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Evidence for funding, organising and delivering health care services targeting secondary prevention and management of chronic conditions

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1. Introduction

It is widely acknowledged that designing and implementing health care services which aim to prevent and manage chronic conditions represents a challenge for all health systems, including the Australian health care system. However, it is a challenge that must be met if the Australian health system of the future is to maintain its reputation of providing care that is relatively accessible, of high quality and satisfactory to most recipients.

In this respect, funding and organisation of services for chronic conditions are of particular concern as the current system, designed to address acute episodes of illness or injury is, from the perspective of dealing with chronic conditions, fragmented. Medicare is limited to mostly medical services and, due to rising pout-of-pocket costs in the form of co-payments, access to specialist medical services is not as equitable as is access to general practice. In recent years, additional MBS items have included care provided by some allied health professionals for some conditions and multidisciplinary care has been recognised as an essential element of care for chronic conditions, but the fee-for-service funding mechanism is generally a clumsy and inefficient means of encouraging the organisation and delivery of services of the highest quality, that is on a coordinated and integrated basis.

A twenty-first century health system has to be able to deal with new ways of delivering services, using new technologies. A number of design features of the Medicare system, which were appropriate at the time it commenced operation may represent barriers to the provision of integrated care. The Medicare system has been designed to focus on face-to- face delivery of services, whereas modern technology allows for different forms of delivery. For example, the use of pacemakers in cardiac patients is well accepted. These must be checked for correct functioning and allow monitoring of new occurrences of arrhythmia. It is technically possible to install devices in the patient's home which read data from the pacemaker, transmit it through broadband connections to a data base, where the data are analysed, and when exceptional results or patterns are detected, an email is sent to the responsible provider, who can then adjust the therapy perhaps by phoning the patient. This is technically possible (though effectiveness has not yet been established); but it would not be funded in the current health system. The monitoring device may be paid by an insurer, if the patient has private insurance. The doctor would not be paid by Medicare, as there has been no face to face encounter. The broadband connection, the data bank and the analytical capacity do not fit any existing funding program. And nowhere is the responsibility and incentive to co-ordinate the process.

Another important feature of the Medicare system is that it is more conducive to patient initiated encounters than ongoing management and provides even fewer incentives for providers to focus on preventing illness. Whilst management is an important aspect of a system designed for chronic conditions, secondary prevention (ie management of risk factors such as hypertension, obesity and smoking and prevention of complications in established disease, such as retinopathy in diabetes) is at least as important as treating a condition once it becomes established.

Numerous countries are facing similar challenges to improving the effectiveness and efficiency of the health care system's ability to deal with chronic diseases. In their recent publication on the role of care coordination in improving health system

performance, the OECD suggests that consideration be given to new models of ambulatory care, that resources dedicated to this sector be reviewed, and that care coordination would be facilitated by wider use of IT and more system wide integration (OECD 2007).

Both the Australian and State/Territory governments have recognised these challenges and a number of projects designed to investigate the means to and outcomes of coordination and/or integration of services have been published. After the results of the Coordinated Care trials indicated that there were a number of important barriers to achieving the goals of the trials, ideas and research concerning integration, integrated care and integrated services delivery models have gained increasing attention from Australian policy makers, planners and service providers.

The recently released final report of the National Health and Hospitals Reform Commission argued that voluntary enrolment in a primary health service-based "health care home" which would help coordinate, guide and navigate access to the right range of multidisciplinary health service providers was their recommended means of encouraging better continuity and coordinated care for people with more complex health problems. This recommendation echoes recent literature emanating from the United States in which the medical home is envisaged as being able to more effectively support the core functions of primary care and management of chronic disease (Fisher 2008).

This paper is designed as an issues paper. Its aim is to set out what evidence is available regarding the effectiveness and efficiency of funding, organisation and delivery of services directed at preventing and managing chronic conditions, and identify what further information is required. The latter will then be used as a means of identifying gaps in information which can be addressed by research. The information is not presented as a comprehensive review of all available evidence but as a preliminary scoping of the results of the most recent literature.

The methods used to address the issues outlined below are discussed briefly in Section 2.

The issues addressed in the paper are organised around the following questions:

- What are chronic conditions? Which ones should be managed in an organised way within the Australian health care system? This is addressed in Section 3.
- What is the evidence for the effectiveness and cost effectiveness of initiatives targeting secondary prevention and management of chronic conditions at the level of both the health system (policy level) and health services (organisation and provider levels)? These issues are discussed in Section 4.
- What are the challenges in designing and implementing interventions, services and programs for preventing and managing these conditions? Section 5 presents a framework for the secondary prevention and management of chronic conditions.

Sections 6 and 7 are short summaries of the issues identified in the Paper and a list of identified research questions, respectively.

2. Methods

The methods used include a preliminary review of the evidence regarding the funding, organisation and delivery of services designed to manage individuals who have developed risk factors for chronic conditions (secondary prevention) and those who have established disease. Most evidence is available regarding organisational and delivery aspects of services targeting chronic conditions. No trial evidence is available regarding funding. However, some suggestions have been published and the information provided in this previous work will be used to develop the proposed research strategy.

An initial literature search was undertaken, using Embase, with the key words 'chronic care models,' 'chronic care management', and 'disease management'. Limiting the results to publications in English, published since 2000, and removing duplicates yielded **6581** publications. This demonstrates that this is a complex and large topic area. The literature was further limited by selecting a sample of reviews and studies from the UK, UK and Europe and Australia which focussed on funding, organisational and delivery issues so that a representative set of issues could be identified and the current evidence summarised.

For the purposes of this paper, a formal systematic review was not undertaken, although the results of some published reviews have been used.

3. What are chronic conditions?

Chronic conditions are those which are long lasting and persistent. They often have multiple and complex risk factors, many of which are common to several conditions. They usually develop over a long time, and, once established, are seldom able to be completely cured. Most are characterised by phases of acute illness followed by remissions. They may be associated with the development of complications which may lead to functional impairment and disability. Their presence is likely to complicate the treatment of other illnesses.

