areas, Taranaki DHB has the biggest potential to improve the health of the population overall.

As a whole these conditions contribute to eighty percent of all deaths and around seventy percent of all health expenditure in New Zealand. The impact on the Taranaki community and the DHB health services mirrors these figures.

The burden of these conditions also falls disproportionately on the Maori population and this project aims to address these inequalities. Improving Maori health is another of the key focus areas highlighted within the District Strategic Plan

Many types of cancer share common risk factors with chronic disease, whilst patients suffering from these conditions may also have common requirements at all stages of their care. For this reason, this project will incorporate an assessment of the suitability of providing an integrated Cancer and Chronic Disease service.

It is essential that a clear strategy is developed in order to ensure an integrated and effective service is delivered for the people of Taranaki. The purpose of this project is to review current service provision across the continuum of care for patients with the above conditions, and to develop a framework for the coordination and reconfiguration of these services.

Cardiovascular Disease

Cardiovascular disease (CVD) is the leading cause of death in Taranaki and New Zealand as a whole, accounting for 40% of all deaths nationally (2000). Of Cardiovascular Diseases, Ischaemic Heart Disease (IHD) results in the highest rate of hospitalisation and mortality in Taranaki, whilst the second most common CVD, stroke, is the greatest cause of disability in older people. It is estimated that CVD accounts for 11% of the total non fatal disease burden.

Respiratory Disease

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in New Zealand as well as being a major cause of disability and hospitalisation. It is the second largest contributor to the burden of disease in New Zealand.

The burden of respiratory disease falls disproportionately on the Māori population - for the period 1997-2003, hospitalisations for COPD increased 83% for non-Māori and 233% for Māori. Incidence rates of Respiratory conditions in Taranaki and nationally are increasing.

Diabetes

Diabetes is a major contributor to other conditions such as Cardiovascular disease, blindness, kidney disease and vascular conditions which can lead to lower limb amputations.

The Ministry of Health forecasts suggest by 2011, the prevalence of Diabetes will have increased by around two thirds. Once again, the increasing incidence of this condition is more significant within the Māori population. According to 1996 figures, the risk of non Māori's contracting Diabetes was around 10% in contrast to over 25% for Māori's whilst further research indicates that over the next two decades, prevalence of diabetes in non-Maori's will increase by 39% compared to 90% for the Maori population.

Cancer

Cancer is a major public health issue in New Zealand, as in other economically developed countries.

In 1998 cancer was the major cause of death, accounting for 29 percent of all deaths (NZHIS 2002)

Furthermore, the burden of cancer – especially tobacco related cancer – falls disproportionately on Māori and on socio-economically disadvantaged individuals, families and communities.

In Taranaki the incidence from cancer has increased by 16.4 percent for non-Māori and 88 percent for Māori in the 10 years 1991 - 2000.

The number of cancer registrations in Taranaki for non Māori increases rapidly from 55 years onwards, peaking at the 70-74 age group, whereas for Māori the highest number occurs at the younger 65-69 age group. Over three-quarters of cancer registrations for non- Māori occur over the age of 55 years.

Cancer is also a key priority area for the Ministry of Health with the strategic direction being set by the Cancer Control Strategy and associated implementation plan.

The development of a cancer plan for the Taranaki region is a key requirement of the cancer control implementation plan and essential for the DHB in effectively planning cancer service delivery .

Māori Health

Improving the health of Māori people in order to address the stark inequalities is also a key area of focus highlighted in the Strategic Plan. By focusing on the conditions mentioned above, this will contribute significantly towards reducing these gross health inequalities.

Cancer has a significant and disproportionate impact on Māori, as does chronic disease, as outlined above. Incidence and mortality rates for Māori and non- Māori

differ for all cancers combined and for specific cancer sites (Pomare, Keefe-Ormsby et al 1995; Minister of Health 2003; NZHIS 2005). Inequalities in cancer death rates between Māori and non- Māori increased during the 1980s and 1990s, as did the contribution of cancer to inequalities in life expectancy between Māori and non- Māori (Ajwani, Blakely et al 2003a;Blakely, Ajwani et al 2004).

Addressing these significant inequalities will be a key priority within the strategic development of cancer and chronic disease services within Taranaki. Ensuring full access to services which are culturally appropriate for Maori, through all stages of the continuum of care, will be essential in reducing the incidence and impact of these conditions within this group.

The Objective

“To develop an integrated and efficient system of care, identifying individuals with chronic conditions (as well as those at ‘high risk’ of developing them) and designing and delivering individualised and culturally appropriate care packages which are founded on evidence based best practice guidelines and protocols.”

Due to the broad scope and limited time frames involved in the production of this report, it will serve as a precursor for the subsequent phase of the project. The aim of this document will therefore be to provide an analysis of current services along with options for future development, based on identified service gaps, and on evidence from alternative national and international models.

The Chronic Care Model

Upon review of the literature regarding chronic disease management, there are a number of key components which are central to most strategies and which are of clear relevance and importance to Taranaki. The majority of models in use internationally have evolved or been developed from Wagner's original Chronic Care Model (1998)

The model aims to link informed and active people with chronic disease with proactive teams of health professionals (Bodenheimer et al 2002)

It identifies six 'pillars' which provided the foundation for services;

- Self Management Support
- Delivery System Design
- Decision Support
- Clinical Information Systems
- Community Resources and Policies
- Health System Organisation of Health Care



(Chronic Care Model, Wagner et al 1998)

Self Management Support emphasizes the importance of the role of the individual in managing and taking control of their own condition. This involves

educating patients and providing them with the necessary tools, skills and support to manage their symptoms to maximise their quality of life

Delivery System Design involves ensuring appropriate services, structures and mechanisms in order to provide effective, integrated, and coordinated care. This involves adopting proactive approaches to maintain health, rather than reacting to exacerbations of illness.

Decision Support encourages the consistent use of evidence based guidelines by embedding them into daily practice. This includes the development and promotion of clear guidelines, as well as strong communication between primary and secondary health care professionals in order to effectively disseminate expert knowledge for the benefit of the greater population.

Clinical Information Systems allow for the monitoring, evaluation and reporting of practice teams and of sub populations enabling progress to be tracked, and helping to identify areas in need of improvement.

Community Resources include NGO's and other community groups which can be mobilised to support systems of care. These should be encouraged to collaborate and work towards an integrated strategy across the continuum of care.

Health System Organisation of Health Care refers to the centrality of effective leadership and culture throughout the system of care. A 'shared vision' across all providers must be created in order to enable change and effectiveness of initiatives.

Numerous studies support the assertion that the model can lead to better processes, health outcomes, service user satisfaction and costs although the extent of the benefits, and their attribution to the specific components of the model, are less clear cut (Singh & Ham 2006, Singh 2006)

The fact that the chronic care model originates in the USA may lead to concerns over transferability given the significant differences in ethos and system design compared to New Zealand. However, the predominant versions of the model – namely, Kaiser Permanente, EverCare and Pfizer, have all been adopted by organisations in the UK. This provides lessons regarding the transferability of the models whilst the UK

healthcare system is also more closely aligned with the New Zealand model. Moreover, within New Zealand, Counties Manukau DHB have successfully developed their approach to Chronic Disease Management based largely on the Kaiser Permanente model.

These approaches share broad commonality in terms of aiming to reduce the burden on health systems by reducing unplanned hospitalisations, and working proactively to prevent patient 'crises'.

The **Kaiser Permanente** model focuses on integration across boundaries, using financial flows as incentives, and stratifying patients according to need using the 'Kaiser Triangle' model:



The base of the pyramid represents the majority of patients with chronic disease. That is, they are individuals who have relatively less severe conditions, and the vast majority of their care is provided by themselves and their families, with the support and guidance of health professionals. The focus here is on providing individuals and their families with the information, skills and knowledge to actively take control of their condition. These issues will be addressed within the Self Management section of this report.

At level two in the pyramid are the 'high risk patients' whereby the model proposes a disease-specific care management approach. This involves providing people who

have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways. Here, patients should be managed within primary care in accordance to evidence based guidelines, with specialist input as required.

