





MANAGING CHRONIC DISEASE IN EUROPE

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EXECUTIVE SUMMARY

Chronic conditions and diseases are the leading cause of mortality and morbidity in Europe, and research suggests that complex conditions such as diabetes and depression will impose an even greater health burden in the future. It has been estimated that in 2005 77% of all Disability-Adjusted-Life-Years (DALYs) and 86% of premature deaths in the WHO European region are related to non-communicable diseases. The condition expected to increase most dramatically is dementia. The main risk factors for chronic disease are tobacco use, overweight and obesity, hypertension, alcohol abuse, and a sedentary lifestyle. Some years ago chronic diseases were meant to be a problem of the rich and elderly population. Today we know that within high income countries, poor as well as young and middle-aged people are affected by chronic conditions.

The economic implications are serious from a macroeconomic perspective as well as from a microeconomic perspective. Chronic diseases depress wages, earnings, workforce participation, labour productivity and hours worked - and they may also lead to early retirement, high job turnover and disability. Disease-related impairment of households' consumption and educational performance impacts on the gross domestic product (GDP) and on its growth rate. Spending on chronic care is rising across Europe and consuming growing portions of public and private budgets. The cost of chronic diseases and their risk factors, as measured by cost-of-illness studies, is sizeable, ranging up to 6.77% of a country's GDP.

Policy makers in Europe need to take action if they want to improve chronic disease management. This report aims to inform decision-making by giving an overview of the available strategies and interventions as well as empirical evidence on their effectiveness and cost-effectiveness. The report also focuses on five areas of managing chronic disease where policy makers must act. Recommendations are given in each area.

Prevention and early detection

To combat chronic conditions, most countries in Europe are applying various approaches of disease prevention and early detection. Prevention includes primary, secondary, or tertiary approaches that differ in aims and target groups. Research indicates that broad approaches combining several interventions are most effective. New Zealand's diabetes prevention programme is an example of a successful multi-level approach. New Zealand's cancer control strategy integrates all those involved and has been implemented across different health care sectors. Many prevention programmes tackle tobacco, alcohol consumption, obesity or hypertension. Cost-effectiveness for tobacco control is clear, but results for interventions to reduce and prevent obesity are inconclusive. Overall, analyses indicate that efficient strategies for prevention and early detection are available for many chronic conditions. Nevertheless, policy makers have to be cautious: cost-effectiveness varies considerably according to regional context and different populations. This means that for each intervention they must examine carefully regional factors and specifically define their target groups. Overall, prevention and early detection programmes are promising, but far from well developed in most countries. Given severe medical, social and economic consequences of chronic diseases, more effort and resources need to be invested in prevention.

New provider qualifications and settings

Health care has recently seen the emergence of new providers, settings and qualifications. Once it became clear that traditional demarcation lines between physicians and nurses could harm quality of care, new professions - such as nurse practitioners, liaison nurses and community nurses - were set up. The tasks and responsibilities of existing professional groups have been shifted and expanded. For example, physicians now have a coordinating role by guiding patients through the health system. Over the past 10 years new ways of providing services have been set up. Collaborative models - such as group practices, medical polyclinics and nurse-led clinics - are more patient-oriented. A key challenge is to support health workers in carrying out their new duties and responsibilities. There is a need for well-targeted training, particularly for those at the lower levels of the professional hierarchy. Evidence on these new qualifications and settings is limited, but pilot studies suggest that primary care nurses with more qualifications and responsibilities provide better care. New qualifications, structures and settings can help to improve the management of chronic diseases. Nevertheless, future research must build on these early results to see whether improvements justify investment, and also to inform future decisions.

Disease management programmes

Disease management programmes (DMPs) have been introduced by many European countries to improve chronic care and contain costs. The aim is to improve coordination by focusing on the whole care process, building on scientific evidence and patient involvement. There are still insufficient rigorously designed large-scale population-based evaluations, but smaller studies suggest that these programmes may improve care. Several studies have shown the benefits of providers following evidence-based guidelines. Patients' behaviour has also changed, as expressed in greater patient satisfaction and adherence to treatment. Generally, the evidence suggests an improvement in the care process. The evidence on medical outcomes, however, is still inconclusive. Only a few studies have shown that disease management programmes affect mortality and other health-related outcomes. The evidence on cost-effectiveness is similarly inconclusive. Economic evaluation studies look only at costs and do not consider the relation of costs and benefits. Providers and insurers must make the data they collect available for research, and evaluation must become an integral part of these programmes.

Integrated care

Integrated care models respond to the fact that chronic diseases can rarely be treated in isolation. Patients often have several chronic diseases or conditions at a time and need care from different providers. These models organise treatment (and prevention) so that services are better integrated across the whole range of care. Examples in Europe are the introduction of case management by the National Health Service (NHS) in the UK, or the pilot projects in Spain in which the whole care process is provided by only one source. All over Europe various forms of provider networks and interventions have been set up to close the gap between primary and hospital services. Between 2004 and 2008, 1% of all payments for physicians and hospitals were earmarked for investing in integrated-care projects. The effectiveness of these projects remains uncertain because so far the evidence is limited. Several components - such as self-management support, delivery system design and decision support - seem to be effective, but there is a lack of large-scale population-based studies. Some of the preliminary results give cause for optimism, but, given the complexity of integrated care models, implementation will be challenging and future studies should focus on this. As for cost-effectiveness, early results are inconclusive. Policy makers must ensure that costs, savings and benefits are studied in more detail.

Given these findings, this report suggests that policy makers should consider the following recommendations if they wish to improve the management of chronic disease in an effective and sustainable manner:

(1) *New pharmaceuticals* and medical devices can help to improve treatment for the chronically ill but will bring new difficulties in terms of marketing authorisation and reimbursement.

(2) Properly applied *financial incentives* can be powerful tools to bring about effective and rapid change. Policy makers need to pay attention to operational aspects, such as the size of variable compensation or funding and issues in goal-setting. In chronic care, benefits tend to appear only after several years, which means that policy makers must realise that often the quality of care will only be improved if providers are confident that they will be able to benefit from their investments. Hence they need to look carefully at which strategy to follow with regard to 'continuity of care'.

(3) Policy makers should recognise that reforms intended to improve *coordination* must be well-prepared and supported by strong political will. They should map out clearly the responsibilities of all the individuals and groups involved. The balance between local autonomy and central authority must be carefully defined. Policy makers will need to provide enough funding to enable reform while at the same time setting up compensation schemes that will encourage professional groups to cooperate. Finally, health workers need adequate training and mutual learning and communication.

(4) To release the full potential of *information and communication technology (ICT)*, agreement must be reached on international technical standards. Solutions must be found for translating the vast amounts of data into meaningful information that health professionals can use.

(5) *Evaluation* should be an integral part of programmes to improve the management of chronic disease. The process should not block effective patient-oriented innovations, which is a dilemma for which new approaches need to be developed and agreed. Because policy makers need better evidence in order to make informed decisions, they should immediately make existing data available for research.

European societies face various health care challenges, such as increasing longevity, changing life-styles and advances in medical technology.

Potentially the most important challenge will be managing chronic diseases – the ‘ongoing management of conditions over a period of years or decades’. They are already the leading cause of mortality and morbidity in Europe, and research suggests that complex conditions such as diabetes and depression will impose an even larger burden in the future.

The economic implications are serious. Chronic diseases depress wages, earnings, workforce participation and labour productivity, and they increase early retirement, high job turnover and disability. Disease-related impairment of households’ consumption and educational performance has a negative effect on the gross domestic product (GDP). As expenditure on chronic care rises across Europe, it takes up increasingly greater proportions of public and private budgets.

Chronic diseases have traditionally been cardiovascular disease, diabetes, and asthma. As survival rates and times have improved, they now also include many types of cancer, HIV/AIDS, mental disorders (such as depression, schizophrenia and dementia) and disabilities such as sight impairment and arthroses. Many chronic diseases and conditions are linked to an ageing society, but also to lifestyle choices such as smoking, sexual behaviour, diet and exercise.

What they have in common is that they need a long-term and complex response, coordinated by different health professionals with access to drugs and equipment, and extending into social care. Most health care today, however, is still structured around acute episodes.

Because policy makers in Europe need to make decisions on how to manage chronic disease, this report evaluates the current situation and proposes future directions. It relies on published sources but is not a ‘systematic review’ (the authors do not claim to have searched for all available pieces of evidence). An important source of information, which the authors gratefully acknowledge, is *Caring for People with Chronic Conditions: A Health System Perspective*, edited by Ellen Nolte and Martin McKee in 2008 by the European Observatory on Health Systems and Policies’ OUP series.

The report consists of three parts (figure 1). The first outlines the burden of chronic disease on patients, groups and societies in Europe. Chapter 2 focuses on the burden of chronic disease and related risk factors in Europe and shows that chronic diseases are no longer confined to the old and rich. Chapter 3 outlines the economic implications of chronic diseases. We distinguish between results generated by microeconomic and macroeconomic analyses.

The second part of the report concentrates on strategies that could combat and prevent chronic diseases, in particular:

- prevention and early detection,
- qualifications and settings of new providers,
- disease management programmes, and
- integrated models of care.

Chapter 4 describes these strategies. Chapter 5 summarises the evidence on effectiveness and chapter 6 summarises the evidence on cost-effectiveness.

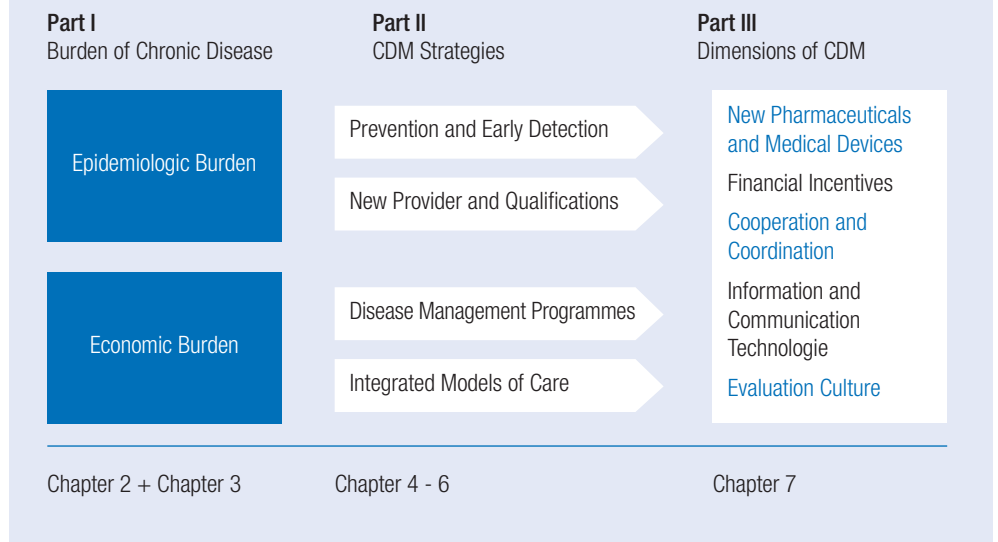
The third part (Chapter 7) draws conclusions from this evidence about the actions policy-makers should take.

We make recommendations in five areas:

- innovations, particularly in pharmaceuticals and medical devices,
- financial incentives,
- coordination and cooperation,
- information and communication technologies, and
- evaluation culture.



Figure 1: Structure of the report



Chapter 8 summarises the report and suggests future research needs.

PART I: BURDEN OF CHRONIC DISEASE

This part of the report will outline the burden of chronic disease on patients, groups and societies in Europe. Chapter 2 will focus on the epidemiology and related risk factors in Europe. Chapter 3 will examine the economic implications.

EPIDEMIOLOGY AND ECONOMIC BURDEN OF CHRONIC DISEASE IN EUROPE

2

This chapter will look at how chronic diseases affect European countries in different ways. It will examine the burden of disease across countries and regions, the prevalence of risk factors (such as smoking and being overweight), and the varying burdens of selected chronic conditions. Finally, it will estimate the future mortality and burden of chronic diseases.

2.1 Current status

The burden of chronic diseases

The World Health Organization (WHO) defines chronic diseases as *diseases of long duration and generally slow progression*. Often the terms *non-communicable disease* and *chronic disease* are treated as exchangeable. But given recent advances in treating communicable diseases this use is no longer precise enough. For example, HIV/AIDS treated with modern medicines has become a disease of long duration and generally slow progression. This report acknowledges this issue, but nevertheless refers to sources that use non-communicable disease as a proxy for chronic disease if no alternative high-quality data is available. Following the WHO classification, cancer is treated as a chronic disease in this report, even though it is acknowledged that the strategies used in chronic disease management are not always applicable to those with this disease.

Chronic disease is responsible for most of the disease and deaths in Europe. One measure for the overall burden of disease, developed by the WHO, is the Disability-Adjusted Life Year (DALY). It is designed to quantify the impact on a population of premature death and disability by combining them into a single measure. The DALY relies on the assumption that the most appropriate measure of the effects of chronic illness is time either spent disabled by disease or lost due to premature death. One DALY equals one year of healthy life lost (WHO 2005). Table 1 shows the numbers of DALYs as well as their percentage as a share of non-communicable diseases for 2005 (Singh 2008; WHO 2005).

Table 1: Disease burden and deaths from non-communicable diseases in the WHO European region by cause (2005)

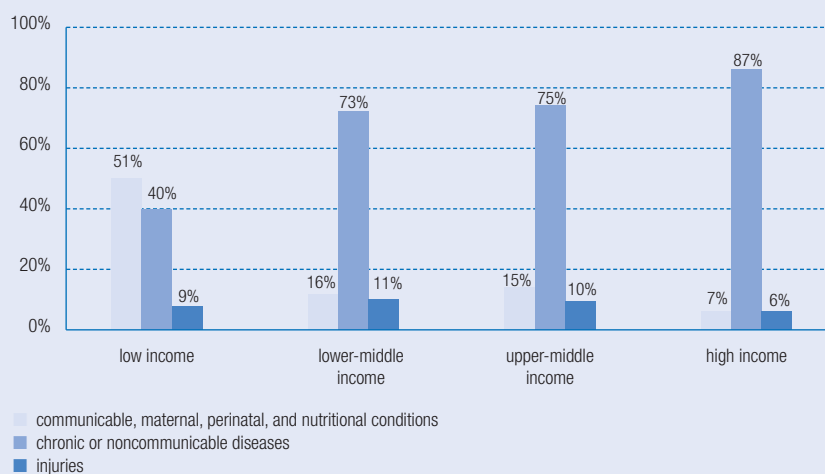
Groups of causes	Disease Burden		Deaths	
	DALYs (thousands)	Proportion from all causes (%)	Number (thousands)	Proportion from all causes (%)
Selected noncommunicable diseases				
Cardiovascular diseases	34.421	23	5.067	52
Neuropsychiatric conditions	29.370	20	264	3
Cancer (malignant neoplasms)	17.025	11	1.855	19
Digestive diseases	7.117	5	391	4
Respiratory diseases	6.835	5	420	4
Sense organ diseases	6.339	4	0	0
Musculoskeletal diseases	5.745	4	26	0
Diabetes mellitus	2.319	2	153	2
Oral conditions	1.018	1	0	2
All noncommunicable diseases	115.339	77	8.210	86
All causes	150.322	100	9.564	100

Source: Singh (2008)

1 The four groups are according to the income categories used by the World Bank.

The incidence of chronic diseases is high in high-income countries. The WHO's project *The Global Burden of Disease* (GBD) estimates incidence, health state prevalence, severity and duration, and mortality for more than 130 major causes. It includes data since 2000 for WHO member states and for sub-regions of the world (WHO 2008). Figure 2 shows the high share of chronic or non-communicable diseases compared with communicable, maternal, perinatal and nutritional conditions, as well as injuries in low-income, lower-middle income, upper-middle income and high-income countries¹ (Suhrcke et al. 2007).

Figure 2: Worldwide share of deaths by causes and countries within different World Bank income categories (2002)



Source: Suhrcke et al. (2007); Mathers et al. (2003)

The WHO project estimates that in 2002 chronic or non-communicable conditions accounted for 87% of deaths in high income countries (figure 1). Only 7% of deaths were attributed to communicable conditions and nutritional deficiencies and 6% to injuries (WHO). The proportion of deaths worldwide caused by non-communicable disease is projected to rise from 59% in 2002 to 69% in 2030 (Mathers and Loncar 2005).

Most studies focus on chronic conditions and on risk factors between countries, and only a few have looked at the distribution within countries. However, increasing data from high-income countries almost unanimously shows that the poor within these countries carry a higher chronic disease burden than the rich (Suhrcke et al. 2007).

The link between disease and age is also crucial from an economic and public-policy standpoint. The proportion of those in European countries aged 65 and older is projected to grow from 15% in 2000 to 23.5% by 2030. The proportion of those aged 80 years and more is expected to more than double from 3% in 2000 to 6.4% in 2030 (Pomerleau et al. 2008; Kinsella and Phillips 2005). This trend is clearly one of the reasons for the growing burden of chronic conditions and diseases.

But older people are not the only ones affected by chronic diseases. Rising numbers of young and middle-aged people have some form of chronic health problem (Pomerleau et al. 2008). The WHO project estimated that 72% of all deaths before the age of 60 in 2002 were due to chronic or non-communicable conditions in high income countries, whereas communicable diseases accounted for only 8% and injuries for 21%. In the same year, 68% of DALYs lost to chronic diseases in high income countries occurred among those of working age. These findings suggest that chronic disease can no longer be considered just a problem of the elderly (Suhrcke et al. 2007; Mathers et al. 2003).

The burden of chronic disease risk factors

The shape of the future burden of chronic disease can be projected by risk factor data (Suhrcke et al. 2007). The main risk factors for chronic disease are tobacco use, overweight and obesity, hypertension, alcohol abuse, and a sedentary lifestyle. Table 2 presents deaths and DALYs attributable to risk factors.