The AIHW reports that there is a high prevalence of chronic conditions, with 77% of Australians having at least one. However, the prevalence and incidence data are imprecise, as they are largely drawn from self-reporting in the National Health Survey, which in turn relies on respondents having been given a diagnosis. Exceptions are cancer (as data are provided by Cancer Registries and cancer is a notifiable disease) and severe kidney disease (as the renal physicians maintain a specialised registry for dialysis and transplant patients). A survey of individuals with at least one of seven chronic conditions undertaken by the Commonwealth Fund (Schoen et al 2008) indicated that 63% of participants had two or more of the seven conditions (hypertension, heart disease, diabetes, arthritis, lung problems, depression and cancer).

Most studies of chronic conditions generally study those which are relatively serious in terms of their impact on at least two of the following aspects: pain, function, quality of life, mortality, utilisation of health services and ability to work. Such conditions tend to include at least some of the following: arthritis, asthma, cardiovascular disease, cerebrovascular disease, chronic kidney disease, chronic

obstructive pulmonary disease, colorectal cancer, diabetes, lung cancer, oral disease, osteoporosis, and depression. Diabetes, COPD and some cardiovascular diseases (eg chronic heart failure) are amongst the most commonly studied.

Undertaking research into appropriate models of care also requires that there be suitable interventions able to prevent and/or manage the condition.

Thus, the 77% prevalence of chronic conditions reported by the AIHW may include some conditions which, whilst chronic according to the definition of being long lasting and persistent, may not have major impacts on health or utilisation of services or (perhaps more importantly) may either not be amenable to prevention or be able to be managed by relatively simple medical means and/or self-management. Conditions such as hay-fever, psoriasis, some allergies and some chronic gastrointestinal diseases may fall into this category.

Chronic conditions are generally associated with ageing. According to the AIHW, there are very few people over the age of 65, and none over the age of 85 with no chronic conditions (based on National Health Survey data). In the survey conducted by the Commonwealth Fund, 56% of those surveyed were aged 50 or older. Indeed, it appears that the number of chronic conditions rather than ageing *per se*, explains the increased use of health services by these older age groups (CHERE unpublished data). Nonetheless, chronic conditions are prevalent in every age group; almost 10% of children aged under 14 have three or more chronic conditions and the highest prevalence of asthma-related admissions is in this age group.

The prevalence of chronic conditions is not evenly distributed across the population: Aboriginal and Torres Strait Islanders, the economically disadvantaged, and those living outside major cities are at higher risk.

Chronic conditions vary in their severity from minor irritant to major disability and pain. Understanding severity represents a major challenge as the level of severity is likely to have an impact on management of the condition and costs. The major conditions listed previously (excluding depression) account for almost 50% of deaths. Most of these deaths occur over 65 years of age. The AIHW report does not present data on the morbidity and functional status associated with different conditions, although there are a number of data sources which could provide some estimates such as the National Health Surveys, the HILDA surveys and the 45 and Up survey in NSW.

4. The evidence for the prevention and management of chronic conditions

Definitions

Prevention is defined as primary, secondary and tertiary prevention.

- **Primary prevention** avoids the development of a disease. Most population-based health promotion activities are primary preventive measures.
- **Secondary prevention** activities are aimed at early disease detection, thereby increasing opportunities for interventions to prevent progression of the disease and emergence of symptoms.
- **Tertiary prevention** reduces the negative impact of an already established disease by restoring function and reducing disease-related complications.

For the purposes of this paper, tertiary prevention will be characterised as management (ie treatment and longer term care) of people with chronic conditions.

In the table, the 12 major chronic conditions identified by the AIHW are defined together with identified means of primary and secondary prevention as well as management. It is important to note that the strategies or interventions listed in the table are not necessarily evidence-based. Further work is necessary to systematically evaluate the types and levels of evidence used in the studies conducted so far, including that for effectiveness and cost-effectiveness. Whilst some interventions have been shown to be effective and/or cost-effective, others have not been evaluated from this perspective.

Much of primary prevention aimed at these conditions centres on the adoption of a healthy lifestyle, characterised by a healthy diet, regular exercise, avoidance of smoking and limited intake of alcohol. In addition, it includes specific strategies to ensure good sexual health such as understanding the physical, social and emotional changes that come with puberty, pregnancy and ageing and how to avoid sexually transmitted infections and blood borne viruses; and to maximise mental health, defined as a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.

Whilst governments and the health system (particularly those aspects involved in implementing public health and health promotion interventions, strategies and programs) are responsible for informing the population about how to maximise good health and avoid poor health, such work may or may not involve the provision of health *care* services directed at individuals. Some services focus on providing information and education (and recently, individual "coaching") aimed at encouraging behaviour change at a population level (eg health promotion campaigns) and implementing policies aimed at maximising and monitoring the public's health (eg immunisation provision, monitoring environmental health and infectious diseases). Others include personal services in some aspects eg asking GPs to recommend their patients attend a screening service and/or provide educational material for GPs to discuss with patients in the target group.

Much primary prevention is delivered outside the health care system (eg via media campaigns, in schools and via community-based organisations). On the other hand, within the health care system, most health services directed at chronic conditions are delivered on an individual basis by health care providers with the aim of treating ill-health and preventing future reoccurrence and/or complications. That is, their objectives centre on secondary prevention and management. The remainder of this paper will focus on the evidence available regarding the optimal means of providing such services, including the issues for which there is no or limited research-based information.

The overall issue to be addressed is how can the health system use appropriate levers (eg incentives, agreements, funding methods etc) to facilitate and incentivise the best quality and amount of care in terms of both prevention and treatment of symptoms.

4.1 Health system level initiatives

At the system level, the major stated objective for services directed at the secondary prevention and management of chronic conditions is coordination and/or integration of care. Whilst the features may vary with different conditions, a common set of characteristics of coordinated care has been described as the provision of:

- A care coordinator, usually a registered nurse who undertakes needs assessment and draws up individual care plans
- Patient education regarding adherence to the care plan, particularly prescribed medications, lifestyle changes, testing and monitoring regimens etc. Such education may be delivered using traditional means (eg lectures, booklets) or using motivational techniques
- Improved coordination of services through enhanced communication between providers, patients and carers, particularly around the transition of care between care sectors (ie primary, secondary, community etc) and the management of polypharmacy.