At the peak of the pyramid are the patients who have highly complex needs and are likely to be (or become) high intensity users of emergency or unplanned care. The model suggests that these patients are allocated 'case managers' who then actively manage them by thoroughly assessing and anticipating their needs and providing or organising care and support, delivered by relevant health professionals.

The approach encompasses all levels and stages of the continuum. There is an emphasis on clinical leadership whilst the primary / secondary interface is diminished by doctors working across sectors and sharing budgets

The **Evercare** model was developed for elderly people with chronic disease and targets the individuals considered to be of highest risk of becoming an intensive service user. The core principles are to provide care in the least invasive manner, in the least intensive setting, with primary care acting as the central organising force.

An 'Advanced Primary Nurse' (APN) role has been developed which provides a case management function targeting those individuals identified at highest risk. The APN integrates health and social care, providing thorough assessment, care and coordination of services aiming to prevent 'crises' where possible, and minimise them when not.

The **Pfizer** model likewise targets those at high risk, however it is characterised by the use of telephone assessment and monitoring as the basis for their case management approach.

Both Evercare and Pfizer models target only the 'level 3' individuals, rather than the comprehensive approach of Kaiser.

The **NHS** has piloted all three models and has developed the role of **Community Matron** (broadly similar to Evercare's APNS) to provide case management functions.

The **NHS Cancer Plan** suggests that the population health approach, outlined by the Kaiser triangle above, is appropriate for the management of cancer. That is, level 1

relates to self management – risk factors associated with some cancer types are the same or similar to other chronic diseases in terms of lifestyle factors such as smoking, nutrition, physical activity.

Level 2, again, relates to disease management. The NHS plan advocates the use of a Multidisciplinary team approach. (all or almost all patients with breast cancer, lung cancer, upper GI and bowel cancers are already cared for under the MDT model in the NHS)

Level 3 advocates a Case Management approach for cancer, working with patients to enhance their ability to cope and ensuring their care is coordinated. As with other chronic diseases, individually tailored packages of care are needed for patients with multiple of complex needs

Counties Manukau District Health Board developed an approach based largely on the Kaiser model. Patients enrolled to their Chronic Care Management programme receive four free GP visits per annum, as well as six hours of nursing time.

Introduction

This report will focus on the following broad subject areas:

- 1. Self Management Support
- 2. System Design
- 3. Decision Support / (Knowledge Management).

An overview of each area will be provided including a supporting evidence base and literature review, as well as a review of current services provided within Taranaki. A review of international experiences will be provided, with consideration of their relevance to Taranaki.

1. Self Management Support

Overview

Self Management is a broad term which encompasses a range of models and service options which are aimed at providing individuals with a greater measure of control and independence in order to maintain and improve their quality of life.

Gruman and Von Korff (1997) offer the following definition following review of the existing literature:

'it involves (the individual with chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms of illness, managing the impact of illness on functioning, emotions, and interpersonal relationships and adhering to treatment regimes

Wagner's Chronic Care model (1998), along with most other approaches to chronic disease management, emphasise the importance of enabling the patient to become an active partner in terms of decision making and managing their own condition.

Self Management is therefore a predominant feature in the Kaiser, Evercare and Pfizer models from the USA, likewise, the NHS Institute for Innovation and Improvement suggests that moving from clinical to self management is a key ingredient in shifting reliance from acute hospital care (Singh 2006, & Department of Health 2006).

The importance of Self Management can be understood by the recognition that chronic illnesses, by their vary nature, affect people in all aspects of their lives, 24 hours a day; contact with health professionals however, is usually only for a very small proportion of this time. Therefore, for the vast majority of the time, it is the patients themselves and their families who must manage and cope with the ongoing challenges caused by their condition(s). (Department of Health 2006)

'The patient should be the primary manager of chronic disease, guided and coached by a doctor or other practitioner to devise the best therapeutic regimen. The practitioner and patient should work as partners, developing strategies that give the patient the best chance to control his or her own disease and reduce the physical,

psychological, social, and economic consequences of chronic illness'. (Clark & Dong 2000)

Improving the skills, knowledge and confidence of individuals and their families to take a more active role in the management of their condition yields significant benefit for the patient, psychologically and physically, whilst also reducing the burden on health services. Numerous studies have demonstrated the association between self management programmes and improvements in care; these have included reducing the severity of symptoms, decreasing levels of pain, reduced anxiety and depression, and improve confidence, resourcefulness and self-efficacy and quality of life, whilst also reducing healthcare costs through a reduction in frequent and unplanned service use. (Barlow et al 1998, Deakin et al 2006, Buzewicz et al 2000, Lorig et al 1999, Bodenheimer et al 2002, Farrell et al 2004, Breslow 1999)

It has also been demonstrated that by developing the knowledge and understanding of patients, the relationship and interactions between the patient and their GP can become more productive and valuable. Patients have regularly reported improved communication with physicians and other health care providers following self management programmes (Department of Health 2006, Lorig et al 1993 & 1999, Singh 2006)

A Cochrane diabetes review further supports the positive effects of programmes designed to increase patients knowledge and skills, and to build their confidence in 'self managing' their own conditions. (VonKorff et al 1997, Norris et al 2001)

Box 1 – Summary of Benefits:

<u>Potential Benefits of Self Management</u>
➤ Reduce severity of symptoms
➤ Decrease level of pain
➤ Reduce anxiety & distress
➤ Improve confidence
➤ Enhance resourcefulness
➤ Improve quality of life
➤ Improve communications with health professionals
➤ Reduce unplanned hospital admission
➤ Reduce healthcare costs

Current Services for Self Management Support

The importance of patient education is already well established in Taranaki, as demonstrated by the specialist group education programmes offered by the DHB.

Programmes for diabetes, cardiac and respiratory care are run by TDHB Educators / Nurse Specialists. They are free of charge and individuals can enroll through self referral, or via referral from their GP or specialist.

The programmes provide a full range of disease specific information as well as lifestyle guidance and risk factor modification advice and coping strategies. All programmes include sessions run by various members of the multidisciplinary team such as podiatrists, physiotherapists, dieticians, and physicians

Education and support of self management is also provided in Primary Care by GP's, Practice Nurses and some Community Nurse input. This is generally on a one-to-one basis

An asthma education service is provided by Tui Ora which includes home visits, group / family sessions, as well as one to one sessions. Similarly, Te Tihi Hauora PHO Disease State Management nurses provide education and care generally within the home.

The Hauora PHO Mobile Health Bus also provides an education function, delivering primary prevention, detection and life style modification of risk factors associated with chronic disease. The service also provides care for some patients with existing chronic conditions who have difficulty in accessing secondary services, or choose not to.

Other support and advice is available to patients through NGO's such as the Diabetes Society, Asthma Society, Heart Foundation and the Cancer Society – predominately in terms of information resources, as well as support groups which sometimes include an educational component. These groups also play a strong role in preventative interventions in terms of health promotion.

Generic Group Education

Stanford Model

'User-led' self management programmes were initially developed at Stanford University in the USA. More recently, the NHS in the UK has developed an 'Expert Patients Programme' which is based largely on the Stanford model.

Professor Lorig (1993), founder of the Stanford Model: Chronic Disease Self-Management Program describes the aims of the initiative as to enable:

'participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviours, and to maintain or regain emotional stability'

Lorig led the Chronic Disease Self-Management Programme (CDSMP), which was generic and aimed at people with various chronic conditions, based on the recognition that people with chronic illness face a range of common problems such as pain management, stress and social issues, on a daily basis. (Farrell et al 2004) The programme aims to help people share and develop coping strategies to improve reduce the impact of their condition and maximise quality of life.

Topics covered include cognitive symptom management, exercise, nutrition, problem solving, social and workplace adjustments, accessing resources and communication with health professionals. An important element for participants is learning from each others experiences, and the principal reason for benefit is growth in confidence in their ability to cope with their disease. (Lorig 1993 & 1999)

The unique aspect to this programme is that it is led by trained lay people who have chronic disease themselves, rather than by health professionals.