Table 2: Deaths and burden of disease attributable to common risk factors, in absolute numbers and percentages of all deaths/DALYs, sorted by contribution to world-wide deaths (2001)

Chronic disease risk factors	Low- and middle-income		High-income		World	
	Deaths	DALYs	Deaths	DALYs	Deaths	DALYs
High blood pressure	6,223 (12.9%)	78,063 (5.6%)	1,392 (17.6%)	13,887 (9.3%)	7,615 (13.5%)	91,950 (6.0%)
Smoking	3,340 (6.9%)	54,019 (3.9%)	1,462 (18.5%)	18,900 (12.7%)	4,802 (8.5%)	72,919 (4.7%)
High cholesterol	3,038 (6.3%)	42,815 (3.1%)	842 (10.7%)	9,431 (6.3%)	3,880 (6.9%)	52,246 (3.4%)
Low fruit and vegetable intake	2,308 (4.8%)	32,836 (2.4%)	333 (4.2%)	3,982 (2.7%)	2,641 (4.7%)	36,819 (2.4%)
Overweight and obesity	1,747 (3.6%)	31,515 (2.3%)	614 (7.8%)	10,733 (7.2%)	2,361 (4.2%)	42,248 (2.8%)
Physical inactivity	1,559 (3.2%)	22,679 (1.6%)	376 (4.8%)	4,732 (3.2%)	1,935 (3.4%)	27,411 (1.8%)

Source: Lopez et al. (2006)

According to the 2002 WHO report *Reducing Risks, Promoting Healthy Life*, tobacco use still remains the leading avoidable cause of death in industrialised nations (WHO 2002). In Europe over the past 30 years the proportion of smokers has dropped from 45% to 30%. However in Eastern European countries, and particularly in the Baltic states, smoking has continued to increase, particularly among young people and women (Novotny 2008).

Alcohol abuse causes chronic illnesses, such as alcohol dependence, vascular disease (such as hypertension), hepatic cirrhosis and various cancers. Of the global loss of DALYs, 4.7% can be explained by alcohol-related diseases. At 10.7%, the share for Eastern Europe is significantly higher (Jamison et al. 2006; Novotny 2008).

Overweight is defined as a body mass index (BMI or kg/m²) of 25 or more. People with a BMI of 30 or more are classified as obese. According to this definition, almost a third of all people living in Europe are overweight. Older age groups show higher prevalence (up to 57% of men in Western Europe aged 70-79 years) (James et al. 2004; Novotny 2008). However, an increasing number of European children are affected: one study by the London Obesity Task Force found that 18% of children in Europe were overweight (Novotny 2008).

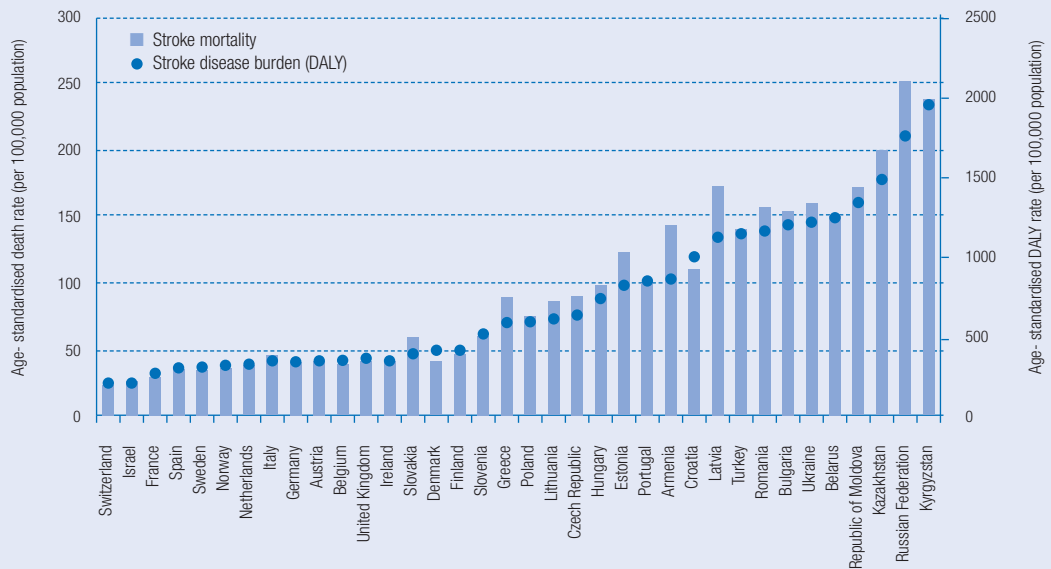
Variation of burden: selected chronic conditions in Europe

The contribution of chronic diseases to the overall mortality and burden of disease varies within the European region, as the leading chronic conditions illustrate. However, with some diseases we do not know how much of this variation is caused by disease, and how much to coding by health professionals in the various countries (Pomerleau et al. 2008).

Cerebrovascular disease or stroke accounted for about 15% of all deaths and about 7% of disease in 2002 in Europe (WHO 2004a). However, the mortality and disease burden attributed to stroke in the European region varies considerably (figure 3). The Russian Federation, Kyrgyzstan and Kazakhstan have up to 10 times higher levels than Switzerland, Israel and France (Pomerleau et al. 2008).



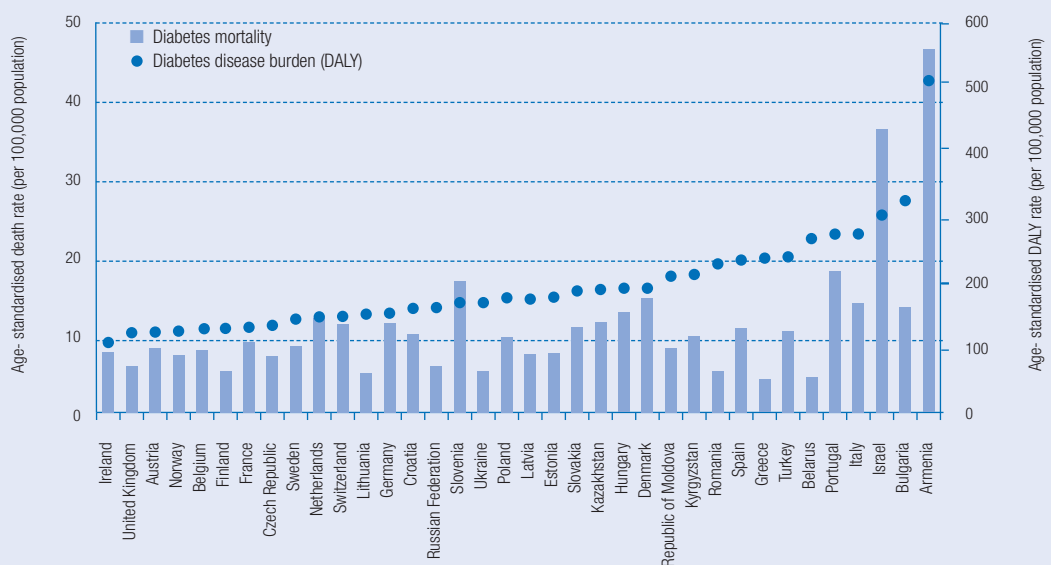
Figure 3: Burden of death and disease attributable to stroke in selected countries in the WHO European region (2002)



Source: Pomerleau et al. (2008); WHO (2004b)

Mortality and disease burden from diabetes mellitus also vary considerably (figure 4). Age-standardised death rates in 2002 ranged from 4.0 per 100,000 in Greece to 17.9 in Portugal, 136.1 in Israel and 46.8 in Armenia. These figures may be an underestimate because diabetes is not always recorded as the underlying cause of death, particularly for older people (Pomerleau et al. 2008).

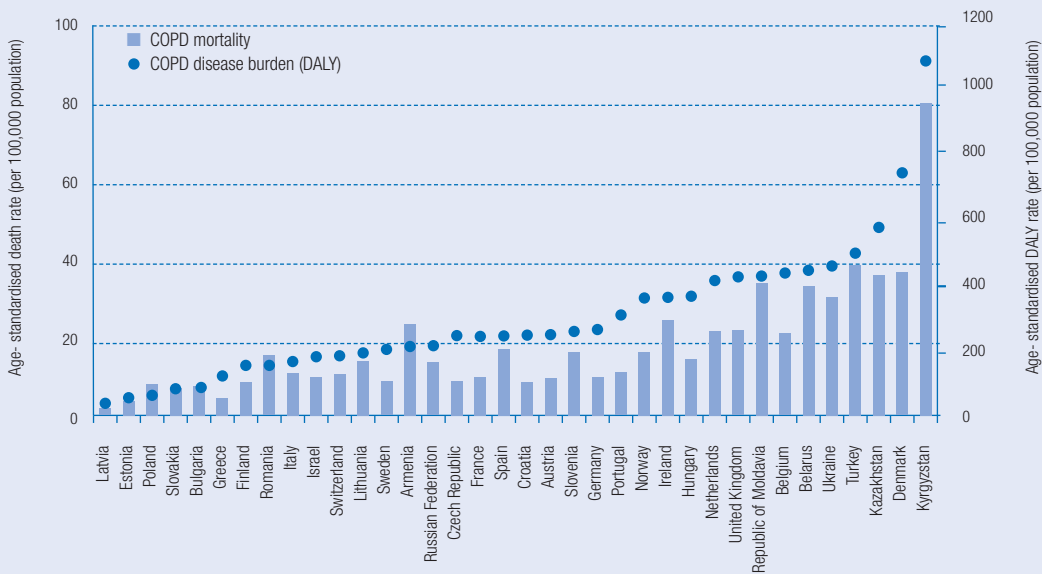
Figure 4: Burden of death and disease attributable to diabetes in selected countries in the WHO European region (2002)



Source: Pomerleau et al. (2008); WHO (2004b)

Chronic obstructive pulmonary disease (COPD) is also one of the leading causes of premature death in Europe and its contribution varies considerably in different countries., COPD is associated with an estimated 5.1 deaths and 70 DALYs per 100,000 population in Latvia, while in Kyrgyzstan it is associated with 80.9 deaths and 1,088 DALYs per 100,000 (figure 4) (Pomerleau et al. 2008).

Figure 5: Burden of death and disease attributable to COPD in selected countries in the WHO European region (2002)



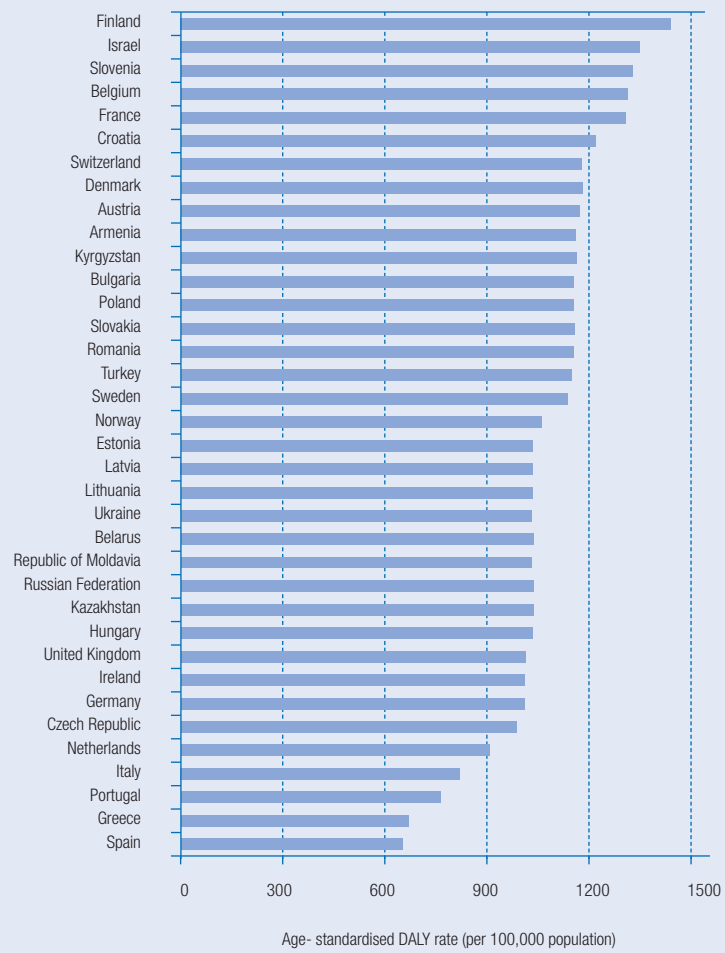
Source: Pomerleau et al. (2008); WHO (2004b)

The prevalence of mental disorders is high in the European region (Kessler, 2007). Dementia among those aged 65 and over in 2000 was estimated to vary between 6% in Eastern Europe and 8% in Northern Europe (Wimo et al., 2003). More recent estimates have placed the prevalence of dementia among those aged 60 and over at 3.8% in Eastern Europe and 5.4% in Western Europe (Ferri et al. 2005).

The WHO has estimated that one person in five will develop depression and that each year 33.4 million Europeans have major depression (WHO Europe 2003). Age-adjusted DALY rates range from 660 to 1,430 DALYs per 100,000 (Figure 5). Rates are lowest in Spain and Greece with DALYs below 700 per 100,000. The highest estimates are for Finland, Israel, Slovenia, Belgium and France, with rates of around 1,250 DALYs (WHO 2004b; Pomerleau et al. 2008). WHO projections suggest that deaths from unipolar depressive disorders in the European region will fall from 0.15 to 0.13 per 100,000 population between 2005 and 2030. However, suicide from depressive disorders is the third leading cause of death among young people in Europe (Pomerleau et al. 2008).



Figure 6: Burden of disease attributable to unipolar depressive disorder in selected countries in the WHO European region (2002)



Source: Pomerleau et al. (2008); WHO (2004b)

2.2 Predictions

Baseline predictions

Projections of future mortality and burden of disease show that chronic diseases will continue to be the biggest contributor to mortality and disability in high-income countries, and chronic disease will increase. The share of DALYs associated with chronic or non-communicable conditions in high income countries is projected to rise from 86% in 2005 to 89% in 2030 (Suhrcke et al. 2007; Mathers and Loncar 2005).

Predictions for selected chronic conditions in Europe

Predictions for specific chronic conditions vary. For example, WHO has projected fewer deaths and DALYs from stroke for both sexes and all ages in the European region by 2030 (WHO 2006). In contrast, Carandang et al. (2006) have estimated more strokes and a greater burden of disease. An ageing population means that more and more people will be prone to strokes, which supports this assumption.

Deaths directly attributable to diabetes are predicted to rise from about 152,000 in 2005 to more than 203,000 in 2030 (WHO 2006). The growth of diabetes type 2 is partly a result of rising obesity levels, especially among children (Pomerleau et al. 2008).

Deaths in Europe from COPD are expected to rise by about 25%, from 270,000 in 2005 to more than 338,000 in 2030. Despite these predictions, the burden of COPD is projected to fall from about 3.44 to 2.95 million DALYs (WHO 2006). However, death rate and DALYs attributable to COPD are expected to decrease in all groups other than women aged 70 and older (Pomerleau et al. 2008).

Unipolar depressive disorders are projected to fall slightly between 2005 and 2030. The WHO has projected a decrease in age-standardised death rates from 0.15 to 0.13 per 100,000. However, the burden of disease from this problem is projected to increase among men from 777 to 785 per 100,000 (1%) and among women by 1.8% (from 1,312 to 1,337 per 100,000) (WHO 2006; Pomerleau et al. 2008).

The condition expected to increase most dramatically is dementia. The number of those in Europe aged 60 and more with dementia is estimated to rise from 7.7 million in 2001 to 10.8 million in 2020. Without effective prevention and treatment, this is expected to double to 15.9 million in 2040. The increase varies between 31% and 51% in different regions (Ferri et al. 2005).

There is considerable evidence on the epidemiology of chronic disease, but little on its economic implications (Suhrcke et al. 2007). This chapter will review recent microeconomic and macroeconomic evidence. The economic implications of specific strategies should not be the main or only guide when making health care decisions, but the main purpose of any intervention must be to improve health cost-effectively. Clearly, policy makers often target economic variables such as cost savings, greater labour productivity or economic growth. But these should not be the main criteria for evaluating specific strategies in chronic disease management. In order to understand the implications of chronic conditions and diseases, the economic implications should be examined.

3.1 The microeconomic perspective

Microeconomics examines the consequences of chronic disease on individuals and households. The evidence from European countries is growing but still limited (Suhrcke et al., 2008). So far it has identified the following effects of chronic conditions (Suhrcke et al. 2007):

Consumption and saving decisions: treating chronic diseases may be particularly costly in countries where a high share of total health spending is paid 'out of pocket'. Spending on addictive products such as tobacco and alcohol may cause poor health, and the household's ability to keep consumption levels constant in the face of 'health shocks' can be very costly.

With regard to *labour supply and labour productivity*, lower wages and earnings have been found. Chronic conditions and diseases mean fewer people in the work force, with early retirement, barriers to employment, and stigma.

Suhrcke et al. (2007) summarise the evidence on the impact of chronic diseases and conditions on labour markets (table 3 and table 4).

There is reasonable evidence on the impact of chronic disease and risk factors on the labour market, showing that chronic disease affects wages, earnings, workforce participation, hours worked, retirement, job turnover and disability.

Education and human capital formation is accepted as a powerful determinant of future earnings and future health. A full assessment of the costs of chronic disease should include the impact on education and the current evidence shows it affects educational performance. The death of a parent can reduce school enrolment (Gertler et al. 2004). Several studies have reported an association between maternal smoking and impaired cognitive and behavioural development, which in turn affects the academic performance of children (Ernst et al. 2001). Alcohol abuse is related to poor performance. This applies to young people in developed countries, where excessive drinking among younger age groups is relatively widespread (Suhrcke et al. 2007). Overweight or obese children are more likely to suffer from low self-esteem as a result of stigmatisation and this leads to absence from school (Latner and Stunkard 2003; Hayden-Wade et al. 2005).

The effects of chronic conditions and diseases on labour market outcomes and education are especially pronounced in low- and middle-income countries. In Europe, health insurance mitigates some of these effects. Nevertheless, the consequences on labour supply, productivity, education and the accumulation of human capital accumulation remain negative.

Overall, the evidence shows that chronic conditions and diseases have a negative effect on the labour market and on the formation of human capital. But the causal linkages are far from clear and these gaps need to be filled by further research.