Research from the US provides some information about the characteristics of well managed services for chronic conditions. Key features seem to be an organisational structure which facilitates the identification of high risk chronic disease patients and the co-ordination of care across a spectrum of services, without the barriers of rigid funding. The VA provides an exemplar; the VA provides comprehensive health care to military veterans and has developed models of co-ordinated care which are considered best practice in providing high quality and efficient service delivery.

Only limited information is available from evaluative studies of how other funding and/or delivery systems (eg US Medicaid or demonstration "Medical Home" projects) respond to the challenges of managing chronic care. What information there is indicates that there is very little evidence that the provision of coordinated care saves money (ie in terms of reduced utilisation of services, medications etc). A review of the evidence generated from research so far indicates that while patients and carers are more knowledgeable, overall, in those programs which have been evaluated, neither behaviour, function nor health-related quality of life improved. Programs with substantial contact between patients and a case manager were more likely to be cost-neutral (Peikes et al 2009).

Fisher (2008) has suggested that whilst expectation about the benefits of systems such as the medical home are high (eg savings in health care costs, reversing the decline in interest in primary care amongst medical students and young physicians), there are several important barriers that need to be addressed if proposed new models of care are to love up to their promise. For example, it is not clear that there are incentives for collaboration amongst different providers and sectors; if incentives are directed at one sector or type of provider (eg primary care), others may oppose or not cooperate with the scheme, particularly if their funding or income is threatened.

These issues largely mirror those reported in the evaluation of the Australian coordinated care trials. The observation that people with chronic conditions in Australia often face challenges in finding the right services and paying for them within the context of a health system which provides a diffuse set of services which are often duplicated under different funding arrangements, provided the rationale for

the implementation of the co-ordinated care trials. In the trials, funds from Medicare, PBS and State services could be pooled and the role of the co-ordinator was to ensure the appropriate delivery of services, irrespective of the sector. Results from the early trials demonstrated that co-ordination alone would not simply ensure better health outcomes and reduced cost of services. In fact, the early trials identified more gaps in care, than duplication. The results from the second round of trials show that care coordination appears to promote overall health awareness, diagnosis and self-management of conditions. These findings may eventually lead to a reduction in hospitalisations compared to usual care but this has not been established yet.

Shared care is an earlier and more limited form of coordinated care, often, but not exclusively, directed at diabetes management. A recent Cochrane review of shared care found that there was no evidence that any aspects of utilisation, outcomes or costs improved except for a general improvement in prescribing (where this was evaluated) (Smith et al 2008). However, the idea of shared care may be becoming redundant as it is not multidisciplinary (it typically only includes general practitioners and specialist medical practitioners), particularly as primary care becomes more multidisciplinary.

The English NHS has moved to organise management for chronic conditions as a three tiered model consisting of self-management, disease management and case management.

- *Self management* is designed to focus on generic, rather than disease-specific skills and to be delivered by trained lay-people. Ham (2008) contends that despite some positive results from initial evaluations, most people with the potential to benefit will not have been able to access such a program as limited resources have been directed towards it. Some disease-specific self-management programs are available from the NHS (eg for diabetes) and from non-government organisations, but these are also limited in scope.

- *Disease management* is designed to be delivered through a primary care-led team and includes disease registries, regular patient review and achievement of specific processes of care (compared with guidelines) and outcomes (eg control of hypertension). The introduction of this model of care has been facilitated by specific aspects of primary care in England – registration of patients with one practice, the expectation that this practice will be the first point of contact for patients and the ability of most practices to provide comprehensive, often multidisciplinary care to their registered patients. The development of the electronic medical record and the absence of financial barriers have also assisted the introduction of disease management. Nurses do much of the work associated with disease management. The Pay-for Performance contract introduced in 2004 has introduced incentives for GPs to enhance the quality of care provided for chronic conditions. Results from evaluations show that a high level of achievement in relation to both process and outcomes was attained after one year and sustained in subsequent years and inequities in access were reduced. The evaluation also indicated that GPs' incomes increased 58% between 2002-03 and 2005-06 and that payments to GPs represented the most expensive element of the overall chronic care policy. More conditions and indicators have been included in a subsequent contract. The development of national services frameworks to set

standards for the quality of care and the continuing appraisal of new drugs and technologies as well as the development of guidelines by NICE has supported the disease management efforts.

- *Case management* is designed for patients with complex needs, generally requiring intensive support. The objective of case management is to enable people (mostly elderly) with a range of chronic conditions to continue to live at home. Although preliminary evaluation of pilot projects in the UK indicates that case management is unlikely to save resources (in terms of emergency admissions to hospital, bed days) or lives, it is considered the most appropriate means of delivering high quality services in an effective manner. Identified benefits include management of polypharmacy to prevent adverse reactions, coordinating care and arranging access to community-based services. The provision of case management has been shown to be highly valued by recipients and their carers. A predictive tool (Patients at Risk of Re-Hospitalisation, PARR) has been developed although examples of its use have not be identified.

In Australia, Swerissen and Taylor (2008) have suggested a regional model of funding and care provision ranging from medical (GP) management only for patients with an uncomplicated clinical and psychosocial profile, to medical management plus multidisciplinary care (MDC) for patients with a more complex clinical profile (eg multiple risk factors and/or chronic conditions) to medical management plus MDC plus social support for patients, who, in addition to presenting with a complex clinical profile, also have psychosocial issues requiring more services than medical, nursing and allied health professionals can provide eg home care or community support services. The implementation of this model of care, whose levels can be seen to be at least partly aligned with the UK's levels of self-management, disease management and case management, would require system level initiatives to realign and extend the current Medicare chronic disease management programs, the adoption of a cross-system model of outcomes-based funding and the integration of social support services with health services.