Expert Patient Programme

The NHS Expert Patients Programme follows the generic approach spanning chronic diseases, focusing on issues such as dealing with acute attacks and exacerbations, making the most effective use of medication and treatments, accessing social and

other services, dealing with fatigue, managing work and developing strategies to deal with the psychological consequences of the illness. (The Expert Patient 2004)

The Stanford model is used by Kaiser Permanente in the US. Counties Manukau District Health Board are in the process of implementing a programme specifically for diabetes (with a view to extending the programme to cover other chronic disease) The programme will be run by a mixture of lay people and health workers – specifically community nurses and dieticians.

The Arthritis society in New Zealand also runs some Expert Patients Programmes.

A strong evidence base now exists to support the effectiveness of expert patient style programmes. (Wilson et al 2005, Newman et al 2004, Wagner 2000, Barlow 1997, Lorig 1993 & 1999, Busewicz 2006)

A randomised study into the effects of the Stanford model demonstrated improvements at 6 months in weekly minutes of exercise, frequency of cognitive symptom management, communication with physicians, self-reported health, health distress, fatigue, disability, and social/role activities limitations. Participants also had fewer hospitalizations and days in the hospital. However, no differences were found in pain/physical discomfort, shortness of breath, or psychological well-being. (Lorig et al 1999)

A study into the UK NHS Expert Patients Programme found that it resulted in a 7% reduction in GP consultations, a 10% reduction in Outpatient visits and a 16% reduction in Emergency Department attendances. (Department of Health, Stepping Stones to Success, 2005) Additionally, 45% of painters felt more confident that common symptoms (pain, fatigue, breathlessness, depression / anxiety) would no longer interfere with their lives, 38% declared that their symptoms were less severe four to six months after the course and 33% felt better prepared for consultations with health professionals. As yet, there is no robust evidence as to whether the EPP in the NHS has led to a reduction in the use of secondary services, although empirical evidence (Singh 2006) suggests an association between the programme and a reduction in the number of hospital days of participants

Culturally Appropriate Group Programmes

As described earlier, the burden of cancer and chronic disease falls disproportionately on Maori communities. The cultural appropriateness of these programmes must therefore be considered.

In the UK, the Expert Patients Programme was modified and designed specifically to target 'hard to reach' communities and redress the issue of inequalities in access to services, and indeed on prevalence of chronic disease and morbidity and mortality. This followed evidence that minority groups derived less benefit from the programmes than the majority groups. (Sheikh et al 2004, Griffiths et al 2005) Griffiths study concluded that a culturally-adapted CDSMP improves self-efficacy and self-care behaviour in South Asian patients with chronic disease in the UK.

Likewise, in the US, the Stanford model was adapted to target the Hispanic population. (Lorig et 2003) This study concluded that participants demonstrated improved health status, health behaviour, and self-efficacy, as well as fewer emergency room visits

Patient Held Care Plans

The Flinders University (Adelaide, Australia – see Battersby 2005) model for self management of chronic diseases emphasises an individualised and structured approach based on strong partnership between the individual and the health professional(s)

It provides a number of tools for health professionals to use in order to identify problems, agree and set targets, and track progress towards meeting these goals. The model consists of an interview, questionnaire, feedback and collaboration with the patient to identify and highlight problems and jointly set and monitor goals, and plan solutions and improvement strategies.

Problems are highlighted by the patient completing a questionnaire regarding the areas of self management. This is followed by a structured interview process which explores these areas in more detail, highlighting reasons for the key problems, or barriers they may perceive to overcoming them.

This collaborative identification process has been identified as a key success factor within self management programmes (Wagner 1996) and is used to develop a tailored care plan for the individual. The approach is generic, working across the range of conditions the individual may have, rather than being disease specific. The care plan articulates the identified issues and priorities, along with the agreed objectives and actions with review dates.

Various studies show that written, patient held care plans can help people better adhere to treatment and may improve health outcomes. (Singh 2006) A Cochrane study asserts that combining self monitoring with written care plans has shown to be a key factor in reducing hospital resources and admission rates.

Counties Manukau DHB implemented patient held care plans, 'The Wellness Plan', as part of their Chronic Care model. This involves an individualised plan including goal setting, medication information and details of ongoing health problems, future appointment details, contact details including advice on who to contact and what to do in case of an exacerbation. The care plan also provides the ability for various health professionals to make comments and updates following contact with the patient, for the GP or other health professionals to then see, improving the consistency and coordination of care. A study into the effect of the Wellness Plan found that 85% of patients rated it as useful or very useful. (CMDHB 2003) Again, It involves a collaborative approach between the patient and the GP towards identifying problems and objectives.

In New South Wales, this is extended to include patient held records. Based on the recognition that the nature of chronic conditions usually involve contact with multiple health professionals. The health record consists of a booklet with information about prescriptions, referrals, medical history, treatments and care management plans. This increase the coordination of care in that different health professionals have instant access to the same information and reduces the need to duplicate and repeat key information. Giving the patient access and responsibility for this is hoped to improve capacity to self manage and facilitate more productive communications with health professionals.

Group Visits

Due to the time limitations for consultations, 'group consultations' have been developed as a possible solution whereby patients with broadly similar problems visit the health professional together. This may be with a GP, but may be of equal relevance for complimentary functions such as with a podiatrist or a dietician, and the agendas are dictated by the patients themselves. (Wagner 2000, Jaber 2005, Noffsinger 1998 & 2003)

Several studies suggest that participants in group consultations experience increased quality of life, slower decline in activities of daily living, greater satisfaction, were more up to date in their preventative care, and reduced use of medical services as a result. (Wagner 2000, Bero et al 2000, Beck et al 1997, Farmer 1990, Goepfinger & Lorig 1997, Singh 2006, Jaber et al 2006, Trento et al 2001)

Studies have shown that education sessions based on providing clinical information provision rather than explicitly supporting self management in the manner of the Stanford and Expert Patients Programmes, can improve satisfaction and feelings of wellbeing as well as adherence to treatment, quality of care and clinical outcomes (see Singh 2006)

Resources for Chronic Disease

In order for Self Management to become a real alternative for some levels of care, people must have access to accurate, concise and timely information and resources. Information must be presented in an appropriate format in a way that people can relate to and understand and apply in a practical way (Hibberd 2003, Singh 2006)

Aside from information available from health professionals, individuals may seek further sources through relevant NGO's or through internet searches. Whilst the NGO's sites are generally excellent sources of information, there are many sources which may not be validated or accurate. As well as the issue of incorrect or conflicting information, many sources can often be 'alarmist' which can cause unnecessary anxiety and distress, as well as confusion.

Kaiser provides patients with a comprehensive education manual, 'HealthWise' available in 'hard copy' to all patients, whilst also being accessible online. This is intended to complement its group education programmes (Kaiser Permanente)

Self Management Recommendations

Develop Generic Group Education Programmes

There is significant commonality amongst chronic disease types in terms of risk factors, as well as their requirements in terms of treatment and support. In particular, lifestyle factors such as diet / nutrition, exercise, smoking cessation are highly relevant across certain cancer types, heart disease, respiratory disease and diabetes. There is a high proportion of patients, around two thirds, who have multiple chronic diseases. (Grumbach 2003, Ogle 2000)

'Disease specific programmes...do not address the clinical reality that patients and their health providers have to deal with more than one condition' (Battersby 2005)
(see also Goepfing 1997)

A generic 'chronic disease' service could reduce the need for providers to duplicate services, whilst reducing the potential need for the patients to attend multiple programmes. The generic programme may also be more appropriate given the relatively small population size of Taranaki. This should be a community based service.

Due to the development of more systematic screening programmes for patients at risk of chronic disease, there is the need for an appropriate pathway for patients which are 'at risk', as well as for the patients who have already suffered an acute episode or have developed a condition or multiple conditions. Education programmes should be offered as an earlier intervention

Patients who are 'at risk' or who already have single or multiple conditions should be enrolled onto a generic chronic disease self management education programme, focused on lifestyle and risk factor modification, coping strategies, practical and

emotional support, and direction for further education, and assistance with advocacy in terms of communication with health service professionals.