Table 3: The impact of chronic disease and risk factors on labour supply, selected examples

Country and study	Year data collected	Chronic condition and Impact of chronic condition on employment indicators / labour supply
Canada Kraut et al. 2001	1983–1990	Diabetes People 2.1-fold less likely to work
Europe Jimenez-Martin et al. 1999	1994–1995	Chronic disease Chronic disease increases the retirement probability Husband's health affects the couple's retirement decisions much more strongly than the wife's health does
Finland Sarlio-Lahteenkorva and Lahelma 1999	1994	Obesity Women face a 2.5-fold higher likelihood of unemployment Women face a 1.4-fold higher likelihood of unemployment
Ireland Gannon and Nolan 2004	2000	Chronic disease Men 61% less likely to work; women 52% less likely to work
	2002	Chronic disease Men 66% less likely to work; women 42% less likely to work
Russia Suhrccke et al. 2005	2002	Chronic disease Retirement age decreases by 2.5 years Men have a 13.6% greater chance of retirement Women have a 14.0% greater chance of retirement
Sweden Lindholm et al. 2001	1979–1997	Chronic disease Unemployment 1.9-fold higher 2.5-fold increase in people on welfare 1.8-fold increase in people with financial difficulties 3.5-fold increase in economic inactivity
United States Serxner et al. 2001	1990–1998	Mental health Absenteeism is 47% higher
		Tobacco use Absenteeism is 19% higher
		Obesity Absenteeism is 23% higher
United States Simon et al. 2000	N/A	Depression 15.3% higher employment rate for depression remission vs. control group
United States Dwyer and Mitchell 1999	1992	Cardiovascular disease Expected retirement age decreases by 0.7 years
		High blood pressure Expected retirement age decreases by 1.0 years
		Diabetes Expected retirement age decreases by 0.12 years
		Cancer Expected retirement age decreases by 0.13 years
United States Pelkowski and Berger 2004	1992–1993	Chronic disease Men work 6.1% fewer hours Women work 3.9% fewer hours
United States McGarry 2002	1992–1994	Self-reported adult health Men 3.5% less likely to work at age 62
United States Coile 2003	1992–2000	Chronic disease Men have a 42% greater probability of retirement and lose 1,030 hours of lifetime work Women have a 31% probability of retirement and lose 654 hours of lifetime work
United States Cawley 2004	1997–2004	Obesity For white people, a 10% weight increase corresponds to a 12% decrease in probability of full-time employment, 5.4% fewer hours worked, 5% fewer months, 16% increase in months on welfare, and 10% lower earnings For African American a 10% weight gain corresponds to a 10.9% increase in months spent on welfare

Source: Suhrccke et al. (2007)

Table 4: The impact of chronic disease and risk factors on wages, earnings or incomes, selected examples

Country and study	Year data collected	Chronic condition and Impact of chronic condition on employment indicators / labour supply
Australia Lee 1999	1980–1989	Tobacco use Wages are 6.6% lower for smokers and 5.5% lower for former smokers
Canada Kraut et al. 2001	1983–1990	Diabetes Wages decrease by 28%
Canada Auld 1998	1991	Tobacco use Daily smokers earn 30% less than nonsmokers.
Finland Sarlio-Lahteenkorva and Lahelma 1999	1994	Obesity Likelihood of low household income increases by 1.5 times Likelihood of low individual income increases by 1.6 times
Indonesia Kosen 1998	1995	Tobacco use Lost annual income is US\$115 for individuals who use tobacco Lost annual income is also US\$115 for family members of tobacco users
Netherlands van Ours 2004	2001	Tobacco use Wages 10% lower
Russia Suhrcke et al. 2005	2002	Chronic disease 5.6% lower median per-person income
United Kingdom Sargent and Blanchflower 1994	1974–1981	Obesity Wages reduced by 6.4% for 23-year-old women
United States Tucker and Friedman 1998	N/A	Obesity Likelihood of absenteeism increases 1.7-fold for men Likelihood of absenteeism increases 1.6-fold for women
United States Pronk et al. 2004	N/A	Obesity Obese employees are less likely to get along with co-workers and more likely to incur work loss days Physical activity Physical activity was positively associated with the quality of work performed and the overall job performance Cardiac fitness Cardio-respiratory fitness is positively associated with the quantity of work performed, and with extra effort exerted at work
United States Fielding 1996	N/A	Physical inactivity Productivity declined 50% in the last two hours of work each day
United States Sloan et al. 2004	N/A	Tobacco use Lifetime wages reduced by US\$40,000
United States Gortmaker et al. 1993	1981–1988	Obesity Income for men is 9% lower (equivalent to a reduction of US\$2,876) Income for women is 22% lower (US\$6,710)
United States Cawley 2004	1981–2000	Obesity For white females, a difference in weight of two standard deviations (roughly 65 pounds) is associated with a difference in wages of 9%. (in absolute value, this is equivalent to the wage effect of roughly one and a half years of education or three years of work experience)
United States Levine et al. 1997	1984–1992	Tobacco use Wages decrease by 4–8%
United States Zagorsky 2004	1985–2000	Obesity A one-point increase in body-mass index reduces net worth by US\$1,000

United States Bhattacharya and Bundorf 2004	1989–1998	Obesity Wages reduced by US\$0.71 per hour
United States Haskins and Ransford 1999	1988	Obesity Higher weight tends to lower the chances for women to enter higher professional or managerial positions
United States Ng et al. 2001	1989	Diabetes 33% reduction in wages (US\$3,700–\$8,700 per year)
United States Averett and Korenman 1999	1990	Obesity White women's wages are reduced by 17%
United States Pelkowski and Berger 2004	1992–1993	Chronic disease Men earn 5.6% less; women earn 8.9% less
United States Mitra 2001	1993	Obesity Women earn US\$1.26 less per hour One-pound increase in weight is associated with 2% decrease in wages for women in professional/managerial positions
United States Berndt et al. 2000	1995	Depression 12–18% lower wages over lifetime
United States Haskins and Ransford 1999	1998	Obesity Higher weight tends to lower the chances for women to enter higher professional or managerial positions

Source: Suhrcke et al. (2007)

3.2 The macroeconomic perspective

The macroeconomic perspective looks at the overall effect in terms of gross domestic product (GDP) or the GDP growth rate.

Health, as measured by life expectancy or adult mortality, is a robust predictor of economic growth. As shown in Chapter 2, chronic disease makes up a major part of the global health burden. Mortality, DALYs and reduced life expectancy from chronic disease can be expected to depress economic growth. However, research on this has been limited, partly because of data and methodological challenges (Suhrcke et al. 2007).

There is evidence that health is a significant determinant of economic growth for high-income countries. A study by Barro et al. (1996) estimated that a five-year advantage in life expectancy explains a 0.3–0.5% higher annual GDP growth rate in subsequent years. Although this study does not focus on chronic disease, these results suggest a significant relationship between health and growth.

More recently, Suhrcke and Urban (2006) found that cost-of-illness studies showed that the cost of chronic diseases and their risk factors on a country's GDP was sizeable, ranging from 0.02% to 6.77%. They looked at the worldwide impact of cardiovascular mortality on economic growth among the working-age population. In high-income countries, they found that a 1% increase in the mortality rate decreased the growth rate of per-capita income in the following five years by about 0.1%. This may appear small in terms of growth, but it becomes quite substantial when calculated over the long term (Suhrcke et al. 2008).

PART II: CHRONIC DISEASE MANAGEMENT STRATEGIES

Part II looks at the strategies available to combat and prevent chronic diseases. Chapter 4 describes them. Chapter 5 presents the evidence on the effectiveness of each of the four strategies, and Chapter 6 summarises the evidence on cost-effectiveness.

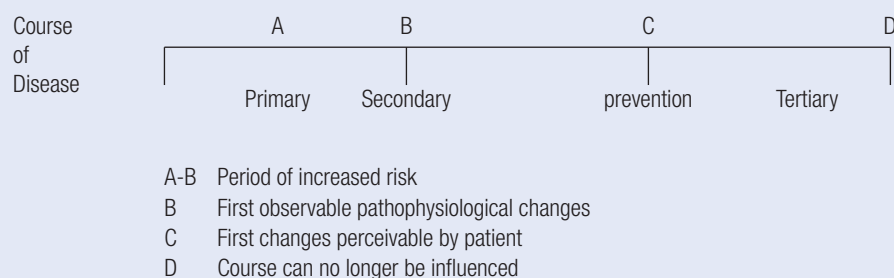
4 STRATEGIES AGAINST CHRONIC DISEASE: WHAT IS BEING DONE?

In this chapter we describe strategies for managing chronic disease, looking at countries that have innovated. These include a range of European countries, as well as Canada, Australia, New Zealand and the USA. They provide important and useful lessons.

4.1 Prevention and early detection

Most countries are experimenting with disease prevention and early detection. Prevention includes primary, secondary, or tertiary approaches that differ in aims and target groups (figure 7).

Figure 7: Prevention and stages of disease



Primary prevention is directed at the prevention of illnesses by removing the causes. The target group for primary prevention is healthy with respect to the target disease.

Secondary prevention aims at identifying the disease at an early stage so that it can be treated. This makes possible an early cure (or at least the prevention of further deterioration). The target group for secondary prevention consists of people who are already ill without being aware of it, or who have an increased risk, or who have a genetic disposition.

Tertiary prevention is directed toward people who are already known to suffer from an illness. This is therefore a form of care. Tertiary prevention includes activities intended to cure, to ameliorate or to compensate. For example, the avoidance of complications or the prevention of progress of disease would be classed as tertiary prevention.

Source: van der Maas and Mackenbach (1999)

The approaches vary according to the health care system and the dominant political opinions. Different countries may place different emphasis on the responsibility of the community and the individual, depending on cultural views about the role of the state and individual autonomy (Busse and Schlette 2007).

Scandinavian policies, for example, attach considerable importance to environmental factors and social conditions. Other countries, such as France, Germany and the United States, focus more on the individual's attitude to risk factors such as tobacco, alcohol and nutrition (Busse et al. 2006).

Other countries, such as the UK, Canada and New Zealand, emphasise integrated approaches, with clinical care systems part of a broader approach that involves public health and health promotion efforts linked to disease management and support for self-care (Novotny 2008). The following section gives an overview of the different prevention strategies.

Tobacco and alcohol interventions

More and more European countries have been tackling tobacco consumption and its negative health consequences (Busse and Schlette 2007). Common elements are:

- *pricing policies*: taxes, minimum duties, minimum prices,
- *information and communication*: limits on advertising and promotion, product displays and marketing, requirements for compulsory labelling,
- *packaging*: minimum size of packs of cigarettes,
- *distribution*: restriction on sales to minors, introduction of cigarette vending machines with youth protection technology,
- *consumption*: smoking bans in public places, bars and restaurants and at the workplace, and
- *smoking cessation*: behavioural assistance.

Similar policies have been developed for alcohol abuse. Raising prices with higher taxes does reduce consumption. Bans on advertising are thought to reduce social acceptance of excess drinking. Sales of alcohol may be restricted to licensed retail outlets or during limited hours, and minimum age restrictions applied. Strict driving laws discourage excessive drinking and prevent traffic accidents (Novotny 2008).

Obesity interventions

There are various approaches to preventing obesity. These include public information and disclosure, targeting children and adolescents, taxing unhealthy food, planning the urban environment, and food prohibitions (Novotny 2008).

The dominant approach in obesity control is primary prevention. The European Commission has developed an action plan for European dietary guidelines based on existing evidence on health promotion programmes. The plan describes population goals for nutrients and lifestyle for the prevention of chronic diseases in Europe (European Commission 2000). Table 5 sets out the components, goals and level of evidence criteria.

Although there are effective interventions to reduce obesity, in many countries the response to the challenge is inadequate. For example, few European nations have average diets containing less than 30% of dietary energy from fat (Novotny 2008).

Hypertension interventions

It is widely agreed that effective approaches to hypertension should be combined with other strategies aimed at reducing risk factors for ischaemic heart disease (Novotny 2008). Such programmes in Europe and elsewhere include weight loss, healthy diet (high in potassium and low in sodium, low fat, adequate fruit and vegetable consumption), physical activity, and moderate alcohol consumption (Chobanian et al. 2003).

Table 5: Population goals for nutrients and features of lifestyle consistent with the prevention of major public health problems in Europe

Component	Population goals	Levels of evidence
Physical activity levels (PAL)	PAL > 1.75	++
Body mass index	BMI 22-22	++
Dietary fat as % of energy	<30	++
Fatty acids % total energy		
Saturated	<10	++++
Trans	<2	++
Polyunsaturated (PUFA)		
n-6	4-8	+++
n-3	2g linoleic + 200mg very long chain	++
Carbohydrates total % energy	>55	+++
Sugary food consumption occasions per day	≤4	++
Fruit and vegetables (g/d)	>400	++
Folate from food (µg/d)	>400	+++
Dietary fibre	>25 (or 3g/MJ)	++
Sodium (expressed as sodium chloride) (g/d)	<6	+++
Iodine (µg/d)	150 (infants -50) (pregnancy – 200)	+++
Exclusive breast feeding	About 6 months	+++

Levels of evidence: (++++) Multiple double blind placebo controlled trials; (+++) single study of double blind analyses (breast feeding – series of non-double blind analyses); (++) ecological analyses compatible with non-double blind intervention and physiological studies; (+) integration of multiple levels of evidence by expert groups.

Source: European Commission (2000)

Examples of specific intervention programmes

The international trend is towards holistic approaches to prevention. For example, the national diabetes prevention programme in New Zealand (Busse et al. 2006) combines primary, secondary and tertiary approaches and thus reaches the whole target population. The programme has 10 fields of action, with specific goals and measures for each (CHSRP 2006). The fields are:

- supporting community leadership and action;
- promoting behaviour change through social marketing;
- changing urban design to support healthy and active lifestyles;
- supporting a healthy environment through cooperation with the food industry;
- strengthening health promotion;
- improving well-child services;
- working with schools to ensure children are 'fit, healthy and ready to learn';
- supporting primary care prevention and early intervention;
- enabling vulnerable families to make healthy choices; and
- improving service integration and care for advanced disease.

Representatives of various sectors - such as local government, the food industry, cultural groups, schools, sports clubs, and public and private health institutions - are working together,

Similarly, New Zealand's strategy against cancer highlights the fact that every public health strategy should try to integrate all aspects of the population's health, to implement programmes across different sectors, and to bring together all those involved. The cancer control strategy has six goals (CHSRP 2005):

- preventing lifestyle-related, infectious and work-related health risks;
- ensuring effective screening programmes;
- ensuring effective diagnosis and treatment;
- improving quality of life for cancer patients and their families through social support, rehabilitation and palliative care;
- improving the delivery of services for all types of cancer care; and
- improving the effectiveness of cancer control through research and surveillance.

For all sectors, the action plan for 2005–2010 determined secondary goals, defined target outcomes, specified steps for actions and established 'milestones'.

The British government formulated a national cancer plan in 2000, specifying targets and standards for prevention, medical care and palliative medicine. Since 2006, this has included a national screening programme for bowel cancer, which pilot studies suggest has been successful (Oliver 2005).

European measures to prevent specific chronic diseases also include *vaccination*. For example, the approval of the human papilloma virus (HPV) vaccine to prevent cervical cancer in Europe is now part of immunisation programmes in Austria, Germany, France and Italy (limited by age and sex), Belgium, Luxembourg, Norway, Sweden, Switzerland, and the UK (Arun 2007).

4.2 New provider qualifications and settings

Chronic diseases increase the complexity of health problems and the provision of care, requiring changes in professional activities, qualifications and care settings. This section will look at new approaches in provider qualifications and settings.

New provider qualifications

Physicians play a key role in guiding patients through the health system and therefore need to be trained to coordinate activities. In the Spanish region of Castile and Leon, medical and social services for chronic care have been integrated. Ensuring that physicians were appropriately qualified was found to be a major precondition (Casado 2003). Australia, the UK and the Scandinavian countries have used 'collaborative methodology' by training physicians to have a guiding role (Haas 2005). This methodology was developed in the 1990s by the US Institute for Healthcare Improvement and has a learning system aimed at improving care in specific areas, such as asthma, diabetes, heart disease and cancer (Busse et al. 2006).

Providers have also been experimenting with new types of care. Many countries are becoming convinced that the traditional demarcation lines between health professions - for example, between physicians and nurses - are harmful, and they are beginning to redistribute responsibilities. A new profession of *nurse practitioner* has been established in the UK, the Netherlands, the US, Canada, Australia, and New Zealand (Busse and Schlette 2007; CHSRP 2006; van Dijk 2003; McIntosh 2006). These university-trained professionals carry out traditional nursing duties, but also assume responsibility for tasks that would traditionally be viewed as part of a doctor's responsibility, such as limited prescribing of pharmaceuticals and giving less complex treatments.

Germany has recently created *community nurses*, similar to nurse practitioners in other countries. They make house visits and are responsible for basic primary care, supported by e-health equipment. This gives chronically ill people in rural regions better access to basic medical care. It also releases family doctors for other work (Busse and Schlette 2007; Blum 2006).

Another new professional group are *liaison nurses* who have been introduced in several European countries. They do follow-ups after discharge, pulmonary rehabilitation for people with COPD, supervision of medication and compliance, patient education, and service navigation. *Case managers* coordinate services for people with long-term conditions or with complex social and medical needs. Their functions include assessing people's needs, developing care plans, helping people access appropriate care, monitoring the quality of this care, and maintaining contact with the person and his or her family (Dubois et al. 2008). In England, for example, case management is part of the strategy in all primary care trusts. These trusts provide primary medical care and community nursing services, and are taking over responsibility for purchasing secondary care. Other groups, such as pharmacists and social workers, have also been able to perform new roles. For instance, a contract introduced in England in 2004 enabled pharmacists to expand their role by providing repeat prescriptions, reviewing medication and compliance, and providing smoking cessation services (Dubois et al. 2008).

New settings

Single handed practices are no longer seen as the role model for medicine. The trend internationally is towards group practices that are more patient-oriented and more cost effective (Busse and Schlette 2003). In Canada, for example, a major part of health reform involves developing models in which doctors work in a team with nurses, social workers, psychologists, dieticians, midwives and physiotherapists. The aim is to create a primary health care system more closely oriented to the needs of the patients: multidisciplinary, well-coordinated, and accessible 24 hours a day (Torgerson 2005). In Germany, polyclinics with general practitioners, specialists and other health professionals were re-introduced in 2004 (Busse et al. 2006).

In many countries where strong primary care teams already exist, such as the UK, the Netherlands and Scandinavia, the management of many chronic diseases has been moving progressively to nurse-led clinics (Nolte and McKee 2008; Buchan and Calman 2005). These clinics have become more common in managing diabetes and hypertension, allergy/asthma/COPD, psychiatry, and heart failure (Karlberg 2008). The main reasons for this growth are economic, and the chance to create new career opportunities for nurses. Other developments improve access through telephone consultations and offer support for elderly persons with communication difficulties.