The Council of Australian Governments (COAG) has identified that people with complex chronic disease (ie they have serious disease, often more than one condition, and have a history of very high levels of health care utilisation) experience problems in relation to timely access to and continuity of care between the number and range of health and community care services they need. This group is estimated to represent approximately 3% of the population. COAG's proposed solution is a disese management model of care, consisting of four components:

- Identification and registration/enrolment of patients who meet specific criteria;
- The development of an evidence-based shared health plan for each patient;
- The use of care coordinators or health coaches working mainly by telephone, to support patients and carer/s self-management and to coordinate and monitor implementation of the shared care plan; and
- Integrated I&CT systems to support clinical decision making, central collection of information and secure sharing of information between providers, services and sectors.

In developing these recommendations, COAG recognised that significant barriers exist in Australia to its immediate implementation in terms of the lack of a standardised e-health system and constraints around workforce supply. No

information is available about the extent to which such a system is currently operating in Australia or whether COAG's recommendations have been implemented in any jurisdiction.

4.1.1 Evaluations of system-level initiatives

Eliaszadeh et al (2001) undertook a cost-benefit analysis of a disease management program for CHF implemented in one hospital in Connecticut. A before-and-after design was used. Results at 12 months following the implementation of the program indicated that the program significantly reduced costs of care, ER visits and length of stay. However, as it was undertaken in one hospital only, enrolled only a small number of patients and utilised an uncontrolled design, the results from this study should be treated with caution.

An evaluation of a randomised trial in Indianan USA for Medicaid recipients with diabetes, congestive heart failure (CHF) or both which compared an intensive nurse care management program for high risk patients and a less intensive telephonic program for low risk patients with usual care, found that cost savings were achieved in CHF patients who received the telephonic intervention (ie low risk group) (Holmes et al 2008). Medicaid claims were lower for low risk diabetes patients (telephonic intervention) and high risk CHF patients (intensive nurse management) but no cost savings were achieved. Amongst high risk diabetes patients claims were higher for the intervention group (intensive nurse management) compared to usual care.

Zhang et al (2007) evaluated the costs and outcomes of a chronic disease management program on the costs and outcomes of Medicaid recipients in Virginia using a pre- and post-quasi experimental design. Physicians and pharmacists were mailed quarterly for three years with educational material, claims feedback, and the latest results of the program which was targeted at 5 chronic conditions (diabetes, CHF, depression, gastro-oesophogeal reflux (GERD), peptic ulcer and COPD. Results indicate that GERD, peptic ulcer disease and CHF are the best candidates for single disease management programs as measured by reductions on ER visits, hospitalisations and prescriptions. The program enabled patients with multiple co-morbidities to reduce adverse drug events and the use of drugs and hospitalisations. The study also demonstrated that while some patients may increase their utilisation of services, if office consultations replace ER visits and hospitalisations, the overall result may be cost saving. Whilst this was a non-randomised study, the experimental and control groups were matched on risk factors and disease states, more than 7000 physicians and pharmacists participated and information was obtained from more than 35,000 patients. Thus, its results are more credible than the previously described evaluation.

4.2 Health service level initiatives

At the health service level, the major objective of implementing a model of care for one of more chronic conditions is to manage risk factors and/or established disease to prevent deterioration.

The most influential model described in the literature is that developed by Wagner and colleagues called the Model for Effective Chronic Illness Care (1996, 1999). This model has influenced many providers and decision makers in this area. The original model was developed using a process of literature synthesis and expert

review. Later revision of the model was informed by site visits to facilities and organisations which claimed to be using the model and by surveys of users and experts. Focused at the health services delivery level, its main requirements are the development of:

- informed, activated patients; and
- prepared, proactive, professional teams of providers.

The formation of such a team requires the establishment of information systems around reminders, feedback etc, explicit plans and practice protocols around roles of the members of the team, close attention to appointments and follow-ups for patients who need additional time, provider training using education and decision support systems, including reminders and feedback, as well as the means to actively involve the patient, using education regarding the condition, self management and behaviour change. A more recent version of the model (Wagner 1999), recognises the need to have in place an appropriately organised and resourced health system (ie taking into account such factors as incentives and leadership) as well as community resources (ie the capacity to effect and support self-management) to support the required changes at both practice and provider level. It was also recognised that the original version did not indicate the mechanisms through which the model operated to produce better process and outcomes (ie the theoretical basis of the model was incomplete). The revised model proposes that *productive interactions* are such mechanisms and through these, improved outcomes such as better clinical care, health status, patient satisfaction, utilisation and cost will be achieved.

Wagner and colleagues (1999) have described a number of programs as effective users of the model: a multidisciplinary team-based program aimed at reducing hospitalisations amongst patients with congestive heart failure (CHF); a primary care health cooperative-based system aimed at delivering high quality care to patients with diabetes, heart disease and depression through primary care; an HMO-based system of structured group-based interventions aimed at improving patient care and provider satisfaction for elderly patients with chronic conditions who were high users of the organisation's services; and a program using nurses as case managers for patients with diabetes. However, effective programs, while using the model successfully as a "checklist" to ensure all areas are being addressed, were limited in their reach and effectiveness in terms of health outcomes. Most were serving a minority of the population using pilot programs, reported weak links between primary and secondary care. The mechanisms by which the most successful programs operated were seen to be i) rigorous use of guidelines and protocols, supported by systems such as reminders, case managers, specialist involvement in care, ii) more intensive follow-up usually involving telephone calls which led to iii) earlier identification of patients needing more intensive or specialised treatment and iv) use of "modern" self-management approaches rather than traditional patient education.

4.2.1 Evaluation of service-level initiatives

The more precisely the objectives of a service can be described, the easier it is to identify potential options which will meet those objectives. For example, for people with diabetes, the objective of a disease management model of care (which may be equivalent to medical management plus MDC in this case) may be to prevent the development of complications such as retinopathy and peripheral vascular disease

(leading to blindness and amputation). For those who already have such complications, the objective of a case management model (which, depending on the circumstances of the patient may be equivalent to medical management plus MDC +/- social support) may be to enable them to maintain maximum independence at home.