Whilst the Stanford model is led by lay people, these services could be led by a combination of health professionals such as nurses, and could involve sessions run by specialists such as dieticians, physiotherapists and psychiatrists. It should be noted that a significant advantage of current configuration of the group programmes relates to the knowledge sharing opportunities between the health professionals involved.

(Note: The Pulmonary Rehabilitation programme includes physical training for people with relatively severe conditions; this would not be suitable for a community based setting and should remain within the hospital)

Develop Culturally Adapted Programme for Maori

In terms of education for Maori, the evidence from the UK and the USA suggest that adapting the models to ensure cultural compatibility and relevance can be effective in delivering the benefits and positive outcomes of the mainstream programmes. A cultural adapted model of the programme should therefore be developed for Maori

Develop Disease Specific Group Visits to Nurse Specialist / Educator

For those patients who have more complex but disease specific problems, they will require specialist education relating to their particular condition(s). Group visits, as described above, have proved to be successful for people with similar conditions and benefits include improved patient satisfaction as a result of peer contact and the feeling of being less rushed, whilst this also involves more efficient use of the time and resources of the health care professionals. However, whilst the models above relate to GP group visits, a group visit to the disease specific nurse specialist / educators ideally complements the generic education programme, providing the high levels of expertise and knowledge in an efficient way.

Currently, there are patients who are followed up in secondary care, purely to receive updates and advice on new developments, techniques and technologies; the Group Visit model is ideally suited to this requirement, providing the opportunity to ask

specific questions and share learning amongst the group. This may also be the case for new insulin dependent diabetics who are currently routinely referred to specialist secondary services.

Patient Held Care Plans

These should be introduced as a simple mechanism to empower patients, enhance their understanding of their care plan, and to improve their communication with health professionals in terms of goal setting and monitoring.

Develop Central Chronic Disease Website

A central repository and knowledge source would provide information, guidance and advice for individuals and their families. Resources to support lifestyle education, and disease specific information should be included with links to the relevant NGO sources.

Many people may simply be unaware of the existence of certain services, or may not know how to access a desired service. The site would therefore include 'signposting' of existing services available through the various providers, along with guidance as to which services would be appropriate to their situation.

This may include:

- Disease specific information
- Lifestyle advice including nutrition and physical activity (information on local sports, gyms etc)
- Links to relevant NGO's with key contact information.
- Information on services and support available in the region
- A Discussion board could also be included in order to provide peer support.
- A Frequently Asked Questions section would aim to address common concerns or fears.
- A question and answer board for individuals to pose questions relating to services or specifically regarding their condition, and the relevant professional could respond, or direct to the appropriate source.

Resource Centre

Another option to improve access to resources and information in order to support self management, would be to support the NGO's towards the development of a coordinated chronic disease resource centre.

This would provide information and resources, as described above, in various formats. This may include providing internet access for those who do not have it, and support with using the internet for those unfamiliar with it.

Currently, NGO's in Taranaki perform vital functions in terms of providing information and support for patients. However, the collaboration of these organisations may help to further strengthen the role that they can play. A collaborative 'joint venture' between the NGO's would allow the pooling of resources, both financially and in terms of volunteer time, whilst reducing the duplication of similar services. Once again, this is based on the facts of commonality between conditions, as well as the high numbers of people with more than one condition.

Due to the rural and geographically dispersed nature of many sections of the Taranaki community, access problems are inevitable in terms of patients physically attending a resource centre on a regular basis. This is of even greater relevance given the mobility problems associated with many chronic disease patients.

Summary of Self Management

To summarise the key messages from this section, there must be a change in focus and emphasis in the way the services are designed. Education programmes should be shifted to include patients earlier in the 'pathway', that is, services should aim to prevent acute events and the development of conditions, as well as supporting those who have more established disease.

Services should become more tailored and appropriate for the needs of this group of patients taking a holistic approach based on the recognition that the majority of individuals have a range of conditions, and their packages of care should reflect this. Moving away from 'disease silos', the generic sessions would aim to meet the fundamental needs of these patients, and disease specific education would be provided as appropriate to the individual.

Finally, a greater proportion of service should be delivered within primary care settings. The principles of coordination and comprehensives which underpin primary care make it ideally suited for these services for which hospital care is unnecessary.

2. Service Design

Overview

Service Design involves the following central themes

- Identifying (and removing) service gaps
- Models of Case Management
- Systems of communication and integration between providers

Predominately then, service design is about ensuring that appropriate services are available and accessible, and that coordinated care is provided across the continuum and across various providers and health care professionals.

Psychosocial Services

Perhaps the most overwhelming and consistent message from this review has been the demand by health professionals for access to psychosocial support for their patients with chronic disease. Currently, there is no dedicated service to this group which represents a significant service gap.

Diagnosis of a cancer or chronic condition is likely to necessitate a wholesale change in lifestyle, not only effecting the individual, but also their family and loved ones in terms of changes to their domestic and working lives, with some patients experiencing problems with daily living, finances and employment. (Schultz et al 1995, Pascoe et al 2004)

Chronic conditions can manifest themselves with ill effects to mental as well as physical health. Depression is strongly associated with other chronic conditions such as diabetes and cardiovascular disease, likewise, psychosocial problems are common patients throughout the cancer journey (Pascoe et al 2004)

The proportion of patients with conditions such as diabetes or rheumatoid arthritis who have an affective disorder is between 20% and 25%.² (Gutrie 1996) The prevalence of depression amongst cancer patients is even higher (30%) (McDaniel 1995) Turner & Kelly (2000) note that even mild depression can reduce motivation to

access health services or to follow treatment plans. Whilst psychosocial interventions have been shown to improve the quality of life of patients with chronic disease.(Schneiderman et al 2001)

Pascoe's review suggests that lack of psychological screening amongst cancer patients in particular may be due to under reporting of symptoms from the patient, or by lack of awareness of psychological morbidity by health professionals. The issue of provider education will be addressed later in this report, however, direction in terms of the recognition and management of psychological morbidity for patients with chronic disease should be strengthened.

At MidCentral DHB, a designated oncology psychological service is established – all patients diagnosed with cancer are offered screening whilst it has been approved for this to be extended for patients with other chronic disease.

It is worthy of note that recommended interventions in terms of health education, stress management and behavioural training including problem-solving techniques, and psychosocial group support (Pascoe 2004) can all be provided by the self management education programmes described in the previous section. However, evidence for the success of group programmes in dealing with psychological status is inconclusive (Lorig 1993) and specialist input into the configuration of the programme should be gained to ensure its relevance.

Cancer Services

Cancer represents a spectrum of conditions with varying characteristics in terms of risk factors as well as treatment and management. In many models of chronic disease management, cancer is included within the range of conditions.

Various definitions of 'chronic disease' exist, characteristics include:

'ongoing or recurring but is not caused by infection and is not passed on by contact'

'An illness that lasts for a long time, an illness marked by long duration or frequent recurrence'

'A disease with one or more of the following characteristics: permanence, leaves residual disability, caused by non-reversible pathological alternation, requires special training of the patient for rehabilitation, or may require a long period of supervision, observation, or care'

It is clear from these definitions that many patients with cancer would be considered to have a 'chronic' disease.

As stated earlier, the NHS Cancer Plan supports the use of the chronic disease model for the management of cancer in terms of applying self management initiatives to the 'level 1' individuals, disease specific management based on multidisciplinary team approach for 'level 2 patients', and intensive case management for 'level 3' patients.

Risk factors for certain cancer types are common with chronic disease in terms of lifestyle issues such as smoking, diet and physical activity. Similarly, patients with these conditions often share common problems in terms of coping with pain, stress, and work and social difficulties. Similarly, we have seen within that the psychosocial issues are equally relevant to cancer and chronic disease, Therefore, the Self Management initiatives described above are equally applicable to some cancer patients as they are to those with other chronic diseases.

The Counties Manukau model does not currently include cancer, however, it is hoped that this will be included at a later stage.