4.3 Coordinating care for individual chronic diseases: disease management programmes

This section will look at care models for individual chronic diseases, and the section after will analyse integrated care approaches. Disease management programmes are normally limited to health care workers while concepts of integrated care often include social workers. However, the concepts of *integrated care* and *disease management* are in some respects similar.

There are several definitions of disease management programmes, but most share three main features: a knowledge base, a delivery system with coordinated care, and a continuous improvement process for a specific disease in a specific population (Hunter and Fairfield 1997). Key elements are shown in figure 8.

Figure 8: Disease management: key elements

- comprehensive care: multidisciplinary care for entire disease cycle
- integrated care, care continuum, coordination of the different components
- population orientation (defined by a specific condition)
- active client-patient management tools (health education, empowerment, self-care)
- evidence-based guidelines, protocols, care pathways
- information technology, system solutions
- continuous quality improvement

Source: Velasco et al. (2003)

To summarise, disease management is a means of coordinating care that focuses on the entire clinical course of a disease. Care is organised and delivered according to scientific evidence and patients are actively involved.

Structured disease management programmes for selected conditions were originally developed in the United States, then in a range of European countries. The approach seems promising, particularly when health care is funded through social insurance. Because these systems tend to allow patients to choose family practitioners and some specialists, doctors are more likely to work as single-handed practitioners. This leads to a separation between the ambulatory and hospital sector, and disease management programmes could overcome this (Nolte and McKee 2008).

Germany in 2002 for example introduced programmes that now cover diabetes type 1 and 2, asthma/COPD, coronary heart disease and breast cancer. In December 2006 there were 10,580 programmes with nearly 2.7 million 2,693,000 patients (BVA 2008). By April 2008, this number had risen to 4.7 million (van Lente et al. 2008). Table 6 gives a breakdown of those disease management programmes.

Table 6: DMP participants in Germany according to indication (2008)

DMP	Number of patients enrolled in DMP
Diabetes mellitus type 2	2,708,154
Diabetes mellitus type 1	93,357
Coronary heart disease	1,221,374
Asthma	313,914
COPD	264,299
Breast cancer	100,499
Total	4,701,597


Source: van Lente et al. (2008)

Until the end of 2008 risk structure compensation schemes took disease management programmes into account by calculating expenditure for these patients separately. This created strong incentives for sickness funds to enrol patients. They also provided sizeable financial incentives for the doctors taking part (Busse 2004). From 2009, participation in disease management programmes alone will not be taken into account as a separate risk-adjustment factor. Instead, the allocation will give supplements for persons suffering from one of 80 (mainly chronic) diseases. For every insured person classified as suffering from one (or several) of these conditions, the sickness funds will get an extra allocation. Classification will be partly based on medication, and there could be a problem in that insurers may try to benefit from extra funding by motivating providers to prescribe certain medications, irrespective of disease severity.

Sweden now has *chains of care* (Andersson and Karlberg 2000), defined as 'coordinated activities within health care' often involving 'several responsible authorities and medical providers' (hgren 2003). County councils are responsible for organising health care and by 2002 most of them had at least one chain of care, mostly designed around patients with diabetes, dementia and rheumatoid disorders (Nolte and McKee 2008).

4.4 Managing care across chronic diseases: integrated care models

Disease management programmes focusing on a single disease have increasingly come under pressure. Doctors and researchers admit they have focused on a straightforward disease-management approach because it was relatively simple. But chronic conditions do not present alone, and so various countries are experimenting with new models of health care delivery - comprehensive *integrated care models* or *provider networks* that can achieve more integrated and more comprehensive services.



Integrated care models developed in the US have been influential in Europe (Nolte and McKee 2008). The redesign of health care services has been guided by approaches taken by US health maintenance organisation Kaiser Permanente (Goodwin et al. 2004), the Evercare model developed by United Health Group (United Health Europe 2005) and the Chronic Care Model (CCM) developed by Edward Wagner (Wagner et al. 1999).

These have been used as the basis for UK National Health Service programmes since 2003 (Nolte and McKee 2008). The Evercare model of managing frail elderly people was piloted in nine primary care trusts (PCTs) in April 2003, and case management then became part of the government's policy for supporting people with chronic conditions. The 2004 NHS Improvement Plan stipulated the introduction of case management in all primary care trusts (PCTs) through appointing senior nurses (known as *community matrons*) by 2007 (Department of Health, 2004).

In 2005, the UK launched a model designed to help health and social care organisations improve care for people with chronic conditions (Singh and Fahey 2008). It built on US approaches such as the Chronic Care Model, the Kaiser Triangle and the Evercare model (Department of Health 2004). It outlined how people with chronic conditions will be identified and receive care according to their needs. The goals of the NHS and social care model are to improve the quality and accessibility of care for people with chronic conditions, and to contain or reduce the associated costs (Singh and Fahey 2008).

Various autonomous communes in Spain have been operating pilot projects on the long-term integration of care for many years. These aim to achieve complete health care by providing complete care from one source only and by having regional strategies. For example, the Spanish region of Valencia has been testing local, population-based integration models in three areas since 1997 (Campoy 2005).

In Germany, various models have been introduced to promote more integrated care, such as disease management programmes (see section 4.3), care models based on the family physician as gatekeeper, integrated care contracts, and medical polyclinics. The integrated care contracts include at least two entities from different health-care sectors or interdisciplinary collaborations. Between 2004 and 2008, 1% of the total payments for physicians and hospitals has been earmarked for investment into integrated care projects. This involves reallocating about 680 million euros a year. There is a remarkable variety of contracts. For example, most of them are related to a specific indication such as stroke, or a specific medical procedure such as hip replacement. Population-based approaches are rarely taken (Busse et al. 2006). Recently analysts recommended the Chronic Care Model as a means of advancing the country-wide approach started in 2002 (Genichen et al. 2006).

Various provider networks have been developed in Europe and elsewhere. In France the 1996 Juppé reforms introduced mechanisms aimed at stimulating local provider networks for ambulatory patients and at the interface between ambulatory and hospital care (Bras et al. 2006; Sandier et al. 2004). Initiatives were formalised in 2002 under the heading of *health networks* (réseaux de santé) (Frossard et al. 2002). These arrangements now include mobile dialysis units, specialised mental health facilities, new cancer centres (combining research, treatment, and prevention) and new centres for managing HIV/AIDS (McKee and Healy 2002).

The Netherlands has also been trying to improve the continuity and quality of care for people with long-term conditions and to close the gap between primary and hospital services. This led to the concept of *transmural care* in the early 1990s (van der Linden et al. 2001), which has since been developed extensively, with an estimated total of over 500 initiatives by 1999 (van der Linden et al. 2001). Most forms of transmural care tend to focus on those who are not able to return to a fully independent life by managing the interface between acute hospital care and alternative settings (Nolte and McKee 2008).

The Canadian province of Ontario has chosen to promote networks of family doctors (family health groups and family health networks) and local health integration networks. The mission of their local care networks is to improve the planning, coordination and integration of health care. Being local organisations, they are expected to be more responsive to local needs (Torgerson 2005).

Evaluating a health programme requires looking at health improvement as measured, for example, by patients' quantity and/or quality of life. This chapter examines the available evidence on various strategies.

5.1 Prevention and early detection

Studies have looked at a range of interventions. Measures to reduce tobacco consumption have been analysed in considerable depth (see section 4.1). Effective interventions include higher prices for cigarettes, public smoking bans, public information, bans on advertising and promotion, smoking cessation programmes, and smuggling controls. Combining various measures is more effective than single measures. Anti-tobacco regulations therefore should be as comprehensive as possible and combine a number of different instruments (Busse and Schlette 2007).

Table 7: Effects of anti-smoking measures on smoker prevalence

Measure	Effect on smoker prevalence
Price increase by 10 percent	Decline by 4 percentage points in countries with high per capita income
Ban on smoking at work	Decline by 5-10 percentage points
Bans on smoking in pubs, restaurants and other public places	Decline by 2-4 percentage points
Advertising ban	Decline by 6 percentage points if ban is absolute
Health warning on cigarette packs	In the Netherlands, 28 percent of all 13- to 18-year-olds said they smoked less as a result of the health warnings; In Belgium, 8 percent of those asked said they smoked less because of warnings.
Media campaigns	Percentage of smokers declines by 5-10 percentage points, depending on how the campaigns are targeted at specific groups
Withdrawal measures; subsidies for treatment	Decline by 1-2 percentage points after 2 years, depending on the people registered

Source: European Network for Smoking Prevention (2004)

Opposition to measures such as smoking bans has come from vested interests and public opinion. More and more countries - such as Ireland, Italy, Malta, New Zealand, Norway, Singapore and Sweden - have introduced a complete ban on smoking in public and at work. Similar regulations have been introduced in other countries, including Australia, Czech Republic, England, Finland, Germany, Hungary, Portugal, Scotland and Spain. However, public support varies considerably. The first countries introduced rigid bans some years ago – and after initial scepticism, people have increasingly come to accept them (Busse and Schlette 2007).

The disease burden from alcohol abuse has been reduced by various policy approaches as well as by integrating advice, screening, and referral within clinical settings (Novotny 2008). For example, non-directive interviewing and counselling was effective in identifying and addressing problem drinking before the onset of chronic problems (Burge and Schneider 1999).

Diet can be affected substantially by changing production processes to reduce unhealthy components of food, such as trans-fat or salt. These changes can be implemented quickly if the private sector and/or governments are supportive. For example, government induced changes in manufacturing processes in Mauritius and Poland appear to have reduced risk factors for chronic diseases (Zatonski et al. 1998).

There is clear evidence that anti-hypertensive and anti-cholesterol medications, as well as aspirin, reduce the risk of ischaemic heart disease and stroke (Rodgers et al. 2006). A combination of education, careful monitoring according to clinical guidelines, and fixed dose therapies improves patient adherence, which is notoriously hard to do (Novotny 2008).

Overall prevention still plays a secondary role in most health systems and few countries have set up programmes to prevent chronic diseases.

5.2 New provider qualifications and settings

Primary care nurses with enhanced roles can provide high quality care in many areas traditionally looked after by family doctors (Dubois et al. 2008). But most studies have included only small numbers of clinicians and have not examined long-term outcomes (Brown and Grimes 1995; Horrocks et al. 2002). It has long been established that the availability of specialist nurses for long-term conditions may improve health outcomes and reduce use of health resources (Boaden et al. 2006; Griffiths et al. 2004; Singh 2005a; Smith et al. 2004). Some researchers have questioned this, suggesting that nurse practitioners and case management of frail elderly people may reduce hospital admissions, but at the same time they introduce more services into primary care (Gravelle et al. 2007; Sargent et al. 2007).

Clinics run by specialist nurses have been associated with better clinical outcomes (Connor et al. 2002; Singh 2005b; Vrijhoef et al. 2000; Vrijhoef et al. 2001; Vrijhoef et al. 2003). Patient satisfaction with nurse-led care is generally high (Horrocks et al. 2002; Kinnersley et al. 2000; Shum et al. 2000). Research in Sweden, for example, showed that nurse-led heart failure clinics - giving education, better treatment and social support - improved survival and self-care behaviour, and reduced the need for hospital care (Cline 2002; Stromberg et al. 2003). However, the precise effect was hard to identify because their implementation was part of an overall reorganisation of care (Dubois et al. 2008).

5.3 Coordinating care for individual chronic diseases: disease management programmes

Evidence on the effectiveness of disease management programmes comes from several systematic reviews and meta-reviews.

In 2002 a meta-review of 118 disease management programmes (DMPs) looked at the effectiveness of different strategies in chronic disease management (Weingarten et al. 2002). Those using provider education, feedback, and/or reminders produced better adherence by providers to care guidelines. However, the meta-review did not show which approaches produced the greatest relative improvement as the studies did not directly compare different approaches. The authors concluded that it was not possible to draw up policy recommendations on developing disease management programmes.

Another study concluded that appropriately evaluated disease management programmes improved the quality of care as measured by the provider's increased adherence to evidence-based standards and by disease control (Velasco et al. 2003). However, evidence for effectiveness of the programmes was found only for diabetes, depression, coronary heart disease and heart failure (McAlister et al. 2001a + b; Weingarten et al. 2002; Norris et al. 2002). For other chronic conditions the results were inconclusive. Effectiveness referred only to process and structure, and no study found any statistically significant impact on (long-) term health outcomes.

The findings on patients' quality of life and on patients' and providers' satisfaction were also inconclusive.

A related study (Ofman et al. 2004) found that improvements in quality of care, as measured by patient satisfaction, were greatest with treatment, patient adherence to treatment recommendations, and measures of disease control. Nolte and McKee suggest that disease management may be an effective way of changing the behaviour of patients and providers (Nolte and McKee 2008).

A recent meta-review (Mattke and colleagues 2007) concluded that disease management programmes improve processes of care and disease control. However, the authors found no evidence of any effect on health outcomes. Disease management did not seem to affect use except for reducing hospitalisation rates among patients with congestive heart failure, and increasing outpatient care and prescription drug use among patients with depression (Mattke et al. 2007).

These are preliminary findings, because most of the empirical work looked at small-scale programmes run for high risk individuals as a demonstration project on a single site. These pilot projects mostly combined individual patient education, care planning, and follow-up delivered by a nurse or case manager. Such levels of support would be difficult in large scale disease management programmes.

Most evidence exists for congestive heart failure (CHF) and diabetes mellitus, with CHF standing out. Sufficient research was also identified for coronary artery diseases (CAD), asthma, COPD, and depression, but not for other chronic conditions such as cancer, dementia, Alzheimer's disease, and musculoskeletal disorders (Table 8).

Table 8: Summary of evidence for various disease management programme outcomes by disease

Disease	Clinical processes Adherence to evidence-based guidelines	Health-related Changes in behaviors	Disease control Changes in intermediate measures	Clinical outcomes	Healthcare utilisation Changes in utilization of services	Financial outcomes	Patient experience Satisfaction, quality of life, etc.
CHF	Improved	Inconclusive evidence	Improved	Inconclusive evidence	Reduced hospital admission rates	Inconclusive evidence	Improved
CAD	Improved	Evidence for no effect	Improved	Evidence for no effect	Inconclusive evidence	Inconclusive evidence	Insufficient evidence
Diabetes	Improved	Evidence for no effect	Improved	Insufficient evidence	Inconclusive evidence	Inconclusive evidence	Insufficient evidence
Asthma	Inconclusive evidence	Inconclusive evidence	Inconclusive evidence	Evidence for no effect	Inconclusive evidence	Evidence for no effect	Insufficient evidence
COPD	Insufficient evidence	Insufficient evidence	Inconclusive evidence	Insufficient evidence	Insufficient evidence	Insufficient evidence	Insufficient evidence
Depression	Improved	N/A	Improved	Inconclusive evidence	Increased utilization	Increased costs	Improved

Source: Mattke et al. (2007)

Generally, the evidence suggests that disease management programmes can improve the care process. Improvements in clinical care affect intermediate outcomes and disease control for CHF, CAD, diabetes mellitus and depression. The impact of these programmes on long-term outcomes is not yet established, so it is impossible to draw any general conclusions.

The evidence on the impact of disease management programmes on utilisation of health services is generally inconclusive. A few studies compare patients taking part in programmes with those following 'normal' care paths. They were found to reduce hospitalisation rates for those with CHF, but increase use of outpatient care and prescription drugs.

Overall, the evidence on disease management programmes is far from satisfactory, given its prominent role. Few studies have looked at the effects of large population-based interventions (Table 9).

What studies there are conclude that population-based interventions improve patient care. The results have to be interpreted carefully, however, because none of the studies was randomised, and only one used a rigorous comparison. The evidence on cost is also inconclusive. Sidorov (2002) and Villagra (2004) found net cost savings for DMPs, but Fireman (2004) examined four chronic conditions and did not find net cost savings.

One large-scale study using a three-armed prospective cluster-randomised design was the German ELSID-Diabetes study, set up in 2005 to assess the effectiveness of a diabetes disease management programme in primary care in two German federal states (Joos et al. 2005). Early results show that the death rate among patients in the programme dropped significantly over two and a half years (10.9%) compared with those receiving 'standard' care (18.8%). Age-adjusted evaluations among severely ill women showed a significant variation: 9.5% of those on the programme compared with 12.3% of others (Szecsenyi et al. 2008). The data for men are not yet available. The study also found that patients taking part in a programme perceived their care as more structured and coordinated than did those receiving standard care (Szecsenyi 2008).

To summarise, there is a lack of systematic evaluations of population-based chronic disease management programmes in Europe. This is partly because disease management programmes have been introduced relatively recently (Nolte and McKee, 2008). Their impact depends heavily on their context, so research from high-income countries outside Europe are of limited value.



Table 9: Findings from studies of large-scale, population-based disease management programmes

Author	Setting	Managed condition(s)	Comparison strategy	Results
Sidorov (2002)	Programme developed and operated by integrated delivery system	Diabetes	Programme participants versus non-participants, controlled for age, sex, insurance type, duration of plan enrollment, presence of pharmacy benefit	Improved quality of care and disease control, lower costs and utilisation, net costs saving
Fireman (2004)	Programme developed and operated by integrated delivery system	CAD, CHF, diabetes, asthma	Patients with the condition against non-diseased group matched by age and sex	Improved quality of care and disease control, costs increased less in intervention group than in reference group, no net cost saving
Villagra (2004)	Programme developed and operated by disease management vendor for health plan client	Diabetes	Natural experiment created by phased roll-out, plus prepost comparison, adjustment for risk, and demographic differences	Improved quality of care, lower cost and utilisation in both comparisons, net cost savings

CAD indicates coronary artery disease; CHF, congestive heart failure

Source: Mattke et al. 2007

5.4 Managing care across chronic diseases: integrated care models

The evidence on different models of integrated care is inconclusive (Nolte and McKee, 2008). Studies have found that one or more components of the chronic care model (CCM) benefits some processes and outcomes, but the evidence does not show whether the whole model is needed to achieve the same benefits (Singh and Ham 2006).

One analysis looked at the effectiveness of the six components of the chronic care model, focusing particularly on primary care (Zwar et al. 2006). From a systematic review and review of reviews they identified a series of effective key elements and approaches.