As the aim of health services is to provide the most cost-effective means of meeting these objectives, it is necessary to assess the costs and benefits (outcomes) of providing each option, including how either or both are likely to differ between high and low risk groups. In many cases, the alternative options identified for secondary prevention and/or management will include some strategies which overlap with for primary prevention- the difference being that the strategies are delivered within the health care setting.

The first step in assessing costs and benefits is to evaluate the relative effectiveness of alternatives. A systematic review of 560 published and unpublished studies including RCTs and reviews regarding the evidence about programs aimed at improving the care for people with chronic conditions has been undertaken by the Surrey and Sussex Primary Care Trust Alliance (Singh et al 2005). The results indicate that such initiatives can enhance satisfaction with care, quality of life and, in some cases, utilisation of services. Initiatives that appear successful include the following:

- Broad management models
- Integrated community and hospital care
- Primary care-led models
- Targeting patients at high risk of complications and hospitalisation
- Involvement of patients in decision making
- Providing accessible structured information for patients, carers and families
- Education in self-management
- Systems that encourage self-monitoring and self-referral
- Electronic and telemonitoring
- Nurse-led strategies, where appropriate

The review found that there was less evidence to support case management, evidence-based pathways or protocols or shared learning for health care professionals and limited information was available about models for commissioning services and linking health services with voluntary and community services.

A review of chronic disease management options (excluding mental health conditions) in the primary care setting in Australia (Dennis et al 2008) found that interventions most likely to be effective were education and training for primary care providers in self-management support and including this element of care in care plans for multidisciplinary care. It also found that Practice Incentive Payments (PIPs) and Services Incentives Payments (SIPs) could be improved to facilitate the use of guidelines and to recognise the need to integrate the management of patients with more than one chronic condition (ie not to manage them as if they had a series of separate chronic conditions). The use of disease registers should be expanded.

5. The challenge of providing prevention and management interventions, services and programs for chronic conditions

Chronic diseases are expensive, with the Australian National Chronic Disease Strategy attributing 70% of total health care expenditure to chronic disease. The extent to which this estimate is credible depends on the definition of chronic conditions. For example, this estimate includes the cost of treating injuries; while some injuries have long term consequences for disability and impairment, others are resolved after an acute episode. Further, these estimates are based on 'top down allocation' where total expenditure is attributed to diseases.

The top 12 conditions account for just over 20% of total health expenditure. Although care of chronic conditions involves all components of the health care system, hospital care is the largest component of the costs, accounting for around one third. How much of this is aimed at primary (preventing development of risk factors) or secondary prevention (managing risk factors to prevent or slow the development of clinical disease) is not identified. For example, the estimate for dental services includes all dentistry including primary prevention and cosmetic interventions. Thus examining only the costs of treatment (disease costs or costs of illness) is less useful for policy and planning than identifying what is preventable or avoidable (see the Table).

It is likely that there is substantial variability across individuals with the same chronic disease in terms of patterns of expenditure and use. The lack of linked or panel data sets has meant this is difficult to investigate in most of Australia[1]. To date, understanding the development of chronic disease over time, and the associated health care use and expenditure, has relied on the recruitment and follow up of specific cohorts. For example, CHERE has undertaken a longitudinal study of the utilisation of services and associated costs of a cohort of people with asthma (ref). This has shown that not only that there is substantial variability in terms of utilisation of services across individuals, but that those individuals with high health care use, particularly hospital admission, are more likely to remain high users and require further hospital admission. What is not clear from our data is whether the high users are people with much more severe asthma, or whether their condition is poorly managed. It should also be noted that the pattern of health services utilisation and costs, and the relationship between severity and utilisation in asthma may not be generalisable to other chronic conditions.

The survey undertaken by the Commonwealth Fund (ref) also provides some information about where patients with chronic conditions face particular problems in the context of the Australian health system. Overall, respondents living in the USA faced the greatest barriers in terms of costs but Australia was second worst in terms of respondents reporting that they had not filled a prescription, seen a doctor or had a test because of the cost. Australia was also second worst in terms of same-day access to care and access to after-hours care (not ER care). Seventeen percent of respondents (the third highest rate) reported that they visited the ER for a condition that could have been treated by a doctor had one been available. In a similar vein, Australia had the lowest reported percentage of respondents waiting between one a two months to

[1] WA is the exception as it has linked its health data with MBS and PBS data

see a specialist doctor, and the second lowest reported percentage waiting less than four weeks. Australians reported the lowest level of being able to obtain advice when they needed it.

In the future, the more widespread availability of linked data and data from panel studies such as HILDA and the 45 and up study will facilitate better understanding in this area. In the meantime however, it is clear that costs and access to both after-hours primary care and timely specialist care are important issues for Australians with chronic conditions.

There is also variability in the out-of-pocket costs associated with chronic disease. User charges may discourage patient compliance with treatment plans, leading to exacerbation of the condition and higher treatment costs. The evidence is strongest for the effect of co-payments for pharmaceuticals.

The care of chronic disease is increasingly likely to involve a range of health care professionals, particularly as medicine becomes more specialised and as innovative services are proposed. Drug treatments often involve undesirable side-effects, for which more drugs can be prescribed, requiring patients to manage complex regimens. Similarly, a feature of chronic disease is that patients may be receiving multiple treatments for their condition, as the first and second line treatments become less effective over time. Chronic disease often requires the patient to understand their condition, monitor it, initiate or change treatment, and know when it is appropriate to seek further medical intervention. Further, the clinical outcomes or indicators used by medical practitioners may not accord with patients' own perceptions of their health and well-being, thus encouraging patients to not adhere to prescribed treatments. Self management may require lifestyle changes. The management and care of chronic conditions affects patients' families and carers.

Chronic conditions do not occur in isolation. Patients will also suffer acute unrelated conditions which require treatment; and many have more than one chronic condition. This can lead to drug interactions and unintended consequences (including hospital admissions). Once a chronic condition is established, the challenge for health services is to maintain and improve patient outcomes through the efficient provision of health services.