Multidisciplinary Team

A Multi-Disciplinary Team (MDT) approach is currently in place for patients with breast cancer. This service is coordinated by a designated Breast Care Nurse (0.5 FTE). The Breast Care Nurse provides a range of functions for all patients diagnosed with breast cancer from diagnosis through to treatment, or referral to Oncology services. The role includes providing more thorough explanations to patients following diagnosis and consultations, and advising of the likely pathway and treatment options that are available to them. The nurse is responsible for the organisation of the MDT meeting.

Whilst the designated specialist nurse and MDT works effectively in providing valuable support to patients with breast cancer and efficiently coordinating their treatment, there is no such service for patients with other forms of cancer.

Once in hospital, these patients may receive support from the hospital case managers (who's role will be described shortly), and may be addressed at the weekly IDT if necessary, however this is only following admission and they would not receive the support prior to admission in the manner of breast cancer patients

It is worthy of note that a full multidisciplinary team approach is used for all cancers at MidCentral District Health Board. Within the NHS, all or almost all patients with breast cancer, lung cancer, upper GI and bowel cancers are already cared for using a multidisciplinary team. (NHS Cancer Plan 2000) The New Zealand Cancer Control Strategy (2003) supports the development of MDT approaches for cancers, based on the evidence of improved outcomes that the approach has been shown to produce.

Case Management

As described earlier, case management plays a crucial role in the strategies of the US models as well as in the NHS.

Fundamentally, case management involves stratifying patients by their severity or level of risk of experiencing a 'crisis' or unplanned hospitalisation and proactively managing their care to prevent any exacerbation. The role is one of coordination; assessing patients needs and ensuring they are met by the relevant health care providers

Current Services

It should be noted that the term 'Case Manager' has no universal definition; as demonstrated by the fact that TDHB case managers role differs significantly from Evercare's Advanced Primary Nurses and the NHS Community Matrons.

Within Taranaki DHB, a team of four 'Case Managers' currently exists and provides a hospital based coordination and discharge planning function for complex patients that have been admitted.

This involves needs assessments, referrals and arrangement of specialist input, and where appropriate, a coordination of an Inter Disciplinary Team.

Little communication with the patients GP takes place, other than ensuring that a discharge summary is produced by the overseeing consultant. There is rarely any follow up of patients following discharge (occasionally, a phone call is made) Patient Management Plans are sometimes produced which includes recommended management / interventions, however this is fairly infrequent.

This role provides an important function in coordination of specialist input and greatly enhances the discharge planning process, hence reducing the length of hospital stay, and improving the experience for the patient. However, the role is focused on managing the patient between admission and discharge from hospital; it is not focused on ongoing and proactive management of the patient outside of hospital in order to prevent a future admission. In summary, this is a secondary focused function with limited integration with primary care.

Evercare Advanced Primary Nurses

Evercare developed the Advanced Primary Nurse (APN) role to fulfill the case management functions and prevent hospitalisations amongst those 'high risk' individuals.

Using data analysis to identify high risk individuals, the APNs take on responsibility for the co-ordination of their care. This role combines assessment and intensive case management acting as providers of care themselves, as well as coordinators of care from other providers and agencies. The APNs are 'extended generalists' rather than specializing in any one condition. (Kane and Huck 2000)

The aim of the programme is to reduce avoidable hospitalisations. Having an APN to act as a single main point of contact helps the user to navigate appropriate services

and access other members of the multidisciplinary team (Department of Health 2005b, p. 25)

United Health Group (UHG), who have published studies regarding the success of the model, (Kane et al 2002a & 2003) state that the Evercare programme reduced hospital admissions by around of 50%, reduced prescription drug costs, produced high client satisfaction, improved prescribing and promoted use of evidence based clinical practice. (see also Natpact 2004)

NHS Community Matrons

Based largely on the APN model, the NHS developed a Community Matron role to provide case management functions, taking responsibility for the assessment, delivery and coordination of care to very high risk individuals (defined as those who have had two or more unplanned hospitalisations within the last twelve months)

The objectives of the Community Matrons are to prevent unplanned hospital admissions, reduce length of stay of hospital admissions, improve health outcomes, provide support and reduce anxiety of the individual and their family, and to improve the patients ability to function and their quality of life. (Department of Health, 2005)

As yet, the impact of Community Matrons is inconclusive, however it should be noted that a recent study (Gravelle et al 2006) suggests that the scheme has failed to significantly positively impact on unplanned admission rates, hospital bed days, or mortality. This study recognizes however, that these results may be a consequence of the case managers identifying high risk patients that were previously 'unknown' – that is, the criteria used by the case managers (two or more unplanned hospitalizations within twelve months) identified a set of patients, of which, only 24 % were previously 'active' on District Nursing case loads.

Case Management Summary:

Nurses who have additional expertise in the clinical and behavioural treatments for chronic disease are central to most chronic disease management models (Wagner 2000) There are however varying degrees of action and intervention on the part of the 'case manager' functions; some may simply be aimed at improving discharge planning and reducing demand on hospital services, and this is perhaps the case with the current model. The more comprehensive models also entail a strong clinical element which does indeed aim to improve the clinical condition of the patient. (Wagner 1998) The role is one which must effectively transcend traditionally boundaries in terms of acting as a bridge between primary and secondary providers, liaising with both to ensure appropriate care is provided in the appropriate setting These initiatives are based on principles of proactive planning and care, and working in partnership with the patient and their family. (Ibid)

Evidence from the US has shown that intensive, on-going and personalised case management can improve the quality of life and outcomes for these patients, dramatically reducing emergency admissions and enabling patients who are admitted to return home more quickly. Nurse led case management has been proved effective in diabetes (Peters 1995, Aubert 1998), cardiovascular disease (DeBusk et al 1994) and heart failure (Rich et al 1995) (see also Wagner 1998 & 2000)

Aubert's study found that nurse led case management can substantially improve outcomes in diabetes and that the gains are largely achieved within the first six months. This may indicate that case management in diabetes could be instituted for an initial period to build the patients skills, knowledge, confidence – and therefore improve their glycaemic control. The patient would then be managed by their GP, unless difficulties are experienced and the case manager is reinstated.

Apart from the US, evidence supporting the use of case management also exists internationally; a review of the success of case management models across several countries concluded that the approach is associated with a decrease in hospital bed days and an improvement in the functional status of the patient. (Hutt et al 2004) (see also Wagner 1998, Aubert et al 1998, Ham & Singh 2006)

'Because they provide guideline-driven clinical management and sophisticated self-management support, nurse-case managers may be the most efficient nidus for building more effective systems of care for chronic illness'. (Wagner 1998)

Hutt's study failed to identify which of the components of case management models are likely to be more successful, this failure was echoed in Singh's review (2006)

Wagner (1998) cites the critical success factors in case management as those which create a more responsive system of care for chronically ill patients. The successful programmes share a number of key common elements.

- *Critical role in supporting self management through education*
- *Service designed in way to allow time with case manager, plus access to array of resources and expertise.*
- *Explicit guidelines and regular communication*
- *Collection and use of data to allow for follow ups, reminders and population data.*

Telephone follow up

Due to the rural nature of the Taranaki community, telephone, or perhaps even electronic communication, provides an option to overcome transport, mobility and access issues for some follow up functions for people with Chronic Disease.

Sustained follow up is important to monitor response to treatment, development of symptoms, compliance and to detect any adverse changes in condition. Randomised trials have shown that telephone management can reduce costs and improve the health status of participants compared to patients receiving usual care (Simon et al 2000, Wagner, 2000, Wasson et al 1992)

Telephone support, or case management via telephone, has been found to improve clinical outcomes or reduce symptoms in people with various chronic diseases (including depression, heart disease, diabetes and asthma) Furthermore, regular telephone calls from nurses have proved to reduce hospital admissions in people with heart disease, asthma and diabetes. (Singh 2006)

Currently in Taranaki, most new insulin dependent diabetics are routinely referred to specialist services. This may not be appropriate in many cases, and adequate support and monitoring could be provided within primary care. In Counties Manukau, new insulin dependent diabetics are subject to daily phone calls to monitor progress and provide support and advice.