Components influencing adherence to guidelines were found to be self-management support and delivery system design, particularly when combined with decision support and clinical information systems.

However, Zwar's conclusions must be treated with caution. The findings are based on the management of adults with type 2 diabetes and may not be transferable to other chronic conditions or other age-groups. It is also unclear whether broader components of the chronic care model - such as health care organisation and/or community resources - have caused the changes. It is difficult to look at the effect of this model in experimental studies, which may explain why such studies are rare (Zwar et al. 2006).

Piatt et al. (2006) found preliminary evidence on the chronic care model as a whole. In an experimental study, they examined the effect on clinical and behavioural outcomes of patients with diabetes. They targeted small practices in an under-served area of Pittsburgh, USA. Substantial improvements were found after 12 months for two clinical outcomes and for self-monitoring of blood-glucose in the chronic care model group compared with control groups (provider intervention; usual care). Otherwise no statistically significant outcomes were found.

Another US study examined the impact of the CCM approach on the quality of care for patients with diabetes, coronary heart disease and depression (Solberg et al. 2006). After two years, the organisation had adopted most elements of the chronic care model, and the quality of care for patients with diabetes and coronary heart disease had improved. Nevertheless, no significant correlation could be established between these changes.

Table 10: Summary of evidence on effectiveness of CCM components

CCM component	Interventions shown to be effective	Outcome measures affected
Patient self-management support	<ul style="list-style-type: none"> • Patient educational sessions • Patient motivational counselling • Distribution of educational materials 	<ul style="list-style-type: none"> • Physiological measures of disease • Patient <ul style="list-style-type: none"> - quality of life - health status - functional status - satisfaction with service - risk behaviour - knowledge - service use - adherence to treatment
Delivery system design	<ul style="list-style-type: none"> • Multidisciplinary teams 	<ul style="list-style-type: none"> • Physiological measures of disease • Professionals adherence to guidelines • Patient service use
Decision support	<ul style="list-style-type: none"> • Implementation of evidence-based guidelines • Educational meetings with professionals • Distribution of educational materials among professionals 	<ul style="list-style-type: none"> • Professionals adherence to guidelines • Physiological measures of disease
Clinical information systems	<ul style="list-style-type: none"> • Audit and feedback 	<ul style="list-style-type: none"> • Professionals adherence to guidelines
Delivery system	Little published experimental evidence	
Community resources	Little published experimental evidence	

Source: Zwar et al. (2006); Nolte and McKee (2008)

Self-management support and delivery systems - identified in other studies as the most important CCM elements (Singh 2005a; Zwar et al. 2006) - did not bring significant improvements. Evidence of the effectiveness of CCM is not overwhelming, but this may be because the model is not being implemented properly. One qualitative study examined potential barriers during the implementation process (Hroszkoski et al. 2006). They found too many competing priorities plus lack of specificity of changes, agreement about the care process, and engagement by health professionals (especially doctors). The authors concluded that the chronic care model is useful as a conceptual framework, but should be supplemented by guidelines on implementation.

There is also limited evidence on the impact of provider networks. Studies in France suggested rather positive effects, with fewer drug prescriptions, fewer hospitalisations and lower mortality rates (Singh 2008).

A study in Canada recently examined provider networks - an ambulatory care centre with a group practice and multidisciplinary teams using electronic medical records. The study looked at nine process outcomes and three clinical outcomes: blood pressure, HbA1c levels, and lipids. The results suggest positive outcomes, especially for blood pressure targets and HbA1c outcomes (Suhrccke et al. 2008).

Although different instruments and approaches have been developed to combat chronic diseases, resources are limited. Policy makers have to prioritise between different strategies. Cost-effectiveness analysis determines how much health improvement is gained for each monetary unit spent and is a systematic and sophisticated tool for deciding on priorities. But cost effectiveness analysis demands considerable data, so many management strategies lack sophisticated evaluations, particularly in Europe. There are also many methodological problems, and it can be difficult to establish whether a specific programme or component is effective from a health perspective. Furthermore, it is not always easy to measure the costs of conducting a specific programme. The following chapter sums up the available evidence on cost-effectiveness.

6.1 Prevention and early detection

Studies on cost-effectiveness have found that individual and group approaches to chronic disease prevention may be highly cost-effective. However, the success of interventions is largely determined by regional differences in cost-structures and in the burden of chronic diseases.

For tobacco control, the World Bank (Jha and Chaloupka 2000) and the Disease Control Priorities Project (2007) have found evidence for cost-effectiveness; this is not surprising considering the health benefits. The main intervention targeted at individuals is over-the-counter nicotine-replacement therapy. These strategies have been applied successfully and are cost-effective (Jha et al. 2006).

The evidence for interventions to prevent or reduce obesity (and consequently diabetes) is inconclusive. Cawley (2007) identified costs for primary, secondary, and tertiary preventions ranging from US\$4,305 for school-based interventions to US\$35,600 for bariatric surgery, using quality-adjusted life years saved as an endpoint (Table 11).

Table 11: Cost per Quality-Adjusted Life Year (QALY) saved by interventions to reduce or prevent obesity

Intervention	Target population	Estimated cost per QALY, US\$	Source
Planet health (a school-based intervention to improve nutrition and increase physical activity)	Middle-school children	In girls, 4,305	(Wang et al., 2003)
Orlistat	Overweight and obese patients with type 2 diabetes mellitus	8,327	(Maetzel et al., 2003)
Bariatric surgery	Middle-aged men and women who are morbidly obese	Women: 5,400-16,100 Men: 10,000-35,600	(Craig & Tseng, 2002)
Diet, exercise, and behaviour modification	Adult women	12,640	(Roux et al., 2006)

Source: Cawley (2007)

Another study found that 'self-management diabetes education', physical activity and diet were cost-effective for preventing diabetes (Narayan et al 2006). Given the dependence of such strategies upon context, cost-effectiveness is likely to vary according to regional settings. Parallel interventions at social, health system, and individual levels would seem to be needed to prevent the rise of obesity and diabetes throughout Europe.

Screening for greater risk of cardiovascular disease is cost-effective, according to the evidence. However, the number of proven screening procedures for chronic diseases is limited (Novotny 2008).

Results differ for primary prevention of cardiovascular disease. Controlling blood pressure with drugs or serum cholesterol is highly cost-effective for those with risk factors, and sometimes cost-effective for the general population. But there are marked differences.

For adults over 45 years with high blood pressure (over 105 mmHg diastolic pressure), drug treatment costs a few hundred dollars per life-year gained. Drug treatment costs US\$4,600 to US\$100,000 per life year gained. Differences in underlying risks, age and cost of medication explain the enormous difference in cost-effectiveness (Rodgers et al. 2006).

Cost-effectiveness ratios for cholesterol-lowering interventions, are improving, but they vary significantly by age and risk level. Some evidence has suggested that dietary interventions for reducing cholesterol can also be cost-effective, costing about US\$2,000 per quality-adjusted life year (QALY) (Posser et al. 2000).

6.2 New provider qualifications and settings

So far there is no conclusive evidence on the cost-effectiveness of new qualifications, such as those for nurse practitioners or case managers.

Studies increasingly confirm that nurse-led clinics give better health outcomes (Nolte and McKee 2008) and often lead also to better use (Vrijhoef et al. 2001; Singh 2005b). There is some evidence, but the findings cannot be generalised (Smith et al. 2001).

6.3 Coordinating care for individual chronic diseases: disease management programmes

The original goal of disease management programmes when first introduced in the USA was to reduce costs (Pilnick et al. 2001). It was expected that using the programmes to change usage would lower hospitalisation and complication rates and be more efficient.

However, few studies included measures of utilisation, such as emergency department visits or hospitalisations. Economic evaluations of disease management programmes tend to focus only on costs, while benefits and cost benefits are rarely considered Velasco et al. (2003) and Ofman et al. (2004). Ofman et al. and Velasco et al. conclude that there is no evidence that DMPs are more cost-effective than standard care.

Mattke et al. (2007) draw similar conclusions. Their comprehensive review found that many studies have methodological flaws, such as incompletely accounting for costs or lacking a suitable control group. Even looking at the reported costs and the savings generated rarely brings any conclusive evidence that disease management brings net savings on direct medical costs.

Furthermore, the long-term and medium-term impact of disease management programmes has not yet been studied satisfactorily. As a consequence, no conclusions can be drawn about the financial returns on investment (Nolte and McKee 2008).

6.4 Managing care across chronic diseases: integrated care models

The economic impact of integrated care models in Europe has not yet been well studied. There is some evidence on the Evercare approach to case management. US-based studies have found it is cheaper to care for older people in nursing homes (Nolte and McKee 2008). The main reason is more appropriate use of resources, especially hospitals and emergency services (Kane et al. 2004; United Health Europe 2005). However, evaluations of the Evercare pilot in England did not find improvements such as lower emergency admissions and fewer bed days (Gravelle et al. 2007).

Bodenheimer et al. (2002b) did a review-of-reviews on the CCM and its impact on use of resources and costs for congestive heart failure, asthma and diabetes. They reviewed 27 studies and found that support for self-management support was the most common component, followed by delivery system redesign (such as the introduction of follow-up by home visits, multi-speciality teams, nurse-led clinics, and case management - mostly for congestive heart failure and diabetes). The findings were mixed. Some approaches showed positive results (for example fewer hospital admissions or visits to emergency departments, and/or cost reductions), but others did not. This means that we can not draw any general conclusions, especially since there was a lack of population-based interventions, context-specific variables were not controlled, and sophisticated comparison with other strategies in chronic disease management was largely absent (Nolte and McKee 2008).

PART III: DIMENSIONS OF CHRONIC DISEASE MANAGEMENT

This part of the report draws conclusions from the evidence presented in chapters 4-6 about what policy makers need to do in order to improve future chronic disease management. Our conclusions cover five areas:

- pharmaceuticals and medical devices,
- financial incentives,
- coordination and cooperation,
- information and communication, and
- evaluation culture.

7

SHAPING THE FUTURE OF MANAGING CHRONIC DISEASES IN EUROPE

Shaping the future of chronic disease management in Europe will be a challenge. The epidemiologic and economic analyses suggest that policy makers should make disease management a top priority. But choosing the right strategies will be difficult, particularly given the limited evidence on effectiveness and cost-effectiveness. Policy makers need more than academic evidence on individual interventions; they also need to know which institutional and organisational conditions favour successful chronic disease management and where the gaps in knowledge need to be closed. This chapter gives policy makers the relevant insights for effective chronic disease management and suggests areas of research that will help them to draw further conclusions.

7.1 New pharmaceuticals and medical devices

Pharmaceuticals and medical devices are essential for diagnosis and treatment. Many licensed drugs - such as anti-hypertensives, insulin, anti-depressants, anti-inflammatories and inhaled steroids - target chronic diseases. These treatments have become increasingly sophisticated, sometimes targeting elements of the disease process that were unknown 20 years ago.

Despite the important role of pharmaceuticals, the debate on chronic disease management tends to concentrate on structures and programmes. The following section will look at new pharmaceutical approaches. Reviewing drug development for individual diseases is beyond the scope of this report: rather, it will examine broad trends and highlight some advances.

Improvement in compliance

Successfully managing chronic disease requires not just effective drugs but also effective and sustained self-management such as medication compliance (Bangalore et al. 2007). Compliance, or adherence, can be defined as the extent to which patients follow medical instructions (WHO 2003). In 2003 the WHO report *Adherence to Long-Term Therapies* found that compliance by patients with long-term diseases - such as cardiovascular diseases or depression - was poor. Only about 50% of patients in developed countries adhered to their treatment: in the United States, for example, the proportion of patients adhering to their high blood pressure regimen was 51%. Similar patterns were reported for other conditions such as depression (40%) and asthma (43% for acute treatments and 28% for maintenance) (WHO 2003).

Many factors affect adherence. Most notable are those related to the complexity of the medical regimen, length of treatment, previous treatment failures, frequent changes in treatment, the immediacy of beneficial effects, and side-effects and the availability of medical support to deal with them (WHO 2003; Bloom 2006). A systematic review (van Dulmen et al. 2007) outlined various ways of improving adherence:

- *Technical interventions*: simpler medication regimens, e.g. dosage, packaging or combining drugs
- *Behavioural interventions*: memory aids and reminders, e.g. by mail, telephone, computer or home visits
- *Educational interventions*: teaching and providing knowledge through individual and group education, face-to-face contact, audio-visual techniques
- *Social support interventions*: practical and emotional support by family, friends, health professionals
- *Structural interventions*: disease management programmes (DMPs), community care
- *Complex or multi-faceted interventions*: combining and adopting different approaches and interventions.

Research into pharmaceuticals and medical devices now recognises the importance of technical interventions that could increase adherence. For example, one meta-review (Bangalore et al. 2008) concluded that fixed-dose combinations can improve compliance by reducing the pill burden (polypharmacy). Fixed-dose combinations also reduced the risk of non-compliance by 24%. Wald and Law (2003) proposed the use of a polypill that would include a statin with 3 antihypertensive medications - a thiazide, a beta-blocker and an angiotensin-converting enzyme inhibitor - in addition to folic acid and aspirin. They estimated that if everyone over 55 with preexisting coronary artery disease took this one pill, the risk of ischaemic heart disease could be reduced by 88% and the risk of stroke by 80%. Whether this 'magic bullet' is practical is open to debate. But these two studies show that compliance and health outcomes can be improved by fixed-drug combinations.

Simplifying the medication regimen also seems to increase compliance. A meta-analysis (Claxton et al. 2001) concluded that 79% ($\pm 14\%$) of patients took 'once daily' doses, 65% ($\pm 15\%$) 'three times daily' and only 51% ($\pm 20\%$) 'four times daily'.

Quality of life in pharmaceutical care

Improvement of adherence is closely linked to the concept of quality of life. In 1948, the WHO defined health as a 'state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO 1991). This broadened the concept of health beyond the biomedical model. Today pharmaceuticals are intended to improve the patient's quality of life as well as achieve better clinical outcomes; this is important with chronic conditions for which there is often no cure. Pharmaceuticals for most chronic diseases aim to prevent and control symptoms, reduce the frequency and severity of exacerbations, and improve general health. A better quality of life is their more realistic objective (Kheir et al. 2004).

The chronically ill are often restricted in their daily lives, with phases of poor functional, mental and social skills. The burden of diagnosis and treatment can be high (for instance, chemotherapy and radiotherapy in cancer treatment) and be accompanied by psychosocial implications, such as social involvement, partnership, workforce, stigma and pain (Petermann 1996). 'Supportive' drugs that improve the quality of life become more important. They are less toxic, often administered orally, and enable patients to spend fewer days in hospital (Wilking and Jönsson 2005).

Taking this into consideration, the assessment of pharmaceuticals in chronic care has to go beyond considering whether the patient has been cured, or not. It seems more appropriate to be using quality of life as a key criterion for chronic disease management. But to use this concept for decisions on approval, therapy and reimbursement requires valid and objective methods of evaluation.

Personalised medicine

Developments in drug therapy aim for a good response with easy application, fixed doses and mild side-effects. The different ways in which patients respond is determined by personal factors (such as genetics, age, gender, other disease and/or drug therapy and environmental agents) and by drug factors (such as pharmacokinetics, pharmacodynamics, adverse effects and drug interactions). Personalised medicine aims to optimise drug therapy in the face of these factors (Lewis 2005). Advances in human genome research have replaced the linear process of drug discovery and development by an integrated and heuristic approach (Ginsburg and McCarthy 2001). Table 12 gives some examples.

Table 12: Personalised medicine

Drug	Disease(s) or condition(s) treated
Abatacept	Rheumatoid arthritis
Adalimumab	Crohn's disease, psoriatic arthritis, rheumatoid arthritis
Anakinra	Rheumatoid arthritis
Efalizumab	Psoriasis
Epoprostenol sodium	Primary pulmonary hypertension
Etanercept	Ankylosing spondylitis, juvenile rheumatoid arthritis, psoriatic arthritis, rheumatoid arthritis
Glatiramer	Multiple sclerosis
Imiglucerase	Gaucher's disease
Infliximab	Ankylosing spondylitis, Crohn's disease, psoriasis, psoriatic arthritis, rheumatoid arthritis, ulcerative colitis
Interferon beta-1a	Multiple sclerosis
Interferon beta-1b	Multiple sclerosis
Laronidase	Hurley's disease
Natalizumab	Multiple sclerosis
Omalizumab	Asthma
Palivizumab	Respiratory syncytial virus
Peginterferon alfa-2b	Hepatitis C
Peginterferon alfa-2a	Hepatitis C
Treporstinil sodium	Primary pulmonary hypertension

Source: Shane (2007)

Cancer research, for example, is now using pharmacogenomics to personalise drug therapy. Advances in genetics are used to explain individual differences in drug responses (Shurin and Nabel 2008). The advances in molecular medicine mean that traditional anti-tumour agents have been replaced by new agents with milder side effects that target disease-specific mechanisms. Gene/protein expression analyses make treatment more accurate as well as improve imaging techniques. Cancer researchers are working on deciphering the human proteome which has considerable potential. The main areas where new agents have been developed and now are used in clinical practice are as follows (Wilking and Jönsson 2005):

- targeting the cell cycle apoptosis,
- replicating/transcribing and repairing DNA,
- inhibiting hormones, growth factors and cell signalling pathways,
- inhibiting new blood vessels (angiogenesis).

Cancer research illustrates that personalised medicine is an important factor in developing innovative pharmaceuticals for the chronically ill. Apart from increasing cures, it may lead to drugs that improve the patient's quality of life.

Policy recommendations

- Personalised drugs are one of the main trends in the development of pharmaceuticals. However, using specialised medication to manage chronic disease brings a new set of problems. In particular, policy makers need to consider how to organise effectively licensing and reimbursements for personalised medicine (Shane 2007). Therapeutic innovations will have to be introduced without sacrificing patient safety; and so far few adequate policy solutions have been proposed.
- Drug development and approval aiming to improve quality of life need different approaches when it comes to assessing cost-effectiveness and cost-benefit. Previous parameters, such as narrow clinical outcomes, are insufficient. Evaluating efficacy, effectiveness or cost effectiveness must be supplemented – within rigorously conducted trials - by patient-related parameters, such as satisfaction and quality of life. Policy makers must adapt their licensing and reimbursement schemes accordingly.
- The required evaluation should not block authorisation and implementation of new pharmaceuticals and medical devices, but be conducted as quickly as possible.