5.1 Framework for the secondary prevention and management of chronic conditions

The information provided above, whilst incomplete, provides important indicators of what to include in a successful system, including funding, organisation and delivery arrangements which are likely to result in improved health care services (in terms of quality, safety and patient satisfaction) and outcomes (in terms of clinical indicators and quality of life) for patients.

Beginning at the care delivery level, what seems to be needed are services which allow patients to be characterised in terms of the stage of the condition and whether they have risk factors for more than one condition, or more than one established condition. Once this information is systematically recorded, services require organisational support and funding mechanisms to be in place which will enable the appropriate type and intensity of care to be delivered, bearing in mind that different

levels of care will involve different mixes of care ranging from self management, through disease management to case management. Finally, support at the State/Territory and National levels in terms of overall funding arrangements, guideline and protocol development, IT initiatives to facilitate the development of electronic registration, storage and communication systems and workforce development will be necessary.

5.1.1 Funding and organisational arrangements at the service level

There are two key elements required in developing appropriate models for organising and delivering care for chronic conditions. The first is to understand the condition and define best practice care for both secondary prevention and management. This requires determining the components or individual services required for a particular disease and evidence supporting their effectiveness and cost-effectiveness in managing the progress of the condition in terms of managing risk factors and preventing or reducing complications. Clinical guidelines have been developed for both acute and chronic conditions, but there is evidence from a range of countries that guidelines generally are not well taken up.

Therefore a second key element required is the structure of service delivery that will provide those components of best practice care. This is likely to be largely generalisable across diseases, though there may be some specific variations; it is also likely to vary across geographical areas and should be coherent with the existing pattern of service delivery. It requires decisions regarding the nature of the services to be provided (eg self-management, disease management or care management or some other model of care provision) attention to incentives, both for practitioners in prescribing the appropriate care, and in ensuring adequate access (geographic, financial). A number of elements are key to this, and incentives will also be needed to ensure that these issues are addressed systematically:

- Determine the objectives of the program. For example, if the program is targeted at reducing hospitalisations in the short term, then it will focus on the currently severe group undergoing multiple admissions now. On the other hand, if it targets the stabilisation of a chronic condition, it will focus on preventing any worsening of the condition and potentially preventing multiple hospital admissions in the future.
- Understand the current infrastructure for chronic disease care. This requires identifying what already exists, in terms of primary care, hospitals and private insurers. It encompasses the workforce and identifiable programs. Then a new program can leverage from what exists rather than imposing another edifice. Likely differences across regional Health Services and even within each region should be considered.
- Understand what does not work in current programs. This should encompass national initiatives such as those on asthma and diabetes. This should look for whether there are groups of people for whom this approach has not worked. This should also show whether interventions which have been successful in one context do not transfer to another, eg programs designed in an urban setting may not work in a rural setting; programs developed and implemented by a highly motivated and charismatic leader my not be as effective when transferred to another team.
- Determine the structure of the program. This should specify

- the role of the general practitioner and other medical providers with whom the patient has an ongoing relationship
- the role of any care planner or co-ordinator
- the point of identification of cases
- the role of education or health coaching
- the process for the provision of evidence based guidelines, and other tools
- medico-legal responsibility

The role of education or coaching is crucial as chronic care management can be improved through self-management and/or partnerships between providers and patients. The idea of health coaching is a further development of the practice of individualised support to enhance work, business and life performance which gained popularity over the 1990s. This in turn is building on the metaphor of sports coaching. Health coaching aims to provide information and support in changing attitudes and behaviours. Palmer et al, writing in 2003, commented on the lack of published evidence on the effectiveness of this approach. The extent to which evidence has been developed since that time requires a substantial review of the published literature. However, it has grown in popularity both within health promotion and with life and health coaches in private practice. Again, an important aspect is ensuring that there are not inconsistent messages or advice, and dealing with all aspects of a patient's care requirements rather than focussing on only one condition. Taking account of the input from and needs of any informal carers is also likely to be critical to the success of any educational or coaching programs.

Depending on the structure chosen, chronic care case management may come from the GP, the specialist, the specialist case co-ordinator or an educator. Whatever model is chosen, there is a need for tools, including but perhaps not limited to, evidence based guidelines. The existing literature is large, and is likely to be growing rapidly. Therefore any program must be supported by a process for assessing evidence and providing these tools to the case manager.

5.1.2 Organisational and delivery arrangements at the system level

The advantages of comprehensive, continuing care are the established relationships between provider and patient, common record keeping, co-ordination of all care, and when set within a wider organisational context, the ability to draw on specialised knowledge and experience. However, as the Co-ordinated Care Trials have shown, it is difficult to graft this type of model onto the current structure of the Australian system and to realise cost savings.

Many countries have initiated changes to funding (eg specific incentives, bundled payments), systems to enhance the storage, provision and exchange of information (eg registries, electronic medical records, telehealth etc) and increased emphasis on self-management when appropriate. Australia, however, seems to have failed to grasp the nettle.

There is growing interest in the US in enhancing the role of primary care in a management and co-ordination function. The term 'medical homes' has been applied to describe this function, where this encompasses not just the primary care doctor as a gatekeeper, but a provider that is accessible after hours and at weekends, and does not just refer but co-ordinates and manages care. The Commonwealth Fund states that this

requires a change from fee for service payment, and an underlying information technology base.

In the UK, recent reforms have focussed on primary care and general practice in restructuring through the establishment of Primary Care Trusts, and providing incentives for better performance through the Quality and Outcomes Framework. This sets a large number of performance measures, across a range of diseases, with financial rewards for achievement.