Pfizer developed the InformaCare model for chronic disease management which uses internet and telephone support, founded on evidence based guidelines, to direct people towards the most appropriate form of support to fit their situation and condition, and enables the tracking of the patient and coordination of their care by the relevant health professionals

Email and 'E-groups' were associated with improved symptoms in people with heart disease, whilst a similar study for diabetes also found improvements in the self management abilities of participants. Internet support groups have also had positive effects for people with depression. There is some evidence that internet contact (through a secure messaging service) between patients and providers may reduce other service usage. (Singh 2006, Wagner)

Telemonitoring

Telemonitoring includes transmitting of clinical indicators gathered by the patient for practitioners to review and monitor.

There is some evidence that this has significantly improved the clinical indicators for people with diabetes, and others which suggest it can result in increased adherence to management plans, improvements to quality of life, and even mortality in people with heart failure. (see Singh 2006)

Various studies have shown that transmitting monitoring data and telephone follow up was associated with reduced healthcare costs and fewer admissions and days spent in hospital for people with heart failure or COPD. (ibid)

A study by Ralston et al (2004) reviewed a web based disease management approach for patients with diabetes in the USA. The objective of the initiative was to

shift the focus of healthcare away from traditional settings and integrate it into the daily home lives of individuals.

The patients uploaded blood glucose readings on a weekly basis and sent secure electronic mail messages when necessary which were then reviewed by the case manager (a nurse practitioner) who coordinated and monitored the results

The system allows for remote collaboration and interactive feedback on nutrition, medications, and exercise using a web based self management tool, with links to validated information sources. The exchanges create and update an electronic patient record, and electronic reminders are created for patients and providers.

One of the key advantages to electronic monitoring that this study highlighted is that the provider can respond when it is convenient, and importantly, the patient knows this. Patients may be reluctant to call their doctor or nurse for what they may consider relatively smaller problems as they fear that they would be disturbing or wasting the time of the health professional.

Another major feature of this type of ongoing management is that the provider can monitor any deteriorations in terms of glucose levels or weight changes for example, and can respond accordingly, that is, arrange for the patient to be reviewed. Once again, the fact that the patient knows that they are being monitored in this way provides the feeling of security and reduced anxiety. (and anxiety can sometimes exacerbate chronic disease) (Ralston 2004)

Similarly, Trent Strategic Health Authority (see references) in the UK are implementing a similar model.

GP's with Special Interests

In the UK, 'GP's with special interests' are being developed in order to increase the level of care that can be provided in the primary setting.

Lewis & Dixon (2004) believe the increasing skill and development of 'special interests' amongst practice nurses and pharmacists, as well as GP's in the NHS will

lead to an increasing capacity of primary care to 'raise the threshold' for referral to secondary services.

As well as providing additional clinical services within primary care, the GP's with Special Interests act as trainers, educators and coaches to other health professionals, aiming to raise overall standards of care (Department of Health 2002)

Due to the early stage in the development of this role in the UK, there is little formal evidence of its impact.

Although less formalized than the UK role, GP's with special interests already exist within Taranaki, namely those involved with Palliative care services.

Non Clinicians role in Care Teams

Due to the limited time of health care professionals, consideration can be given to the use of non clinicians to support the process where possible. For patients receiving ongoing care, a non clinician could obtain relevant information from them via telephone for example, prior to their consultation in order to reduce the time pressure of their time with the health professionals, whilst also potentially making the visit more constructive if the health professional views the information and can therefore prepare. (Singh 2006, Rothman & Wagner 2006) Davis et al (2000), Simon et al (2000) also support the notion that some elements of follow up can be done by non-medical team members using the telephone

Service Design Recommendations

Develop Psychosocial Support - This is a priority in that it is recognised currently as a service gap. Psychological input should be included as part of the education and self management programmes, and should also be a priority in terms of provider education (see Knowledge Management section) in order to improve the ability of primary care to recognise and effectively manage these conditions. Consideration

should be given to the routine availability of screening for stress for individuals with chronic disease.

Integrate Cancer Services- Whilst it must be recognised that this only applies to certain types of cancers, these conditions share commonality with other chronic diseases in numerous ways. Services for chronic disease should therefore be available for cancer patients when appropriate.

Develop Multidisciplinary Team Approach - In line with the New Zealand Cancer Control Strategy, the Multidisciplinary team approach should be extended to other forms of cancer due to its proven effectiveness in improving outcomes for patients (Ministry of Health, Cancer Control Strategy, 2003 and Department of Health, Cancer Plan, 2000)

Develop Primary Based Case Management - In order to support patients with complex needs throughout the continuum of care, primary driven case management functions should be established. This will aim to identify the most high risk patients and coordinate their care across primary and secondary services. The extended use of telephone and electronic assessments to fulfil these functions should be considered where appropriate.

Establish Clinical Champions - Dr Gary Sinclair emphasizes the crucial role that clinical champions in primary care played in establishing the new model at Counties Manukau DHB. GP's with a Special Interest in chronic disease should be developed to fulfill this role. Within Taranaki, there are already GP's who have particular specialties (for example Palliative care) and this should be encouraged within the field of chronic disease management to act as champions to lead change.

Health Intranet – The development of the TDHB internet site may provide the opportunity to include 'health intranet' facilities which would allow GP's to track patients in terms of diagnostic results and appointments for example, which would improve coordination.

Service Design Summary

In order to for a seamless service to be achieved whereby patients full range of needs are met by the appropriate health professional in the appropriate setting, structures must be in place to ensure the coordination of services.

Once again, it is recommended that a shift in emphasis be made, by developing a community based, primary case management function which will focus on the prevention of acute episodes, rather than simply managing the patients once these 'crises' or unplanned admissions occur.

This aligns with the overall strategy of reconfiguration to provide more community based interventions which take place earlier in the pathway, reducing the burden on secondary services – both planned and unplanned.

Similarly, the recommendation to integrate cancer services within the chronic disease model is in line with the strategy outlined in the previous section of integrating those services where clear commonality exists between the needs of patients, and where the prevalence of multiple conditions is high. Again, this provides services which are more suited to the patient whilst making more efficient use of resources by removing duplicate services, and working to prevent deterioration of conditions and subsequent burden on secondary services.

3. Knowledge Management

Overview

The term Knowledge Management in this context is used broadly to incorporate the following

- Disseminating expert knowledge throughout the health care system
- Embedding evidence-based guidelines into daily clinical practice
- Integrating specialist expertise and primary care
- Raising the level of care available in primary settings

At the core of the international models is a shift in emphasis towards primary care management for patients with chronic conditions. This involves achieving the right balance between the various levels and providers of care, ensuring that the roles of health professionals are clearly defined. A core component of the Evercare strategy is that treatment should be the 'least invasive manner, in the least intensive setting possible'.(see NatPact doc 2004)

As stated previously, the nature of primary care is such that it should provide for the large majority of personal health care needs and should be based on partnerships with patients within the context of their family and community (Donaldson 1996) As such, primary care is ideally positioned as the central function for Chronic Disease management, given the need for continuity and comprehensiveness (Rothman & Wagner 2006)

Opposition to this shift towards primary based chronic disease management is often based on assertions that specialists are more knowledgeable about conditions (within their specialty) and more likely to follow guidelines in terms of tests, medication and management whilst also being more quick to adjust their practices in light of new developments. (Rothman & Wagner 2006) However, rather than demonstrating that care should be moved away from primary settings, these issues highlight areas within general practice which need to be addressed in order to provide a consistently high quality service across the broader population.

The role of the specialists should be to care for the individuals with highly complex needs which cannot be adequately managed within primary care, whilst also taking

on responsibility to provide support and training to other health professionals within the primary care team. (Gask 2000)

It must be recognised that the majority of people with chronic disease may never see the specialist. By adopting a population health approach, specialists should look to provide care for those patients that they will never see, as well as the ones that they do. (ibid) The challenge, therefore, is to effectively disseminate the expertise of the specialist to those health care professionals who do have contact with these patients (Wagner 2005)

Whilst many GP's and Practice Nurses are excellent in managing chronic disease appropriately, this level of care is not 'standardised'

Currently, there may be a degree of reluctance from specialists to 'step' patients back into primary care as they may be unsure as to what care they would then receive. Furthermore, there is currently concern regarding conflicting messages being delivered to patients by the various providers.