7.2 Financial incentives

When discussing quality of care, health professionals tend to stress the importance of professional ethos, motivation, adequate staffing levels, and education and training. Research indicates that these dimensions are limited in their capacity to change behaviour (Busse and May 2008). Instruments allowing more rapid change are needed, and one of the tools available is financial incentives.

Using financial incentives effectively often means eliminating incentives that make chronic care or disease management less effective. But, however motivated stakeholders may be to improve chronic care, few will operate against their economic interest (Leatherman et al. 2003).

Financial flows influence most of the relationships in a health system, i.e. act as incentives – with intended or unintended effects. This section will try to define the financial flows/ incentives between patients, providers, financial poolers and payers/purchasers. It will also look at the intentions and (theoretical) justifications behind these flows, and the results so far.

Financial incentives can be used to target certain processes or outcome-related goals, but this can be challenging. The treatment needs of patients are complex, and effective management involves a range of people in different sectors. The aim of this section is to give policy makers the insights they need to think critically about designing financial incentives. First, it identifies different financial mechanisms in the health system. Second, it presents different types of financial incentives and reviews the evidence on their impact. Third, it gives some policy recommendations.

Financial incentives in health systems

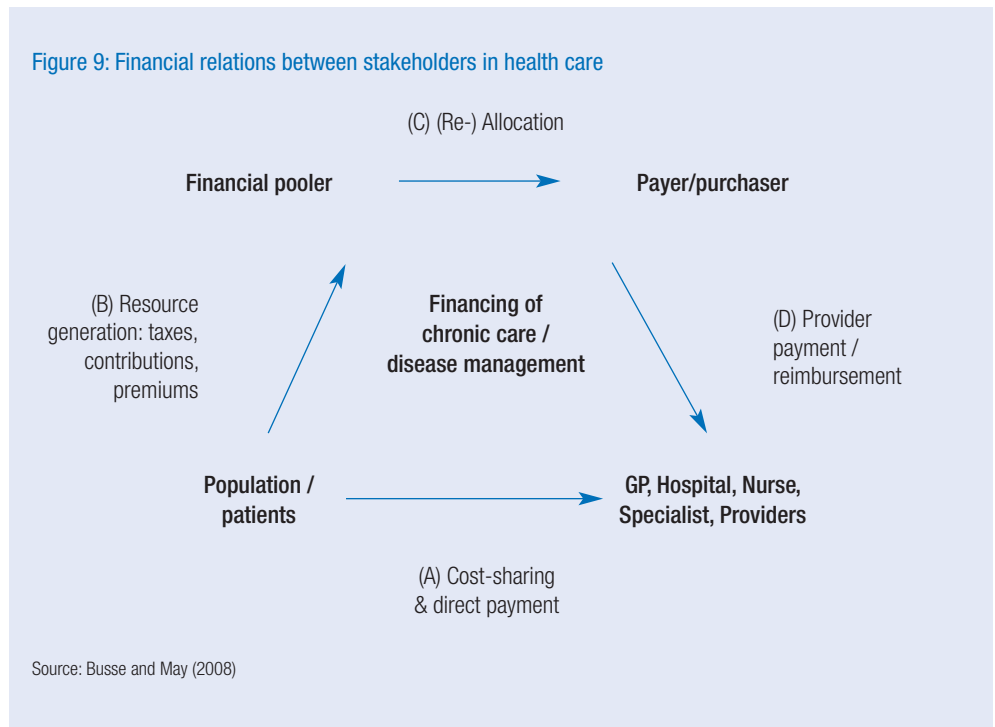
Given the complexity of most health systems, we need a model that will analyse the financial mechanisms as well as show policy makers how to design that will improve care for those with chronic diseases. Busse and May (2008) recently developed the *extended triangular model*. It distinguishes between population/payers, providers, and financial intermediaries. The latter are subdivided into *financial poolers* and *payer/purchasers* (Figure 9).

This analytical framework allows us to group financial mechanisms and incentives in the following way:

- *Relationship A*: patient → provider: cost -sharing, co-payments
- *Relationship B*: population → financial pooler: resource generation, taxes, contributions, premiums
- *Relationship C*: financial pooler → payer/purchaser: (re-)allocations to payer/purchasers
- *Relationship D*: payer/purchaser → provider: provider remuneration

Currently the main debate is how to remunerate providers (Relationship D). This is central to the discussion in this section. But the other three relationships will also be discussed.

Figure 9: Financial relations between stakeholders in health care



Provider remuneration in chronic care

There are currently three different approaches to paying health professionals from pooled resources.

(1) *Capitation* gives the health professional a fixed sum to care for patients over a period of time, irrespective of the services provided. Financial poolers and payers/providers find it easy to budget under this type of payment, but the financial incentives for the health professional can give cause for concern. The danger is that they will offer as little a service as possible to each patient because they are bearing the cost. Services may become under-used. Capitation may have worse outcomes for chronic care. Unless there are risk adjustments, providers will not be interested in treating these patients because the cost to them will be more than a capitation sum based on average patients (Busse and Mays 2008).

(2) *Fee-for-service* (FFS) involves paying for each unit of service provided. It is generally assumed that more services will be provided where margins are high in order to maximise income. This may lead to some services being overused. The effect on chronic care is two-fold. On the one hand, overprovision may be counterproductive. On the other hand, given sensible payments, there are no incentives for underuse. The fee-for-service approach can also be applied to pay institutions rather than individuals and in this case the incentive structure works in the same way.

(3) *The salary approach* splits the cost of health care into one part human resource and one part covering other costs. The health professional is compensated by a fixed amount irrespective of productivity. There is no specific incentive for underuse or overuse of services. At the same time there is no specific incentive to provide good care for chronic patients with chronic illnesses (Busse and Mays 2008).

On the institutional level, approaches include *per diem* payments and *case fees*. Per Diem payments (a standard amount per patient per day) have a bad effect on chronic disease. Institutions tend to avoid chronic patients because of their high cost, or keep them in hospital longer than necessary in order to make up the costs through higher overall reimbursement.

Case fees were used originally to pay fixed amounts for each patient with a certain diagnosis. Early systems in the US assumed that all patients in each DRG generated similar costs, thus sharing financial risk with providers. This led to seriously ill patients with chronic or multiple diseases being avoided, and also resulted in premature discharge. Approaches in France, Germany and the Netherlands (Busse et al. 2006) defined outliers with higher payments and based their classifications on hospital procedures. This turned European DRGs into a hybrid with fee for service. This reduces the adverse selection, but risks overprovision. Institutional budgets have similar incentives for professional salaries. The effect on chronic care will depend on specific arrangements in each context.

Getting financial incentives for providers in line: new initiatives

Beyond these 'traditional' approaches, a new set of tools for paying providers has been developed in Europe. Table 13 summarises the main ways in which payers can encourage appropriate chronic disease care. Financial incentives can apply to structure, processes and outcomes.


Table 13: Incentives used to improve chronic care in European countries

Financial incentives targeting the individual	Financial incentives targeting structures of care	Financial incentives targeting processes of care	Financial incentives targeting outcomes of care
<ul style="list-style-type: none"> • Piloting of 'year of care' payment for the complete package of chronic disease management required by individuals with chronic conditions (e.g. based on validated 'care pathways' for diabetes) (DK; UK) 	<ul style="list-style-type: none"> • Per patient bonus for physicians for acting as gatekeepers for chronic patients and for setting care protocols (FR) • Bonus for DMP recruitment and documentation (GER) • 1% of overall health budget available for integrated care (GER) • Points for reaching structural targets (UK: GP contract) 	<ul style="list-style-type: none"> • Points for reaching process targets (UK: GP contract) 	<ul style="list-style-type: none"> • Points for reaching outcome targets (UK: GP contract)
	<ul style="list-style-type: none"> • Additional services (e.g. patient self-management education) only reimbursable if physicians and patients participate in DMP (GER) 		

Note: DMP = disease management program; DK = Denmark; FR = France; GER = Germany; UK = United Kingdom
 Source: own table based on Busse and Mays (2008)

Financial incentives aimed at improving chronic care tend to focus on the structure, processes and outcomes of care (Busse and May 2008). But there are regional differences. Most financial incentives in European countries relate to the structure or process of care. Only the UK NHS contract for general practitioners specifically includes incentive payments focused on the delivery of particular outcomes (Smith and York 2004; Roland 2004). Generally focus has been shifting from approaches which simply take into account the presence (or potential presence) of patients with chronic disease towards funding incentives designed to encourage providers to make specific structural and process responses (Glasgow et al. 2008; Bodenheimer et al. 2002a + b).

Empirical evidence: There are only a few good studies of the impact of different payments on quality and/or efficiency of care for chronic disease. Many generate their conclusions from single cases rather than from comparative studies. It is difficult to draw firm conclusions on effectiveness or cost-effectiveness.



Studies of financial incentives for providers in Europe have tended to suggest that clear conclusions are impossible because of a lack of evidence. One recent US study (Peterson et al. 2006) recently generated some preliminary conclusions and these might be used to inform the European debate. Their conclusions were:

- Designs setting out a few narrow goals may lead to excessive focus on the incentivised tasks or areas of quality, generating 'gaming' or better reporting without any true improvements in care quality. These problems are well-documented in other sectors (Baron and Kreps 1999).
- The impact of financial incentives is not the same for different groups of providers. Those with high, average or poor performance will each react differently.
- Mixed approaches combining different payment schemes (such as fee-for-service and case fees) may reduce the negative effects of either approach applied alone.
- The size of the incentive clearly matters. Studies in other sectors suggest that a significant percentage of income has to be variable before providers can be expected to change their behaviour. Overly large incentives, on the other hand, may lead to providers focusing too much on incentivised goals.
- Motivational theory suggests that financial incentives will be less effective for groups of providers than they will be for individuals (Baron and Kreps 1999). This is because the individual's effort is only partly reflected in group benefits, with colleagues earning the same for less work. As a result, individuals are less motivated to improve quality. On the other hand, on the provider-group level risk-adjustment can be practised, which can not be done for individuals.
- Small to medium-sized multidisciplinary teams tend to provide positive outcomes (Bodenheimer et al. 2002a+b), suggesting that this could be an appropriate way of providing financial incentives to providers, especially when combined with rigorous performance monitoring and benchmarking (Kerr and Fleming 2007).

Clearly, one cannot deduce that these conclusions apply in the European context, but they offer a good starting point for future investigation.

Some evidence has been generated about the Quality and Outcomes Framework (QOF) in the UK, which set up pay-for-performance for general practitioners, using outcomes and quality variables and making about 25% of practice income dependent on quality rewards. The programme is still controversial but in general it has had a positive effect on quality of care, and particularly chronic care (Campbell et al. 2007). Most researchers conclude that improvements are likely to be the result of better organisation of general practices. In particular, it seems that patients are benefiting from more systematic care (Wang et al. 2006)

Financial incentives for payers/purchasers

Few policy approaches use financial incentives to target payers and/or purchasers. One exception is the 2002 health reform in Germany which changed the way of allocating individual sickness funds. Before the reform, it was unattractive to insure patients with chronic diseases or to set up disease management programmes for people with chronic illnesses. After the reform, sickness funds received extra funding when enrolling patients in disease management programmes. This led to a rapid growth of such programmes. No systematic reviews on the impact of these programmes on health outcomes or the use of resources have yet been published. Some critics have already attacked the formula on the grounds that putting people into disease management programmes this does not necessarily mean they get better care.

Another health reform in Germany, being implemented from January 2009, provides extra financial incentives for payers and insurers by taking individual morbidity criteria into account (individually risk-rated capitations). This has already been implemented in the Netherlands (van Ginneken et al. 2008).

Financial incentives for patients

There are relatively few financial incentives for patients to take part in chronic disease management programmes. France and Germany are exceptions because they apply (modest) cost-sharing. This may be reduced or waived in Germany when patients enrol in a programme. This incentive was mainly used to attract people to take part in disease management programmes. Patients taking part also have access to extra services. Patients in France become exempt from co-payments for chronic disease care if they present their previously agreed care protocol at every physician visit. Neither scheme has yet been systematically analysed.

Financial incentives for promoting better chronic disease management are rarely used to affect the relationship between financial poolers and the population (relationship B in figure 8). One such incentive would be to lower premiums or contribution rates for those with chronic diseases who take part in a disease management programme. There are no such schemes in Europe.

Policy recommendations

This section has shown that early findings suggest that financial incentives can be used to promote better quality care when properly applied and when certain prerequisites are fulfilled. This section makes recommendations for policy makers considering new financial incentives. It builds on the findings in this section and incorporates relevant findings from other sections. It separates structural and operational recommendations.

Structural policy recommendations

- Most European countries have set up programmes to promote chronic disease management, but these programmes rarely give financial compensation to integrated approaches targeting several chronic diseases. Research shows that chronic illnesses and chronic conditions are increasingly inter-related (Busse and May 2008). Policy makers should therefore consider integrating or linking chronic care programmes.
- Continuity of care is a key prerequisite for payer or provider investment in chronic disease management programmes. Any net returns from investments in infrastructure tend to come five years later (Fahey et al. 2008); and benefits from avoiding severe complications come after 5-10 years (Eastman et al. 1997). Health systems that have traditionally focused on 'patient choice', little enrolment with particular providers and/or fee-for-service payments – all of which led to relatively poor continuity of care - face the greatest difficulties in aligning financial incentives to promoting better management. Given this, policy makers should consider strengthening or introducing financial incentives that will encourage 'continuity of care'.
- In most European countries, different professional groups are paid according to separate schemes. However, effective care often depends on the co-operation of multidisciplinary teams. Different incentives for different members of the same team may frustrate common efforts, where economic interests motivate different treatments. Policy makers should align compensation schemes for health professionals working together in chronic care.

Operational policy recommendations

- Financial incentives encouraging a few narrow goals can lead to excessive focus on these goals, together with 'gaming' or better reporting without any improvements in quality. Policy makers should set out quality indicators that reflect different aspects of quality (structure, process and, where possible, outcome).
- Since the impact of financial incentives is likely to differ across different groups of providers, policy makers should decide which they want to incentivise and then design the incentive accordingly.
- Policy makers should consider mixed payment approaches, since this can mitigate negative effects of single approaches.
- Theory and empirical evidence suggest that a substantial amount of income has to be variable before providers can be expected to change their behaviour. Incentives should not therefore be too large, given the sensitivity of quality in health care and lack of clarity about the impact of different payment schemes. Where possible, pilot studies should be conducted before programmes are rolled out.
- Financial incentives for individuals may undermine cooperation, while financial incentives to organisations may have little impact on the motivation of individuals. Using small to medium multidisciplinary teams seems to yield positive outcomes (Bodenheimer et al. 2002a+b), so policy makers should consider targeting these when introducing financial incentives.

7.3 Improving coordination

Research suggests that one of the major obstacles to better care for those with chronic disease is the lack of coordination in health care systems. Structured approaches such as disease management programmes and integrated multi-disease care models tend to fall between different layers of increasingly differentiated health systems (Busse 2004; Epping-Jordan et al. 2004; Velasco et al. 2003; Pelikan et al. 1998). This section will look at different ways of co-ordinating services, and at the structural, organisational and operational barriers. Finally, it will make recommendations so that policy makers can define strategies for better co-ordination.

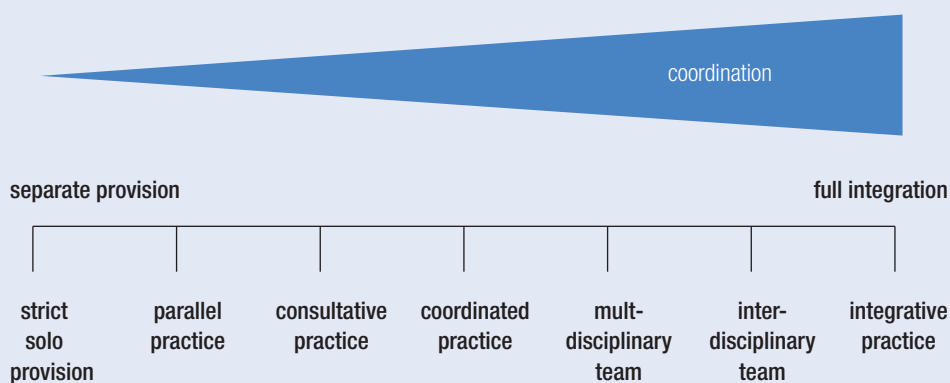
Dimensions of coordination in chronic care

Clearly, involving more providers requires better coordination. Chronic care often involves multi-provider settings, and since patients with chronic conditions often have several diseases, coordination is particularly appropriate. Research confirms that patients' perception of the quality of care is largely determined by how successful this coordination is. The following dimensions are important:

- *getting in* - getting access to appropriate care
- *fitting in* - adapting the care to their requirements
- *knowing what's going on* - receiving information
- *continuity* - of staff and also coordination and communication among professionals and
- difficulties in making progress through the system, mainly due to failures in the other four areas (Preston et al. 1999).

Boon et al. (2004) identified seven types of provision with varying degrees of coordination (Figure 9). At one end of the continuum is *strict solo provision*. At the other is *full integration of disciplines* for curative, rehabilitative and preventive services. Second on the non-coordination side of the continuum is *parallel practice*, where practitioners work independently and carry out services independently. *Consultative practice* is where information on patients is shared informally case by case. In *coordinated practice* the exchange of data on patients is related to particular diseases, and therapies are administered through a formal structure. Often a case coordinator will supervise the exchange of patient records. An advanced model of the former is the *multidisciplinary team*, which is more formalised, has more team members, and often clear team structures with sub-teams and team leaders. An *interdisciplinary team* is where group decisions are made, shared policies developed, and regular face-to-face meetings held. Finally, *integrative practice* is based on a shared vision and provides a 'seamless continuum of decision-making and patient-centred care and support'.

Figure 10: Types of care provision with varying degrees of coordination



Source: own figure based on Boon et al. (2004)

Barriers to coordination

The problems of coordinating health care systems have been the subject of wide-ranging discussions for decades (Grundmeyer 1996). This report concentrates on structural, organisational and operational problems.