This approach has, to some extent, been adopted in Australia. Initiatives such as the Practice Incentives Program, the Service Incentives Program and Enhanced Primary Care and Chronic Disease Management have been implemented with new items available under Medicare MBS. No evaluative studies of these initiatives have been identified and this is a potential area for new research and evaluation projects. These initiatives have not been introduced as part of a coordinated program of changes and their objectives in terms of managing chronic conditions have been largely directed at GPs, who, whilst important providers of care, are not the sole providers of care for people with chronic conditions. Thus, in terms of organisational change, these initiatives can be regarded as marginal at best, so it is not surprising they do not appear to have led to major improvements in the care of chronic conditions. Ham () is of the opinion that in order for substantive changes to occur, it is necessary to act on several fronts at once ie strengthen the capacity of primary care to deal with chronic conditions, initiate a system-wide framework such as the one previously described involving self-management, disease management and care management. Both Ham and the Commonwealth Fund recommend that ways be found to decrease the divisions between primary and secondary care so that the common goals (eg reducing unnecessary hospitalisations and increasing the integration of care) are the goals of all levels of the system.

In the Australian system, the GP still has a primary role in the comprehensive care of individual including those with chronic disease. However, once individuals have established chronic disease they are likely to have a relationship with other specialists, often these involve ongoing care. Across health care systems, patients have reported difficulty in receiving treatment and advice from a range of professionals, as this can led to inconsistent advice and interactions of therapies. Hence the role of existing providers has to be considered.

Further, medical practitioners are the access point to MBS and PBS funded services. These services should continue to be used appropriately, and not fund services that can be funded form these programs. The care co-ordinator role has to be designed to co-ordinate not to add another inconsistent source of advice. Care co-ordinators could take a separate role to medical providers; alternatively they could work in a supplementary role, supporting care providers.

No one country has been able to outline a truly successful solution to the issue of preventing and managing chronic conditions. Although the framework above begins at the level of service delivery, crucial system-wide issues such as i) increased cooperation between primary and secondary care, ii) increased use of practice nurses and other non-medical providers as case managers, iii) enhanced multidisciplinary teamwork and iv) the provision of s sophisticated IT network will not be solved at the

practice or service organisation level. They require a national response. The most important response should be in terms of funding and incentives to address issues i) to iii) as issue iv), the IT system, is a tool for the use of service providers and managers. Reform of the funding and incentive system currently in place is seriously hampered by what Hickie (2009) has described as "basic financial and professional distortions" more in line with a 19th rather than a 21st century health system.

Australia has experienced one major reform of the health system with the introduction of Medicare, originally in 1973. Unfortunately, in subsequent years, the necessary political leadership has been lacking to undertake further fundamental reforms to funding arrangements to provide incentives which will allow integrated teams of health professionals to work and communicated together and with patients to provide care across primary and secondary care, at home or in hospital and to facilitate the coordinated and collaborative use of electronic communication systems.

6. Summary of Issues

A national response in cooperation with States and Territories is needed to identify and provide funding solutions (particularly in terms of the structure of reimbursement and incentives for providers) to address such issues as how to facilitate increased cooperation between primary and secondary care, increased use of practice nurses and other non-medical providers as case managers, enhanced multidisciplinary teamwork and the provision of s sophisticated IT network.

At national, State/Territory and local organisation level, attention needs to be paid to the issue of guidelines. Clinical guidelines have been developed for both acute and chronic conditions, but there is evidence from a range of countries that guidelines generally are not well taken up. Therefore a second key element required is the structure of service delivery that will provide those components of best practice care. This is likely to be largely generalisable across diseases, though there may be some specific variations; it is also likely to vary across geographical areas and should be coherent with the existing pattern of service delivery. It requires decisions regarding the nature of the services to be provided (eg self-management, disease management or care management or some other model of care provision) attention to incentives, both for practitioners in prescribing the appropriate care, and in ensuring adequate access (geographic, financial).

Specifically at the organisational and service delivery levels, important issues which need to be addressed include how to identify and "stage" individuals with chronic conditions, the development and implementation of guidelines (including what resources are required for this and what incentives are needed) and the development, implementation and use of specialised IT systems to facilitate the coordination of care and the evaluation of both processes and outcomes of health care delivery.

7. Potential Research Agenda

The research agenda outlined below is drawn from the issues identified in this Working Paper. The list is by no means comprehensive and can be adjusted at any time.

1. What are chronic conditions?
    - *What is the proportion of individuals with one, two, three or more chronic conditions?*

- *What are the socioeconomic and sociodemographic characteristics of individuals with one, two, three or more chronic conditions?*
- *Can the utilisation of health services be described for each group and has utilisation change over time (if possible for the same individuals but also by comparing cross sectional surveys)*
- *What OOP costs are faced by individuals in each group and overall and have these changed over time?*

2. What is the evidence about preventing and managing chronic conditions?
   - *The information provided in the Table is preliminary. There is a need to systematically evaluate the types and levels of evidence used in the studies conducted so far, including that for effectiveness and cost-effectiveness.*
   - *Using data from panel data sets to describe patterns of care for chronic conditions, particularly in terms of the predictors of high and low use of medical and hospital services.*
   - *Expand the analysis of the Commonwealth Fund survey eg to describe and characterise respondents such as the 26% who reported that their care was poorly organised and the 53% who visited the ER in the past 2 years.*

3. What are the challenges for the Australian health system in terms of preventing and managing chronic conditions?
   - *How well have funding incentives such as the Practice Incentives Program, the Service Incentives Program and Enhanced Primary Care and Chronic Disease Management worked in terms of preventing and managing chronic conditions?*
   - *What funding reforms and incentives around provider reimbursement are likely to be successful in enhancing the performance of providers in relation to the prevention and management of chronic conditions?*

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Table: Chronic conditions and interventions aimed at preventing and managing them