The lack of consistent application of best practices within primary care can lead to patients remaining in the care of secondary services when the clinical situation is such that primary care management should be appropriate. Conversely, patients who may benefit from specialist input may not receive the opportunity. By addressing this, the appropriate balance between primary and secondary services can be achieved and patients can be 'stepped' up or down, as clinically appropriate.

As well as providing consistency, specialist input into primary care guidance is important in order to 'up skill' general health professionals and keep pace with new developments in treatment and management.

Furthermore, closer working in this way may also help to improve trust, communication and therefore coordination between specialists and general practice, helping to bridge the gap between primary and secondary services and helping to provide a more integrated, seamless service for patients.

Finally, if a greater proportion of patients are to effectively managed in primary care, this will enable the specialists more time to provide more guidance, support and expertise to primary care professionals.

Workforce Development:

It should be noted that some perceptions exist regarding the accreditation, training and qualifications of some health professionals relative to others, despite the fact they may share the same job title or position.

This, once again, leads to concerns which may create a barrier to effective integration of services. This issue may be compounded by the existence of three PHO's, meaning that there is no single process for accreditation and training.

Evidence Based Guidelines

"It is necessary to ensure that healthcare personnel are aware of existing evidence-based guidelines for the treatment of chronic conditions in order to ensure that the patient receives optimal care" (World Health Organisation 2000)

Whilst evidence based guidelines for the managements of patients with chronic disease exist, they are not universally adhered to. Many GP's provide excellent management for their patients with chronic disease, this is not consistent across all practices and concern over varying degrees of quality of service are widespread

Counties Manukau DHB established disease specific advisory groups who developed guidelines which were largely based on current New Zealand guidelines (NZGG) as well as Australian directives.

Access to Specialist Advice

As well as providing effective guidelines for general practice teams, it is important that they have access to the specialists when they have further questions. This may serve to avoid unnecessary referrals to specialists in cases where GP's may simply require a single response or confirmation.

Currently, some GPs and other health care professionals do contact specialists for advice in this manner. However, the fact that no formal system or mechanism exists means that those specialists who do make themselves available, face mounting workload pressures, compared to colleagues who may not provide this access. Similarly, it is a core group of primary care professionals who take up this opportunity at present; this should be extended to all GPs' / practices.

In the UK, the National Library Service offers a web based question posting service where GP's (or other professionals) can pose their questions and receive answers. In the National Library Service, the answers are provided by trained librarians who base their response on guidelines.

Provider Education

Provider education and feedback is associated with significant improvements in provider adherence to guidelines (Weingarten et al 2002)

In a meta analysis of numerous studies, Wiergarten et al (2002) reviewed the effect of provider education, provider feedback, and provider reminders on disease control and provider adherence to guidelines. Overall, they concluded that chronic disease programmes that included provider education showed a modest but significant improvement in disease control, and a significant improvement in provider adherence to guidelines..

Similarly, the impact of provider feedback regarding inappropriate referrals and management was found to have a modest but significant impact on disease control, and improved provider adherence to guidelines

Whilst current education is offered to providers on an ad hoc bases, this is often only attended by a core group of GP's, thus failing to reach the entire group and achieve consistency. Similarly, whilst the specialist nurses / educators run some clinics in primary care concurrently with practice nurses, as well as some in-service sessions, access to their specialist knowledge must be available more widely.

Inconsistency in training within primary care may be exacerbated by the existence of three PHO's which provide varying training, generally independently from each other.

IT Based Decision Support Tool

Guidelines or protocols are useful starting points. But effectiveness studies consistently show that introducing guidelines has only a minimal impact on quality unless guidelines are integrated into the practice through education, reminders, specialist involvement, or other decision support interventions' (Lewis & Dixon 2004)

The only way to realistically ensure consistent application of the guidelines and protocols is to embed them into normal practice, ensuring they are instantly accessible and 'user friendly' and including features which are of benefit to the GP to encourage use.

Counties Manukau operate a system of templates / structured notes within practice software which facilitate the consistent application of evidence based care. Resource materials are embedded into the system. It also includes features such as memory of static data (height, family history for example), auto calculates scores such as Body Mass Index, Framingham risk, and also automatically generates recall appointments

Systems have been shown to improve prescribing practice reduce serious medication errors, enhance delivery of preventative care services, and improve adherence to recommended care standards (Kawamoto 2006) Electronic decision supports replaces the need for large volumes of paper guidelines, and provides rapid access which is individualised based on the patients clinical information.

A review by Kawamoto et al (2006) (cited by CMDHB) found that electronic decision support systems significantly improved clinical practices in 68% of trials. This review concluded that there were four independent predictors for effective decision support

- Systems that generate decision support automatically as part of the normal clinical workflow i.e. are trigger activated
- The advice is delivered at the time and place of decision making i.e. in 'real time'
- The decision support is delivered electronically

- The support provided offers specific patient tailored recommendations rather than generic assessments.

94% of clinical decision support systems with all four of these characteristics improved practice compared with only 46% of systems that lack any one of these features. (Ibid)

Hawkes Bay DHB have recently implemented the BestPractice Decision Support tool specifically for chronic disease management. The system has been developed by the Best Practice Advocacy Centre Inc (BPAC Inc) which is a not for profit organisation

The system provides clinicians with a pathway customised to an individual patient's clinical state. Recommendations for management are customised to the condition and history of each patient. The tool can generate prescriptions with direct links to prescribing information, direct links to the latest evidence based management, pre-populate known clinical information into referrals and also provides access to relevant patient information which can be printed and given to the patient.

All clinical modules are based on current New Zealand guidelines and best practice.

Knowledge Management Recommendations

Establish clinical advisory boards

The role of disease specific clinical advisory groups would be establish and promote evidence based practice guidelines. Where the New Zealand Guidelines Group protocols are appropriate, these should be distributed to GP's along with specific advice on local services. That is, where advice is given, there should be direction on what local services are available, and how they can be accessed. Where guidelines do not exist, or are inappropriate, they should be modified or created.

Establishing these guidelines will be a crucial step towards integrating a full IT Decision Support system.

These groups could also be responsible for the accreditation of staff across providers in the region, to reduce fragmentation and inconsistency between roles and services currently offered by different organisations.

Develop Web Based Q&A Facility for GP's

Formal access to Specialist advice in situations where the GP requires direction is an important tool in reducing inappropriate referrals and helping to raise the threshold of referral. A web based facility would enable to posting of a question to which the relevant specialist can reply at a convenient time. This would also enable other GP's (or Practice Nurses and other health professionals) to access the responses in order to share this learning.

Extend Provider Education

Further developing provider education would also help to coordinate the training and skill levels of various providers and reduce the inconsistency that exists. As stated, some education already takes place in terms of lectures and presentations; however, these are not accessible / accessed by many health care professionals. If consistent application of best practice is to be achieved, incentives or mechanisms must be established to engage GP's and practice nurses with these programmes. Once again, this would help to increase the knowledge and capabilities of primary care thus allowing a greater proportion of care to be undertaken within this setting.

Clear Referral Criteria & Feedback to GP's

The referral criteria for GPs to specialist services should be established or clarified and communicated, and where management of patients is found to be contrary to that of evidence based guidelines, feedback should be provided to the GP.

Currently, there is no systematic feedback loop to the GP's (although some specialists do contact GP's in this case) which means there is no 'learning loop' for the GP and the inappropriate referrals are likely to continue.

This may involve include reviewing patients who access the Emergency Department to ascertain what management they are receiving, and whether it has been appropriate. Given that some GP's appear to make disproportionately few referrals, a review of this may nature may indicate the full impact of this.

Integrate an IT Decision Support Tool

Counties Manukau DHB refer to '*making the right thing easy*' in terms of successfully embedding evidence based guidelines into daily practice. That is, using guidelines which are not integrated into the consultation process can be impractical due to time constraints. An IT Decision Support Tool, such as BestPractice however, makes following the established protocols and guidelines simple, and adds further value to the process, by producing the relevant patient information for example.