Structural problems of coordination

Structural problems are often rooted in different ways of working across different sectors (primary or secondary; public or private). Providers have incentives to compete rather than to cooperate. Individuals or professional groups are compensated for separate activities rather than for cooperation. There is rivalry over resources and power struggles between professional groups, as well as overlapping responsibilities and unclear accountability between divisions and providers. Figure 11 summarises common structural barriers in Europe.

Figure 11: Structural barriers to coordination

- Competing operation cultures and management approaches in different sectors (social care vs. health care; primary sector vs. secondary sector, home practice vs. general practice)
- Different ownership structures (lack of universal standard for the interfaces between the public and the private sector)
- Separate and competing providers with no incentives to cooperate
- Rivalries between professional groups
- Lack of clarity about competencies and accountability (national vs. regional actors for policy initiatives; general practice vs. specialists for the process of care)

Source: own compilation based on Nolte and McKee (2008)

These problems exist in varying degrees in most European health systems, but different problems arise in countries where general practice has a central gatekeeping position. Gatekeeping is designed to promote integration and coordination of care provision (Catlan et al. 2006). The various coordination problems can be summarised as follows.

Structural problems of coordination in gatekeeping countries

In gatekeeping countries, general practice guides patients through the health care system. Those entitled to regular care are registered with a general practice and the general practitioner has access to their records. General practice is usually the first point of access, irrespective of medical problem or need. Other providers, such as specialists, are only accessible after consultation with or referral by the GP. Drugs tend to be provided by prescription only. In this context general practice has two main roles: (1) controlling the use of specialist services, which is meant to reduce or contain health care costs; and (2) acting as a coordinator, providing navigation, continuity of care and encouraging the system to be more responsive (Catlan et al. 2006). This latter function should benefit patients with chronic disease, because different professionals are involved at different stages and continuity of care is essential.

Nevertheless, the record of gatekeeping approaches in providing better coordination is mixed. Some evaluations have found that gatekeeping approaches are successful (Starfield 2001; Gervas et al. 1994; Gross et al. 2000), while others have pointed out that there is no conclusive evidence that gatekeeping contains health care costs or enhances the quality of care (Halm et al. 1997). There are several reasons for the contradictions: implementation and operational problems (which will be discussed in more detail below), and also context-specific structural problems. For example, in many countries the role of GPs is unclear once the patient has passed through the gate into the rest of the system (Catlan et al. 2006). Also, conflicts rooted in the traditional hierarchy of the medical professions may undermine the success of gatekeeping models. General practice is often at the lower end of the doctors' hierarchy, even though the gatekeeping model places them in a central position. The new 'governance' model challenges the well-established hierarchy, and may lead to conflicts about legitimacy, power and resources. Depending on the intensity, these conflicts may lead to less rather than more coordination among different professionals.

Structural problems of coordination in non-gatekeeping countries

Coordination problems are different in countries with no gatekeepers. Patients can visit a GP or specialist without a referral. If they prescribe care or tests, patients usually have the right to choose who should do this. It is not necessary to be registered with one general practice. Patients have a greater choice of providers, but no single health professional is responsible for the full process. Navigation through the system and through different stages of care is not a part of the system, so patients have to organise their own way. This can produce serious problems, particularly regarding continuity of care. France, for example, did not introduce gatekeeping to promote navigation through the health system until 2005. Evaluations indicated that this was not good for chronic care. Treatment for diabetes for example, was fragmented (Bras et al. 2006) and as a result national guidelines only rarely respected (Catlan et al. 2006).

Organisational and operational problems of coordination

In addition to structural problems, the following organisational and operational aspects impede effective coordination.

Funding and finance: Some European countries have invested considerably to improve chronic care, but those measures intended to increase cooperation are often cut after early success. Governments seem to expect that measures to improve coordination will 'self-fund' from savings (Leutz 1999). However, evaluations show that these expectations are unrealistic, and threaten the success of efforts to improve coordination. In many cases, 'self-funding' expectations are seen as a threat by those in the organisation, particularly if ambitious savings are expected. They may fear that they will have to make the 'efficiency gains' by cutting resources. Given strong incentives to protect these resources, willingness to cooperate has been found to be low (Leutz 1999).

Research also indicates that coordination initiatives seldom generate short-term savings. Also, improving co-ordination does not compensate for a lack of resources (Freeman et al. 2007), and so is not an easy way to solve funding problems.

Human resources and pay: Integrated approaches (such as disease management programmes or gatekeeping models) that bridge traditional professional boundaries need well defined roles and competencies (Nolte and McKee 2008). In many countries, legal barriers have to be redrawn before competencies can shift between professional groups (Durand-Zaleski 2008; Orbrecht 2008). Reimbursement schemes have to be adapted in order to compensate participation in new schemes, such as multidisciplinary teams to treat chronic diseases (Glasgow et al. 2008). The evidence clearly shows that professional groups will be less involved in integrated care models unless they have pay incentives (Steuten et al. 2002; Schiotz et al. 2008).

In addition, performance-related pay schemes may set incentives which undermine cooperation (Hofmarcher et al. 2007). Specialist doctors are particularly worried about shifting competencies to other professional groups, such as nurses or GPs, and this can undermine coordination of chronic care (Rosemann et al. 2006). The lack of training for staff undertaking new roles is a serious problem. Doctors in most countries are rarely trained to 'navigate' patients through the health system. Nurses having to perform new and demanding tasks are often inadequately prepared and supported.

Strategies for better coordination

Policy makers increasingly recognise the importance of coordination for the quality of care (Boerma 2006), patients' care experience (Alazri et al. 2006; Schoen et al. 2007; Turner et al. 2006) and cost containment. Accordingly, governments in most European countries have developed appropriate strategies.

Many of these strategies have been applied to the structural, organisational and operational problems of coordination. Some countries, such as Denmark and England, have developed national strategies for chronic care, integrating health promotion, prevention and management under a common framework. Other countries, where professionals are more fragmented, have developed strategies focusing on specific aspects of chronic care and chronic disease (France, Germany, the Netherlands, Sweden) (Nolte and McKee 2008).

Table 14 summarises recent policy initiatives in selected European countries. It distinguishes between those with a common framework and thus a national strategy, and those using *parallel strategies*.

Table 14: Recent policy initiatives to improve coordination and quality of chronic care

Country	Policy initiatives	Goals / mechanisms
Denmark	National strategy	
	• Development of a national Vision of chronic disease control: Healthy throughout Life (2002)	• Facilitate easier access to chronic care via Municipal Centres
	• National targets to increase life expectancy	• Increase transparency and accountability via defined targets
	• Reallocation of responsibilities between regions and municipalities	
United Kingdom	• Municipal health centres for elderly and patients with chronic disease (limited to the provision of non-physician services)	
	National strategy	
	• Development of a national Vision for chronic care: Choosing Health (2004)	• Improve navigation through the system via case management
	• Implementation of casemanagement	• Define adequate policies for patients via stratification and clustering
	• Risk stratification	• Develop integrated chronic care via multidisciplinary teams
	• Multidisciplinary care teams	• Establish the provision of high quality care for selected chronic conditions in primary practice via a new compensation scheme
France	• New payment system for primary care	• Increase access to chronic care for specific patient groups via multiple points of entry
	• Establishment of "NHS Walking-in centres" and "NHS-Direct"	
	Parellel strategies	
	• Introduction of "health networks"	• Improve exchange of experience between providers via networks
	• Target-setting for health and risk indicators	• Increase transparency and accountability via defined targets
Germany	• Universal and mandatory registration with general practice (GP)	• Increase the use of evidence-based guidelines in chronic care via financial incentives
	• Financial incentives (reduction of co-payments) for the use of evidence-based guidelines in provision of long term conditions	• Improve navigation through the system via universal gatekeeping by general practice
	Parellel strategies	
	• Attractive compensation for disease management programmes (2002 and 2004)	• Establish integrated and structured care models via attractive financial compensation for the establishment of DMPs
The Netherlands	Parellel strategies	
	• Establishment of transmurial care (focusing on the interface between acute hospital care and alternative setting)	• Improving the interface between acute hospital care and ambulatory care via new initiatives / cooperation between existing actors in transmurial care
	• Development of disease management programmes	• Development of integrated care models via financial for the establishment of disease management programmes

Country	Policy initiatives	Goals / mechanisms
Sweden*	<p>Parallel strategies</p> <ul style="list-style-type: none"> • Strong emphasis on primary care centres for chronic care guided by regional and local guidelines • Nurse lead chronic care • Development of chains of care • Development of “local healthcare” initiatives 	<ul style="list-style-type: none"> • Improve navigation, accessibility and continuity of care via chronic care in primary care centres and nurse lead chronic care • Improve quality of chronic care via the development of common guidelines for chronic care across professional and provider boundaries (“chains of care”) • Increase continuity of care and accessibility for elderly and patients with chronic diseases via locally coordinated health care strategies

*Sweden devolves significant responsibilities for health care to provinces and other lower levels of government. Therefore policy approaches differ across the country. These are only selected policy initiatives.

Source: own compilation based on Nolte and McKee (2008) and Catlan et al. (2006)

Despite these initiatives, problems with coordination and continuity of care persist irrespective of health care system and the policy approach (Catlan et al. 2006). Given the lack of research, short duration of the initiatives and relationship to country-specific variables, only tentative conclusions can be drawn. One is that, while gatekeeping countries such as the Netherlands and the UK still have problems of coordination and continuity of care, these problems tend to be worse in health systems with no systematic gatekeeping and where patients are left to navigate through the system on their own.

Also many governments try to improve coordination of services in primary, specialist and social care, of community services through joint committees, and of shared care. Evaluations suggest that the success of these approaches is limited, and depends on the cooperation of different professionals (Evans 1996).

Finally, increasing points of entry with *walk-in centres* or *call-in centres* comes at a cost. It tends to split primary care and undermine continuity of care (Anderson et al. 2002; Salisbury 2004). For some patients, especially those with chronic and multiple conditions, these may make it harder to improve quality of care (Calnan et al. 1994).

Policy recommendations

There is no agreed best practice for better coordination. Problems persist in all European health systems and the impacts of various policies differ. Formulating policy is difficult, but studies have informed the following recommendations.

Strategic policy recommendations

- Policy makers must recognise that they need to act. The complexity and variety of people involved in chronic care means that better coordination will not emerge spontaneously (Nolte and McKee 2008). Decision makers must make better cooperation a priority in order to overcome deeply-rooted vested interests and professional scepticism. Better coordination will only become a realistic goal if it is adequately managed and politically supported.
- Policy makers must decide early whether change can be implemented in the existing system, or whether fundamental reform is needed. This applies particularly where there are central structural barriers to cooperation (Glasgow et al. 2008; Nolte and McKee 2008; Plochg and Klayinga 2002).
- All European health systems face increasing demands on health outcomes, medical progress and finances. Policy makers should take into account the consequences of restructuring when designing policies specifically targeting coordination (Nolte and McKee 2008).

Structural policy recommendations

- Policy makers should decide what mix of *centrally-controlled parameters* and *local autonomy*, or *top-down* and *bottom-up* management they want for improving coordination (Ahlgren and Axelsson 2007). Policy makers must take into account the likelihood of bringing about change. They should also consider whether their approach will fit in with established mechanisms of accountability and responsiveness. In Germany, strict national guidelines for disease management programmes have been praised for ensuring common standards, but they have also been criticised for making it difficult to respond to local requirements and conditions (Siering 2008). In England, a perceived lack of regulation has been blamed as the main cause of a highly differentiated and fragmented set of programmes.
- Similarly, policy makers should choose between *parallel policy initiatives* or one *integrated national strategy*.
- Policy makers should decide which patient group they are targeting. The debate about whether to increase access through multiple entry points or strengthen continuity of care and improve navigation with gatekeeping shows that policies to improve chronic care often involve trade-offs for different groups of patients. Policy makers should define the target (patient) population of their strategies in order to minimise unintended consequences and side-effects.
- Separate and shared responsibilities within and between providers should be clearly defined in order to prevent duplication or omissions (Catlan et al. 2006).

Organisational and operational policy recommendations

- Policy makers should provide enough funding for start-up costs and sustained operations. Expectations of self-funding tend to be unrealistic and often produce rivalry over resources (Leutz 1999).
- Policy makers should set up remuneration schemes that will allow cooperation across primary and secondary sectors, professional groups and competing providers.
- Policy makers should enable health professionals to fulfil their new responsibilities. This means setting up the appropriate legal framework, providing training, and helping to build trust between professional groups that are not used to working together.

7.4 Information and communication technologies (ICT)

There is growing international agreement that introducing modern information communication technologies (ICT) may lead to a more effective use of resources, an improvement of the quality of care, and to greater attention paid to the needs and wishes of patients (Busse et al 2006). In particular, disease management programmes and integrated care models need strong and effective systems for exchanging information and collecting data if they want constant quality control (Hofmarcher et al. 2007; Leutz 1999).

The European Union has therefore proposed various information technology initiatives – for example, within the framework of the eEurope action plan – and many governments have been motivated to strengthen their efforts (eEurope 2005). For the health sector, the EU presented the action plan e-health which encourages member states to develop their e-health strategies. It also seeks to set up agreed international standards for exchanging health data (European Commission 2004). This section will give policy makers an overview of the effectiveness of different decision-support systems. It will also highlight how various countries are reforming their e-health platforms and electronic health records.

Clinical decision support systems

Clinical decision-making is supported by a wide range of interventions. These rely increasingly on electronic systems for their delivery. The main goals are to increase the quality of care through standardising the delivery of care in accordance with evidence-based practice, while at the same time containing costs (Glasgow et al. 2008). Clinical care processes are more likely to become standardised when evidence-based practice guidelines or protocols and clinical pathways are being used. They are intended to reduce variation in health care and thereby increase quality of outcomes and reduce medical error. Coiera (2003) points out that these electronic systems range from presenting information (treatment requirements for specific conditions or diagnosis) to undertaking complex functions as in *expert systems* and *machine learning systems*. Evidence suggests that formal decision-support systems are beneficial, and they have been studied for conditions such as hypertension, diabetes, depression, heart failure, asthma, COPD, osteoarthritis, and end stage renal failure.

Table 15 summarises the evidence of effectiveness of decision support in clinical practice.

Table 15: Evidence of effectiveness: Computerised clinical decision support (CDSS)

(Abbreviated) title	Year	Study design	Condition / treatment	Target	Type of Intervention	Patient objective outcomes	Patient subjective outcomes	Quality of care	Reduced healthcare costs/ use of services
Effects of computerised clinical decision support systems (Garg et al., 2005)	2005	Systematic review	n/a	Practitioner	CDSS		+	+	
Decision aids for people facing health treatment or screening decisions* (O'Connor et al., 2003)	2003	Systematic review	n/a	Patients	Computer and web-based decision aids		+		-
Effect of computerised evidence based guidelines on management of asthma and angina in adults (Eccles et al., 2002)	2002	RCT	Asthma angina	GP	Computerised guidelines	-	-	-	-
Effect of computer-aided management on the quality of treatment in anticoagulated patients (Manotti et al., 2001)	2001	RCT	Oral Anti-coagulant treatment	Anti-coagulant clinic physicians	Computer aided dosing	+		+	+
A randomized trial using computerized decision support to improve treatment of major depression in primary care (Rollman et al., 2002)	2002	RCT	Major depression	GP	CDSS with diagnostic and feedback on treatment	-	-	-	
Lessons from a randomized controlled trial designed to evaluate computer decision support software to improve the management of asthma (McCowan et al., 2001)	2001	RCT	Asthma	GP	CDSS	~~			~~
Failure of computerized treatment suggestions to improve health outcomes of outpatients with uncomplicated hypertension (Murray et al., 2004)	2004	RCT	Hyper-tension	Physicians, pharmacists	Evidence based treatment suggestions using eHR	-	-	-	
Can computer-generated evidence care suggestions enhance evidence based management of asthma and chronic obstructive pulmonary disease? (Tierney et al., 2005)	2005	RCT	Asthma, COPD	GP	Computer-based evidence care suggestions	-	-	-	-
Randomised controlled trial of an informatics-based intervention to increase statin prescription for secondary prevention of coronary disease (Lester et al., 2006)	2006	RCT	Ischaemic heart disease	GP	CDSS	+		+	
Cost effectiveness of an intervention based on the Global Initiative for Asthma (GINA) recommendations using a computerized clinical decision support system (Plaza et al., 2005)	2006	RCT	Asthma	Specialist and GP	CDSS		+		+

Note: "+", "-" intervention improves the outcome; "~~" intervention does not show any effect on the outcome; "*" This majority of studies included in this review concerned cancer screening and treatment; also, 25% of the decision-aids reviewed at were not computer/web-based. However, the review provides important evidence on the use of decision aids for patients and was therefore included here.

Source: Glasgow et al. (2008)

The evidence so far indicates that progress has been made in some disease areas. Nevertheless, many challenges exist if we are to make full use of the potential of decision supports (Glasgow et al. 2008).

E-health platforms and electronic health records

Many governments support holistic information and communications systems such as e-health platforms and electronic health records or cards. The aim is to improve data exchange between key people such as doctors, patients, hospital workers, pharmacists, care workers, health insurers and public administrators. E-health platforms are meant to improve access, increase patient participation, improve efficiency of delivery and improve coordination. Often the platforms have guidelines for professionals, information and education programmes for patients, and eligibility criteria for benefits.

Examples of such platforms include the Canadian Health Infoway, MedCom in Denmark, Connecting for Health NHS in Britain, Health Connect Australia and in France an internet portal for chronic conditions (Glasgow et al. 2008). Cross-sectoral electronic health records are used for the long-term collection and documentation of relevant patients. They contain personal data and a wealth of medical information, such as the medical history of the carrier, important laboratory results, physicians' letters, records of operations, and digital data from investigations (Busse et al. 2006). Only a small amount of evidence is available, but some studies have found positive effects on the care process, while others have found no effect on subjective or objective outcomes (O'Connor et al. 2005; Tierney et al. 2005).