Condition	Definition	Primary prevention	Secondary prevention	Management
Arthritis	Arthritis means inflammation of a joint. There are more than one hundred different forms of arthritis. They are similar to each other in the symptoms they produce, which includes sore, stiff, inflamed, and painful joints.	Injury prevention Avoid obesity Adequate exercise[3]	Adequate strengthening & flexibility exercises Weight loss	Adequate strengthening & flexibility exercises Avoid obesity Medication Orthopaedic surgery
Asthma	Asthma is a chronic lung disease. It is disorder of the airways that is complex and characterized by variable and recurring symptoms, airflow obstruction, bronchial hyper-responsiveness (bronchospasm), & an underlying inflammation. The interaction of these features of asthma determines the clinical manifestations & severity of asthma & the response to treatment	Avoid allergens Avoid smoking	Asthma management plan Regular checkups including spirometry Preventer medication Identify/avoid triggers	Asthma management plan Regular checkups including spirometry Preventer medication Reliever medication Avoid triggers
Cardiovascular disease	Any abnormal condition characterized by dysfunction of the heart & blood vessels. CVD includes atherosclerosis (especially coronary heart disease, which can lead to heart attacks), cerebrovascular disease (eg, stroke), & hypertension (high blood pressure).	Avoid smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Manage risk factors: • Hypertension • Dislipidaemia • Cholesterolaemia Quit smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	All interventions as for primary and secondary prevention PLUS • Surgery (eg stents, CABG etc) • Cardiac rehabilitation
Cerebrovascular disease	Disease of the blood vessels &, especially, the arteries that supply the brain. Cerebrovascular disease is usually caused by atherosclerosis & can lead to stroke	Avoid smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Manage risk factors: • Hypertension • Atrial fibrillation	All interventions as for primary and secondary prevention PLUS • Medical management of acute CV events eg stroke • Rehabilitation post stroke

[2] Adequate nutrition = adhering to nutritional guidelines regarding intake of meat, vegetables, fruit and dairy products; limiting fat and sugar intake, particular foods regarded as energy dense and sweetened drinks.

[3] Adequate exercise = adhering to recommendations provided by experts in relation to aerobic and strengthening exercise. The current recommendations are that adults undertake at least 30 minutes of moderate intensity physical activity on most, preferably all, days and, if possible, incorporate some regular, vigorous activity.

[4] Current recommendations for intake of alcohol are that on average men consume no more than four standard drinks a day, and women no more than two. On any single occasion, men should consume no more than six drinks and women no more than four. One or two days a week should be alcohol free.

Chronic kidney disease	Chronic kidney disease (CKD), also known as chronic renal disease, is a progressive loss of renal function over a period of months or years.	Avoid smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Medical intervention to delay progression of kidney failure	Medical management of kidney failure • Drug therapy • Renal dialysis Kidney transplant
Chronic obstructive pulmonary disease	Refers to chronic bronchitis and emphysema, two commonly co-existing diseases of the lungs in which the airways become narrowed This leads to a limitation of the flow of air to & from the lungs causing shortness of breath. The limitation of airflow is poorly reversible & usually gets progressively worse over time.	Avoid smoking Avoid occupational & environmental pollution	Manage asthma Manage episodes of bronchitis and other infections Vaccinate against influenza Avoid infections through use of good hygeine	Medical management of COPD using drugs and supplemental oxygen Manage acute exacerbations by avoiding infections (eg flu vaccinations) and treating infections early Monitor nutrition Pulmonary rehabilitation
Colorectal cancer	Colorectal cancer, also called colon cancer or large bowel cancer, includes cancerous growths in the colon, rectum and appendix. Many colorectal cancers are thought to arise from adenomatous polyps in the colon. These mushroom-like growths are usually benign, but some may develop into cancer over time.	Avoid smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Regular checkups including colonoscopy Quit smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Surgery, chemotherapy, radiotherapy as indicated by published guidelines
Diabetes	A syndrome of disordered metabolism, usually due to a combination of hereditary and environmental causes, resulting in abnormally high blood sugar levels (hyperglycemia).	Avoid obesity Avoid smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Medication &/or dietary control Quit smoking Adequate exercise HBAC1 test Eye examination Foot examination and care	Medication &/or dietary control Quit smoking Adequate exercise HBAC1 test Eye examination Foot examination and care Care of established complications (eg retinopathy, vascular disease) according to published guidelines.
Lung cancer	Lung cancer is a disease of uncontrolled cell growth in tissues of the lung. This growth may lead to metastasis, which is the invasion of adjacent tissue and infiltration beyond the lungs.	Avoid smoking Adequate nutrition[2] Avoid environmental & occupational smoke	No definitive strategies identified ? Quit smoking	Surgical, chemotherapy & radiotherapy as indicated by type of cancer & published guidelines.

	The vast majority of primary lung cancers are carcinomas of the lung.			
Oral disease	Oral disease refers to a number of inflammatory diseases affecting the periodontium — that is, the tissues that surround and support the teeth. Periodontitis involves progressive loss of the alveolar bone around the teeth, & if left untreated, can lead to the loosening and subsequent loss of teeth. Chronic Periodontitis, the most common form of the disease, progresses relatively slowly & typically becomes clinically evident in adulthood.	Fluoridate water Avoid smoking Adequate nutrition[2] Limited alcohol intake[4] Clean teeth & gums regularly	Clean teeth & gums regularly Avoid excess consumption of sugar Avoid smoking Limited alcohol intake	Dental treatment Clean teeth & gums regularly Avoid excess consumption of sugar Avoid smoking Limited alcohol intake
Osteoporosis	Osteoporosis is a disease of bone that leads to an increased risk of fracture. In osteoporosis the bone mineral density (BMD) is reduced, bone microarchitecture is disrupted, & the amount and variety of non-collagenous protein in bone is altered.	Ensure sufficient intake of calcium & vitamin D Avoid smoking Adequate nutrition[2] Adequate exercise[3] Limited alcohol intake[4]	Hormone therapy Vitamin D supplements Calcium supplements Drug treatment to prevent further bone loss and fractures Prevention of falls Hip protectors Exercise	Hormone therapy Vitamin D supplements Calcium supplements Drug treatments Exercise
Depression	Depression is a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, & poor concentration. These problems can become chronic or recurrent & lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities. At its worst, depression can lead to suicide.	No definitive strategies identified	It is difficult to prevent all recurrences of depression. However, it may be possible to prevent or reduce the severity of future episodes using by prescribed medication, CBT, exercising regularly, ensuring good nutrition & avoiding alcohol & drugs.	CBT Prescribed medication Regular exercise Good nutrition Avoid alcohol Avoid drugs