It is crucial that TDHB take the lead with regards to integrating a system which spans PHO's and providers to avoid fragmentation of services.

Knowledge Management Summary

If care is to be shifted towards a community based model, the threshold of referral must be raised, requiring consistently higher levels of expertise within primary care.

This requires the support of specialists to disseminate their expertise and knowledge, and to work towards a more integrated system across primary and secondary services.

To ensure that the appropriate balance is achieved, evidence based guidelines and referral criterion must be clear and mechanisms must exist to enable and promote adherence through education, access to specialist advice, and the integration of a district-wide IT decision support tool.

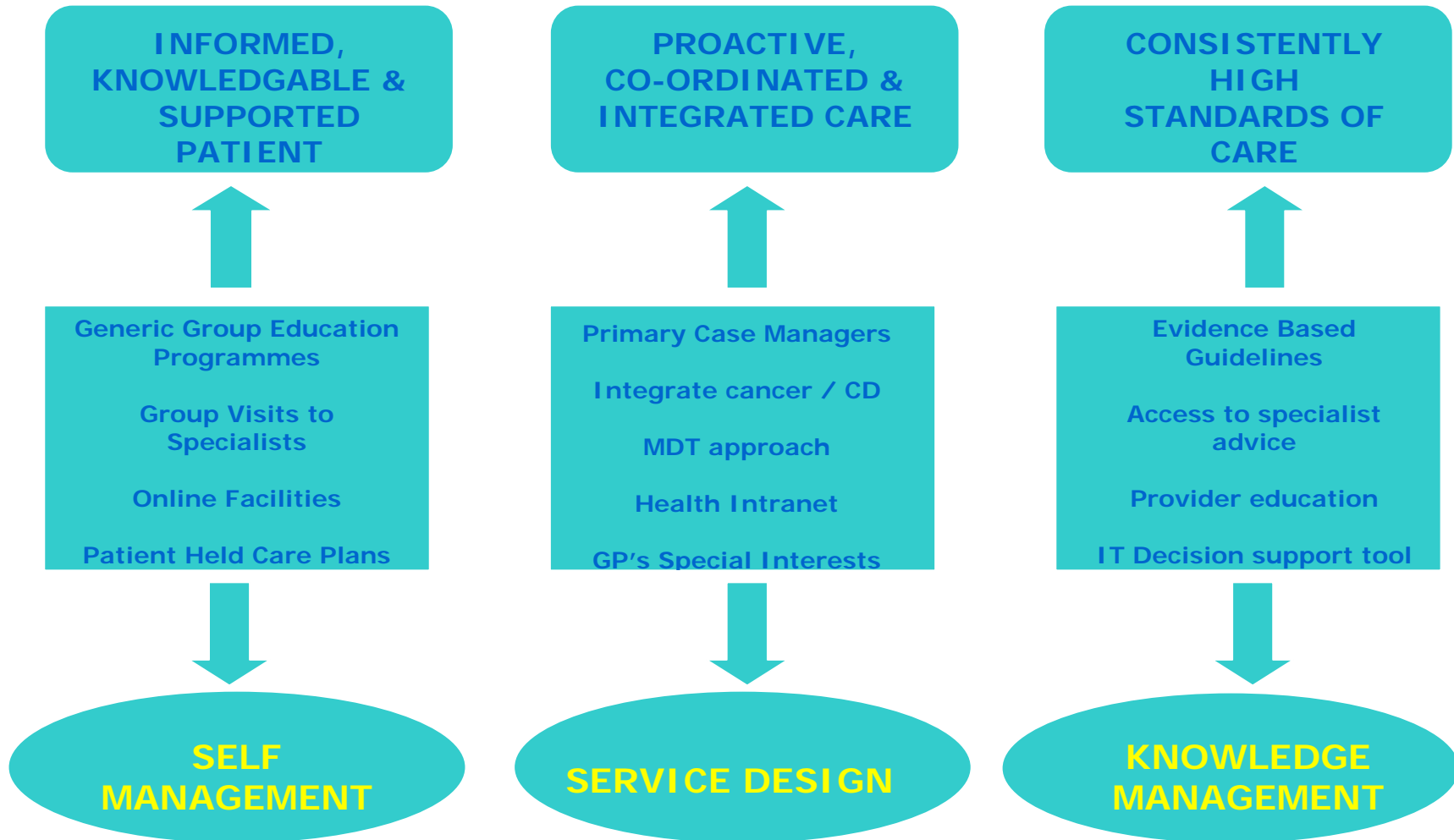
Report Summary

In summary, the report provides a range of recommendations which aim to strengthen the ability of primary care to manage the significant majority of patients through community based services configured in such a way as to present packages of care relevant to the range of conditions they may have. This shift is enabled through the extension and formalisation of links between primary and secondary providers to break down these traditional barriers to integration.

Whilst elements of current services are excellent, opportunities exist for development which can potentially provide significant benefit in terms of providing a more coordinated and seamless service, based on the holistic needs of the patient, and underpinned by more consistently high standards of care.

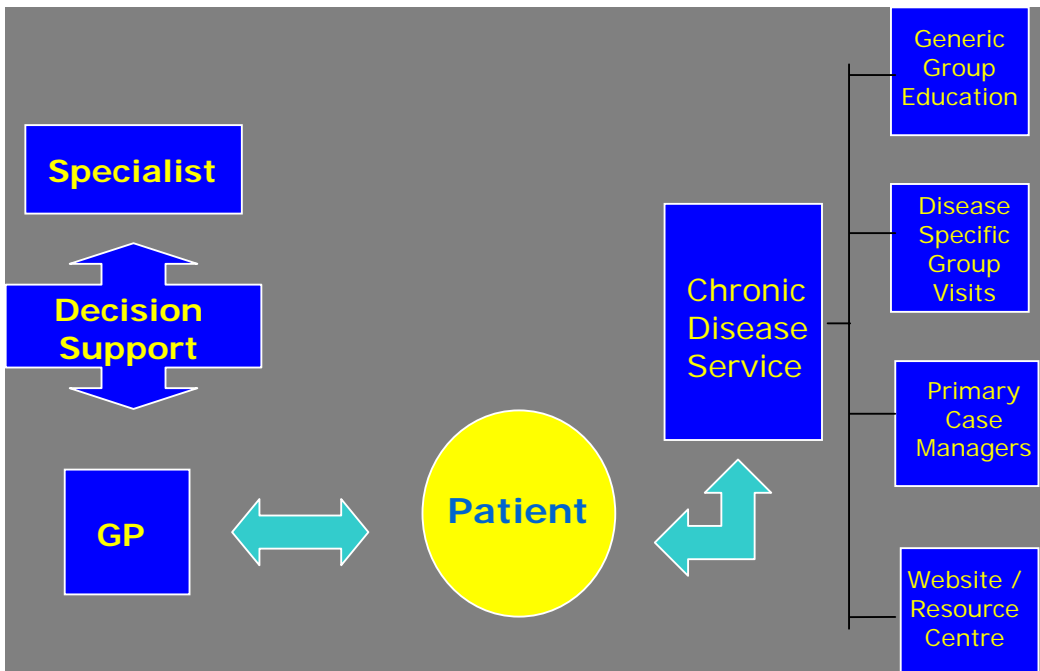
Services must be arranged in such a way as to provide relevant pathways for those individuals who can be identified as at 'high risk' and appropriate interventions should be delivered in order to prevent deterioration and the resulting burden on the patient, and indeed on secondary health services.

This report aims to act as a catalyst to drive forward the development and improvement of chronic disease services in Taranaki in order to reduce the significant impact it currently has on the health of our community.



Reconfigured Service Model

The reconfigured service model centres around the patient who works in partnership with their GP to identify their requirements and set goals. Based on clinical guidelines, and directed where necessary by specialists via decision support mechanisms, the GP directs the patient to the appropriate package of care provided by a community based chronic disease service.



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