Policy recommendations

- Agreeing on technical standards is essential because one of the key challenges is to achieve functional interoperability within health systems. Policy makers should get those involved together and ensure that they agree on goals and standards for information technology.
- More important is how the vast amounts of data generated by medical treatments can be merged into meaningful information. Modern information technology can store vast amounts of data, but health professionals usually need carefully selected pieces of information combined in a specific way. Since time is critical, both in terms of costs and medical treatment, intelligent ways of compressing, aggregating and interpreting information must be found. ICT providers often ignore this, but policy makers should insist that systems are developed in order to meet the needs of health professionals.
- The use of information technology has to be more broadly evaluated. Pilot projects in Austria, Canada, France, Germany, Italy, Japan, Switzerland and the United States have found relatively high costs, budget overruns and many unforeseen difficulties (Hendy et al. 2005; Tuffs 2004; Tuffs 2006; Burton et al. 2004; Scott et al. 2005). There is a clear need to assess the benefits of information technology and long term cost-benefit analyses should be undertaken.
- Policy makers should ensure that patients accept the new electronic systems. Data protection is a key part of new designs, but patients often demand full access to their own data. Where necessary, laws must be passed to ensure strict standards on data protection, and to affirm patients' rights to access their records.

7.5 Evaluation culture

This report has shown that many aspects of chronic disease management have not yet been properly evaluated and neither the effectiveness nor the cost-effectiveness of various interventions have been established. Those making policy for chronic care lack good-quality information, based on scientifically valid methods, to support their decisions. This section outlines how technologies (medical devices and pharmaceuticals) and strategies are evaluated in different countries, describes what methodology should be used, and outlines which steps could be taken to improve evaluations.

Evaluation is described here as the comparative appraisal of technologies and strategies used to manage chronic disease - pharmaceuticals, programmes, projects, services or organisations - using methodically aggregated and analysed data (Ovretveit 2002). The evaluation can relate to the structure, process and results of an intervention. Evidence-based assessment and quality development must be transparent and must provide the conditions necessary for rational health planning and control (Busse et al. 2006). Unlike basic research, evaluation addresses the specific questions of decision makers on efficacy, cost-effectiveness and equity.

Evaluation of medical procedures and devices

Evaluating chronic disease management needs careful preparation, and should be built into a programme from the start. However, few countries have adopted the idea that evaluation should be an integral part of public health programmes. Exceptions include the Netherlands, Canada, Australia and the UK (Suhrcke et al. 2008). Since the 1990s the global trend has been towards more evidence-based policy. Many countries are trying to evaluate medical technologies and procedures, for instance, including those for chronic diseases. This is usually carried out by health technology assessment (HTA) institutions (cf. accompanying report on HTA). Most European HTA agencies are independent of government but publicly-funded, with the mandate of supporting policy-making and decision-making (Velasco-Garrido and Busse 2005). An increasing number of European countries can draw on their experiences evaluating health technologies and supporting policy decisions (Busse et al. 2006).

Evaluation of pharmaceuticals

Those with multiple diseases have become much more complex to manage as new, more powerful, but also potentially more dangerous drugs become available (Nolte and McKee 2008). Until recently, there was only limited evidence for the pharmacological management of chronic disease. That was particularly the case for new drugs that had proven their safety and efficacy in randomised controlled trials (RCTs - often against a placebo as a control), and were licensed to be marketed. But it was unclear whether they offered any additional benefits – especially in real-life conditions – over existing pharmaceuticals. Were they really innovative or simply patented ‘me too’ products with no (or very limited) added value?

Many countries have therefore introduced a post-licensing evaluation before making decisions on price, eligibility for reimbursement, and recommendations (in clinical guidelines) for use (Zentner et al. 2005). The number of groups assessing evidence for the added value of a drug has grown continuously over the past decade. Examples of such bodies are the Swiss Federal Office of Public Health and Confederate Pharmaceutical Commission, the Swedish Pharmaceutical Benefits Board Committee and the National Institute for Health and Clinical Excellence in the United Kingdom (Zentner et al. 2005).

Negative reviews from these bodies cause the pharmaceutical industry to criticise the lengthy evaluation procedures and the quality of the evidence-based evaluations. Reimbursement decisions have been contested successfully in litigation, for example in France (Naudin and Sermet 2003; Couffinhal 2003). The example of Australia (van Gool 2005) shows how drug evaluation and regulation increasingly come into conflict with a global market. The free trade agreement with the United States obliges Australia to allow an independent assessor to review negative decisions by its Pharmaceutical Benefits Advisory Committee. One of the challenges facing policy-makers is to develop internationally accepted standards and methods of evidence-based evaluation, and to increase the transparency of the procedures and of policy decisions (Busse et al. 2006).

Methods of evaluation

Chronic disease management tries to strike the right balance between scarce resources on the one hand and high-quality health care on the other. If models are to be acceptable their impact needs to be proven. Disease management programmes, for example, should comply with the standards of evidence-based medicine. These standards should also apply to evaluation. Prospective, randomised, controlled evaluation is seen as the best way of generating empirical evidence on structured health care. From a statistical point of view, observational studies are weaker when evaluating the effectiveness of chronic care models, even though the observation of a cohort can be larger than an RCT sample size. However, RCTs allow different programmes to be compared in addition to evaluating one intervention (Sawicki et al. 2006; Beyer et al. 2006).

Developing a study design for a randomised controlled trial in disease management would face methodological problems. These would include defining primary target criteria, guaranteeing a ‘naturalistic’ intensity of intervention, and creating a control group that is not significantly affected by spill-over effects (such as the physicians using knowledge they have gained from the programme or because implementation becomes mandatory during the evaluation period). Evaluations considering relevant health outcomes also need a long observation time.

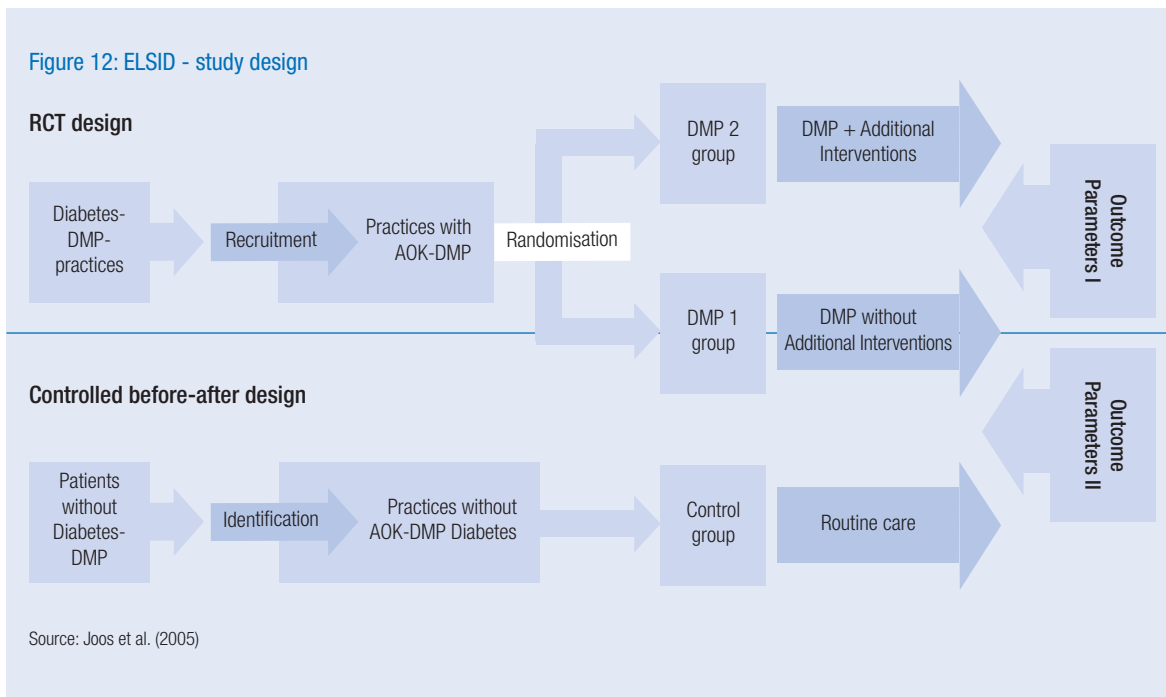
These problems can be addressed scientifically (through cluster randomisation with physicians having either only or no disease management programme patients). However, scientists face challenges when conducting adequate evaluations, because decision makers need rapid answers and might encourage measuring process rather than outcomes.

Evaluation of strategies in chronic disease management

Evaluating strategies in chronic disease management is a part of health services research (HSR). It examines how social factors, financial systems, organisational structures and processes, health technologies and personal behaviours affect access to health care, the quality and cost of health care - and, ultimately, the health and wellbeing of citizens (Lohr and Steinwachs 2002; AcademyHealth 2007). It does this at a *macro-level*, which is the health care system at large (regionally, nationally or internationally) and at the *micro-level*, which is the interaction between patients and providers. Health Technology Assessment concentrates on the *micro-level* when evaluating new pharmaceuticals or medical devices (cf. accompanying report on HTA). The *meso-level* focuses on health care organisations and the services they provide, as in disease management programmes.

Several small-scale research projects are studying single elements of disease management programmes, such as patient enrolment or documentation. Until now there have been few large-scale, population-based evaluations of chronic care.

One example is the German study *Evaluation of a Large Scale Implementation of Disease Management Program* (ELSID). In 2003, the first disease management programmes for patient with diabetes mellitus type 2 were introduced in Germany. The Social Code Book V made evaluation obligatory by and a prerequisite for further accreditation. The regional health funds commissioned independent scientists to evaluate the disease management programme for type II diabetes in primary care in two German states. They designed a three-armed prospective cluster-randomised comparison of a DMP, a DMP providing extra services such as quality circles or outreach visits, and routine care without a DMP as a control group. Figure 12 shows the study design (Joos et al. 2005).



This is an example of best practice. It allows valid data to be collected and conclusions drawn about the effectiveness of a disease management programme. This randomised controlled trial seems promising.



Policy recommendations

- Policy makers should understand the relevance and basic methodological requirements of evaluation. They should use this knowledge to ensure that evaluation is an integral part of programmes to improve chronic disease management. Adequate incentives or regulations should be applied to encourage programme designers to take account of the need for evaluation. For example, constant quality control through defined evaluation should be compulsory for large scale publicly-funded programmes.
- Given increasing globalisation, policy-makers need to develop internationally agreed standards and methods of evidence-based evaluation. They also need to make their procedures and policy decisions more transparent (Busse et al. 2006; cf. accompanying report on HTA).
- The need for evaluation should not unnecessarily hinder innovation nor should it be used as an excuse for uncontrolled implementation. Policy makers must use a step-by-step approach, such as getting a small number of providers to use the technology, strategy or organisational component on a small number of patients. Once positive results are available, the numbers of providers and/ or patients may be increased.
- Data routinely available in different sectors of the health system (for example, for reimbursement) should be made available so that independent researchers can carry out in-depth analyses of effectiveness and cost-effectiveness.

Chronic conditions and diseases are already the leading cause of mortality and morbidity in Europe. Research suggests that conditions such as diabetes and depression will impose an ever larger burden in future.

The economic implications of chronic diseases and conditions are serious. They depress wages, earnings, workforce participation, labour productivity and hours worked – and may also lead to early retirement, high job turnover and disability. Disease-related impairment of household consumption and educational performance affect GDP and economic growth. Spending on chronic care is rising across Europe, and takes up an increasing part of public and private budgets.

European policy makers must start to improve chronic disease management. In order to inform decision-making, part I of this report described the available strategies and the evidence on their effectiveness and cost-effectiveness.

On *prevention and early detection*, this report has shown that most countries are trying to combat chronic conditions by experimenting with prevention and early detection. These approaches aim to reduce the burden of chronic disease by activities that avoid impairment to health, or make it more unlikely. Prevention includes primary, secondary or tertiary approaches which differ in aims and target groups. Research indicates that approaches combining several interventions at once are most effective. Cost-effectiveness analyses indicate that there are efficient strategies to combat chronic disease, but they are rarely more cost-effective than therapeutic interventions. Cost-effectiveness varies considerably according to region and population group. Regional factors for each intervention must be carefully examined, and relevant target groups defined carefully so that policy makers can do more than just choose between: broad implementation or no implementation at all. Prevention interventions are far from developed in most countries. Because of the severe medical, social and economic consequences of chronic diseases, more effort and resources have to be invested in prevention and early detection.

Health care has recently seen the emergence of *new providers, new settings and new qualifications*. New professions such as nurse practitioners, liaison nurses and community nurses have been set up, and the tasks and responsibilities of existing professional groups have been moved and expanded. New settings have been established, such as nurse-led clinics, group practices and medical polyclinics. A key challenge is to enable those working in chronic care to meet their new duties and responsibilities (Busse et al. 2006; Casado 2003). Some countries have recognised this challenge, but gaps remain. In particular, there is often a shortage of well-targeted training for those in lower status professions. Empirical evidence on new qualifications and settings is limited, but pilot studies suggest that new qualifications, structures and settings can help to effectively manage chronic diseases. Nurses with wider roles and clinics run by specialist nurses seem to improve chronic care. The cost-effectiveness of such measures has rarely been studied systematically, but some research points out that use of resources improves. Future research should build on these early results to decide whether investment is justified and where the priorities should lie.

Disease management programmes have been introduced into many European countries. The aim is to improve the coordination of care by focusing on the whole clinical process, building on scientific evidence and involving patients. There is a lack of large-scale and rigorous population-based evaluations, but small-scale studies suggest that disease management programmes may benefit the process of care. Both the evidence on medical outcomes and on cost-effectiveness is inconclusive (Mattke et al. 2007). Providers and insurers must make the data they collect available to researchers, and evaluation must become an integral part of chronic disease management.

Integrated care models respond to the fact that chronic diseases can only rarely be treated in isolation. Often patients suffer from several chronic diseases or conditions. These models organise treatment (and prevention) to achieve more integrated services across the whole range of care. The effectiveness of integrated care models is controversial, because the lack of large-scale population-based studies does not allow far-reaching conclusions. Early results suggest that some improvements may be generated but, given the complexity of integrated care, implementation is a key challenge. Future studies must examine implementation problems. Also it is not clear which components of integrated care bring about individual improvements. Evidence on cost-effectiveness is also limited: preliminary results are inconclusive (Nolte and McKee 2008).

The third part of the report used this evidence to draw conclusions about what policy makers should do. It also made specific recommendations on how to shape the future. *Pharmaceutical and medical innovations* will continue to play a major part. New pharmaceuticals may lead to better adherence and better quality of life. At the same time, innovative pharmaceuticals will provide a challenge to challenge marketing authorisation and reimbursement schemes as well as the evaluation of outcomes.

This report has argued that properly applied *financial incentives* can be a powerful way of triggering effective and rapid change in chronic disease management. But policy makers need to pay attention to the size of variable compensation or funding and issues in goal-setting. Benefits in chronic illness often occur only in the mid- or long-term, so policy makers must be aware that often the quality of care can only be improved when providers are sure their investment is worth-while. Policy makers must consider carefully which strategy they follow when aiming to improve continuity of care.

Better *coordination* is critical, because chronic care involves many providers. Research confirms that patients' perception of the quality of care is largely determined by successful coordination (Preston et al. 1999). But structural, organisational and operational barriers persist. Preliminary conclusions, based on past experience and recent research, suggest that strategic, organisational and operational variables must be taken into account if coordination is to be improved. In particular, policy makers must recognise that well-organised interests tend to benefit from fragmented care, so reforms aimed at improving coordination should be well-prepared, and supported by strong political will. Policy makers also need to monitor other reforms on coordination. They must decide early whether to depart radically from the current structure, or build on established norms, institutions and practice. Structurally, policy makers need to define clearly responsibilities for those involved. The balance between local autonomy and central authority also needs to be defined. Operationally, enough funding is needed to pay for reforms, while at the same time compensation schemes need to be set up that encourage cooperation rather than stress professional separation. Finally, the workforce must be prepared to fulfil its new roles, which means adequate training, learning and communication.

Another important building block is *information and communication technology (ICT)*. Theoretical models and some small-scale pilot studies suggest that computerised decision support and data collection can generate many benefits. Using electronic protocols and clinical pathways to support evidence-based medicine is particularly attractive, because it could improve outcomes and reduce medical error. However, the evidence is weak with only a few rigorous studies on effectiveness and cost-effectiveness. Experience in many countries has been disappointing: most ICT initiatives run into unexpected difficulties with budget-overruns and high costs. If ICT is to meet its potential in chronic disease management, problems of functional interoperability need to be solved through agreement on technical standards. Policy makers must bring about consensus. Even more important, they must find solutions for translating vast amounts of data into meaningful information for health professionals. They also need to ensure that public concerns about data protection are taken into account, and appropriate legislation introduced.

This report also shows that many aspects of chronic disease management are not properly *evaluated*. The effectiveness and cost-effectiveness of various prevention and treatment interventions are not well established. Policy makers are therefore not best equipped to make informed decisions. An important cornerstone for improving knowledge is the development of health technology assessment institutions in several European countries (Busse et al. 2006). Policy makers need better grounded empirical evidence on effectiveness and cost-effectiveness, generated through methodological approaches such as prospective, randomised, controlled evaluation. Policy makers must ensure that evaluation is an integral part of public programmes. They should also act immediately to make existing data available for research and review, so that an independent and in-depth analysis can take place of effectiveness and cost-effectiveness across different technologies, settings and providers. In the face of increasing globalisation of pharmaceutical and health care markets, policy-makers need to ensure that standards and methods of evidence-based evaluation become internationally accepted. They also need to increase the transparency of procedures and policy decisions (Busse et al. 2006).

Finally, this report indicates that policy makers do not yet have the information and evidence they need to understand and shape chronic disease management. Future research should concentrate on the following issues:

- Evidence based on rigorous research designs needs to be generated with regard for the strategies available to prevent or combat chronic diseases, such as prevention and early detection, new providers and qualifications, disease management programmes and integrated care. The research should make use of routine population-based data to evaluate key outcomes such as appropriateness, effectiveness and cost-effectiveness, as well as to identify what makes an approach succeed or fail.
- Equally important is that future research examines how specific financial incentives interact with 'continuity of care' in different health systems. This question is of fundamental importance for chronic diseases because investment tends to generate health and economic benefits only after 5-10 years. Incentives that make providers or insurers make frequent changes may undermine quality of care and cost containment.
- This report suggests that future research should investigate how to translate the vast amounts of data that information and communication technology can store into meaningful information for health professionals.
- Finally, there is a need for international agreement on the acceptability (or even uniformity) of evaluation standards, methods and conduct as well as for the transparency in applying them. There are still no agreed standards and methods, especially regarding the core conflict of fast access to effective technologies and the need for proper, time-consuming comparative evaluation.

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